

DEPARTMENTS OF LABOR, HEALTH AND HUMAN  
SERVICES, EDUCATION, AND RELATED AGENCIES  
APPROPRIATIONS FOR 2014

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HEARINGS  
BEFORE A  
SUBCOMMITTEE OF THE  
COMMITTEE ON APPROPRIATIONS  
HOUSE OF REPRESENTATIVES  
ONE HUNDRED THIRTEENTH CONGRESS  
FIRST SESSION

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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 RE-  
LATED AGENCIES APPROPRIATIONS FOR  
2014**

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**OUTSIDE WITNESSES TESTIMONY**

**WEDNESDAY, MARCH 13, 2013.**

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**TRIO PROGRAMS**

**WITNESS**

**DR. CHERYL D. DOZIER, PRESIDENT, SAVANNAH STATE UNIVERSITY**

Mr. KINGSTON. I think my friend, the ranking member, probably got stuck in the hallway with a conversation because there are so many people out there. Oh, she made it. [Laughter.]

Ms. DELAURO. Would I leave you in a lurch?

Mr. KINGSTON. So she did get stuck in the hallway, but she finished the conversation. We are glad to have you here today.

This is a great day. We always enjoy the special witnesses, and we wish there was time for all and that we could even get to more. We had over 150 groups ask to testify, and just because of time constraints, we narrowed it down to 24. But essentially all groups do have the opportunity to submit written testimony. But because it is a very tight clock, we are going to have to go with the 5-minute rule. So I know that everybody has lots to say and we have lots to learn and lots of questions. So it is going to be very frustrating for all of us, but this is the way we need to do that.

So with that, I will yield to the ranking member, Rosa DeLauro.

Ms. DELAURO. Thank you very much, Mr. Chairman, and thank you for the hearing this morning.

I want to say a thank you to all of our speakers for the hard work that you all put in on behalf of America's families.

As the chairman mentioned, there are 24 witnesses. It is a wide array of important issues that come under the jurisdiction of this subcommittee. And again as the chair has pointed out, the sheer number of requests that we received today I think is a testament to how critically important the labor, health, and education programs under the purview of this subcommittee are to so many people in the Nation.

I think a quick fact is important here. If you do adjust for inflation and population, the Labor, Health and Human Services, and Education budget has been cut by about \$12,000,000,000 over the last decade. And we see that the Budget Control Act and those

spending caps will take another \$9,000,000,000 from the account over the next 10 years. And despite those cuts, the sequestration that went into effect earlier this month threatens to slash another \$7,000,000,000 from these programs in 2013.

The cuts, in my view, will really have a serious impact on the lives of families across this Nation. We will see fewer children have access to vaccinations, special needs education, and Head Start, less money for biomedical research, for disease prevention and control, LIHEAP, Meals on Wheels. Low-income seniors suffer from these efforts. Families will lose out on child care, women on cancer screenings, workers on job training, and young people on the opportunities like Job Corps and Americorps.

So my hope this morning is that our witnesses will share with us the real impact of the work that you are doing and the impact on the people who you serve to help to make their lives different and what, in fact, the backing off of resources will do. And we need you to help us to define where our priorities should be. So thank you all very, very much for being here today.

Mr. Chairman.

Mr. KINGSTON. Thank you very much, Ms. DeLauro.

Does anybody else have an opening statement?

Mr. FLEISCHMANN. I have got Little Debbies for everybody. [Laughter.]

Mr. KINGSTON. Very important. You know, we have a healthy— an unhealthy maybe—competition going on between Italian pastries and now Tennessee Little Debbies. This is a very competitive program. I will take a granola bar and pass the bag. [Laughter.]

Mr. KINGSTON. The first witness is a friend of mine, Dr. Cheryl Dozier from Savannah State University. I think the last time we saw each other, I was looking for my float in your homecoming parade. Among other duties that day, you were showing me where to go. But I have certainly enjoyed a great working relationship with you and I appreciate everything that Savannah State does. So welcome to the U.S. Congress and the floor is yours.

Ms. DOZIER. Good morning and thank you, Chairman Kingston, and to the other subcommittee members for this opportunity to testify about the importance of TRIO programs throughout Savannah, Chatham County, Georgia, and the Nation.

As the President of Savannah State University, the first institution of higher education in the City of Savannah and the oldest historically black university in Georgia, I know firsthand of your personal commitment, Chairman Kingston, to quality education and to equal opportunity to all people of our great State and the United States.

Since 1966 Savannah State University has hosted TRIO programs, and the effectiveness of these programs is evident in the business leaders, entrepreneurs, educators, engineers, scientists, military officers that we interact with daily in Chatham County and throughout Georgia.

Since TRIO started at Savannah State, we have seen over 20,000 alumni of the program move on to amazing lives. Many of these alumni have stayed in Savannah and the region and have contributed to the advancement of the community. Georgia has a long history with TRIO, and this year alone, there are 59 TRIO programs

throughout Georgia serving nearly 20,000 students. The TRIO programs complement and leverage our Federal investment in financial aid programs.

Nationally TRIO serves nearly 800,000 low-income students, many who aspire to be the first in their families to earn college degrees. TRIO students come from diverse backgrounds, including 33 percent African American, 33 percent Caucasian, 21 percent Hispanic, 5 percent Asian and Pacific Islanders, and 3 percent are Native American. Thus, it can truly be said that TRIO cross cuts all sectors of our society as poverty does not discriminate.

At Savannah State University, we are fortunate to host three TRIO programs: Upward Bound, Talent Search, and Student Support Services. Our pre-collegiate programs, Talent Search and Upward Bound, work with over 1,000 neighboring middle and high school students providing intensive academic tutoring and counseling, as well as with standardized test preparation and assistance with college admission and financial aid application. These tools make it clear to students that college is a real possibility for them. Indeed, it is a destination.

Our work has been effective as in recent years both our Talent Search and Upward Bound programs have seen more than 80 percent of graduating high school seniors enrolling directly in college. Ultimately these types of services are crucial for Georgia's low-income and first generation youth.

As poverty often correlates with poor academic performance, the Talent Search and Upward Bound programs at Savannah State University are helping to transform local communities.

Additionally, hundreds of undergraduates at Savannah State University benefit from TRIO's Student Support Services program which provides intensive and intrusive academic counseling and coursework that ensures that students are prepared to engage successfully in college-level work. As a result, our Student Support Services program can boast of a significantly higher graduation rate than that of other low-income students on campus. There is no doubt about it. TRIO is the fiscal insurance policy that helps ensure that our State and Nation's students succeed.

The TRIO program at Savannah State University represents just a portion of our students' success, which includes programming that helps military veterans and out-of-work adult learners return to the classroom and earn post-secondary credentials. In turn, all of these programs fuel local economies by helping families transition out of poverty and creating an educated workforce.

As the President of Savannah State University, I am keenly aware of the importance of supportive and sustainable services to make real the aspirations of so many young people and adults who are working hard to create better lives for themselves and their families. Georgia, as you well know, is undergoing significant change. We are growing quickly. In fact, our population grew 18 percent over the last decade. We are also a younger State as more than one-quarter of our citizens are under the age of 18. TRIO programs are an important component of an opportunity infrastructure that allows all of our citizens to reach their full potential.

I recognize that we are in an era of great austerity, particularly with the recent implementation of sequestration. Despite our ca-

capacity to do more with less and reducing the average cost per student over the last 8 years, TRIO programs cannot lose the ability to serve more than 120,000 students. Chairman Kingston, I know that you have a strong commitment to the education of all of Georgia's citizens and citizens of the Nation, and I very much hope that under your leadership that this subcommittee will increase support for TRIO in future years to come.

Thank you.

Mr. KINGSTON. Thank you very much, Dr. Dozier.

We are tight on time. Do you want to ask some questions?

Ms. DELAURO. I think you answered my question in your last comment, but I think it is important to note, Dr. Dozier—thank you—that TRIO programs work. They really do work.

But it is important to note that between 2010 and 2012, we have lost \$12,000,000 in TRIO programs. If you add what appears to be the direction we are going in—and that is to solidify this sequester effort—that is \$40,000,000 more in a loss. That would bring you to the 2002 levels in terms of TRIO. If we are serious about allowing people to get an education that we need to move forward, to be able to become economically viable, to participate in a growing economy, we cannot afford, in my view—I am going to make a presumption that you share my view.

Ms. DOZIER. I do.

Ms. DELAURO. Am I accurate?

Ms. DOZIER. You are accurate. If we are going to build the kind of a workforce economy here in America, we must have TRIO programs that prepare our young students for the college education that they need.

Ms. DELAURO. Can you survive with this kind of a cut?

Ms. DOZIER. We cannot survive with this kind of a cut. It is imperative that we not have future cuts in TRIO programs that are going to impact the young minds that are our future in America.

Ms. DELAURO. Thank you very much.

Mr. KINGSTON. Mr. Alexander. Mr. Fleischmann.

Okay. Dr. Dozier, we will stay in touch with you on it. This committee, as I understand it, has not cut Trio. Some of this is dictated to us through Budget and other committees. But we will certainly work with you and be engaged with you on it.

Ms. DOZIER. Thank you all.

Mr. KINGSTON. Thank you.

The next, Vicki Modell, co-founder and Vice President of the Jeffrey Modell Foundation. Thank you very much for being here.

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WEDNESDAY, MARCH 13, 2013.

**JEFFREY MODELL FOUNDATION**

**WITNESS**

**VICKI MODELL, CO-FOUNDER AND VICE PRESIDENT, JEFFREY MODELL FOUNDATION**

Ms. MODELL. Good morning, Mr. Chairman and members of the subcommittee, and thank you for this incredible honor and opportunity.

I am Vicki Modell, co-founder of the Jeffrey Modell Foundation. My testimony will request \$2,000,000 for the HRSA Genetic Services Branch to save the lives of one in 30,000 babies who are born each year with SCID. I will explain.

In 1987, my husband and I established the Jeffrey Modell Foundation in memory of our son Jeffrey who died from complications of primary immune deficiency. Since its earliest phase, the foundation has worked in close collaboration with NIH on research and CDC on a public awareness and physician education program.

In recent years, we have increased our efforts and our resources to implement population-based newborn screening for severe combined immune deficiency, or SCID as we call it, working with CDC, HRSA, the States, and private industry. This condition, often referred to as "boy in the bubble" disease, is fatal in the first year of life if not diagnosed and treated early. Babies born with SCID appear perfectly normal at birth which causes delayed diagnosis until the babies are repeatedly hospitalized with life-threatening infections, which is a nightmare for any family.

But there is now screening technology called TREX which is more than 99 percent accurate and is relatively inexpensive. A bone marrow transplant has a better than 95 percent success rate to cure this fatal disease if identified in the first 3 and a half months of life.

The Secretary's advisory committee recently voted 26 to nothing to recommend that all infants in the U.S. be screened for this condition. We contacted every State to implement the Secretary's recommendation, but as you know, the States have significant budget problems. At the same time, we heard from too many grieving parents whose infants died because their State does not screen for this fatal disease. Their stories are tragic.

Fred and I knew we could not wait another day. With limited foundation resources, 1 year ago we offered start-up funds to all of the States for the assays, lab equipment and educational materials. Almost immediately many States, including Georgia I might say, responded that they would begin population screening for SCID if we would commit the start-up funding.

The economic benefits are overwhelmingly persuasive. The cost of the test is \$4 per baby. The cost of a transplant in the first few months of life is \$100,000. If the baby is not screened and treated, the baby will develop overwhelming infections and hospitalizations in the pediatric intensive care unit, and the cost of care in the first year of life will be \$2,000,000 to \$4,000,000 if the baby survives. Three Federal agencies, EPA, FDA, and Transportation, estimate the value of a life saved to be \$7,700,000.

A newborn baby with SCID that is screened and treated within the first few months generates more than \$64 in contributions to society for every \$1 we invest. \$64 to \$1. That is the economics.

And so here we are today. 2 years ago, there were two States screening for SCID. Today 20 States are screening or piloting, and 23 States, including the State of Georgia, are prepared to begin as soon as we can help. Together, these States represent 93 percent of the 4,000,000 babies born annually in this country. We can finish the job. We can actually eradicate this disease now. And in this

rich and extraordinary country in which we live, why should it really matter what State a baby is born in to live or die?

Our foundation is not strong enough to finish the job. We cannot do it without you. This is a small investment with an outcome that is priceless. I know because I have personally held these babies and I have laughed with these babies and I have also shared tears with others.

So I accept the reality that science and discovery did not come in time to save my Jeffrey, but we are dedicated and committed to working to save the lives of all the Jeffreys in the future. Let's go forward together on this journey beginning now. This can be an historic moment, and together, we will look back to this day when we decided to eradicate this fatal disease that takes these beautiful babies from us and shatters their parents' hopes and dreams.

Mr. Chairman, thank you. Thank you for what you do every day in service to our Nation and especially what we can do together to save more precious lives. Thank you for this opportunity.

Mr. KINGSTON. Thank you, Ms. Modell.

Ms. DELAURO. Mr. Chairman, I just want to say that you hear in the voice of Vicki Modell the passion with which she is engaged in this effort. I would just tell you, having worked with Vicki and with Fred—I say this to my colleagues as well—they took great tragedy and adversity and they took their own personal resources to turn this effort around for newborns. And they have made a substantial commitment, and they do need our help. But they have truly been in the business of providing the gift of life to newborns. And it has been an honor and a pleasure to work with the Modells over these years. Thank you.

Ms. MODELL. Thank you. We feel the same way. It has been an absolute privilege to work with this committee. You enable us to have done the work that we have done over the last 25 years, and we are extremely grateful. And if we just could get to the end of this tragic disease, life would be a lot better. So thank you so much.

Mr. KINGSTON. Well, you truly are honoring Jeffrey and all the other children of this tragedy.

Ms. MODELL. Thank you so much. Thank you.

Mr. KINGSTON. Next we have Calaneet Balas, Chief Executive Officer of the Ovarian Cancer National Alliance. You are already seated.

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WEDNESDAY, MARCH 13, 2013.

## OVARIAN CANCER NATIONAL ALLIANCE

### WITNESS

**CALANEET BALAS, CHIEF EXECUTIVE OFFICER, OVARIAN CANCER NATIONAL ALLIANCE**

Ms. BALAS. Yes. Good morning.

Mr. KINGSTON. The floor is yours.

Ms. BALAS. Thank you. Thank you, Chairman Kingston, Ranking Member DeLauro, and of course, distinguished members for having us here today.

My name is Calaneet Balas, and I am the CEO of the Ovarian Cancer National Alliance.

The Ovarian Cancer National Alliance is a powerful voice for everyone touched by ovarian cancer. We connect survivors, women at risk, caregivers, and health care providers with information and resources that they need. We ensure that ovarian cancer is a priority for lawmakers and agencies in Washington, D.C. and throughout the country. We help our community raise their voices on behalf of every life that has been affected by this disease, and I am honored to be here to testify on their behalf today.

Ovarian cancer is the deadliest gynecological cancer. Fewer than half the women survive 5 years, and after 10 years, only one-third are still alive.

At this point, there is no reliable test that we can use to catch or screen for this disease early. The majority of women who have this disease have at least one recurrence, and for many of them, treatment eventually stops working. That is why research and public health programs are so important for ovarian cancer.

The National Cancer Institute and the CDC both do significant and valuable work around ovarian cancer. We are grateful for the committee's continued support of these agencies and the programs that they undertake to lower the burden of ovarian cancer. The NCI is the single largest nonprofit funder of ovarian cancer research domestically, funding approximately 75 percent of all ovarian cancer research in the U.S.

Recent highlights of this research include a large trial of a new ovarian cancer drug, Avastin, which has shown to improve the time that women's cancers stay in remission. Studies showing that prophylactic surgery for high-risk women, including the removal of just a woman's fallopian tubes, significantly reduced the odds of developing ovarian cancer. And a study showing that screening of average-risk women with our current tools does not reduce mortality.

The results of a cancer genome atlas, another study funded by NCI, showed us how important personalized medicine really is for ovarian cancer. The atlas told us that each case of ovarian cancer is genetically unique. So we have our work cut out for us in identifying targets and to develop and test drugs for this disease.

The CDC has two programs directly related to ovarian cancer. The first raises awareness of the risks and symptoms of gynecological cancer through advertising and educational materials. As of December 2012, PSAs of gynecological cancer had generated 2,600,000,000 impressions and paid media generated 187,000,000 audience impressions. Studies conducted by the CDC have shown that both women and health providers are unaware of the symptoms of ovarian cancer and current recommendations against screening. This data shows the clear need for continued education.

The CDC's second program is focused on epidemiological research. Current research includes evidence of birth control as an intervention for those at high risk of developing ovarian cancer, a study of barriers to determine why women do not seek specialists for surgery, as well as an analysis on disparities of other patterns of survival.

While we clearly have a long way to go, we have made progress in understanding ovarian cancer. We have seen new treatments de-

veloped over the past 20 years, and we have a better understanding of where ovarian cancer develops and who is at risk of this deadly disease. In addition, we have a larger, stronger network of survivors and family members who can actually support one another.

I would like to thank you today on behalf of these women, the women that I serve, for continuing to support programs that help health providers and other women treat ovarian cancer. We know these programs have reduced suffering. We know those whose lives have been saved by knowing they are at high risk, and those who have gotten new treatments to keep their cancer at bay respectfully request that you submit and maintain support for all of these activities.

Thank you.

Mr. KINGSTON. Thank you very much.

Any questions?

Ms. DELAURO. I do have a question.

Mr. KINGSTON. Dr. Harris.

Mr. HARRIS. Thank you very much, Mr. Chair.

If I can just ask a brief question because I think within the past week, there was actually a study that showed—or some news release that showed that women potentially could have about an 11-month longer survival if they had the state-of-the-art techniques. And there was another one that mentioned intraperitoneal versus intravenous chemotherapy.

As the committee decides how to fund things, what would be the best strategy to deal with those newest findings that a lot of women could have better survival if they availed themselves of the best available techniques?

Ms. BALAS. Thank you for that question.

Yes, sir. There has been a lot in the news this last week.

And what we know and what we have seen is that really two-thirds of women do not get appropriate referral after being diagnosed with ovarian cancer. So they are not referred on to an oncologist-gynecologist, and so therefore, they do not get the appropriate treatment. So the best way to go forward is really to continue funding of these awareness programs through the CDC that I had mentioned. People need to know.

Ms. DELAURO. Mr. Chairman, I would just say as a 27-year survivor of ovarian cancer, I am grateful for biomedical research and the grace of God for being able to be here.

I think what the alliance does is two things. One is the research and the other is the education. And as we saw in that New York Times piece, women and physicians need to know about making that referral to a gynecological oncologist so that you can get the best treatment. And that is one of the significant roles that the Alliance plays.

And then I am sorry to say that even 27 years later, there still is no marker for ovarian cancer. It is not like a mammogram or other kinds of tests in which you can get some sense. There is lots of work being done and there is great promise, but again, 27 years later, there is still not a marker so there is a need for continued research because 15,000 women die every year from ovarian cancer.

And if you catch it in its early stages—and as I say, I was blessed. It was first stage ovarian cancer—you can survive.

So thank you for great work.

Ms. BALAS. Thank you.

Mr. KINGSTON. Thank you, Ms. Balas.

I also wanted to mention to you the Department of Defense has a lot of cancer research.

Ms. BALAS. Yes.

Mr. KINGSTON. Do you engage with them as well?

Ms. BALAS. We do engage with them and we are absolutely blessed that they do happen to have some research dollars given towards ovarian cancer.

Ms. DELAURO. It is important to note on that effort, Jack, that really the committee and Chairman Murtha and others have been very forthcoming, whether it is breast cancer or whether it is ovarian cancer, or cervical cancer research at the Department of Defense. It is really great.

Mr. KINGSTON. Thank you very much.

Ms. BALAS. Thank you.

Mr. KINGSTON. Susie Trotochaud with the Usher Syndrome.

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WEDNESDAY, MARCH 13, 2013.

## **COALITION FOR USHER SYNDROME RESEARCH**

### **WITNESS**

#### **SUSIE TROTOCHAUD, COALITION FOR USHER SYNDROME RESEARCH**

Ms. TROTOCHAUD. Good morning, Chairman Kingston and members of the committee. Thank you for the honor of appearing before you today.

My name is Susie Trotochaud from the State of Georgia, and I am here on behalf of the Coalition for Usher Syndrome Research to respectfully request this committee encourage NIH funding of \$20,000,000 for fiscal year 2014 to promote more research into Usher syndrome.

Usher syndrome is the number one cause of deaf-blindness. Imagine sitting here in this room unable to hear my words and unable to see me. Silence and darkness.

In the United States, it is estimated that about 45,000 people have this rare genetic disorder. Two of them are my children, Corey and Joni Dorfman.

Corey and Joni were born early, and before they were released from the hospital, they were given a newborn hearing screening. At that time, we were told that they were both profoundly deaf. As we struggled to understand what this meant, I realized that they would never be able to hear me say “I love you,” and I would never hear those sweet words from their lips. The sounds of our life were suddenly silenced.

But our heartache changed to hope when we found out about the cochlear implant. By the time they were 3 years old, we realized that they could be mainstreamed, go on through high school and even college just like their peers. Although they would always have to work a little harder, the sounds of opportunity returned to our

lives. And I remember my husband saying to me at that time, at least they are not blind.

About a year ago, all of that changed. After Joni entered a darkened hallway and asked me where the bathroom was when the door was literally 4 feet in front of her, we knew we had a problem. Testing confirmed what we by then already knew. Joni had type 1 Usher syndrome. Reading the description of type 1 Usher was like reading her biography: born profoundly deaf, delayed development, especially walking, balance issues, and loss of night vision beginning around 10. What would follow would be loss of peripheral vision, leading to tunnel vision, and eventually blindness.

With no intervention, my 12-year-old daughter will be blind by 20. And although my son currently has less vision issues, testing confirms he also has Usher. He may retain some of his vision into his 30s.

Usher is a rollercoaster ride of loss, grief, adjustment, and loss again that never ends as one more setback always lies around the corner.

Like you, my hopes and dreams for my children have always been that they grow up happy, attend college, get meaningful jobs, and give back to their community. But the reality we are facing is that 8 out of 10 deaf-blind people are unemployed, not to mention the physical and emotional hardships, the stereotypes of being deaf-blind, the loss of productivity and ability to do a job, ultimate depression, and perhaps even suicide. Add to that the reality that our country spends an estimated \$27,000,000,000 annually in care and support services for people with major visual disorders, not to mention the costs associated with hearing impairment. Those are statistics. People with Usher aren't.

The Coalition for Usher Syndrome Research has begun bringing Usher people together with brilliant researchers who are working on developing treatments every day, but we cannot find a cure for the tens of thousands who have Usher syndrome without Federal support. We believe that \$20,000,000 this year and an increase of that amount over the next several years would lead to viable treatments for those with Usher syndrome within a decade. 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 NIH, Usher syndrome is not even listed. Rare diseases with similar incidence rates average around \$50,000,000 annually. These investments have resulted in significant discoveries for these diseases, and there is no reason to believe that we cannot see the same results or better for Usher. The researchers are there waiting to discover what we only dare dream of: an opportunity to allow deaf children and adults who are going blind a chance to see.

I will leave you with the words of Helen Keller: it is a terrible thing to see but have no vision. I hope that this committee will have the vision to see the opportunities before them. Together, we can find a way to end deaf-blindness.

I thank you on behalf of all those with Usher syndrome, their families, and most important to me, my children, Corey and Joni. I am happy to answer any questions you may have.

Mr. KINGSTON. Thank you very much for this very stirring testimony. We very much appreciate it.

Are your children here today?

Ms. TROTOCHAUD. No, they are not.

Mr. KINGSTON. With the cochlear implant, what percentage of hearing do they get?

Ms. TROTOCHAUD. They still have what is considered a mild to moderate hearing loss. It is more difficult in some environments than others. But they are mainstreamed. They are on grade. They actually get pretty much all A's in a normal school with no additional assistance. So the cochlear implant has pretty much minimized any effects that their loss of hearing has. Loss of sight is a different issue.

Mr. KINGSTON. My father lost his sight through macular degeneration, but in the early stages, there are certain exercises that you can do to prolong losing your sight. Are there similar exercises that your children can do?

Ms. TROTOCHAUD. No, there are not. There are things you can try to do. There is some research that shows vitamin A in very high doses may allow vision to last a little bit longer. Those researchers have not proven that is true in Usher type 1 patients, but it has been successful with adult RP patients. So we are doing it and hopeful that that might make a difference. That may give them a few more years of sight, but that is it.

Ms. DELAURO. I just would say thank you for your courage in being here and the courage of you and your children. My hope is that the research on the sight issue can move at a pace that allows some opportunity for your children to take advantage of it.

Ms. TROTOCHAUD. Thank you. I appreciate that.

Mr. KINGSTON. Anyone else?

Thank you very much.

Ms. TROTOCHAUD. Thank you.

Mr. KINGSTON. Next is Kayla Brathwaite, a 10th grade student from greater New York. Now, is that in Manhattan or where is the Greater New York YMCA, YWCA?

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WEDNESDAY, MARCH 13, 2013.

## YMCA OF GREATER NEW YORK

### WITNESS

#### KAYLA BRATHWAITE, YMCA OF GREATER NEW YORK

Ms. BRATHWAITE. They are spread all over New York City.

Mr. KINGSTON. So where do you live?

Ms. BRATHWAITE. In Queens.

Mr. KINGSTON. That is great. Well, we welcome you here and the floor is yours.

Ms. BRATHWAITE. Okay. Good morning. My name is Kayla Brathwaite, and I am currently in 10th grade at Park East High School in New York City. I am honored to be here today representing 1,000,000 young people who are involved in after-school and summer learning programs supported through the 21st Century Community Learning Center program at the U.S. Department of Education.

I am here to tell you about my experience in the program and to request that your committee provide a level of funding of \$1,150,000,000 for the 21st CCLC program for the fiscal year of 2014 appropriations process.

Before I begin, I would like to say that I am here with my mother who probably appreciates these funds and programs they provide even more than I do since the programs allow my mother to be at her job knowing that I am at a safe place at the YMCA. Thank you, Mother, for making the trip with me today. I promise you that this is just as educational as being in school. [Laughter.]

Mr. KINGSTON. Why don't you stand up, Mom?

[Applause.]

Ms. BRATHWAITE. First, let me briefly tell you a little bit about my neighborhood and school. I live in Queens, New York, the most diverse county in the United States, a place where most families have two working parents when times are good and where after-school programs are not a luxury but a necessity.

As I said, I go to Park East High School, a small public high school in Manhattan. Although I like my school and my neighborhood, I know that I am one of the lucky ones, one of the lucky kids in New York City who has the support of people around them and an organization like the YMCA to help them succeed.

Outside of the after-school program, there are really few positive opportunities for kids in my neighborhood. You are either in an after-school program or you are just hanging out. It really is not a surprise to me that between the hours of 3:00 and 6:00 p.m. are the peak hours of juvenile crime and experimentation of drugs, alcohol, and cigarettes. Also, during the summer months, first-time use of alcohol, tobacco, and drugs peaked among the kids 12 to 17.

I have been participating in the YMCA programs funded by the 21st CCLC funds since I was 8 years old. When I was in middle school, I was lucky enough to have access to enter a school program at MS210 in Queens. The program kept me safe and off the streets during the after-school hours, but more importantly, this program had a special focus on teaching me about advocacy, public policy, leadership skills, and the importance of civics education and being part of the solution to our society's problems. As a matter of fact, this program gave me the skills and confidence to be here today. I learned that in the program my opinion is important and my voice is powerful. I am proud that I am able to put that lesson to work for you today.

Now that I am in high school, I still participate in the YMCA program, Teens Take the City. The program teaches me about how government works and how I can make a difference. Last year, I was even elected Queens Borough President by my peers. I have run for election, drafted and proposed legislation to help debate some issues important to my work group. I feel like I have a taste for what all of you do, and I can decide later about whether to pursue a career much like yours.

It has been an incredible experience, all made possible through the funding for after-school programs like the 21st Century Community Learning Center funds. The program is a partnership between the YMCA and the school and provides hands-on activities for me and other participants. The best part of after-school pro-

grams is that they help lessons that we have learned in school come alive. The programs complement but don't replicate the learning that takes place during the school day.

But enough about me. I am here today for all the youth that need these programs to succeed and for all the parents who need these programs to help keep their jobs and for the employers who employ those parents. We should not forget that these programs or the lack of these programs will have an effect on the economy. I believe that spending \$1 on the 21st Century Community Learning Center gives you the benefit of spending \$3, one on an academic enhancement program, one on a high-quality child care program, and one on an economic development program. No matter how you look at it, the program benefits us all.

One point I think is really important is that the funding you provide generates a lot of funding from other sources. In New York, the YMCA has received over \$10,000,000 in private donations to help support after-school programs and other services for kids and families, from donors like NY Life Foundation, Bloomberg, and Morgan Stanley Foundation.

I know that funding is tight and now is not the time to be asking for increases in spending. However, it is important for you to know that the After-School Alliance reports there are 15,000,000 children who are left to take care of themselves after school every day. The 21st CCLC program provides services for only 1,000,000 children. So there is obviously a huge need to someday expand the programs so that all young children have the same opportunities that I had.

While I have heard it is a little challenging for Congress to agree on things, I am thankful that the 21st CCLC program has been supported by Republicans and Democrats in the past. I encourage you to continue with the support and provide a level funding of \$1,150,000,000 for the 21st Century Community Learning Centers program. Of all the thousands of programs in the Federal Government, this is the one that means the most to me. I would not be here without it.

Thank you so much for giving me the opportunity speak to you this morning.

Mr. KINGSTON. Well, thank you very much, Ms. Brathwaite. We appreciate your eloquence and you have done a very good job.

Ms. DeLauro.

Ms. DELAURO. You are really a wonderful advocate for the after-school program which is something that this committee has in the past in a bipartisan way been very supportive of for the very reasons that you mentioned, for what it does for you but also what it does for parents as well.

And I am happy to tell you—and, Mr. Chairman, I want you to know that I used to teach in the after-school program. I taught calligraphy and modern dance. Can you believe that, Mr. Chairman? [Laughter.]

Ms. DELAURO. So great, great work, and congratulations to you, Kayla. And I am glad that that provided you with the confidence to come and speak up today.

Ms. BRATHWAITE. Thank you.

Mr. KINGSTON. I do want you to know that I was raised in the YMCA myself in somewhat of an after-school program my mom engaged me in. It is a great institution.

Ms. BRATHWAITE. It really is. Thank you.

Mr. KINGSTON. Thank you.

The next witness, a friend of mine, Dr. Will Hardin from Camden Schools. He is a superintendent of schools and has presided over a tremendous growth in the Camden County public education program and is here to talk about Impact Aid.

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WEDNESDAY, MARCH 13, 2013.

**NATIONAL ASSOCIATION OF FEDERALLY IMPACTED  
SCHOOLS**

**WITNESS**

**WILL HARDIN, SUPERINTENDENT OF CAMDEN COUNTY SCHOOLS,  
GEORGIA, NATIONAL ASSOCIATION OF FEDERALLY IMPACTED  
SCHOOLS**

Mr. HARDIN. Thank you and good morning, Chairman Kingston, Ranking Member DeLauro, as she leaves the room, and members of the subcommittee. My name is Will Hardin, as Chairman Kingston said, and I am Superintendent of Camden County Schools in Kingston, Georgia.

As I listened this morning, I realize the task that is laid before me as I hear the pleas of people who are scrapping over the scarce resources we have in our country right now. My job, however, pales in comparison to yours as you try to establish those priorities. And I want you to know I appreciate that fact.

In Kingston, we are very pleased to serve the families, men and women, of Kings Bay Naval Submarine Base. I have enjoyed a 30-year career as a superintendent, first as a teacher, principal, district administrator, and then finally the role that I have now as the superintendent of schools.

While I acknowledge this extraordinary difficult time in our Nation's history, I ask this morning that Impact Aid be made a congressional priority by maintaining 2012 funding levels. This year alone the Impact Aid program lost over \$60,000,000 through sequestration.

Impact Aid was first signed into law by President Truman in 1950. This program provides payments in lieu of taxes to 1,400 school districts serving 11,000,000 students across our Nation. Non-federally impacted schools are funded locally by taxes on privately held residential and commercial property, but since Federal property and activity are exempt from taxes, a portion of a federally connected school district's tax digest is forfeited by the local community. Now, while there may be partial compensation for lost taxes to commercial interests from a halo effect, the economic activity around a base, there is still that loss for the unique funding mechanism that schools enjoy.

Kings Bay is larger than many small towns. We have a workforce of 9,000 employees, which includes over 5,000 active duty military men and women. We have 543 homes for families on the base and 1,500 beds for bachelors. Similarly, the Navy exchange

and commissary have annual sales of \$32,000,000. All the land, improvements, commercial activity and homes are exempt from taxes. Kings Bay and other Government property accounts for 69 percent of the value of our tax digest and are exempt from taxes that support education.

Our schools serve 9,100 students and 4,046 of those are federally connected. Local support for students in our district is funded by just 31 percent of our digest which is not exempt. In a perfect world, Impact Aid would provide Camden County an amount equal to 69 percent of the digest reflecting that non-taxable property that it occupies.

The Impact Aid level nationwide has slipped from 62 percent to 53 percent in the past decade. Reductions are inescapable and even essential in times of crisis such as these. But federally connected schools like Camden, like Groton in Connecticut, and the Blackfoot School District in Idaho need you to understand that when the Federal Government is unable to pay its fair share, the local communities have to make up that difference. In return for the freedoms, the services, and the protections that we all enjoy as citizens, we dutifully pay our fair share to the Federal Government, and we contend that the Federal Government's obligation is no less imperative.

Schools in my State and all of yours have experienced unprecedented losses in revenue over the last several years. In Camden County, we saw a 30 percent decline in State revenue between 2007 and 2012, or \$1,569 per student. This all came while fuel, health care, and other inescapable costs like providing a free and appropriate education for the 12 percent of our students who are special needs populations remains regardless of appropriations.

Over the last 4 years in Camden County, we have eliminated art and music from elementary schools. We have decreased advance placement offerings at the high school, eliminated 272 of the 1,486 positions, increased class sizes by five students in every grade, reduced our instructional calendar from 180 days to 166 lengthened days, and furloughed teachers 6 days, administrators, 8 for the last 3 years. Consequently, furloughs and a reduction in force removed \$5,300,000 in annual salary from the local economy.

And these reductions left their mark. On March 25th, 2009, I met with 28 teachers to tell them that they would not have jobs in the succeeding year. In those two succeeding years, I had the same conversation with nurses, music teachers, technology instructors, and ordinary classroom teachers to explain that though they were faithful to their students and loyal to the community and devoted to their profession, that they would be losing their jobs.

As leaders, we accept an obligation to make difficult decisions when necessary. Our communities need you to know that a minus sign on a budget spreadsheet here in Washington often represents a real person or a program in our schools. Your appropriation for Impact Aid is inseparably linked to our budgets and our budgets are inseparably linked to people.

Ms. Jennifer Mathis is one of the teachers that I met with on March 25th of 2009. While I do not know all of the 700 teachers in our district, I did know Ms. Mathis, and the reason I knew her is that just a few months earlier, before I met with her to tell her

that she did not have a job, I visited her home and her two sons when her husband was killed in an accident. Regardless of that fact, my responsibility was to protect the school system and ensure that we could live to fight another day. So she was a casualty of those cuts.

I hope you agree that as leaders, when we fail to recognize the human costs of our decisions, we fail to serve those that we lead.

Property owners in Camden County already bear a significant financial obligation to support schools. Raising taxes in federally connected communities because the Federal Government cannot pay its tax bill is indefensible. The Federal Government must meet its obligation for military dependents and to fulfill the trust responsibility for Native American students. I respectfully ask you to lead others in recognizing these communities deserve to be a priority through adequate Impact Aid funding.

And finally, I thank you for this opportunity.

Mr. KINGSTON. Thank you very much, Dr. Hardin.

Questions?

You also get some money out of the DOD. Do you know what the balance is between the Department of Education and the Department of Defense?

Mr. HARDIN. The Department of Defense for us provides \$200,000–\$250,000. It is an appropriation each year just like Impact Aid is. In comparison, Impact Aid funding for our district is between \$4,000,000 and \$5,000,000, again depending on appropriations. So quite an imbalance.

Mr. KINGSTON. Well, thank you very much.

Mr. HARDIN. Thank you.

Mr. KINGSTON. And on the subject of the Department of Defense, I also wanted the witnesses to know that on cancer research, the Department of Defense spends \$120,000,000 on breast cancer, \$16,000,000 on ovarian, \$80,000,000 on prostate, and \$12,800,000 on other type cancers, for a total of \$228,000,000. So just for the record.

Well, thanks a lot.

Dr. Peter McPherson.

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WEDNESDAY, MARCH 13, 2013.

**ASSOCIATION OF PUBLIC AND LAND-GRANT  
UNIVERSITIES (APLU)**

**WITNESS**

**PETER McPHERSON, PRESIDENT, ASSOCIATION OF PUBLIC AND  
LAND-GRANT UNIVERSITIES (APLU)**

Mr. McPHERSON. Yes, sir.

Mr. KINGSTON. Association of Public and Land-grant Universities and a Michigan State Spartan.

Mr. McPHERSON. Yes, sir.

Good to be here today. My association is the association of large public and land-grant universities in the country. You mentioned the University of Tennessee, Idaho, Idaho State, of course, Georgia. I was President of Michigan State for 11 years, and our chair spent a little time at Michigan State. He told me just before the hearing.

Good to be here. We have schools in every State in the country. They are the large publics that you know so well.

Let me be brief because I see all those people behind me. So I will be brief.

The sequester I know we all feel has been a blunt instrument, an indiscriminate instrument. It is important that, as I know you are all so well aware, that you put together a balanced budget that in my view needs entitlement reform, tax reform, and some resources. I appreciate the hard work that you are doing here in this and it is so important.

A few comments about NIH funding. We have heard today—and they are really quite compelling stories—about the importance about NIH health funding, research. In 2011, where we have clear figures of the outcome, \$31,000,000,000 produced a \$62,000,000,000 economic impact, over 400,000 jobs. That is the immediate economic impact.

But I think what is especially important to also look at is that over the last few decades, we have had an era of information technology that has spawned so much of our economic growth, and the information technology now feeds into what we are seeing as biotechnology at large. This is going to be so much part of our economy in the decades ahead. And I know you all feel it is really not smart to cut back on some of the foundation, the basic research that that will fuel. Other countries in the world are increasing their research. It is a competitive disadvantage for us not to continue to keep this lead. In my view, it is an investment issue. That is true in terms of economics, but the lives saved. We know about cancer, AIDS, Alzheimer's and so forth.

It is interesting that a small bit of this has an impact upon international health and humanitarian work. The University of Georgia, for example, has a little project, Mr. Chairman, that looks at how to better treat malaria, very important work, and is really pressing work.

A few comments about student aid. We appreciate the leadership of this committee to continue this. Some 10,000,000 students receive Pell Grants in this country. I will tell you a figure. If there is anything I have said today I would love to have you take away—we have got a real problem here. Of the top income quartile in this country, 85 percent of those students, those young people, get a degree. Of the bottom quartile, the bottom 25 percent, only 8 percent of those young people get degrees. What a dramatic change. We know that is not all intelligence or initiative or something. 85 to 8 percent. That is something.

Now, universities clearly have a role. And the big publics have a huge role. But key also is the student aid. Having been running this campus with 40,000-plus students for 11 years, I have just talked to hundreds of students. A few hundred dollars often is the question of whether you stay in school or not. It is just really true. Coming from a family with no money, just a little money makes the difference.

Now, the big publics have made a commitment. We went through this process last year. Almost 500 public universities in the country, which is pretty much everybody, have made a commitment to increase—we got a number, driving toward increasing the number

of our graduates so that by 2025 we will make up our share of the population so that 60 percent in this country have a degree. We need a high number because there is no way you can get there without this dramatic shift of this 8 to 85.

I would make one last comment, Mr. Chairman and committee, that there appears to be a surplus Pell this year. Be sure to use it for 2014 and don't let anybody else take it.

Those are my comments, folks. It is an important job you have and we appreciate what you do.

Mr. KINGSTON. Well, thank you.

I had one question. If kids went to school 4 years, we could save a lot of money. Do you know what the statistics are on more than 4 years now in college preparedness coming out of our high schools?

Mr. MCPHERSON. The 4-year figures are less than 50 percent. The 6-year figures are 65 percent or so. The figures that you typically see, the Department of Education figures, are much lower because they only look at full-time entering freshman class, what happens to that group. They do not count the transfer-ins and outs.

Now, having said that, I mean, when most of you went to school, I suspect if you did not graduate in 4 years, it was sort of a disgrace. Certainly when I went to school, it was a disgrace not to do that. And Vietnam and Watergate really shifted that in many ways. That is when you began to take less than 15 credits.

There are many schools in this country that now have on the table an incentive plan to graduate in 4 years. The University of Florida, for example, has now decided that they are going to admit students in the summer or in the winter so they have the institution used full-time.

My belief is that there is real progress being made on getting more graduates, but we have got a lot more to do. This is a topic for another day, but I think that student financial aid needs to be moved from just an access program, how it is structured, to access plus completion. A long topic, and I am into it up to my neck every day, and except for the 15 people behind me, I would love to tell you all about it.

Mr. KINGSTON. We could save a lot of money if we had more people graduating—

Mr. MCPHERSON. Absolutely. Students have to take more credits. If we can facilitate going in the summer—remember, every semester a student cuts off, they begin to earn money sooner. They do not bear the cost of the expenses, of the living expenses.

I would love to come up and talk to you individually or otherwise about what is happening. I do not believe enough is happening yet, but I think that I can point to dozens of examples where some important things are happening. One of the reasons we put together this commitment to increase the number of graduates is because that pulls along everything else.

Mr. KINGSTON. It really is different. It is interesting, the cultural change. When I transferred from Michigan State to the University of Georgia, I lost one class, a credit that did not transfer. So I still finished in 4 years, but I took a class by correspondence to graduate, but I went to work. That class, by the way, was political science 101. [Laughter.]

Mr. MCPHERSON. Congratulations, Mr. Chairman.

Mr. KINGSTON. Well, thank you very much.

Our next witness is Dr. Dan Salinas with Children's Healthcare, children's hospital, of Atlanta. And he is going to be testifying on behalf of the Children's Hospital Association.

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WEDNESDAY, MARCH 13, 2013.

## CHILDREN'S HEALTHCARE OF ATLANTA

### WITNESS

#### DAN SALINAS, M.D., CHILDREN'S HEALTHCARE OF ATLANTA

Dr. SALINAS. Chairman Kingston and distinguished members of the committee, thank you very much for this opportunity to testify in support of Children's Hospitals Graduate Medical Aid Education program, or CHGME.

Basically what I am here to ask for today is that we continue and increase the investment in providing a pediatric workforce in America and providing access and care for America's children.

I am Dan Salinas. I am the chief medical officer for Children's Healthcare of Atlanta. On behalf of Children's and the Children's Hospital Association, I would like to thank the chairman and the committee for the ongoing support that you have provided to the CHGME program.

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

This funding has had a tremendous impact since its inception in 1999, enabling children's hospitals to increase their overall training by more than 45 percent since the program began.

In addition, the CHGME program has accounted for more than 75 percent growth in the number of new pediatric subspecialists being trained in this country. Today, the 55 hospitals that receive CHGME, representing less than 1 percent of all hospitals in this country, train over 6,000 pediatric residents and fellows annually. This equates to the training of 49 percent of all the pediatric residents in this country, including 45 percent of the general pediatricians and 51 percent of the pediatric specialists. So half of the pediatric workforce in America is the result of this funding that Congress makes in the Children's Hospitals Graduate Medical Education fund.

The children's hospitals around the country continue to experience significant shortages in many of the pediatric subspecialties. Some of the causes for this include a limited supply of specialists, rising debt burden because a lot of people who train in medicine do not go into pediatrics because the salaries are noncompetitive, changing lifestyles, and then an overall decline in physicians seeking specialty training.

The pediatric specialty shortages in this country affect children and their families in a significant way, specifically the ability to receive timely, appropriate care in pediatrics. An average wait in a children's hospital for a visit is about 2 weeks. In some of our subspecialties today in America in pediatrics, the wait time can be anywhere from 3 to 6 months. If this program were to be eliminated, this would serve to severely hamper patient access to care and exacerbate the shortage of pediatric doctors in this country.

While final decisions on fiscal year 2013 funding are pending, Congress will soon turn to consideration for fiscal year 2014 funding. Funding in the amount of \$317,500,000 for CHGME is critical based on the continued growth in children's demographic in this country and the continuing workforce needs.

On behalf of CHA and Children's Healthcare of Atlanta, I respectfully request that the subcommittee provide \$317,500,000 for the CHGME program in fiscal year 2014. This request is based on the continued growth of the children's demographic in this country and the continuing needs in the pediatric workforce especially in respect to subspecialty shortage.

We recognize greatly that the fiscal climate is extraordinarily challenging and that Congress has a significant 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. Remember, an investment of this type to keep our children healthy and to make our children healthy today leads to a healthier adult in America tomorrow.

On behalf of Children's Healthcare of Atlanta and the Children's Hospital Association and the children and families that we serve, thank you for your past support for this critical program, your leadership in protecting children's health. I strongly urge you to continue to support the CHGME program in fiscal year 2014 so that we can continue to train the next generation of general and specialized pediatricians. Remember, this an investment in America's children.

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

Mr. KINGSTON. Thank you, Dr. Salinas.

One thing that I would just recommend to you is to make sure that your hospital associations and your hospital members have invited Members of Congress to look at particularly the emergency room for small children and do a visit because it is very educational.

Ms. Roybal-Allard, any questions?

Ms. ROYBAL-ALLARD. Some people have argued that Medicaid GME should be able to pay for pediatric residents. Can you talk about why that will not work for, say, States like California?

Dr. SALINAS. I do not know enough about the program to answer that question, but I will get an answer for you.

Ms. ROYBAL-ALLARD. Okay, thank you.

Mr. KINGSTON. I do want to say that the President's request last year was \$88,000,000 and this committee funded it at 275. But we don't get the budget directly ourselves. So at this point, sometimes we don't set that number.

Dr. SALINAS. Thank you.

Mr. KINGSTON. Next is Mary Reese speaking for the people with intellectual and developmental disabilities, a VOR board member. Welcome to the committee.

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WEDNESDAY, MARCH 13, 2013.

**VOR**

**WITNESS**

**MARY REESE, BOARD MEMBER, VOR**

Ms. REESE. Good morning. Chairman Kingston and members of the committee, thank you for this opportunity to meet with you today on behalf of VOR.

My name is Mary Reese and I am a resident of Maryland and a VOR board member. VOR is a national organization advocating for high-quality care and human rights for people with intellectual and developmental disabilities, also known as IDD.

VOR respectfully requests the subcommittee's support for language to prohibit the use of Health and Human Services appropriations in support of de-institutionalization activities which evict vulnerable individuals with IDD from HHS-licensed Medicaid facilities. Upon review of VOR's written testimony and after listening to my comments today, I hope you will agree that HHS-funded closure activities which target HHS-funded and licensed homes are an absurd and cruel use of Federal funding. These closures have often led to human tragedy and violate Federal law.

Like the vast majority of VOR members, my family member, Ginger—and here is her picture—is my motivation. Ginger has profound intellectual disabilities, many medical issues, and counts on me to be her voice. She has no language skills, but her eyes speak volumes. Ginger recently moved to Holly Center, a State Medicaid intermediate care facility. It took 8 long years to secure the services she requires for her health and happiness. While we fought for admission, Ginger endured many health emergencies, inconsistent nursing care, and often neglect and injuries at the hands of poorly trained staff in her community setting.

Ginger is not alone in her past suffering. Headlines across the country tell widespread tragedies in small settings serving people with IDD. There are reports of 1,200 unnatural and unknown deaths in New York State, 100-plus deaths in Connecticut, 53 deaths in Illinois, and many more reports of abuse, neglect, and death in a majority of the States, and they are alarming.

It is a fact that the very health and human service agencies that Congress has entrusted to protect people with IDD rarely concern themselves with community-based tragedies and routinely dismantle the HHS-licensed and funded homes that provide highly specialized care in favor of non-federally regulated group homes in the community.

Both the Administration on Intellectual and Developmental Disabilities, AIDD, and the National Council on Disabilities, NCD, are HHS-funded and pursue the closure of HHS-funded facilities with-

out regard to Federal laws which require individual choice and individual and family decision-making.

AIDD oversees the federally funded Developmental Disabilities Act programs located in each State. It has been 13 years since Congress last reauthorized the DD Act. Authorizations for the DD Act appropriations expired in 2007. However, Congress continues to fund these programs with virtually no independent oversight.

AIDD and DD Act programs achieve de-institutionalization through class action suits, advocacy, and other tactics routinely disregarding outcomes, individual choice, and the legal right to appropriate services. The DD Act expressly recognizes that individuals with developmental disabilities and their families are primary decision-makers with regard to residential care, supports, and policies.

HHS-funded The National Council on Disabilities has also shown callous disregard for rights and outcomes. In October, NCD published "De-institutionalization: Unfinished Business," a 300-page paper calling on advocates to engage in advocacy and file lawsuits to close all homes with four or more people. Affected individuals and their families and legal guardians were not consulted. Instead, NCD unconscionably accuses caring families and guardians, parents like me, of violating our family members' civil rights simply because we choose a care setting of four or more people. Neither Medicaid law, which expressly requires residential choice, nor Olmstead, the Supreme Court decision so frequently cited in support of de-institutionalization, mandates of even allows these actions. The Olmstead's Court's own words are: we emphasize that nothing in 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 regulation that community-based treatment be imposed on patients who do not desire it.

VOR implores the subcommittee to take action. HHS agencies should not be filing lawsuits or pursuing advocacy against HHS programs. Please support language to prohibit the use of HHS appropriations in support of de-institutionalization activities which evict vulnerable individuals with IDD from HHS-licensed Medicaid facilities. No Federal agency should define choice so narrowly and illegally as to disenfranchise the most vulnerable segment of our disabled population. Such actions are a cruel and absurd use of Federal funding that is exacting great harm on our Nation's most vulnerable citizens.

Thank you so much for this opportunity and for your consideration.

Mr. KINGSTON. Thank you very much, Mrs. Reese.

Questions?

And she is your daughter?

Ms. REESE. Actually she is the daughter of the gentleman I was engaged to and he passed away at 97. His last years, he asked me to co-guardian her, and one of the first things I did after he took his last breath was march myself to the circuit court in Montgomery County and apply for full guardianship.

I saw her last weekend because she has only lived at Holly Center for a couple of months now. And she saw me coming towards her in the hall. She has no language skills. She is in a wheelchair.

She is profoundly mentally retarded. And she threw her arm over my shoulder and hugged me. And I said, oh, you are doing great and you are happy to see me again. That is wonderful.

Mr. KINGSTON. Well, God bless you.

Ms. REESE. Thank you.

Mr. KINGSTON. Thank you.

Next, Dr. Walter Curran, Executive Director of Winship Cancer Institute of Emory University. Dr. Curran.

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WEDNESDAY, MARCH 13, 2013.

## ASSOCIATION OF AMERICAN CANCER INSTITUTES

### WITNESS

**WALTER J. CURRAN, JR., M.D., FACR, EXECUTIVE DIRECTOR, WINSHIP CANCER INSTITUTE OF EMORY UNIVERSITY**

Dr. CURRAN. Chairman Kingston, Ranking Member DeLauro, and members of the subcommittee, thank you for the opportunity to testify before you on the relationship with the National Institutes of Health and our Nation's cancer centers.

My name is Dr. Wally Curran of Winship Cancer Institute of Emory University. As Winship's Executive Director, a cancer researcher, and a practicing radiation oncologist, I am happy to be here on behalf of the American Association of Cancer Institutes to discuss the critical importance of NIH support to our Nation's cancer centers.

Chairman Kingston, thank you for your ongoing support of cancer research and your understanding of how research improves our care of cancer patients. I would also like to thank you for your visit to Winship last year. I believe our Nation's leaders should visit cancer centers in order to witness the vital role our institutions play in the health of our constituents as they face a battle with cancer.

Chairman Kingston, your support of Winship's application for an NCI funding level, as well as your backing of our recent application to become a lead academic participating site for NCI, is also appreciated. I hope your colleagues take the time to visit our cancer centers in and near their own districts and see the outstanding work my colleagues do at this institutions.

As you are well aware, the NCI is one of the NIH's institutes. NCI awards its designation to cancer centers who demonstrate expertise in research through successful completion for a cancer center support grant. Winship received NCI designation in 2009, joining a prestigious group of then 64 NCI-designated cancer centers. Winship just successfully renewed its designation and CCSG through a competitive renewal process, receiving a rating of outstanding by a panel of our peers. We are the first and only NCI-designated cancer center in Georgia, which is now the eighth most populous State in the Nation and home to 3.2 percent of the entire country.

While Congress continues to debate the remainder of the fiscal year 2013 budget, NIH and NCI have prepared for cuts through fiscal year 2021. It is estimated that NIH will experience a cut of \$1,600,000,000 of which NCI will lose approximately \$250,000,000.

These cuts will have a real impact on progress against cancer at Winship and other cancer centers across the country. Continued progress in cancer research is dependent on the sustained efforts of highly skilled research teams working at cancer centers across the country and supported by the NCI. A budget cut to NIH and ultimately NCI will decrease funding to cancer research and impact many of the research teams working on new treatments and new cures. Rebuilding these teams could take years.

As an example, Winship has an outstanding research team making real progress in understanding how mutations causing lung cancer, the type of cancer causing the most deaths in our country. We are observing an increase in the number of lung cancer patients who have little or no tobacco use history, and we are just beginning to understand the genetic and genomic risk factors of such individuals for developing lung cancer. A break in funding of this and other projects could delay finding new and effective therapies for thousands of patients by a matter of years.

Our Nation's cancer patients deserve greater research attention to this deadly disease. Cancer is the leading cause of death in Georgia and more than 1,600,000 Americans were diagnosed with cancer in 2012, with over half a million dying from this disease. With 25 percent of all deaths in the United States caused by cancer, the disease is the Nation's second leading cause of death. The NCI estimates 41 percent of us will receive a cancer diagnosis at some point in our lifetime.

At Emory's Winship Cancer Institute, we are excited about the new proton beam therapy facility now under construction in Atlanta, as well as the increasing number of our patients being enrolled on cancer clinical trials. We see the impact of budget cuts through fiscal year 2021 has already begun to affect our progress in research. Immediate effects will be felt in our research labs with promising research slowed or even shut down pending projects wiped off the books, and bright, young researchers unable to learn cancer research at the side of experts.

At Winship, we enrolled over 700 cancer patients on trials testing new treatments in 2012 from all across the State of Georgia and beyond, each of whom has his or her amazing cancer journey to tell. We aspire to increase the number of cancer patients that we can offer such hope, but we need sustained support to achieve this. The reduction in funding to the cancer centers will directly affect our ability to provide the critical infrastructure necessary for a robust research program.

We are particularly excited about Winship's and other cancer centers' ability to offer new and promising therapies to our patients in what we refer to as our phase I unit. This is our specialized center, which allows us to carefully study all the beneficial and any harmful effects of these therapies. We have offered such groundbreaking phase I treatments to nearly 200 patients per year at Winship.

In addition to cancer centers, NCI supports cancer research in all of your communities through the National Clinical Trials Network and its newly reorganized five cancer cooperative groups. I have the great honor of co-leading one of these five research groups, and we have dedicated volunteer physicians and staff in every State

and every congressional district in the Nation offering hope to our cancer patients through our menu of over 200 cancer clinical trials. 20,000 to 25,000 patients choose to participate in these network trials each year, and this research has defined many of the best treatments for today and tomorrow's cancer victims among us.

This research is well coordinated with our cancer centers and is necessary for outreach beyond our research universities into community medical practices and for finding answers to some of the toughest cancer research questions as quickly as possible. It is through this network that patients in such locations as southeastern Georgia are able to enroll in these cancer clinical trials with their community oncologists.

Unfortunately, NCI support for these cancer cooperative groups has remained flat for over a decade. Sustaining this support is critical in providing your constituents the best access to outstanding cancer care available through their participation in federally supported clinical trials.

NIH plays a vital role in our cancer research but also impacts our Nation's economy. An analysis released last month projected that the Nation's life science sector, which includes cancer research, would lose more than 20,000 jobs and \$3,000,000,000 in economic impact due to cuts to NIH. These serious consequences for our biomedical jobs and local economies would mean funding cuts could undermine U.S. competitiveness at a time other nations are aggressively boosting their investments in research and development.

At Winship, this threat is real and we cannot afford to experience such loss. Such declines in funding could prevent us from quickly moving to a broader platform of personalized cancer care and research. This personalized approach requires a time- and resource-intensive approach to every patients' cancer to best understand what is the very best approach to each patient's care. This effort is well underway at Winship and other centers and will require a sustained and significant level of support.

So in conclusion, NIH's full support of NCI-designated cancer centers and their programs remains a top priority for our Nation's cancer centers. We are on a clear path to dramatic breakthroughs both at Winship and other centers. We have come too far in cancer research progress to lose Congress' full support of NIH and NCI. And your constituents deserve the very best we have to offer in providing lifesaving treatment.

Thank you.

Mr. KINGSTON. Thank you, Dr. Curran. And it was a very good visit to your operation. And also we had a great hearing last week with Dr. Collins. And I met many times with you guys.

Any questions?

Thank you very much.

Dr. CURRAN. Thank you.

Mr. KINGSTON. And next we have Dr. John Maupin, President of Morehouse School of Medicine. Dr. Maupin.

WEDNESDAY, MARCH 13, 2013.

**MOREHOUSE SCHOOL OF MEDICINE****WITNESS****JOHN E. MAUPIN, D.D.S., MOREHOUSE SCHOOL OF MEDICINE**

Dr. MAUPIN. Good morning. Chairman Kingston, Ranking Member DeLauro, and members of the subcommittee, I thank you for giving me this opportunity to present my concerns and recommendations to you today. It is a distinct honor and privilege.

My testimony highlights the key sources of funding which allow Morehouse School of Medicine, the other three historically black medical schools, Howard University College of Medicine, Meharry Medical College, and Charles Drew University School of Medicine and Science, and other community-focused medical schools who share our mission, to continue their training, research, and service emphasis on expanding the number of primary care physicians working in underserved communities, increasing racial and ethnic diversity in the health professions, eliminating racial and ethnic health disparities, and reducing preventable deaths and promoting healthier lifestyles for all Americans, placing emphasis on vulnerable populations.

Specifically, the related agencies and programs, which I discuss in greater detail in my written testimony, include the Health Resources Service Administration of HHS and its Title VII health professions training programs including Minority Centers of Excellence, Health Careers Opportunities Program, and the Area Health Education Centers, National Institutes of Health, National Institute of Minority Health and Health Disparities, the Office of Assistant Secretary in the Department of Health and Human Services' Office of Minority Health, the Office of post-Secondary Education at the Department of Education and its Strengthening Historically Black Graduate Institutions Program.

Now, ensuring that the supply of physicians and other health professions keeps pace with the disease-specific needs of the country's growing and aging population is the single most critical resource issue facing the U.S. health care system with far-reaching implications on access, cost, and quality of care. And I am sure this committee is well aware of this challenge. Many national studies project the critical shortage of the health workforce, including estimates of a projected shortage of 90,000 physicians by 2020, with half of this shortage in the primary care specialty fields of medicine. Moreover, this looming crisis is exacerbated by a lack of workforce diversity and inadequate distribution by geography. Quite frankly, there is little left to discover or dispute with respect to the benefits of achieving greater racial and ethnic diversity of the Nation's health professions. The attention once again must shift to identifying the most effective and sustainable methods to do so.

Morehouse School of Medicine, along with the other historically black medical schools and similarly focused institutions, occupy a unique niche among the Nation's array of academic health centers. They are a vital component of the American health care system supporting the national resolve to create a healthier America, particularly for medically underserved and under-represented popu-

lation segments. Importantly, the core mission and goals of these institutions is perfectly aligned with national health and health care priorities.

Specifically, Morehouse School of Medicine commands national respect for its distinctive primary care-anchored mission. Most recently in the first-ever study published in the June 15, 2012 issue of the *Annals of Internal Medicine* entitled “The Social Mission of Medical Education” ranking the schools, Morehouse School of Medicine ranked first among U.S. medical schools for its contribution to the social mission of medical education as measured by the production of primary care physicians, under-represented minority graduates, and graduates practicing in medically underserved areas.

Ironically, it is this distinctive mission focus that places Morehouse School of Medicine and its sister institutions in a uniquely disadvantaged position from an economic perspective as compared to the majority of the Nation’s academic medical centers. Unlike subspecialty-oriented, research-intensive institutions with higher margin clinical services and integrated hospital system, substantial research enterprises—technology is great until you push the wrong button. [Laughter.]

Dr. MAUPIN. Unlike these integrated hospital systems, substantial research enterprises, sizeable endowments and a critical mass of wealthy donors, these institutions are faced with an unprecedented set of adverse factors that challenge the financial viability, again directly related to mission. Consequently, they are disproportionately dependent upon the various Federal programs I have highlighted to support their core public purpose.

While the financial position of most of the country’s 130 medical schools is challenged by declining funding streams, from patient care revenues, and growing cost structures associated with technology advancement and regulatory requirements, many have been able to make course corrections primarily through leveraging the resources of their hospital systems.

However, community-based medical schools like Morehouse School of Medicine with our primary care focus and orientation towards general medical education and extraordinary commitment to serving socio-economically disadvantaged and underserved rural and urban populations have limited ability to respond to these challenges. Therefore, State government support and funding from Federal programs highlighted in this presentation are even more essential today than ever before for our viability.

In 1987, the U.S. Congress acknowledged their appreciation in the value of the role historically black medical schools play in enhancing the diversity of America’s health profession workforce. Congress also demonstrated its understanding of the unique economic circumstances associated with their mission by amending part F of Title VII of the Public Health Services Act, through passage of Public Law 100–97, the Excellence in Minority Education and Care Act, creating HRSA’s Center for Excellence programs. Congress later went on to authorize the establishment of additional categories.

Respectfully, I submit in closing—

Mr. KINGSTON. Okay. I was going to cut you off, but you sound like you are finishing.

Dr. MAUPIN. Respectfully, I submit that now is the time for targeted investments not reductions in the very programs that help to ensure a steady pipeline of minority health care professionals and bioscience professionals and support research that will ultimately lead to the elimination of health disparities and health inequities. To that end, my written testimony provides very specific recommendations for each of these programs to continue to support the vital missions of these important schools.

I will take your questions, sir.

Mr. KINGSTON. Thank you very much, Dr. Maupin.

Questions?

How is Dr. Sullivan doing?

Dr. MAUPIN. Dr. Sullivan is doing wonderful. I speak to him on a monthly basis so that I can give him an assignment before he gives me one. [Laughter.]

Dr. MAUPIN. And he continues to, with his Sullivan Alliance, support the very same mission focus that we have and continue our programs. So he has been a great asset to me as a follow-on president to his leadership.

Mr. KINGSTON. Please give him my best. He is a great American.

Dr. MAUPIN. Well, my written statement provides some additional context of this, and we continue to thank you for your support of these special programs.

Mr. KINGSTON. Thank you, Dr. Maupin. Good to see you.

Dr. MAUPIN. Good to see you again, sir.

Mr. KINGSTON. Next, Mr. Joseph McNulty, Executive Director of Helen Keller National Center.

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WEDNESDAY, MARCH 13, 2013.

## HELEN KELLER NATIONAL CENTER

### WITNESS

**JOSEPH J. McNULTY, EXECUTIVE DIRECTOR, HELEN KELLER NATIONAL CENTER**

Mr. McNULTY. Thank you, Mr. Chairman.

I am the Executive Director of the Helen Keller National Center. We are headquartered up in New York. We have a network of regional offices across the country that serve deaf-blind people in all 50 States.

We are also a line item in the Federal budget, one of the real small line items in the Federal budget. And in fiscal year 2012, we received \$9,100,000. With the impact of the sequestration this year, we expect to be closer to \$8,600,000. And so we are asking for an additional \$2,000,000 in fiscal year 2014. For all intents and purposes, we have been level-funded for the past 15 years, and if we had received a simple COLA over that period of time, our funding would be in excess of \$12,000,000, which is 40 percent below what we are currently funded at. So we think that the \$2,000,000 is justified.

In June of 2011, the Westat Corporation issued a report on a 2-year evaluation of the center that was commissioned by the U.S. Department of Education. And among the findings they had were that the center is, indeed, meeting its congressional mandate and

in their words in the opinion of the stakeholders, the National Center is the gold standard in the provision of services to people who are deaf-blind. So, obviously, we are very pleased with the report and we do take a great deal of pride in the work we have done for the past 45 years.

But in order for us to continue to meet that congressional mandate, we are facing a couple of challenges that we are going to need that \$2,000,000 for: specifically the increased number of individuals who are eligible for our services and then the shortage of trained personnel around the country to meet the needs of people who are deaf-blind.

In the HKNC Act that authorized the center, Congress had charged us with training individuals who are deaf-blind, each person who is deaf-blind in the United States, and training those professionals to provide the services at the State and local level. When the center was opened in 1969, they estimated there would be 50,000 to 70,000 deaf-blind people in the country. A study was conducted by the Research and Training Center on Blindness and Low Vision at Mississippi State University, and they estimate that the number of people with combined vision and hearing loss in the country is now at 1,200,000. Now, these are not Helen Kellers. Most of them, 90 percent of them, are over 55 years of age experiencing age-related vision and hearing impairments. But by definition, they are deaf-blind and they are eligible for services from the National Center.

Tied into this ballooning number is the growing shortage of trained personnel. If you talk to individuals who are deaf-blind around the country and their families, they will tell you the number one barrier to them reaching their full potential is there simply are not people qualified to work with them in all aspects of their life. This includes the DD system, the aging system, vocational rehabilitation, independent living.

So we are asking for this money for a wide range of people. 1,200,000 does not seem like a lot in the overall population in the United States, but whether it is those 12-year-old twins from Georgia that their mom spoke about this morning who, God willing, in 10 to 12 years are going to have a college degree and be looking for their first job and a place to live in the community or a 75-year-old grandmother who is experiencing vision and hearing loss as a result of aging and is in danger of losing her place that she has had for 55 years in her community because of her independent living skill needs, they both require trained professionals.

At the risk of bragging a little bit, we think we at the center have acquired a body of knowledge and a skill set that we can be of help to both ranges, both ends of the population. We just need the resources to do so.

And as everybody has said before me and will say after, you are facing a very, very difficult task. I think we would all agree that everybody presenting here is doing God's work and how you reach the decision in terms of how you are going to spend those limited dollars is a tremendous challenge. I do not envy you, but I would ask that you would consider the needs of a very needy population, small in number, comprehensive needs as you do your deliberations.

Thank you.

Mr. KINGSTON. Thank you very much.

Do you do much with Usher syndrome?

Mr. McNULTY. We do. Usher syndrome was a major focus when the center was opened in 1969. Because of the graying of America, they have become a relatively small percentage of the overall deaf-blind population. But for individuals who are seeking employment who come to the center's headquarters in New York for training to find a job and have the skills to go back and live in their community, they often make up between 35 and 50 percent of the student population at the center at one time.

And through genetic studies, the identification of folks with Usher syndrome is improving, and 20-25 years ago, they would estimate that 2.5 to 4 percent of the deaf population in this country had Usher syndrome, and now they are revising those to almost double that. So there is a lot of work that is being done with genetics, and I would support everything that was said earlier from the group that is behind Usher syndrome research.

Mr. KINGSTON. Well, thank you very much.

Ms. Roybal-Allard, any questions?

Mr. KINGSTON. Thank you, Mr. McNulty.

Next, Dr. Paul Jarris, who is the Executive Director of the Association of State and Territorial Health Officials.

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WEDNESDAY, MARCH 13, 2013.

**THE ASSOCIATION OF STATE AND TERRITORIAL  
HEALTH OFFICIALS (ASTHO)**

**WITNESS**

**PAUL JARRIS, M.D., M.P.H., EXECUTIVE DIRECTOR, THE ASSOCIATION  
OF STATE AND TERRITORIAL HEALTH OFFICIALS (ASTHO)**

Dr. JARRIS. Thank you, Chairman Kingston and Ranking Member DeLauro and members of the subcommittee.

My name is Dr. Paul Jarris and I serve as the Executive Director of the Association of State and Territorial Health Officials, or ASTHO. ASTHO is a national nonprofit organization representing public health agencies in the United States, the U.S. territories, and the District of Columbia, and over 100,000 public health professionals who serve the public. I appreciate the opportunity to appear before you today to discuss the value and role of public health and the impact Federal funding in programs have on protecting health in the U.S., our States, and territories, and in our communities.

The best way to explain what public health is and what public health does every day to protect everyone in this room, your constituents, and everyone across the Nation is to tell you a story. While this is one story about one recent disease outbreak, it is representative of thousands of other examples of public health in action, whether an infectious disease such as the recent whooping cough outbreak or West Nile virus outbreak, a natural disaster such as Superstorm Sandy, or a manmade disaster such as Deep Water Horizon.

This is a story of a recent fungal meningitis outbreak and how, with direct action by the public health system at the State, Federal, and local levels, and made possible through the Federal investment of this subcommittee, public health agencies reduced the death rate from nearly one in two infected patients down to zero, saving countless lives.

On September 18th, 2012, Dr. Marion Kainer of the Tennessee Department of Health received an email from a physician at Vanderbilt University Medical Center. A young, otherwise healthy patient had meningitis caused by a fungus, something rarely seen. Dr. Kainer immediately began her investigation. She learned that the patient recently had an epidural back injection at a pain clinic. Dr. Kainer alerted the clinic at once. Dr. Kainer contacted the CDC but did not stop there.

Due to her extensive training and knowledge as a public health disease detective, she recognized the significant public health threat. She inspected the pain clinic to examine their sterile procedures and identified the injectable steroid as a likely source of infection, and she and Tennessee Health Commissioner, Dr. John Dreyzhner, sent a health alert warning all Tennessee physicians.

Dr. Kainer determined that injections were coming from New England Compounding Center, NECC, and contacted the Massachusetts Department of Health. NECC voluntarily recalled the implicated medicine. Public health convened experts to advise patients and doctors how to identify, diagnosis, and treat this rare fungal meningitis. Public health tracked down patients as far away as Yosemite National Park who had received the tainted steroid and directed them to their doctors. Without public health professionals partnering with doctors, many more Americans would have died.

I will repeat. With public health activation the death rate fell from nearly one in two down to zero. Had Dr. Kainer been on furlough day when the call had come in, if the public health lab had been short-staffed, had the alert networks not been deployed to notify and advise clinicians, had preparedness and response plans not been exercised, more Americans would have died. Time is of the essence in an infectious outbreak.

This outbreak represents a significant tragedy for the 14,000 potentially exposed individuals across 23 States, the 720 families sickened, and the 48 families who lost loved ones. Each one of the Federal public health programs listed in the table at the beginning of my written testimony plus others contributed to the fungal meningitis response.

I encourage you to look favorably on our funding recommendations for these programs in fiscal year 2013 and 2014.

As a family physician and former State health commissioner, I know that not every health care decision is made in a single doctor's office for a single patient. Most of the health promotion, protection, and disease prevention decisions take place in our communities. Public health approaches to sanitation, vaccination, outbreak control, and other health threats have added 30 years to life expectancy in this country since 1900, far more than medical care. We can continue our progress based on evidence-based science and

approaches, but we rely upon the basic financial support from Federal, State, and local government.

State health agencies rely on a mix of Federal grants funds, State general funds, fees, and other sources. The largest portion, 45 percent, is discretionary Federal funds followed by State general funds at 23 percent. The Federal Government's role is significant. Diseases and public health emergencies such as natural disasters do not recognize State borders. Since 2008, 91 percent of State health agencies have cut budgets. More than 46,000 jobs have been lost at State and local public health departments combined, which is nearly 21 percent of the total workforce.

But the real story cannot be told in numbers alone. The real story is told by narratives that accompany these numbers, the newborn baby who gets whooping cough because her mom and dad were not vaccinated, the young adult who does not get screened for HIV due to cuts in testing at our health department, the furloughs that keep a laboratorian or disease detective from discovering a disease outbreak and arresting it. These are the very real everyday occurrences that keep all of us in public health awake at night.

In conclusion, public health is at a breaking point. Unless we start supporting our public health system in a more sustained way, our capacity will continue to erode and our ability to respond quickly will completely evaporate. Put simply, additional cuts in discretionary public health programs will put the health, safety, and security of all Americans at risk.

Mr. KINGSTON. Thank you very much, Dr. Jarris.

Dr. JARRIS. Thank you.

Mr. KINGSTON. Thank you very much.

Mr. Lacy, Rotary International's Polio Eradication.

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WEDNESDAY, MARCH 13, 2013.

**ROTARY INTERNATIONAL'S POLIO ERADICATION  
ADVOCACY TASK FORCE FOR THE UNITED STATES**

**WITNESS**

**JAMES LACY, CHAIR, ROTARY INTERNATIONAL'S POLIO ERADICATION  
ADVOCACY TASK FORCE FOR THE UNITED STATES**

Mr. LACY. Thank you, sir. Chairman Kingston, members of the subcommittee, Rotary International really appreciates this opportunity to submit testimony in support of the polio eradication activities of the U.S. Centers for Disease Control and Prevention.

Chairman Kingston, 2 weeks ago you remarked on the modern miracle of polio eradication, which we in the United States take for granted. You noted the outstanding leadership of the Centers for Disease Control and Prevention, Rotary International, and other partners in this achievement. Thank you for recognizing the effective public-private partnership.

The Global Polio Eradication Initiative, GPEI, is a 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, one in which is increasingly being combined with opportunistic, complementary intervention. We celebrate our

progress toward a polio free world and 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 2013 request of \$126.4 for the polio eradication activities of the CDC. While we have not seen the President's 2014 request, we would support at least a minimum of that level of funding in 2014. We have made tremendous progress toward a polio free world thanks to this committee's leadership in appropriating funds for the polio eradication activities of CDC.

In 2012, India was removed from the list of endemic countries. India has not had a case of polio for more than 2 years.

Overall, polio cases have decreased by 99 percent since the launch of GPEI in 1988. And in 2012, there were fewer cases in fewer places than at any point in recorded history with only 223 cases of polio. All but 6 of these cases were in the 3 remaining polio endemic countries of Afghanistan, Pakistan, and Nigeria. Only 9 cases of polio have been reported in 2013.

Rotary International contributed thousands of hours of volunteer service, plus more than \$1.2 billion toward this polio free world. This represents the largest contribution by an international service organization to a public health initiative ever.

Rotary greatly appreciates this subcommittee's support of CDC's polio eradication activities. Congressional support has enabled CDC to develop dashboard monitoring system to collect and analyze key indicators of campaign performance in real time to identify and address issues in advance to ensure high quality campaigns in Nigeria. CDC also implemented a nomad strategy in Nigeria, which identified and reached more than a half a million children under the age of 5 with polio vaccine.

Continued funding will allow CDC to provide direct support and build capacity to continue intense supplementary immunization activities in the remaining polio-affected countries, and will also help maintain essential certification standards surveillance.

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. Coal chain transport and communication 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 of Vaccine* estimated that GPEI could provide net benefits of at least \$40 to \$50 billion, U.S., if transmission of the polio virus is stopped within the next 5 years.

Polio eradication is a cost-effective public health investment with permanent benefits. More than 10 million children will be paralyzed in the next 40 years if the world fails to capitalize on the more than \$10 billion already invested in eradication. Success will ensure the significant investment made by the U.S., Rotary Inter-

national, Bill and Melinda Gates Foundation, and many other countries and entities are protected in perpetuity.

Thank you so very much, Mr. Chairman, for this consideration.

Mr. KINGSTON. Thank you very much, Mr. Lacy.

Any questions?

Thank you, and keep up the good work.

Our next witness is Dr. Hendrik Scholl of the National Alliance of Eye & Vision.

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WEDNESDAY, MARCH 13, 2013.

## NATIONAL ALLIANCE OF EYE & VISION

### WITNESS

#### HENDRIK SCHOLL, M.D., NATIONAL ALLIANCE OF EYE & VISION

Dr. SCHOLL. Jim Kingston, Ranking Member DeLauro, members of the subcommittee, thank you for the opportunity to appear today in support of appropriations for the National Institutes of Health, NIH, and the National Eye Institute, NEI.

I am Dr. Hendrik Scholl, and I serve as the Dr. Frieda Derdeyn Bambas professor of ophthalmology at the Wilmer Institute at Johns Hopkins School of Medicine in Baltimore, Maryland. I am representing the National Alliance of Eye and Vision Research, NAEVR, an alliance of 55 member organizations representing professional societies in ophthalmology and optometry, patient and consumer groups, and industry.

NAEVR serves as the Friends of the National Eye Institute and advocates for adequate funding of NEI's mission of saving and restoring vision.

I am here today to urge your support for a Fiscal Year 2014 NIH funding increase to a level of at \$32 million U.S., as well as an increase of NEI funding to a level of \$730 million U.S. This recommendation reflects the minimum investment necessary to make up for the 20 percent loss in purchasing power over the last decade due to flat funding and biomedical inflation, as well as the impact of the sequester, which cuts 5.1 percent of the \$1.6 billion from the NIH budget.

I received my medical degree in Germany and did a fellowship in London, so I bring an international perspective to the need for adequately funding medical research. The NIH has long held a unique role in the world as a driver of biomedical research and a leader in the competitive innovation-based global marketplace. Without continued adequate investment, the United States will not only lose its leadership position, it will also fail to build upon the past investment in research to understand the basis of disease and to develop treatments that save and improve lives.

Vision research at the NEI has also been affected by the sequester, cutting \$36 million from its \$703 million budget. This could potentially result in about 90 new grants not getting funded, any one of which could halt the promise for saving and restoring vision.

This funding cut could not come at a worse time. During the decade 2010 to 2020, the majority of the 78 million baby boomers will turn age 65 and be at greatest risk of aging IDCs, such as age-re-

lated makuladegeneration or AMD, glaucoma, diabetic retinopathy, or cataracts.

I am a clinician scientist who focuses on diseases of the retina, especially AMD, which is the leading cause of blindness in the industrialized world due to aging of the population. Each year, 200,000 Americans developed advanced AMD, resulting in the loss of central vision and inability to read, drive, and conduct activities of daily living.

The NEI has been a leader in determining the genetic basis of IDCs. NEI's AMD Gene Consortium, a network of international investigators, has just discovered 7 new regions of the human genome called loci that are associated with an increased risk of AMD. These loci implicate a variety of biological functions, such as the regulation of the immune system. By understanding the genetic basis of the disease and the underlying disease mechanism, NEI can develop appropriate diagnostic and therapeutic applications.

The NEI is also supporting research that restores vision. In February this year, just a month ago, the FDA approved an implanted retinal prosthesis to treat completely blind patients with advanced retinitis pigmentosa. The bionic eye may have been a fantasy just a few years ago, but the NEI has always envisioned the future.

In closing, I would like to note that in public opinion polls over the past 40 years, Americans have consistently identified fear of vision loss as second only to fear of cancer. In summary, NAEVR requests Fiscal Year 2014 NEI funding at \$730 million since our Nation's investment in vision health is an investment in 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. It can also increase productivity, help individuals to maintain their independence, and generally improve the quality of life.

Thank you very much.

Mr. KINGSTON. Thank you very much, Doctor.

Questions?

Ms. DELAURO. I want to say, thank you very, very much, Doctor. I think you make a very serious point here on the effect of sequestration for this year. And it would appear that we have moved forward on it. It is going to be locked in as to the NIH of about \$1.6 billion.

I want to make note of the work that you are doing, and I refer to the chair and what he at his remarks talked about the disease that his dad had.

Dr. SCHOLL. Yes, AMD.

Ms. DELAURO. Right, and I have family members with that same problem. I also looked to one of our earlier witnesses, Susie Trotochaud, and her 2 children with Usher Syndrome.

What we are potentially looking at here, it is easy to talk about the numbers and to say, well, that is, you know, the way it has to be. But the numbers have a very profound effect on the lives of real people, and what will be there and what will not be there to address serious disease prevention and treatment.

We need to—and I say not about you—we need to take a very, very hard look at where or responsibilities are and where our prior-

ities are in terms of addressing the needs of the American people and their health concerns.

Thank you, Mr. Chair.

Dr. SCHOLL. I am very happy about your comment. Thank you.

Mr. KINGSTON. Thank you very much, Doctor.

The next witness is Dr. Christopher Kus, associate medical director of the Division of Family Health within the New York State Department of Health. And you are speaking on behalf of the Association of Maternal and Child Health Programs.

Dr. KUS. Yes.

Mr. KINGSTON. Welcome.

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WEDNESDAY, MARCH 13, 2013.

**ASSOCIATION OF MATERNAL AND CHILD HEALTH PROGRAMS**

**WITNESS**

**CHRISTOPHER KUS, M.D., ASSOCIATE MEDICAL DIRECTOR OF THE DIVISION OF FAMILY HEALTH, NEW YORK STATE DEPARTMENT OF HEALTH, ASSOCIATION OF MATERNAL AND CHILD HEALTH PROGRAMS**

Dr. KUS. Thank you.

Chairman Kingston, Ranking Member DeLauro, and members of the subcommittee, it is an honor to testify before you today on behalf of the Association of Maternal and Child Health Programs. My name is Chris Kus. I am a pediatrician who works in the Maternal and Child Health Program within the New York State Department of Health, and I represent the Association of Maternal and Child Health Programs, which represents maternal and child programs in States and territories throughout the United States.

My message today is simple. No more budget cuts. Non-discretionary programs cannot continue to bear the brunt of efforts to reduce our nation's deficit. Sequestration cuts will undermine our efforts to promote and protect the health of women, children, and families. Together, public health systems and WIC, the Women and Children Nutrition Program, will be absorbing \$1.2 billion in cuts over the next 7 months. These cuts will cause pain and reduce our capacity to prevent suffering.

The Title 5 maternal and child health services block grant, in particular, has been reduced by \$124 million since Fiscal Year 2003. Let me repeat that. A program dedicated to improve the health and well-being of women, children, children with special health care needs, and their families, has been reduced by 17 percent and sinking to its lowest level of funding since 1991.

My bottom line is we have done our part to reduce the deficit, which is why I am asking you for sustained funding of \$640 million for the Title 5 block grant for Fiscal Year 2013, 2014, and beyond.

The Title 5 block grant is the core pillar of public health programs dedicated to these vulnerable populations. It is the foundation upon which State maternal and child health programs are built. Without Title 5, States would lack the critical means for coordinating and managing our efforts to assist these populations.

No one would be looking at the system of care for children with special health care needs, and no one else would bring together academics, non-profits, and administrators to tackle the complex issues surrounding infant mortality, maternal mortality and morbidity, and childhood obesity. Without Title 5, States would lose the ability to address the most pressing state needs.

Let me highlight some of the identified needs in your States, Mr. Chairman: reduce motor vehicle crash mortality among children 15 to 17 years of age, reduce repeat adolescent pregnancy, increase developmental screening for children in need, improve childhood nutrition, decrease obesity among children and adolescents, and increase the percent of qualified medical providers who accept Medicaid and who serve children with special health care needs.

Title 5 can be used to address these identified needs, but without adequate resources we will fall short, and our population will suffer. In my State of New York, I am going to highlight 3 things that cuts in funds will hinder our efforts.

We are working on reducing infant mortality, which is higher than it should be in the United States and in our State. We are also reducing maternal mortality and morbidity. We have a program where we work with hospitals to reduce the rate of elective C-sections and inductions that do not have medical indications. This means mothers can be healthier and babies can be healthier. And it will also limit our ability to help children with special health care needs and their families. These are families that are going to have a hard time navigating the changing health care delivery system.

Despite these cuts, we still have made progress over the past decade. Oftentimes the State public health employees whose livelihood these cuts will jeopardize just work harder, longer, and smarter. Because they care so deeply about their mission, all States are moving to screening for a core panel of treatable metabolic conditions. As we heard before, the SCID condition.

Many States are working toward reducing infant mortality rates and, again, elective C-sections and inductions that are not medically indicated. We continue to partner with Medicaid to improve and explore ways in which we can reduce costs to the health care system.

These advances in public health do not happen without dedication, resources, and true Federal-State partnership. Sustained funding is needed, necessary, and critical to ensure the health and well-being of our mothers, our children, our families, and our country.

Thank you.

Mr. KINGSTON. Thank you very much, Dr. Kus.

Any questions?

Okay. Well, thank you. Stay in touch.

Next, Dr. Alice Thornton, medical director of the Bluegrass Care Center, Ryan White Medical Providers Coalition.

WEDNESDAY, MARCH 13, 2013.

**RYAN WHITE MEDICAL PROVIDERS COALITION****WITNESS****ALICE THORNTON, M.D., MEDICAL DIRECTOR, BLUEGRASS CARE CLINIC, RYAN WHITE MEDICAL PROVIDERS COALITION**

Dr. THORNTON. Good morning or afternoon now maybe. Chairman Kingston and other members of the subcommittee, thank you for this opportunity to be here today. Just an aside, listening to everyone else reminds me of why I went into medicine and why I am happy to be an American. And we are doing, I think someone said, God's work, and I am happy to be part of that. I am happy that you are listening to us. It is very important.

As I said, I am Alice Thornton, and as you pointed out, I am from the University of Kentucky at the Bluegrass Care Clinic. And I am here today to submit my testimony on behalf of the Bluegrass Care Clinic and all the patients that I have served for the last 15 years. I am here to submit my testimony on behalf of the Ryan White Medical Providers Coalition, which I co-chair, and the HIV Medical Association of which I am a member.

Thank you for the opportunity to describe the lifesaving HIV/AIDS care and treatment provided by Ryan White Part C funded programs, including my own.

The Bluegrass Care Clinic, as I have mentioned, is part of the University of Kentucky, and it has provided HIV primary care in 63 counties—in Kentucky we like to have a lot of counties—63 counties of central and eastern Kentucky for the past 23 years. Over half of the counties that I serve are economically distressed, and the BCC cares for 74 percent of the people living with HIV in that region. There is no one else to take care of them.

Over the past 10 years, our numbers of patients have increased by 136 percent. In 2001, someone approached me that we should apply for Ryan White Part C funding. At that time, we had 400 patients. This year we just turned in our Federal report, and we have 1,110 patients, and we are not advertising.

The annual outpatient medical appointments have increased by almost 400 percent. We continue to get anywhere from 4 to 7 new patient calls a week with folks asking to come in and establish with us. The university incurs an annual deficit of approximately \$1.2 million a year to just let us exist there.

In addition to the Ryan White Part C funding that provides direct Federal grants for comprehensive medical clinics like the BCC, most Part C clinics, including us, also receive support from other parts of the Ryan White program that help provide access to medications, additional medical care, such as dental services, and key support services, such as case management and transportation. The transportation, I was thinking of you, Mr. Kingston, in Georgia. I visited some of the sites there and in Kentucky. That is so important. And then our cities. So all this comes together to provide that wonderful care that we provide.

These are essential components of the highly-effective Ryan White HIV care model. The Ryan White program is critical to providing both effective and efficient HIV care.

I thank the subcommittee for its support of the Ryan White Part C program in Federal Year '12 and this first part of Federal Year '13. And while I am grateful for this support and know that times are tough, I request a \$21.5 million increase for Ryan White Part C programs in Fiscal Year '14.

While this is a lot of funding, it is well below the estimated need, and Ryan White providers would spend those dollars effectively and efficiently in caring for these patients.

And my favorite thing to say is, I have never thought of myself as being a huge government person, but I am a huge supporter of these types of programs and this program. I can tell you that these dollars are spent very effectively. And HRSA has done a great job of trying to get folks to be very transparent in how we are spending our dollars.

I would like to share with you a quick story of a patient that I cared for. I am calling her Mary. She was a patient of mine. She was only 28 years old. She was employed and had a very supportive family, like a lot of folks you may know. Sadly, Mary had suffered a sexual assault years before and had been exposed to her HIV. When Mary became sick, she did not get tested and treated for HIV despite several medical appointments with a range of clinicians.

By the time I started taking care of Mary, she had full-blown AIDS and had Kaposi's sarcoma in her lungs. She spent a long time, 2 to 3 months, fighting for her life. One of her comments that will haunt me is her looking at me and saying, Dr. Thornton, please help me live. Please, I do not want to die.

In the hospital, Mary received top line care that was very expensive because we got her at the end. This intensive care with intubation that she required cost \$4,000 a day. Had she been detected early and been in our clinic, it would have cost maybe, not counting the medications, but just the care, \$3,000 a year. So you can see that is a huge difference.

After a long stay in the hospital, I am sorry to say that Mary did not live. She did die of her AIDS.

Ryan White Part C funds comprehensive expert and effective HIV care and treatment, services that are responsible for the dramatic decrease in AIDS-related mortality and morbidity over the last decades.

In a sample of 8 Ryan White funded Part C programs from the rural South to the Bronx, retention and care ranged from 87 to 97 percent, well above the CDC estimates that only 37 percent of all people with HIV nationally are in regular care.

Mr. KINGSTON. Dr. Thornton, I hate to—

Dr. THORNTON. Yeah, that will be fine.

Mr. KINGSTON [continuing]. But we have your written testimony.

Dr. THORNTON. Yes.

Mr. KINGSTON. But you are obviously very passionate about your work, and it is really good that people like you are willing to do what you do. You are doing the Lord's work.

Dr. THORNTON. Thank you.

Mr. KINGSTON. Lucille, Do you have any questions?

Dr. THORNTON. Thank you so much.

Mr. KINGSTON. Well, thank you.

Next, Mr. Carl Schmid, deputy executive director of The AIDS Institute.

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WEDNESDAY, MARCH 13, 2013.

**THE AIDS INSTITUTE**

**WITNESS**

**CARL SCHMID, II, DEPUTY EXECUTIVE DIRECTOR, THE AIDS INSTITUTE**

Mr. SCHMID. Good afternoon. The AIDS Institute is pleased to offer comments in support of critical domestic HIV programs. We thank you for your support over the years, and hope you will do your best to adequately fund them in the future.

HIV remains one of the world's worst health pandemics. In our own country, we have had over 600,000 people who have already died. There are 50,000 new infections every year and a record number of 1.1 million people living with HIV. Persons of minority races, and ethnicities, and the poor are disproportionately affected.

The U.S. government has played a leading role in fighting AIDS. The vast majority of the discretionary programs supporting domestic AIDS programs are funded through this subcommittee. We are keenly aware of the budget constraints and competing interests, but programs that prevent and treat HIV are inherently in the Federal interest as they protect the public health against a very highly infectious virus. If left unaddressed, it will certainly lead to increased infections, more deaths, and higher costs.

With the advent of anti-retroviral medicines, HIV has turned from a certain death sentence to a treatable chronic disease if people have access to health care and medications. Through prevention, care and treatment, and research, we now have the ability to actually end AIDS. HIV treatment not only saves lives, but it also reduces transmission. But people have to be diagnosed through testing, linked to and retained in care.

We also have a national AIDS strategy that sets clear goals and priorities and brings all Federal agencies together to ensure resources are well coordinated. With all of these positive developments, it would be a shame to go backwards, but that is what could happen given the continuing the resolution, sequestration, and budget cuts now on the table.

The Ryan White program provides care, medications, and support services to over a half a million people. With people living longer, new diagnoses, and the demands on the program continue to grow, and there are many unmet needs. According to the CDC, only 33 percent of the people with HIV in our country have been prescribed anti-retroviral treatment. As you can see, we have a long way to go to realize an AIDS-free generation.

The AIDS Assistance Program, ADAP, provides medications to over 200,000 people. As testing increased and people lost their jobs and health insurance, demand on the program far outpaced the budget, which led to wait lists of over 9,000 people, the longest being in the State of Georgia. We are thankful that Federal funding was increased and the wait list now is less than 100.

But with the continuing resolution and sequestration, this could all change. Sequestration could force States to stop paying for medications to over 7,000 people currently taking drugs. This is very dangerous as once treatment begins, the drugs must be taken every day without interruption.

We urge you to prevent this and fund ADAP and the rest of the Ryan White program to keep up with the growing demand. Just last year, ADAP enrollment increased by over 13,000 people, or 8 percent.

In terms of prevention, we only allocate 3 percent of AIDS spending towards prevention at the CDC. All the care and treatment costs that I just talked about would be saved if we did not have infections in the first place.

With more people living with HIV than ever before in our country, there are greater chances of transmission. The CDC is doing its best with limited resources to keep the number of infections stable, but that is not good enough. It is focusing its resources on those populations and communities most impacted and investing in those programs that prevent the most infections.

With over 200,000 people living with HIV who are unaware of their infection, the CDC is also focused on increased testing. We have made great strides in the area of AIDS, but 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, thank you for your continued support. We have made great progress, but we are still far from achieving our goals 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.

Mr. KINGSTON. Thank you, Mr. Schmid. And I have visited a number of PEPFAR facilities, and I know a lot of the great results have come because of the major commitment to fighting AIDS in Africa. And I know you are sharing lots of that information, and we will both benefit from it.

Mr. SCHMID. Thank you.

Mr. KINGSTON. Thank you very much.

Next, Dr. Jeff Levi.

Dr. LEVI. Levi, you got it right.

Mr. KINGSTON. Okay, I want to make sure. Executive director of the Trust for America's Health.

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WEDNESDAY, MARCH 13, 2013.

## TRUST FOR AMERICA'S HEALTH

### WITNESS

**JEFF LEVI, M.D., EXECUTIVE DIRECTOR, TRUST FOR AMERICA'S HEALTH**

Dr. LEVI. Good afternoon, Chairman Kingston, Congresswoman Roybal-Allard. I am Jeff Levi. I am executive director of Trust for America's Health, a non-profit, non-partisan organization dedicated to making disease prevention a national priority.

As you craft legislation for the HHS appropriations for Fiscal 2014, I want to urge you to include adequate funding for prevention and preparedness programs at the Centers for Disease Control and Prevention and other public health agencies.

Cuts to the CDC, our Nation's lead public health agency, have already been stark. Compared to Fiscal 2010, when you include sequestration, the CDC will have seen its budget authority cut by 18 percent over 3 years.

Cuts in CDC funding, combined with the recession, mean that State and local public health capacity, our front line in protecting us from communicable diseases via terrorist threats and natural disasters, have also been greatly diminished. Indeed, we have seen a 20 percent loss in the State and local health department workforce. Overall, scarce resources means CDC will be forced to make extremely tough, sometimes life and death, choices.

My written testimony submitted for the record includes a number of specific recommendations concerning funding for chronic disease prevention, preparedness, environmental health, and other budget lines for CDC. I would like to focus my oral comments today on outlining the crucial public health investments that will be required to help solve our health and fiscal crises.

As a Nation, we face daunting economic and fiscal challenges. To a large degree, these are driven by high health care costs. Indeed, we spend roughly 75 percent of our Nation's \$2.5 trillion in health care spending on preventable chronic diseases.

Despite this expenditure of scarce resources, we are managing sickness, not preventing it, and are faced with the grim prospect that if we remain on our current trajectory, our children may be the first in U.S. history to live less healthy lives than their parents.

Fortunately, the vast majority of our chronic disease burden is preventable through proven approaches that focus primarily on increased physical activity, improved nutrition, and reduced tobacco use. A recent Trust for America report estimates that if the average mass index were reduced by 5 percent, which is a very small change, in just 5 years the United States would save \$30 billion in health care costs and prevent millions of cases of diabetes, heart disease, stroke, arthritis, and cancer.

The Prevention and Public Health Fund is a first of its kind mandatory investment towards improving health. To date, the fund has invested \$2.25 billion since Fiscal 2010 to support State and local public health efforts to transform and revitalize communities, build epidemiology and laboratory capacity to track and respond to disease outbreaks, train the Nation's public health and health workforce, prevent the spread of HIV/AIDS, expand access to vaccines, reduce tobacco use, and help control the obesity epidemic.

Continuing the investments in the Prevention and Public Health Fund is vital to bending the health care costs curve, and assuring that Americans across the Nation have the health promotion they rightly expect.

The Community Transformation Grants Program, administered by the CDC, is one of our best prevention opportunities. CTG grants empower States and localities to address the drivers of chronic disease as determined by local leadership. This is a locally-driven program. Most importantly, it requires communities to cre-

ate partnerships to achieve sustainable solutions to help make the healthy choice the easy choice.

Strategies of the Community Transformation Grants deploy must be by law evidence-based, and all grantees have rigorous health outcomes improvement goals that must be met. I want to emphasize this point. CTG grantees, unlike many of our other health programs have health outcome standards that they are held accountable for. It is also important to note that as required by law, at least 20 percent of the CTG funds must be targeted to reach rural or frontier communities.

However, with current levels of funding, only 4 in 10 Americans are reached by the CTG Program. Therefore, we recommend that the committee allocate \$300 million from the Prevention Fund for the CTG Program in Fiscal 2014, which will allow the program to reach millions more Americans.

Investing in disease prevention is the most effective, common sense way to improve health and help address our long-term deficit. Hundreds of billions of dollars are spent each year via Medicaid, Medicare, and other Federal health care programs to pay for health care services once patients develop an acute or chronic illness or injury, and they present for treatment in our health care system.

A sustained and sufficient level of investment in public health and prevention efforts is essential to reduce these high rates of disease and these high costs, and improve the health of Americans.

Thank you.

Mr. KINGSTON. Thank you very much, Dr. Levi. And I am going to move on, Rosa, yes, if that is okay.

Ms. DELAURO. I just want to say thank you. We have to stop saying that the Prevention Fund—I am sorry, Mr. Chairman—that the Prevention Fund is the way to fund CDC and let us do in the Prevention Fund while we cut the appropriations for CDC, which has been a pattern of this committee. We have got to turn it around. Thank you for what you are doing.

Dr. LEVI. Thank you.

Mr. KINGSTON. Okay. Caitlin Connolly, project manager of Eldercare.

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WEDNESDAY, MARCH 13, 2013.

**ELDERCARE WORKFORCE ALLIANCE**

**WITNESS**

**CAITLIN W. CONNOLLY, PROJECT MANAGER, ELDERCARE WORKFORCE ALLIANCE**

Ms. CONNOLLY. Thank you. Mr. Chairman, Ranking Member DeLauro, and members of the committee, good afternoon, and thank you very much for the opportunity to speak before you.

My name is Caitlin Connolly, and I am here on behalf of the Eldercare Workforce Alliance, a coalition of 28 national organizations representing health care professionals, including direct care workers, as well as consumers, providers, and family care givers. We joined together to form this coalition, united in our mission to

address the immediate and future workforce crisis in caring for an aging America.

Roughly 10,000 Americans turn 65 every day, and they will do so every day for the next 16 years. And an unprecedented number of adults, 19 million, will be over 85 by 2050 as compared to 5.5 million today. Yet our workforce is ill prepared to meet the needs of this unique group who require unique care.

As the subcommittee begins consideration of funding for Fiscal Year 2014, the Alliance urges you to provide adequate funding for programs designed to increase the number of health care professionals prepared to care for the growing senior population, as well as train the entire workforce, and support family care givers and the essential role that 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, as well as cognitive impairments. It is estimated that an additional 3.5 million trained health care workers will be needed just to maintain the current levels of access.

Unless we expand training and educational opportunities, the workforce will be even more constrained in its ability to care for the growth of the elderly population as the baby boomer generation ages. Reflecting this urgency, the Health Resources and Services Administration, HRSA, has identified enhancing geriatric eldercare training and expertise as one of its top 5 priorities.

The Geriatrics Health Profession Training Programs administered through HRSA and authorized under Title 7 and Title 8 of the Public Health Service Act, are integral to ensuring that America's health care workforce is prepared to care for the Nation's rapidly-expanding population of older adults.

The Title 7 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 training programs, the geriatric academic career awards, geriatric education centers, and geriatric training programs for physicians, dentists, behavioral and mental health professions, as well as the Title 8 nursing program, the Comprehensive Geriatric Education Program, offer critically important training for a health career workforce overall to improve the quality of care for older adults.

In total, these programs provided training to more than 120,000 people in the 2010–2010 academic year alone. Of equal importance is supporting the legions of family caregivers who provide billions of hours of unpaid, uncompensated care that allow for older adults to remain in their homes and in their communities.

Family caregivers can face physical, emotional, mental, and financial challenges in their unique role. The Family Caregiver Support Program, authorized through Title 3 of the Older Americans Act, as well as the Alzheimer's Disease Demonstration grants to States and the Lifespan Respite Care Programs, administered through the Administration for Community Living, offer crucial supports to older adults and their family caregivers.

The estimated economic value of family caregivers' unpaid care was approximately \$450 billion in 2009. Without these Federal pro-

grams, family caregivers helped by them may be unable to confront the challenges of their role.

To just maintain the level of training and support, we ask for \$42.1 million in support of Title 7 and Title 8 health professions programs, and \$173 million for programs supporting family caregivers.

On behalf of the members of the Eldercare Workforce Alliance, we commend you on your past support, for geriatric workforce training programs, as well as family caregiver support programs, and ask that you join us in ensuring that these programs continue to meet the needs of older adults, for all Americans deserve quality care, now and in the future.

Mr. KINGSTON. Thank you very much, Ms. Connolly. Those are some astounding statistics, and a really great attention grabber.

Next we have Kristen Sands, who is a school counselor, Jacksonville Heights Elementary School, on behalf of the American School Counselor Association. Welcome.

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WEDNESDAY, MARCH 13, 2013.

## **AMERICAN SCHOOL COUNSELOR ASSOCIATION**

### **WITNESS**

**KRISTEN SANDS, M.ED., SCHOOL COUNSELOR, AMERICAN SCHOOL COUNSELOR ASSOCIATION**

Ms. SANDS. Yes, thank you. Good afternoon. My name is Kristen Sands, and I have been an elementary school counselor in Duval County Public Schools located in Jacksonville, Florida, for the past 3 years, and I am an active member of the American School Counseling Association.

I am here to speak to you today about the Elementary and Secondary School Counseling Program grants that are funded by the U.S. Department of Education. We are respectfully requesting funding of \$75 million for Fiscal Year 2014.

In 2010, Duval County received the Elementary and Secondary School Counseling Program Grant to improve the ratio of school counselors, school psychologists, and school social workers to students. Our focus has been on reducing the number of discipline referrals and increasing direct counseling services at 4 identified schools. One of those is Jacksonville Heights Elementary, where I work in a position funded by the grant.

Jacksonville Heights has 2 full-time school counselors as well as a half-time school psychologist and a social worker serving as our counseling team. This type of staffing also has been put in place at 3 other schools in Duval County, improving the average ratio of school counselors, school psychologists, and school social workers to students from 602 to 1 to 264 to 1.

The grant has had a tremendous impact on our students and helped improve student achievement at our school, which serves 779 students in grades kindergarten through 5. A Title 1 school, Jacksonville Heights is located in an area greatly affected by high poverty and high crime. Our students have parents who are incarcerated. Many are being raised predominantly by single mothers or grandparents. They are victims or witnesses to violence, receive in-

adequate supervision, and have few, if any, positive role models. Their caregivers often are in crisis mode and unable to participate in their child's education.

We have a very diverse student body: 76 percent of our students are minorities, 80 percent qualify for free or reduced price lunch, and 18 percent have disabilities. My school has 3 self-contained classrooms for students with severe emotional and behavior disabilities, and is home to 2 classrooms designed for students who have been retained 2 or more years.

In 2008–09 school year, on average, 1 discipline referral was written for every 2 students at our school for reasons ranging from disruption to violent behavior towards staff. It is crucial that children develop the skills they need during the elementary grades so that they can become successful learners and grow to become productive members of our society, especially in schools with high needs.

Nationally, 1 in 3 black males and 1 in 6 Latino boys born in 2001 are at risk of imprisonment during their lifetime according to the Children's Defense Fund. A significant number of girls are also in the juvenile justice system. The rate of incarceration is endangering children at younger and younger ages. This is America's pipeline to prison, a path that leads to marginalized lives and often premature death.

Although the majority of our Nation's fourth grades cannot read at grade level, States spend about 3 times as much money per prisoner as per public school pupil.

It is imperative to continue for the grants like the one I am working on so that we can increase academic achievement and prevent future incarcerations. This grant has allowed us to put early preventative supports and intervention programs in place that did not exist before.

Every Jacksonville Heights student now receives classroom instruction using research-based programs from a counseling team on a variety of topics, such as how to manage anger, make good decisions, and resolve conflicts. Before we received this grant, only 40 percent of our 3rd through 5th grade students reported having knowledge about goal setting, career college information, study skills, self-calming coping strategies. Today, 93 percent of these students report having knowledge of these skills.

We have also developed partnerships with neighboring high school students, the U.S. Navy and Big Brother/Big Sister to provide students with mentors. Mentors check in weekly to encourage our students and monitor their progress academically and behaviorally.

Just last month, a fifth grade student in the program wrote a letter to school staff about how she wants to turn her life around, stop being a follower and become a leader. The student has a history of discipline issues and was indeed headed down the wrong path. Her behavior and attitude has improved drastically, and she will be joining us on a trip to the University of Florida in May to explore college and career options. She has decided that she wants to become a doctor one day.

On a typical day at Jacksonville Heights, you will find students using our calm down bean bag chairs to practice self-calming cop-

ing strategies or even our peace corner and peer mediation program to work out conflicts with friends. Our students are acquiring the skills necessary to be more proactive and in control of their own behavior and future instead of being reactive to situations and conflicts. These are skills that they will need for the rest of their lives, and it is powerful to witness these students making decisions to use these on their own.

The expanded counseling team has a full schedule of individual and small group counseling sessions, classroom observations, and behavior intervention plans, and problem-solving team meetings to address student needs. We have even developed a student check in/check out system that allows us to counsel with a greater number of students. Students who are at risk check in with a member of the counseling team at the beginning and the end of the week to make sure that they stay on track. Students look forward to it and enjoy the positive attention. Additionally, our grant funded social worker conducts home visits for these students to further address issues that are interfering with learning.

Students, teachers, and parents now seek our counseling services and are lined up outside our office doors at any given time of the day. Just last week, a student came to me and said, Ms. Sands, I heard that you teach anger management groups, and I need to be in one.

Mr. KINGSTON. Ms. Sands, that is rolling over here. Thank you very much.

Mr. KINGSTON. Any questions?

Ms. DELAURO. I just want to say if we are serious in this body about addressing the issue of prevention of violence, sometimes it leads to gun violence, but the prevention of violence, then we would heed your words about counseling, and professional counselors in our schools to help youngsters deal with anger management and help them with conflict resolution.

Thank you.

Ms. SANDS. Thank you.

Mr. KINGSTON. Overall, do you rate Duval County Schools good, bad, medium?

Ms. SANDS. Good.

Mr. KINGSTON. Put you on the spot here.

Ms. SANDS. We have a new—I know. We have a new superintendent this year, so a lot of changes, but good things on the horizon.

Mr. KINGSTON. Well, thank you very much for your testimony.

Ms. SANDS. Yes, thank you.

Mr. KINGSTON. Our next witness is Dr. Richard Furie of the Lupus Research Institute.

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WEDNESDAY, MARCH 13, 2013.

**LUPUS RESEARCH INSTITUTE**

**WITNESS**

**RICHARD FURIE, M.D., LUPUS RESEARCH INSTITUTE**

Dr. FURIE. Chairman Kingston, Ranking Member DeLauro, Representative Roybal-Allard, and members of the committee, I am a rheumatologist in New York, but today I am speaking on behalf of the Lupus Research Institute, the Nation's only non-profit organization solely dedicated to novel, pioneering, and high risk research in lupus.

We believe that innovative research is the key to finding safer and more effective treatments, and eventually a cure for lupus. Now, sounding a little bit like a broken record, but this is a vital issue.

Our primary request for your consideration as you prepare the Fiscal 2014 appropriations bill is to strengthen support for biomedical research at the National Institutes of Health by providing at least \$30 billion.

Imagine a disease that is a leading cause of heart attacks, stroke, and kidney disease among young women. Imagine a disease that randomly strikes the innocent without warning. It attacks the brain the heart, lungs, or blood, virtually any organ. Imagine a disease with no known cause or cure. And finally, imagine a disease that waited over 50 years before receiving its first new drug for treatment. That disease is lupus.

Although there are over 100 autoimmune diseases, lupus is the prototypic autoimmune disease. And I can assure you, based on my 30 years of personal experience in clinical practice and also in research, this is a dangerous, debilitating, and heartbreaking disorder. It affects over 1.5 million persons in the U.S. Ninety percent of patients are women, and the disease disproportionately affects American Americans, Hispanics, Asians, and Native Americans. Lupus is 3 times more common in American Americans than in Caucasians.

And lupus has no respect for age. It affects young children, adolescents, and adults, but approximately 80 percent of new cases of lupus develop among young women, women in their childbearing years.

During the course of my career, approximately 100 of my lupus patients have died, and countless have had strokes or have gone on to kidney failure. I could fill the entire day with heartbreaking stories. Our goal is to cure this disease so there are no more stories.

The Lupus Research Institute was founded 12 years ago. Its mission has been to invest in pioneering, innovative research searching for the cause and the cure. The LRI's investment has provided academic-based investigators with the ability to initiate studies, make breakthroughs, and become successful in obtaining highly-competitive NIH funding to continue their research.

We and similar private research organizations all depend on a strong and vibrant biomedical research enterprise fueled and led by the NIH. We could never be successful without it. However, the fiscal climate of the past few years has threatened the stability of the biomedical research enterprise.

The first phase of sequestration now underway will cap 3 years of flat funding for the NIH. As \$1.6 billion in cuts are applied over the next 7 months, vital research will be delayed, halted, or per-

haps even abandoned. The effects on the private sector researchers and institutions across the country will be absolutely devastating.

Over the past 10 years, the NIH budget has effectively fallen by nearly 20 percent after inflation. Stagnant investment will have a huge and damaging effect, and this will be long lasting, on our already dwindling pipeline of young investigators. And austere research spending program will no doubt jeopardize the position of the United States as a global leaders in biomedical research. But the ultimate fallout is a negative impact on the Nation's health.

The \$30 billion level that we seek for 2014 represents a modest 2.7 percent increase. We request that you provide at least that amount. I think someone asked for \$32 billion. We will up that even more.

We support efforts to permanently replace sequestration. We respectfully urge Congress and the Administration to work together on a solution that addresses the Nation's fiscal needs while preserving the national investment in biomedical research and the health of the American people.

As you develop the Fiscal 2014 appropriations bill, the Lupus Research Institute, on behalf of patients, on behalf of scientists, and lupus health care providers, urges your committee to support the NIH, our critically important national research agency.

I thank you.

Mr. KINGSTON. Thank you very much.

Rosa.

Ms. DELAURO. Amen.

Dr. FURIE. Yeah. [Laughter.]

Mr. KINGSTON. Thank you, Dr. Furie.

Next, Harry Johns, the president and CEO of Alzheimer's Association.

Mr. Johns.

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WEDNESDAY, MARCH 13, 2013.

## ALZHEIMER'S ASSOCIATION

### WITNESS

#### HARRY JOHNS, PRESIDENT AND CEO, ALZHEIMER'S ASSOCIATION

Mr. JOHNS. Good afternoon. Mr. Chairman, Ranking Member DeLauro, members of the subcommittee, thank you so much for allowing us to speak before you today. I am Harry Johns, president and CEO of the Alzheimer's Association, the leading voluntary health organization in Alzheimer's research care and support.

I also have the privilege to serve on the Advisory Council on Alzheimer's Research Care and Services, which was created by Congress through the National Alzheimer's Project Act.

Ladies and gentlemen, no other condition has such devastating human effects on so many, kills so many, drives so much cost to both Medicare and Medicaid, and as of yet there is no way to stop it, yet is so underfunded to change its course.

Alzheimer's is not just a little memory loss. It is progressive, it is degenerative, and it is fatal. It will likely take—it will ultimately take every memory and every bodily function from someone that

has it. It also has the potential to be devastating to our Federal budget.

The numbers related to Alzheimer's are just staggering. Today there are 5 million Americans living Alzheimer's, 15 million others are their unpaid caregivers. It is not normal aging, but age is the biggest risk factor. So with baby boomers, like me, I am not turning 65 yet, but with baby boomers turning 65 at a rate of 10,000 each and every day, within just 37 years, the number of people who will have the disease will likely be near 14 million or even higher.

Right now it is the 6th leading cause of death, and while thankfully deaths from other major diseases, including heart disease, stroke, breast cancer, prostate cancer, HIV, have significantly declined, regrettably those from Alzheimer's have increased 68 percent between 2000 and 2010. In fact, it is the only one of the top 10 leading causes of death that has no way to stop it, no way to prevent it, or no way to even slow its progress.

In 2012, America spent an estimated \$200 billion on direct costs for care for Alzheimer's and other dementias alone, and \$140 billion of that amount went to Medicare and Medicaid costs. Unless something is done, those costs are projected to soar to \$1.1 trillion in Fiscal Year 2050, in that year alone. And that is not inflated. That is in today's dollars. That is more than the total discretionary spending cap for 2013 established by the Budget Control Act of 2011.

So taken over time, caring for people with Alzheimer's and other dementias will cost \$20 trillion over the next 40 years. That is enough to pay the current national debt and also still send a check for \$10,000 to every man, woman, and child in America. As your subcommittee seeks solutions to our Nation's fiscal challenges, you will be hard pressed to find something that has better long-term opportunity than Alzheimer's.

The average per person Medicare costs for those with Alzheimer's and other dementias are 3 times higher for someone else in the program who does not have dementia. Three times higher. For Medicaid, it is 19 times higher. A treatment that would even just delay onset or progression of Alzheimer's by 5 years would save more in Medicare alone in 1 year than all the money the Federal government has committed to Alzheimer's research funding to this point in all of history.

So any discussion of entitlement reform really must include addressing Alzheimer's in order to have the kind of significant impact in controlling future Medicare and Medicare spending. Until recently at the Federal government level, there was no strategy to address this crisis, but in 2010, thanks to bipartisan support from Congress, the National Alzheimer's Project Act, or NAPA, passed unanimously. It requires an annually updated strategic national Alzheimer's plan to help those facing the disease today, and to change the course of the disease for the future. But unless the resources are available to implement this plan, we cannot hope to succeed.

Congress must provide the resources that scientists need to find the answers, and we need to do it soon. Consistent with the congressional direction in NAPA, the President's Fiscal Year 2013 budget request included \$80 million for Alzheimer's research, and

\$20 for education, and outreach, and support. These funds are a down payment on the essential research and services that Americans so badly need.

It is vital that we commit the resources that were laid out in that budget, and for Fiscal 2014 the Alzheimer's Association urges Congress to fully fund the priority activities of the National Alzheimer's Plan.

So in closing, the Alzheimer's Association certainly appreciates your steadfast support at the subcommittee level and the priority setting activities that you pursue. And we also look forward to working with Congress to adequately address the Alzheimer's crisis because, ladies and gentlemen, if we do not act soon, it could be too late to save the baby boomer generation and all the associated costs of care that future generations will have to pay.

Thank you.

Mr. KINGSTON. Thank you, Mr. Johns. It is a scary situation.

Any questions?

If not, we have one more witness.

Mr. JOHNS. Thank you.

Mr. KINGSTON. Thank you very much. Well done.

Next, Lorrie Kaplan, chief executive officer of the American College of Nurse-Midwives. Welcome.

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WEDNESDAY, MARCH 13, 2013.

## AMERICAN COLLEGE OF NURSE-MIDWIVES

### WITNESS

**LORRIE KLINE KAPLAN, EXECUTIVE DIRECTOR, AMERICAN COLLEGE OF NURSE-MIDWIVES**

Ms. KAPLAN. Thank you so much. My husband says I like to have the last word.

Mr. KINGSTON. You got it today. You earned it.

Ms. KAPLAN. All right, thank you very much.

Chairman Kingston, Ranking Member DeLauro, Representative Roybal-Allard, members of the subcommittee, thanks so much for the opportunity to appear before you today.

My name is Lorrie Kline Kaplan. I am the chief executive officer of the American College of Nurse-Midwives. We represent more than 12,000 certified nurse-midwives and certified midwives in the United States. So I appreciate the opportunity to discuss who we are and why midwives are more relevant than ever in these times of primary and maternity care provider shortages, sobering health care disparities, and runaway costs. I will also discuss the vital importance of Federal funding for midwifery programs and Title 8 of the Public Health Service Act, the National Health Service Corps, and the National Institute for Nursing Research.

First, our story briefly. With roots dating to 1929, ACNM sets the standards for excellence in midwifery education and practice in the United States. We are the organization that has led and is leading midwifery care in the U.S. into the 21st century. In nearly all other developed countries, midwives are the primary providers of care for women in pregnancy and birth. But here, as you know, it is not the case.

But if we want to one day afford and achieve the first rate, high value maternity care our daughters and granddaughters deserve, no matter where they live, regardless of race, or ethnicity, or economic status, we need a larger, highly-skilled midwifery workforce. And this model would also be highly cost-effective.

Our members have a well-documented track record of excellence, achieving excellent birth outcomes, but with low cesarean and medical intervention rates, which reduces costs. We often serve women with limited access to health services through Medicaid, or in the Indian health service, or in federally qualified health centers.

In 2009, our midwives attended more than 320,000 births in the United States, and about 96 percent of those were in hospitals. This represents an all-time high of 8.1 percent of all births, and over the past decade, the percentage of vaginal births attended by midwives is up nearly 21 percent.

Our members are highly educated. They complete a graduate education from one of 39 accredited programs, including Emory, Yale, and Cal-State Fullerton, based largely in schools of nursing. We are well represented in this room I have to say, but also in schools of health sciences, public health, or medicine. CNMs are licensed to write prescriptions in all 50 States and U.S. territories. Certified midwives also earn a master's degree and sit for the same certification exam as CNMs, and are authorized to practice in Delaware, Missouri, New Jersey, New York, and Rhode Island.

While we are best known as maternity care providers, midwives are also recognized federally as primary care providers for women throughout the life span, from adolescence through menopause.

Medicaid reimbursement for CNMs is mandatory, and Medicare pays the same fee for certified nurse-midwives as it does to OB/GYNs or other physicians for the exact same service.

Now, I will transition to the policy implications. Title 8 of the Public Health Service Act provides vital support for training all levels of nurses from associate degree through post-graduate. Midwifery education is supported through the Advanced Nursing Education Program and the Advanced Education Nursing Traineeship administered by the Health Resources and Services Administration. These programs help expand existing programs, open new ones, and provide tuition support for students, and they are essential for meeting our health care workforce needs.

ACNM asks the committee to urge HRSA to identify maternity care shortage areas as it does now for primary care, mental health, and dental care. The American College of Obstetricians and Gynecologists published a new report in May 2011 that documented that 50 percent of our counties currently have no OB provider. And they projected these shortages are only going to get worse.

So identifying a maternal care short area will allow us to directly address these critical shortages, including developing new midwifery programs and services in urban and rural maternity care shortage areas.

We urge the committee to continue to strengthen the National Health Service Corps. Midwives are placed as primary care providers through the NHSC currently. With the maternity care shortage designation, the NHSC could also place maternity providers in areas of greatest need.

Lastly, ACNM urges the committee to enhance Fiscal Year 2014 funding for the National Institute of Nursing Research with a particular focus on maternity care. There are more than 4 million births annually, and this accounts for \$100 billion in health expenditures in the United States. And over 40 percent of that cost is paid by our Medicaid programs, our taxpayers. More than 30 percent of these babies are delivered by cesarean section at twice the cost of a normal delivery, and experts agree that one-half to two-thirds of these surgeries are unnecessary. We can and we must do much better. A recent report estimates that cutting the cesarean rate to 15 percent would save \$5 billion a year or \$451 million in California alone each year.

Let us focus more research now on how best to promote normal, healthy births in all families in all communities.

Thank you so much for your patience and for this opportunity to bring these issues to your attention. We look forward to working with you and welcome your questions. Thank you.

Mr. KINGSTON. Well, thank you and Mr. Johns for the patience, among others.

Lucille, do you have any questions?

Ms. ROYBAL-ALLARD. Yes, I do. Actually I have several, but in the interest of time, I will just ask the one question. But before I do, I do want to thank you, Mr. Chairman, for having this public witness hearing, which I believe is one of the most important hearings that this subcommittee can have.

I also want to thank you for having the American College of Nurse-Midwives represented here today. I believe this is the first time you have been able to testify before this subcommittee.

Ms. KAPLAN. Indeed, thank you.

Ms. ROYBAL-ALLARD. So I thank you for your testimony.

And just can you briefly talk to us a bit about what makes midwifery care different, how evidence-based care works in the context of midwifery care, and why this is important to lowering our maternity care costs, which are among the highest in the developed world.

Ms. KAPLAN. Thank you so much, Representative Roybal-Allard, and thank you so much for your leadership in the area of maternity care. You are a true champion. Thank you.

Midwifery care is uniquely designed to meet the needs of low-risk women, and the vast majority of women in pregnancy are low risk. It is very highly individualized, high touch, and it is evidence-based.

The evidence supports that facilitating normal, healthy physiologic birth is what is best for most women. So midwives are the most highly-trained in how to support normal physiologic birth and labor, and promoting wellness and care throughout a woman's lifetime as well. So very family focused, patient centered care.

And as I said, it is the standard of care in many other countries, and we believe there are great opportunities to both improve health, improve value, and reduce costs if we can increase our midwifery workforce.

Ms. ROYBAL-ALLARD. Okay, thank you.

Ms. KAPLAN. Thank you.

Ms. ROYBAL-ALLARD. Thank you, Mr. Chairman.

Mr. KINGSTON. Ms. Kaplan, thank you very much.

Ms. KAPLAN. Thank you. Thank you, Chairman.

Mr. KINGSTON. We certainly appreciate it.

And this brings the hearing to a close.

Ms. DELAURO. Thank you, Mr. Chairman.

**Labor, Health and Human Services and Education Appropriations Subcommittee Hearing**

**Testimony of Dr. Cheryl Davenport Dozier**

**President of Savannah State University**

**March 13, 2013**

Good morning and thank you, Chairman Kingston, for this opportunity to testify about the importance of the TRIO programs throughout Savannah, rural Georgia, and throughout the United States. As the President of Savannah State University, the oldest, public historically Black university in Georgia, I know firsthand of your personal commitment to providing opportunity to all the people of our great state. Since 1966, Savannah State University has hosted TRIO programs and the effectiveness of these programs is seen in the business leaders, entrepreneurs, educators, engineers, scientists, and military officers I interact with daily in Chatham County.

The TRIO programs are authorized under the Higher Education Act to complement and leverage the effectiveness of our federal investment in financial aid programs. Nationally, TRIO serves 790,000 low-income students who aspire to be the first in their families to earn college degrees. TRIO students come from all racial and ethnic backgrounds, with African American and Caucasian students each accounting for 33% of all TRIO students. Another 21% are Hispanic. Meanwhile, Asian and Pacific Island students comprise 5% of the TRIO student population and 3% of TRIO students are Native American. The remaining students come from multi-racial backgrounds. Thus, it can truly be said that TRIO cross-cuts all sectors of our society as poverty does not discriminate.

At Savannah State University, we are fortunate to host three TRIO programs, Talent Search, Upward Bound, and Student Support Services. Our pre-college programs, Talent Search and Upward Bound, work with over 1,000 neighboring middle and high school students, providing intensive academic tutoring and counseling, as well as standardized test preparation and assistance with college admission and financial aid applications. These tools make it clear to students that college is a real possibility for them. Our work has been effective as in recent years both our Talent Search and Upward Bound programs have seen more than 80% of graduating high school seniors enroll directly in college. Ultimately, these types of services are crucial for Georgia's low-income youth. Currently, 46.8% of public schools students statewide qualify for free and reduced lunch. As poverty often correlates with poor academic performance, the Talent Search and Upward Bound programs at Savannah State University are helping to change the tide in our local community.

Additionally, hundreds of undergraduates at Savannah State University benefit from our Student Support Services program, which provides intensive and intrusive academic counseling that includes remediation for students who find themselves ill-prepared for the rigors of college work and course advising to ensure that students stay on the path to degree completion. As a result of these services, our Student Support Services program can boast of a significantly higher graduation rate than that of other low-income students on campus. TRIO programs work hand-in-hand with our federal investment in financial aid and, even other supports for low-income children and families, to boost completion rates for low-income college students. As such, TRIO is the fiscal insurance policy that helps ensure our nation's students succeed.

The programs at Savannah State University represent just a portion of the success resulting from TRIO, which includes programming that helps military veterans and out-of-work adult learners return to the classroom and earn postsecondary credentials. In turn, all of these programs fuel local economies by helping families transition out of poverty and creating an educated workforce.

There is no doubt in my mind that collectively, the pipeline of TRIO programs is invaluable to the economies of communities across Georgia. I'm sure that there are academic leaders at institutions across the nation who could share similar sentiments about the impact of the TRIO programs. Indeed, TRIO programs operate in virtually every congressional district of the United States and have successfully been producing college graduates for nearly 50 years.

In my current role as the President of Savannah State University, I recognize the importance of supportive services to make real the aspirations of so many young people and adults who are working hard to create better lives for themselves and their families. The support and information provided to low-income and first-generation students at critical times is often the difference in determining whether they persist and succeed in completing their college educations.

Georgia, as you well know, is undergoing significant change. We are growing quickly; in fact, our population grew 18% over the last decade. Such growth was driven largely by the migration of African Americans and Hispanics to the state. We are also a younger state, as more than one

quarter of our citizens are under the age of 18. We are an increasingly diverse state with the Hispanic population growing by nearly two-thirds in the last decade. TRIO programs are an important component of an opportunity infrastructure that allows all of our citizens to reach their full potential.

I recognize that we are in an era of extreme austerity, particularly with the recent implementation of sequestration. However, all of your constituents believe that it is Congress' responsibility to make the hard decisions, to set priorities, and to protect initiatives aligned with those priorities. Despite doing more with less and reducing the average cost per student, over the last 8 years, including sequestration, TRIO programs will have lost the ability to serve more than 120,000 students. I very much hope that under your leadership, Chairman Kingston, that this Subcommittee will reverse the TRIO cuts seen in the past and boost funding for these programs in future years. Thank you.



Jeffrey Modell  
Foundation

Curing PI. Worldwide

Mr. Chairman and members of the Subcommittee, thank you for this opportunity. I am Vicki Modell, Co-Founder of the Jeffrey Modell Foundation. My testimony will request \$2.0 million for the HRSA Genetic Services Branch to save the lives of the 1 in 30,000 babies born each year with SCID. I will explain.

In 1987, my husband Fred and I established the Jeffrey Modell Foundation in memory of our son Jeffrey, who died at the age of 15 from complications of Primary Immunodeficiency.

Since its earliest days, our Foundation has worked in close collaboration with the NIH on Research and with CDC on a Public Awareness and Physician Education Program. In recent years, we have increased our efforts and resources to implement population based newborn screening for Severe Combined Immune Deficiency or SCID, working with CDC, HRSA, the states, and private industry.

This condition, often referred to as “Boy in The Bubble Disease”, is fatal in the first year of life if not diagnosed and treated early. Babies born with SCID appear completely

normal at birth, causing delayed diagnosis, until the babies are repeatedly hospitalized with life threatening infections, a nightmare for any family. But there is now a screening technology, called TRECS, which is more than 99% accurate and is inexpensive. A bone marrow transplant has a better than 95% success rate to cure this fatal disease, if identified in the first 3 ½ months of life.

The Secretary's Advisory Committee recently voted 26-0 to recommend that all infants in the U.S. be screened for this condition. We contacted every state to implement the Secretary's recommendation. But the states had significant budget problems. At the same time, we heard from too many grieving parents whose infants died because their state does not screen for this fatal disease. Their stories are tragic.

Fred and I knew we couldn't wait another day. With limited Foundation resources, one year ago, we offered "start-up" funds to all of the states for the assays, lab equipment, and educational materials for clinicians and parents. Almost immediately many states, including Georgia, responded that they would begin population screening for SCID in their states, if we would commit start-up funding.

The economic benefits are overwhelmingly persuasive according to peer reviewed scientific journals:

1. The cost of the test is \$4 per baby.

2. The cost of a transplant in the first few months of life is \$100,000.
3. If the baby is not screened and treated, the baby will develop overwhelming infections and hospitalizations in a pediatric intensive care unit, and the cost of care in the first year of life will be \$2-4 million, if the baby survives.
4. Three federal agencies: EPA, FDA, and Transportation estimate the value of a life saved to be \$7.7 million.
5. A newborn baby with SCID, that is screened and treated in the first 3 ½ months of life, generates more than \$64 dollars in contributions to society for every \$1 dollar we invest. 64 to 1! That's the economics!

And so, here is where we are... 2 years ago, there were 2 states screening for SCID. Today, 20 states are screening or piloting, and 23 states, including the state of Georgia, are prepared to begin as soon as we can help them with start-up funds. Together, those states represent 93% of the 4 million babies born annually in our country. We can finish the job and eradicate this disease NOW. In this rich and extraordinary country, why should it matter what state a baby is born in to live or die?

Our Foundation is not strong enough to finish the funding completely on our own and we cannot do this without you! This is a small investment with an outcome that is priceless!

I know, because I have held these babies and I have laughed with these babies...*and I have shared tears with others.*

Fred and I accept the reality that science and discovery did not come in time to save Jeffrey. But, we are dedicated and committed to working with you to save all of the Jeffreys in the future. Let's go forward together on this journey beginning now.

This can be an historic moment, and together, we will look back to this day, when we decided to eradicate this fatal disease that takes these beautiful babies from us and shatters their parents' hopes and dreams.

Mr. Chairman, thank you for what you do every day in service to our nation, and what we can do together to save more precious lives.

Ovarian Cancer National Alliance Testimony  
Committee on Appropriations Subcommittee on Labor, Health and Human Services, Education and  
Related Agencies  
Wednesday, March 13, 2013  
Statement of  
Calaneet Balas, Chief Executive Officer  
Ovarian Cancer National Alliance

Chairman Kingston, Ranking Member DeLauro and distinguished members of Congress: good morning. Thank you for inviting me to testify today. My name is Calaneet Balas. I am here as the Chief Executive Officer of the Ovarian Cancer National Alliance to respectfully request appropriations for the National Cancer Institute and the Centers for Disease Control and Prevention.

The Ovarian Cancer National Alliance is a powerful voice for everyone touched by ovarian cancer. We connect survivors, women at risk, caregivers and health providers with the information and resources they need. We ensure that ovarian cancer is a priority for lawmakers and agencies in Washington, DC, and throughout the country. We help our community raise their voices on behalf of every life that has been affected by this disease. I am honored to be here to testify on behalf of our community.

Approximately 22,000 women are diagnosed with ovarian cancer every year, and 15,000 women die from the disease. Ovarian cancer is the deadliest gynecologic cancer; fewer than half of women survive five years from diagnosis and only one-third survive ten years. At this point, there is no reliable test we can use to screen women or catch the disease early. There are some known risk factors, including having a genetic mutation that increases risk of breast and ovarian cancer, using hormone replacement therapy and aging. Factors that decrease the risk of developing ovarian cancer include the use of oral contraceptives,

breastfeeding and removal of the fallopian tubes and/or ovaries. The majority of women with the disease have at least one recurrence, and for many of them, treatment eventually stops working. Ovarian cancer is the fifth leading cause of cancer deaths among women in the United States. All of the above are reasons why research and public health programs are so important for ovarian cancer.

The National Cancer Institute (NCI) and the Centers for Disease Control and Prevention (CDC) both do significant and valuable work around ovarian cancer. We are grateful for the Committee's continued support of these agencies, and the programs they undertake to lower the burden of ovarian cancer.

The NCI is the single largest nonprofit funder of ovarian cancer research domestically, funding approximately 75 percent of all nonprofit ovarian cancer research done in the United States. In Fiscal Year 2011, the NCI spent approximately \$110 million on ovarian cancer research, including large grants to cancer centers and cooperative groups, as well smaller grants for research on topics including overcoming drug resistance, angiogenesis—cutting off blood supply to tumors, and exploring the link between high density breasts and risk for ovarian cancer.

Recent highlights of NCI funded research include: a large trial of a new ovarian cancer drug, Avastin, which was shown to improve the time women's cancer stayed in remission; studies showing that prophylactic surgery for high risk women, including the removal of just a woman's fallopian tubes, significantly reduces the odds of developing ovarian cancer; and a study showing that screening average risk women with our current tools does not reduce mortality. The results of The Cancer Genome Atlas—another study funded by NCI—showed us

how important personalized medicine is for ovarian cancer. The Atlas told us that each case of ovarian cancer is genetically unique, so we are going to have our work cut out for us to identify targets and develop and test drugs.

The CDC has two programs directly related to ovarian cancer. The first raises awareness of the risks and symptoms of gynecologic cancers through advertising and educational materials. As of December 2012, PSAs about gynecologic cancer had generated 2.62 billion audience impressions and paid media generated 187 million audience impressions. Studies conducted by the CDC have shown that both women and health providers are unaware of the symptoms of ovarian cancer and current recommendations against screening. This data shows the clear need for continued education.

The second CDC program is focused on epidemiological research. Current research includes an evidence review of birth control as an intervention for those at high risk of developing ovarian cancer, a study of barriers to determine why women don't see specialists for surgery, and analyses of data on disparities and other patterns of survival.

While we clearly have a long way to go, we have made progress in our understanding of ovarian cancer. We have seen new treatments developed over the past twenty years, and we have a better understanding of where ovarian cancer develops and who is at risk for this deadly disease. In addition, we have a larger and stronger network of survivors and family members who can support one another.

The Alliance maintains a long-standing commitment to work with Congress, the Administration and other policymakers and stakeholders to improve the survival rate for women with ovarian cancer through education, public policy, research and communication.

Please know we appreciate and understand that our nation faces many challenges, including limited financial resources. I thank you, on behalf of the women I serve, for continuing to support programs that help women and health providers better understand and treat ovarian cancer. We know these programs have reduced suffering. We know women whose lives have been saved by knowing they were at high risk or who got new treatments that kept their cancer at bay. We respectfully request that you maintain support for these critical activities.

Thank you for your time today. I am happy to answer any questions you have.

**One Voice Against Cancer FY14 Appropriations Requests**

<b>Program</b>	<b>Amount (millions)</b>
<b>National Institutes of Health</b>	<b>\$32,632</b>
National Cancer Institute	\$5,349
National Institute on Minority Health and Health Disparities	\$283
<b>Centers for Disease Control and Prevention</b>	<b>\$515</b>
Comprehensive Cancer Control Initiative	\$50
Cancer Registries	\$65
National Breast & Cervical Cancer Early Detection Program	\$275
Colorectal Cancer	\$70
Skin Cancer	\$5
Prostate Cancer	\$25
Ovarian Cancer	\$10
Geraldine Ferraro Blood Cancer Program	\$4.67
Johanna's Law: The Gynecologic Cancer Education and Awareness Act	\$10
Office of Smoking and Health	\$197

**One Voice Against Cancer Members**

Alliance for Prostate Cancer Prevention	Malecare Prostate Cancer Support
American Academy of Dermatology Association	Men's Health Network
American Association for Cancer Research	National Alliance of State Prostate Cancer Coalitions
American Cancer Society Cancer Action Network	National Association of Chronic Disease Directors
American College of Surgeons Commission on Cancer	National Brain Tumor Society
American Congress of Obstetricians and Gynecologists	National Cervical Cancer Coalition
American Social Health Association	National Coalition for Cancer Research (NCCR)
American Society of Clinical Oncology	National Coalition for Cancer Survivorship
American Society for Radiation Oncology	National Patient Advocate Foundation
Asian & Pacific Islander American Health Forum	Oncology Nursing Society
Association of American Cancer Institutes	Ovarian Cancer National Alliance
Bladder Cancer Advocacy Network	Pancreatic Cancer Action Network
Cancer Support Community	Pennsylvania Prostate Cancer Coalition
Charlene Miers Foundation for Cancer Research	Prevent Cancer Foundation
Colon Cancer Alliance	Preventing Colorectal Cancer
CureSearch for Children's Cancer	Sarcoma Foundation of America
Fight Colorectal Cancer	Society of Gynecologic Oncology
Friends of Cancer Research	Susan G. Komen for the Cure Advocacy Alliance
Intercultural Cancer Council Caucus	Us TOO International Prostate Cancer Education and Support Network
International Myeloma Foundation	
LIVESTRONG	
Leukemia & Lymphoma Society	

**Testimony of Susie Trotochaud of Georgia  
Before the Labor, Health and Human Services, Education and Related Agencies  
Appropriations Subcommittee of the  
U.S. House of Representatives Committee on Appropriations  
March 13, 2013**

**Parent of 12 year old twins with Usher Syndrome, Parent Advocate representing the  
Coalition for Usher Syndrome Research and individuals with Usher Syndrome**

Good morning Chairman Kingston and Members of the Committee. Thank you for the honor of appearing before you today. My name is Susie Trotochaud from the state of Georgia. I am here on behalf of the Coalition for Usher Syndrome Research to respectfully request this committee encourage NIH funding of \$20 million in FY2014 to promote more research into Usher Syndrome.

Usher Syndrome is the number one cause of deaf-blindness. Deaf-Blindness. Imagine sitting here unable to hear my words and unable to see me. Silence and darkness. In the United States, it is estimated that about 45,000 people have this rare genetic disorder. Two of them are my children, Cory and Joanie Dorfman.

Cory and Joanie were born 8 weeks early. Although they spent several weeks in ICU fighting to learn basic survival skills, like breathing and eating, these would not be their greatest challenges. Before they were released from the hospital, they were given a newborn hearing screening. It was determined that they were both profoundly deaf. As we struggled to understand what this meant and how this could have happened, I realized that they would never be able to hear me say "I love you" and I would never hear those sweet words from their lips. The sounds of our life, children laughing, singing, school plays, graduations, celebrations, were suddenly silenced.

Our heartache changed to hope when we found out about the cochlear implant. By 12 months, Cory and Joanie were implanted and began hearing their first sounds. By 1-1/2 years, they had said their first words, and by 3 years, we realized that they could be mainstreamed, go on through high school and even college, just like their peers. Although they would always have to work a little harder, the sounds of opportunity returned to our lives. And I remember my husband saying to me at that time, "At least they're not blind."

But about a year ago, that all changed. After my daughter entered a darkened hallway in a restaurant and asked me where the bathroom was, when the door was literally four feet in front of her, we became concerned. When she gingerly stepped down a pathway at night, seemingly feeling her way with her feet, we knew we had a problem. Many months of extensive testing and waiting confirmed what we, by then, already knew. Joanie had Type I Usher Syndrome. Reading the description of Type I Usher was like reading her biography: Born profoundly deaf, delayed development especially walking, balance issues, and loss of night vision beginning at around 10 years of age. What would follow would be loss of peripheral vision leading to tunnel vision, and eventually blindness. With no intervention, my 12 year old daughter will be blind by 20. And although my son currently has less vision issues, testing confirms he also has Usher. He may retain some of his vision into his 30s.

That's the thing with Usher. It strikes in varying time frames. Type I, like with my children, is characterized by profound deafness at birth followed by blindness in early adolescence; Type II individuals may have moderate to severe hearing loss followed by blindness; and Type III experience loss of hearing and sight throughout their lives. How quickly and how completely each person loses their vision also varies, but the way it happens is consistent. Night blindness, then peripheral vision is lost as darkness closes in on their sight.

Usher is a rollercoaster ride of loss, grief, adjustment, and loss again that never ends as one more setback always lies around the corner.

People with Usher Syndrome, like Cory and Joanie, have worked hard to overcome some of their hearing challenges by using cochlear implants, hearing aids, sign language and more. But how do you overcome the loss of sight? Think of yourself, sitting here communicating by sign, knowing that you are losing your vision, knowing you are about to lose your way of communicating with the world around you. Frightening, isn't it?

Like you, my hopes and dreams for my children have always been that they grow up happy, do well in school, attend good colleges, get meaningful jobs and give back to their community. But the reality we are facing is that 8 out of 10 deaf-blind people are unemployed, not to mention the physical and emotional hardships, the stereotypes of being deaf-blind, the loss of productivity and ability to do a job, ultimate depression, and perhaps even suicide.

Add to that the reality that our country spends an estimated \$27 billion annually in care and support services for people with major visual disorders. That doesn't even include the costs associated with hearing impairment.

Those are statistics; people with Usher aren't. Since joining the Coalition for Usher Syndrome Research, I have spoken with or met dozens 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 23 countries.
- Sponsoring annual family conferences, webinars and monthly conferences that provide information and support to all of those living with Usher.
- Paving the way for an International Symposium on Usher Syndrome Research in 2014 to develop a roadmap for future research projects to bring us closer to viable clinical trials.

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 this year. Researchers in Louisiana, who have been able to rescue the hearing in mice with Usher Syndrome using a drug 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. My daughter, Joanie, will be blind within 10 years; my son, Cory, in 20. Jessica, a 17-year old with Usher, remains hopeful that something will help her retain her vision before she loses it at 30. Megan, a promising architect, has already altered her career goals as her vision has begun to slowly fade and every day she prays for something to help. Moira has lived well into her adult life working harder than everyone else to compete in a hearing and seeing world, but complete blindness is now taking away her ability to lip read and communicate with her friends and family.

We cannot help any of these people or 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 believe that \$20 million in support this year and an increase of that amount over the next several years would lead to viable treatments for those with Usher Syndrome within a decade. 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. The researchers are there, waiting to discover what we only dare dream of: An opportunity to allow deaf children and adults who are going blind, a chance to see.

I will leave you with the words of Helen Keller. "It is a terrible thing to see, but have no vision." I hope that this committee will have the vision to see the opportunities before them. Together, we can 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 children, Cory and Joanie. I am happy to answer any questions you might have.



**FOR YOUTH DEVELOPMENT  
FOR HEALTHY LIVING  
FOR SOCIAL RESPONSIBILITY**

**Kayla Brathwaite  
Program Participant  
YMCA of Greater New York**

Good morning - my name is Kayla Brathwaite and I am currently in 10th grade at Park East High School in New York City. I am honored to be here today representing the one million young people who are involved in afterschool and summer learning programs supported through the 21<sup>st</sup> Century Community Learning Center Program at the U.S. Department of Education. I am here to tell you about my experience in the program and to request that your committee provide level funding of \$1.15 billion for the 21<sup>st</sup> CCLC program in the fiscal year 2014 appropriations process.

Before I begin, I would like to say that I am here today with my mother who probably appreciates these funds and the programs they provide even more than I do since these programs allow my mother to be at her job knowing that I am in a safe place at the YMCA. Thanks mom for making the trip with me today. I promise you that this is just as educational as being in school.

First, let me briefly tell you a little about my neighborhood and my school. I live in Queens, New York – the most diverse county in the United States. A place where most families have two working parents when times are good and where after school programs are not a luxury but a necessity. As I said, I go to Park East High School, a small public high school in Manhattan. Although I like my school and I like my neighborhood, I know that I am one of the lucky ones,

one of the lucky kids in New York City who has the support of the people around her and an organization like the YMCA to help her succeed. Outside of the afterschool program, there really are very few positive opportunities for kids in my neighborhood. You are either in an afterschool program or you are just hanging out. It really isn't a surprise to me that the hours between 3 and 6 p.m. are the peak hours for juvenile crime and experimentation with drugs, alcohol and cigarettes. Also, during the summer months, first time use of alcohol, tobacco and drugs peaks among kids 12 to 17.

I have been participating in YMCA programs funded through 21st CCLC funds since I was 8 years old. When I was in middle school I was lucky enough to have access to an after school program at MS210 in Queens. The program kept me safe and off the street during the afterschool hours, but more importantly, this program had a special focus on teaching me about advocacy, public policy, leadership skills and the importance of civics education and being a part of the solution to our society's problems. As a matter of fact, it's this program that gave me the skills and confidence to be here today. I learned in the program that my opinion is important and my voice is powerful. I'm proud that I am able to put that lesson to work for me here today.

Now that I am in high school, I participate in two Y programs – Teens Take the City and Youth and Government. Both programs teach me about how government works and how I can make a difference. This year, I was even elected Queens Borough President by my peers. I have run for election, drafted and proposed legislation and helped debate some issues important to my work group. I feel like I have a taste for what all of you do and can decide later about whether to pursue a career much like yours. It has been an incredible experience, all made possible

through public funding for after school programs like 21<sup>st</sup> Century Community Learning Center funds. The program is a partnership between the YMCA and the school and provides hands-on activities for me and the other participants. The best part of afterschool programs is that they help lessons we learned in school come alive. The programs compliment – but don't replicate – the learning that takes place during the school day.

Enough about me, I am here today for all youth who need these programs to succeed and for all parents who need these programs to help keep their jobs and for the employers who employ those parents – we should not forget that these programs or the lack of these programs will have an effect on our economy. I believe that spending one dollar on a 21<sup>st</sup> Century Community Learning Center gets you the benefit of spending three dollars – one on an academic enhancement program, one on a high quality child care program and one on an economic development program. No matter how you look at it, the program benefits us all.

One point that I think is really important is that the funding that you provide generates a lot of funding from other sources. In New York City, the YMCA has received over \$10 million in private donations to help support afterschool programs and other services for kids and families from donors like the NY Life Foundation, Bloomberg and the Morgan Stanley Foundation.

I know that funding is tight and now is not the time to be asking for increases in spending, however, it's important for you to know that the Afterschool Alliance reports that there are 15 million children who are left to take care of themselves after the school day ends each day. The 21<sup>st</sup> CCLC program provides services for only one million children, so there is obviously a

huge need to someday expand the program so that all young people have the same opportunities that I had.

While I've heard that it is difficult for Congress to agree on things, I'm thankful that the 21<sup>st</sup> CCLC program has been supported by both Republicans and Democrats in the past. I encourage you to continue with this support and provide level funding of \$1.15 billion for the 21<sup>st</sup> Century Community Learning Centers Program. Of all the thousands of programs in the federal government, this is the one that is most important to me. I wouldn't be here without it.

Thanks so much for giving me the opportunity to speak to you this morning.

Dr. Will Hardin, Superintendent  
Camden County Schools, Georgia  
March 13, 2013

Good morning Chairman Kingston, Ranking Member DeLauro, and members of the Subcommittee. My name is Will Hardin. I am the Superintendent of Camden County Schools in Kingsland, Georgia. I also serve on the Board of Directors of the National Association of Federally Impacted Schools. I have enjoyed a 30-year career as an educator serving as a teacher, school social worker, principal, district administrator and finally superintendent. I come today to appeal to you to help me ensure my community and others like it can continue the crucial work in schools of developing the lifeblood of a free and democratic society, our children. We need acknowledgement by this committee that Impact Aid funding, through the U.S. Department of Education, lost over \$60 million through the sequester this year. Recognizing this extraordinarily difficult time in our nation's history, Impact Aid funding must be a Congressional priority maintained at the FY 2012 funding levels.

Our district is privileged to serve the service men, women and families of Kings Bay Naval Submarine Base. While I will speak specifically today about the importance of Impact Aid to our community, there are countless parents, teachers and school leaders who can provide evidence just as compelling to demonstrate the importance of Impact Aid in their communities. There are 1,400 school districts impacted by a federal presence nationwide serving 11,000,000 students near military installations, federal property or on Indian lands. Despite geographic and cultural differences, one characteristic distinguishes them from their non-federally connected counterparts: They rely on your support more than typical school districts. Our school districts struggle to provide the support children need to be successful in the 21<sup>st</sup> century and witness

first-hand the economic and human costs to children and communities resulting from inadequate resources.

The Impact Aid program provides justifiable benefits to communities and students. Impact Aid, first signed into law by President Truman in 1950, compensates communities for federal activity that disrupts the traditional financial base for schools. Non-federally impacted schools are typically funded locally by taxes on privately held residential and commercial property. Since federal property and activity conducted on that property are exempt from taxes, a portion of a federally-connected school district's tax digest is forfeited by the local community. While there may be partial compensation for lost taxes to commercial interests due to a "halo effect" (additional economic activity associated with federal activity around the property), the unique tax structure for schools is disrupted while the demand for services - due to an increased enrollment of students - often increases. Businesses and homes located on federal property are exempt from property taxes and purchases made on that property are tax-free. Acknowledging this consequence of a significant federal presence, Congress, through Impact Aid, provides payments to school districts in lieu of lost taxes to assist with the educational needs of all students.

Kings Bay Naval Submarine Base is larger than many municipalities across the nation with a workforce of nearly 9,000 including over 5,000 active duty service men and women. The base sits on 17,000 acres in Camden County and includes 543 homes for military families and 1,490 beds for bachelors. Similarly, the Navy Exchange and commissary have annual sales of \$32 million. All land, improvements, commercial activity and homes are exempt from taxes. As a result of the substantial presence of Kings Bay and other government property in Camden

County, <sup>1</sup>69% of the value of our tax digest is exempt from property taxes that support education. The 12 schools in our district serve 9,100 students; 4,046 of those are federally connected. Local support for all students in our district, whether federally connected or not, is funded by the 31% of our tax digest which is not exempt. In a perfect world, Impact Aid would compensate Camden County an amount equal to 69% of the digest reflecting the non-taxable property it occupies. On average, the Impact Aid payment level, based on a district's calculated maximum payment, has slipped from 62% to 53% in the past decade, partially because appropriations have not kept pace with the increased costs of education. Reductions are inescapable and even logical in times of real crisis such as these, but federally connected school districts – like mine, like Groton Board of Education in Connecticut and Blackfoot School District in Idaho - need you to understand that when the federal government fails to pay their fair share, local taxpayers make up the difference. In return for the freedoms, services, resources and protections I receive as a citizen, I pay my fair share to the federal government despite any personal challenges I may be facing. Why, then, would there be an expectation by the federal government that their obligation to pay their fair share in a community where they enjoy benefits is any less imperative?

Schools in my state and yours experienced unprecedented losses in revenue over the last several years. Camden County saw a 30% decline in state revenue between 2007 and 2012 of \$1,569 per student while expenses for fuel, health care and other inescapable costs continued to rise. When states fail to meet their obligation, federally connected districts are penalized disproportionately to their non-federally connected peers due to their federal impaction. Over the course of the last four years we have eliminated art and music from elementary schools, and

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<sup>1</sup> 2011 Georgia County Guide, Center for Agribusiness and Economic Development, UGA, Athens, GA.

decreased Advanced Placement offerings. We eliminated 272 of the 1,486 positions from our schools and increased class sizes by five students in every grade. We reduced our instructional calendar from 180 days to 166 lengthened days, furloughed teachers six days and administrators eight for each of the last three years. Consequently, we watched as lost wages from furloughs and three consecutive years of a reduction in force removed \$5.3 million in annual salary from the local economy. Some of our costs are fixed. We must continue to provide a free, appropriate education for the 12% of our students considered special needs with an Individualized Educational Plan (IEP), irrespective of budget challenges or inadequate funds.

These budget reductions left their mark. On March 25, 2009 I traveled to each school in our district meeting personally with 28 people, informing them they would not be rehired in the coming year. Unfortunately, that same scenario played out in much the same way in the two succeeding years. I met with school nurses, elementary music teachers, technology instructors and ordinary classroom teachers to try and explain that, though they were faithful to their students, loyal to the community and devoted to their profession, they were losing their jobs.

As leaders, we accept and dutifully fulfill our obligation to make difficult decisions when necessary, the emotional toll of those decisions, however, for those affected by them must never be taken for granted. By saying this I want to remind you that a minus sign on a budget spreadsheet here in Washington often represents a real person or program in our schools. Either of which may mean the difference between a child's success or failure. Your appropriation for Impact Aid is inseparably linked to our budget in federally connected schools and our budgets are connected to people. Mrs. Jennifer Mathis is one of the teachers I met with on March 25, 2009 to tell her I couldn't offer her a job. Although I'm sorry to say I don't know all of the 600 teachers in our schools, I did know Mrs. Mathis. My first meeting with her and her two teenage

sons came a few months earlier when I visited her home following her husband's death as a result of a traffic accident. Were it not for this opportunity to share Mrs. Mathis' story it might be easy to dismiss the number on your spreadsheet that represents Mrs. Mathis and her two boys. By remembering the faces and stories of those affected by my decisions though I galvanize my determination to fulfill my responsibility to the students, teachers and community you and I both serve and ensure my persistence is equal to their sacrifice. I hope you all agree that when we fail to recognize the human cost of our decisions, as leaders, we fail those we serve.

Property owners in Camden County already bear a significant financial obligation to support local schools due to unprecedented state reductions and dismal economic conditions. They amplify the importance of Impact Aid in all federally connected schools. Raising additional taxes on federally connected communities to support schools because states and the federal government fail to recognize their obligation to children is unforgivable and even unrealistic for many communities with foreclosures and unemployment rates at record highs. Without Impact Aid the negative consequences to federally impacted communities are undeniable. Funding to replace lost revenue from tax exempt property allows schools to fill the gaps and ensure children are insulated to the extent possible from the most economically challenging period any of us can recall in our nation. A time when choosing priorities is more important than ever.

Through Impact Aid, the Federal Government must meet its obligation to citizens in federally connected communities across this country so our schools have adequate resources to support all children, meet the unique needs of military-dependents and fulfill the trust responsibility of a free and appropriate education for Native American students. I respectfully ask members of this subcommittee to lead others in recognizing that federally connected schools deserve the same level of support.

**Public Witness Testimony on Fiscal Year 2014 Appropriations**  
House Committee on Appropriations Subcommittee on Labor,  
Health and Human Services, Education and Related Agencies  
**Wednesday, March 13, 2013**

**Statement of M. Peter McPherson**  
President of the Association of Public and Land-grant Universities  
President Emeritus, Michigan State University

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Good morning, Chairman Kingston, Ranking Member DeLauro, and distinguished Members of the Subcommittee. Thank you for allowing me to testify on behalf of the 217 public research universities, land-grant institutions, state university systems, and related organizations that comprise the Association of Public and Land-grant Universities (APLU). It's an honor to appear before you this morning to discuss the importance of NIH funding and student aid.

I want to quickly note that each member of the Congress has an APLU member institution in their congressional district or state. Our member campuses have 3.6 million undergraduate and 1.1 million graduate students, employ more than 670,000 faculty and administrators, and conduct nearly two-thirds of all university-based research.

**Sequestration**

While I know that we are here to discuss the Fiscal Year (FY) 2014 appropriations bill, I must first briefly address sequestration since it's inherently linked to future funding levels. Sequestration will do much damage in FY 2013, bluntly cutting NIH and certain student financial aid programs by 5 percent. In FY 2014 and for the following seven years, the sequester will cut even deeper, harming our ability to maintain our role as the world's leading innovator and severely impacting the ability of Congress to fund the important education and research programs that grow our economy and reduce our deficit.

Sequestration solely falls on the back of discretionary spending – the spending that is the prerogative of this Subcommittee – rather than taking into consideration the two-thirds of the budget that is the real problem. I strongly urge you to work with your colleagues on the relevant committees to end sequestration and come to a big, bold, and balanced budget agreement that includes entitlement reform, revenue, and tax reform.

### **NIH Funding**

As we look ahead to the FY 2014 appropriations process, I want express strong support for the critical biomedical research initiatives that the NIH is undertaking at universities across the nation. With a \$31 billion budget in 2011, the NIH generated \$62 billion in new economic activity while supporting an estimated 432,000 jobs and enabling 13 states to each see job growth in excess of 10,000 jobs, according to a report from United for Medical Research.

I recognize the extraordinary fiscal circumstances our nation is confronting. This Subcommittee must make many tough decisions. Now more than ever, Congress must focus on allocating resources in a way that maximizes the return on its investments. NIH research is one such area that yields far more economically than what it costs the government initially.

It's crucial to note that the basic research the NIH funds is research that private companies will not perform. Rather, industry utilizes the basic research conducted at our universities to develop drugs, devices and other medical breakthroughs. It's vital that we protect NIH research because it's the foundation for the U.S. biotech, pharmaceutical, and biomedical industries.

The economic benefits of NIH-sponsored research are impressive, but the dollar figures don't eclipse the value of saving and improving lives with the advancements that research yields. There's wide belief within the scientific community that we're on the verge of achieving

enormous medical breakthroughs. Cures for cancer, Alzheimer's, AIDS, and other diseases that have claimed far too many lives are believed to not be so far off in the distant future anymore. The U.S. is playing a leading humanitarian role by helping to find better treatments for diseases that largely impact other parts of the world. The University of Georgia is collaborating in a five-year project to identify how malaria attacks the body so that better treatments can be developed. If we cut NIH funding then we'll unnecessarily risk delaying treatments for people suffering from various diseases now and jeopardize achieving those future medical milestones altogether.

We also risk ceding these biomedical innovations and their associated economic growth to other countries, which are increasing investments in research at the same time we're looking at further cuts. Right now, researchers at the University of North Carolina are developing a synthetic version of the blood-thinner heparin that could eliminate the need to continue importing the drug, which is derived from pig intestines, from China. Unfortunately, this research project is at risk due to NIH funding cuts. If that happens, we may lose yet another extraordinary opportunity for economic growth rooted in NIH funding. There are many other stories like this at university laboratories across the country, which is why we must provide the resources necessary to achieve these biomedical discoveries here in the U.S.

On many campuses, NIH is the largest single funder of research. In addition to generating new discoveries, this funding helps support and educate students, the biomedical workforce of the future. Stagnant or decreasing NIH budgets will discourage students from pursuing fields in the life sciences, which will ultimately impact the private sector as well as academia.

Research leads to technology, which leads to new and growing companies, which leads to new jobs, which leads to new revenue, which leads to more investments in new innovation. This

economic circle of life is critical for our country's long-term success. I urge this Subcommittee to support this important component of future economic growth and fully fund NIH research.

### **Student Aid**

I also want to address another vital investment in our country's future economic growth, which will pay for itself many times over. Student aid is the financial lifeline for millions of young adults who seek an education that will lead to a better life for themselves and their families, while also improving society overall.

Unfortunately, a child's family's economic status overwhelmingly corresponds with that child's ability to earn a college degree. There is currently an uneven playing field in which those at the bottom find themselves in a seemingly perpetual cycle from which it's very hard to break free. Right now, a child from a family in the top quartile of income has an 85 percent chance of earning a college degree while a child whose family is in the bottom quartile of income has just an 8 percent chance. That's simply unacceptable.

While there are admittedly many factors why children from families at the bottom of the economic ladder may not succeed academically, the lack of financial resources needed to go to college and earn a degree is undoubtedly a major one. Without federal aid, that already narrow path to achieve the American Dream is greatly diminished, taking with it the hopes and dreams of millions of young people who want a better life, but simply can't afford to take those first few steps toward a higher education degree. And the cycle renews itself anew.

The Pell Grant program serves nearly 10 million students and currently provides a total maximum award of \$5,550. To truly support those students who need our help the most, we ask

that the maximum appropriated Pell Grant award be maintained at its current level of \$4,860. In addition, in order to preserve the long-term health of the Pell program, please protect the projected surplus in the program for future use for Pell.

APLU is fully committed to providing increased access to students who want to attend college, but we know that the value of an education is only fully realized when that access results in a degree. To reclaim the United States' position as the world leader in degree attainment, APLU and the American Association of State Colleges and Universities (AASCU) recently created Project Degree Completion. This initiative consists of pledges from 500 four-year public colleges and universities to boost student completion by 3.8 million bachelor's degrees so that 60 percent of U.S. adults will possess a college degree by 2025.

For the student, a degree means expected lifetime earnings of more than \$1 million above someone with only a high school diploma and greater contributions to their community. For us as a society, we know that a college graduate is far less likely to commit crime or be dependent upon lifelong government support through programs like Medicaid and unemployment insurance. A well-educated society will require less support from its government and earn more income, which will go a long way toward helping reduce our deficit. Investing in student aid programs now will help relieve this Subcommittee of greater financial burdens in the future.

### **Closing**

Thank you once again for the opportunity to appear before you. I'd be more than happy to answer any questions you have now. Additionally, those of us at APLU would be happy to serve as a resource for you as you move forward with the legislative process. Thank you.



**Testimony of Dan Salinas, M.D.**

Chief Medical Officer, Children's Healthcare of Atlanta, Atlanta, GA

*March 13, 2013 - 10:00 a.m.*

on behalf of

Children's Hospital Association  
Alexandria, Virginia

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**Summary of Testimony in Support of Funding for the Children's Hospitals Graduate Medical Education Program respectfully submitted to the Subcommittee on Labor, Health and Human Services, Education, and Related Agencies of the House Committee on Appropriations**

Dr. Dan Salinas will testify about the importance of the Children's Hospitals Graduate Medical Education (CHGME) program. CHGME is administered by the Bureau of Health Professions in the Health Resources and Services Administration at the Department of Health and Human Services.

Dr. Salinas's testimony focuses on the purpose of CHGME and its benefit to all children. Further, the testimony describes how CHGME has allowed Children's Healthcare of Atlanta to fulfill its academic and clinical care missions.

The testimony respectfully asks the subcommittee to appropriate \$317.5 million for CHGME in Fiscal Year 2014.

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**CHILDREN'S HOSPITAL ASSOCIATION**

*formerly CHCA, NACHRI and N.A.C.H.*

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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. Dan Salinas, Chief Medical Officer 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% since the program began in 1999. In addition, the CHGME program has accounted for more than 74% of the growth in the number of new pediatric subspecialists being trained nationwide.<sup>1</sup> 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% of all pediatric residents in the country, including 45% percent of general pediatricians and 51% of pediatric specialists.

CHGME benefits all children. CHGME hospitals trains doctors who go on to care for children living in every state - in cities, rural communities, suburbs and everywhere in between. In 2012, Children's Healthcare of Atlanta offered full time training slots for 180 residents and fellows. Through those full time slots, 514<sup>1</sup> actual residents and fellows were trained. Those residents and fellows go on to serve not only in Atlanta, but throughout Georgia and much of the southeastern region. Of our residents trained, 76% of pediatric residents who train at Children's stay in Georgia to practice.

Congress created CHGME with bipartisan support in 1999 because it recognized that the absence of dedicated GME support for independent children's teaching hospitals created gaps in the training of pediatric providers, which potentially threatened access to care for children. At that time, independent children's hospitals were effectively left out of federal GME support provided through Medicare because we treat children and not the elderly, and received less than 0.5 percent of the GME support of other teaching hospitals. CHGME still only provides children's hospitals on a per-resident basis with about 68 percent of the support Medicare provides to adult teaching hospitals. CHGME is an example of a well functioning public-private partnership because each of the participating Children's Hospitals is investing millions into the success of this program along with the federal dollars they receive.

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<sup>1</sup> Received by Kris Rogers, Director of Clinical Research at CHOA, stating this is a statistic from the American Medical Association.

While much has been achieved under CHGME, much remains to be done. In Georgia, a survey by the Georgia Board of Physician Workforce resulted in data showing that nearly 40% of Georgia counties did not have a pediatrician practicing within its borders in 2010.

A growing child population is colliding with shortages of pediatric specialists and pediatricians resulting in impaired access to pediatric care, longer wait times for appointments and greater travel distances for families.

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. Causes include limited supply of specialists, rising debt burden, noncompetitive salaries, changing lifestyles and a decline in physicians seeking specialty training.

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

Could you imagine your child needing life saving interventions from a specialist but, you have to wait weeks and months to even get an appointment with that physician? Today, should you be concerned of a developmental delay with your child, on average across the country, you will have to wait greater than 3 ½ months for an appointment with a developmental pediatrician. Should you need help from a pediatric neurologist, endocrinologist or dermatologist, on average, you will wait between a month and half and two months to bring your child the services they may desperately need. And, these wait times are with a functioning national training program under the CHGME umbrella. The growing need is still is outpacing our physician supply for kids. If we were to reduce our CHGME program in any way....the impact-our nation's children will not get the timely and appropriate healthcare services they need. We cannot allow that to occur.

Unfortunately, funding for this program has been significantly reduced in recent years, from \$317.5 million in FY 2010 to \$265.2 million in 2012, a reduction of 15%. These cuts hurt the ability of children's hospitals to train enough pediatricians and pediatric specialists to keep up with growing demand at local, state, and national levels.

Furthermore, there are no adequate substitutes for CHGME. Other potential sources of support, such as Medicaid GME or competitive grants, are not available to many children's hospitals and cannot come close to supporting training on the scale necessary to meet workforce needs. Failing to adequately support CHGME would take us back to the same flawed system that was not meeting the needs of America's children.

The President has yet to release his FY 2014 budget request for CHGME. The president's FY 2013 budget included \$88 million for CHGME. While an improvement over the previous year, when the president proposed eliminating the program entirely, this amount represented a dramatic cut of two-thirds from prior year funding.

Last year, this Subcommittee included \$275 million for CHGME in its FY 2013 bill, an increase of 3.77% over the final FY12 appropriated amount. Again, we are extremely grateful to the members of the Subcommittee for their outstanding support for this program.

On behalf of CHA and Children's Healthcare of Atlanta, I respectfully request that the Subcommittee provide \$317.5 million for the CHGME program in FY 2014. This request is based on the continued growth of the children's demographic in the United States, and continuing needs in the pediatric workforce, in particular with respect to sub-specialty shortages. 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 2014 so that we may continue to train the next generation of general and specialized pediatricians.

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For more information and to review the specific data collected in the 2012 *Children's Hospital Association survey* on the impact of pediatric specialist physician shortages on access to care, please visit <http://www.childrenshospitals.org/>

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The Children's Hospital Association advances child health through innovation in the quality, cost and delivery of care. Representing more than 220 children's hospitals, the Association is the voice of children's hospitals nationally. The Association champions public policies that enable hospitals to better serve children and is the premier resource for pediatric data and analytics, driving improved clinical and operational performance of member hospitals. Formed in 2011, Children's Hospital Association brings together the strengths and talents of three organizations: Child Health Corporation of America (CHCA), National Association of Children's Hospitals and Related Institutions (NACHRI) and National Association of Children's Hospitals (N.A.C.H.). The Children's Hospital Association has offices in Alexandria, VA, and Overland Park, KS.

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<sup>1</sup> Received from Kris Rogers 3.7.13 12:03pm



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## TESTIMONY OF MARY REESE, VOR BOARD MEMBER

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

March 13, 2013

#### I. Introduction

VOR is a national organization advocating for high quality care and human rights for all people with intellectual and developmental disabilities (I/DD). VOR is *not* requesting appropriations. Instead, VOR requests the Subcommittee's support for language to ***prohibit the use of HHS appropriations in support of deinstitutionalization activities which evict eligible individuals with I/DD from HHS-licensed Medicaid facilities, 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 are a cruel and absurd use of federal funding.<sup>1</sup> These closures often lead to human tragedy. Medicaid-licensed facility homes, including Intermediate Care Facilities for People with Intellectual Disabilities (ICFs/ID), 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.

<sup>1</sup> The U.S. Department of Justice also investigates HHS-licensed, state-operated homes for people with I/DD, and files federal lawsuits against states, for the purpose of downsizing and closing these homes.

**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 13 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.<sup>2</sup> 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. I03-442 (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”).

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<sup>2</sup> See, VOR Federal Comments Urging Objective Performance - Not More Self-Reporting - of DD Act Programs (January 25, 2012) ([vor.net/images/VORCommentDDActEvaluationJan2012.pdf](http://vor.net/images/VORCommentDDActEvaluationJan2012.pdf))

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 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/ID) as "clueless" and "unaware,"<sup>3</sup> a view not shared by the Supreme Court.<sup>4</sup>

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/ID. 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, and more, plus many, many more reports of abuse, neglect and death across the majority of all states.<sup>5</sup>

### **III. Using HHS Funds to Eliminate HHS-Supported Homes:**

#### **National Council on Disability (NCD)**

NCD is a small, HHS-funded, independent federal agency that advises the President,

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<sup>3</sup> June 14, 2010 and July 30, 2007 letters to Congress referring to families as "unaware" and "clueless," respectively.

<sup>4</sup> "... 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." *Heller v. Doe*, 509 U.S. 312, 329 (1993).

<sup>5</sup> Widespread Abuse, Neglect and Death in Small Settings Serving People with Intellectual Disabilities (VOR, 2013)

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.

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 made it very clear that the ADA requires individual choice before community placement can be imposed, expressly recognizing an ongoing role for facilities:

“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) (*see also, Id.* at 2191 (Kennedy, concurring) (it would be “unreasonable” and “tragic” if the ADA were interpreted to “drive those in need of medical care and treatment out of appropriate care and into settings,” not capable or prepared).

Likewise, **Medicaid law** and regulation requires that ICF/ID 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/ID 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.

**VOR urges the Subcommittee on Labor, HHS, Education and Related Agencies to act:** 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 facilities (e.g., ICFs/ID)**. Federal law and policy supporting a full array of options reflect societal values which respect individual and family decision-making. No federal agency should define “choice” so narrowly and illegally as to disenfranchise the most vulnerable segment of our disabled population.

**House Committee on Appropriations  
Subcommittee on Labor, Health & Human Services,  
Education and Related Services**

**Witness Disclosure Form**

**Clause 2(g) of rule XI of the Rules of the House of Representatives requires non-governmental witnesses to disclose to the Committee the following information, in addition to a C.V., as part of the written statement of prepared testimony submitted in advance of their appearance. A non-governmental witness is any witness appearing on behalf of himself/herself or on behalf of an organization other than a federal agency, or a state, local or tribal government.**

<p>Your Name, Title, Organization, Business Address, and Telephone Number:</p> <p><b>Mary Reese, VOR Board Member; Member, Legislative Committee VOR, Speaking out for people with intellectual and developmental disabilities 836 S. Arlington Heights Rd., #351 Elk Grove Village, IL 60007 240-602-4224 cell; 301-460-8833 home</b></p>
<p>1. Are you appearing on behalf of yourself or a non-governmental organization? Please list organization(s) you are representing.</p> <p><b>I will be representing a non-governmental organization: VOR, Speaking out for people with intellectual and developmental disabilities.</b></p>
<p>2. Have you or any organization you are representing received any Federal grants or contracts (including any subgrants or subcontracts) since October 1, 2010?</p> <p style="text-align: center;">Yes      <input checked="" type="checkbox"/> No</p>
<p>3. If your response to question #2 is "Yes", please list the amount and source (by agency and program) of each grant or contract, and indicate whether the recipient of such grant or contract was you or the organization(s) you are representing.</p> <p style="text-align: center;">N/A</p>

Signature: *Mary L Reese*

Date: March 7, 2013

**Mary Reese**  
**VOR Board Member**  
**Member, VOR Legislative Committee**

Mary has over 50 years' experience serving on nonprofit county and state boards, and on committees representing individuals with intellectual and developmental disabilities (I/DD) and in leadership capacities encouraging volunteerism. She is the former Volunteer Services Director of a Maryland ICF/ID and the former Executive Director of Prince George's County Volunteer Center.

In 2012, Mary was elected to the Board of Directors for VOR, a national organization advocating for high quality care and human rights for all people with I/DD. Mary's advocacy is motivated by her step-daughter, Virginia, who has profound I/DD and medical challenges. Mary is Virginia's legal guardian and for years worked tirelessly to ensure adequate community supports while seeking admission to a state operated ICF/ID.

Recently, after a legal fight over many years, Mary secured placement at Holly Center for Virginia. Her story is featured on VOR's website (<http://vor.net/images/VirginiasStory.pdf>) and was recently the topic of WBAL 11 I Team report (<http://www.wbaltv.com/news/maryland/i-team/Caretaker-fights-state-to-get-disabled-woman-needed-care/-/10640252/19003378/-/item/0/-/npe49ez/-/index.html>).

Mary resides in Rockville, Maryland.

**Congressional Testimony for Public Witness Hearing**

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

**Wednesday, March 13, 2013**

**Statement of Walter J. Curran, Jr, MD, FACP**  
Executive Director of Winship Cancer Institute of Emory University  
On behalf of the Association of American Cancer Institutes

Chairman Kingston, Ranking Member DeLauro, and members of the subcommittee: Thank you for the opportunity to testify before you on the relationship of the National Institutes of Health (NIH) and our nation's cancer centers. My name is Dr. Walter J. Curran, Jr. of Winship Cancer Institute of Emory University. As Winship's Executive Director, a cancer researcher, and a practicing radiation oncologist, I am happy to be here on behalf of the Association of American Cancer Institutes (AACI) to discuss the critical importance of NIH support to our nation's cancer centers.

Chairman Kingston, thank you for your ongoing support of cancer research and your understanding of how research improves our care of cancer patients. I would also like to thank you for your visit to Winship in January 2012. I believe that our nation's leaders should visit cancer centers in order to witness the vital role our institutions play in the health of their constituents as they face a battle with cancer. Chairman Kingston, your support of Winship's recommended National Cancer Institute (NCI) funding level as well as your backing of our recent application to become a Lead Network Participating Site for NCI's National Clinical Trials Network (NCTN) is also appreciated. I hope your colleagues take the time to visit the cancer centers in or near their own districts and states to observe the outstanding work my colleagues do at their institutions.

### **NIH and Cancer Centers**

As you are well aware, the NCI is one of the NIH's institutes. NCI awards its designation to cancer centers who demonstrate expertise in laboratory, clinical, and behavioral and population-based cancer research through the successful competition for a Cancer Center Support Grant (CCSG). Winship first received NCI-designation in 2009; joining a prestigious

group of then 64 NCI-designated cancer centers. Winship just successfully renewed its designation and CCSG through a competitive renewal process, receiving a rating of “Outstanding” by a panel of our peers. Winship is the first and only NCI-designated cancer center in Georgia.<sup>1</sup> Today, Georgia is the 8<sup>th</sup> most populous state in the nation and is home to 3.2 percent of the entire U.S. population.

While Congress continues to debate the remainder of the FY2013 budget, NIH and NCI have prepared for cuts through FY2021. NIH will suffer a cut of \$1.6 billion, of which NCI will lose approximately \$250 million. These cuts will have a real impact on progress against cancer at Winship and other cancer centers across the country. Continued progress in cancer research is dependent on the sustained efforts of highly skilled research teams working at cancer centers across the country and supported by the NCI. A budget cut to NIH and ultimately NCI will decrease funding to cancer research in all parts of the country and impact many of the research teams working on new treatments and new cures. Rebuilding such teams, even after a short break in funding, could take years. As an example, Winship has an outstanding research team making real progress understanding how to target newly discovered mutations causing lung cancer, the type of cancer causing the most deaths in our country. We are observing an increase in the number of lung cancer patients who have little or no tobacco use history, and we are just beginning to understand the genetic and genomic risk factors of such individuals for developing lung cancer. A break in funding support of this and other projects could delay finding new and effective therapies for thousands of patients by years.

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<sup>1</sup> “Cancer Centers List.” *National Cancer Institute: Office of Cancer Centers*. National Cancer Institute. Web. 8 Mar 2013. <[http://cancercenters.cancer.gov/cancer\\_centers/index.html](http://cancercenters.cancer.gov/cancer_centers/index.html)>.

Our nation's cancer patients deserve greater research attention to this deadly disease. Sadly, cancer is the leading cause of death in Georgia, as we rank the 36<sup>th</sup> state for health outcomes overall.<sup>2</sup> More than 1.6 million Americans were diagnosed with cancer in 2012, with more than 570,000 people dying from the disease. With 25 percent of all deaths in America caused by cancer—almost 1,600 deaths per day—the disease is the nation's second leading cause of death. NCI estimates that 41 percent of individuals born today will receive a cancer diagnosis at some point in their lifetime.<sup>3</sup>

At Emory's Winship Cancer Institute, we are excited about the new proton beam therapy facility that is now under construction in Atlanta as well as the increasing number of our patients being enrolled on cancer clinical trials. We see that the impact of budget cuts through FY2021 has already begun to affect our progress in research. Immediate effects will be felt in our research labs, with promising research slowed or even shut down, pending projects wiped off the boards, the next generation of bright young researchers unable to learn cancer research at the side of experts, and layoffs among trained cancer staff, including those who coordinate clinical trials that test new cancer therapies. At Winship, we enrolled over 700 cancer patients on trials testing new treatments in 2012 from all across the state of Georgia and beyond, each of whom has his or her own amazing cancer journey to tell. We aspire to increase the number of cancer patients that we can offer such hope, but we need sustained support to achieve this. The reduction of funding to the CCSG program will directly impact our ability to provide the critical infrastructure necessary for a robust research program.

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<sup>2</sup> *America's Health Rankings*. United Health Foundation. 2012. <http://www.americashealthrankings.org/GA>

<sup>3</sup> *Cancer Trends Progress Report – 2011/2012 Update*, National Cancer Institute, NIH, DHHS, Bethesda, MD, August 2012, <http://progressreport.cancer.gov>.

We are particularly excited about Winship's and other cancer centers' ability to offer new and promising therapies to our patients in what we refer to as our phase I unit. This is our specialized center, which allows us to carefully study all the beneficial and any harmful effects of these therapies. We have offered such groundbreaking phase I treatments to nearly 200 patients per year at Winship.

#### **Overall Relationship with NIH**

In addition to cancer centers, the NCI supports cancer research in all of your communities through the National Clinical Trials Network and its newly reorganized five cancer cooperative groups. I have the great honor of co-leading one of these five research groups, and we have dedicated volunteer physicians and staff in every state and every congressional district in the nation offering hope to our cancer patients through a menu of over 200 cancer clinical trials. Twenty to twenty-five thousand patients choose to participate in these network trials each year, and this research has defined many of the best treatments for today and tomorrow's cancer victims among us. This research is well coordinated with our cancer centers and is necessary for outreach beyond our research universities into community medical practices and for finding answers to some of the toughest cancer research questions as quickly as possible. It is through this network that patients in such locations as southeastern Georgia are able to enroll in these cancer clinical trials with their community oncologists. Unfortunately, NCI support for these cancer cooperative groups has remained flat for over a decade. Sustaining this support is critical in providing your constituents the best access to the outstanding cancer care available through their participation in NCI-supported clinical trials.

### **NIH Impacts the Economy**

NIH plays a vital role in our cancer centers' research and also impacts our nation's overall economy. A United for Medical Research analysis released in January of 2013 projected the nation's life sciences sector, which includes cancer research, would lose more than 20,500 jobs and \$3 billion in economic output due to cuts to NIH. These serious consequences for biomedical jobs and local economies mean that funding cuts will undermine U.S. competitiveness, at a time when other nations are aggressively boosting their investments in research and development. We risk driving an entire generation of young cancer physicians and researchers either abroad, to seek opportunities to practice their craft and advance their careers, or out of the field altogether. At Winship this threat is real and we cannot afford to experience such loss. Such declines in funding will prevent Winship and other centers from quickly moving to a broader platform of personalized cancer care and research. This personalized approach requires a time- and resource-intensive approach to every patients' cancer to best understand what is the very best approach to each patient's care. This effort is well underway at Winship and other centers and will require a sustained and significant level of support to yield the positive results that we expect.

### **Conclusion**

NIH's full support of NCI-designated centers and their programs remains a top priority for our nation's cancer centers. We are on a clear path to dramatic breakthroughs, both at Winship and cancer centers throughout the country. We have come too far in cancer research progress to lose Congress' full support of NIH, and ultimately, NIH's funding of NCI-designated cancer centers and the National Clinical Trials Network. Your constituents deserve the best NIH, NCI, and our cancer centers have to offer in order to provide life-saving treatment.



**Testimony of the American College of Nurse-Midwives**

**Before the Committee on Appropriations of the Subcommittee  
on Labor/Health and Human Services/Education and Related  
Agencies regarding Fiscal Year 2014 Funding**

**Lorrie Kline Kaplan, Chief Executive Officer**

**March 13, 2013**

Chairman Kingston, Ranking Member DeLauro and members of the Committee, thank you for the opportunity you have provided the American College of Nurse-Midwives to appear before you today to provide testimony in relation to the federal budget for fiscal year 2014. While there are many segments of the federal budget I would like to touch on today, my testimony will be limited to three essential areas: 1. Funding for midwifery programs and Title VIII of the Public Health Service Act, 2. Funding of the National Health Service Corp and the role midwives play in addressing needs in shortage areas, and 3. Funding for the National Institute for Nursing Research (NINR).

The American College of Nurse-Midwives (ACNM) is the professional association that represents certified nurse-midwives (CNMs) and certified midwives (CMs) in the United States. The CM credential emerged several years ago as another pathway to midwifery practice outside of the typical nursing pathway. CNMs and CMs are primary care providers for women throughout the lifespan, with a special emphasis on pregnancy, childbirth, and gynecologic and reproductive health.

CNMs are licensed and maintain prescriptive authority in all fifty (50) states, Washington, DC, American Samoa, Guam and Puerto Rico. CMs are authorized to practice in five (5) states: DE, MO, NJ, NY, RI; and have prescriptive authority in NY. The Medicaid program reimburses CNMs as a mandatory service and Medicare pays the same fee to CNMs as it does to OBGYNs for similar services.

Today, 95.7% of CNM and CM attended births occur in hospitals, 2.2% in freestanding birth centers, and 2% in private residences. There are 11,799 CNMs in the U.S. today and 77 CMs. In many states, CNMs are licensed and regulated as Advanced Practice Nurses (APNs or APRNs).

Midwifery as practiced by CNMs and CMs encompasses a full range of primary health care services for women from adolescence beyond menopause. These services include primary care, gynecologic and family planning services, preconception care, care during pregnancy, childbirth and the postpartum period, care of the normal newborn during the first 28 days of life, and treatment of male

partners for sexually transmitted infections. Midwives provide initial and ongoing comprehensive assessment, diagnosis and treatment. They conduct physical examinations; prescribe medications including controlled substances and contraceptive methods; admit, manage and discharge patients; order and interpret laboratory and diagnostic tests and order the use of medical devices. Midwifery care also includes health promotion, disease prevention, and individualized wellness education and counseling. These services are provided in partnership with women and families in diverse settings such as ambulatory care clinics, private offices, community and public health systems, homes, hospitals and birth centers.

#### **Midwifery Education**

Presently there are thirty-nine (39) midwifery programs in the U.S. that train CNMs and CMs, thirty-five (35) are based in schools of nursing, others in schools of health sciences, public health or medicine. The Accreditation Commission for Midwifery Education accredits each of these programs. Today, the Masters degree is entry to practice in the profession.

Congress has authorized several important nursing education programs under Title VIII of the Public Health Service Act. These programs are vital to students, faculty and the educational programs themselves in training all levels of nurses from associate degree through post-graduate. Of particular importance today for midwifery programs are the Advanced Nursing Education Program and the Advanced Education Nursing Traineeship administered by the Health Resources and Services Administration (HRSA). Funding for these programs helps establish new

programs, aids in the growth of existing programs, and provides tuition support for nurse-midwifery students. As the shortage of maternity care providers continues to expand, as projected by the American College of Obstetricians and Gynecologists and others, these programs are vital to midwives meeting workforce demands in the U.S.

ACNM asks the Committee to urge HRSA to identify maternity care shortage areas in the U.S. as it presently does for shortages of primary care, mental health and dental care. Once such shortages are identified, ACNM believes federal, state, and private entities will be better able to target resources to address these needs. This may include development of additional midwifery programs in these urban and rural maternity care shortage areas.

#### **National Health Service Corp**

Also vital to meeting the health workforce demands of the future is a robust National Health Service Corp. Midwives continue to be placed through the NHSC as primary care providers in many areas of the nation. ACNM asks the Committee to continue to strengthen this program. ACNM also believes the NHSC can benefit from establishment of maternity care shortage areas as well, enabling the program to place midwives, obstetricians and other maternity care providers (practicing within their full scope of practice) across the nation in areas of critical need.

#### **National Institute of Nursing Research**

Clinical research remains an important component for improving our nation's health care system. NINR is dedicated to improving the health and health care of

Americans through the funding of nursing research and research training. Its mission is to promote and improve the health of individuals, families, communities, and populations. This mission is accomplished through support of research in a number of science areas. Among those areas of research are chronic and acute diseases, health promotion and maintenance, symptom management, health disparities, caregiving, and self-management, to name a few. NINR also supports the training of new investigators who bring new ideas and help to further expand research programs. The ultimate goal of our research is its dissemination into clinical practice and into the daily lives of individuals and families. ACNM appreciates the support the NINR has received and urges the Committee to enhance this funding for FY2014. ACNM asks that the Committee urge the NINR to focus additional efforts on maternity-related research in FY2014 and beyond.

As one of the most utilized health service areas with more than 4 million births annually, maternity care represents nearly \$100 billion of our nation's health care expenditures each year. Over 40 percent of these births are occurring within the Medicaid program and over 30 percent of these births are performed via cesarean delivery at a cost that is twice that of a normal physiological birth. More research is required to determine the best ways to promote normal physiological birth while taking into consideration the wishes of each woman.

Thank you for this opportunity to bring these issues to the attention of the Appropriations Committee. Thank you for your service.

JOHN E. MAUPIN, D.D.S., MBA  
PRESIDENT

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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, 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 ADMINISTRATION**

**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) 2014, 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 Meharry 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 FY14, 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 FY14, 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 FY13, 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 FY14, 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 FY14, 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.

**Joseph J. McNulty, Executive Director  
Helen Keller National Center**

The Helen Keller National Center (HKNC) is authorized through the Helen Keller National Center Act (CFDA No. 84.128) and is under the jurisdiction of the Labor/HHS Appropriations Subcommittee in the House and Senate. It is currently funded at \$9.1 million. The Center is requesting an increase of \$2 million in FY 2014.

The HKNC Act identifies five purposes of the Center:

- (1) to provide specialized intensive services, or any other services, at the Center or anywhere else in the United States, which are necessary to encourage the maximum personal development of any individual who is deaf-blind;**
  
- (2) to train family members of individuals who are deaf-blind at the Center or anywhere else in the United States, in order to assist family members in providing and obtaining appropriate services for the individual who is deaf-blind;**
  
- (3) to train professionals and allied personnel at the Center or anywhere else in the United States to provide services to individuals who are deaf-blind; and**
  
- (4) to conduct applied research, development programs, and demonstrations with respect to communication techniques, teaching methods, aids and devices, and delivery of services.**
  
- (5) to maintain a national registry of individuals who are Deaf-Blind.**

To accomplish its mission, the Center operates a comprehensive rehabilitation training program at its headquarters in Sands Point, NY, and ten (10) regional offices in MA, NY, MD, GA, IL, KS, TX, CO, WA and CA.

The following is a breakdown of HKNC's funding for fiscal years 1999-2013:

<u>Fiscal Year</u>	<u>Appropriation</u>
1999	\$ 8,550,000
2000	\$ 8,550,000
2001	\$ 8,717,000
2002	\$ 8,717,000
2003	\$ 8,660,000
2004	\$ 8,666,000
2005	\$10,581,000
2006	\$ 8,511,000
2007	\$ 8,511,000
2008	\$ 8,362,000
2009	\$ 8,362,000
2010	\$ 9,181,000
2011	\$ 9,163,000
2012	\$ 9,146,000
2013	\$ 8,680,000 *

\* Reflects a 5.1% reduction through sequestration.

**With the exception of a one-time increase of \$2 million in FY 2005 and a \$1 million increase in 2010, HKNC has been level funded for the last 15 years. Had the Center received an annual COLA over this period of time, its funding would be at more than \$12 million – approximately 40% above its current level.**

**In June of 2011, the WESTAT Corporation completed a two year evaluation of HKNC on behalf of the U.S. Department of Education's Rehabilitation Services Administration. Among its conclusions were that, "HKNC appears to be meeting its mandate to provide services to any deaf-blind individual, family members, and service providers, and conduct applied research and demonstrations" and that, "the preponderance of evidence from multiple data sources indicates that HKNC is providing services to address the vocational and independent living needs of D-B individuals, and many stakeholders familiar with HKNC's work consider HKNC to be the 'gold standard' for provision of services to D-B individuals."**

**If the Center is to continue to successfully meet its Congressional mandate, it must address two significant challenges: a rapidly growing number of people eligible for its services and a critical shortage of personnel across the country trained to work with people who are dual sensory impaired.**

**At the time HKNC was established in 1967, it was estimated there were approximately 70,000 individuals in the United States who were Deaf-Blind. Due to a combination of medical advances that have enabled significantly disabled infants to survive into adulthood, improved genetic testing to better identify people with dual sensory impairments, and the "Graying of America," a 2007 study conducted by the Research and Training Center on Blindness and Low Vision at Mississippi State University estimated that the number of individuals in this country with a combined vision and hearing impairment is nearly 1.2 million, the overwhelming majority of whom are 55 years of age and older.**

**For a Deaf-Blind person, the greatest barrier to finding employment and living a full, productive life is the lack of people with the skills to help him or her reach their full potential. The shortage of highly qualified personnel in Special Education and Rehabilitation is well documented. In the area of low incidence disabilities, particularly Deaf-Blindness, it is at crisis levels.**

**A good example of this is the recently created National Deaf-Blind Equipment Distribution Program (NDBEDP) whereby the Federal Government has set aside up to \$10 million each year for the training in and purchase of telecommunications equipment for people who are Deaf-Blind. Recent advances**

in technology have led to greater community participation and opportunities for employment in careers that were not thought possible as recently as ten years ago. People with combined vision and hearing loss are now able to communicate with their families, neighbors and coworkers and can access information on the web, e-mailing, instant messaging and joining in chat rooms and list serves. Unfortunately, due to the small number of assistive technology instructors capable of working with individuals who are Deaf-Blind, there are many people unable to take advantage of this program.

With the support of short term funding from two foundations, the Center has recently established two significant programs to address this crucial need for qualified personnel. The first is a series of one week, "train the trainer" seminars that prepare assistive technology instructors to effectively teach people who are Deaf-Blind on the use of various types of equipment available through the NDBEDP such as iOS devices, smart tablets and refreshable braille displays. The second is the Information, Research and Professional Development (IRPD) Department at HKNC which is creating an expanded web site that will offer, among other things, distance learning opportunities and on-line courses in a variety of disciplines and content areas.

Unfortunately, both these projects are only funded for one more year and will be discontinued without the more permanent funding provided by an increase in HKNC's Federal appropriation.

Helen Keller was the first Deaf-Blind person in history to earn a college degree, graduating from Radcliffe College in 1904. It was fifty years before Robert Smithdas followed in her footsteps and graduated from St. John's University. Bob went on to earn a Master's in Rehabilitation Counseling at New York University, becoming the first Deaf-Blind person to receive a graduate degree.

Today, it is not a question of whether or not Deaf-Blind people can live and work in their communities. There are Deaf-Blind people across the country with high school diplomas and college degrees, holding down jobs in a wide range of careers, and enjoying full, rich lives. It is up to us as a society to give them the resources of a quality education, vocational and independent living training and sufficient follow-up supports to reach their full potential.

An increase of \$2 million in HKNC's FY 2014 appropriation will provide the Center with the capacity to maintain and expand its programs designed to increase the number of professionals throughout the United States trained to work with individuals with dual sensory impairments.

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Testimony of Harry Johns, President and CEO of the Alzheimer's Association  
 Fiscal Year 2014 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 13, 2013

The Alzheimer's Association appreciates the opportunity to comment on the Fiscal Year (FY) 2014 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. While deaths from other major diseases, including heart disease, stroke and HIV continue to experience significant declines, those from Alzheimer's have increased 68 percent between 2000 and 2010.

With the first of the baby boomer generation now turning 65, the U.S. population aged 65 and over is expected to double by 2030. Although Alzheimer's is not normal aging, age is the biggest risk factor for the disease. Taken together, these factors will result in

the compassion to care, the leadership to conquer

more and more Americans living with Alzheimer's - as many as 16 million by 2050, when there will be nearly one million new cases each year. 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 2012, America will have spent an estimated \$200 billion in direct costs for those with Alzheimer's, including \$140 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. Unless something is done, the costs of Alzheimer's in 2050 are estimated to total \$1.1 trillion (in today's dollars). Costs to Medicare and Medicaid will increase nearly 500 percent and there will be a 400 percent increase in out-of-pocket costs.

With Alzheimer's, it is not just those with the disease who suffer - it is also their caregivers and families. In 2011, 15.2 million family members and friends provided unpaid care valued at over \$210 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 \$8.7 billion in additional health costs in 2011.

### **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 will, for the first time, enable 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. 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 much progress. If we are going to succeed in the fight against Alzheimer's, Congress must provide the resources the scientists need. Understanding this, the President's FY 2013 budget request included \$80 million for Alzheimer's research and \$20 million for education, outreach and support. 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 \$31,000 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 were laid out in the President's FY 2013 budget. While the President's budget requested \$100 million for research and support services, the needs of the Alzheimer's community has grown. **The Alzheimer's Association urges Congress to fully fund the research, education, outreach and support activities and the 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, 2011, 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 FY2013 Senate Labor-HHS bill included report language commending HBI for its leadership in bringing attention to the public health crisis of Alzheimer's disease and for its work on cognitive impairment data collection in 45 states, the District of Columbia and Puerto Rico. Additionally, the committee noted that developing a population-based surveillance system with longitudinal follow-up is a key recommendation in the National Public Road Map to Maintaining Cognitive Health, which was developed jointly by the CDC and the Alzheimer's Association. The bill increased funding for HBI by \$10 million in order to further develop this system and to develop effective public health messages to promote cognitive health in older adults. **The Alzheimer's Association urges Congress to support \$11.8 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.

House Appropriations Labor, HHS, Education, and Related Agencies Subcommittee  
 Public and Outside Witness Hearing  
 March 13, 2013

Testimony of

**Paul E. Jarris, MD, MBA**

*Executive Director, Association of State and Territorial Health Officials*

*(\$\$ in millions)*

<b>Program</b>	<b>FY 2012 Appropriation</b>	<b>FY 2013 and 2014 ASTHO Recommendation</b>
CDC Preventive Health and Health Services Block Grant	79.5	100.0
CDC Core Infectious Diseases	184.7	195.0
CDC Healthcare-Associated Infections/National Healthcare Safety Network	26.6	40.0
CDC Public Health Emergency Preparedness Cooperative Agreements	641.7	715.0
ASPR Hospital Preparedness Program	379.6	426.0
CDC Section 317 Immunization Program and Program Operations	620.2	720.0
CDC Food Safety	27.1	43.8
CDC National Public Health Improvement Initiative	40.2	40.2

Chairman Kingston and Members of the Subcommittee, my name is Dr. Paul Jarris and I serve as Executive Director of the Association of State and Territorial Health Officials (ASTHO). ASTHO is the national nonprofit organization representing public health agencies in the United States, the U.S. Territories, and the District of Columbia, and over 100,000 public health professionals these agencies employ. ASTHO members, the chief health officials of these jurisdictions, formulate and influence sound public health policy and ensure excellence in state-based public health practice.

I appreciate the opportunity to appear before you today to discuss the value and role of public health and the impact federal funding and programs have on protecting the public's health in the U.S., in our states and territories, and in our communities.

The best way to explain what public health is and what public health does every day to protect everyone in this room, your constituents, and everyone across the nation is to tell you a story. While this is one story about one recent disease outbreak, it is representative of thousands of other examples of public health in action whether it is an infectious disease, such as the recent whooping cough outbreak or West Nile virus outbreaks; natural disaster, such as the Joplin, Missouri tornado or Superstorm Sandy; or man-made disasters, such as Deepwater Horizon.

#### **Major Multi-State Outbreaks in 2012**

- **West Nile virus:** 5,890 cases of West Nile virus disease, including 243 deaths, have been reported across 49 states.
- **Fungal meningitis:** 693 cases and 45 deaths across 10 states, caused by a fungal infection associated with the injection of methylprednisolone acetate solution from a single compounding pharmacy.
- **Salmonella Bredeney infections.** 42 people across 20 states were infected with the outbreak strain of *Salmonella* Bredeney linked to peanut butter.
- **Salmonella infections.** 261 cases and three deaths across 24 states, caused by the outbreak of *Salmonella* Typhimurium and *Salmonella* Newport infections linked to cantaloupes.
- **Whooping Cough (pertussis).** In 2012, there were 41,000 reported cases of pertussis and 18 pertussis-related deaths. The majority of deaths continue to occur among infants younger than 3 months of age.

This is the story of the recent fungal meningitis outbreak and how, with the direct involvement and coordination of the public health system at the federal, state, and local levels and through the federal investments made by this subcommittee, public health agencies reduced the death rate from nearly half of infected patients dying down to zero and saved countless lives.

On Sept. 18, 2012, Dr. Marion Kainer who works at the Tennessee Department of Health (TDH) received an email from a physician at Vanderbilt University Medical Center. A young, otherwise healthy patient had meningitis caused by a fungus – something rarely seen. Dr. Kainer immediately began her investigation. Upon learning that the patient recently had an epidural injection at a pain clinic, Dr. Kainer notified the clinic at once.

Although fungal meningitis is rare, it is not a notifiable disease. No other cases had been reported to CDC at that point in time. On Sept. 20, 2012, Dr. Kainer contacted CDC, but she didn't stop there. Due to her extensive training and knowledge as a public health disease detective, she saw the potential for significant public health consequences. She visited the pain clinic to review their sterile procedures and identified the injectable steroid as a likely source; and she and the Tennessee Health Commissioner, John Dreyzehner, sent a health alert to all Tennessee clinicians.

By Sept. 25, 2012, Dr. Kainer contacted the Massachusetts Department of Public Health because she determined that injections were coming from the New England Compounding Center (NECC) located in that state and soon thereafter NECC voluntarily recalled lots of the implicated product. Public health convened experts to advise patients and clinicians how to identify, diagnose, and treat patients with fungal meningitis. Public health tracked down patients who had received the tainted steroid and directed them to their doctors. Without public health professionals partnering with doctors many more Americans would have died.

Had this astute state health disease detective not been there, if she had been on a furlough day when that call had come in, if the public health lab had been short staffed, had the alert networks not been deployed to connect public health with clinicians, had preparedness and response plans not been exercised...the outbreak could have been even more devastating. Time is of the essence in a disease outbreak. This outbreak represents a significant tragedy for the 14,000 potentially exposed individuals, 720 families sickened, and the 48 families across 23 states that lost loved ones. Those losses cannot be ignored. Each one of the federal public health programs listed in the table at the beginning of my written testimony, plus others, contributed to

the fungal meningitis response and I encourage you to look favorably on our funding recommendations for those programs in fiscal years 2013 and 2014.

Not every healthcare decision is made in a single doctor's office for a single patient. Most of the health promotion and protection and disease prevention decisions are population-wide and take place every day in our communities. Public health departments work 24/7 to ensure your health and safety is protected in your communities and in your states through such activities as responding to outbreaks, conducting food safety and restaurant inspections, and to ensure that healthy choices are the easy choices for your constituents and for everyone living in the U.S.

Public health professionals are an integral part of disaster response alongside police, fire, and emergency response agencies. They train and are equipped to respond to all hazards that impact human health – natural disasters, disease outbreaks, terrorist attacks – in order to limit illness, death, and disability. Public health approaches to sanitation, vaccination, outbreak control, and other health threats have added 30 years to life expectancy in this country since 1900 – far more than medical care. We can continue our progress based on evidence-based science and approaches, but we rely upon the basic financial support from federal, state and local government.

We are the doctors, nurses, community health and social workers, environmental health specialists, behavioral health professionals, disease detectives, laboratorians, and health policy experts that protect and promote health where you live, work, and play.

Public health is an enterprise. On the governmental side, we are made up of local, state, tribal, territorial, and federal government entities. But we also have significant partnerships in other community-based organizations, such as hospitals, universities, nonprofit provider and patient groups, civic organizations, and faith-based organizations. Each piece of that enterprise is

essential to ensure the system works. The federal government's role is significant. Diseases and public health emergencies, such as natural disasters, do not recognize state borders.

State health agencies rely on a mix of federal grant funds, state general funds, fees, and other sources. The largest portion—45 percent—is discretionary federal funds, followed by state general funds—23 percent.

Federal, state, and local government budget cuts are jeopardizing a decade or more of significant gains made by state and territorial health agencies. Since 2008, 91 percent of state health agencies have experienced budget reductions. More than 46,000 jobs have been lost at state and local health departments combined, which is nearly 21 percent of the total state and local health department workforce.

What are the consequences of public health funding reductions? The real story cannot be told in numbers alone. The real story is told by the narratives that accompany these numbers. The negative consequences: the adult who doesn't get vaccinated to protect their newborn baby against a preventable disease, like whooping cough; the young adult who doesn't get screened for HIV due to lack of testing services at the health department; the furlough days that keep a laboratorian or disease detective from discovering a disease outbreak to stop it from spreading... these are not possibilities, but are very real everyday occurrences that keep all of us in public health up at night.

In conclusion, public health has historically been asked to do more with less. It is now at a breaking point. Unless we start supporting our public health system in a more sustained way, our capacity will continue to erode and our ability to respond quickly and competently will evaporate. Our ability to protect the public's health will be threatened.

Getting our federal deficit under control is important. But so is protecting the health and safety of everyone in the U.S. It is a tough job you have before you over the next weeks and months to fund the federal government responsibly. Put simply, additional cuts in discretionary public health programs would put the health, safety, and security of all Americans at risk.



**Paul E. Jarris, M.D., MBA**, Executive Director, Association of State and Territorial Health Officials

Dr. Paul E. Jarris is the executive director of the Association of State and Territorial Health Officials (ASTHO), which represents public health agencies in the United States, its territories and freely associated states, and over 100,000 public health professionals these agencies employ. Jarris joined ASTHO in June of 2006, having served for three years on its board of directors.

Jarris takes seriously ASTHO's mission to transform public health within states and territories to help members dramatically improve health and wellness. In his executive capacity, he works with ASTHO's board of directors to implement the association's strategic plan and advance its policy goals. Jarris champions the governmental public health enterprise. Through his leadership, ASTHO became one of the founding organizations for the Public Health Accreditation Board, which manages and promotes the national public health accreditation program, and the Alliance to Make US Healthiest, a nonpartisan public-private organization that facilitates partnerships to make the U.S. the healthiest nation in a healthier world. Additionally, during the 2009 H1N1 crisis, Jarris led ASTHO's efforts to help states respond to the pandemic and supports state and national health transformation to improve the public health system.

Jarris came to ASTHO with more than 18 years of experience in public health and healthcare leadership. From 2003 to May 2006, he served as state health official for the Vermont Department of Health. While there, he implemented the Vermont Blueprint for Health Chronic Care Initiative, a statewide public-private partnership to improve the health of Vermont residents while reforming the state's health care system. Jarris also led the establishment of Vermont's first inpatient substance abuse treatment program for adolescent and women's care.

As medical director for Community Health Plan from 1992-1996 and for Vermont Market, Kaiser Permanente Northeast Division from 1996 to 1999, Jarris oversaw medical functions such as quality improvement, resource management, practice relations and medical affairs for a 140,000 members. As a family physician, he worked tirelessly with Vermont's underserved populations in a federally qualified health center, inner city school, and homeless shelter for adolescent youth.

Jarris is a 1984 graduate of the University of Pennsylvania School of Medicine and received a master's degree in business administration from the University of Washington in 1989. He is certified by the American Board of Family Medicine and the American Board of Medical Management. He chairs the National Quality Forum's National Priorities Partnership subcommittee on Healthy People/Healthy Communities and co-chaired its Population Health Measures Working Group. He is also a member of the Institute of Medicine's Board on Health Sciences Policy and numerous professional societies and committees.

In addition to his dedication to public health and healthcare, Jarris is a devoted husband and father and an avid outdoorsman. He cofounded Vermont's Catamount Trail, North America's longest cross-country ski trail that spans the 300-mile length of the Green Mountains.

*Written Testimony of James Lacy, Past President, on behalf of Rotary International – 13 March 2013  
House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Programs*

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). Chairman Kingston, two weeks ago you remarked on the “modern miracle” of polio eradication which we in the United States take for granted. You noted the outstanding leadership of the Centers for Disease Control and Prevention, Rotary International, and other partners in this achievement. Mr. Chairman, I thank you for recognizing the effective public private partnership that has brought us so close to a polio free world. 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 a safe, cost-effective public health intervention of polio immunization, one which is increasingly being combined with opportunistic, complementary interventions such as the distribution of life-saving vitamin A drops. We celebrate our progress toward a polio free world and 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 2013 request of \$126.4 million for the polio eradication activities of the CDC. While we have not seen the President’s 2014 request, we would support *at least* that level of funding in 2014 to fully implement the polio eradication strategies and innovations outlined in the new *Polio Eradication and Endgame Strategic Plan (2013-2018)*.

#### **PROGRESS IN THE GLOBAL PROGRAM TO ERADICATE POLIO**

Significant strides were made toward polio eradication in 2012 thanks to this committee’s leadership in appropriating funds for the polio eradication activities of the CDC.

- India was removed from the list of endemic countries in February 2012, and has not had a case of polio for more than two years.

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- Eradication efforts have led to more than a 99% decrease in cases since the launch of the GPEI in 1988. In 2012 there were fewer cases in fewer places than at any point in recorded history with only 223 cases of polio – a 65% decrease compared to 2011. All but six of these cases were in the three remaining polio endemic countries of Afghanistan, Pakistan, and Nigeria.
- Only nine cases of polio have been reported in 2013.
- Incidence of type 3 polio is at historically low levels. There were 21 cases of type 3 polio in 2012 compared to 67 in 2011. Type 3 polio is also found in fewer areas than ever before.
- Angola and the Democratic Republic of Congo, two of four countries considered to have reestablished transmission of polio, reported no cases of polio in 2012. Chad, another of the reestablished transmission countries has not reported a case of polio since June of 2012.

A new *Polio Eradication and Endgame Strategic Plan (2013-2018)* 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. However, this support has declined as a proportion of the GPEI expenditures from approximately 19% just five years ago to 13% in 2012. A resumption of funding to the earlier 19% level would ensure vital funding for the GPEI and send a strong signal of continued leadership and commitment by the United States as the new strategic plan is implemented. Notably, funding provided by the polio affected countries themselves and by private sector donors – led by Rotary International and the Bill & Melinda Gates Foundation, has increased in recent years. The ongoing support of donor countries, like the United States, is

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essential to assure the necessary human and financial resources are made available to polio-endemic and at risk countries to take advantage of the window of opportunity to forever rid the world of polio. The current sequestration reduces the amount of funds provided for global polio eradication efforts and appears to the global community as a reduction in US support at a time when commitment is being redoubled to finish the job. Continued leadership of the United States is essential to capitalize on past progress and 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 support of CDC’s polio eradication activities. The United States is the leader among donor nations in the drive to eradicate this crippling disease. Congressional support, in FY 2012 and FY 2013 enabled CDC to:

- continue engagement of the Emergency Operations Center (EOC) to harness agency-wide technical expertise to implement the agency’s polio response in a rapid and efficient manner;

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- develop a “dash board” monitoring system to collect, analyze, and visualize key indicators of campaign performance in real time to identify and address issues in advance to ensure high quality campaigns. This system, modeled on lessons from India and Pakistan, was piloted in Nigeria in July 2012 in 11 states and then fully implemented during the October campaigns.
- implement a nomad strategy in Nigeria which identified more than 560,000 children under five years old through census taking activities; reached more than 22,000 settlements with polio vaccine; and identified more than 4,000 settlements never visited by a vaccination team.
- provide the trained and experienced human resources to strengthen detection of polioviruses through the Stop Transmission of Polio (STOP) volunteer consultants. Since the December 2, 2011 EOC activation, the STOP program has deployed more than 500 individuals in 33 countries. CDC also developed the National STOP program (NSTOP) to build local capacity by recruiting highly trained public health professionals to work at the state and local levels to support polio eradication. In Nigeria, NSTOP is an innovative strategy that has deployed 70 staff across northern polio affected states.
- purchase 195 million doses of oral polio vaccine for use in polio campaigns in 2012;
- conduct AFP surveillance reviews, and support WHO Expanded Program on Immunization (EPI) reviews; and
- provide 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.

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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, more than 10 million children will be paralyzed in the next 40 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.



**NAEVR**

National Alliance For  
Eye And Vision Research

*Serving as Friends of the National Eye Institute*

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**Hearing on Fiscal Year (FY) 2014 Budget Priorities for Labor, Health and Human  
Services, and Related Agencies Appropriations before the  
Subcommittee on Labor, HHS, and Education and Related Agencies  
March 13, 2013  
10:00 am**

**Testimony by Hendrik P.N. Scholl, M.D., M.A.  
The Dr. Frieda Derdeyn Bambas Professor of Ophthalmology  
Wilmer Eye Institute/Johns Hopkins University School of Medicine  
Baltimore, Maryland  
On behalf of the National Alliance for Eye and Vision Research**

The National Alliance for Eye and Vision Research (NAEVR) requests Fiscal Year (FY) 2014 National Institutes of Health (NIH) funding at \$32 billion and National Eye Institute (NEI) funding at \$730 million. This funding represents the minimum investment necessary to make up for the twenty percent loss in purchasing power in the last decade due to flat funding and biomedical inflation, as well as the sequester's impact.

Good morning Chairman Kingston, Ranking Member DeLauro, and members of the Subcommittee, and thank you for the opportunity to appear today in support of appropriations for the National Institutes of Health (NIH) and the National Eye Institute (NEI). I am Hendrik Scholl, M.D., and I serve as The Dr. Frieda Derdeyn Bambas Professor of Ophthalmology at the Wilmer Eye Institute of the Johns Hopkins School of Medicine in Baltimore, Maryland.

I am representing the National Alliance for Eye and Vision Research (NAEVR), an Alliance of 55 member organizations representing professional societies in ophthalmology and optometry, patient and consumer groups, and industry. NAEVR serves as the "Friends of the National Eye Institute" and advocates for adequate funding for NEI's mission of saving and restoring vision.

I am here today to urge your support for a Fiscal Year (FY) 2014 NIH funding increase to a level of at least \$32 billion, as well as an increase in NEI funding to a level of \$730 million. This recommendation reflects the minimum investment necessary to make up for the twenty percent loss in purchasing power over the last decade due to flat funding and biomedical inflation, as well as the impact of the sequester, which cuts 5.1 percent or \$1.6 billion from NIH's \$30.6 billion budget.

I received my medical degree in Germany and did a fellowship in London, so I bring an international perspective to the need for adequately funding medical research. The NIH has long held a unique role in the world as the driver of biomedical research, the training ground for the next generation of scientists, a creator of jobs and source of economic development, and a leader in the competitive, innovation-based global marketplace. Without continued adequate investment, the United States will not only lose its leadership position, it will also fail to build upon the past investment in research to understand the basis of disease and develop treatments that save and improve lives. Vision research at the NEI has also been affected, with the sequester cutting \$36 million from its \$703 million budget. This could potentially result in about 90 new grants not getting funded—any one of which could hold the promise for saving or restoring vision.

The FY2013 cut and the potential for reduced, flat, or a minimal increase in FY2014 funding could not come at a worse time. During the decade 2010-2020, the majority of the 78 million "Baby Boomers" will turn age 65 and be at greatest risk of aging eye disease. More than 38 million Americans age 40 and older already experience blindness, low vision, or an age-related eye disease such as age-related

macular degeneration (AMD), glaucoma, diabetic retinopathy, or cataracts. This number is expected to grow to more than 50 million Americans by the year 2020.

In 2009, both the House and Senate spoke volumes in passing resolutions that designated 2010-2020 as *The Decade of Vision* in anticipation of the extraordinary vision challenges presented by this "Silver Tsunami." We are asking Congress to ensure that the NEI has the funding necessary to address these challenges.

I am a clinician-scientist who focuses on diseases of the retina, which is the light-sensitive back of the eye necessary for vision. My specialty is retinal degenerations, especially AMD, which is the leading cause of vision loss in individuals over 60 years old and the leading cause of vision loss in the industrialized world due to the aging of the population. Each year, 200,000 Americans develop advanced AMD, resulting in a loss of central vision and an inability to read, drive, and conduct activities of daily living.

Fifteen years ago, there was not a lot new in AMD research, but now it is one of the hottest areas. In 2010, NIH Director Dr. Francis Collins testified before the House Energy and Commerce Committee, stating that:

"Twenty years ago, we could do little to prevent or treat AMD. Today, because of new treatments and procedures based in part on NIH research, 1.3 million Americans at risk for severe vision loss over the next five years can receive potentially sight-saving therapies."

The NEI has been a leader in determining the genetic basis of eye disease. In fact, one-quarter of all genes discovered to-date have been associated with both common and rare eye diseases. The NEI has especially been a leader in the genetic basis of AMD. NEI's AMD Gene Consortium, a network of international investigators, has just discovered seven new regions of the human genome—called loci—that are associated with increased risk of AMD. They also confirmed 12 loci already identified in

previous studies. These loci implicate a variety of biological functions, including regulation of the immune system, maintenance of cellular structure, growth and permeability of blood vessels, lipid metabolism, and atherosclerosis. By understanding the genetic basis of the disease and the underlying disease mechanism, NEI can develop appropriate diagnostic and therapeutic applications.

The NEI is also supporting research that restores vision. In February, the Food and Drug Administration (FDA) approved an implanted retinal prosthesis to treat adult patients with advanced Retinitis Pigmentosa (RP), a rare genetic condition that damages the retina and leads to blindness. A small video camera mounted on a pair of glasses sends images to a video processing unit that converts them to electronic data that is wirelessly transmitted to an array of electrodes implanted onto the retina. The device is enabling those who are otherwise completely blind to identify doors, crosswalks, and even utensils on a table.

Although this "Bionic Eye" may have been a fantasy just a few short years ago, the NEI has always envisioned the future. In late February, it hosted an *Audacious Goals* Development meeting where 200 representatives from every sector of the vision community, as well as government scientists and regulators from various disciplines and even entrepreneurs, met to shape NEI's research agenda well beyond its five-year strategic plan. The discussion topics were 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*, a worldwide competition for compelling one-page ideas to advance vision science. These ideas included restoring light sensitivity to the blind, precision correction of defective genes, and growing healthy

tissue from stem cells for ocular tissue transplants. But making these goals a reality will take adequate funding.

In closing, I'd like to note that, in public opinion polls over the past 40 years, Americans have consistently identified fear of vision loss as second only to fear of cancer. Patients with moderate to severe vision loss would trade years of remaining life for perfect vision. For example, patients who are legally blind due to diabetes would be willing to trade up to 36 percent of their remaining life to regain perfect vision.

In summary, NAEVR requests FY2014 NEI funding at \$730 million since our nation's investment in vision health is an investment in 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 to maintain their independence, and generally improve the quality of life, especially since vision loss is associated with increased depression and accelerated mortality.

#### **ABOUT NAEVR**

The National Alliance for Eye and Vision Research (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 and vision research. Visit NAEVR's Web site at [www.eyeresearch.org](http://www.eyeresearch.org).

Christopher Kus, M.D., M.P.H.  
Association of Maternal and Child Health Programs, Public Witness Testimony  
House Labor, Health and Human Services and Education Appropriations Subcommittee  
March 13, 2013

On behalf of the Association of Maternal and Child Health Programs (AMCHP), I am pleased to submit testimony describing AMCHP's request for **\$640 million in funding for fiscal year 2014 for the Title V Maternal and Child Health (MCH) Services Block Grant administered by the Health Resources and Services Administration Maternal and Child Health Bureau**. This funding request represents a \$90 million decrease from its highest level of \$730 million in fiscal year 2003. Non defense discretionary programs cannot continue to bear the brunt of efforts to reduce the federal deficit. Specifically, sequestration combined with reductions throughout the past ten years resulted in a \$124 million decrease bringing funding for the Title V MCH Block Grant to its lowest level since 1991. The Title V MCH block grant is the foundation upon which core public health programs dedicated to improving the lives of our families is built and I strongly urge you to halt the erosion of funding for this critical program.

In 2011 the Title V MCH Block Grant provided support and services to 44 million American women, infants and children, including children with special health care needs. It has been proven a cost effective, accountable, and flexible funding source used to address the most critical, pressing and unique MCH needs of each state. States and jurisdictions use the Title V MCH Block Grant to design and implement a wide range of maternal and child health programs. Although specific initiatives may vary among the states and jurisdictions, all of them work with local, state, and national partners to accomplish the following:

- Reduce infant mortality and incidence of disabling conditions among children;
- Increase the number of children appropriately immunized against disease;

- Increase the number of children in low-income households who receive assessments and follow-up diagnostic and treatment services;
- Provide and ensure access to comprehensive perinatal care for women; preventative and child care services; comprehensive care, including long-term care services, for children with special health care needs; and rehabilitation services for blind and disabled children and
- Facilitate the development of comprehensive, family-centered, community-based, culturally competent, coordinated systems of care for children with special health care needs.

In addition to providing services to over 40 million Americans, Title V MCH Block Grant programs save federal and state governments' money by ensuring that people receive preventive services to avoid more costly chronic conditions later in life. Below are some examples of the cost effectiveness of maternal and child health interventions and the role of this program:

- **Total medical costs are lower for exclusively breastfed infants than never-breastfed infants since breastfed infants typically need fewer sick care visits, prescriptions and hospitalizations.** State MCH programs promote breastfeeding by developing educational materials for new mothers on breastfeeding practices and providing information on breastfeeding to all residents of their states through websites, toll free telephone lines and coordinating with other local and state programs.
- **Studies demonstrate that every \$1 spent on smoking cessation counseling for pregnant women saves \$3 in neonatal intensive care costs.** State MCH programs fund state-wide smoking cessation or "quit lines" for pregnant women and provide education within their state about the dangers of smoking during pregnancy, helping moms and moms-to-be quit smoking and reducing their risk of premature birth.

- **Every \$1 spent on preconception care programs for women with diabetes can reduce health costs by up to \$5.19 by preventing costly complications in both mothers and babies. Investing \$10 per person per year in community based disease prevention could save more than \$16 billion annually within five years.** State MCH and chronic disease programs work together at the state and community levels to educate women, children and families about the importance of physical activity, nutrition and obesity prevention throughout the lifespan.
- **Early detection of genetic and metabolic conditions can lead to reductions in death and disability as well as saved costs.** For example, phenylketonuria (PKU) a rare metabolic disorder affects approximately one of every 15,000 infants born in the US. Studies have found that PKU screening and treatment represent a net direct costs savings. State MCH programs are responsible for assuring that newborn screening systems are in place statewide and that clinicians are alerted when follow up is required.
- **Early detection of physical and intellectual disabilities results in more efficient and effective treatment and support for children with special health care needs.** High-quality programs for children at risk produce strong economic returns ranging from about \$4 per dollar invested to over \$10 per dollar invested. State MCH programs administer the state and territorial Early Childhood Comprehensive Systems Initiative to support state and community efforts to strengthen, improve and integrate early childhood service systems.
- **The injuries incurred by children and adolescents in one year create total lifetime economic costs estimated at more than \$50 billion in medical expenses and lost productivity.** State MCH programs examine data and translate it into information and policy to positively impact the incidence of infant mortality and other factors that may contribute to

child deaths. State MCH programs invest in injury prevention programs, including state and local initiatives to promote the proper use of child safety seats and helmets. Additionally state MCH programs promote safe sleeping practices to prevent Sudden Infant Death Syndrome (SIDS).

- **The total cost of adolescent health risk behaviors is estimated to be \$435.4 billion per year. Risky behaviors have impact on the health and well being of adolescents included smoking, binge drinking, substance abuse, suicide attempts and high risk sexual behavior.** State MCH programs and their partners address access to health care, violence, mental health and substance use, reproductive health and prevention of chronic disease during adulthood. State MCH programs often support state adolescent health coordinators who work to improve the health of adolescents within their states and territories.

I know that some Members of Congress contend that savings in such as these will not be realized in the near future and therefore will not result in immediate savings in these tight fiscal times. But today we can highlight a real-time example of how the Title V MCH Block Grant has played a role in helping save millions in annual health care costs. In Ohio, Title V played a lead role in providing funding for the Ohio Perinatal Quality Collaborative (OPQC). The OPQC is charged with reducing preterm births and improving outcomes of preterm newborns. Using the Institute for Healthcare Improvement Breakthrough Series, OPQC worked with 20 maternity hospitals (47% of all births in the state) through a collaborative focused on several obstetric improvement projects. OPQC reports that as a result of their efforts over 9,000 births are full term and that approximately 250 NICU admissions have been avoided. OPQC estimates approximately **\$10 million in annual health care cost savings**. Other states have similar initiatives and we are tracking their successes.

Another key component of the Title V MCH Block Grant is the Special Projects of Regional and National Significance (SPRANS). SPRANS funding complements and helps ensure the success of State Title V, Medicaid and CHIP programs by driving innovation, training young professionals and building capacity to create integrated systems of care for mothers and children. Examples of innovative projects funded through SPRANS include guidelines for child health supervision from infancy through adolescence (i.e. Bright Futures); nutrition care during pregnancy and lactation; recommended standards for prenatal care; successful strategies for the prevention of childhood injuries; and health safety standards for out of home childcare facilities.

Without a sustained federal investment the aforementioned savings will not be realized, program capacity and supports will be diminished and our nation's ability to address the most pressing needs of these vulnerable populations will not be possible. The Title V MCH Block Grant supports a system which treats a whole person, not by their specific disease and I therefore strongly urge you to sustain this investment at \$640 million in fiscal year 2014.

In addition to the Title V MCH block grant AMCHP is extremely concerned about any future proposals to cut funding from other core programs designed to assure the health of our nation's families. We strongly urge you to sustain funding for the Centers for Control and Prevention (CDC). It is short sighted and counterproductive to further cut discretionary funding for prevention in the interest of deficit reduction. CDC programs should be protected from further cuts that will have profound consequences on our capacity to address the needs of the most vulnerable.

## Ryan White Medical Providers Coalition

Testimony Presented by Alice Thornton, MD

Medical Director of the Bluegrass Care Clinic in Lexington, Kentucky,  
Co-Chair of the Ryan White Medical Providers Coalition, and

Member of the HIV Medicine Association

to the U.S. House Appropriations Subcommittee on

Labor, Health and Human Services, Education and Related Agencies

Regarding Part C of the Ryan White Program at the HIV/AIDS Bureau of the Health  
Resources and Services Administration in the Department of Health and Human Services

March 13, 2013

Good morning Chairman Kingston, Ranking Member DeLauro, and my home state Representative, Chairman Rogers. My name is Dr. Alice Thornton, and I serve as Medical Director of the Bluegrass Care Clinic in Lexington, Kentucky. I am here to submit testimony today on behalf of the Bluegrass Care Clinic; the Ryan White Medical Providers Coalition, which I Co-Chair; and the HIV Medicine Association, of which I am a member.

Thank you for the opportunity to describe the lifesaving HIV/AIDS care and treatment provided by Ryan White Part C funded programs, including my own. The Bluegrass Care Clinic (BCC), a university-affiliated clinic, has served as the source for HIV primary care in the 63 counties of central and eastern Kentucky for the past 23 years. Over half of the counties served are federally recognized as economically distressed, and BCC cares for 74% of the people living with HIV in the region. Over the past 10 years, the number of patients has increased by 136%, and the annual number of outpatient medical care appointments has increased by almost 400%. *The University incurs an annual deficit of approximately \$1.2 million from operating the clinic.*

In addition to critical funding that Part C provides through direct federal grants for comprehensive medical care clinics like BCC, most Part C clinics, including BCC, also receive support from other parts of the Ryan White Program that help 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 the results in excellent outcomes for our patients.

Adequate funding of the Ryan White Program is essential to providing both effective and efficient care for individuals living with HIV/AIDS, and I thank the Subcommittee in particular for its support of Ryan White Part C Programs in FY 12 and this first part of FY 13. And while I am grateful for this support, and understand that times are tough, I request a **\$21.5 million increase for Ryan White Part C programs in FY 14. While I know that this is a lot of funding, it is in fact well below the estimated need, and Ryan White providers would spend those dollars effectively and efficiently caring for patients.**

**Ryan White Part C Programs Support Comprehensive, Expert and Effective HIV Care**

Part C of the Ryan White Program funds comprehensive, expert and effective HIV care and treatment -- services that are directly responsible for *the dramatic decrease in AIDS-related mortality and morbidity over the last decade*. The Ryan White Program has supported the development of expert HIV care and treatment programs that have become *patient-centered medical homes* for individuals living with this serious, chronic condition. In 2011, a groundbreaking clinical trial -- *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% -- proving that HIV treatment is also HIV prevention*.

The comprehensive, expert HIV care model that is supported by the Ryan White Program has been highly successful at achieving positive clinical outcomes with a complex patient population.<sup>1</sup> In a convenience sample of eight Ryan White-funded Part C programs ranging from

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<sup>1</sup> See *Improvement in the Health of HIV-Infected Persons in Care: Reducing Disparities* at <http://cid.oxfordjournals.org/content/early/2012/08/24/cid.cis654.full.pdf+html>.

the rural South to the Bronx, *retention in care rates ranged from 87 to 97 percent*. In estimates from the Centers for Disease Control and Prevention (CDC) – only 37 percent of all people with HIV are in regular care nationally.<sup>2</sup> Once in care, patients served at Ryan White-funded clinics do well— *with 75 to 90 percent having undetectable levels of the virus in their blood*. This is much higher than the estimate from the CDC that just 25 percent of all people living with HIV in the U.S. are virally suppressed.

### **Investing in Ryan White Part C Programs Saves Both Lives and Money**

Early and reliable access to HIV care and treatment both helps patients with HIV live relatively *healthy and productive lives* and is more *cost effective*. One study from the Part C Clinic at the University of Alabama at Birmingham found that patients treated at the later stages of HIV disease required *2.6 times more health care dollars* than those receiving earlier treatment meeting federal HIV treatment guidelines. *On average it costs \$3,501 per person per year to provide the comprehensive outpatient care and treatment available at Part C funded programs.*

The comprehensive services provided often include lab work, STD/TB/Hepatitis screening, ob/gyn care, dental care, mental health and substance abuse treatment, and case management. At the BCC clinic we provide a similar wide range of services that are crucial to our success of medically managing our patients.

### **Current Challenges – Future Promise**

This effective and comprehensive HIV care model, however, is not completely supported by Medicaid or most private insurance. *While most Ryan White Program clients have some form of insurance coverage, without the Ryan White Program, they would risk falling out of care.*

Barriers include poor reimbursement rates; benefits designed for healthier populations that fail to

<sup>2</sup> See CDC's *HIV in the United States: The Stages of Care*  
<http://www.cdc.gov/nchhstp/newsroom/docs/2012/Stages-of-CareFactSheet-508.pdf>.

cover critical services, such as care coordination; and inadequate coverage for other important services, such as extended medical visits, mental health and substance use treatment. Full implementation of the Affordable Care Act plus continuation of the Ryan White Program will dramatically improve health access and outcomes for many more people living with HIV disease.

**Ryan White Programs Are Struggling to Meet Demand**

Additionally, as a result of funding cuts and shortfalls, as well as increased patient demand, a 2012 Ryan White Medical Providers Coalition (RWMP) survey of over 100 Ryan White Part C providers nationwide demonstrated that *approximately half* of the programs surveyed have had to make cuts or other program changes. More specifically:

- *54 percent* reported that they had reduced or cut services, including *27 percent* that had reduced or cut support for medications, and *19 percent* that had reduced coverage for laboratory monitoring.
- *40 percent* had longer wait times for new and/or existing patient appointments.
- *31 percent* had laid off staff, and *30 percent* had frozen hiring.

In my own clinic, we had to close BCC to new patients for several weeks last year because we were not able to handle the demand for services.

**Fully Funding and Maintaining Ryan White Part C Programs Is Essential**

Because of both the inadequacy of insurance coverage for people with complex conditions like HIV and the fact that some individuals will remain uncovered, even after Affordable Care Act implementation, *fully funding and maintaining the Ryan White Program is essential to providing comprehensive, expert and effective HIV care nationwide.* According to the 2012 RWMP survey of over 100 Ryan White Part C programs, if federal funding is cut by 10 percent through sequestration and/or additional deficit reduction measures, that would force *66 percent*

of clinics surveyed to *further cut or reduce services; 57 percent to cut or reduce staff; and 13 percent to close to new patients.*

While RMWPC understands the difficulty of the current economic climate, *reducing funding for HIV care and treatment is not cost-effective and will hamper the ability of Ryan White Part C programs to achieve the best possible patient outcomes.* It also will jeopardize our nation's ability to capitalize on recent scientific breakthroughs that could move us toward an AIDS-free generation. Without ready access to comprehensive, expert, and effective HIV care and treatment, patients will use expensive emergency care more, and receive less effective treatment at later stages of HIV disease. Restricted access to effective HIV care and treatment also will result in reduced rates of retention in care, resulting in increased patient viral loads and increased numbers of HIV infections. And most importantly, there will be those who will lose their lives because they are not able to access these lifesaving services at all.

### **Conclusion**

These are challenging economic times, and we recognize the significant fiscal constraints Congress faces in allocating limited federal dollars. However, the significant financial and patient pressures that we face in our clinics at home propel us to make the request for a **\$21.5 million increase in FY 14 funding for Ryan White Part C programs.** This funding would help to support medical providers nationwide in delivering life-saving, effective HIV/AIDS care and treatment to their patients, and save millions is wasted health care dollars treating patients too late or in inappropriate, higher cost settings.

Thank you for your time and consideration of this request. If you have any questions, please do not hesitate to contact the Ryan White Medical Providers Coalition Convener, Jenny Collier, at [jennycollierjd@yahoo.com](mailto:jennycollierjd@yahoo.com) or 202-295-7188.



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 13, 2013**

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 programs as part of the FY2014 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 the 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, linked to and retained in care and treatment.

We also have a National HIV/AIDS Strategy that sets clear goals and priorities, and brings all the federal agencies addressing HIV together to ensure federal resources are well coordinated.

With all these positive developments it would be a shame to go backwards, but that is what could happen given the sequestration and budget cuts now on the table that will impact the Ryan White Program at HRSA, prevention programs at the CDC, and research at the NIH.

#### **The Ryan White Program**

The Ryan White HIV/AIDS Program provides some level of medical care, drug treatment, and support services to approximately 546,000 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. As you can see we have a long way to go before we can realize the dream of an AIDS-free generation. With continued funding we can reverse these trends.

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 reduced the wait lists to less than 100 people today. With sequestration that could all change. This would be different than the recent wait lists states created for patients *wanting* to take medications. Sequestration would reduce funding that could force states to stop paying for medications to over 7,400 people *currently taking* medications. This would be very dangerous as once antiretroviral treatment begins, the drugs must be taken every day without interruption or resistance to medications will occur.

We urge you to do all you can to prevent this and ensure ADAP and the rest of the Ryan White Program receives adequate funding to keep up with the growing demand. According to NASTAD, enrollment in ADAP increased last year by 13,500 people, or 8 percent. With this increased demand for medications comes a corresponding increase in medical care and support services provided by all other parts of the program.

We are looking forward to implementation of the expanded opportunities for health care coverage under the Affordable Care Act (ACA). While it will result in some cost shifting for

medications and primary care, it will never be a substitute for the Ryan White Program. Almost 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 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. For example, Part D of the Ryan White Program provides family-centered care to women, infants, children, and youth living with HIV/AIDS. 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.

#### **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 \$355,000 in future lifetime medical costs. Preventing all the new 50,000 cases in just one year would translate into an astounding \$18 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. This means more of its resources will be going to the South and focusing on gay men. 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. It is estimated that sequestration would reduce the annual number of HIV tests by 424,000.

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. To compound matters, the HIV Division of Adolescent and School Health (DASH) lost 25 percent of its budget in FY12. We ask that the Subcommittee restore this \$10 million cut.

#### **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. Sequestration will mean loss of \$163 million in HIV/AIDS research funding, and 297 HIV/AIDS research grants would go unfunded.

Again, we thank you for your continued support of these critical programs important 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.



**Written Statement of Jeffrey Levi, PhD  
Executive Director, Trust for America's Health  
House Appropriations Subcommittee on Labor, Health & Human Services, Education and  
Related Agencies**

I'm Jeffrey Levi, Executive Director of Trust for America's Health (TFAH), a nonprofit, nonpartisan organization dedicated to saving lives by protecting the health of every community and working to make disease prevention a national priority. As you craft the FY2014 Labor, Health & Human Services, Education and Related Agencies (LHHS) appropriations bill, I urge you to include adequate funding for prevention and preparedness programs at the Centers for Disease Control and Prevention (CDC) and other public health agencies.

As a nation, we face daunting economic and fiscal challenges. To a large degree, these are driven by high health care costs. Indeed, we spend roughly 75 percent of our nation's annual \$2.5 trillion in health care spending on preventable chronic diseases. Despite this expenditure of scarce resources, we are managing sickness, not preventing it – and are faced with the grim prospect that, if we remain on our current trajectory, our children may be the first in U.S. history to live shorter, less healthy lives than their parents.

Fortunately, the vast majority of our chronic disease burden is preventable through proven approaches that focus primarily on increased physical activity, improved nutrition, and reduced tobacco use. A recent TFAH report estimates that if average body mass index were reduced by five percent, in just five years the United States would save \$30 billion and prevent millions of cases of diabetes, heart disease, stroke, arthritis, and cancer. The Prevention and Public Health Fund and National Prevention Strategy provide an important framework on which we can build efforts to put greater emphasis on prevention, turn our "sick care" system into one that provides true health care, and help Americans lead longer, more productive, healthier lives.

*March 13, 2013*

The future health of the nation depends on supporting both investments within the health sector that promote prevention inside and outside the clinic, as well as partnerships between health and crucial partners in education, transportation, housing, and other sectors, and we must maintain our investment in Federal wellness and prevention programs.

We also cannot forget the critical role that CDC and state and local health departments play in protecting us from communicable diseases, bioterrorist threats and natural disasters. That core capacity has been diminished in recent years because of federal budget cuts and the economic downturn, resulting in a 20 percent loss (48,000 jobs) in the state and local health department workforce.

Meeting these twin challenges of preventing disease and protecting the American people from natural and man-made threats can only occur with continued support for key programs at the CDC – ranging from the Prevention and Public Health Fund and Community Transformation Grant program to preparedness programs and other funding streams that assure that all health departments have the foundational capabilities to respond to all health threats.

#### **Centers for Disease Control and Prevention (CDC)**

Cuts to the CDC, our nation's lead public health agency and a critical partner in our long-term efforts to prevent disease and illness have already been stark. Compared to FY 2010, with sequestration the CDC will have seen its budget authority cut by 18% over just three years. These cuts have played a big part in the aforementioned workforce cuts. Overall, scarce resources means CDC will be forced to make extremely tough, sometimes life and death choices.

#### **The Prevention and Public Health Fund**

Significant cuts to the Fund contained in the Middle Class Tax Relief and Job Creation Act of 2012 will be compounded with additional cuts under sequestration. To date, the Fund

has invested \$2.25 billion since FY2010 to support state and local public health efforts to transform and revitalize communities, build epidemiology and laboratory capacity to track and respond to disease outbreaks, train the nation's public health and health workforce, prevent the spread of HIV/AIDS, expand access to vaccines, reduce tobacco use, and help control the obesity epidemic. An additional \$1 billion in investments will be allocated for FY 2013.

#### **Community Transformation Grants**

The Community Transformation Grants (CTG) program, administered by the CDC, is one of our best prevention opportunities. CTG grants empower states and localities to address the drivers of chronic disease. Most importantly, it requires communities to create partnerships to achieve sustainable solutions to help make the healthy choice the easy choice. CTGs must *deploy strategies that are evidence-based and all grantees have rigorous health outcomes improvement goals that must be met.* It is important to note, that as required by law, at least 20 percent of CTG funds must be targeted to reach rural or frontier communities. Even with current levels of funding, only about 4 in 10 Americans are reached by the CTG program. **We recommend the Committee allocate \$300 million from the Prevention Fund for the CTG program in FY2014, which will allow the program to reach millions more Americans.**

#### **National Center for Chronic Disease Prevention and Health Promotion**

Over the past several years, the Chronic Disease Center at CDC has made progress in an effort to move away from the traditional categorical approach to funding chronic disease prevention and towards more coordinated, cross-cutting strategies. In 2011, CDC awarded coordinated chronic disease state grants to all 50 states to begin to build a core capacity to address common risk factors and implement comprehensive strategies for promoting health. While funding is no longer available for those grants, the Chronic Disease Center at CDC

recently released a new funding opportunity announcement (FOA) aimed at integrating prevention approaches for addressing heart disease, obesity, school health, and diabetes.

Diminishing federal dollars for CDC has meant that not all 50 states receive funding under our existing categorical grants. Coordinated approaches like this can help to ensure that we fund all state health departments to achieve cross-cutting, core chronic disease prevention capacity. Past proposals from President Obama and others have included plans to consolidate budget lines for the Center, another approach that could further aid coordination of national and state chronic disease prevention. However, consolidation would need to be thoughtfully designed so it meaningfully improves our chances of improving health, not just serve as a budget gimmick that will further harm our ability to address our growing chronic disease burden.

#### **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. However, it remains one of the most critically underfunded parts of CDC. Since fiscal year 2009, NCEH funding has been cut approximately 25 percent. In fiscal year 2012, for example, the CDC Healthy Homes and Lead Poisoning Prevention program was nearly eliminated, putting 600,000 children at risk of the terrible effects of lead poisoning. **We recommended that you fund NCEH at \$146.151 million in fiscal year 2014** to help begin to rebuild the lead control program and ensure that no additional ground is lost in addressing the environmental causes of disease.

#### **Public Health Emergency Preparedness**

The State & Local Preparedness & Response Capability program at the CDC supports health departments in preparing for, and responding to, all types of disasters, including bioterror attacks, natural disasters, and infectious disease outbreaks. The centerpiece is the Public Health

Emergency Preparedness (PHEP) Cooperative Agreements. PHEP grants support 15 core capabilities, including biosurveillance, community resilience, countermeasures and mitigation, incident management, information management, and surge management. These capabilities are tiered so that grantees can identify areas of greatest need and target their resources accordingly.

**TFAH recommends providing \$657.4 million for the CDC State and Local Preparedness line for fiscal year 2014** in line with the authorized amount included in the recently-passed reauthorization of the Pandemic and All-Hazards Preparedness Act (PAHPA). Cuts mean the loss of highly-trained frontline public health preparedness workers, reduction of the number of high-level laboratories, defunding academic and research centers, and eroding training, exercise, planning, epidemiology, and surveillance capacity. Preparedness is dependent on maintaining a well-trained public health workforce, and inconsistent funding results in serious gaps in our ability to respond to new health threats. It is unreasonable to expect our first responders to continue to be able to confront more threats with fewer resources.

#### **Conclusion**

Investing in disease prevention is the most effective, common-sense way to improve health and help address our long-term deficit. Hundreds of billions of dollars are spent each year via Medicare, Medicaid, and other federal health care programs to pay for health care services once patients develop an acute illness, injury, or chronic disease and present for treatment in our health care system. A sustained and sufficient level of investment in public health and prevention efforts is essential to reduce high rates of disease and improve health in the United States.

**Eldercare Workforce Alliance  
Outside Witness Testimony**

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

March 13, 2013

Public Testimony \*\* Regarding Funding Requests for Eldercare Workforce Programs  
of the Department of Health and Human Services

Submitted on behalf of the  
Eldercare Workforce Alliance  
By

Caitlin W. Connolly  
Project Manager, Eldercare Workforce Alliance

Mr. Chairman, Ranking Member DeLauro, and Members of the Subcommittee:

Thank you for this opportunity to speak before you today. My name is Caitlin Connolly and I am here on behalf of the Eldercare Workforce Alliance, a coalition of 28 national organizations – representing health care professionals, including direct-care workers, as well as providers, consumers, and family caregivers. We joined together to address the immediate and future workforce crisis in caring for an aging America.

Roughly ten thousand Americans turn 65 every day - and will do so every day for the next sixteen years – and an unprecedented number of adults, 19 million, will be over 85 by 2050,

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*\*\*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.*

compared to an estimated 5.5 million today. Yet our workforce is ill-prepared to provide the unique care that is required by older adults.

As the Subcommittee begins consideration of funding for FY 2014, the Alliance\*\* urges you to provide adequate funding for programs designed to increase the number of health care professionals prepared to care for the growing senior population, as well as train the entire workforce, and 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 conditions and cognitive impairments. It is estimated that an additional 3.5 million trained health care workers will be needed just to maintain the current level of access. Unless we 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.

The geriatrics health profession training programs, administered through HRSA and authorized under Titles VII and VIII of the Public Health Service Act, are integral to ensuring that America's health care workforce is prepared to care for the nation's rapidly expanding population of older adults. 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 training programs, the Geriatric Academic Career Awards (GACA), Geriatric Education Centers (GEC), and Geriatric Training Program for Physicians, Dentists and Behavioral and Mental Health Professions Fellowships (GTPD), as well as the Title VIII nursing

program, Comprehensive Geriatric Education Program (CGEP), offer critically important training for the healthcare workforce overall to improve the quality of care for America's elders. In total, these programs provided training to more than 121,407 people in the 2010 -2011 academic year alone.

Of equal importance is supporting the legions of family caregivers who provide billions of hours of uncompensated care that allows older adults to remain in their homes and communities. Family caregivers can face physical, emotional, mental, and financial challenges in their caregiving role. The Family Caregiver Support program, authorized through Title III of the Older Americans Act, as well as the Alzheimer's Disease Demonstration Grants to States and Lifespan Respite Care programs, administered through the Administration for Community Living, offer crucial supports to older adults and their family caregivers. The estimated economic value of family caregivers' unpaid care was approximately \$450 billion in 2009. Without these federal programs, family caregivers helped by them may be unable to confront the challenges of their role.

To just maintain this level of training and support, we ask for \$42.1 million to support Title VII and VIII geriatrics health profession training programs and \$173 million for programs supporting family caregivers.

On behalf of the members of the Eldercare Workforce Alliance, we commend you on your past support for geriatric workforce and family caregiver support programs and ask that you join us in ensuring these programs continue to meet the needs of older adults at this critical time -- for all older Americans deserve quality of care, now and in the future.

Testimony of  
Kristen Sands, School Counselor  
Jacksonville Heights Elementary School  
On Behalf of the  
American School Counselor Association (ASCA)  
US House of Representative Committee on Appropriations  
Labor, Health and Human Services, Education and Related Agencies Subcommittee  
March 13, 2013

Testimony of Kristen Sands  
School Counselor, Jacksonville Heights Elementary School  
Duval County Public Schools  
Jacksonville, Florida

Good morning. My name is Kristen Sands and I have been an elementary school counselor in Duval County Public Schools in Jacksonville, Fla., for the past three years and I am an active member of the American School Counselor Association. I'm here to speak to you today about the Elementary and Secondary School Counseling Program grants that are funded by the U.S. Department of Education. We are respectfully requesting funding of 75 million dollars for Fiscal Year 2014.

Duval County is the 22<sup>nd</sup> largest school district in the nation, and the 6<sup>th</sup> largest in Florida. Our district, which serves more than 125,000 students in 183 schools, has many of the issues common to large, urban school systems across the nation. Fifty-five percent of our district's students are enrolled in free or reduced-price lunch programs, and sixty percent are minority.

In 2010, Duval County received the Elementary and Secondary School Counseling Program grant to improve the ratio of school counselors, school psychologists and school social workers to students. Our focus has been on reducing the number of discipline referrals and increasing direct counseling services to students at four identified schools. One of those is Jacksonville Heights Elementary, where I work in a position funded by the grant.

Jacksonville Heights has two full-time school counselors as well as a half-time school psychologist and a social worker serving as our counseling team. This type of staffing also has been put in place at the other three schools in Duval, improving the average ratio of school counselors, school psychologists and school social workers to students from 602 to 1 to 264 to 1.

This grant has had a tremendous impact on our students and helped improve student achievement at our school, which serves 779 students in grades kindergarten through five. A Title I school, Jacksonville Heights is located in an area greatly affected by high poverty and high crime. Our students have parents who are incarcerated. Many are being raised predominately by single mothers or grandparents. They are victims or witnesses to violence, receive inadequate supervision, and have few if any positive role models. Their caregivers often are in crisis mode and are unable to participate in their child's education.

We have a very diverse student body, Seventy-six percent of our students are minorities, eighty percent qualify for free or reduced-price lunch, and eighteen percent have disabilities. My school has three self-contained classrooms for students with severe emotional and behavioral disabilities and is home to two classrooms designed for students who have been retained two or more years. In 2008-09, on average, one discipline referral was written for every two students at our school for reasons ranging from disruption to violent behavior toward staff.

It is crucial that children develop the skills they need during the elementary grades so they can become successful learners and grow to become productive members of society in our ever-changing world, especially in schools with high needs. Nationally, 1 in 3 black males and 1 in 6 Latino boys born in 2001 are at risk of imprisonment during their lifetime, according to the Children's Defense Fund. A significant number of girls also are in the juvenile justice system. The rate of incarceration is endangering children at younger and younger ages. This is America's pipeline to prison — a path that leads to marginalized lives and often-premature death. Although the majority of our nation's fourth graders cannot read at grade level, states spend about three times as much money per prisoner as per public school pupil.

It is inherent to continue funding for grants like the one I'm working on so we can increase academic achievement and prevent future incarcerations. This grant has allowed us to put early preventive supports and intervention programs in place that did not exist before. Every Jacksonville Heights student now receives classroom instruction using research-based programs from our counseling team on various topics, such as how to manage anger, make good decisions, and resolve conflicts. Before we received this grant, only forty percent of our third through fifth grade students reported having knowledge about goal setting, career/college information, study skills, and self-calming/coping strategies. Today, ninety-three percent of these students report having knowledge of these skills.

We have developed partnerships with neighboring high school students, the U.S. Navy, and Big Brothers Big Sisters to provide students with mentors. These mentors check in weekly to encourage our students and monitor their progress academically and behaviorally. Just last month, a fifth grade student in this program wrote a letter to school staff about how she wants to turn her life around, stop being a follower, and become a leader. This student has a history of discipline issues and was indeed headed down the wrong path. Her behavior and attitude has improved drastically and she will join us on a trip to the University of Florida in May to explore career and college options. She has decided she wants to become a doctor one day.

On a typical day at Jacksonville Heights you will find students using "calm down" bean bag chairs to practice self-calming/coping strategies or our "peace corner" and peer mediation program to work out conflicts with friends. Our students are acquiring the skills necessary to be more proactive and in control of their own behavior and future instead of being reactive to situations and conflicts. They will use skills like these for the rest of their lives and it is powerful to witness students making the choice to use these strategies on their own.

The expanded counseling team has a full schedule of individual and small group counseling sessions, classroom observations and behavior intervention plans, and problem-solving team meetings to address specific student needs. We have even developed a check in/check out system that allows us to counsel with greater numbers of students. Students who are at risk check in with a member of the counseling team at the beginning and end of each week to make sure they stay on track. Students look forward to it and enjoy the positive attention. Additionally, our grant-funded social worker conducts home visits for these students to further address issues that are interfering with learning.

Students, teachers, and parents now seek our counseling services and are lined up outside our office doors at any given time of the day. Just last week a student came to me and said, "Mrs. Sands, I heard you teach anger management groups. I need to be in one." We have built positive relationships within the school community. They know where to come if they need support, and they have voiced their concerns about what will happen once the grant funding ends as we will no longer be at Jacksonville Heights. They are worried, and so are we.

We have also developed several programs to increase parent involvement to get parents excited about their child's learning. In December we hosted a "donuts for dads" breakfast before school to thank our involved dads and provide them with learning tools to help assist them to continue their child's learning at home. Prior to the grant, 10 to 12 parents would attend a family workshop or event at our school. Today, an average of 100 parents come to each family workshop and event.

Last school year, a third-grader was hit by a car and killed outside the apartment complex where many of our students live. Several of our students witnessed the tragic accident and our school community was struck with grief. We were so fortunate to have our expanded counseling

team during this difficult time. The team immediately mobilized: the social worker connected families to community resources, and the school counselors and psychologist provided crisis response services to ensure the school environment remained safe and calm.

We have developed another partnership with a local church that provides food for the weekend to approximately 45 Jacksonville Heights students. These partnerships help ensure our students' basic needs are being met. We also recently started a girls group, called "Jax Heights Elite Ladies," that is for girls with the highest number of discipline referrals. We are teaching them social etiquette, self-respect, and how to carry themselves as ladies so that they will use these skills to be positive role models for our school and their classrooms.

As you can see, the grant has allowed Jacksonville Heights to develop a data-driven comprehensive school counseling program that reaches all students. Last month, we received notification that our program has been recognized as a national model school counseling program. In 2011-12, discipline referral rates dropped by twenty five percent at our school. Despite all of this good news, we still have much work to do. Please continue to fund grants like ours so that this work can continue not only in Jacksonville, but all over the country. Thank you.



**FY 2014 Public Witness Testimony**  
Appropriations Subcommittee on Labor, Health and Human Services,  
Education and Related Agencies  
March 13, 2013

**Dr. Richard Furie**

Director, Systemic Lupus Erythematosus and Autoimmune Disease Treatment Center  
and Program in Novel Therapeutics  
Chief, Division of Rheumatology and Allergy-Clinical Immunology  
North Shore - Long Island Jewish Health System  
Great Neck, NY

Representing:

**The Lupus Research Institute**  
330 Seventh Ave.  
Suite 1701  
New York, New York 10001

Chairman Kingston, Ranking Member DeLauro, and Members of the Committee,

Today I am speaking on behalf of the Lupus Research Institute, the nation's only nonprofit organization solely dedicated to novel, pioneering and high-risk research in lupus. We believe that innovative research is the key to finding safer and more effective treatments -- and eventually a cure for lupus.

Our primary request for your consideration as you prepare the Fiscal 2014 appropriations bill is to strengthen support for biomedical research at the National Institutes of Health by providing at least \$30 billion.

Mr. Chairman and Representative DeLauro, imagine a disease that is a leading cause of heart attack, stroke and kidney disease among young women. Imagine a disease that strikes the innocent, without warning and at random. It attacks the brain, heart, lungs, or blood -- virtually any organ. Imagine a disease with no known cause or cure. And finally, please imagine a disease that waited over 50 years before receiving its first new drug for treatment.

That disease is lupus! Although there are over 100 autoimmune disorders, lupus is the prototypic autoimmune disease. It is a major public health issue. I can assure you based on my 30 years of personal experience in clinical practice and research: this is a

dangerous, debilitating and heartbreaking disorder. It affects over one-and-a-half million persons in the United States. Ninety percent of patients are women, and the disease disproportionately affects African Americans, Hispanics, Asians and Native Americans. Lupus is three times more common in African Americans than in Caucasians. Lupus has no respect for age. It affects young children, adolescents and adults, but approximately 80 percent of new cases of lupus develop among young women, women in their childbearing years.

During the course of my career, approximately 100 of my lupus patients have died, and countless have had strokes or have gone on to kidney failure and required dialysis. I could fill the entire day with heartbreaking stories. Our goal is to cure this disease so there are no more stories.

The Lupus Research Institute was founded 12 years ago. Its driving mission has been to invest in pioneering, innovative research searching for the cause and cure. Our program has been highly successful. Fourteen new candidate biomarkers have been discovered, and some are already in clinical investigation. We are currently announcing the largest private sector grants ever awarded in lupus -- our Global Distinguished Innovator Awards program focused on the basic cause of the disease. The LRI's investment has provided academic-based investigators with the ability to initiate studies, make breakthroughs and become successful in obtaining highly competitive NIH funding to continue their research. Our hard earned private funding is leveraged at a very high rate with our investigators going on to receive subsequent NIH funding.

However, we and similar private research organizations all depend on a strong and vibrant biomedical research enterprise fueled and led by the NIH. We could never be successful without it.

Clearly, tomorrow's advances in lupus and other autoimmune diseases depend on today's investments in NIH research. Sustained, dependable, long-term growth in NIH-funded medical research brings the promise of new knowledge and technologies in pursuit of cures for patients. The fiscal climate of the past few years has threatened the stability of the biomedical research enterprise.

The first phase of sequestration now underway will cap three years of flat funding for the National Institutes of Health. As \$1.6 billion in cuts are applied over the next seven months, vital research will be delayed, halted or even abandoned. The effects on private sector researchers and institutions across the country will be devastating. Over the past 10 years, the NIH budget has effectively fallen by nearly 20 percent after inflation.

Stagnant investment will have a huge damaging and long-lasting effect on our already dwindling pipeline of young investigators. An austere research spending program will no doubt jeopardize the position of the United States as a global leader in biomedical research and development. But, the ultimate fallout is the negative impact on the nation's health.

A wide range of Institutes at the NIH support investigation into lupus. I can assure you that lupus patients rely on all types of biomedical research supported by the NIH, including basic and genomic research, translational studies and clinical trials. These activities will help lead to new treatment options and a better understanding of the mechanisms of this devastating chronic disease.

Because of research in the public and private sector, two years ago, the lupus community finally witnessed its first new drug ever approved for lupus by the FDA in more than 50 years. But that is not enough. A desperate need for safer and more effective treatment options exists.

Today, most current treatments for lupus are toxic with devastating and debilitating effects on the body. Drugs are prescribed "off label" in an attempt to control the ravages of the disease. But in attempting to control the disease, patients might also sustain bodily injury from these same treatments. For example, twenty-year-old women may need to have joint replacements because of damage caused by steroids prescribed to counter lupus symptoms. Physicians need a better arsenal of treatments.

Mr. Chairman and Representative DeLauro, racial disparities also play a key role in lupus. New initiatives are desperately needed to eliminate numerous barriers to early medical diagnosis of lupus.

In a special report to your Appropriations Committee in January 2010, the Department of Health and Human Services highlighted the effect of disparities on lupus patients. The report stated: "Many still die prematurely from lupus because of complications of the disease, late diagnosis, and co-occurring chronic conditions such as arteriosclerosis, hypertension, and diabetes."

The report reinforces the need for efforts to ameliorate disparities, stating: "Until researchers discover a cure or new ways of identifying at risk individuals as well as diagnosing and treating lupus, educating health care professionals about the importance of early diagnosis and teaching patients how to manage and cope with lupus provide the best opportunity for improving quality of life for patients and for controlling morbidity and mortality."

Many lupus patients often visit multiple doctors and go years before receiving a correct diagnosis. As a result, patients at the time of diagnosis can be in very acute stages of the disease. Through enhanced research efforts, we can develop new methodologies, and we must strive to permanently improve diagnosis and treatment and reduce health disparities among those suffering with lupus.

NIH research has an impressive track record of producing just such tangible improvements in the diagnosis, treatment and prevention of disease. The success of the Human Genome Project and other subsequent projects are providing a powerful foundation for a new level of understanding in human biology. A new window is opening into causes of disease, and it is now a time of great scientific discovery. Tapping into

that potential and pursuing new initiatives to bring research from “bench to bedside” can only be continued with sustained investments.

The \$30 billion level we seek in Fiscal 2014 represents a modest 2.7 percent increase and would allow the NIH to continue to innovate in areas of exceptional promise for patients. We respectfully request that you provide at least that amount in an effort to reduce the burden of disease and save lives.

We support efforts to permanently replace the need for sequestration. We respectfully urge Congress and the Administration to work together on a solution that addresses the nation's fiscal needs while preserving the national investment in biomedical research and the health of the American people.

Mr. Chairman, Ranking Member DeLauro and Committee Members, as you develop the Fiscal 2014 appropriations bill, the Lupus Research Institute -- on behalf of patients, scientists and lupus healthcare providers -- urges your Committee to support this critically important national research agency.

I thank you and the other Committee Members for this important opportunity to appear before you today.

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 15, 2013  
Kaitlin Christenson, Director, Global Health  
Technologies Coalition

National Institutes of Health and Centers for Disease Control and Prevention FY 2014 Appropriations  
Chairman Kingston, Ranking Member DeLauro, and members of the Committee, thank you for the opportunity to provide testimony on the fiscal year (FY) 2014 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 over 25 nonprofit organizations working together to promote the advancement of 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 the US investment in global health research and product development, (2) requiring leaders at the National Institutes for Health, the Centers for Disease Control and Prevention, the Food and Drug Administration and the Secretariat of the US Department of Health and Human Services to join leaders of other US agencies to develop a five-year cross-government strategy for global health research and product development, and to ensure that global health R&D is robust, efficient, coordinated, and streamlined, 3) instructing the NIH and CDC, in collaboration with other agencies involved in global health, to continue their commitment to global health in their R&D programs, and to document coordination efforts between agencies for the use of Congress and the public, and (3) to request that the newly-formed National Center for Advancing Translational Sciences (NCATS) expand its clinical trials mandate to include all stages of research.

**Critical need for new global health tools**

Our nation's investments have made historic strides in promoting better health around the world: nearly six 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 (ARV), 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 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. For example, in November 2010, the NIH announced the results of the iPrEx clinical trial, a large, multi-country research study examining pre-exposure prophylaxis (PrEP). The study found that a daily dose of two anti-retroviral drugs could provide an average of 44 percent additional protection to high-risk populations who also received a comprehensive package of HIV prevention services. Additional studies supported by the CDC and the University of Washington confirmed that a daily oral dose of ARV drugs used to treat HIV infection can reduce the risk of HIV acquisition among uninfected individuals by between 63 and 73 percent.

The NIH is the largest funder of global health research in the US government, and the agency continues to demonstrate growing interest in global health issues, particularly in the area of translational research. NIH Director Francis Collins has made global health one of his top five priorities for the future of the NIH, and our coalition members have been pleased to see this implemented via the launch of a new Center for Global Health Studies at the Fogarty International Center, new initiatives on global health at the National Cancer Institute, ongoing exceptional work of the National Institute for Allergy and Infectious Diseases (NIAID), and the creation of the new National Center for Advancing Translational Sciences (NCATS). Additionally, the Model Non-Profit License Agreement for NTDs, HIV, TB, and Malaria Technologies was created for nonprofit institutions and PDPs with a demonstrated commitment to neglected diseases to apply for the use of patented inventions and non-patented biological materials from the NIH and the FDA intramural laboratories. Finally, NCATS recently began a pilot partnership between NCATS and private industry aimed at finding new cures and treatments using a library of compounds that already exist. Each of these efforts built on the historic work carried out by the agency which contributes to improved health around the world.

With operations in more than 54 countries, the CDC is engaged in many global health research efforts. The work of CDC scientists has led to major advances against devastating diseases. Although the CDC is known for its expertise and participation in HIV, TB, and malaria programs, it also operates several activities for neglected diseases in its National Center for Zoonotic, Vector-Borne, and Enteric Diseases. The CDC's Center for Global Health employs 1,100 staff members, and has people on the ground in 55 countries.

#### **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 sixteen 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 of 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 \$600 million in health care costs over the next decade. In addition, new therapies to treat drug-resistant tuberculosis have the potential to reduce the price of tuberculosis 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 one of the nation's highest priorities. In keeping with this value, the GHTC respectfully requests that the Committee do the following:

- Sustain and support US investment in global health research and product development by fully funding NIH, CDC, and FDA to carry out their work.
- Require leaders at the National Institutes for Health, the Centers for Disease Control and Prevention, the Food and Drug Administration and the Secretariat of the US Department of Health and Human Services to join leaders of other US agencies to develop a five-year cross-government strategy for global health research and product development, and to ensure that global health R&D is robust, efficient, coordinated, and streamlined.
- Instruct the NIH and CDC, in collaboration with other agencies involved in global health, to continue their commitment to global health within their R&D programs, and to request that the newly-formed National Center for Advancing Translational Sciences (NCATS) expand its clinical trials mandate to include all stages of research.
- Instruct the FDA to continue to elevate global health in its mandate by creating an office of neglected diseases, building stronger partnerships with global regulatory stakeholders, ensuring that it can review health products for all neglected diseases, taking steps to increase transparency by reporting to Congress on its neglected disease activities, and strengthening its internal capacity on global health.

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.

**Testimony of John E. Anderson, M.D.,  
President, Medicine and Science, American Diabetes Association  
Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related  
Agencies (LHHS), U.S. House of Representatives  
Contact: Lisa Cox, Associate Director, American Diabetes Association, 703-253-4363,  
lcox@diabetes.org**

Thank you for the opportunity to submit testimony on behalf of the American Diabetes Association (Association). As President of Medicine and Science for the Association, I represent 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. Because this is a future that our country cannot afford, for Fiscal Year (FY) 2014, 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, or at risk for, diabetes. We ask the Subcommittee to provide \$2.216 billion for the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) at the National Institutes of Health (NIH), \$86.3 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 care for patients with diabetes every day in my practice in Nashville, Tennessee, and I can testify to the continuing need for federal investment in diabetes research and prevention programs. Nearly 26 million Americans have diabetes, and another 79 million have prediabetes, a condition putting them at high risk for developing 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. When I walked through the Intensive Care Unit at my hospital I was struck that half of the patients there have diabetes. Diabetes robs us of our limbs, our sight and our lives. It should not be ignored by anyone, including Congress and the Administration.

In addition to the horrendous physical toll, diabetes is economically devastating to our country. A new report by the Association 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. Approximately one out of every five health care dollars is spent caring for someone with diagnosed diabetes, while one in ten health care dollars is directly attributed to diabetes. An astonishing one of every three of Medicare dollars is associated with treating diabetes and its complications.

As the nation's leading non-profit health organization providing diabetes research, information and advocacy, the American Diabetes Association understands the critical need for increased federal funding for diabetes research and prevention programs. We acknowledge the challenging economic climate and support fiscal responsibility, but our country cannot afford the consequences of failing to adequately fight this growing epidemic. The recently implemented sequestration has only heightened our concern about the future of key diabetes programs at NIDDK and DDT. If we hope to leave our children a physically and fiscally healthy nation, we can't afford to turn our backs on promising research providing the keys to preventing diabetes, better managing the disease, and bringing us closer to a cure. The rising tide of diabetes in America is daunting, but not insurmountable. The Association is pressing forward by supporting research and expanding education and awareness efforts, but we cannot do it alone. Congress must step up its response to this epidemic.

### **Background**

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**

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 the NIDDK, people with diabetes now manage their disease with a variety of insulin formulations and regimens far superior to those used in decades past. For example, the continuous glucose monitor and insulin pumps many of my patients use allow them to better manage their blood glucose levels – and better pave the way to a healthier futures.

Examples of NIDDK-funded breakthroughs 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 progress has been great, much more needs to be done. Without increased funding, NIDDK will slow or halt promising research that would enable individuals with the disease to live healthier, more productive lives. The percentage of promising research proposals NIDDK was able to fund decreased last year and is expected to decrease again this year without additional funding.

Increased FY 2014 funding would allow the NIDDK to support additional research to further improve prevention and treatment, and close in on a cure. For example, additional funding will support a new comparative effectiveness clinical trial testing different medications for type 2 diabetes. Additionally, NIDDK will be able to continue to support researchers studying how insulin-producing beta cells develop and function, with an ultimate goal of creating therapies for replacing damaged or destroyed

beta cells in people with diabetes. Funding will also support a clinical trial testing therapies to prevent type 2 diabetes.

### **The Division of Diabetes Translation (DDT) at the CDC**

DDT leads efforts to prevent diabetes and its terrible complications. Recently, the CDC released a combined chronic disease grant application for state diabetes, heart disease, obesity, and school health programs. While we think coordination across chronic disease programs at CDC is an important endeavor, Congress must ensure the needs of people with, and at risk for, diabetes are adequately addressed in this new funding process. Increased resources must be provided for this effort and delivery of primary, secondary, and tertiary diabetes prevention and performance measures must be a prime focus of combined grant activities in every state.

Given the DDT's funding has not kept pace with the magnitude of the growing diabetes epidemic, the federal investment in DDT programs should be substantially increased to a minimum of \$86.3 million in FY 2014.

The DDT works to eliminate the preventable burden of diabetes through proven educational programs, best practice guidelines, and applied research. It performs important work in primary prevention of diabetes and in preventing its complications. Funding for the DDT must focus on maintaining state-based Diabetes Prevention and Control Programs (DPCPs), supporting the National Diabetes Education Program, defining the diabetes burden through the use of public health surveillance, and translating research findings into clinical and public health practice. For example, the DPCPs, located in all 50 states, the District of Columbia, and all U.S. territories, work to prevent diabetes, lower blood glucose and cholesterol levels, and reduce diabetes-related emergency room visits and hospitalizations. This work is designed to improve education and awareness of diabetes by engaging health providers, health systems and community-based organizations to ensure these outcomes are achieved. DDT funding also supports translational research like the *SEARCH for Diabetes in Youth* study, a joint

NIDDK-DDT effort designed to determine the impact of type 2 diabetes in youth to improve prevention efforts aimed at young people.

With additional funding, the DDT will be able to expand the efforts of DPCPs to improve primary, secondary and tertiary prevention efforts at the state and local levels. Supporting the work of the DDT will allow it to build upon its work in reducing health disparities through vital programs such as the Native Diabetes Wellness Program, which delivers effective health promotion activities tailored to American Indian/Native Alaskan communities. Funding will also enable the DDT to expand its translational research work to improve public health interventions.

#### **The National Diabetes Prevention Program (CDC)**

The National Diabetes Prevention Program supports the national network of community-based sites where trained staff provides those at high risk for diabetes with cost-effective, group-based lifestyle intervention programs. The program is a proven means of combating a growing epidemic, and research has shown it can reduce the risk of type 2 diabetes by 58% for individuals with prediabetes – at a cost of only about \$300 per participant. Currently, there are over 200 CDC recognized programs and the largest program, run by the Y-USA, has 420 sites across the country. The National Diabetes Prevention Program began with a successful NIDDK study in a clinical setting. Additional translational research was then done by NIDDK and DDT, proving the program also works in the less-costly community setting. This is *exactly* the program we should be bringing to scale if we hope to conquer our country's diabetes epidemic. We urge Congress to provide \$20 million for the National Diabetes Prevention Program in FY 2014 to expand it nationwide.

#### **Conclusion**

The American Diabetes Association is counting on Congress to significantly expand its investment of programs in FY 2014 at NIDDK and the DDT, including the National Diabetes Prevention Program, to prevent, treat, and cure diabetes. Thank you for the opportunity to submit this testimony. The Association looks forward to working with you to stop diabetes.

**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 15, 2013**

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 2014 Labor-Health and Human Services-Education appropriations bill.

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](http://www.nacacnet.org)). Our members include school counselors, independent educational consultants, community-based organizations and counselor educators and college admissions officers, 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 FY14 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 40 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 FY2014 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 FY2014 as it received in FY13 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. 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 FY14.

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](mailto:dhawkins@nacacnet.org).



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March 13, 2013

**Testimony for the Record by Nsedu O. Witherspoon, MPH  
Executive Director, Children's Environmental Health Network  
for the Subcommittee on Labor, Health & Human Services, Education & Related Agencies  
United States House Committee on Appropriations**

We at the Network thank Chairman Kingston and Ranking Member DeLauro for this opportunity and for your ongoing concern about environmental risks to children. Our statement focuses on key programs and activities that safeguard the health and the future of all of our children:

- Centers for Disease Control and Prevention (\$7.8 billion), especially the National Center for Environmental Health (\$143.7 million) and its programs:
  - Healthy Homes and Lead Poisoning Prevention Program
  - National Asthma Control Program
  - National Environmental Public Health Tracking Program
  - Environmental Health Laboratory
  - Healthy Community Design Initiative (HCDI).
- the National Institute of Environmental Health Sciences (NIEHS) (\$717.7 million), especially Children's Environmental Health Research Centers of Excellence
- Pediatric Environmental Health Specialty Units (PEHSUs) (\$1.8 million)

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The Children's Environmental Health Network (CEHN) is a national organization created to protect the developing child from environmental health hazards and promote a healthy environment.

Investments in programs that protect and promote children's health will be repaid by healthier children with brighter futures. (For example, removing lead in gasoline has saved the U.S. an estimated \$200 billion each year since 1980 in the form of higher IQs for that year's newborns).

Protecting our children -- those born as well as those yet to be born -- from environmental hazards is truly a national security issue.

Our nation's future will depend upon its future leaders. 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. Additionally, American competitiveness depends on having healthy educated children who grow up to be healthy productive adults. Yet, growing numbers of our children are diagnosed with chronic and developmental illnesses and disabilities such as obesity, asthma, learning disabilities, and autism. A child's environment plays a role in these chronic conditions and contributes to the distressing possibility that today's children may be the first generation to see a shorter life expectancy than their parents due to poor health. 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 take a balanced approach to deficit reduction that does not include further cuts to children's environmental health programs. Key programs in your jurisdiction, which CEHN urges you to support, include:

**Centers for Disease Control and Prevention (CDC)**

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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 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 2014.

The **National Centers for Environmental Health (NCEH)** is particularly important to protecting the environmental health of young children. NCEH's programs are key national assets. Yet, since fiscal year 2009, NCEH funding has been cut approximately 25 percent while, as mentioned above, environment plays a role in the cause, prevention, or mitigation of today's pediatric epidemics of obesity, asthma, learning disabilities, and autism.

We continue to be concerned about the elimination of **Healthy Homes and Lead Poisoning Prevention Program** funding for state and local programs in FY 2012. The loss of vigilant surveillance, primary prevention activities, and case management has jeopardized the health of children living in homes where exposure to lead, asthma and other illnesses related to rodent and insect infestation, chemical exposures, and other risk factors is likely. We must sustain reducing lead poisoning by supporting effective local and state efforts.

NCEH's **National Asthma Control Program** funds 36 states and territories to conduct asthma surveillance, educate asthma patients, families, and health care providers, and help health departments eliminate potential asthma triggers. Now is the time to maintain our commitment to asthma control, not cut funding.

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. Public health officials need integrated health and environmental data so that they can protect the

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public's health. This network currently operates in 23 states and New York City to help public health officials and key policymakers make better policy decisions to improve population health. Participation in the tracking network development will decline further under any further cuts and erase the progress we have made across the country to better link data with public health action. CEHN also strongly supports CDC's **Environmental Health Laboratory** and the **Healthy Community Design Initiative** (HCIDI). The HCIDI provides essential expert assistance and consultation across HHS and national leadership on the impacts of the built environment on health including physical activity levels.

#### **National Institute of Environmental Health Science (NIEHS)**

NIEHS is the leading institute conducting research to understand how the environment influences the development and progression of human disease. NIEHS plays a vital role in our efforts to understand how to protect children, whether it is identifying and understanding the impact of substances that are endocrine disruptors or understanding childhood exposures that may not affect health until decades later. CEHN recommends that \$717.7 million be provided for NIEHS' FY 2014 budget.

#### **Children's Environmental Health Research Centers of Excellence**

The Children's Environmental Health Research Centers, jointly funded by the NIEHS and the U.S. Environmental Protection Agency (EPA), play a key role in providing the scientific basis for protecting children from environmental hazards. With their modest budgets, which have been unchanged for more than 10 years, these centers generate valuable research. The scientific output of these centers has been outstanding.

Several Centers have established longitudinal cohorts, which have resulted in valuable research results. The Network is concerned that as a Center's multi-year grant ends and the Center is

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shuttered, these cohorts and the invaluable information they can provide are being lost. The Network urges the Subcommittee to assure that NIEHS has the funding and the direction to support Centers in continuing these cohorts. The work of these Centers has also shown us that, in addition to research regarding a specific pollutant or health outcome, research is desperately needed in understanding the totality of the child's environment -- for example, all of the exposures the child experiences in the home, school, and child care environment -- and how to evaluate those multiple factors. CEHN urges you to support these Centers to assure they receive full funding and are extended and expanded as described above.

#### **Pediatric Environmental Health Specialty Units**

Funded jointly by the Agency for Toxic Substances and Disease Registry (ATSDR) and the EPA, the Pediatric Environmental Health Specialty Units (PEHSUs) form a valuable resource network, with a center in each of the U.S. Federal regions. PEHSU professionals provide medical consultation to health care professionals on a wide range of environmental health issues, 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 to help increase the public's understanding of children's environmental health, 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 2014.

In conclusion, healthier children with brighter futures will repay investments in programs that protect and promote children's health, an outcome we can all support. Thank you for the opportunity to submit testimony.

**WRITTEN TESTIMONY  
BEFORE THE HOUSE APPROPRIATIONS SUBCOMMITTEE ON  
LABOR, HEALTH AND HUMAN SERVICES, EDUCATION  
FISCAL YEAR 2014 BUDGET**

**Statement of**

**Jon Reyhner, Ed.D.**

**Professor of Education, Northern Arizona University and  
Coordinator, Stabilizing Indigenous Languages Symposia Steering Committee  
March 13, 2013**

**Promoting Language Revitalization as a Community Health Measure**

Indigenous language and culture revitalization programs funded by the Esther Martinez Native Language Programs under the Administration for Native Americans in the Department of Health and Human Services are teaching tribal languages to develop a strong positive sense of identity in children and improve their chances for success in school and in life. I have been involved for the last 20 years in the annual Stabilizing Indigenous Languages symposia (see <http://nau.edu/TIL>). Again and again I have seen that Native American children who are not embedded in their traditional values often are academically behind in school and are only too likely in modern America to pick up a unhealthy lifestyle of consumerism, consumption, competition, comparison, and conformity. Furthermore Hallett, Chandler and LaLonde's (2007), examining data from 150 First Nations communities in British Columbia, found that communities with less conversational knowledge of their native language had suicide rates six times greater than those with more knowledge.

Northern Arizona University Professor Dr. Evangeline Parsons Yazzie (1995) found in her research that "Elder Navajos want to pass on their knowledge and wisdom to the younger generation. Originally, this was the older people's responsibility. Today the younger generation does not know the language and is unable to accept the words of wisdom" She concluded, "The use of the native tongue is like therapy, specific native words express love and caring Knowing the language presents one with a strong self-identity, a culture with which to identify, and a sense of wellness" (p. 3). An elder told her stated in Navajo: "television is robbing our children of language" (p. 135). As indigenous children learn English or other "National" languages and cultures through the media and in schools, they increasingly become separated from their heritage, and some cannot speak to their grandparents. As one of Parson Yazzie's informants told her, "Older people who speak only Navajo are alone" (p. 4). Many American Indians see language as the key to their identity, and they question whether one can be Navajo, Crow, Seminole, and so forth without speaking their tribal language.

In the 1970s, the Rock Point Community School Board in the Navajo Nation felt "that it was the breakdown of a working knowledge of Navajo kinship that caused much of what they perceived as inappropriate, un-Navajo, behavior; the way back, they felt was to teach students that system" (Holm & Holm, 1990, p. 178). To counter the decline in behavior the Board established a bilingual education program that promoted literacy in Navajo and English along with an extensive Navajo Social Studies component that included the theory of Navajo kinship.

This program has been modified and continued in the Window Rock Public School's Navajo Immersion School where it was found that, "More-traditional Navajo expectations of children were that they would work hard and act responsibly—in adultlike ways. Anglos tend to expect children to act in more childlike ways.... More-traditional parents tend to perceive such [childlike] behavior as self-indulgent and irresponsible. At worst, children come to exploit the gap between parental and teacher expectations" (Arviso & Holm, 2001, p. 209). At Window Rock, a researcher found, "Navajo values are embedded in the classroom pedagogy" (Reyhner, 2006, p. 79) and changed students' behavior for the better. The Navajo Nation's "*Diné Cultural Content Standards* [for schools] is predicated on the belief that firm grounding of native students in their indigenous cultural heritage and language, is a fundamentally sound prerequisite to well developed and culturally healthy students" (Office, 2000, p. v).

Other Native Nations have similar views. Janine Bowen's 2004 case study of an Ojibwe language program found that the decline in the use of the Ojibwe language was correlated "with a loss of Ojibwe traditions, the unraveling of the extended family, depression among Band members, high drop out rates among Ojibwe students, and an increasing amount of gang activity among youth" (p. 4). A former Ojibwe Commissioner of Education argued, "By teaching the language we are building a foundation for a lifetime of productive citizenship.... Ojibwe values are inextricably linked to the language. These values, such as caring for the environment, healing the body and mind together, and treating all creation with respect are taught most effectively when they are taught in Ojibwe" (p. 4).

Drs. Castagno and Brayboy (2008) review the extensive literature supporting culturally responsive education and find that recent educational reform efforts in the United States, including the No Child Left Behind Act of 2001 of the Bush Administration and "Race to the Top" of the Obama Administration are having a negative effect on Indian education (the new push for a "common core" curriculum also is likely to have a negative effect on culturally responsive teaching). The National Indian Education Associations *Preliminary Report on No Child Left Behind in Indian Country* (2005) also found negative consequences. Romero-Little, Ortiz and McCarty (2011), (Beaulieu and Figueira (2006), Reyhner (2011, 2010), Reyhner and Singh (2010a, 2010b), Reyhner, Gilbert & Lockard (2011), and Reyhner and Lockard (2009) document extensive research supporting culturally appropriate education that includes utilizing indigenous languages as an instructional medium. Dr. Willard Sakiestewa Gilbert (2007) in his testimony to the U.S. House of Representatives Education and Labor Committee On the Reauthorization of No Child Left Behind in Indian Country, testified that Native children perform better academically when they are taught in a manner that is consistent with their traditions, languages, and cultures. Arizona State University Professor Dr. Teresa McCarty (1996) states that data from the immersion school experience indicates that language immersion students experience greater success in school measured by consistent improvement on local and national measures of achievement. Finally, the 2007 Declaration on the Rights of Indigenous Peoples recently supported by President Obama Article 13-1 of the declaration reads "Indigenous peoples have the right to revitalize, use, develop and transmit to future generations their histories, languages, oral traditions, philosophies, writing systems and literatures, and to designate and retain their own names for communities, places and persons" and Article 14-1 reads "Indigenous peoples have the right to establish and control their educational systems and institutions providing education in their own languages, in a manner appropriate to their cultural methods of teaching and learning."

Please accept my strong support for the reauthorization of the Esther Martinez Native Language Programs under the Administration for Native Americans in the Department of Health and Human Services for the sum of \$12,000,000 as an essential measure to support the health and welfare of American Indian children.

### References

- Arviso, M., & Holm, W. (2001). Tséhootsooídi Ólta'gi Diné Bizaad B́hoo'aah: A Navajo immersion program at Fort Defiance, Arizona. In L. Hinton & K. Hale (Eds.), *The green book of language revitalization in practice* (pp. 203-215). San Diego, CA: Academic.
- Beaulieu, D., & Figueira, A.M. (eds.), (2006). *The power of Native teachers: Language & culture in the classroom* (pp. 63-92). Tempe, AZ: Center for Indian Education, Arizona State University.
- Bowen, J.J. (2004). *The Ojibwe language program: Teaching Mille Lacs Band youth the Ojibwe language to foster a stronger sense of cultural identity and sovereignty*. Cambridge, MA: Harvard Project on American Indian Economic Development.
- Castagno, Angelina E., & Brayboy, B.M.J. (2008). Culturally responsive schooling for Indigenous youth: A Review of the literature. *Review of Educational Research*, 78, 941-993.
- Gilbert, W.S. (2007) The Reauthorization of No Child Left Behind in Indian Country: Hearing before the U.S. House of Representatives Education and Labor Committee, 110<sup>th</sup> Congress, 1<sup>st</sup> Session. Testimony of Dr. Willard Sakiestewa Gilbert, President-Elect, National Indian Education Association).
- Hallett, D., Chandler, M.J., & Lalonde, C.E. (2007) Aboriginal language knowledge and youth suicide. *Cognitive Development*, 22, 392-399.
- Holm, A., & Holm, W. (1990). Rock Point, a Navajo way to go to school: A valediction. *The Annals of the American Academy of Political and Social Science*, 508, 170-184. doi:10.1177/0002716290508001014.
- McCarty, T., Dick, G.S. (1996) Mother Tongue Literacy and Language Renewal: The Case of the Navajo. Proceedings of the 1996 World Conference on Literacy, University of Arizona: Tucson, AZ. 1996.
- National Indian Education Association. (2005). *Preliminary report on No Child Left Behind in Indian country*. Washington, DC: Author.
- Office of Diné Culture, Language & Community Service, Division of Diné Education. (2000). *T'áa Shá Bik'ehgo Diné B́ Ná Nitin dóó Íhoo'aah* (Diné cultural content standards). Window Rock, AZ: Author.
- Parsons-Yazzie, E. (1995). A study of reasons for Navajo language attrition as perceived by Navajo speaking parents. EdD dissertation, Northern Arizona University.
- Reyhner, J. (2011). Healing families and strengthening communities through language revitalization. In M.E. Romero-Little, S. Ortiz & T.L. McCarty (Eds.), *Indigenous language across the generations: Strengthening families and communities* (pp. 281-303). Tempe, AZ: Center for Indian Education, Arizona State University.
- Reyhner, J. (2010). Indigenous language immersion schools for strong Indigenous identities. *Heritage Language Journal*, 7(2), 138-152.
- Reyhner, J. (2006). Issues facing new Native teachers. In D. Beaulieu & A.M. Figueira (Eds.), *The power of Native teachers* (pp. 63-92). Tempe, AZ: Center for Indian Education, Arizona State University.

- Reyhner, J., & Singh, N.K. (2010a). Aligning language education policies to international human rights standards. *eJournal of Education Policy*.
- Reyhner, J., & Singh, N.K. (2010b). Cultural genocide in Australia, Canada, New Zealand, and the United States: The destruction and transformation of Indigenous cultures. *Indigenous Policy Journal*, 21(4), 1-26.
- Reyhner, J. (2006). Issues in the Classroom. In D. Beaulieu & A.M. Figueira (Eds.), *The power of Native teachers: Language & culture in the classroom* (pp. 63-92). Tempe, AZ: Center for Indian Education, Arizona State University.
- Reyhner, J., Gilbert, W.S., & Lockard, L. (eds.). (2011). Honoring our heritage: Culturally appropriate approaches for teaching Indigenous students. Flagstaff, AZ: Northern Arizona University.
- Reyhner, J., & Lockard, L. (Eds.). (2009). *Indigenous language revitalization: Encouragement, guidance & lessons learned*. Flagstaff, AZ: Northern Arizona University.
- Romero-Little, M.E., S. Ortiz & T.L. McCarty (eds.) (2011). *Indigenous language across the generations: Strengthening families and communities* (pp. 281-303). Tempe, AZ: Center for Indian Education, Arizona State University.
- United Nations. (2007). Declaration on the Rights of Indigenous Peoples. A/RES/61/295.

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

Budget Fiscal Year 2014

Statement of Nāmaka Rawlins, Outreach Specialist

'Aha Pūnana Leo, Inc.

13 March 2013

**REQUEST FOR LEVEL FUNDING** (enacted amount of 12 million annually) to Administration for Native Americans, in support of Native American Languages-Esther Martinez Initiative. The FY 2010 Omnibus Spending bill includes current report language that states "**12 million for ANA Language Programs with no less than 4 million of this funding be allocated to language immersion programs**". We recommend that this language be amended to clearly state "***with no less than 4 million for immersion schools as defined by Esther Martinez Language Nest and Survival Schools***". This report language will remove any ambiguity surrounding Congressional intent to set aside 4 million for Immersion Schools as the Esther Martinez Act clearly defines the minimum of instruction hours in an academic year that follow best practices of the Hawai'i model of language revitalization.

Chairman Kingston, Ranking Member DeLauro and Members of the Committee: my name is Nāmaka Rawlins, Outreach Specialist for the 'Aha Pūnana Leo, a Native Language educational non-profit, the Liaison of both the state of Hawai'i Hawaiian language college and the k-12 school program, Ke Kula 'o Nāwahīokalani'ōpu'u in the outer island community of Hilo. These entities work together and represent Hawai'i's education system from preschool through to the doctorate in a Native American language. We run a statewide network of Hawaiian language preschools and a K-12

laboratory school program through the medium of Hawaiian. Thank you for the opportunity to submit testimony to your committee on the importance of our Native American languages and to share the positive results of our efforts here in Hawai'i.

First, the academic results of our efforts have been quite strong. For example, our main model K-12 Hawaiian laboratory school has had a 100% high school graduation rate, and an 80% college attendance rate for the past 15 years. Our graduates enrolled or have graduated from local and national universities and colleges including the University of Hawai'i, Notre Dame de Namur University, Long Island University Post, Stanford, Loyola Marymount, Northern Arizona University and Washington State. Our graduates have also entered the United States Armed Forces or have joined the workforce in our state. We are very proud of our students, staff and families. In addition, there are other advantages being realized in an education focused on native language revitalization. We have a high rate of school attendance, a high rate of community "grown" teachers and a high rate of family participation in our program. The student body is over 95% Native Hawaiian and over 70% qualify for free and reduced lunch an indicator of a socio-economic disadvantaged population.

Especially important to us has been our language revitalization results. When we began our efforts, children in our community had not spoken Hawaiian for over a generation. Today all the children in our programs are highly fluent in Hawaiian, with some 2,500 of them educated from preschool to graduate school through Hawaiian. We are now seeing our high school and college graduates raise their own children from birth in Hawaiian. The language is coming back in the community and those associated with speaking it are well educated and contributing positively to our Native and broader

society. Furthermore, besides graduating from high school fluent and literate in English, our students study other languages starting in elementary school, with the most common being Japanese.

The 1990 Native American Languages Act is federal policy that protects and supports the use of American Indian, Alaska Native and Native Hawaiian languages. The Hawai'i preschool through doctorate is the most developed program in a Native American language. Over half of all students studying through a Native American language are in our schools in Hawai'i. Our strengths are in early childhood, secondary programming, teacher training, assessment, research, and graduate education. We host many visitors and provide technical hands-on assistance to support Native communities wishing to reclaim and revitalize their Native languages.

The 'Aha Pūnana Leo is celebrating its 30<sup>th</sup> anniversary since the establishment of its language nest preschools where Hawaiian language is used as the medium of instruction. We were the first such program in the United States. The immersion method of exclusive use of a Native American language is the most successful model of reversing language loss, while also providing a strong background in English and other languages in specially designed classes. Besides Hawai'i, this method is being implemented in other states, New Mexico, Alaska, Montana, Oklahoma, New York, Minnesota, Wyoming, North and South Dakota in Navajo, Ojibwe, Yupik, Blackfeet, White Clay, Lakota, Mohawk and Arapaho to mention a few of these endangered languages. There are less than 5,000 children in the entire United States below the age of 18 that are in a Native American language immersion method of education. Our Native communities are depending on this next generation of speakers to keep our

languages alive!

The Administration for Native American programs in Language Preservation, Esther Martinez, in particular, is the only federal program dedicated to the revitalization of our Native Languages. Funding for the Esther Martinez initiative is vital to many communities struggling to increase the use of the targeted Native American language in maintaining language nests and survival schools.

Funding from ANA Language- Esther Martinez is helping the 'Aha Pūnana Leo to provide additional training to over 80 staff members in 11 language nests sites over 5 islands to enhance native language fluency and professional development in our unique methodology unavailable in standard community college and university settings. We are using technology to deliver online videoconference classes. We have removed barriers for our teaching staff to participate in training and professional teacher development while remaining in their rural communities.

The 'Aha Pūnana Leo and our consortium partners strongly urges that the ANA Language-Esther Martinez program be funded. Given the language revitalization success and the high academic outcomes of the full Native American language immersion/medium model, it is amazing that support for this sort of education is not better integrated into federal programming for Native American peoples on a broader level.

Support for the revitalization of our Native American Languages is well documented in numerous resolutions from the National Indian Education Association, the National Congress of American Indians and the National Alliance to Save Native Languages. I urge you to protect current level funding for this important program.

**Testimony Submitted on behalf of the  
The Neurofibromatosis (NF) Network**

Kim Bischoff, Executive Director  
The NF Network  
Wheaton, IL

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 too 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 2014 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. 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, and NF preclinical mouse models consortia. The Committee urges NHLBI to expand its NF research investment based on the increased prevalence of hypertension and congenital heart disease in this patient population. 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. In addition, the Committee encourages the NICHD and NIMH to expand funding of basic and clinical NF research in the area of learning and behavioral disabilities. Children with NF1 are prone to*

*severe bone deformities, including scoliosis; the Committee therefore encourages NIAMS to expand its NF1 research portfolio. 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. Based on the increased incidence of optic gliomas, vision loss, cataracts, and retinal abnormalities in NF, the Committee urges the NEI to expand its NF research portfolio. Finally, given that NF represents a tractable model system to study the genomics of cancer predisposition, learning and behavior problems, and bone abnormalities translatable to individualized medicine, the Committee encourages NHGRI to increase its investment in NF 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, 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 three times more common than Muscular Dystrophy and Cystic Fibrosis combined. There are three types of NF: NF1, which is more common, NF2, which primarily 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:

### **Pain Management**

Severe and unmanageable pain is seen in all forms of NF, particularly in schwannomatosis, and significantly impacts quality of life. Over the past 3 years, Schwannomatosis research has made significant advances and new research suggests that the molecular or root cause of schwannomatosis pain may be the same as phantom limb pain. Understanding what causes this pain, and how it might be treated, has been a fast-moving area of NF research over the past few years, and CDMRP NFRP funding has been critical in supporting this.

### **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.

### **Wound Healing, inflammation and blood vessel growth**

Wound healing requires new blood vessel growth and tissue inflammation. Mast cells are critical mediators of inflammation in wound healing, and they must be quelled and regulated in order to

facilitate this healing. Mast cells are also important players in NF1 tumor growth. In the past few years, 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. The result is that tumors grow slower. As researchers learn more about blocking mast cell signals in NF, this research could be translated to the management of mast cells in wounds and wound healing.

#### **Bone growth and repair/Orthopedic abnormalities and amputation**

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. NF1 bone defects research has been a fast-moving field in recent years and CDMRP NFRP has funded a number of important studies in this area..

#### **Brain Function/Learning Disabilities**

Learning disabilities affect two-thirds of person 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. 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.

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 eleven institutes are currently supporting NF research, and NIH's total NF research portfolio has increased from \$3

million in FY1990 to an estimated \$24 million in FY2012. 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.

Submitted by

James S. Bernstein

Director, Government & Public Affairs

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**Written Testimony of the American Society for Pharmacology & Experimental Therapeutics**

**House Appropriations Subcommittee on Labor, Health and Human Services,**

**Education & Related Agencies**

**Fiscal Year 2014 Appropriations for the National Institutes of Health**

The American Society for Pharmacology and Experimental Therapeutics (ASPET) is pleased to submit written testimony in support of the National Institutes of Health (NIH) FY 2014 budget. ASPET recommends a budget of at least \$32 billion for the NIH in FY 2014.

Sustained growth for the NIH should be an urgent national priority. Research funded by the NIH improves public health, stimulates our economy and improves global competitiveness. Several years of flat funding and mandatory budget cuts required by sequestration in the current fiscal year prevents and delays advances in medical research, jeopardizes potential cures and eliminates jobs. Additionally, the nation will lose a generation of young scientists who see no prospects for careers in biomedical research, creating a “brain drain” as many graduate students, post-doctoral researchers, and early career scientists leave the research enterprise or look for employment in foreign countries.

The 5% sequestration cut further diminishes NIH’s research capacity that has already fallen 20% since 2003 as a result of flat funding and inflation. With sequestration, NIH’s purchasing

power will be reduced by nearly 25% since 2003. Continued erosion of NIH's research capacity will accelerate further the diminishment of American leadership and innovation in biomedical research. Without a commitment to sustained funding for the NIH, the nation's biomedical research capacity will erode further.

A \$32 billion budget for the NIH in FY 2014 is a start to help restore NIH's biomedical research capacity. Currently, the NIH only can fund one in six grant applications, the lowest rate in the agency's history. Furthermore, the number of research project grants funded by NIH has declined every year since 2004.

A budget of at least \$32 billion in FY 2014 will help the agency manage its research portfolio effectively without having to withhold funding for existing grants to researchers throughout the country. Scientific research takes time. Only through steady, sustained and predictable funding increases can NIH continue to fund the highest quality biomedical research to help improve the health of all Americans and continue to make significant economic impact in many communities across the country.

There is no substitute for a steady, sustained federal investment in biomedical research. Industry, venture capital, and private philanthropy can supplement research but cannot replace the investment in basic, fundamental biomedical research provided by NIH. Industry and venture capital both face their own economic challenges and venture capital investment in biomedicine has declined since 2007. Neither the private sector nor industry will be able to fill a void for NIH funded basic biomedical research. Much of industry support is applied research that builds upon the discoveries generated from NIH-funded projects. The majority of the investment in basic biomedical research that NIH provides is broad and long-term providing a continuous development platform for industry, which would not typically invest in research that may be of higher risk and

require several years to fully mature. In addition to this long term view, NIH also has mechanisms in place to rapidly build upon key technologies and discoveries that have the ability to have significant impact on the health and well being of our citizens. Further, industry research is focused on developing drugs that are protected by patents and often does not make their data publicly available.

Many of the basic science initiatives supported by NIH have led to totally unexpected discoveries and insight that have transformed our mechanistic understanding of and our ability to treat a wide range of diseases

### **Diminished Support for NIH will Negatively Impact Human Health**

Continued diminishment of funding for NIH will mean a loss of scientific opportunities to discover new therapeutic targets. Without a steady, sustained federal investment in fundamental biomedical research, scientific progress will be slower and potentially helpful therapies or cures will not be developed. For example, more research is needed on Parkinson's disease to help identify the causes of the disease and help develop better therapies; discovery of gene variations in age-related macular degeneration could result in new screening tests and preventive therapies; more basic research is needed to focus on new molecular targets to improve treatment for Alzheimer's disease; and diminished support for NIH will prevent new and ongoing investigations into rare diseases that FDA estimates almost 90% are serious or life-threatening.

Historically, our past investment in basic biological research has led to many innovative medicines. The National Research Council reported that of the 21 drugs with the highest therapeutic impact, only five were developed without input from the public sector. The significant past investment in the NIH has provided major gains in our knowledge of the human genome, resulting in the promise of pharmacogenomics and a reduction in adverse drug reactions that

currently represent a major worldwide health concern. Several completed human genome sequence analyses have pinpointed disease-causing variants that have led to improved therapy and cures but further advances and improvements in technology will be delayed or obstructed with inadequate NIH funding.

### **Investing in NIH Helps America Compete Economically**

A \$32 billion budget in FY 2013 will also help the NIH train the next generation of scientists and provide a platform for broader workforce development that is so critical to our nation's growth. Many individuals trained in the sciences via NIH support become educators in high schools and colleges. These individuals also enter into other aspects of technology development and evaluation in public and private sectors to further enrich the community and accelerate economic development.

This investment will help to create jobs and promote economic growth. Limiting or cutting the NIH budget will mean forfeiting future discoveries and jobs to other countries.

The U.S. share of global research and development investment from 1999-2009 is now only 31%, a decline of 18%. In contrast, other nations continue to invest aggressively in science. China has grown its science portfolio with annual increases to the research and development budget averaging over 23% annually since 2000, including a 26% increase in 2012. Russia plans to increase support for research by 65% over the next five years. And while Great Britain two years ago also imposed strict austerity measures to address that nation's debt problems, that nation had the foresight to keep its strategic investments in science at current levels. The European Union, despite great economic distress and the severe debt problems of its member nations, has proposed to increase spending on research and innovation by 45% between 2014 and 2020

NIH research funding catalyzes private sector growth. More than 83% of NIH funding is awarded to over 3,000 universities, medical schools, teaching hospitals and other research institutions in every state. One national study by an economic consulting firm found that federal (and state) funded research at the nation's medical schools and hospitals supported almost 300,000 jobs and added nearly \$45 billion to the U.S. economy. NIH funding also provides the most significant scientific innovations of the pharmaceutical and biotechnology industries.

### **Conclusion**

ASPET appreciates the many competing and important spending decisions the Subcommittee must make. The nation's deficit and debt problems are great. However, NIH and the biomedical research enterprise face a critical moment. The agency's contribution to the nation's economic and physical well being should make it one of the nation's top priorities. With enhanced and sustained funding, NIH can begin to reverse its decline and help meet its potential to address many of the more promising scientific opportunities that currently challenge medicine. A budget of at least \$32 billion in FY 2014 will allow the agency to begin moving forward to full program capacity, exploiting more scientific opportunities for investigation, and increasing investigator's chances of discoveries that prevent, diagnose and treat disease. NIH should be restored to its role as a national treasure, one that attracts and retains the best and brightest to biomedical research and provides hope to millions of individuals afflicted with illness and disease.

*ASPET is a 5,100 member professional society whose members conduct basic, translational, and clinical pharmacological research within the academic, industrial and government sectors. Our members discover and develop new medicines and therapeutic agents that fight existing and emerging diseases, as well as increase our knowledge regarding how therapeutics affects humans.*

**Medical Library Association and Association of Academic Health Sciences Libraries  
Statement for the Record on FY14 Appropriations for the National Library of Medicine  
Submitted to the House Subcommittee on L-HHS, Education & Related Agencies  
March 15, 2013**

**Summary of FY14 Recommendations**

Support funding for the National Library of Medicine (NLM) at the highest possible level, and support the medical library community's role in NLM's outreach, telemedicine, disaster preparedness, health information technology initiatives, and health care reform implementation.

**Introduction**

The Medical Library Association (MLA) and Association of Academic Health Sciences Libraries (AAHSL) thank the Subcommittee for the opportunity to submit testimony regarding FY14 appropriations for the National Library of Medicine (NLM), an agency of the National Institutes of Health (NIH). Working in partnership with the NIH and other Federal agencies, NLM is the key link in the chain that translates biomedical research into practice, making the results of research readily available to all who need it.

**NLM Leverages NIH Investments in Biomedical Research**—In today's challenging budget environment, we recognize the difficult decisions Congress faces as it seeks to improve our nation's fiscal stability. We thank the Subcommittee for its long-standing commitment to strengthening NLM's budget. In FY14 and beyond, it is critical to continue augmenting NLM's baseline budget to support expansion of its information resources, services, and programs which collect, organize, and make readily accessible rapidly expanding biomedical knowledge resources and data. NLM maximizes the return on the investment in research conducted by the NIH and other organizations. The Library makes the results of biomedical information more accessible to researchers, clinicians, business innovators, and the public, enabling such data and

information to be used more efficiently and effectively to drive innovation and improve health. NLM plays a critical role in accelerating nationwide deployment of health information technology, including electronic health records (EHRs) by leading the development, maintenance and dissemination of key standards for health data interchange that are now required of certified EHRs. NLM also contributes to Congressional priorities related to drug safety through its efforts to expand its clinical trial registry and results database in response to legislative requirements, and to the nation's ability to prepare for and respond to disasters.

**Growing Demand for NLM's Basic Services**—Everyday, medical librarians across the nation use NLM services to assist clinicians, students, researchers, and the public in accessing information they need to save lives and improve health. NLM delivers more than a trillion bytes of data to millions of users daily that helps researchers advance scientific discovery and accelerate its translation into new therapies; provides health practitioners with information that improves medical care and lowers its costs; and gives the public access to resources and tools that promote wellness and disease prevention. Without NLM, our nation's medical libraries would be unable to provide the quality information services that our nation's health professionals, educators, researchers and patients increasingly need.

NLM's data repositories and online integrated services such as GenBank, PubMed, and PubMed Central are revolutionizing medicine and ushering in an era of personalized medicine in which care is based on an individual's unique genetic profile. GenBank is the definitive source of gene sequence information. PubMed, with more than 22 million citations to the biomedical literature, is the world's most heavily used source of bibliographic information. Approximately 760,000 new citations were added in FY12, and it was searched more than 2.2 billion times. PubMed Central is NLM's freely accessible digital repository of full-text biomedical journal

articles. On a typical weekday more than 700,000 users download 1.4 million full-text articles, including those submitted in compliance with the NIH Public Access Policy.

As the world's largest and most comprehensive medical library, NLM's traditional print and electronic collections continue to steadily increase each year, standing at more than 11.4 million items—books, journals, technical reports, manuscripts, microfilms, photographs and images. By selecting, organizing and ensuring permanent access to health sciences information in all formats, NLM ensures the availability of this information for future generations, making it accessible to all Americans, irrespective of geography or ability to pay, and guaranteeing that citizens can make the best, most informed decisions about their healthcare.

**Encourage NLM Partnerships**—NLM's outreach programs are essential to MLA and AAHSL membership and to the profession. Through the National Network of Libraries of Medicine (NNLM), with over 6,000 members in communities nationwide, these activities educate medical librarians, health professionals and the general public about NLM's services and train them in the most effective use of these services. The NNLM promotes educational outreach for public libraries, secondary schools, senior centers and other consumer-based settings, and its emphasis on outreach to underserved populations helps reduce health disparities among large sections of the American public. NLM's "Partners in Information Access" program improves access by local public health officials to information which prevents, identifies and responds to public health threats and ensures every public worker has electronic health information services that protect the public's health.

NLM's MedlinePlus provides consumers with trusted, reliable health information on more than 900 topics in English and Spanish. It has become a top destination for those seeking information on the Internet, attracting nearly 850,000 visitors daily. Other products and services

that benefit public health and wellness include NIH *MedlinePlus Magazine* and NIH *MedlinePlus Salud*, available in doctors' offices nationwide, and NLM's MedlinePlus Connect—a utility which enables clinical care organizations to implement specific links from their electronic health records systems to patient education materials in MedlinePlus.

MLA and AAHSL applaud the success of NLM's outreach initiatives, and we look forward to continuing to work with NLM on these programs.

**Emergency Preparedness and Response**—Through its Disaster Information Management Research Center, NLM collects and organizes disaster-related health information, ensures effective use of libraries and librarians in disaster planning and response, and develops information services to assist responders. NLM responds to specific disasters worldwide with specialized information resources appropriate to the need, including information on bioterrorism, chemical emergencies, fires and wildfires, earthquakes, tornadoes, and pandemic disease outbreaks. MLA and NLM continue to develop the Disaster Information Specialization (DIS) program to build the capacity of librarians and other interested professionals to provide disaster-related health information outreach. Working with libraries and U.S. publishers, NLM's Emergency Access Initiative makes available free full-text articles from hundreds of biomedical journals and reference books for use by medical teams responding to disasters. MLA and AAHSL ask the Subcommittee to support NLM's role in this crucial area which ensures continuous access to health information and use of libraries and librarians when disasters occur.

**Health Information Technology and Bioinformatics**—For more than 40 years, NLM has supported informatics research, training and the application of advanced computing and informatics to biomedical research and healthcare delivery including telemedicine projects. Many of today's informatics leaders are graduates of NLM-funded informatics research

programs at universities nationwide. A number of the country's exemplary electronic and personal health record systems benefit from findings developed with NLM grant support.

The importance of NLM's work in health information technology continues to grow as the nation moves toward more interoperable health information technology systems. A leader in supporting the development, maintenance, and dissemination of standard clinical terminologies for free nationwide use (e.g., SNOWMED), NLM works closely with the Office of the National Coordinator for Health Information Technology to promote the adoption of interoperable electronic records, and has developed tools to make it easier for EHR developers and users to implement accepted health data standards in their systems.

MLA is a nonprofit, educational organization with 4,000 health sciences information individual and institutional members. Founded in 1898, MLA provides lifelong educational opportunities, supports a knowledge base of health information research, and works with a network of partners to promote the importance of quality information for improved health to the health care community and the public. The Association of Academic Health Sciences Libraries (AAHSL) supports academic health sciences libraries and directors in advancing the patient care, research, education and community service missions of academic health centers through visionary executive leadership and expertise in health information, scholarly communication, and knowledge management.

Thank you again for the opportunity to present our views. We look forward to continuing this dialogue and supporting the Subcommittee's efforts to secure the highest possible funding level for NLM in FY14 and the years beyond to support the Library's mission and growing responsibilities. Information about NLM and its programs can be found at <http://www.nlm.nih.gov>.

# **Testimony**

**Submitted to**

**House Appropriations Subcommittee on Labor, Health  
and Human Services and Education**

**Addressing  
Fiscal Year 2014  
National Institutes of Health/National Institute on  
Aging**

**March 15, 2013**

Submitted by:  
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**Testimony**  
**Linda Krogh Harootyan, Chair, Friends of the National Institute on Aging (NIA)**  
**Fiscal Year 2014**  
**House Subcommittee on Labor, Health and Human Services and Education**  
**National Institutes of Health/National Institute on Aging**  
**March 15, 2013**

Congressman Kingston, Congresswoman DeLauro, and members of the Subcommittee, this testimony is being submitted on behalf of the Friends of the National Institute on Aging (FoNIA), a coalition of over 50 academic, patient-centered and not-for-profit organizations that conduct, fund or advocate for scientific endeavors to improve the health and quality of life for people as they age. We appreciate the opportunity to provide testimony in support of the National Institute on Aging (NIA) and to comment on the need for sustained, long-term growth in aging research. Considering the resources the federal government spends on the health care costs associated with age-related diseases, we feel it makes sound economic sense to increase federal resources for aging research. Specifically, given the unique funding challenges facing the NIA, and the range of promising scientific opportunities in the field of aging research, the FoNIA recommends \$1.4 billion in FY 2014 for NIA. In addition, to ensure that progress in the nation's biomedical, social, and behavioral research continues, the Coalition also endorses the Ad Hoc Group for Medical Research in supporting \$32 billion for NIH in FY 2014.

The 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 increase dramatically in the coming years due to increased life expectancy and the aging of the baby boom generation. According to the U.S. Census Bureau, the number of people age 65 and 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 threefold, to 19 million. As the 65+ population increases, so will the prevalence of diseases disproportionately affecting older people—most notably, Alzheimer’s disease (AD). NIA is the primary federal agency responsible for (AD) research and receives nearly 70 percent of the NIH Alzheimer’s disease research funding. Yet, we know that as many as 5 million Americans aged 65 years and older may have AD with a predicted increase to 13.2 million by 2050 (Hebert, Weuve, Scherr, et al, 2013). Last year, NIA led the AD Research Summit, which brought together officials representing federal agencies, scientific researchers, providers, caregivers, patients and their families to develop final recommendations to the National Alzheimer’s Project Act Advisory Council. NIA also supported research that identified relevant AD biomarkers through the groundbreaking Alzheimer’s Disease Neuroimaging Initiative, along with a deeper understanding of the disease’s pathology and clinical course. This led to the first revision of the clinical diagnostic criteria in AD in 27 years. In a recent, highly promising pilot trial, a nasal-spray form of insulin delayed memory loss and preserved cognition in people with a range of cognitive deficits. A larger-scale study to confirm and extend these results is under development. NIA is making great strides, but the resources are inadequate given the explosion of people with AD that is predicted.

NIA’s current budget does not reflect the tremendous responsibility it has to meet the health research needs of a growing U.S. aging population. While the current dollars appropriated to NIA seem to have risen significantly since FY 2003, when adjusted for inflation, they have decreased almost 18 percent in the last nine years. According to the NIH Almanac, out of each dollar appropriated to NIH, only 3.6 cents goes toward

supporting the work of the NIA-compared to 16.5 cents to the National Cancer Institute, 14.6 cents to the National Institute of Allergy and Infectious Diseases, 10 cents to the National Heart, Lung and Blood Institute, and 6.3 cents to the National Institute of Diabetes and Digestive and Kidney Diseases. With an infusion of much needed support in FY 2014, NIA can achieve greater parity with its NIH counterparts and expand promising, recent research activities, such as:

- implementing new prevention and treatment clinical trials, research training initiatives, care interventions, and genetic research studies developed as part of the National Alzheimer's Action Plan;
- launching trans-NIH research initiatives developed by the NIH Geroscience Interest Group to reduce the burden of age-related disease;
- understanding the impact of economic concerns on older adults by examining work and retirement behavior, health and functional ability, and policies that influence individual wellbeing;
- supporting family caregivers by enhancing physician-family communication during end-of-life and critical care; and,
- increasing healthy lifespan in humans by testing and applying evidence derived from animal models.

NIA is poised to accelerate the scientific discoveries that we as a nation are counting on. With millions of Americans facing the loss of their functional abilities, their independence, and their lives to chronic diseases of aging, there is a pressing need for robust and sustained investment in the work of the NIA. In every community in America, healthcare providers depend upon NIA-funded discoveries to help their patients and

caregivers lead healthier and more independent lives. In these same communities, parents are hoping NIA-funded discoveries will ensure that their children have a brighter future, free from the diseases and conditions of aging that plague our nation today. Chronic diseases associated with aging afflict 80 percent of the age 65+ population and account for more than 75 percent of Medicare and other federal health expenditures. Unprecedented increases in age-related diseases as the population ages are one reason the Congressional Budget Office projects that total spending on healthcare will rise to 25 percent of the U.S. GDP by 2025—it is 17 percent of GDP today.

Recent significant findings from NIA's Division of Biology Aging that could help advance understanding of a range of chronic diseases, include the discovery of the drug rapamycin, which has been shown to extend median lifespan in a mouse model. Grantees supported by this program have also identified genetic pathways that regulate the maintenance of the stem cell microenvironment in aging tissues.

A signature project of the Behavioral and Social Science Research Division is the Health and Retirement Study (HRS), the nation's leading source of combined data on health and financial circumstances of Americans over age 50. HRS data provide evidence about the effects of early-life exposures on later-life health, factors associated with cognitive and functional decline, and trends in retirement, savings, and other economic behaviors. The study is being replicated in 30 other countries. Last year, genetic data from approximately 13,000 individuals were posted to NIH's online database, including approximately 2.5 million genetic markers from each person. These data are available for analysis by qualified researchers and will enhance the ability to track the onset and progression of diseases and conditions affecting the elderly.

Research that can be translated quickly into effective prevention and efficient health care will reduce the burden of a “Silver Tsunami” of age-associated chronic diseases. Breakthroughs from NIA research can lead to treatments and public health interventions that could delay the onset of costly conditions such as arthritis, heart disease, stroke, diabetes, bone fractures, age-related blindness, Alzheimer’s, ALS, and Parkinson’s diseases. Such advances could save trillions of dollars by the middle of the current century.

We do not yet have the knowledge needed to predict, preempt, and prevent the broad spectrum of diseases and conditions associated with aging. We do not yet have sufficient knowledge about disease processes to fully understand how best to prevent, diagnose, and treat diseases and conditions of aging, nor do we have the knowledge needed about the complex relationships among biology, genetics, and behavioral and social factors related to aging. We do not yet have a sufficient pool of new investigators entering the field of aging research. Bold, visionary, and sustainable investments in the NIA will make it possible to achieve substantial and measurable gains in these areas sooner rather than later, and perhaps too late.

We recognize the tremendous fiscal challenges facing our nation and that there are many worthy, pressing priorities to support. However, we believe a commitment to the nation’s aging population by making bold, wise investments in programs will benefit them and future generations. Investing in NIA is one of the smartest investments Congress can make.

Ref. Alzheimer disease in the US (2010-2050) estimated using the 1990 Census, Liesi E. Hebert, Jennifer Weuve, Paul A. Scherr, et al., *Neurology*; Published online before print February 6, 2013; WNL.0b013e31828728f5

## Friends of the National Institute on Aging

Alliance for Aging Research  
 Alzheimer's Association  
 Alzheimer's Foundation of America  
 American Academy of Dermatology  
 American Association for Geriatric Psychiatry  
 American Chronic Pain Association  
 American Federation for Aging Research  
 American Geriatrics Society  
 American Heart Association  
 American Pain Foundation  
 American Psychological Association  
 American Public Health Association  
 American Society for Bone and Mineral Research  
 American Society for Nutritional Sciences  
 American Society of Consultant Pharmacists  
 American Society of Hematology  
 American Society on Aging  
 Arthritis Foundation  
 Association of Jewish Aging Services  
 Association for Psychological Science  
 Association of Population Centers  
 B'nai B'rith International  
 BrightFocus Foundation  
 Brown Medical School  
 Consortium of Social Science Associations  
 Council on Social Work Education  
 Hospice Foundation of America  
 IEEE-USA  
 Institute for the Advancement of Social Work Research  
 National Association of Social Workers  
 National Council on the Aging  
 National Hispanic Council on Aging

International Cancer Advocacy Network (ICAN)  
 International Foundation for Anti-Cancer Drug Discovery  
 International Longevity Center – USA  
 Merck Institute of Aging and Health  
 National Alliance for Caregiving  
 National Association of Social Workers  
 National Council on the Aging  
 National Hispanic Council on Aging  
 National Hospice and Palliative Care Organization  
 National Vision Rehabilitation Association  
 Oral Health America  
 Parkinson's Action Network  
 Population Association of America  
 Society for Neuroscience  
 Society for Women's Health Research  
 Special Care Dentistry  
 The Ellison Medical Foundation  
 The Endocrine Society  
 The George Washington University Medical Center  
 The Gerontological Society of America  
 The North American Menopause Society  
 The Paget Foundation  
 The Simon Foundation for Continenence  
 University of Pennsylvania Institute on Aging  
 University of Virginia  
 USAgainstAlzheimer's

**Spina Bifida Association**  
**Written Testimony to the House LHHS Appropriations Subcommittee**  
**Regarding Fiscal Year 2014 Spina Bifida Related Funding**  
**Ana Ximenes, SBA Chairman**  
**March 15, 2013**

**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) appreciates the opportunity to submit public written testimony for the record regarding fiscal year (FY) 2014 funding 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 and 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 2014 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 2014. This funding will support applied and basic biomedical, psychosocial, educational, and rehabilitative research to improve the understanding of the etiology, prevention, cure and treatment of Spina Bifida and its related conditions. In addition, SBA respectfully requests that the Subcommittee include the following language in the report accompanying the FY 2014 LHHS appropriations measure:

"The Committee encourages NIDDK, NICHD, and NINDS to study the causes and care of the neurogenic bladder in order to improve the quality of life of children and adults with Spina Bifida; to support research to address issues related to the treatment and management of Spina Bifida and associated secondary conditions, such as hydrocephalus; and to invest in understanding the myriad comorbid conditions experienced by children with Spina Bifida, including those associated with both paralysis and developmental delay."

**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 2014 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.

**Testimony Submitted on behalf of the  
Association of University Programs in Occupational Health and Safety (AUPOHS)**

Fred Gerr, MD

President, Association of University Programs in Occupational Health and Safety  
Professor, Department of Occupational and Environmental Health  
College of Public Health, University of Iowa

**March 14, 2013**

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 nine 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 2014 Labor, Health and Human Services Appropriations bill include level funding of \$24.268 million for the Education and Research Centers and \$22 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: ERC's 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 nine 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 immigrant, part-time, contract and seasonal labor. Thus, many AFF workers are excluded from labor protections, including many of those enforced by OSHA.

In 2010 the AFF sector had a work-related fatality rate of 28 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 100 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 completed 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.



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**FY 2014 HOUSE APPROPRIATIONS COMMITTEE PUBLIC TESTIMONY  
SUBMITTED BY THE ENDOCRINE SOCIETY  
FOR THE SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,  
EDUCATION, AND RELATED AGENCIES  
DIRECTED AT THE DEPARTMENT OF HEALTH AND HUMAN  
SERVICES/NATIONAL INSTITUTES OF HEALTH**

The Endocrine Society is pleased to submit the following testimony regarding Fiscal Year 2014 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 16,000 members worldwide. Our organization is dedicated to promoting excellence in research, education, and clinical practice in the field of endocrinology. The Society's membership includes thousands of researchers who depend on federal support for their careers and their scientific advances. The Endocrine Society recommends that NIH receive at least \$32 billion in FY 2014. 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.

A half century of 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 NIH specifically has had a significant impact on the United States' global preeminence in research and fostered the development of a biomedical research enterprise that remains unrivaled throughout the world. However, the preeminence of the US research enterprise is being tested due to consistently flat funding for federal research agencies coupled with the increasing cost of

conducting basic biomedical research. Meanwhile, emerging economies such as China and India continue to recognize the importance of investing in scientific research. China's R&D spending is expected to increase by 11.6% in the coming year while India's spending for R&D is expected to rise by nearly 12%, keeping pace with the past several years<sup>1</sup>.

The societal benefits of biomedical research, from improvements in diabetes care to personalized genomics, include treatments, technologies, and cures that extend lifespan and improve quality of life. The foundation for these benefits is the NIH research grants that support the basic 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 successfully being awarded a grant has dropped from 31.5% in 2000 to 17.6% in 2012; this means that experienced scientists are increasingly spending time writing fruitless grant applications instead of applying their expertise to productive research. Meanwhile younger, highly skilled Ph.D. holders struggle to find a job in the United States that makes use of the unique skills generated during graduate education. The Chinese government, in contrast, has created incentives to draw biomedical researchers to institutions in China<sup>2</sup>. The potential loss of technical skills and knowledge generated by the investment of resources in training could reduce the long-term international competitiveness of the United States and result in innovative new biomedical therapeutics being developed in other countries.

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<sup>1</sup> Global R&D Funding Forecast 2013- Battelle

<sup>2</sup> Building a World-Class Innovative Therapeutic Biologics Industry in China – China Association of Enterprises with Foreign Investment R&D-based Pharmaceutical Association Committee, in coordination with The Biotechnology Industry Organization and the support of The Boston Consulting Group

The United States cannot afford to fall further behind while the rising burden of chronic disease (now at 75% of total healthcare expenditure) places a tremendous strain on the national economy. Nearly half of all Americans have a chronic medical condition, and these diseases now cause more than half of all deaths worldwide. Deaths attributed to chronic conditions could reach 36 million by 2015 if the trend continues unabated. In order to prevent and treat these diseases, and save the country billions in healthcare costs, significant investment in biomedical research will be needed. The national cost of diabetes in 2012 is estimated at \$245 billion<sup>3</sup>, while the cost of obesity has been estimated at \$147 billion<sup>4</sup>; many Endocrine Society members study these diseases and stand ready to conduct valuable research to improve care and reduce the financial burden of disease. To do so, however, they require funding from the NIH.

Besides improving healthcare delivery and reducing costs, basic biomedical research represents a source of new wealth for the nation and jobs for its citizens. The translation of new knowledge into innovative products can be shown by the frequency in which patents are granted to University researchers. Data compiled by the Association of University Technology Managers (AUTM) shows that academic research institutions were issued 4,700 patents in 2011. These patents can then be used to form the intellectual property foundation for a startup, or licensed to a large company to generate future revenue streams from the patented technology. In 2011, AUTM reported 4899 university technologies were licensed to companies, demonstrating the potential economic value of the products of federally-funded basic research to private companies. Basic research at academic universities and research institutions, funded in part by NIH, generated 617 startup companies and 591 new commercial products in 2011 alone. AUTM

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<sup>3</sup> Economic Costs of Diabetes in the U.S. in 2012 - American Diabetes Association

<sup>4</sup> Finkelstein, EA, Trogon, JG, Cohen, JW, and Dietz, W. Annual medical spending attributable to obesity: Payer- and service-specific estimates. *Health Affairs* 2009; 28(5): w822-w831.

also reported \$36 billion in net product sales generated from university-initiated companies, while recent startups reported supporting nearly 25,000 jobs. From 1996 to 2007, a “moderately conservative estimate” yields a total contribution to GDP for this period of more than \$82 billion<sup>5</sup> from university technologies.

Because the financial risks associated with basic biomedical research projects are high, and the economic realization of an investment in biomedical research could take years to decades, private sector businesses are unlikely to make the financial commitments necessary to support basic biomedical research. The private sector, in fact, “cannot appropriate the benefits such research generates, particularly at the early, basic stages of the research process”<sup>6</sup>. Consequently, the private sector investment in basic science represents only 20% of the total national investment. While the private sector investment in applied research and development is much greater, basic research represents the crucial first step in the process of developing an innovative biomedical product. Indeed, Congress has acknowledged the critical and unique role of the government in funding basic research to realize the unique and powerful economic benefits to society<sup>7</sup>.

The past year alone has seen astonishing medical breakthroughs from NIH funded research, such as advances in HIV prevention and genomic characterization of cancer cells. Endocrinologists have made discoveries on the link between birth order and diabetes risk, the generational effects

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<sup>5</sup> The Economic Impact of Licensed Commercialized Inventions Originating in University Research, 1996-2007. Biotechnology Industry Organization, September 2009

<sup>6</sup> An Economic Engine: NIH Research, Employment and the Future of the Medical Innovation Sector, United for Medical Research, May 2011.

<sup>7</sup> The Pivotal Role of Government Investment in Basic Research - Report by the U.S. Congress Joint Economic Committee “ May 2010

of BPA exposure, and the relationship between a mother's vitamin D levels and infant health. A member of The Endocrine Society, Robert Lefkowitz, was one of two recipients of the 2012 Nobel Prize in Chemistry for his work on hormone receptors. The NIH has exciting programs for the future, including a collaboration to develop "3-D human tissue chips containing bio-engineered tissue models that mimic human physiology... to use these chips to better predict the safety and effectiveness of candidate drugs."<sup>8</sup> Members of The Endocrine Society will continue to conduct important work, including research on the public health impact of chronic disease and endocrine-disrupting chemicals. These projects, however, may not come to fruition if the current NIH budget, and the cut from sequestration, remain in place.

The Endocrine Society remains deeply concerned about the future of biomedical research in the United States without sustained support from the federal government. The Society strongly supports 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 of the preeminent research enterprise. The Endocrine Society therefore recommends that NIH receive at least \$32 billion in FY 2014.

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<sup>8</sup> <http://www.ncats.nih.gov/research/reengineering/tissue-chip/funding/funding.html>

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**Statement of the American Psychiatric Association**

**To the House Appropriations Subcommittee on  
Labor, Health & Human Services and Education**

**March 15, 2013**

### ***I. Introduction & Background***

The American Psychiatric Association (APA), a medical specialty society representing over 33,000 psychiatrists nationwide, is pleased to present the APA's recommendations regarding the Fiscal Year 2014 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.

While the APA recognizes the Subcommittee faces difficult decisions in a constrained budget environment, a continued commitment to critical programs supporting physician workforce development should remain a high priority. ~~Additionally, strong~~ Additionally, strong, sustained investment in research and public mental health service programs is necessary to ensure the health of Americans and the nation's economic prosperity. Federal investment is absolutely vital in order for the National Institutes of Health (NIH) to sustain its mission of improving health through medical science breakthroughs and maintaining international leadership in science and biomedical research. Federal programs for mental health and substance use services are a key adjunct to keep people productively engaged in their communities.

#### **Impact of Budget Cuts on America's Health**

Sequestration will have a tremendous impact on the nation's medical schools and teaching hospitals and the patients they serve. The 2 percent cut in Medicare reimbursements that results from sequestration will jeopardize these institutions' ability to provide critical patient care services such as psychiatric units often unavailable elsewhere in communities. Deficit reduction proposals to reduce Medicare GME support, including reductions in Indirect Medical Education (IME) payments would threaten access to critical services unavailable elsewhere and reduce physician training at a time when patient needs are

increasing. For the next 19 years, 10,000 people a day will turn 65, creating a significant increase in demand for psychiatric care and other medical specialties. Reductions in physician payments will further restrict access to community-based care.

## ***II. Federal Investments in Biomedical Research***

Sequestration also will hurt patients by cutting vital federal funding for NIH medical research—\$1.5 billion in the first year alone. The APA is especially concerned with research on mental illnesses and substance use disorders. The National Institute of Mental Health (NIMH) conservatively estimates the total costs associated with serious mental illnesses, those 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 health care expenditures and \$24.3 billion disability benefits). The costs associated with mental illness 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 and lost earnings among people with serious mental illness. More specific diagnostic tools, earlier treatment and medications with fewer side effects and the potential of genomic-sensitive treatments are priorities for NIMH. As is investigating the important differences occur in patterns of mental illness/mental health care services use between women and men and among ethnic minorities. 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.

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 drug abuse 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.

### ***III. Federal Investments in Services***

State mental health authorities are reporting an increased service demand from adults and children with mental health and substance use disorders during these difficult economic times. Meanwhile, many states are being forced to cut mental health care funding because of the economic downturn. States have been forced to cut mental health care funding by a total of nearly \$3.2 billion from 2009 to 2012 (source: National Association of State Mental Health Program Directors). Additionally, 60 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, services for children and the elderly, and Minority Fellowship Training funding. The APA supports the new SAMHSA initiatives to assist returning military and their families as well as the program to co-locate mental health care with primary services. SAMHSA's Center for Substance Abuse Treatment (CSAT) and Center for Substance Abuse Prevention (CSAP) provides millions to the states in the form of block grants for flexibility in responding to need. 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 Program promotes ethnic diversity and supports access to care for vulnerable populations. The APA supports a \$5.8 million FY14 appropriations for CMHS' Minority Fellowship Program.

***APA Request***

As Congress prepares for FY 2014 it should act to protect funding for vital mental health and substance use services and vigorously support research into causes and new treatments for mental illnesses and addiction. Congress should ensure that people living with mental illnesses and substance use disorders—including seniors, children, and other vulnerable groups – have access to the care needed to improve quality of life.

Finally, the APA supports a 10% increase in clinical services funding for the Indian Health Service, \$440 million increase in FY2014. 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. Integrating health care programs which incorporate treatment for high blood pressure, diabetes, smoking cessation and screening for mental health and addiction issues have been demonstrated to be effective care delivery protocols in rural areas. Such integrated care requires training and adequate staff support.

To continue to improve our nation's health and economic well-being, America needs more investment in medical research and the physician workforce, not less. The American Psychiatric Association appreciates the opportunity to submit its statement on FY14 funding priorities to the Subcommittee.

Thank you.

Testimony Submitted by the  
American Congress of Obstetricians and Gynecologists (ACOG)

US House Committee on Appropriations  
Subcommittee on Labor, Health and Human Services and Education  
Department of Health and Human Services (HHS)

Contact Person: Anna Hyde, Government Affairs Staff, [ahyde@acog.org](mailto:ahyde@acog.org), 202-863-2512

The American Congress of Obstetricians and Gynecologists, representing 57,000 physicians and partners in women's health care, is pleased to offer this statement to the House Committee on Appropriations, Subcommittee on Labor, Health and Human Services, and Education. We thank Chairman Kingston, and the entire Subcommittee for the opportunity to provide comments on some of the most important programs to women's health. Today, the US lags behind other nations in healthy births, yet remains high in birth costs. ACOG's Making Obstetrics and Maternity Safer (MOMS) Initiative seeks to improve maternal and infant outcomes through investment in all aspects of the cycle of research, including comprehensive data collection and surveillance, biomedical research, and translation of research into evidence-based practice and programs delivered to women and babies, and we urge you to make this a top priority in FY14.

Data Collection and Surveillance at the Centers for Disease Control and Prevention (CDC)

In order to conduct robust research, uniform, accurate and comprehensive data and surveillance are critical. The National Center for Health Statistics is the nation's principal health statistics agency and collects state data from records like birth certificates that give us raw, vital statistics. The birth certificate is the key to gathering vital information about both mother and baby during pregnancy and labor and delivery. The 2003 US-standard birth certificate collects a wealth of knowledge in this area, yet not all states are using it. States without these resources are likely underreporting maternal and infant deaths and complications from childbirth and causes of these deaths remain unknown. Use must be expanded to all 50 states, ensuring that uniform, accurate data is collected nationwide.

**For FY14, ACOG requests \$162 for the National Center for Health Statistics and \$18 million within that funding request to modernize the National Vitals Statistics System, which would help states update their birth and death records systems.**

The Pregnancy Risk Assessment Monitoring System (PRAMS) at CDC extends beyond vital statistics and surveys new mothers on their experiences and attitudes during pregnancy, with questions on a range of topics, including what their insurance covered, whether they had stressful experiences during pregnancy, when they initiated prenatal care, and what kinds of questions their doctor covered during prenatal care visits. By identifying trends and patterns in maternal health, researchers better understand indicators of preterm birth and other health conditions. This data allows CDC and state health departments to identify behaviors and environmental and health conditions that may lead to preterm births. Only 40 states use the PRAMS surveillance system today. **ACOG requests adequate funding to expand PRAMS to all US states and territories.**

#### Biomedical Research at the National Institutes of Health (NIH)

Biomedical research is critically important to understanding the causes of prematurity and developing effective prevention and treatment methods. Prematurity rates have increased almost 35% since 1981, and cost the nation \$26 billion annually, \$51,600 for every infant born prematurely. Direct health care costs to employers for a premature baby average \$41,610, 15 times higher than the \$2,830 for a healthy, full-term delivery. Research into maternal morbidity, beginning with developing a consensus definition for severe maternal morbidity, is an important component of understanding pregnancy outcomes, including prematurity. The National Institute on Child Health and Human Development (NICHD) has included in its Vision Statement a goal of determining the complex causes of prematurity and developing evidence-based measures for its prevention within the next ten years. **Sustaining the investments at NIH is vital to achieving this goal, and therefore**

**ACOG supports a minimum of \$32.623 billion for NIH and \$1.37 billion within that funding request for NICHD in FY14.**

Adequate levels of research require a robust research workforce. The average investigator is in his/her forties before receiving their first NIH grant, a huge dis-incentive for students considering bio-medical research as a career. Complicating matters, there is a gap between the number of women's reproductive health researchers being trained and the need for such research. Programs like the Women's Reproductive Health Research (WRHR) Career Development program, Reproductive Scientist Development Program (RSDP), and the Building Interdisciplinary Research Careers in Women's Health (BIRCWH) program all seek to address the shortfall of women's reproductive health researchers. At least 79% of BIRCWH grantees go on to apply for NIH grants, and 51% receive NIH grants, much higher than the average NIH success rate. Sequestration and other budget cuts threaten to undermine these programs at a critical juncture. For example, every \$500,000 cut to the BIRCWH program results in one less BIRCWH scholar. A sustained investment in NIH funding will help ensure the continuation of these programs and help mitigate the negative consequences of budget uncertainty on the future research workforce.

Public Health Programs at the Health Resources and Services Administration (HRSA) and the Centers for Disease Control and Prevention (CDC):

Projects at HRSA and CDC are integral to translating research findings into evidence-based practice changes in communities. Where NIH conducts research to identify causes of preterm birth, CDC and HRSA fund programs that provide resources to mothers to help prevent preterm birth, and help identify factors contributing to preterm birth and poor maternal outcomes. The Maternal Child Health Block Grant at HRSA is the only federal program that exclusively focuses on improving the health of mothers and children. State and territorial health agencies and their partners use MCH

Block Grant funds to reduce infant mortality, deliver services to children and youth with special health care needs, support comprehensive prenatal and postnatal care, screen newborns for genetic and hereditary health conditions, deliver childhood immunizations, and prevent childhood injuries.

These early health care services help keep women and children healthy, eliminating the need for later costly care. For example, every \$1 spent on preconception care for women with diabetes can reduce health costs by up to \$5.19 by preventing costly complications in both mothers and babies. Every \$1 spent on smoking cessation counseling for pregnant women saves \$3 in neonatal intensive care costs. The MCH Block Grant has seen an almost \$30 million decrease in funding in the past 5 years alone. **ACOG urges you not to cut the MCH Block Grant any further and for FY14 we request \$640 million for the Block Grant to maintain its current level of services.**

Family planning is essential to helping ensure healthy pregnancies and reducing the risk of preterm birth. The Title X Family Planning Program provides services to more than five million low-income men and women at more than 4,500 service delivery sites. Every \$1 spent on family planning results in a \$4 savings to Medicaid. Services provided at Title X clinics accounted for \$3.4 billion in health care savings in 2008 alone. **ACOG supports \$327 million for Title X in FY14 to sustain its level of services.**

The Healthy Start Program through HRSA promotes community-based programs that help reduce infant mortality and racial disparities in perinatal outcomes. These programs are encouraged to use the Fetal and Infant Mortality Review (FIMR) which brings together ob-gyn experts and local health departments to help specifically address local issues contributing to infant mortality. Today, more than 220 local programs in 42 states find FIMR a powerful tool to help reduce infant mortality, including understanding issues related to preterm delivery. For over 20 years, ACOG has partnered

with the Maternal and Child Health Bureau to sponsor the designated resource center for FIMR Programs, the National FIMR Program. **ACOG supports \$.5 million in FY14 for HRSA to increase the number of Healthy Start programs that use FIMR.**

The Safe Motherhood Initiative at CDC works with state health departments to collect information on pregnancy-related deaths, track preterm births, and improve maternal outcomes. The Initiative also promotes preconception care, a key to reducing the risk of preterm birth. **For FY14, we recommend a sustained funding level of at least \$44 million for the Safe Motherhood Program, and re-instatement of the preterm birth sub-line at \$2 million to ensure continued support for preterm birth research, as authorized by the PREMIE Act.**

State and regional quality improvement initiatives encourage use of evidence-based quality improvement projects across hospitals and medical practices to reduce the rate of maternal and neonatal mortality and morbidity. For example, under the Ohio Perinatal Quality Collaborative, started in 2007 with funding from CDC, 21 OB teams in 25 hospitals have decreased scheduled deliveries between 36 and 39 weeks gestation, in accordance with ACOG guidelines, significantly reducing pre-term births. According to a study conducted by Avalere, the estimated savings from initiatives aimed at reducing elective inductions pre-39 weeks ranges from \$2.4 million to \$9 million a year. **ACOG urges you to provide sufficient resources to HHS to help states expand upon or establish maternity and perinatal care quality collaborative programs.**

Again, we would like to thank the Committee for its consideration of funding for programs to improve women's health, and we urge you to consider our MOMS Initiative in FY14.



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

Public and Outside Witnesses Hearing  
Wednesday, March 14, 2013

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) 2014 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. We are very concerned that across-the-board sequester cuts will have a devastating impact on the nation's progress toward advances in vital treatments, diagnostics and cures, which not only lead to improved health outcomes but also yield significant overall savings to the health care system. The Roundtable encourages Congress to reverse these across-the-board spending cuts, and urges this Committee to prioritize NIH-sponsored research in the FY2014 appropriations bill.

At the Subcommittee's recent oversight hearing on Health and Human Services Public Health and Research Organizations, several Members highlighted the need for increased coordination of research to improve efficiencies and reduce duplicative efforts both throughout the federal government and within specific agencies. The Roundtable supports the concept of improved

coordination and believes that one way to maximize current resources is to establish a Critical Care Coordinating Council at the NIH.

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<sup>i</sup>. 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 17% of all hospital costs, and total costs of critical care services in the U.S. exceeding \$121 billion annually.<sup>ii</sup>

Given the unique nature of care in the ICU, the critical care community has long been proactive in the development of new knowledge regarding the pathophysiology and effective treatment of critical illness. Yet, notwithstanding the significant role critical care medicine plays in providing high quality health care and its impact on health care costs, as a country there is disproportionately little research focused on critical care medicine. 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.”<sup>iii</sup>

This discrepancy is likely due to the multidisciplinary nature of the field, resulting in the scattering of critical care-related projects throughout the NIH’s 27 Institutes and across the federal government, ultimately limiting the progress of research.

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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<sup>i</sup> Society of Critical Care Medicine. Critical care statistics in the United States.

<http://www.sccm.org/AboutSCCM/Public%20Relations/Pages/Statistics.aspx>

<sup>ii</sup> Halpern NA, Pastores SM. "Critical Care Medicine in the United States 2000-2005: An analysis of bed number, occupancy rates, payer mix and costs," *Critical Care Medicine* 37 no.1 (2010)

<sup>iii</sup> 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)



NATIONAL INDIAN HEAD START DIRECTORS ASSOCIATION

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“FUNDING FOR QUALITY AND EXPANSION - FY 2014”  
AMERICAN INDIAN AND ALASKA NATIVE HEAD START

Written Testimony of

Jacki Haight, President

National Indian Head Start Directors Association

before the

House Committee on Appropriations Subcommittee on

Labor, Health and Human Services, Education, and Related Agencies

**Introduction.** Thank you for the opportunity to submit testimony on behalf of the National Indian Head Start Directors Association (NIHSDA) with regard to the Department of Health and Human Services FY 2014 Budget.

**Funding Request.** The American Indian and Alaska Native Head Start program receives its funding through a formula established in the Head Start Act for the distribution of Head Start funds. That formula provides for Indian Head Start to receive special expansion funds to make up for errors in the application of the formula a decade ago. Indian Head Start requests that

Head Start be funded at a level that would trigger the special expansion funding provisions of the Head Start Act. (Note: those provisions did not take into account what happens when the initial authorization under the Head Start Act expired.) As a general matter, there should be a sufficient increase in funding to make up for the effects of inflation over the last several years.

**Importance of Indian Head Start.** Indian Head Start is the most important and successful Federal program focused on the dire circumstances faced by all too many Native children, principally by addressing health, education, family and community needs in a holistic manner that is akin to traditional Native learning styles and cultural practices. Indeed, Indian Head Start is on the frontline in the preservation of Native language and culture, which have proven to be key elements in Native student confidence and success in later years.

**In making decisions regarding the funding of Indian Head Start, the following should be considered:**

- **Indian reservations suffer from depression-era economics, with terrible crime and health statistics to match.** The Indian reservation poverty rate is 31.2%, nearly three times the national average of 11.6%. The Indian reservation rate is comparable to the national rate at the height of the Great Depression. The Indian reservation unemployment rate is approximately 50%, ten times the national unemployment rate of 5.2% (and on some reservations the rate is 80-90%). When you consider that 31.2% of Indian families live in poverty and that high levels of poverty bring significant problems to reservations

where few resources are available, a need arises for Head Start to address chronic community social issues.

- **Most Indian communities are remotely located** and there are no other resources besides Head Start to address the special needs of young Indian children who, on a daily basis, must deal with the conditions described above.
- *The synergistic confluence of all of these negative factors is overwhelming.* Indian Head Start may be the best Federal program in place that actually addresses the dire situation in much of Indian country, but more resources are needed.
- **The Federal Government has a Trust Responsibility to Indian Peoples, especially in the Education Area.** The Constitution of the United States, treaties, federal statutes, executive orders, Supreme Court doctrine and other agreements define the Federal government's trust obligation to protect the interests of Indian peoples, especially in the education area.
- **When it came to Native issues, the Federal government historically has displayed a keen understanding of the central importance of our ancient ways, beliefs, culture and language to tribal unity and strength and for years made every effort to destroy those beliefs.** This effort to kill our minds and our spirits failed, but not without first doing great damage. Indian languages are in retreat. Native students perform far below their potential. Federal paternalism has created a crippling mentality for some in Indian country that is founded on poor self-esteem. Extraordinarily, the Native spirit has endured and, in recent years, grown stronger. Much of the harm inflicted upon Native peoples is being undone, to the extent it can be undone, by Native people themselves.

*And yet the resources needed to complete this great task can only be found with the originator of the harm – the Federal Government.*

- **It is a mark of America’s unique character that the racist policies of the past have been replaced with more humane policies. For example, Title VII of the NCLB provides:** *“It is the policy of the United States to fulfill the Federal Government’s unique and continuing trust relationship with and responsibility to the Indian people for the education of Indian Children. The Federal Government will continue to work with local educational agencies, Indian tribes and organizations, postsecondary institutions, and other entities toward the goal of ensuring that programs that serve Indian children are of the highest quality and provide for not only the basic elementary and secondary educational needs, but also the unique educational and culturally related academic needs of these children.”* (NCLB, Section 7101)

Only about 16% of the age-eligible Indian child population is enrolled in Indian Head Start. Of the approximately 562 federally recognized Tribes, only about 188 have Head Start programs funded through 154 grantees in 27 states. That means 374 Tribes do not have Head Start available for their age-eligible children. These programs employ approximately 6,627 individuals and 331 contracted people: 3,191 of these employees are either former or current Head Start/Early Head Start parents and 86 people under contract are either former or current parents. There are approximately 34,901 volunteers, 22,942 of which are parents, working in the American Indian/Alaska Native Head Start programs.

**Conclusion.** Thank you for this opportunity to share with the Subcommittee the nature and needs of the American Indian and Alaska Native Head Start program. Its value to Indian Country is beyond measure. We urge your prioritization of Head Start in your funding decisions.

**For further information, please contact:**

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Written Statement for the Record by

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House Appropriations Subcommittee on Labor, Health and Human Services, and Education  
 2358B Rayburn House Office Building, Washington, DC

March 15, 2013

**FY 2014 Appropriations Request Summary**

	<b><u>FY13 Actual</u></b>	<b><u>FY14 Budget</u></b>	<b><u>AANA FY 14 Request</u></b>
HHS / HRSA / BHPPr Title 8 Advanced Education Nursing, Nurse Anesthetist Education Reserve	Awaiting grant allocations—in FY 12 awards amounted to approx. \$3.5MM	Grant allocations not specified	\$4 MM for nurse anesthesia education
Total for Advanced Education Nursing, from Title 8	\$60.8 MM for Advanced Education Nursing postsequester estimate	Not yet available for Advanced Education Nursing	\$83.925 MM for advanced education nursing
Title 8 HRSA BHPPr Nursing Education Programs	\$220.4 MM postsequester estimate	Not yet available	\$251.099 MM

**About the American Association of Nurse Anesthetists (AANA) and Certified Registered Nurse Anesthetists (CRNAs)**

The AANA is the professional association for more than 45,000 CRNAs and student nurse anesthetists, representing over 90 percent of the nurse anesthetists in the United States. Today, CRNAs deliver approximately 33 million anesthetics to patients each year in the U.S. CRNA services include administering the anesthetic, monitoring the patient's vital signs, staying with

the patient throughout the surgery, and providing acute and chronic pain management services. CRNAs provide anesthesia for a wide variety of surgical cases and in some states are the sole anesthesia providers in almost 100 percent of rural hospitals, affording these medical facilities obstetrical, surgical, and trauma stabilization, and pain management capabilities. CRNAs work in every setting in which anesthesia is delivered, including hospital surgical suites and obstetrical delivery rooms, ambulatory surgical centers (ASCs), pain management units and the offices of dentists, podiatrists and plastic surgeons.

Nurse anesthetists are experienced and highly trained anesthesia professionals whose record of patient safety is underscored by scientific research findings. The landmark Institute of Medicine report *To Err is Human* found in 2000 that anesthesia was 50 times safer then than in the 1980s. (Kohn L, Corrigan J, Donaldson M, ed. *To Err is Human*. Institute of Medicine, National Academy Press, Washington DC, 2000.) Though many studies have demonstrated the high quality of nurse anesthesia care, the results of a new study published in *Health Affairs* led researchers to recommend that costly and duplicative supervision requirements for CRNAs be eliminated. Examining Medicare records from 1999-2005, the study compared anesthesia outcomes in 14 states that opted-out of the Medicare physician supervision requirement for CRNAs with those that did not opt out. (To date, 17 states have opted-out.) The researchers found that anesthesia has continued to grow more safe in opt-out and non-opt-out states alike. (Dulisse B, Cromwell J. No Harm Found When Nurse Anesthetists Work Without Supervision By Physicians. *Health Aff.* 2010;29(8):1469-1475.)

CRNAs provide the lion's share of anesthesia care required by our U.S. Armed Forces through active duty and the reserves, staffing ships, remote U.S. military bases, and forward surgical teams without physician anesthesiologist support. In addition, CRNAs predominate in rural and medically underserved areas, and where more Medicare patients live (Government Accountability Office. Medicare and private payment differences for anesthesia services. GAO-07-463, Washington DC, Jul. 27, 2007. <http://www.gao.gov/products/GAO-07-463>).

### **Importance of and Request for HRSA Title 8 Nurse Anesthesia Education Funding**

Our profession's chief request of the Subcommittee is for \$4 million to be reserved for nurse anesthesia education and \$83.925 million for advanced education nursing from the HRSA Title 8 program, out of a total Title 8 budget of \$251.099 million. We request that the Report accompanying the FY 2014 Labor-HHS-Education Appropriations bill include the following language: "Within the allocation, the Committee encourages HRSA to allocate funding at least at the fiscal year 2012 level for nurse anesthetist education." This funding request is justified by the safety and value proposition of nurse anesthesia, and by anticipated growth in demand for CRNA services as baby boomers retire, become Medicare eligible, and require more healthcare services. In making this request, we associate ourselves with the request made by The Nursing Community and Americans for Nursing Shortage Relief (ANSR) with respect to Title 8 and the National Institute of Nursing Research (NINR) at the National Institutes of Health.

The Title 8 program, on which we will focus our testimony, is strongly supported by members of this Subcommittee in the past, and is an effective means to help address nurse anesthesia workforce demand. In expectation for dramatic growth in the number of U.S. retirees and their

healthcare needs, funding the advanced education nursing program at \$83.925 million is necessary to meet the continuing demand for nursing faculty and other advanced education nursing services throughout the U.S.,. The program funds competitive grants that help enhance advanced nursing education and practice, and traineeships for individuals in advanced nursing education programs. It also targets resources toward increasing the number of providers in rural and underserved America and preparing providers at the master's and doctoral levels, thus increasing the supply of clinicians eligible to serve as nursing faculty, a critical need.

Demand remains high for CRNA workforce in clinical and educational settings. A 2007 AANA nurse anesthesia workforce study found a 12.6 percent CRNA vacancy rate in hospitals and a 12.5 percent faculty vacancy rate. The supply of clinical providers has increased in recent years, stimulated by increases in the number of CRNAs trained. From 2002-2012, the annual number of nurse anesthesia educational program graduates increased from 1,362 to 2,469, according to the Council on Accreditation of Nurse Anesthesia Educational Programs (COA). The number of accredited nurse anesthesia educational programs grew from 85 to 113. We anticipate increased demand for anesthesia services as the population ages, the number of clinical sites requiring anesthesia services grows, and a portion of the CRNA workforce retires.

The capacity of our 113 nurse anesthesia educational programs to educate qualified applicants is limited by the number of faculty, the number and characteristics of clinical practice educational sites, and other factors – and they continue turning away hundreds of qualified applicants. A qualified applicant to a CRNA program is a bachelor's educated registered nurse who has spent at least one year serving in an acute care healthcare practice environment. They are prepared in

nurse anesthesia educational programs located all across the country, including Arkansas, California, Connecticut, Georgia, Kentucky, Maryland, New York, Ohio, and Tennessee. To meet the nurse anesthesia workforce challenge, the capacity and number of CRNA schools must continue to grow and modernize with the latest advancements in simulation technology and distance learning consistent with improving educational quality and supplying demand for highly qualified providers. With the help of competitively awarded grants supported by Title 8 funding, the nurse anesthesia profession is making significant progress, but more is required.

This progress is extremely cost-effective from the standpoint of federal funding. Anesthesia can be provided by nurse anesthetists, physician anesthesiologists, or by CRNAs and anesthesiologists working together. Of these, the nurse anesthesia practice model is by far the most cost-effective, and ensures patient safety. (Hogan P et al. Cost effectiveness analysis of anesthesia providers. *Nursing Economic*, Vol. 28 No. 3, May-June 2010, p. 159 et seq.) Nurse anesthesia education represents a significant educational cost-benefit for competitively awarded federal funding in support of CRNA educational programs.

### **Support for Safe Injection Practices and the Alliance for Injection Safety**

As a leader in patient safety, the AANA has been playing a vigorous role in the development and projects of the Alliance for Injection Safety, intended to reduce and eventually eliminate the incidence of healthcare facility acquired infections. In the interest of promoting safe injection practice, and reducing the incidence of healthcare facility acquired infections, we associate ourselves with the AIS recommendation.

# # #

**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 15, 2013**

Mr. Chairman,

Amyloidosis is an often misdiagnosed, often fatal disease. I ask that you include language in the Committee's report for fiscal year 2014 urging the National Institutes of Health and other health agencies to fund research for amyloidosis and to increase awareness of the disease.

In previous testimony before this Committee, I described my efforts to combat the life-threatening disease primary amyloidosis. I have obtained treatment for amyloidosis and want to use my experience to help others.

Amyloidosis can literally kill people before they even know that they have the disease. It often leads to heart, kidney, liver and other organ failure. Left untreated, there is an average survival of 15 months from the time of diagnosis.

I'm happy to report that, since I began appearing before this Subcommittee several years ago, progress has been made in research and treatment for various types of amyloidosis. However, only limited research is currently being funded. Much, much more needs to be done.

Thousands of people die because they were diagnosed too late to obtain effective treatment. Thousands of others die never knowing they had amyloidosis. The small numbers of those with amyloidosis who are able to obtain treatment face challenges that can include high dose chemotherapy and stem cell replacement or organ transplantation.

Amyloidosis is vastly under-diagnosed. This is especially the case in the African-American community.

### **AMYLOIDOSIS**

Amyloidosis occurs when cells malfunction and produce proteins that deposit 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.

In addition to primary amyloidosis, a blood or bone marrow disorder, there are also cases of inherited or familial amyloidosis and secondary or reactive amyloidosis. All three types of amyloidosis, left undiagnosed or untreated, are fatal.

There is no explanation for how or why amyloidosis develops and there is no known reliable cure.

### **AMYLOIDOSIS TREATMENT**

Boston University School of Medicine and other centers for amyloidosis treatment have found that high dose intravenous chemotherapy followed by stem cell replacement, or rescue, 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 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.

- There has been increased basic and clinical research at the Boston University Amyloid Treatment and Research Program: a model for the disease is under development; factors that cause protein misfolding are being identified; and new clinical trials are underway.
- Increased Federal funding for research, equipment and treatment has been another important element. This is essential to speed the pace of discovery for basic research.

**REQUEST FOR FISCAL YEAR 2014**

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 for Submission**

Oscar Mairena  
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To the House Committee on Appropriations  
 Subcommittee on Labor, HHS, Education and Related Agencies for FY2014

The Hepatitis Appropriations Partnership (HAP) is a national coalition of community-based organizations, public health and provider organizations, national hepatitis and HIV organizations and diagnostic, pharmaceutical and biotechnology companies that works with policy makers and public health officials to increase federal support for viral hepatitis prevention, testing, education, research and treatment. On behalf of HAP, we urge your support for increased funding for viral hepatitis in the FY2014 Labor-Health-Education Appropriations bill, and thank you for your consideration of the following critical funding needs in FY2014:

<b>Agency</b>	<b>Program</b>	<b>HAP Funding Request</b>
Centers for Disease Control and Prevention	Division of Viral Hepatitis	\$35 million

The Centers for Disease Control and Prevention (CDC) estimate 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 percent are not aware of their infection. However, these figures are based on National Health and Nutrition Examination Survey (NHANES) data, which does not include homeless individuals, those with unstable housing, the incarcerated, and many immigrant and migrant communities – populations disproportionately affected by viral hepatitis. In 2010 alone, the CDC estimated that 35,000 Americans were newly infected with HBV and 17,000 with HCV. Unfortunately, due to the lack of an adequate surveillance system, these estimates are likely only the tip of the iceberg. Without the necessary access to care and/or treatment, viral

hepatitis can lead to chronic liver disease, cirrhosis, liver cancer and liver failure and complications from these chronic infections claim 15,000 lives annually. Analyses of viral hepatitis-related morbidity and mortality have found that the mortality rate attributed to viral hepatitis has increased over the last several years.

Additionally, viral hepatitis disproportionately impacts several communities, particularly people who inject drugs (PWID), men who have sex with men (MSM), African Americans, Asian Americans, Latinos and residents of rural and remote areas with limited access to medical treatment and culturally and linguistically-appropriate services. Persons born between 1945 and 1965 have the greatest risk for HCV-related morbidity and mortality and CDC released new HCV screening guidelines in 2012 recommending that providers offer the screening to anyone born in this birth cohort. 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.

#### **CDC Division of Viral Hepatitis**

HAP encourages a total funding of **\$35 million** for the CDC Division of Viral Hepatitis (DVH) to more effectively combat the epidemics. In FY2012, DVH received \$10 million from the PPHF for the creation of a viral hepatitis screening initiative. The President's budget for FY2013 sought to continue this initiative by providing a budget authority to DVH of \$29.7 million. A minimum increase of \$5.3 million above the recommended FY2013 funding level is needed for DVH in FY2014. This request pales in comparison to the CDC's professional judgment budget (PJ) which recommended a total of \$170.3 million for DVH in FY2014 to bring prevention programming to scale. However, 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 *HHS Action Plan for Viral Hepatitis*, and the CDC testing guidelines for baby boomers. HAP recommends that DVH receive a total funding level of \$35 million for FY2014.

#### **Viral Hepatitis Prevention Coordinator Program**

We ask for the Viral Hepatitis Prevention Coordinator program to receive additional funding to total **\$10.4 million** to support and expand programs in all existing funded 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, the cornerstone implementers of national public health policies, to coordinate prevention and surveillance efforts via the Viral Hepatitis Prevention Coordinator program (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. In FY2012, the VHPC program received \$5.2 million to fund a total of 55 jurisdictions. This program provided an average award to states of \$94,000 to support a coordinator, leaving little to no money for the provision of public health services, such as public education and access to prevention services like testing and hepatitis A and B vaccinations. Even without funding for programmatic activities, coordinators administered nearly 90,000 tests nationwide in FY2011 by leveraging state and other funds. The previously noted increase of HCV infection among young persons who inject drugs makes the need to enhance and expand these prevention efforts all the more urgent. In September of 2011, the

Senate Appropriations Committee approved a committee report that supported the VHPC program and “encourage[d] the Division of Viral Hepatitis to maintain this program in all previously funded jurisdictions to build the Federal response for both low- and high-impacted areas.” HAP supports this recommendation and encourages the Committee to continue to support and expand the VHPC program in all currently-funded jurisdictions by increasing the VHPC budget to \$10.4 million in FY2014.

**Viral Hepatitis Testing, Education and Surveillance**

HAP requests an increase of at least **\$10 million** in DVH’s budget authority for the continuation of the FY2012 screening initiative and the development of national education and surveillance initiatives. Congress must engage in additional efforts to successfully decrease incidence and increase awareness of viral hepatitis through a national testing initiative that provides funding and infrastructure for testing, develops a national testing goal and supports a monitoring and evaluation component. At present, only 25-35 percent of people living with chronic viral hepatitis are aware of their infection. According to the PJ for viral hepatitis, the top priority is to identify persons with viral hepatitis early and refer them to care by strategically increasing access to testing nationwide. The *Action Plan* established a goal of increasing the proportion of persons who are aware of their HBV infection from 33 percent to 66 percent and from 45 percent to 66 percent for HCV. The FY2012 PPHF funding for a screening initiative must continue in FY2014 in order to maintain the first-ever DVH viral hepatitis testing initiative.

With an increase in testing, the second priority is to improve the monitoring of viral hepatitis. There are currently no funds for a national surveillance system of chronic viral hepatitis, limiting the access to information about viral hepatitis available to states, health departments, policy makers, and service providers. CDC currently funds only four state health

departments and two local health departments to create surveillance systems for their jurisdictions. By creating a national surveillance system, Congress will provide stakeholders with information that is critical to understanding the impact of the hepatitis epidemics, identifies and averts outbreaks, and that will best target resources to the most impacted communities. HAP recommends that the Congress continue to provide funding to the currently funded surveillance projects and expand the program to begin the creation of a national infrastructure for monitoring the viral hepatitis epidemics.

#### **Prevention and Public Health Fund**

The Prevention and Public Health Fund tackles critical epidemics, such as viral hepatitis. The fund is a unique opportunity to decrease health care spending related to viral hepatitis treatment and care, and invest in viral hepatitis prevention and screening efforts. We encourage you to utilize the Prevention and Public Health Fund to support a broad testing and screening initiative that would include neglected diseases such as viral hepatitis in order to capture patients before they progress in their liver disease and increase costs to public healthcare systems.

As you contemplate the FY2014 Labor, HHS and 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 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.



**Kiwanis**<sup>®</sup>

www.kiwanis.org

**STATEMENT BY**

**PETER MANCUSO, PRESIDENT OF KIWANIS INTERNATIONAL FOUNDATION**

**SUBMITTED TO**

**THE SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,**

**AND RELATED AGENCIES COMMITTEE ON APPROPRIATIONS**

**U.S. HOUSE OF REPRESENTATIVES**

**MARCH 8, 2013**

Mr. Chairman, I am Peter Mancuso, the president of Kiwanis International Foundation. I live in North Bellmore, New York, and I am representing more than 5,100 Kiwanis clubs and more than 432,000 Kiwanis-family members in the United States.

My testimony is in support of The Eliminate Project: Kiwanis eliminating maternal and neonatal tetanus. Tetanus is a preventable disease that kills one baby every nine minutes. We are advocating to protect mothers and newborns in 30 developing countries from maternal and neonatal tetanus. I ask that the Committee endorse this private and public sector project and take steps to encourage the Centers for Disease Control to support efforts to eliminate maternal and neonatal tetanus.

On behalf of Kiwanis International and Kiwanis International Foundation, I want to thank you for your past and continuing support of our first Global Campaign for Children, ending Iodine

Deficiency Disorders. I urge you to also support our second and current campaign to eliminate maternal and neonatal tetanus from the face of the earth.

### **MATERNAL AND NEONATAL TETANUS & THE ELIMINATE PROJECT**

The Eliminate Project: Kiwanis eliminating maternal and neonatal tetanus is a global campaign that will save or protect more than 61 million mothers and newborns. Tetanus can infect newborns, spreading quickly, causing terrible pain and killing within days. It's a terrible disease where mothers cannot even touch or comfort their babies due to the excruciating pain. But it is highly preventable.

During this project, Kiwanis International is focusing where the need is greatest—on the populations least served. In fact, we are tackling the hardest leg of a difficult journey. MNT is on the brink of elimination, but sorely needs a champion to complete the work.

Kiwanis International is committed to raising \$110 million to immunize more than 61 million women in countries where the disease is still a major health problem. Kiwanis' global volunteer network and strength in reaching communities and leaders, along with the UNICEF's field staff, technical expertise and unbeatable supply chain, will help eliminate this cruel, centuries-old disease.

**MATERNAL AND NEONATAL TETANUS**

MNT occurs when tetanus spores, which are present in soil everywhere, enter the bloodstream. It is mainly caused by a lack of access to sanitary birthing conditions, unclean instruments used to cut the umbilical cord and unclean post-partum cord care.

Once the disease is contracted, a newborn usually dies within seven days. The fatality rate can be as high as 100 percent in underserved areas.

Most mothers and newborns who die of tetanus live in Africa, and South and Southeast Asia, where many women are poor, have little access to health care, have limited information about safe delivery procedures and continue harmful cord care practices.

MNT is easily prevented by giving women of childbearing age a series of three vaccine doses, which costs roughly \$1.80. This cost includes the vaccinations, syringes, safe storage, transportation and more. Coupled with education on clean birthing practices, the tragedy of MNT can easily be prevented.

Women who are properly vaccinated with the tetanus vaccine will have immunity through most of their childbearing years. Babies born to mothers who have been vaccinated will be protected through the first two months of life.

When women are vaccinated for tetanus and learn about maternal health, they become empowered to take control of their well-being and that of their newborns. We believe these

women matter, they deserve to give birth to healthy babies and their babies deserve to achieve their full human potential.

## **PROGRESS**

The Eliminate Project supports UNICEF and its partners, which have already eliminated MNT in 29 countries. Thirty countries remain at risk.

Between 1999 and 2010, nearly 100 million women in some of the most remote places were protected against tetanus, saving thousands of newborns from death due to tetanus every year.

Kiwanis International is now taking on this cause. We will raise \$110 million by 2015. Since launching our fundraising campaign July, 2011, more than \$27 million has been raised, nearly 5,700 Kiwanis members have committed to four years of volunteer service and more than 3,500 clubs have contributed to the fundraising campaign.

I can visualize a world without tetanus. I have met Dr. Francois Gasse, “Dr. Tetanus”, who launched this initiative more than twenty years ago. He has witnessed vaccination campaigns, social mobilization and birth attendant training. He shared with me how UNICEF’s supply chain works and how they get vaccines to the most remote places. Dr. Gasse is filled with hope at the thought that Kiwanis will finally bring an end to his lifelong campaign to end MNT.

The elimination plans are in place. Countries are ready for implementation. All that remains is one final funding push. One push to rid the earth of this devastating disease.

Mr. Chairman, I ask you to join us in this final push. Help us to eliminate this terrible disease and ensure that no baby suffers this excruciating seven-day death ever again.

Thank you for your time and your consideration.



**Helen Keller**  
INTERNATIONAL

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**STATEMENT BY**  
**JENNIFER BUDA**  
**TRUSTEE**  
**HELEN KELLER INTERNATIONAL**  
**SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,**  
**EDUCATION AND RELATED AGENCIES**  
**COMMITTEE ON APPROPRIATIONS**  
**U.S. HOUSE OF REPRESENTATIVES**  
**MARCH 15, 2013**

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 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 low income families in fiscal year 2014.

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. 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 correct this error, 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 1.5 million children and delivered over 206,000 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, 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, and does so in a pragmatic and cost-effective manner. I ask this Subcommittee to recommend in its fiscal year 2014 Committee report that the United States Department of Education support programs that provide vision care for children from low income families. These Department of

Education funds will support ongoing programs and will provide vision screening and prescription eyeglasses for economically disadvantaged children during the 2013-2014 school year.

As our founding board member Helen Keller said: *Alone we can do so little; together we can do so much.*

STATEMENT TO THE HOUSE APPROPRIATIONS SUB COMMITTEE  
ON  
LABOR, HEALTH AND HUMAN SERVICES, EDUCATION  
FISCAL YEAR 2014 BUDGET

Administration for Native Americans

Esther Martinez Native American Languages Preservation Act (Public  
Law 109-394)

Please approve funding to the Esther Martinez Native Language Programs  
be funded at 12million for FY2014 with 4 million going towards immersion  
schools.

Statement of:

**Elvera Sargent (Akwesasne Mohawk)**

**Director**

**Friends of the Akwesasne Freedom School**

**March 13, 2013**

Akwekon Tekwanonweratens, (Greetings to all of you), Please approve  
funding to the Administration for Native Americans be funded at \$12  
million for FY2014 with \$4 million going towards immersion schools.

On behalf of the students, staff and parents of the Akwesasne Freedom  
School, I am pleased to submit this written testimony to the House L-HHS-E

Appropriations Committee on the importance of our children and families receiving an Indian education. I am going to address the importance of Native languages, culturally based education and their vital importance to the academic success of Native learners.

It is imperative for Onkwehonwe (Native) children to receive an education in their own languages and cultures before venturing out into the dominant society because we are given strength from knowing “who we are” which we get through knowing our language and culture. That is the reason for our school: the Akwesasne Freedom School (AFS) was created as a place for wholly Mohawk education. Grounding learning and teaching Mohawk lifeways, the School has survived many challenges to become a respected and supported institution of the Mohawk community. Through the ongoing efforts of parents, families and the larger Mohawk Nation community, the AFS has played a critical role in the formation of Mohawk identity, citizenship, and nationhood extending even beyond those who attend the school and into the next generations of Mohawk leadership..

Our school, the Akwesasne Freedom School, was founded in 1979 by Mohawk parents who wanted to take back control of who, how and what their children would be taught. The school has had great success in teaching knowledge and skills related to traditional earth based cultural practices to our youth and promoting Mohawk language fluency in our students. Because AFS does not seek or receive any US Federal or state educational funding, the school is constantly struggling to locate funding for its yearly operations. In addition, financial limitations have

severely hampered our attempts to expand the school's curriculum so that a culture based, Mohawk language component could be offered up to grade 12. The lack of middle/high school educational programs creates serious impediments to our youth achieving full fluency and proficiency in Kanien'kéha. If a Mohawk immersion program for these upper levels students is not implemented very soon, we will lose this invaluable opportunity to prepare our youth to engage in culturally important subsistence practices that will protect their health and the health of future generations.

While the AFS does not seek or receive federal or state funding, its sponsoring 501C3 organization, the Friends of the Akwesasne Freedom School, has on two occasions been awarded funding through the Administration for Native Americans - Esther Martinez Native American Languages Preservation Act (Public Law 109-394) to enhance our programming by sponsoring new language initiatives, that includes the "Kanien'kéha Fluency and Teacher Training Program" in which 15 adults with intermediate Mohawk language skills were able to improve their fluency and were trained to become immersion teachers. In addition the second grant was for the Orihwakaionhnéha "In The Manner Of The Old Ways Project" to build an immersion component into its grades 7 and 8 utilizing holistic, culturally appropriate, hands-on, total participatory response (TPR) teaching methods based on Kanien'kehá:ka oral tradition. Content was taught thematically, through speaking reading, writing, singing, dancing, scientific inquiry and student participation in traditional cultural activities. Our cultural educators for this

project were both fluent Mohawk language speakers, knowledgeable of the Akwesasne Freedom School and the Mohawk culture were hired to provide the teachings to our older students. In addition the professional services of elders, scientists and knowledgeable community members fluent in the Mohawk language, were asked to teach in these upper grade levels, as well as assist older students in their efforts to educate younger children at the school.

Across the United States there are huge efforts to revitalize all our Native American languages and it is an opportunity for the federal government to join us in these vital efforts. I urge continued funding to the languages programs under the Administration for Native Americans. **Once again, please approve funding to the Administration for Native American be funded at \$12 million for FY2014 with \$4 million going towards immersion schools.**

Niawen ko:wa! (thank you very much)



# SOCIETY FOR PUBLIC HEALTH EDUCATION

*Global Leadership for Health Education & Health Promotion*

**Public Record Testimony of the Society for Public Health Education**

Submitted by: Elaine Auld, Chief Executive Officer, SOPHE

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

Regarding FY 2014 Funding for Disease Prevention and Wellness Programs  
March 15, 2013

The Society for Public Health Education (SOPHE) is a 501 (c)(3) professional organization founded in 1950 to provide global leadership to the profession of health education and health promotion. SOPHE contributes to the health of all people and the elimination of health disparities through advances in health education theory and research; excellence in professional preparation and practice; and advocacy for public policies conducive to health. SOPHE is the *only* independent professional organization devoted exclusively to health education and health promotion. SOPHE's two scientific peer-reviewed journals, electronic newsletters, listservs, websites, new Center for Online Education (CORE), as well as its national conference help ensure that vital public health activities and programs in various regions are expeditiously disseminated. Members include behavioral scientists, faculty, practitioners, and students engaged in disease prevention and health promotion in both the public and private sectors. Collectively, SOPHE's 4,000 national and chapter members work in universities, medical/health care settings, businesses, voluntary health agencies, international organizations, and all branches of federal/state/local government. There are currently 20 SOPHE chapters covering more than 30 states and regions across the country.

SOPHE's vision of a healthy world through health education compels us to advocate for increased resources targeted at the most pressing public health issues. For the FY 2014 funding

*SOPHE Testimony to the House Labor/HHS/Education Appropriations Subcommittee, 3/15/ 2013*

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cycle, SOPHE encourages the Labor, Health and Human Services, Education and Related Agencies (Labor-HHS) Subcommittee to increase funding for public health programs that focus on preventing chronic disease and other illnesses in adults as well as youth, and eliminating health disparities. In particular, SOPHE requests the following FY 2014 funding levels for Labor-HHS programs:

- **\$7.8 billion for the Centers for Disease Control and Prevention (CDC)**
- **\$1 billion for the Prevention and Public Health Fund**
- **\$226 million for the Community Transformation Grants (CTG) Program**
- **\$18.6 million for CDC's School Health Program**

The discipline of health education and health promotion, which is some 100 years old, uses sound science to plan, implement, and evaluate interventions that enable individuals, groups, and communities to achieve personal, environmental and population health. There is a robust, scientific evidence-base documenting not only that various health education interventions work but that they are also cost-effective. These principles serve as the basis for our support for the programs outlined below and can help ensure our nation's resources are targeted for the best return on investment.

#### Preventing Chronic Disease

The data are clear: chronic diseases are the nation's leading causes of morbidity and mortality and account for 75 percent of every dollar spent on health care in the U.S. Collectively, they account for 70 percent of all deaths nationwide. Health care now accounts for 18 percent of GDP, and it's expected to account for 19.6 percent by 2021. Yet evidence shows that investing just \$1 in preventing disease will yield a \$5 return on investment.

**SOPHE is requesting a FY 2014 funding level \$7.8 billion for CDC** in order to prevent chronic diseases and other illnesses, promote health, prevent injury and disability, and ensure

preparedness against health threats. CDC is at the forefront of U.S. efforts to monitor health, detect and investigate health problems, conduct research to enhance prevention, develop sound public health policies, and foster safe and healthful environments. More than 80% of all CDC funds go back to states to address state and local health issues. Studies show that spending as little as \$10 per person on proven preventive interventions could save the country over \$16 billion in just five years. The public overwhelmingly supports increased funding for disease prevention and health promotion programs. Small investments now in community-led, innovative programs will help to increase our nation's productivity and performance in the global market; help ensure military readiness; decrease rates of infant mortality, deaths due to cancer, cardiovascular disease, diabetes, and HIV/AIDS, and; increase immunization rates.

**SOPHE is requesting a FY 2014 funding level of \$1 billion for the Prevention and Public Health Fund** to sustain essential core public health infrastructure, the workforce, and our capacity to improve health in our communities. The Prevention Fund helps states tackle the leading causes of death and root causes of costly, preventable chronic disease; detect and respond rapidly to health security threats; and prevent accidents and injuries. With this investment, the Fund helps states and the nation as a whole focus on fighting disease and illness *before* they happen. The evidence is overwhelming: investing in prevention saves lives and money. A July 2011 study published in the journal *Health Affairs* found that increased spending by local public health departments can save lives currently lost to preventable illnesses; a 2011 Urban Institute study concluded that it is in the nation's best interest from both a health and economic standpoint to maintain funding for evidence-based, public health programs that save lives and bring down costs; and finally, a 2011 study in *Health Affairs* showed combination of three strategies – delivering better preventive and chronic care, expanding health insurance coverage, and focusing on protection is more effective at saving lives and money than

implementing any one of these strategies alone. Although the enactment of the Middle Class Tax Relief and Job Creation Act of 2012 will reduce the Prevention and Public Health Fund by more than \$5 billion over the next ten years, SOPHE strongly discourages further reductions in the Fund so that we can continue to strengthen core public health infrastructure, the workforce, and our capacity to improve health in our communities.

**SOPHE is requesting a FY 2014 funding level of \$226 million for the CTG program** to empower communities to transform places where people live, work, learn, and play to promote prevention and improve health by lowering rates of chronic disease. The CTG program supports states and communities tackle the root causes of poor health so Americans can lead healthier, more productive lives. All grantees work to address the following priority areas: 1) tobacco-free living; 2) active living and healthy eating; and 3) quality clinical and other preventive services. In FY2012, CTG awards were provided to areas with fewer than 500,000 people in neighborhoods, school districts, villages, towns, cities, and counties to increase opportunities to prevent chronic diseases and promote health. Awarded communities will implement broad, sustainable strategies to reduce health disparities and expand clinical and community preventive services that will directly impact about 9.2 million Americans.

**As part of the CTG initiative, SOPHE strongly supports CDC's Racial and Ethnic Approaches to Community Health Across the U.S. (REACH U.S.) program**, which addresses health risk behaviors in both children and adults. Chronic diseases account for the largest health gap among populations and increase health disparities among racial and ethnic minority groups. As the U.S. population becomes increasingly diverse, the nation's health status will be heavily influenced by the morbidity of racial and ethnic minority communities. With CTG funding, the National REACH Coalition will address strategies in the areas of tobacco-free living, active living and healthy eating, clinical and other preventive services, social and

emotional wellness, and healthy and safe physical environments—with a primary focus on African-American/Black, Hispanic/Latino, Asian, Native Hawaiian/Pacific Islander, and American Indian/Alaskan Native populations.

**SOPHE is requesting a FY 2014 funding level of \$18.6 million to CDC's Division of Population Health's School Health Branch (SHB).** The increase in funding will allow SHB to create a coordinated, national response to school health and chronic disease, maximizing program effectiveness, and accelerating health improvements. More importantly, it will allow CDC to fund coordinated school health programs in all 50 states. Currently only 23 state and tribal entities receive funding for coordinated school health. Coordinated school health programs use a holistic approach by addressing eight key components: health education, physical education, school meals, health services, healthy school environments, staff health promotion, and family/community involvement. Almost 80 percent of young people do not eat the recommended five servings of fruits and vegetables each day. Daily participation in high school physical education classes dropped from 42 percent in 1991 to 32 percent in 2001. Health and fitness are linked to improved academic achievement and grades, cognitive ability, and behavior as well as reduced truancy.

CDC's Coordinated School Health Programs have been shown to be cost-effective in improving children's health, their behavior, and their academic success. This funding builds bridges between state education and public health departments to coordinate health education, nutritious meals, physical education, mental health counseling, health services, healthy school environments, health promotion of faculty, and parent and community involvement.

Thank you for this opportunity to present our views to the Subcommittee. We look forward to working with you to prevent chronic illness, improve the quality of lives, and save billions of dollars in health care spending.

Testimony of Research!America  
Concerning fiscal year 2014 Appropriations for the NIH, CDC, and AHRQ  
Submitted for the Record, March 15, 2013

Research!America, the nation's largest public education and advocacy alliance committed to advancing U.S. medical innovation, appreciates your stewardship over such a critical subset of our nation's discretionary funding priorities. As the Subcommittee begins the process of prioritizing fiscal year 2014 funding, we ask you to consider the following thoughts on funding for the National Institutes of Health (NIH), Centers for Disease Control and Prevention (CDC), and the Agency for Healthcare Research and Quality (AHRQ).

The funding, or lack of it, allocated to these agencies will bear on the longevity, independence, and basic health and safety of this and future generations. Since the biosciences sector is a major force in our economy, funding decisions around these agencies will also affect business development, jobs and export capability, today and tomorrow.

**NIH as a driver of innovation and affordable health care**

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 allowed us to convert HIV/AIDS from a death sentence to a treatable chronic disease; has reduced the costly toll of premature heart disease death and disability and made childhood cancers treatable diagnoses; the secrets of diabetes, Alzheimer's, Parkinson's, and host of cancers and many other diseases can and will be unlocked

by science – the question is not if but when we will dedicate sufficient brainpower and infrastructure resources to the task.

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 trillions of dollars over the next 20 years. Ultimately, we must prevent and cure disease in order to tackle the costs associated with it. One of the best tools we have for addressing the cost challenge lies in funding health economics research. Such research has provided insight into improving our health care system and understanding how socioeconomic trends affect the health of Americans. For instance, we know that preventing as few as five percent of new cases of chronic conditions, including obesity and related complications, would reduce Medicare and Medicaid spending by nearly \$5.5 billion a year by 2030.<sup>1</sup> While health economics research can produce results that should be vetoed when placed in the context of other health care priorities, it is fundamental to identifying and verifying potential options for bending the health care cost curve.

One of the reasons the NIH has been successful in its mission to improve health is due to the autonomy that the agency has had in setting scientific priorities. Congress should continue to provide oversight and scrutiny of the agency to ensure that tax dollars are being used most effectively. However, it is crucial that we resist the urge to micromanage the agency. According to a national poll conducted August 2012, 48% of Americans believe that scientists should direct our national investments in research while only 9% of respondents said that elected officials should. Micromanaging the research process could have disastrous outcomes for science that will ultimately slow progress and hamstring the NIH's ability to invest in the most promising science.

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<sup>1</sup> Robert Wood Johnson Foundation

**The CDC as a proactive protective measure**

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, 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 keeping health care costs under control**

Research supported by the AHRQ identifies inefficiencies in health care delivery that inflate the cost of public and private insurance. AHRQ-supported research also improves the quality of care to help reduce the length and intensity of disability and disease, and helps patients and physicians make informed treatment decisions, improving outcomes and reducing 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 roll-out 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.<sup>2</sup> Given the enormity of the challenge of inefficiency in health care delivery, AHRQ is severely under-powered.

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<sup>2</sup> Pronovost P, Needham D, Berenholtz S, et al. An intervention to decrease catheter-related bloodstream infections in the ICU. *New England Journal of Medicine* 2006;355(26):2725-32

**Investments that Americans believe in and that keep America on track**

Research!America appreciates the difficult task facing Members of Congress as it seeks to simultaneously confront the budget deficit, strengthen the U.S., and promote the wellbeing of Americans. We firmly believe that investing in NIH, CDC, and AHRQ is a means of advancing all three of these fundamental goals.

Americans not only value medical research that leads directly to advances in health care, they appreciate the importance of basic research that lays the groundwork for these discoveries, as well as health research, which focuses on such goals as improving health care delivery and identifying effective prevention strategies.

We know from our recent poll that not only do a majority (57%) of likely voters have negative reactions to decreased medical research funding, but a wide majority (85%) are concerned about the effects of stagnant funding. Nearly half (48%) of the respondents indicated that government funding of medical research isn't enough. Americans take medical research very personally as 66% believe it has improved the quality of their lives in the past decade. More than half (54%) identify research as important for controlling the rising cost of health care.

**Research to maintain global competitiveness**

Our nation's hold on global leadership in the R&D arena is precarious, and Americans know it. The U.S.'s leadership position *will* evaporate if policymakers shortchange government investment in the basic research and development that fuels private sector innovation. As it stands, China, Japan and India are investing more than 10% of their GDP on R&D, while the U.S. invests less than 3%. At this pace, China will begin to outspend the U.S. within the next five to ten years. Other nations are ramping up research and innovation – taking a page from our playbook – even as we are facing cuts. We must stay globally competitive.

Finally, cuts to funding for biomedical and health research jeopardize the product of years of investment in our nation's research capabilities. Those investments have produced the most sophisticated and productive medical research enterprise in the world. If funding declines, so will opportunities for young scientists. So will the capacity for our nation's researchers to break new ground. So will the pipeline that fuels private sector innovation and jobs. Federal investments in research support hundreds of thousands of high-paying jobs in all 50 states and the District of Columbia (over 432,000 in FY2011).<sup>3</sup> We are particularly concerned because annual, across-the board cuts to medical research are a reversal of our nation's long-standing support for medical discovery. For these reasons, we urge you to champion funding for medical research in FY 2014 in beyond.

**Investing in medical research is a “utility tool” that does all of this, and more**

There are few federal investments that confer as many benefits as research to improve health -- new cures, new businesses, new jobs, new answers to ballooning health care costs, and new fuel to drive U.S. leadership in a global economy shaped by the ability of countries to continuously innovate.

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 wellbeing of Americans. We firmly believe that investing in NIH, CDC, and AHRQ is a means of advancing all three of these fundamental goals. Thank you, Mr. Chairman and Members of the Subcommittee. We know that your task is extraordinarily difficult, and that our nation is fortunate to have two such pragmatic, committed, and gifted leaders at the helm.

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<sup>3</sup> United for Medical Research (2012). *NIH's role in sustaining the U.S. economy: A 2011 update*.

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OFFICIAL STATEMENT

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**American Physical Therapy Association: Congressional Statement**  
Committee on Appropriations Subcommittee on Labor, Health and Human Services, Education  
and Related Agencies

**Friday, March 15, 2013**

**Statement of**

President, Paul Rockar, Jr, PT, DPT, MS  
American Physical Therapy Association (APTA)

The American Physical Therapy Association represents more than 84,000 physical therapists, physical therapist assistants and students of physical therapy. Physical therapist clinicians and researchers are deeply invested in the enhancement of research that strengthens the scientific basis of our profession and ultimately improves the lives of the more than 750,000 people whom we serve every day.

Given the current uncertainty surrounding FY 2013 appropriations and the President's FY 2014 budget request, we expect this testimony to be only the beginning of an ongoing conversation between the Subcommittee and stakeholders on the FY 2014 funding needs of the National Institutes of Health (NIH). At this time, the APTA recommends \$32 billion in FY14 funding level for NIH and encourages the subcommittee to stop the continued cuts to research funding that threaten to slow medical progress and inhibit invaluable scientific opportunities that are necessary to improving our nation's health. In addition, the APTA requests Congressional support for the following initiatives to continue investment in key programs involved in biomedical and rehabilitation research:

Funding requests for U.S. Department of Health and Human Services (HHS), National Institutes of Health:

- \$32 billion in FY2014 funding for the National Institutes of Health
- \$1.37 billion in FY2014 for the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), the housing Institute for the National Center for Medical Rehabilitation Research
- \$1.64 billion in FY2014 for the National Institute of Neurological Disorders and Stroke (NINDS)

- \$539 million in FY2014 for arthritis and musculoskeletal research within the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)

Toward this end, the American Physical Therapy Association also supports recent findings by the Blue Ribbon Panel on Medical Rehabilitation Research at the NIH. APTA supports the spirit of the report and its finding that rehabilitation research needs greater investment, coordination, and strategy to meet the growing need for rehabilitation services, such as physical therapy, and the value of these services to advance the health of our citizens. APTA believes that rehabilitation research significantly advances the mission of the NIH to seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce the burdens of illness and disability. Disability impacts 15% of society globally and 13%-14% of citizens in the United States. Unfortunately, the funding for rehabilitation research only accounts for 1%-2% of the NIH's budget. Aligning our resources in research with the potential to improve the quality of life and participation of individuals with disabilities is a priority that reflects APTA's core principles. Further, we believe enhanced support for of rehabilitation research is critical to meeting the NIH's mission and impacting society in a positive manner. APTA supports the findings of the Blue Ribbon Panel, specifically the following recommendations that call for the:

- Development and implementation of a NIH Rehabilitation Research plan that is periodically updated.
- Elevation of the role of the National Center for Rehabilitation Research within the NIH's structure.
- Elimination of "medical" from the name of the Center to better reflect the inclusive and multidisciplinary nature of rehabilitation.

- Adoption of a rehabilitation research definition of “the study of mechanisms and interventions that prevent, improve, restore, or replace lost, underdeveloped, or deteriorating function, where “function” is defined at the level of impairment, activity, and participation according to the World Health Organization (WHO) International Classification of Function (ICF) model.
- Increased participation of individuals with disabilities and public advocates in development of a research plan for rehabilitation research at NIH.

We strongly urge the subcommittee to support these findings and encourage NICHD, the umbrella agency that houses the NCMRR to adopt the Blue Ribbon Panel recommendations. If proper funding is aligned with research, we believe NCMRR can support research efforts to 1) evaluate the efficacy and establish optimal schedules and settings of movement-based rehabilitation interventions, such as therapeutic exercise, to improve physical function in individuals with musculoskeletal conditions including arthritis, back pain, hip fracture, and major joint replacements; and 2) garner further knowledge of the underlying mechanisms of repair, regeneration, and recovery of these interventions.

Adequate funding and consideration of the Blue Ribbon Panel’s findings will be helpful in addressing some to the most pressing issues confronting rehabilitation research today. One of those issues is the development of secondary disability, particularly among individuals with impaired mobility whether it is short-term or chronic. Secondary disability poses substantial costs to the health care system and diminishes the quality of life of all affected persons. According to Healthy People 2010, a report on disability and secondary conditions led by the

Centers for Disease Control (CDC), and the National Institutes of Disability Research and Rehabilitation (NIDRR), the direct medical and indirect annual costs associated with disability are more than \$300 billion, or 4 percent of the gross domestic product. This total cost includes \$160 billion in medical care expenditures (1994 dollars) and lost productivity costs approaching \$155 billion. Research is needed to identify the risk factors for secondary disability and effective methods for minimizing or eliminating that risk. Particularly needed are reliable and valid indicators or surveillance strategies to identify rehabilitative needs to assure timely access to services from providers such as physical therapists.

In general, the technology for identifying and meeting an individual's rehabilitative needs across the life-span requires sustained funding with special emphasis on interdisciplinary collaboration. Emerging opportunities to foster collaboration between bioengineers and therapists should be bolstered through specific funding, both at the project level and the training level.

A substantial advance in disability-related health services research should determine the optimal level of function for individuals with disability as well as alternative models of service delivery that ensure optimal functioning in the community. Currently, we are very successful in improving function and quality of life when individuals are in the medical "pipeline" of acute admission or exacerbation through to rehabilitation and discharge to home. Research has not adequately addressed how individuals can best re-access services without another complete trip through the "pipeline" to access the array of services that might be needed at any one point in time. This is particularly crucial for individuals, especially older adults with chronic disabilities for whom the medical event which initiated the trajectory of disability is no longer relevant.

In general, the NIH plays a significant and well-documented role in the U.S. economy by advancing the frontiers of medical research while laying the foundation for new products, services and technologies. These discoveries help maintain America's leading role in an increasingly competitive global health services sector. Unfortunately, the current sequestration will have a devastating impact on our nation's medical research enterprise and on U.S. economic growth and job creation. A recent report by United for Medical Research illustrates the impact of a 5.1 percent sequester on NIH extramural spending on our nation's economy, jobs and economic output, in all 50 states. The report also found that at current funding levels, NIH supports roughly 402,000 jobs and \$57.8 billion in economic output. Subsequently, the total number of NIH awards would drop by 1,849 and total employment supported by NIH awards would fall by 33,704. A 5.1 percent sequester is estimated to cut the total number of jobs supported by NIH extramural spending by more than 20,500 and reduce new economic activity by \$3 billion.

For these reasons, we strongly support continued funding programs that support rehabilitation research. Much more research is needed to understand how the emergence of exercise and physical activity can play a key role in prevention methods for the general public, and how these concepts might enhance function and improve quality of life. Physical therapists are key resources for designing research strategies and implementing evidence-based recommendations to bring prevention and risk reduction/disease management strategies into the community beyond the traditional, and generally institutional, medical model of service delivery.

**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 15, 2013

This statement includes the Fiscal Year 2014 (FY 2014) 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. TCUs, funded under Title III-A Sec. 316, which are truly developing institutions, are providing quality higher education opportunities to some of the most rural, 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 global, competitive workforce. Yet, in FY 2011 this critical program was cut by over 11 percent and by another four percent in FY 2012. *The TCUs urge the Subcommittee to appropriate \$30 million in FY 2014 for HEA Title III-A section 316.*

- **TRIO:** Retention and support services are vital to achieving the national goal of having the highest percentage of college graduates globally 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 higher education for many low-income and first-generation students and students with disabilities. Therefore, in addition to maintaining the maximum Pell Grant award level, it is critical that Congress also sustains student assistance programs such as Student Support Services and Upward Bound so that low-income and minority students have the support necessary to allow them to remain enrolled in and ultimately complete their postsecondary courses of study.

**Pell Grants:** The importance of Pell Grants to TCU students cannot be overstated. A majority 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, last summer the Department of Education changed its regulations limiting Pell eligibility from 18 to 12 full-time semesters, without consideration of those already in the process of attaining a postsecondary degree. This change in policy will impede many 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.

Recent placement tests administered at TCUs to first-time entering students indicated that 64 percent required remedial math, 78 percent needed remedial writing, and 60 percent required remedial reading. 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 is intending to produce graduates with postsecondary degrees by 2020, this 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 pursue it. The goal of a well-trained technical 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 funding, TCUs must find a way 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. There is an extensive need for adult basic educational programs, and TCUs must have adequate and stable funding to provide these essential activities. *TCUs request that the Subcommittee direct that \$8 million 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.*

#### **JUSTIFICATIONS FOR FY 2014 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 final FY 2011 Continuing Resolution eliminated all of the Department of Housing and Urban Development's Minority Serving Institutions (MSIs) community-based programs, including a critical 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 or none of these facilities existed. Important STEM programs, operated 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. 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

*AIHEC/Tribal College and Universities FY 2014 Labor-HHS Appropriations Statement*

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, and NSF 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 ask the Members of the Subcommittee for their continued investment in the nation's TCUs and full consideration of our FY 2014 appropriations needs and recommendations.

***Testimony Submitted for the Record to the Subcommittee on  
Labor, Health and Human Services, Education and Related Agencies  
on FY 2014 Appropriations for HIV/AIDS Programs  
Submitted by the HIV Medicine Association  
Michael Horberg, MD, FIDSA  
Chair, HIV Medicine Association  
March 13, 2013***

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 throughout the U.S., lead HIV prevention programs and conduct research to develop effective HIV prevention and treatment options. We work in communities across the country and around the globe as medical providers and researchers dedicated to the field of HIV medicine.

We recognize the difficult fiscal environment Congress is facing. However, as you make tough spending decisions for FY2014, we strongly urge you to maintain adequate funding for critical HIV/AIDS treatment, prevention and research programs. Our past investment in HIV-related research has supported critical discoveries that now allow leaders worldwide to envision a world without AIDS.

Despite our remarkable progress in HIV prevention, diagnosis and treatment, HIV/AIDS remains a serious and significant epidemic in the United States with a record 1.2 million people living with HIV and an estimated 50,000 new infections occurring annually. HIV disease disproportionately impacts racial and ethnic minority communities and low income people who depend on public services for their life-saving health care and treatment. Early and reliable access to HIV care and treatment help patients with HIV live healthy and productive lives and is cost effective. In addition, having persons living with HIV virologically suppressed on antiretroviral therapy decreases transmission of HIV and thus is critical in curbing the epidemic. The comprehensive, expert HIV care model that is supported by the Ryan White Program has been highly successful at achieving positive clinical outcomes with a complex patient population. In fact, Ryan White funded clinics have become models for "medical homes". Once in care, patients who attend at least one Ryan White medical visit do well— with 70 percent of those on antiretroviral treatment having undetectable levels of the virus in their blood. This is much higher than the estimate from the CDC that just 25 percent of people living with HIV in the U.S. are virally suppressed. ***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.**

In order to dramatically change the trajectory of the HIV epidemic in the U.S. and around the world, we strongly urge you to sustain and grow funding for the Centers for Disease Control and Prevention (CDC)'s HIV and STD prevention programs and the Ryan White Program at the Health Resources and Services Administration, along with continuing to invest in the medical research supported by the National Institutes of Health. Failure to maintain adequate funding for these critical priorities will set us back in the fight against HIV infection and harm the nation's health and fiscal well-being. 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 strengthen our investment in combatting HIV disease and meet the need in communities across the country.

**Health Care Reform:** We strongly support at a minimum the President's prospective FY2014 request level for health care reform discretionary funding under the Patient Protection and Affordable Care Act (ACA). Of particular importance is funding to support health care workforce education and training programs under Titles VII and VIII of the Public Health Service Act (PHSA); health care quality improvement programs, and Medicare and Medicaid demonstration programs.

If we are to succeed in improving the quality and efficiency of our health care delivery system while addressing health care costs, it is essential to fully fund the Centers for Medicare and Medicaid Innovation (CMMI). In particular, we would hope to see CMMI evaluate the health outcomes and cost effectiveness of managing the care of people with HIV through "patient centered medical homes." HIV disease is included among the qualifying chronic disease conditions under the new state Medicaid Health Home option that allows Medicaid enrollees with at least two chronic conditions to designate a provider as a health home. Since a majority of people with HIV rely on Medicaid for their health care coverage, it is vital that this model of care is pilot-tested and supported by Medicaid programs.

**HIV/AIDS Bureau of the Health Resources and Services Administration:** We strongly urge you to increase funding for the Ryan White Program by \$276 million in fiscal year 2014 with at least an increase of \$21.5 million over the FY2013 continuing resolution level for Part C. Ryan White Part C funds comprehensive HIV care and treatment -- services that are directly responsible for the dramatic

decreases in AIDS-related mortality and morbidity over the last decade. On average it costs \$3,501 per person per year to provide the comprehensive outpatient care available at Part-C funded programs (excluding medications), including lab work, STD/TB/Hepatitis screening, ob/gyn care, dental care, mental health and substance abuse treatment, and case management. Part C funding covers a small percentage of the total cost of providing comprehensive care with some programs receiving \$450 or lower per patient per year to cover care. The HIV medical clinics funded through Part C have been in dire need of increased funding for years, but efforts to bring more people with HIV into care through routine HIV screening along with ongoing economic pressures are creating a crisis in communities across the country. An increase in funding is critical to prevent additional staffing and service cuts and ensure the public health of our communities. **At a bare minimum, we strongly urge you to support an increase of \$20 million over fiscal year 2013 appropriated funding for Ryan White Part C.**

**Center for Disease Control and Prevention's (CDC) National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP):** HIVMA strongly urges total FY2014 funding of **\$1.424 billion for the CDC's NCHHSTP**, an increase of \$314 million over the FY2013 level, **including increases of: \$180 million for HIV prevention and surveillance, \$5.3 million for viral hepatitis and \$102.7 million for Tuberculosis prevention.**

Every nine and a half minutes a new HIV infection happens in the U.S. with more than 60 percent of new cases occurring among African Americans and Hispanic/Latinos. The CDC estimates that the 50,000 new HIV infections each year in the U.S. may result in \$56 billion in medical care and lost productivity costs. Despite the known benefit of effective treatment, nearly 20 percent of people living with HIV in the U.S. are still not aware of their status and as many as 36 percent of people newly diagnosed with HIV progress to AIDS within one year of diagnosis. A sustained commitment to HIV prevention funding is critical to enhance HIV/AIDS surveillance and expand HIV testing and linkage to care, in order to lower HIV incidence and prevalence in the U.S. Particularly in light of steep state budget cuts, a failure to invest now in HIV prevention will be costly. **At a bare minimum we strongly urge the Committee to at least support an increase of \$180 million for HIV prevention and an increase of \$5.3 million for viral hepatitis at the CDC. We also support a funding level of at least \$363 million for CDC's global health programs, which includes resources for the agency's essential role in implementing PEPFAR programs in developing nations.**

**Agency for Health Care Quality and Research (AHRQ): HIVMA urges the Committee to provide \$2 million for the HIV Research Network (HIVRN).** The HIVRN is a consortium of 19 HIV primary care sites co-funded by AHRQ and HRSA to evaluate health care utilization and clinical outcomes in HIV infected children, adolescents and adults in the US. The Network analyzes and disseminates information on the delivery and outcomes of health care services to people with HIV infection. These data help to improve delivery and outcomes of HIV care in the U.S. and to identify and address disparities in HIV care that exist by race, gender, and HIV risk factor. The HIVRN is a valuable and highly utilized source of information on the cost and cost-effectiveness of HIV care in the U.S. at a time when such data is particularly needed to inform health systems reform and the development and implementation of a National HIV/AIDS Strategy.

**National Institutes of Health (NIH) – Office of AIDS Research (OAR): HIVMA strongly supports an FY 2014 funding level of \$36 billion for the NIH, including \$3.6 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.**

Our past investment in a comprehensive portfolio was responsible for the dramatic gains that we made in our HIV knowledge base, gains that resulted in reductions in mortality from AIDS of nearly 80 percent in the U.S. and in other countries where treatment is available. Gains that also helped us to reduce the mother to child HIV transmission rate from 25 percent to 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 an effective National HIV/AIDS Strategy. In every state across the country, the NIH supports research at hospitals, universities and medical schools, and community based service organizations. This includes the creation of jobs that will be essential to future discovery. Sustained increases in funding are also essential to train the next generation of scientists and prepare them to make tomorrow's HIV discoveries.

The benefits of HIV research are far reaching. Researchers have applied HIV research methods and findings to studying and treating other serious conditions, such as cancer, and hepatitis B and C virus. Congress should ensure the nation does not delay vital HIV/AIDS research progress. We must increase

HIV/AIDS research funding to sustain medical research capacity and maintain our worldwide leadership in HIV/AIDS research leadership and innovation.

**Policy Riders – Remove the Harmful Ban on Federal Funding for Syringe Exchange Programs:**

HIVMA strongly urges re-instatement of language 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. It is well proven that syringe exchange programs are a cost-effective means to lower rates of HIV/AIDS and viral hepatitis, reduce the use of illegal drugs and help connect people to medical treatment, including substance abuse treatment. 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 we have lost ground in recent years, as funding priorities have shifted away from public health and research programs. We appreciate the many difficult decisions that Congress faces this year, but urge you to recognize the importance of investing in HIV prevention, treatment and research now to avoid the much higher cost that individuals, communities and broader society will incur if we fail to support these programs. We must seize the opportunity to limit the toll of this deadly infectious disease on our planet, 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.

**RAILROAD RETIREMENT BOARD  
FISCAL YEAR 2014 BUDGET REQUEST**

**Statement for the Record, April 15, 2013**

**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 2014 budget request of \$111,739,000 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 2012, the RRB paid \$11.4 billion, net of recoveries, in retirement/survivor benefits to about 573,000 beneficiaries. We also paid \$76 million in net unemployment/sickness insurance benefits to about 26,000 claimants. Temporary extended unemployment benefits paid were \$7.2 million. In addition, the RRB paid benefits on behalf of the Social Security Administration amounting to \$1.4 billion to about 114,000 beneficiaries.

### **PROPOSED FUNDING FOR AGENCY ADMINISTRATION**

The President's proposed budget would provide \$111,739,000 for agency operations, which would enable us to maintain a staffing level of 860 full-time equivalent staff years (FTEs) in 2014. The proposed budget would also provide \$2,860,500 for information technology (IT) investments. This includes \$2,100,000 for the final phase of our system processing for excess earnings data (SPEED) application. The remaining \$760,500 would be used for other technology investments in network operations, and e-Government. In addition, the proposed budget would provide \$600,000 for a Voice over the Internet Protocol system that provides a significant return on investment to our communications infrastructure in the areas of day-to-day operations and cost containment.

### **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 65 percent of our employees have 20 or more years of service, and over 36 percent of our current workforce will be eligible for retirement by fiscal year 2014. To help prepare for the expected staff turnover in the near future, we are placing increased emphasis on modernization strategies to convert manual workloads to automated and strategic management of human capital. Our human capital plans provide for

employee support and knowledge transfer, which will enable the RRB to continue achieving its mission. In addition, with the agency's formal human capital plan, succession plan and various action plans in place, we are ensuring that succession management supports a systematic approach to ensuring a continuous supply of the best talent through helping individuals develop to their full potential.

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 hire attorneys through competitive civil service.

#### **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 2014, funding is included for contractor support to complete the full design of the System Processing Excess Earnings Data (SPEED) application. The SPEED application, started in 2006, is being built in phases to accommodate complex transactions and system interconnections. Once completed, SPEED will automate time consuming and complex manual processing of annuity adjustments resulting from post retirement work/earnings by employee and spouse annuitants. We expect automation of this

workload to reduce staffing requirements and reduce improper payments through increased timeliness in handling.

#### **OTHER REQUESTED FUNDING**

The President's proposed budget includes \$39 million to fund the continuing phase-out of vested dual benefits, plus a 2 percent contingency reserve, \$780,000, 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 continues to coordinate its activities with the National Railroad Retirement Investment Trust (Trust), which was established by the Railroad Retirement and Survivors' Improvement Act of 2001 (RRSIA) to manage and invest railroad retirement assets. Pursuant to the RRSIA, the RRB has transferred a total of \$21.276 billion to the Trust. All of these transfers were made in fiscal years 2002 through 2004. The Trust has invested the transferred funds, and the results of these investments are reported to the RRB and posted periodically on the RRB's website. The net asset value of Trust-managed assets on September 30, 2012, was approximately \$23.6 billion, an increase of almost \$1.5 billion from the previous year. Through December 2012, the Trust had transferred approximately \$13.9 billion to the Railroad Retirement Board for payment of railroad retirement benefits.

In June 2012, we released the report on the railroad retirement system required by Sections 15 and 22 of the Railroad Retirement Act of 1974, and Section 502 of the Railroad Retirement Solvency Act of 1983. The 25<sup>th</sup> Actuarial Valuation addressed the 75-year period 2011-2085, and included projections of the status of the retirement trust funds under three

employment assumptions. These indicated 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.

**Railroad Unemployment Insurance Account** – The RRB’s latest annual report on the financial status of the railroad unemployment insurance system was issued in June 2012. The report indicated that even as maximum daily benefit rates rise 44 percent (from \$66 to \$95) from 2011 to 2022, experience-based contribution rates are expected to keep the unemployment insurance system solvent, except for small, short-term cash-flow problems in 2015, under the most pessimistic assumption. However, projections show quick repayment of any loans by the end of fiscal year 2016.

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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Thank you for your consideration of our budget request. We will be happy to provide further information in response to any questions you may have.

**RAILROAD RETIREMENT BOARD  
OFFICE OF INSPECTOR GENERAL  
FISCAL YEAR 2014 BUDGET REQUEST**

**SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,  
EDUCATION AND RELATED AGENCIES  
OF THE COMMITTEE ON APPROPRIATIONS  
U.S. HOUSE OF REPRESENTATIVES**

**MARTIN J. DICKMAN, INSPECTOR GENERAL**

**STATEMENT FOR THE RECORD**

**April 15, 2013**

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) 2014 would provide \$8,877,000 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 2014, 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 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 2014, OA will focus on areas affecting program performance; the efficiency and effectiveness of agency operations; and areas of potential fraud, waste, and abuse. OA will continue its emphasis on long-term systemic problems and solutions, and will address major issues that affect the RRB's service to rail beneficiaries and their families. OA has identified four broad areas of potential audit coverage: Financial

Accountability; Railroad Retirement Act & Railroad Unemployment Insurance Act Benefit Program Operations; Railroad Medicare Program Operations; 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 2014, OA will complete the audit of the RRB's FY 2013 financial statements and begin its audit of the agency's FY 2014 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 2012

<u>Civil Judgments</u>	<u>Indictments/Informations</u>	<u>Convictions</u>	<u>Recoveries/Receivables</u>
26	106	85	\$77,405,487 <sup>1/</sup>

OI anticipates an ongoing caseload of about 450 investigations in FY 2014. During FY 2012, OI opened 168 new cases and closed 258. At present, OI has cases open in 48 states, the District of Columbia, and Canada with estimated fraud losses of nearly \$124 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.

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<sup>1/</sup> 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 (23 have pled guilty), and OI agents will likely have to spend a substantial amount of time traveling to New York for continuing investigations and trial preparation in FY 2014.

During FY 2014, 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 2014, the OIG will continue to focus its resources on the review and improvement of RRB operations and will conduct activities to ensure the integrity of the agency's trust funds. This office will continue to work with agency officials to ensure the agency is providing quality service to railroad workers and their families. The OIG will also aggressively pursue all individuals who engage in activities to fraudulently receive RRB funds. The OIG will continue to keep the Subcommittee and other members of Congress informed of any agency operational problems or deficiencies. The OIG sincerely appreciates its cooperative relationship with the agency and the ongoing assistance extended to its staff during the performance of their audits and investigations. Thank you for your consideration.



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TESTIMONY  
BEFORE THE HOUSE APPROPRIATIONS SUB COMMITTEE ON LABOR,  
HEALTH AND HUMAN SERVICES, EDUCATION  
FISCAL YEAR 2014 BUDGET

Statement of:

Marina Drummer,

Administrator

Advocates for Indigenous California Language Survival

To the Sub-committee members:

We are writing to you today in hopes that you will heed the letters you are receiving from across Indian Country and uphold the budget for the ANA with it's specific allocation of twelve million dollars for the Esther Martinez Native language programs

ADVOCATES FOR INDIGENOUS CALIFORNIA LANGUAGE SURVIVAL

221 IDORA AVENUE, VALLEJO, CALIFORNIA 94591

707-644-6575 707-644-3623 FAX

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Our organization is not funded by the ANA Language program, but, as the sole language resource organization in the state, we are witness to the difference ANA support has made to so many California tribal communities. California has the largest number of tribal communities in the country with over one hundred tribes of which less than fifty still have any fluent speakers. Without the recognition and support of the ANA's language program, there is virtually nothing available to assist tribal groups in learning and revitalizing their languages, which are the keys to their culture and their sense of who they are in this world.

We know that you are receiving testimony from many scholars and linguists who are sharing the vast amount of research and statistical evidence indicating the importance of language revitalization within Native communities, but we can only speak to the remarkable change we witness in our program participants and the renaissance we see within the many Native communities that we work in. It has taken over a decade for the fruits of ANA funding and the work of organizations like ours across the country to be visible. We are deeply distressed to consider the possibility that the government would once again withdraw support after so much progress has been made.

When we first began the Advocates in 1992, there was slim hope that participants could do more than learn some songs and ceremonial prayers as

so much of the language had disappeared. Now, a little over twenty years later, we are witness to amazing breakthroughs in community after community, where language is being spoken again and children are learning their heritage languages. This is nothing short of a miracle considering the obstacles that exist in this English-only country.

What we have witnessed is Native individuals who have had just a hope and a dream of regaining their cultural community, who are empowered by the work they are doing and the skills they are learning and the support of other like minded and goaled individuals. We beg the sub-committee to think long and hard about cutting off funds to the first peoples of this country who have so long been disenfranchised and marginalized.

The Advocates for Indigenous California Language Survival was founded in 1992 by a group of Native language activists and Dr. Leanne Hinton, linguist at U.C. Berkeley. Over the past twenty years, the Advocates have provided training in Total Physical Immersion to California Natives and supported Master Apprentice teams, coupling a fluent speaker and an apprentice for three years of intensive language work, put on numerous conferences and workshops and worked extensively with tribal communities throughout the State. Many of our past apprentices have gone on to start language programs in their own community and quite a few of these programs have been favored

by ANA funding, such as Carol Lewis of the Yurok tribe, Julie Turner working with the Kawaiisu and many more that we can identify from the Karuk.

There is an ever-increasing demand for the services we provide through the Advocates that set the stage for the funding that ANA delivers to Native communities. Without both the grassroots level of the Advocates and the more substantial and supportive ANA language funding, California's many Native tribes will have little chance of continuing their language and cultural work unless they happen to be connected to a thriving casino tribe. Once again, we beseech the committee to recognize the amazing transformations that are occurring in tribal communities and to continue to support the core of this transformation through re-funding the ANA Language Act.

Sincerely,

A handwritten signature in cursive script that reads "Marina Drummer". The signature is written in black ink and is positioned below the word "Sincerely,".

Marina Drummer

Administrator

**Sealaska Heritage Institute**

**Rosita Worl, PhD**

**Testimony**

House Committee on Appropriations

Subcommittee on Labor, Health and Human Services,

Education, and Related Agencies

March 13, 2013

Sealaska Heritage Institute strongly supports the appropriations of \$12,000,000 in the Administration for Native Americans and the Esther B. Martinez Language Revitalization Act.

**Sealaska Heritage Institute**

Sealaska Heritage Institute was founded in 1980 at the request of Tribal Elders. The Elders in our region approached Sealaska Corporation, the regional corporation created under the Alaska Native Claims Settlement Act of 1971. They told the Board of Directors that it was their responsibility to ensure that our traditional cultures survived. In response to this directive, Sealaska Corporation established the Sealaska Heritage Institute to assume its educational and cultural responsibilities to our tribal shareholder members and later created an educational endowment to provide annual scholarships for our youth attending college.

The Mission of Sealaska Heritage Institute is to preserve and enhance the cultures of the Tlingit, Haida and Tsimshian. Key to our mission is the integration of our cultural values, language and history into our educational system. The primary foci of SHI have been in curriculum and materials development, teacher training and youth leadership development. We are also deeply involved in Native language revitalization. Ongoing evaluations of SHI language and culture programs indicate that the academic standards of Native students improve when language and culture are integrated into the schools.

SHI is governed by a Native Board of Trustees representing communities across Southeast Alaska, and guided by a Council of Traditional Scholars, a panel of clan leaders and Native Elders who advise SHI on its programs. SHI is headquartered in Juneau and majorly relies on grants to fund its programs.

### **Need**

- The need for federal support for language and education programs in our region is great. Southeast Alaska has 27 communities separated from each other by water and mountain ranges. Travel to each is by small airplanes or boat.
- The Tlingit, Haida and Tsimshian languages are severely endangered languages. With each obituary, we mourn the loss of an elder and another fluent speaker.
- There are about 120 fluent Tlingit speakers, three speakers of Alaskan Haida and ten fluent Tsimshian speakers.

### **The need for language funding is critical.**

- Through ANA, we operate programs which document the Native languages, teach the language to teachers and students and develop curriculum materials.

- ANA has also supported Latseen basketball camps which incorporate Tlingit and Haida languages into week-long basketball camps in the small communities throughout Southeast Alaska.
- Through ANA SEDS (Social Economic Development), SHI has been able to offer a traditional arts certificate to one community and an annual Latseen Youth Leadership Camp. The Latseen academies teach traditional history, arts, traditional food harvesting and preparation, Native languages and academic content with culturally relevant and place-based curriculum.

Native languages contain intellectual wealth accumulated through thousands upon thousands of years. They convey how Native people see and use the land. SHI recently published the most extensive cultural atlas of Southeast Alaska: "*Haa Léelk'w Hás Aani Saax'u, Our Grandparents' Names on the Land*", edited by Thomas Thornton. This atlas contains thousands of indigenous place names of Southeast Alaska. These names, more than anything, remind all of us that this is truly *Haa Aani*, our land. If this is truly our land, then maybe we should all know something about the languages of our land.

As tribal groups across the country struggle to maintain, enhance and revitalize their languages, they apply for limited Federal funding. Two problems with this system is that tribal groups have to compete with each other for equally good, much-needed programs. The second problem is that the funds are all on three-year cycles. Programs need to be sustained longer than three years to show real change.

**Recommendation**

Sealaska Heritage Institute strongly supports the continued appropriations for programs that support and encourage indigenous people of Southeast Alaska to be strong, educated, contributing members of their communities. We encourage the Subcommittee to keep the funding levels for ANA and the Esther B. Martinez Language Revitalization Act at their current levels which are sorely inadequate already. Twelve million dollars in the Esther B. Martinez Act has a four million dollar set-aside for the language immersion schools and the remaining eight million for other language revitalization efforts across the country. Ideally, we would like those funds to be increased significantly. However, we realize in this time of funding decreases, we cannot expect that to happen. Sealaska Heritage Institute strongly encourages the Subcommittee to keep this funding level.

We believe that the collective wisdom of our ancestors and the beauty of culture hold our promise for the future. We firmly believe that Native students who know and accept who they are, even in the context of living in a society that devalues Native-ness or cultural and physical differences, will succeed academically, emotionally and socially. The transmission of our culture and language is the key to our survival and success. Moreover, we believe that one of the greatest richness of this Nation is represented by its cultural and linguistic diversity, and we must ensure that this remains a characteristic of the United States.

Gunalchéesh

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**Testimony on behalf of the American Society of Pediatric Nephrology  
Submitted by Dr. Joseph T. Flynn, President**

I am Dr. Joseph Flynn, President of the American Society of Pediatric Nephrology (ASPEN). I am pleased to submit written testimony on behalf of the ASPEN in support of federal funding for the National Institutes of Health, including the National Institutes for Diabetes, Digestive and Kidney Diseases (NIDDK) and Eunice Kennedy Shriver National Institute for Child Health and Human Development (NICHD). In FY 2014 we urge you to support an appropriation of \$32 billion for the NIH, including at least \$2.03 billion for NIDDK and \$1.37 billion for NICHD.

Founded in 1969, the American Society for Pediatric Nephrology (ASPEN) is a professional society composed of pediatric nephrologists whose goal is to promote optimal care for children with kidney disease and to disseminate advances in the clinical practice and basic science of pediatric nephrology. The ASPEN currently has over 700 members, making it the primary representative of the pediatric nephrology community in North America.

The mission of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) is to support and conduct research to combat diabetes and other endocrine and metabolic diseases, liver and other digestive diseases, nutritional disorders, obesity, and kidney, urologic, and hematologic diseases. The NIDDK's broad mission covers chronic, common and costly diseases that have very tangible monetary consequences for our nation. For example, estimates of chronic kidney disease (CKD) show that more than 23 million Americans are affected, and over 550,000 have irreversible end-stage renal disease (ESRD). ESRD's cost to our bottom line is also felt at the Centers for Medicare and Medicaid Services, as ESRD is covered

by Medicare regardless of a patient's age so includes children and adults. NIDDK-funded investigations intended to prevent this disease would have a significant impact on many Americans.

Without research funded by the NIH and NIDDK, advances in the care and treatment of adults and children afflicted with kidney disease would not have been accomplished. For instance, hereditary diseases such as cystinosis—a metabolic disorder that affects the kidneys, eyes, thyroid, pancreas, and brain—can now be treated so as to prevent or delay its worst effects on children. The NIDDK supports a wide range of medical research through grants to universities and other medical research institutions across the country. The Institute also supports government scientists who conduct basic, translational, and clinical research across a broad spectrum of research topics and serious, chronic diseases and conditions related to the Institute's mission. In addition, the NIDDK supports research training for students and scientists at various stages of their careers and a range of education and outreach programs to bring science-based information to patients and their families, health care professionals, and the public. Developing the next generation of researchers through grant support will solidify future novel therapeutics and improved outcomes for children with kidney disease.

Established in 1963, the NICHD was initially founded to support the world's best minds in investigating human development throughout the entire lifespan, focusing on understanding developmental disabilities, including intellectual and developmental disabilities, and illuminating important events that occur during pregnancy. Since then, the NICHD has achieved an impressive array of scientific advances in its pursuit to enhance lives throughout all stages of human development, from preconception through adulthood, improving the health of children, adults, families, communities, and populations. Recent efforts by the NICHD to improve the

availability and safety of drugs for children will have significant impact on pediatric therapeutics. Research supported and conducted by the NICHD has helped to explain the unique health needs of many, and has brought about novel and effective ways to fulfill them.

An estimated 150,000 children and adolescents currently suffer from kidney disease; about 10,000 of them suffer from ESRD and receive chronic dialysis or have a kidney transplant. Children and adolescents undergoing dialysis or transplants are different from adults, with different underlying diseases, dependence on adult caregivers, and the need to continue growing and developing.. Renal transplantation is the best treatment for children who reach ESRD, as transplant allows better growth and school attendance and a more normal life for affected children and families. The ASPN works to educate the public, Members of Congress and their staffs, and the medical community about these unique needs of pediatric patients with kidney disease. Nonetheless, without adequate funding from the NIH, pediatric nephrologists are unable to focus on this challenging pediatric population.

The ASPN supports improving the quality of life for pediatric kidney patients, especially those with kidney transplants, through the following initiatives:

**Increased research focused on the prevention and early identification of pediatric kidney disease to decrease the growing need for renal transplantation:** The dramatic increase in childhood obesity puts more than 15 percent of America’s children at risk for Type 2 diabetes, hypertension, and chronic kidney disease later in life. The fastest growing segment of patients waiting for a kidney transplant today have ESRD related to complications of diabetes and hypertension, making it ever more difficult to keep up with the demand for kidney transplants. The ASPN advocates for more research to address ways to keep children with Type 2 diabetes

and hypertension from becoming adolescents and young adults with ESRD. We also advocate for additional research to investigate the common causes of CKD and ESRD including progressive glomerular diseases and congenital anomalies of the kidney and urinary tract. Furthermore, we strongly support investigations into common sequelae of CKD and ESRD such as acidosis and kidney stones as well as those that can accelerate the progression from CKD to ESRD such as urinary tract infections, toxins, and acute kidney injury.

**Improved transition of patients from pediatric to adult medical care:** The ASPN collaborates with pediatric and adult nephrology professionals to improve the transition of adolescents to adult care. The ASPN advocates for better access to medical insurance coverage and anti-rejection medications for transitioning patients to help reduce the high incidence of loss of transplant function in adolescents and young adults which leads to dialysis treatment of these individuals and costs a great deal more.

Kidney disease continues to be a major cause of illness and death among the most vulnerable segment of the population—our children – and research being conducted at the NIH will allow us to better understand how to reduce its impact. An estimated 150,000 children and adolescents currently suffer from kidney diseases for which a cure or treatment does not exist; about 10,000 of them suffer from ESRD and are on dialysis or have a kidney transplant. With adequate funding for NIH, scientists will work to find cures or more effective treatments.

We urge you to support the work conducted by NIDDK for research focused on pediatric kidney disease. ASPN is enthusiastic and encouraged by the discoveries made by such research. Because many adult kidney diseases originate prenatally or during childhood, we hope you can support NIDDK efforts to assign a higher priority to research that explores pediatric renal

disease, focusing on the causes, outcomes and consequences of such diseases. Due to the unique challenges of recruiting children into clinical trials, NIDDK should fund research endeavors that include support for infrastructure and the enhancement of collaborative and comparative multicenter pediatric prospective clinical/translational trials that aim to improve patient outcomes.

Additionally, normal child development is essential for promoting a healthy adult society. Diseases that pose a substantial burden in adults, such as hypertension and chronic kidney disease, may have their origins during childhood years or may be patterned in early fetal life. Cognitive development and cardiovascular health in children, which depend upon normal physiology, are essential for children to become healthy, productive adults. Yet the importance of normal kidneys to normal intrauterine and childhood growth, and its impact on the risk of subsequent disease later in life, has not been well studied. We urge you to support collaboration between NICHD and NIDDK to undertake efforts to examine the role of normal kidney development and/or function in neonatal and child health. Specific opportunities to be addressed include: examining kidney function in low-birth weight infants; clarifying how chronic acidosis, untreated hypertension or recurrent urinary tract infections affect child development; determining the impact of childhood onset hypertension on adult cardiovascular health; and identifying genetic factors that may result in kidney injury and progression of hypertension and chronic kidney disease.

Thank you for the opportunity to provide testimony in support of these vital programs. We look forward to continuing to work with you in the future on these important issues.



*Submitted for the Record to the House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies  
March 14, 2013*

William Lang, Vice President of Policy and Advocacy  
Phone: 703-739-2330 Email: [wlang@aacp.org](mailto:wlang@aacp.org)

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The American Association of Colleges of Pharmacy (AACCP) is pleased to submit this statement for the record regarding FY2013 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, AACCP 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) AACCP supports the Friends of HRSA recommendation of \$7.0 billion for HRSA in FY14.** Faculty at schools of pharmacy are integral to the success of many HRSA programs conducting research rural health delivery to reduce healthcare costs through the integration of pharmacist-provided patient care services. Schools of pharmacy are supported by HRSA to operate nine of the 57 **Poison Control Centers** and, this year, Dr. Elizabeth J. Scharman at the West Virginia University received a \$118,000 poison center "stabilization and enhancement grant." AACCP supports the **Bureau of Health Professions** and the **National Center for Health Workforce Analysis**. Through the Pharmacy Workforce Center, AACCP joins HRSA-funded efforts to compile national health workforce statistics to better inform future health professions workforce needs in the United States. **AACCP supports the Health Professions and Nursing Education Coalition (HPNEC) recommendation of \$520 million for Title VII and VIII programs in FY14.** AACCP member institutions are active participants in BHP 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

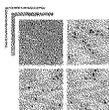
education sites for student pharmacists and other health professions students. Dr. David Elliot, at the West Virginia University School of Pharmacy is a faculty member in the West Virginia Geriatric Education Center. Pharmacy schools are eligible to participate in the **Centers of Excellence** program 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 \$430 million for AHRQ programs in FY14**. Pharmacy faculty are strong partners with the Agency for Healthcare Research and Quality (AHRQ). The University of Washington School of Pharmacy is a partner with the Pacific Northwest Evidence-based Practice Center, supported by AHRQ funding, at the Oregon Health Sciences University. Dr. Christopher Gillette, a faculty member at the University of North Carolina Chapel Hill Eshelman School of Pharmacy, is supported by AHRQ for his work "The Effect of Risk and Side Effect Communication on Asthma Medication Adherence." **Centers for Disease Control and Prevention (CDC)** - AACP supports the **CDC Coalition recommendation of \$7.8 billion for CDC core programs in FY14 and the Friends of NCHS recommendation of \$162 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 established through the AACP Center for the Advancement of Pharmaceutical Education 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. Marie A. Abate, at the West Virginia University School of Pharmacy, is funded by the CDC for her research

into mortality related to concurrent drug and alcohol use. **National Institutes of Health - AACP supports the Adhoc Group for Medical Research recommendation of at least \$32 billion for NIH funding in FY14.**

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 2011, 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. Drs. Rick G. Schnellmann and Kenneth Tew, at the South Carolina College of Pharmacy, are the lead researchers on a \$10.5 million grant from the National Center for Research Resources Centers of Biomedical Research Excellence (COBRE) aimed at increasing the research capacity of institutions. Dr. Peter L. Anderson, at the University of Colorado Skaggs School of Pharmacy, is supported by the NIH for work he is conducting on the use of daily, oral antiretroviral drugs prior to exposure to HIV.

**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 \$5,550 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 \$80 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.



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**Mesothelioma Applied Research Foundation  
Subcommittee on Labor, Health and Human Services, Education and Related  
Agencies**

**Committee on Appropriations  
United States House of Representatives  
In Support of Funding of FY 2014 Funding for the NIH and NCI  
Mary Hesdorffer, NP**

**Executive Director of the Mesothelioma Applied Research Foundation  
Submitted for the Record, March 15, 2013**

Chairman Kingston and Members of the Subcommittee, I am grateful for the opportunity to provide written testimony. My name is Mary Hesdorffer and I am the Executive Director of the Mesothelioma Applied Research Foundation. I am testifying on behalf of the mesothelioma community composed of patients, physicians, caregivers and family members. I am a Nurse Practitioner with over ten years' experience working with mesothelioma patients in the clinical setting. I would like to take this time to stress the importance of increased funding for the National Institutes of Health (NIH), including the National Cancer Institute (NCI), and the Centers for Disease Control and Prevention (CDC), both of which play a critical role in discovering and delivering treatments for mesothelioma.

Mesothelioma is an aggressive cancer known to be caused by exposure to asbestos. Doctors say it is among the most painful and fatal of cancers, as it invades the chest, abdomen and heart, and crushes the lungs and vital organs.

The harsh reality for patients with malignant mesothelioma is a median survival time of 12.3 months; five-year survivals are rare. Left untreated, survival ranges six to nine months, and in the largest trial of chemotherapy median survival is 12.3 months.

For the last 15 years, I have watched my patients succumb to this horrible disease regardless of their faith and willingness to fight. With only one FDA approved treatment available, they face a trial and error approach to treatment, making agonizing decisions each step of the way. Most patients must make the tough decision to go into a clinical trial, knowing they may see no benefit whatsoever. They do this with a powerful hope they can help doctors learn how to treat mesothelioma, possibly live a while longer and prevent others from enduring the same experience. Unfortunately, the looming sequester and its draconian cuts to medical research leave these patients in fear they may not have access to even experimental treatments.

Fortunately, there are brilliant researchers dedicated to mesothelioma. The Food and Drug Administration (FDA) has approved one drug which has some effectiveness, proving that the tumor is not invincible. Two of the most exciting areas in cancer research – gene therapy and biomarker discovery for early detection and treatment– look particularly promising in mesothelioma. The Mesothelioma Applied Research Foundation has made a significant investment, funding a total of \$8.2 million to support research in hopes of giving researchers the first seed grant they need to get started. We need the continued partnership with the federal government to develop the promising findings into effective treatments.

Some other research initiatives that look promising for mesothelioma patients:

- There is currently a clinical trial underway which uses the measles virus to attack mesothelioma cells, is currently enrolling pleural mesothelioma patients regardless of whether they've undergone prior therapy. The goal of the trial is to determine the level of toxicity of the agent and to establish the optimal dose.
- A mutation in the BAP1 gene has been identified as a possible identifier of a familial predisposition to development of malignant mesothelioma, suggesting the **BAP1** pathway may be a valuable therapeutic target.

It is efforts like these that give mesothelioma patients hope. I am grateful for the federal government's investment in mesothelioma research and I want to see it continued and increased. The imminent sequester will have a devastating effect on medical research, as we are now facing a 5.6 percent cut to the National Institutes of Health (NIH) resulting in fewer medical research grants being awarded. In FY2012, the NIH funded 23 grants to mesothelioma research. Theoretically, a 5.6 percent cut would mean 2 less grants would be made to mesothelioma research in 2013. These cuts will stifle medical discoveries that lead to better treatments and ultimately a cure for mesothelioma. **Unless researchers have the funds to continue, patients will run out of treatment options and more will die from this disease.**

The mesothelioma community asks that the Subcommittee recognize the National Institutes of Health (NIH) as a critical national priority by providing at least \$32 billion in funding in the FY 2014 Labor-HHS-Education Appropriations bill. 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.

I look to the Labor, Health and Human Services, Education and Related Agencies Appropriations Subcommittee to provide continued leadership and hope to the people who develop this deadly cancer. You have the power to lead this battle against mesothelioma. Thank you for the opportunity to submit testimony and for funding the National Institutes of Health and the National Cancer Institute at the highest possible level so that patients receiving the deadly diagnosis of mesothelioma may someday see better treatments and a cure.

**About the Mesothelioma Applied Research Foundation:**

The Mesothelioma Applied Research Foundation is the nonprofit collaboration of patients and families, physicians, advocates, and researchers dedicated to eradicating the life-ending and vicious effects of mesothelioma. We believe in a cure for mesothelioma. Given the human toll of suffering the disease causes, the compassion and energy of the mesothelioma community, the moral, legal and economic aspects of asbestos, and the benefits of mesothelioma research to cancer research generally, we believe that the resources to accomplish this cure are available and must be mobilized. We seek to marshal and utilize these resources responsibly, as effectively as possible, with financial transparency and by adhering to health policy guidelines that foster ethical clinical and administrative practices, and ethical decision making to:

- Offer hope and support to patients and families by educating them on the disease, helping them to obtain the most up-to-date information on treatment options and to connect with mesothelioma treatment specialists, and providing them assistance, emotional support and community with others;
- Fund the highest quality and most promising mesothelioma research projects from around the world through rigorous peer-review; and

- Raise awareness of mesothelioma, and advocate that the public and private sectors partner in the effort to cure it by directing the resources needed to stop this global tragedy



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*Tlingit*

**Founder**

**Joanna Hess**

**Honorary Board**

**Oren Lyons**  
*Onondaga*

**Native Language Fund  
Campaign**

**Joel M. Frank, Sr.**  
*Seminole*  
Campaign Committee Chair

**Wes Studi**  
*Cherokee*  
Honorary Chair

**WRITTEN TESTIMONY FOR THE RECORD  
BEFORE THE HOUSE COMMITTEE ON APPROPRIATIONS  
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,  
EDUCATION  
FISCAL YEAR 2014 BUDGET**

**Statement of**

**Inée Y. Slaughter**  
**Executive Director**  
**Indigenous Language Institute (ILI)**  
**Santa Fe, New Mexico**

The Indigenous Language Institute (ILI) strongly recommends the reauthorization of the Esther Martinez Native Language Programs Grant under the Administration for Native Americans (ANA) in the Department of Health and Human Services for the sum of \$12,000,000 as an essential measure to support the health and welfare of American Indian children and communities.

ILI is a non-profit national center founded in 1993 in Santa Fe, New Mexico that provides vital language related services to all Native American communities to help create speakers of the endangered languages while we still have speakers left. ILI Researches, Teaches and Shares best practices in language teaching and learning, and through our training workshops we empower communities with skills and tools to develop effective language programs.

**WRITTEN TESTIMONY FOR THE RECORD BEFORE THE HOUSE COMMITTEE ON  
APPROPRIATIONS - SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION  
FISCAL YEAR 2014 BUDGET  
Statement of Inée Y. Slaughter, Indigenous Language Institute**

The Esther Martinez Native Language Programs Grant under the ANA has been very instrumental in providing the means for Native American communities to start and sustain effective language programs. We have observed over the years, a great increase in numbers of language initiatives, and today we are beginning to witness the lifeblood of our Native American cultures – our languages – run through the veins of cultural identity.

We have merely begun breaking ground and laying the foundation to rebuild our languages. Language reclamation and revitalization is a long-term process, and the reauthorization of the Esther Martinez Native Language Programs Grant will be critical in taking this successful program to maturity.

What does a community secure and confident in one's self-identity look like? It becomes the oasis of rich cultural knowledge that builds self-confident children who know who they are and where they come from. Self-confident children function well in society, have hopes and goals, strengthen their ties to their communities, and build a positive sense of belonging.

What does the United States that honors its indigenous populations look like? It demonstrates to the world our country's commitment to justice, to human rights, and to the principal of unity in diversity.

Most respectfully, the Indigenous Language Institute recommends the reauthorization of the Esther Martinez Native Language Programs Grant for the sum of \$12,000,000 annually.

Angela L. Sharpe, COSSA, (202) 842-3525 (alsharpe@cosssa.org)

**Statement of the Consortium of Social Science Associations on FY 2014 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 15, 2013**

**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) 2014 appropriations for the **National Institutes of Health (NIH), Centers for Disease Control and Prevention (CDC)** and the **Agency for Healthcare Research and Quality (AHRQ)**. *We join the Ad Hoc Group for Medical Research in recommending the highest possible funding level for NIH. We join the CDC Coalition in requesting \$7.8 billion in funding for CDC in FY 2014. Finally, COSSA urges the continuation of AHRQ's appropriation so that it can carry out its important activities.*

COSSA is an advocacy group for the social and behavioral sciences supported by 115 professional associations, scientific societies, universities and research centers. COSSA 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 the NIH, CDC, and AHRQ. Strong, sustained funding 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. 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

*Consortium of Social Science Associations*

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 recently released National Academies' 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 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.

Social and behavioral scientists have made significant strides in shedding light on the basic social and cultural structures and processes that influence health. Social and cultural factors influence health by affecting exposure and vulnerability to disease, risk-taking behaviors, the effectiveness of health promotion efforts, and access to, availability of, and quality of health care. Social and cultural factors also play a role in shaping perceptions of and responses to health problems and the impact of poor health on individuals' lives and well-being. In addition, such

factors contribute to understanding societal and population processes such as current and changing rates of morbidity, survival, and mortality.

Despite the dramatic contributions that behavioral and social science research has made to date, much more remains to be understood in the role behavioral and social factors play in disease and how to use that knowledge to improve the nation's health. Breakthroughs in the behavioral and social sciences over the next 20 years will be critical to addressing our most pressing public health challenges and transforming health care.

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 necessary to bring the promise of this knowledge to fruition requires a sustained investment in NIH. COSSA expects this testimony to be only the beginning of an ongoing conversation between the Subcommittee and stakeholders on the FY 2014 funding needs of NIH, given the current uncertainty surrounding FY 2013 appropriations and the President's FY 2014 budget request.

**CDC Behavioral and Social Science Research:** The CDC is the nation's leading health protection agency. Its mission is to keep Americans safe, healthy and secure. The agency's behavioral and social scientists are involved in a range of activities, including designing, analyzing and evaluating behavioral surveillance systems, public health interventions, and health promotion and communication programs using a variety of both quantitative and qualitative methods.

The health of Americans is declining, as recently noted in the recently released 2013 National Academies' report, *U.S. Health in International Perspective: Shorter Lives, Poorer Health*. Accordingly, we as a nation cannot continue to neglect prevention strategies that address the underlying factors that lead to chronic health conditions. Prevention works. When we invest in

prevention, we save lives and money for individuals, families, the health care industry, businesses and the government.

The National Center for Health Statistics (NCHS) is the nation's principal health statistics agency. Housed within CDC, 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. 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. Federal agencies such as the Census Bureau use NCHS data in informing their population estimates and projections, and the USDA uses NCHS data in developing nutrition policies that undergird multibillion-dollar federal food assistance programs. Likewise, state and local governments and public health officials; federal policymakers; and demographers, epidemiologists, health services researchers, and other scientists all use NCHS data. The health data collected by NCHS are an essential part of the nation's statistical and public health infrastructure.

**AHRQ's Health Services Research: COSSA was deeply disappointed with this Subcommittee's recommendation to zero-out AHRQ's funding for FY 2013.** AHRQ-supported research and science also provide consumers and their health care professionals with valuable information allowing them to make the right health care decisions for themselves and their families. AHRQ's research also provides the basis for designing protocols that prevent medical errors and reduce hospital-acquired infections and improve patient confidence, experiences and outcomes in hospitals, clinics, nursing homes and physician offices.

COSSA would be pleased to provide any additional information on these issues.

**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. 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 FY 12 levels of \$30.6 billion for the National Institutes of Health (NIH) and \$1.052 billion for NIDA in your Fiscal 2014 Labor, Health and Human Services, Education and Related Agencies Appropriations bill.

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, such as prescription drug abuse, remain and 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 to 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 FY2014 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.



American Society for Nutrition  
*Excellence in Nutrition Research and Practice*

March 15, 2013

Testimony from Teresa A. Davis, Ph.D.

2012-2013 President, American Society for Nutrition

Professor of Pediatrics

USDA/ARS Children's Nutrition Research Center

Baylor College of Medicine

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:

**The American Society for Nutrition (ASN) respectfully requests \$32 billion for the National Institutes of Health (NIH) and \$162 million for the Centers for Disease Control and Prevention/ National Center for Health Statistics (CDC/ NCHS) in fiscal year (FY) 2014. ASN is dedicated to bringing together the world's top researchers**

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info@nutrition.org | www.nutrition.org



to advance our knowledge and application of nutrition. ASN has nearly 5,000 members working throughout academia, clinical practice, government, and industry, who conduct research to help all Americans live healthier, more productive lives.

### **National Institutes of Health**

The National Institutes of Health (NIH) is the nation's premier sponsor of biomedical research and is the agency responsible for conducting and supporting 86 percent (approximately \$1.4 billion) of federally-funded basic and clinical nutrition research. Nutrition research, which makes up about four percent of the NIH budget, is truly a trans-NIH endeavor, being conducted and funded across multiple Institutes and Centers. Some of the most promising nutrition-related research discoveries have been made possible by NIH support. In order to fulfill the full potential of biomedical research, including nutrition research, **ASN recommends an FY 2014 funding level of \$32 billion for the NIH**, a modest increase over the current funding level of \$30.64 billion.

The modest increase we recommend is necessary to maintain both the existing and future scientific infrastructure. The discovery process—while it produces tremendous value—often takes a lengthy and unpredictable path. Economic stagnation is disruptive to training, careers, long range projects and ultimately to progress. NIH needs sustainable and predictable budget growth to achieve the full promise of medical research and to improve the health of all Americans. It is imperative that we continue our commitment to

biomedical research and continue our nation's dominance in this area by making the NIH a national priority.

Over the past 50 years, NIH and its grantees have played a major role in the growth of knowledge that has transformed our understanding of human health, and how to prevent and treat human disease. Because of the unprecedented number of breakthroughs and discoveries made possible by NIH funding, scientists are helping Americans to live healthier and more productive lives. Many of these discoveries are nutrition-related and have impacted the way clinicians prevent and treat heart disease, cancer, diabetes and other chronic diseases. By 2030, the number of Americans age 65 and older is expected to grow to 72 million, and the incidence of chronic disease will also grow. Sustained support for basic and clinical research is required if we are to successfully confront the health care challenges associated with an older, and potentially sicker, population.

#### **CDC National Center for Health Statistics**

The National Center for Health Statistics (NCHS), housed within the Centers for Disease Control and Prevention, is the nation's principal health statistics agency. The NCHS provides critical data on all aspects of our health care system, and it is responsible for monitoring the nation's health and nutrition status through surveys such as the National Health and Nutrition Examination Survey (NHANES), that serve as a gold standard for data collection around the world. Nutrition and health data, largely 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 conducted by the Department of Health and Human Services in partnership with the U.S. Department of Agriculture/ Agricultural Research Service is a unique and critically important surveillance function in which dietary intake, nutritional status, and health status are evaluated in a rigorous and standardized manner. Nutrition monitoring is an inherently governmental function and findings are essential for multiple government agencies, as well as the public and private sector. Nutrition monitoring is essential to track what Americans are eating, inform nutrition and dietary guidance policy, evaluate the effectiveness and efficiency of nutrition assistance programs, and study nutrition-related disease outcomes. Funds are needed to ensure the continuation of this critical surveillance of the nation's nutritional status and the many benefits it provides.

Through learning both what Americans eat and how their diets directly affect their health, the NCHS is able to monitor the prevalence of obesity and other chronic diseases in the U.S. and track the performance of preventive interventions, as well as assess 'nutrients of concern' such as calcium, which are consumed in inadequate amounts by many subsets of our population. Data such as these are critical to guide policy development in

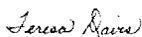
the area of health and nutrition, including food safety, food labeling, food assistance, military rations and dietary guidance. For example, NHANES data are used to determine funding levels for programs such as the Supplemental Nutrition Assistance Program (SNAP) and the Women, Infants, and Children (WIC) clinics, which provide nourishment to low-income women and children.

To continue support for the agency and its important mission, **ASN recommends an FY 2014 funding level of \$162 million for NCHS**. Sustained funding for NCHS can help to ensure uninterrupted collection of vital health and nutrition statistics, and will help to cover the costs needed for technology and information security upgrades that are necessary to replace aging survey infrastructure.

Thank you for the opportunity to submit testimony regarding FY 2014 appropriations for the National Institutes of Health and the CDC/ National Center for Health Statistics.

Please contact John E. Courtney, Ph.D., Executive Officer, at 301.634.7078 or [jcourtney@nutrition.org](mailto:jcourtney@nutrition.org) if ASN may provide further assistance.

Sincerely,



Teresa A. Davis, Ph.D.

2012-2013 President, American Society for Nutrition

**The Infectious Diseases Society of America's (IDSA) Fiscal Year 2014 Funding Statement  
Submitted to the House Appropriations Subcommittee on Labor, Health and Human  
Services, Education and Related Agencies  
March 15, 2013**

The Infectious Diseases Society of America (IDSA) represents more than 10,000 infectious diseases (ID) physicians and scientists devoted to patient care, prevention, public health, education, and research. Investment in ID research and public health efforts can reduce health care costs, save lives, and create jobs. IDSA urges you to provide strong funding for the Department of Health and Human Services' (HHS) National Institutes of Health, Centers for Disease Control and Prevention, Office of the Assistant Secretary for Preparedness and Response, and Biomedical Advanced Research and Development Authority as well as adopt appropriate report language for the Centers for Medicare and Medicaid Services.

**NATIONAL INSTITUTES OF HEALTH (NIH)**

**National Institute of Allergy and Infectious Diseases (NIAID)**

IDSA recommends that the Subcommittee continue to invest strongly in medical research funding at the NIH, and at NIAID, in particular, so that patients may continue to benefit from the live-saving benefits that medical research affords. Given the growing crisis related to antibiotic-resistant infections and the lack of new antibiotics in development (read more at [www.AntibioticsNow.org](http://www.AntibioticsNow.org)), we believe it is particularly imperative that NIAID invest more vigorously in antibacterial resistance research, including related diagnostics research, so that our nation can better respond to these dangerous and expensive pathogens, which threaten patient care, public health and national security. Our funding goal for NIAID's antibacterial resistance and related diagnostics efforts is at least \$500 million annually by the end of FY 2014. As part of this effort, we believe NIAID should invest at least \$100 million/year in the antibiotic-resistance focused clinical trials network that the institute now is establishing and which should

be up and running in 2014. NIAID should be applauded for establishing this new network, but unfortunately, the planned investment of \$10 million/year over the next seven years will not be sufficient to undertake the critical studies needed to address what are quickly becoming untreatable infections.

The Subcommittee also should adopt report language urging NIAID to invest in research on new antiviral drugs and related diagnostics that are effective against emerging drug-resistant influenza variants. The dearth of novel antiviral influenza drugs is of concern, especially as resistance grows.

IDSA also urges the Subcommittee to restore the salary cap for NIH grantees to Executive Level I. The salary cap reduction enacted in FY2012 disproportionately affects physician-investigators and serves as a deterrent to their recruitment into research careers.

#### **CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)**

##### **National Center for Emerging and Zoonotic Infectious Diseases (NCEZID)**

IDSA supports strong funding for NCEZID, which houses CDC's antimicrobial resistance activities. We must be able to track resistance, understand its driving factors and measure the impact of efforts to limit resistance. State and local public health laboratories are key, but they depend largely upon CDC for funding, and currently only about half of them can provide some level of antimicrobial susceptibility testing. NCEZID also needs strong funding to enhance data collection on antimicrobial use and to promote the uptake of antimicrobial stewardship programs to help protect the effectiveness of these precious drugs. IDSA also urges strong funding for (1) the Emerging Infections Program (EIP) to assess the epidemiology of emerging resistant pathogens in infectious diseases of public health importance; and (2) the National Healthcare Safety Network (NHSN), which funds the EpiCenter Program focused on developing, implementing, and evaluating strategies to reduce healthcare acquired infections.

IDSA also encourages the Subcommittee to adopt antimicrobial resistance report language to encourage the following activities to the extent possible given the current budgetary constraints:

- Urging CDC to implement prevention collaboratives with state health departments to prevent the transmission of significant resistant pathogens across health care settings.
- Encouraging CDC to expand academic public health partnerships through the EpiCenters.
- Recommending CDC pilot and test quality measures to help measure antimicrobial use.

**National Center for Immunization and Respiratory Diseases (NCIRD)**

IDSA recommends strong funding for NCIRD, including the Section 317 Immunization Program, to help providers obtain and store vaccines; establish and maintain vaccine registries; provide education about vaccines; and promote vaccination of health care workers. IDSA recommends report language urging CDC to work with state and local governments to ensure immunization recommendations, defined by the Advisory Committee on Immunization Practices (ACIP), are implemented except when medically-contraindicated.

Given that recent outbreaks of pertussis, or whooping cough, are among the largest in the U.S. during the past half century, it is particularly important to ensure that more individuals receive this vaccination.

Also worrisome, influenza vaccination rates among healthcare workers overall remained stagnant in 2012. Funding to address this issue is critical to protect the health of those individuals most needed to respond to influenza outbreaks and pandemics, and to protect patients at risk of infection.

In IDSA's recently updated Pandemic and Seasonal Influenza Principles for United States Action ([www.idsociety.org/influenzapinciples](http://www.idsociety.org/influenzapinciples)), the Society recommends strong funding for influenza preparedness activities, including public health infrastructure and countermeasures

as well as long-term governmental coordination and planning. Lack of sufficient funding could lead to an increased incidence and severity of influenza, hospitalization costs and mortality.

The recent fungal meningitis outbreak has underscored the need for a strong investment to maintain our capacity to detect and respond to emergencies, such as outbreaks and natural disasters like Hurricanes Katrina and Sandy. Funding is needed to provide coordination, guidance and technical assistance to state and local governments; support the Strategic National Stockpile; strengthen and sustain epidemiologic and public health laboratory capacity; and provide clear and effective communications during an emergency.

**The National Center for HIV, Viral Hepatitis, STD and TB Prevention**

IDSA urges a strong investment to implement CDC’s new hepatitis C screening policy, including funding to support education, testing, referral, vaccination and surveillance. Hepatitis B and C affect nearly six million Americans, the vast majority of whom do not know they are infected. These infections lead to chronic liver disease, with a loss of 15,000 lives each year<sup>1</sup>, liver cancer, and increased transplantations for those suffering liver failure.

IDSA recommends strong funding to support federal, state, and local health tuberculosis (TB) detection, treatment, and prevention efforts. Adequate funding must also be directed to the *TB Trials Consortium* that is testing new TB therapeutics—an urgent need as the threat of drug-resistant TB grows.

**ASSISTANT SECRETARY FOR PREPAREDNESS AND RESPONSE (ASPR)**

In addition to strongly investing in ASPR’s critical preparedness and response activities, IDSA urges the subcommittee to adopt report language to encourage the development of clear federal guidelines for conducting research during a public health emergency. Specifically, report language should urge the ASPR to include the Office for Human Research Protections (OHRP)

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<sup>1</sup> “Combating the Silent Epidemic of Viral Hepatitis: Action Plan for the Prevention, Care and Treatment of Viral Hepatitis,” U.S. Department of Health and Human Services (May, 2011).

and other HHS offices and agencies involved in public health emergency research in the ASPR-led discussions concerning a public health emergency research review board. Also, ASPR should issue appropriate provisions and guidances to reduce ambiguity and improve harmonization among various agencies.

**Biomedical Advanced Research and Development Authority (BARDA)**

IDSA supports robust funding for BARDA to facilitate advanced research and development (R&D) of medical countermeasures, including therapeutics, diagnostics, vaccines, and other technologies, as well as new antibiotics to address both intentional attacks and naturally emerging infections. BARDA is a critical source of funding for public-private collaborations for antibiotic R&D.

**Independent Strategic Investment Firm**

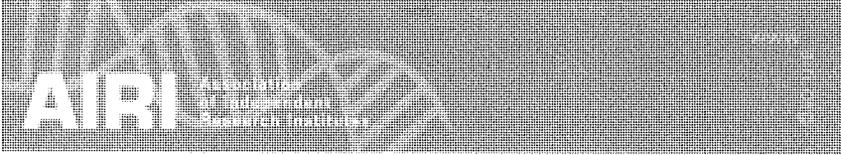
IDSA supports the establishment and funding of the Medical Countermeasure Strategic Investor (MCMSI), proposed by the ASPR in August 2010. The MCMSI would be a non-government, non-profit entity that would partner with small “innovator” companies and private investors to address urgent needs, including novel antimicrobials.

**CENTERS FOR MEDICARE AND MEDICAID SERVICES (CMS)**

IDSA urges the Subcommittee to adopt report language urging CMS to help address the growing problem of antimicrobial resistance by working with healthcare institutions to develop and implement physician-led antimicrobial stewardship programs in all healthcare facilities.

Moreover, we ask for report language that supports the submission by acute care hospitals of summary data on influenza vaccination of health care personnel and the expansion of this requirement to all hospitals and nursing facilities.

Thank you again for the opportunity to submit this statement on behalf of the nation’s infectious diseases physicians and scientists. Forward any questions to [ajezek@idsociety.org](mailto:ajezek@idsociety.org).



**Written Statement for the Record for the  
Subcommittee on Labor, Health and Human Services, Education and Related  
Agencies  
Committee on Appropriations  
United States House of Representatives**

**Fiscal Year 2014 Funding for the  
National Institutes of Health, Department of Health and Human Services  
March 15, 2013**

**Submitted by:**

Larry Keinath  
President, Association of Independent Research Institutes  
The Wistar Institute  
3601 Spruce Street, Philadelphia, PA, 19104  
[keinath@wistar.org](mailto:keinath@wistar.org) 215-898-3700

The Association of Independent Research Institutes (AIRI) respectfully submits this written testimony for the record to the House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies. AIRI appreciates the commitment the Members of this Subcommittee have made to biomedical research through your strong support for the National Institutes of Health (NIH) and **recommends providing NIH with the highest possible funding level in fiscal year (FY) 2014**, despite the difficult fiscal environment. Given the current uncertainty surrounding FY 2013 appropriations and the President's FY 2014 budget request, we expect this testimony to be only the beginning of an ongoing conversation between the Subcommittee and stakeholders about the FY 2014 funding needs of NIH.

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 ARI 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 reduction of federal funds to support research, including the five percent cut in NIH funding under sequestration, harms our nation's ability to advance scientific discoveries that improve human health, bolster the economy, and help keep our nation globally competitive.

Furthermore, the impact of sequestration has been compounded by ongoing funding constraints caused by ten years of flat NIH budgets, which have resulted in a loss of purchasing power and affected the ability of NIH-funded scientists to pursue promising new avenues of research. At the same time that scientists are facing these funding challenges, they are poised like 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.

Not only is NIH research essential to advancing health, it also plays a key economic role in communities nationwide. Approximately 84 percent of NIH funding is spent in communities across the nation, creating jobs at more than 2,500 research institutes, universities, teaching hospitals, and other institutions. NIH research also 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.

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.

**Pursuing New Knowledge** – 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 embraced 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, imaging, and other technologies, AIRI researchers advance therapeutics development and drug discovery.

**Translating Research into Treatments and Therapeutics** – As a network of efficient, flexible

independent research institutes that have been conducting translational research for years, AIRI plays a key role in bringing research from the bench to the bedside. The following examples of AIRI members' translational research successes demonstrate the value NIH funding brings to human health:

*Scientists at the **Fred Hutchinson Cancer Research Center** (Seattle, WA) have pioneered a method to improve the use of umbilical cord blood for blood stem cell transplants, a technique that is bringing transplants and cures to many of the 16,000 leukemia patients each year who are unable to find a matching bone marrow donor. In related work, scientists have also developed a strategy to prevent many cases of infection with the virus known as cytomegalovirus, a leading cause of complications and death in cord blood transplant recipients. Starting with fundamental research on a genetic pathway that blunts the immune response to cancer, scientists at the **Lankenau Institute for Medical Research** pioneered a new type of drug therapy that destroys a key immune barrier and greatly heightens the efficacy of radiotherapy and chemotherapies used to treat most human cancers. On the basis of groundbreaking proof-of-concept studies at Lankenau, similar inhibitor programs have been started by several pharmaceutical companies. The resulting lead compound has been rated by an NCI workshop as one of the most promising immunotherapeutics in the field, now in Phase Ib/II trials.*

**Providing Efficiency and Flexibility** – 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.

**Supporting Local Economies** – AIRI is unique from other biomedical research organizations in that our membership consists of institutions located in regions not traditionally associated with cutting-edge research. 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.

**Fostering the Next Generation Scientific Workforce** – 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. 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 robust funding for NIH in the FY 2014 appropriations bill**. AIRI looks forward to working with Congress to support research that improves the health and quality of life of all Americans.

**Alliance for Aging Research  
Testimony on FY 2014 National Institutes of Health Appropriations**

**Submitted to:  
House Subcommittee on Labor, Health and Human Services,  
Education and Related Agencies**

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**March 15, 2013**

Chairman Kingston, Ranking Member DeLauro, and members of the subcommittee, for more than 25 years the not-for-profit Alliance for Aging Research, [www.agingresearch.org](http://www.agingresearch.org), has advocated for medical research to improve the quality of life and health for all Americans as we grow older. Our efforts have included supporting increased federal funding of aging research by the National Institutes of Health (NIH), through the National Institute on Aging (NIA) and other NIH institutes and centers. The Alliance appreciates the opportunity to submit testimony highlighting the important role that the NIH plays in facilitating aging-related medical research activities and the ever more urgent need for sustained federal investment and focus to advance scientific discoveries to keep individuals healthier longer.

The Alliance for Aging Research supports funding the NIH at \$32 billion in FY 2014 with a minimum of \$1.4 billion in funding for the NIA specifically. This level of support would allow the NIH and the NIA to adequately fund new and existing research projects, accelerating progress toward findings which could prevent, treat, slow the progression or even possibly cure conditions related to aging.

The National Institute on Aging (NIA) at NIH leads the national scientific effort to understand the nature of aging in order to promote the health and well-being of older adults. Congress established the NIA in 1974 to conduct research on aging processes, age-related diseases, and special problems and needs of the aged; train and develop research scientists; provide research resources; and disseminate information on health and research advances. NIA is also the primary federal agency on Alzheimer's disease research. The NIA has been at the forefront of some of the most important advances in aging research and translational programs, including:

- Development of the drug-eluting coronary stent, used to open arterial blockages in the heart during angioplasty. Nearly two million people worldwide have received these stents, which reduce subsequent narrowing rates to three to six percent.
- The NIA's Diabetes Prevention Program demonstrated that diet and exercise were the most effective ways to reduce the risk of diabetes in high-risk older

people. The clinical trial intervention showed a 71 percent reduction in diabetes among participants 60 and older.

- Karlene Ball, an NIA grantee, developed Useful Field of View (UFOV), which is the area where someone can extract visual information at a glance without head or eye movements. Research found that training UFOV can prospectively reduce automobile crash rates by half. Several state Motor Vehicle Departments are using and testing UFOV, and Allstate Insurance Company and State Farm offer discounts with this training.
- NIA-funded research led by Mary Tinetti, M.D., of the Yale University School of Medicine found that training clinical staff in falls prevention practices and strategies can help reduce serious falls by nine percent and the need for related medical care by 11 percent among seniors aged 70 and older, reducing the incidence and cost of hospitalizations.
- Researchers from the Alzheimer's Disease Neuroimaging Initiative showed that changes in the levels of certain proteins in cerebrospinal fluid may correlate with the risk and progression of Alzheimer's disease. These biomarkers may be used in the future to identify individuals at risk of developing the disease. In addition, measuring amyloid in the brain may prove promising as a diagnostic tool. A
- NIA-funded clinical trials REACH I and REACH II developed and tested strategies for helping caregivers manage the stress and emotional burden of caring for people with dementia. The first study showed a significant improvement in caregivers' sense of burden, social support, depression and health, as well as in care recipients' behavior problems and mood.<sup>17</sup> The U.S. Department of Veterans Affairs successfully used REACH strategies in a demonstration project with 19 of its Home Based Primary Care programs, which treat frail individuals with dementia and caregivers in their homes, and it is now considering using REACH throughout its system. Additionally, the REACH OUT program at the Administration on Aging is beginning to implement these strategies through local social service agencies.

Research toward healthier aging has never been more critical for so many Americans. Older Americans now make up the fastest growing segment of the population. According to the U.S. Census Bureau, the number of people age 65 and 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 three-fold, to 19 million. Diseases such as type 2 diabetes, cancer, neurological diseases, heart disease, and osteoporosis that largely occur late in life are increasingly driving the need for healthcare services in this country. Many other dreaded diseases of aging like Alzheimer's disease are expected to become more prevalent as the number of older Americans increases. We believe that preventing, treating or curing diseases of aging is perhaps the single most effective strategy available to reduce national spending on health care.

Consider that the average 75-year old has three chronic health conditions and takes five prescription medications. Six diseases- heart disease, stroke, cancer, diabetes, Alzheimer's and Parkinson's diseases – cost the U.S. over \$1 trillion each year. The number of Americans age 65 and older with Alzheimer's disease is projected to more than double over the next 17 years. Cancer incidence is projected to increase by about 45 percent between 2010-2030, largely

because of cancer diagnoses in older Americans and minorities. By 2030, people aged 65 and older will represent 70 percent of all cancer diagnoses in the U.S.

The rising tide of chronic diseases of aging threatens to overwhelm the U.S. health care system in the coming years. Research which leads to a better understanding of the aging process and human vulnerability to age-related diseases could be the key to helping Americans live longer, more productive lives, and simultaneously reduce the need for care to manage costly chronic diseases. Scientists who study aging now generally agree that aging is malleable and capable of being slowed. Rapid progress in recent years toward understanding and making use of this malleability has paved the way for breakthroughs that could increase human health in later life by opposing the primary risk factor for virtually every disease we face as we grow older—aging itself. Better understating of this “common denominator” of disease could usher in a new era of preventive medicine, enabling interventions that stave off everything from dementia to cancer to osteoporosis. As we now confront unprecedented aging of our population and staggering increases in chronic age-related diseases and disabilities, a modest extensions of healthy lifespan could produce outsized returns of extended productivity, reduced caregiver burdens, lessened Medicare spending, and more effective healthcare in future years.

The NIA leads national research efforts within the NIH to better understand the aging process and ways to better maintain the health and independence of Americans as they age. NIA is poised to accelerate the scientific discoveries. The science of aging is showing increasing power to address the leading public health challenges of our time. Leaders in the biology of aging believe it is now realistically possible to develop interventions that slow the aging process and greatly reduce the risk of many diseases and disabilities, including cancer, diabetes, Alzheimer’s disease, vision loss and bone and joint disorders. While there has been great progress in aging research, a large gap remains between promising basic research and healthcare applications. Closing that gap will require considerable focus and investment. Key aging processes have been identified by leading scientists as potentially yielding crucial answers in the next 3-10 years. These include stress response at the cellular level, cell turnover and repair mechanisms, and inflammation.

A central theme in modern aging research—perhaps its key insight—is that the mutations, diets, and drugs that extend lifespan in laboratory animals by slowing aging often increase the resistance of cells, and animals, to toxic agents and other forms of stress. These discoveries have two main implications, each of which is likely to lead to major advances in anti-aging science in the near future. First is the suggestion that stress resistance may itself be the facilitator (rather than merely the companion) of the exceptional lifespan in these animal models, hinting that studies of agents that modulate resistance to stress could be a potent source of valuable clinical leverage and preventive medicines. Second is the observation that the mutations that slow aging augment resistance to multiple varieties of stress—not just oxidation, or radiation damage, or heavy metal toxins, but rather resistance to all of these at the same time.

The implication is that cells have “master switches,” which, like rheostats that can brighten or dim all lights in a room, can tweak a wide range of protective intracellular circuits to tune the rate of aging differently in long-lived versus short-lived individuals and species. If this is correct, research aimed at identifying these master switches, and fine-tuning them in ways that slow aging without unwanted side-effects, could effectively postpone all of the physiological disorders of aging through manipulation of the aging rate itself. Researchers have formulated,

and are beginning to pursue, new ways to test these concepts by analysis of invertebrates, cells lines, laboratory animals and humans, and by comparing animals of species that age more quickly or slowly.

One hallmark of aging tissues is their reduced ability to regenerate and repair. Many tissues are replenished by stem cells. In some aged tissues, stem cell numbers drop. In others, the number of stem cells changes very little—but they malfunction. Little is currently known about these stem cell declines, but one suspected cause is the accumulation of “senescent” cells. Cellular senescence stops damaged or distressed cells from dividing, which protects against cancer. At advanced ages, however, the accumulation of senescent cells may limit regeneration and repair, a phenomenon that has raised many questions. Do senescent cells, for instance, alter tissue “microenvironments,” such that the tissue loses its regenerative powers or paradoxically fuel the lethal proliferation of cancer cells? A robust research initiative on these issues promises to illuminate the roots of a broad range of diseases and disabling conditions, such as osteoporosis, the loss of lean muscle mass with age, and the age-related degeneration of joints and spinal discs. The research is also essential for the development of stem cell therapies, the promise of which has generated much public excitement in recent years. This is because implanting stem cells to renew damaged tissues in older people may not succeed without a better understanding of why such cells lose vitality with age. Importantly, research in this area would also help determine whether interventions that enhance cellular proliferative powers would pose an unacceptable cancer risk.

Acute inflammation is necessary for protection from invading pathogens or foreign bodies and the healing of wounds, but as we age many of us experience chronic, low-level inflammation. Such insidious inflammation is thought to be a major driver of fatal diseases of aging, including cancer, heart disease, and Alzheimer’s disease, as well as of osteoporosis, loss of lean muscle mass after middle age, anemia in the elderly, and cognitive decline after 70. Just about everything that goes wrong with our bodies as we age appears to have an important inflammatory component, and low-level inflammation may well be a significant contributor to the overall aging process itself. As the underlying mechanisms of age-related inflammation are better understood, researchers should be able to identify interventions that can safely curtail its deleterious effects beginning in mid-life, broadly enhancing later-life, and with negligible risk of side effects.

While important advances have been made toward understanding how aging is linked to disease in an effort to add healthy years to life, such a goal cannot be achieved in a timely way without financial support. An increase in funding for aging research is urgently needed to enable scientists to capitalize on the field’s recent exciting discoveries. For the past year and a half, the Alliance for Aging Research, has led the Healthspan Campaign—an awareness campaign to educate the public and policymakers about the need to focus and adequately fund basic research into the underlying processes of aging—that if targeted can extend a person’s healthy years of life. In addition to increased resources, we believed that the field could benefit from the creation of a trans-NIH initiative that could improve the quality and pace of research that advances the understanding aging, its impact on age-related diseases, and the development of interventions to extend human healthspan. Throughout the first half of 2012 the Alliance and its Healthspan Campaign partners met with leadership of the National Institute on Aging (NIA), the National Institute of Neurological Diseases and Stroke (NINDS), the National Institute of Arthritis Musculoskeletal and Skin Diseases (NIAMS), the National Institute of Diabetes Digestive and

Kidney Diseases (NIDDK), the National Heart Lung and Blood Institute (NHLBI), and the National Cancer Institute (NCI). As a result of this advocacy, in less than six months the NIA—through its Division of Aging Biology—took the lead in establishing a Geroscience Interest Group (GSIG) to coordinate discussion and action across the NIH on understanding the role aging plays in our susceptibility to age-related diseases. Of the 27 Institutes and Centers that make up the NIH, 20 are now members of the GSIG—making it the top interest group at the NIH.

The GSIG was written up in the March/April 2012 issue of “The NIH Catalyst,” the NIH’s intramural research newsletter, and Dr. Felipe Sierra, NIA Division of Aging Biology Director and GSIG Coordinator, was awarded an NIH Director’s award for his groundbreaking work with the GSIG. The work of the GSIG was recognized in report language in the FY 2013 Senate Labor, Health and Human Services (LHHS) Appropriations bill. In addition L-HHS Subcommittee Chairman, Senator Tom Harkin (D-IA), asked a question of NIA Director Dr. Richard Hodes about the GSIG at the April 2012 hearing. To date the GSIG has held four educational seminars on topics ranging from age-dependent mechanisms in Alzheimer’s and Parkinson’s diseases to insights on aging from Hutchinson-Gilford Progeria Syndrome. The group convened a major workshop on inflammation and aging in the fall of 2012 that resulted in a meaningful joint funding proposal across several NIH institutes. Planning is now underway for a larger and more impactful meeting in fall of 2013 on multiple processes of aging and disease. This meeting will produce many other promising priority areas for further collaboration.

The field of aging research is poised to make transformational gains in the near future but we can only capitalize on this potential if the NIH is properly resourced across institutes and centers. Few if any areas for investing research dollars offer greater potential returns for public health. The Alliance for Aging Research supports funding the NIH at \$32 billion in FY 2014 with a minimum of \$1.4 billion in funding for the NIA specifically. This level of support would allow the NIH and the NIA to adequately fund new and existing research projects, accelerating progress toward findings which could prevent, treat, slow the progression or even possibly cure conditions related to aging. With a tsunami of age driven chronic ailments looming as our population grows older, an increased emphasis on NIH’s aging research activities has never been more urgent, with potential to impact so many Americans.

Therapies that delay aging would lessen our healthcare system’s dependence on a strategy of trying to address diseases of aging one at a time, often after it is too late for meaningful benefit. They would also address the fact that while advances in lowering mortality from heart attack and stroke have dramatically increased life expectancy, they have left us vulnerable to other age-related diseases and disorders that develop in parallel, such as Alzheimer’s disease, diabetes, and frailty. Properly focused and funded research could benefit millions of people by adding active, healthy, and productive years to life. Furthermore, the research will provide insights into the causes of and strategies for reducing the periods of disability that generally occur at the end of life.

Mr. Chairman, the Alliance for Aging Research thanks you for the opportunity to outline the challenges posed by the aging population that lie ahead as you consider the FY 2014 appropriations for the NIH and we would be happy to furnish additional information upon request.

**Statement of Gary E. Knell  
President and CEO, National Public Radio  
Before the Subcommittee on Labor, Health and Human Services, Education and Related  
Agencies, U.S. House Committee on Appropriations**

March 15, 2013

Dear Chairman Kingston, Congresswoman 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, every American will continue to have free access to the best in educational, news, information and cultural programming.

As the President and CEO of NPR, I offer this testimony on behalf of the public radio system, a uniquely American public service, non-for-profit media enterprise that includes NPR, our more than 950 public radio station partners, other producers and distributors of public radio programming including [American Public Media](#) (APM), [Public Radio International](#) (PRI), the [Public Radio Exchange](#) (PRX), and many stations, both large and small, that create and distribute content through the [Public Radio Satellite System](#) (PRSS).

Funding provided by Congress to the CPB supports the entire foundation of a system that has been one of America's most successful models of a community-centric grant program. The cost of public broadcasting is only 0.01% of the entire federal budget. The revenue base provided by Congress enables stations to raise \$6 for every federal grant dollar. This federal financial investment permits local stations to invest more deeply in their own local news and cultural programming which in turn enables our stations to provide the American public with an enduring and daily return on investment that is heard, seen, read, and experienced in public radio broadcasts, apps, podcasts, and on online.

With support from CPB's community service grants, each of the hundreds of independently operated public radio stations is responsible for curating and creating the mix of programs that best addresses the needs of their local community. These stations and their programming choices are as diverse as the people who live in the communities they serve. Some have all-news formats. Others have all-music formats and still other blend news, talk, commentary and music into their program offerings. Close to thirty percent of our stations' daily programming is locally generated. Every year the federal government invests roughly \$90 million dollars in the operation of America's local public radio stations. And these stations provide service to all of America's congressional districts and states.

In our congressional testimony last year we highlighted three essential contributions of public radio to Americans: our deeply rooted local community connections from which all staffing, management and programming decisions are made; public radio's significant and

growing contributions to music and local music economies; and public radio's indispensable role as a life line information source during times of local and regional crises.

These unique contributions remain clearly in view as public radio adjusts to America's changing demographics and undergoes renewal to accommodate the demands of our audience and the opportunities presented by the march of technology.

Mr. Chairman, 2013 marks the 12<sup>th</sup> year of armed overseas conflict, the longest period of sustained warfare in United States history. Some 2.3 million Americans have now served in the wars in Iraq and Afghanistan, with more than 32,000 casualties, and tens of thousands more enduring the mental strains of combat. Now, with the military drawdown taking place, these men and women are returning home, with many facing difficult transitions. NPR and its public radio station partners are delving deeply into the lives of America's veterans to foster an understanding of the impact of war to the public and to policymakers. Through unique and dedicated reporting and through the *Military Voices Initiative*, a major national project by StoryCorps, the stories and lives of America's veterans are being told and preserved. Doing so, we believe, will bring closer connections to our nation's civilian population and military communities.

Public radio is pushing forward together to expand local news coverage in key subject areas through StateImpact, a new journalistic collaboration among local stations and NPR. In Florida, Idaho, Indiana, New Hampshire, Ohio, Oklahoma, Pennsylvania and Texas, public radio uses radio and web platforms to dig deeply into and explain how state policies in education, energy and the economy affect people's lives.

This important new initiative adds to the existing 4500 professionals with direct responsibilities for originating news or public affairs content who currently work in public media. Some 3200 journalists are working at the local level and roughly 1300 at the national level. More than half of these professionals are working in the public radio system in 21 domestic and 17 foreign bureaus and stations across the United States representing a robust and growing on-the-ground commitment to news gathering and journalism.

When the storm clouds of Hurricanes Isaac and most recently Sandy gathered, so did the reporters of local public radio stations and NPR. Stations in the affected areas worked nonstop to deliver updates on damage, relief assistance, places of refuge and safety. The public radio system worked together to bring these local struggles and challenges to a national audience.

The work of WNYC – New York Public Radio – perfectly illustrates all of public radio's commitment to nonstop coverage during emergencies and crises. Despite losing power to its Lower Manhattan headquarters on the evening Sandy struck, and later its AM transmitter in New Jersey, WNYC stayed on the air, via an emergency generator, in order to provide the critical news and information its local citizens needed. Its news websites, [wnyc.org](http://wnyc.org) and [npublicradio.org](http://npublicradio.org), operated on back-up servers but provided up-to-date news and interactive

tools like maps tracking transit options, flooding and power outages. More than 4.6 million visitors came to its sites for Sandy information.

And the commitment of public radio to bring news to all Americans during emergency events is also reflected in a recent award from the U.S. Department of Homeland Security (DHS) and the Federal Emergency Management Agency (FEMA) to [NPR Labs](#). This contract will enable demonstration of delivery of emergency alerts to people who are deaf or hard-of-hearing in Gulf Coast states through local public radio stations and the Public Radio Satellite System (PRSS). This is the first effort to deliver real-time accessibility-targeted emergency messages, such as weather alerts, via radio broadcast texts.

Mississippi Congressman Steven Palazzo commented on this activity by saying, "As we work to promote disaster preparedness and awareness, it is important we remember to equip every member of our communities. This valuable partnership with Mississippi's local public radio stations promises to expand the reach of our disaster alert systems, and I can think of no better place to conduct this trial than the Gulf Coast."

We are committed to bringing the breadth of America's diverse voices to our programs so that our audience has the benefit of hearing the full rundown of ideas, thoughts and policy perspectives that populate our country's political, cultural and social conversation. Capturing the diversity of expression ... political, age, racial and ethnic and geographic ... is at the center of our determination to serve as America's public radio.

A further commitment to exploring and serving the changing nature of America's citizens can be found in our newly launched [initiative on race, ethnicity and culture](#). With support from CPB, NPR is forming a new team of six journalists to identify and report news and perspectives, and present new voices and conversations that capture the issues that define an increasingly diverse America. This team will work across public radio to identify compelling stories and conversations for all of our platforms.

Mr. Chairman and Congresswoman DeLauro, NPR and the public radio system are committed to being America's public radio where rationale, fact-based, accurate and civil reporting and conversation are our top priorities. We have no political agenda and we do not take sides. Public radio plays an important, significant and growing role in news, journalism, talk and music/cultural programming. Our stations are essential to, and part of, the communities they serve.

Through news, talk, music and cultural programming, public radio stations are reaching out to 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.

**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 15, 2013*

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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 2014 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/hpniec/members.htm>) dedicated to ensuring the health care workforce is trained to meet the needs of the country's growing, aging, and diverse population. Designed to provide education and training opportunities to aspiring health care professionals, in 2013, the programs celebrate 50 years of helping the workforce adapt to Americans' changing health care needs. With a focus on primary care, Titles VII and VIII are the only federal programs designed to train providers in interdisciplinary, community-based settings to meet the needs of the country's special and underserved populations, increase minority representation in the health care workforce, and fill the gaps in the supply of health professionals not met by traditional market forces. Further, the programs are able to advance timely priorities, such as strengthening education and training opportunities in geriatrics to better care for the nation's aging population and closing the gap in access to mental and behavioral health services.

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 VIII programs would jeopardize activities to fill these vacancies and to prepare 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. Approximately one-half of primary care providers trained through these programs work in underserved areas, compared to 10 percent of those trained in other programs. The *General 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 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 *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 trained mental and behavioral 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, including the Eighth National Sample Survey of Registered Nurses, the nation's most extensive and comprehensive source of statistics on registered nurses. Reflecting the need for better health workforce data to inform both public and private decision making, the *National Center for Workforce Analysis* serves as a source of such analyses.
- 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 receive minimal 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 2005 and 2010, supported over 400,000 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 *Nursing Student Loan* (NSL) is for 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 health professions students from disadvantaged backgrounds.

The Title VII and Title VIII programs improve the supply, distribution, and diversity of the nation's health professionals. Further, with the Bureau of Labor Statistics projecting that the health care industry will generate 3.2 million jobs through 2018 (more than any other industry), these programs can help individuals in reaching their career 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 immense fiscal pressures 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 2014 and into the future.

**Association of Rehabilitation Nurses**  
**Written Testimony to the House Labor-Health and Human Services**  
**Appropriations Subcommittee**  
**Regarding Fiscal Year 2014 Nursing and Rehabilitation Related Funding**  
**Submitted by: ARN President, Michelle Camicia MSN RN CRRN**  
**(202) 230-5197 and [jeremy.scott@dbr.com](mailto:jeremy.scott@dbr.com)**  
**March 15, 2013**

Introduction

On behalf of the Association of Rehabilitation Nurses (ARN), I appreciate having the opportunity to submit written testimony to the House LHHS Appropriations Subcommittee regarding funding for nursing and rehabilitation related programs in fiscal year (FY) 2014. 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. The rehabilitation nurse often teaches patients and their caregivers how to access systems and resources.

Rehabilitation nursing is a philosophy of care, not a work setting or a phase of treatment. We base our practice on rehabilitative and restorative principles by: (1) managing complex medical issues; (2) interprofessional collaboration with other specialists; (3) providing ongoing patient/caregiver education; (4) setting goals for maximum independence; and (5) establishing plans of care to maintain optimal wellness. Rehabilitation nurses practice in all settings, including freestanding rehabilitation facilities,

hospitals, long-term subacute care facilities/skilled nursing facilities, long-term acute care facilities, comprehensive outpatient rehabilitation facilities, home health, and private practices, just to name a few.

As we celebrate the third anniversary of the *Affordable Care Act (ACA)* – which focused on creating a system that will increase access to quality care, emphasizes prevention, and decreases costs – it is critical that a substantial investment be made in the nursing workforce programs and in the scientific research that provides the basis for nursing practice. To ensure that patients receive the best quality care possible, ARN supports federal programs and research institutions that address the national nursing shortage and conduct research focused on nursing and medical rehabilitation, e.g., traumatic brain injury. Therefore, ARN respectfully requests that the Subcommittee provide increased funding for the following programs:

Nursing Workforce and Development Programs at the Health Resources and Services Administration

(HRSA)

ARN supports efforts to resolve the national nursing shortage, including appropriate funding to address the shortage of qualified nursing faculty. Rehabilitation nursing requires a high-level of education and technical expertise, and ARN is committed to assuring and protecting access to professional nursing care delivered by highly-educated, well-trained, and experienced registered nurses for individuals affected by chronic illness and/or physical disability.

According to the Bureau of Labor Statistics' *Employment Projections for 2010-2020*, the expected number of practicing nurses will grow from 2.74 million in 2010 to 3.45 million in 2020, an increase of 712,000 or 26%. The projections further explain the need for 495,500 replacements in the nursing workforce, bringing the total number of job openings for nurses due to growth and replacements to 1.2 million by 2020. 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. The Institute of Medicine has released recommendations on how to help the nursing workforce meet these new demands, but we are destined to fall short of these lofty goals if there are not enough nurses to facilitate change.

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 2010 alone, the Title VIII programs supported over 400,000 nurses and nursing students as well as numerous academic nursing institutions, and healthcare facilities. Educating new nurses to fill these vacancies is a great way to put Americans back to work and simultaneously enhance an ailing health care system.

**ARN strongly supports the national nursing community's request of \$251 million in FY 2014 funding for federal Nursing Workforce Development programs at HRSA.**

National Institute on Disability and Rehabilitation Research (NIDRR)

The National Institute on Disability and Rehabilitation Research (NIDRR) provides leadership and support for a comprehensive program of research related to the rehabilitation of individuals with disabilities. As one of the components of the Office of Special Education and Rehabilitative Services at the U.S. Department of Education, NIDRR operates along with the Rehabilitation Services Administration and the Office of Special Education Programs.

The mission of NIDRR is to generate new knowledge and promote its effective use to improve the abilities of people with disabilities to perform activities of their choice in the community, and also to expand society's capacity to provide full opportunities and accommodations for its citizens with disabilities. NIDRR conducts comprehensive and coordinated programs of research 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 2014 funding level.**

National Institute of Nursing Research (NINR)

ARN understands that research is essential for the advancement of nursing science, and believes new concepts must be developed and tested to sustain the continued growth and maturation of the rehabilitation nursing specialty. The National Institute of Nursing Research (NINR) works to create cost-effective and high-quality health care by testing new nursing science concepts and investigating how to best integrate them into daily practice. 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. NINR's recent areas of research focus include the following:

- End of life and palliative care in rural areas;
- Research in multi-cultural societies;
- Bio-behavioral methods to improve outcomes research; and
- Increasing health promotion through comprehensive studies.

**ARN respectfully requests \$150 million in FY 2014 funding for NINR to continue its efforts to address issues related to chronic and acute illnesses.**

Traumatic Brain Injury (TBI)

According to the Brain Injury Association of America, 1.7 million people sustain a traumatic brain injury (TBI) each year.<sup>1</sup> This figure does not include the 150,000 cases of TBI suffered by soldiers returning from wars in Afghanistan and conflicts around the world.

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<sup>1</sup> <http://www.biausa.org/living-with-brain-injury.htm>

The annual national cost of providing treatment and services for these patients is estimated to be nearly \$60 million in direct care and lost workplace productivity. Continued fiscal support of the Traumatic Brain Injury Act will provide critical funding needed to further develop research and improve the lives of individuals who suffer from traumatic brain injury.

Continued funding of the TBI Act will promote sound public health policy in brain injury prevention, research, education, treatment, and community-based services, while informing the public of needed support for individuals living with TBI and their families.

ARN strongly supports the current work being done by the Centers for Disease Control and Prevention (CDC) and HRSA on TBI programs. These programs contribute to the overall body of knowledge in rehabilitation medicine.

**ARN urges Congress to support the following FY 2014 funding requests for programs within the TBI Act: \$10 million for CDC's TBI registries and surveillance, prevention and national public education and awareness efforts; \$8 million for the HRSA Federal TBI State Grant Program; and \$4 million for the HRSA Federal TBI Protection and Advocacy Systems Grant Program.**

#### Conclusion

ARN appreciates the opportunity to share our priorities for FY 2014 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 2014 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.

To: Subcommittee on Labor, HHS, Education and Related Agencies, Committee on Appropriations, U.S. House of Representatives  
From: Coalition for Health Funding, 600 Maryland Avenue, SW Suite 835W, Washington DC  
Re: FY 2014 Funding for Health Agencies and Programs

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The Coalition for Health Funding is pleased to provide the House Labor, Health and Human Services, Education and Related Agencies Appropriations Subcommittee with a statement for the record on FY 2014 funding levels for the National Institutes of Health, Centers for Disease Control and Prevention, Health Resources and Services Administration, Substance Abuse and Mental Health Services Administration, and Agency for Healthcare Research and Quality. Since 1970, the Coalition has advocated for sufficient and sustained discretionary funding for these agencies and programs to address the mounting and evolving public health challenges confronting the American people.

Every day, in ways most Americans don't even realize, the federal government supports public health programs that keep them safe and secure. The agencies and programs of the Department of Health and Human Services conduct health research to discover cures; prevent disease, disability, and injury; assure food, water and drug safety; protect the public and respond in times of crisis; educate the next generation of scientists, health care providers, and public health professionals; and care for our nation's most vulnerable.

The Coalition's 83 national, member organizations—representing the interests of more than 100 million patients, health care providers, public health professionals, and scientists—believe that the federal government is an essential partner with state and local governments and the nonprofit and private sectors in improving our nation's health. We are very concerned that

deficit reduction efforts to date—both actual and those under consideration—have relied almost exclusively on cuts to public health, health research, and other discretionary programs to balance the budget, which will adversely affect the success of these partnerships. Funding for public health and health research programs have experienced three consecutive years of cuts. Under sequestration, these cuts will be even deeper—nearly \$4 billion from health programs within the subcommittee’s jurisdiction in FY 2013 alone.

Public health and health research represented only 1.6 percent of all federal spending in FY 2012—a small and shrinking share of the budget. These programs are not the root cause of our fiscal crisis, and cutting them further will not bring the budget into balance. On the contrary, with greater investment, these programs are an integral part of the solution. Evidence abounds—from the Department of Defense to the U.S. Chamber of Commerce—that healthy Americans are stronger on the battlefield, have higher academic achievement, and are more productive in school and on the job.

The Coalition realizes the pressure Congress and the administration face to reduce the national debt. However, our nation’s health programs have already contributed substantially to deficit reduction. Earlier this year the Coalition was joined by more than 3,200 national, state, and local organizations in urging Congress and the administration to work together to find a balanced approach to deficit reduction that does not include further cuts discretionary programs, including public health and health research. These programs discover cures for debilitating diseases and keep our food and water safe. They provide needed mental health services to our returning wounded, and they help families rebuild their lives after natural

disasters. Eroding the public health infrastructure through continued cuts will do Americans more harm than good.

The Coalition appreciates this opportunity to provide FY 2014 funding recommendations for public health and health research agencies within the Subcommittee's jurisdiction. These funding levels are consistent with our request for discretionary health programs (Function 550), which was endorsed this month by 430 national, state, and local organizations.

#### **National Institutes of Health (NIH)**

The Coalition joins the research community in seeking at least \$32 billion in FY 2014. 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. As the primary federal agency responsible for conducting and supporting medical research, NIH drives scientific innovation and develops new and better diagnostics, improved prevention strategies, and more effective treatments.

#### **Centers for Disease Control and Prevention (CDC)**

The Coalition joins the CDC Coalition in seeking \$7.8 billion in FY 2014. This funding level will enable the CDC to fulfill its core mission through activities and programs that are essential to protect the health of the American people. CDC continues to be faced with unprecedented challenges and responsibilities, ranging from chronic disease prevention, eliminating health disparities, bioterrorism preparedness, to combating the obesity epidemic. In addition, CDC funds community programs in injury control; health promotion efforts in schools and workplaces; initiatives to prevent diabetes, heart disease, cancer, stroke, and other chronic

diseases; improvements in nutrition and immunization; programs to monitor and combat environmental effects on health; prevention programs to improve oral health; prevention of birth defects; public health research; strategies to prevent antimicrobial resistance and infectious diseases; and data collection and analysis on a host of vital statistics and other health indicators.

### **Health Resources and Services Administration (HRSA)**

The Coalition joins the Friends of HRSA in seeking \$7.0 billion in FY 2014. HRSA is a national leader in providing health services for individuals and families, serving as a health safety net for the medically underserved. The requested level of discretionary funding for FY2014 is critical to allow the agency to carry out critical public health programs and services that reach millions of Americans, including developing the public health and health care workforce; delivering primary care and preventive services through community health centers; improving access to care for rural communities; supporting maternal and child health care programs; providing health care to people living with HIV/AIDS; and many more. In the long term, much more is needed for the agency to achieve its ultimate mission to improve health and achieve health equity through access to a skilled health workforce and quality services.

### **Substance Abuse and Mental Health Services Administration (SAMHSA)**

The Coalition joins the Mental Health Liaison Group and the addictions community in recommending an overall funding level of \$3.8 billion in FY 2014. According to results from a national survey conducted by SAMHSA, 45.1 million American adults in the United States experienced mental illness last year. However, nearly two-thirds of adults and 80 percent of

children and adolescents in the U.S. with mental illness did not receive mental health services. In fact, suicide claims over 38,000 lives annually, the equivalent of 104 suicides per day; one suicide every 13.5 minutes. Last year, 8.7 million adults aged 18 or older thought seriously about committing suicide, 2.5 million made a suicide plan, and 1.1 million attempted suicide. The funding for community mental health services from SAMHSA has never been more critical, especially in light of states cutting nearly \$5 billion in state mental health funding for programs serving this vulnerable population over the last three years.

#### **Agency for Healthcare Research and Quality (AHRQ)**

The Coalition joins the Friends of AHRQ in recommending an overall funding level of \$430 million in FY 2014. AHRQ is the federal agency with the sole purpose of improving health care. As the agency for health services research, AHRQ funds science that discovers cures for our health system in universities, medical centers, and research institutions across the nation. This research is used by patients, health care providers, public health professionals, hospitals, and public and private payers to enhance consumer choice, improve patient safety, and promote high quality care. Specifically, the science funded by AHRQ provides consumers and their health care professionals with valuable evidence to make the right health care decisions for themselves and their families. AHRQ's research also provides the basis for protocols that reduce hospital-acquired infections, and improve patient confidence, experiences, and outcomes.

**TESTIMONY ON BEHALF OF THE SOCIETY FOR MATERNAL-FETALMEDICINE  
SUBMITTED BY DR. BRIAN MERCER, PRESIDENT**

On behalf of the Society for Maternal-Fetal Medicine (SMFM), I am pleased to submit testimony in support of funding for the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD). We urge your support of at least \$32 billion for NIH, including \$1.37 billion for NICHD in FY2014.

Established in 1977, SMFM is dedicated to improving maternal and child outcomes and raising the standards of prevention, diagnosis, and treatment of maternal and fetal disease. Maternal-fetal medicine specialists, known as MFM specialists, perinatologists, or high-risk pregnancy physicians, are highly trained obstetricians/gynecologists with advanced expertise in obstetric, medical, and surgical complications of pregnancy and their effects on the mother and fetus. The complex problems faced by some mothers may lead to death as well as short-term or life-long problems for both mothers and their babies. Such complications be understood, treated, prevented and eventually solved through research.

NICHD's mission is to ensure that every child is born healthy and that women suffer no harmful effects from reproductive processes. NICHD-supported basic, clinical, translational, and multidisciplinary research studies address a myriad of issues in pregnancy including:

***Preterm birth:*** Delivery before 37 weeks' gestation is associated with increased risks of death in the immediate newborn period as well as in infancy, and can cause long-term complications. About 20% of premature babies die within the first year of life, and although the survival rate is improving, many preterm babies have life-long disabilities including cerebral palsy, mental retardation, respiratory problems, and hearing and vision impairment. Preterm birth costs the U.S. \$26 billion annually.

***Stillbirth:*** Defined as the death of a fetus at 20 or more weeks of gestation, stillbirth complicated nearly 26,000 pregnancies in the United States in 2005. Stillbirth is more than twice as common

among African Americans as Caucasian women. Other maternal risk factors for stillbirth include advanced age, obesity, and co-existing medical disorders such as diabetes or hypertension. The impact of environmental exposures on stillbirth risk remains unknown. Of known stillbirth causes, the most common are genetic abnormalities, alterations in the number or structure of the chromosomes, maternal infection, hemorrhage, and problems with the umbilical cord or placenta. However, the cause remains unknown in about half of all stillbirths.

***Hypertensive diseases in pregnancy:*** High blood pressure (hypertension) during pregnancy is the second leading cause of maternal death in the United States, accounting for 15% of all deaths. For the mother, it is associated with increased need for delivery because of pregnancy complications, stroke, pulmonary or heart failure, and death. The likelihood and severity of these complications increases as the severity of the hypertension increases, and if preeclampsia develops. Preeclampsia is characterized by high blood pressure and the presence of protein in the urine. Its cause remains one of the greatest mysteries in obstetrics and is a major cause of maternal, fetal, and neonatal mortality worldwide.

***Pregestational and gestational diabetes:*** The hormonal changes of pregnancy can seriously worsen preexisting diabetes and often bring about a diabetic state (gestational diabetes) in predisposed women. Whether diabetes mellitus existed before conception or gestational diabetes develops during pregnancy, maternal glucose intolerance can have significant medical consequences for both mother and baby. Poorly controlled diabetes is associated with miscarriage, congenital malformations, abnormal fetal growth, stillbirth, obstructed labor, increased cesarean delivery, and neonatal complications. Up to 200,000 pregnancies are affected by gestational diabetes each year.

Great strides are being made through NICHD-supported research to address the complex situations faced by mothers and their babies. One of the most successful approaches for testing research questions is the NICHD research networks which allow researchers from across the country to collaborate and coordinate their work to change the way we think about pregnancy complications and change medical practice across the country. These networks deal with different aspects of pregnancy: the problem of preterm birth and its consequence.

The Stillbirth Collaborative Research Network (SCRN) was created to study the extent and causes of stillbirth in the United States, and is conducting a geographic population-based determination of the incidence of stillbirth and is determining the causes of stillbirth using a standardized protocol that includes clinical histories, autopsies and pathologic examinations of the fetus and placenta as well as other postmortem tests to illuminate genetic, maternal and environmental influences. The information from this Network will benefit families who have experienced a stillbirth, women who are pregnant or who are considering pregnancy, and obstetric care providers. In addition, the knowledge gained from this Network will support future research aimed at improving preventive and therapeutic interventions and at understanding the mechanisms that lead to fetal death.

Another important network is the Maternal-Fetal Medicine Units Network (MFMU), established in 1986 to achieve a greater understanding and pursue development of effective treatments for the prevention of preterm births, low birth weight infants and medical complications during pregnancy. The MFMU Network has identified new effective therapies and will put an end to practices that are not useful. It is the only national research infrastructure capable of performing the much needed large trials that provide the evidence on which sound medical practice is based. The MFMU Network is also the ideal vehicle to collaborate with other

NIH networks, as well as international networks in order to improve global health. Since its inception, the Network has made several exciting scientific advancements and has been able to rapidly turn laboratory and clinical research into diagnostic examinations and treatment procedures that directly benefit those affected:

- Following a series of studies in the 1970s and 1980s, an MFMU Network clinical trial showed that progesterone treatment resulted in a substantial reduction in the rate of preterm delivery among women who had a previous preterm birth, reduced the risk of newborn complications, and was effective in both African American and Non-African American women.
- The MFMU Network conducted the largest, most comprehensive trial to date to test whether magnesium sulfate given to a woman in labor with a premature fetus (24 to 31 weeks out of 40) would result in a reduction in cerebral palsy. In August 2008, NIH announced that magnesium sulfate, when administered to women at risk of imminently delivering preterm, reduces the risk of cerebral palsy in surviving preterm infants by 45%.
- The MFMU Network provided the first conclusive evidence that treating pregnant women who have even the mildest form of gestational diabetes can reduce the risk of common birth complications among infants, as well as blood pressure disorders among mothers. These findings will change clinical practice and lead to better outcomes for both mothers and babies.

Vigorous support of the MFMU Network is needed so that therapies and preventive strategies that have significant impact on the health of mothers and their babies will not be

delayed. Until new options are created for identifying those at risk and developing cause specific interventions, preterm birth will remain one of the most pressing problems in obstetrics.

The NuMoM2b network was developed to use current genomic and proteomic techniques in combination with traditional markers for the prediction of adverse pregnancy outcomes, including preterm birth, preeclampsia, fetal growth restriction, and stillbirth in first pregnancies, since adverse pregnancy outcomes are at increased risk for complications in future pregnancies and over 40% of pregnancies in the United States are first pregnancies. The NuMoM2b study of 10,000 women provides the infrastructure for additional multicenter study of sleep disordered breathing in pregnancy. Epidemiologic studies have shown that a woman's health status during pregnancy is associated with her long-term health after pregnancy, suggesting that findings in pregnancy may be a better indicator for determining a woman's future health status than traditional risk factors. The NuMoM2b study could serve as the basis for long-term studies to determine the relationships between adverse pregnancy outcomes and long-term maternal health.

Opportunities for future study include collaborative work by NICHD, NHLBI and NIDDK to more closely study these epidemiologic findings in an effort to identify predictive markers during pregnancy for subsequent heart disease and diabetes; develop tests to evaluate health after pregnancy; and test interventions both during and after pregnancy that may mitigate risk.

Research is the cornerstone for improving our understanding of the physiology and pathophysiology of pregnancy, the interrelationship between the mother and fetus, the impact of medical conditions on pregnancy and the impact of medical diseases and pregnancy outcomes on the long term health of both mother and child. With your support, researchers can continue to peel away the layers of complex problems of pregnancy that have such devastating consequences.

Testimony on behalf of the  
**Population Association of America/Association of Population Centers**  
Regarding the Fiscal Year 2014 Appropriation for the  
**National Institutes of Health and National Center for Health Statistics**  
Submitted to the  
House Committee on Appropriations  
Subcommittee on Labor, Health and Human Services and Education  
By Mary Jo Hoeksema, Director, Government Affairs  
Population Association of America/Association of Population Centers  
[paaapc@crosslink.net](mailto:paaapc@crosslink.net), 202-341-7283

**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) and the National Center for Health Statistics (NCHS). Given the uncertainty of the Fiscal Year 2013 final appropriations deliberations and the delayed release of the President's FY 2014 budget, we urge the subcommittee to provide the highest possible funding level for NIH and NCHS and to not go below the FY 2013 requested level for these agencies. Further, we encourage the Subcommittee to stop the pernicious cuts to research funding and statistical agencies that squander invaluable scientific opportunities and threaten the ability of our members to continue making important contributions towards improving the health and well being of the American people, to train the next generation of population scientists, and to prevent the permanent loss of key longitudinal data.

**Background on the PAA/APC and Demographic Research**

The Population Association of America (PAA) ([www.populationassociation.org](http://www.populationassociation.org)) is a scientific organization comprised of over 3,000 population research professionals, including demographers, sociologists, statisticians, and economists. The Association of Population Centers (APC) ([www.popcenters.org](http://www.popcenters.org)) is a similar organization comprised of over 40 universities and

research groups nationwide that foster collaborative demographic research and data sharing, translate basic population research for policy makers, and provide educational and training opportunities in population studies.

Demography is the study of populations and how or why they change. Demographers, as well as other population researchers, collect and analyze data on trends in births, deaths, and disabilities as well as racial, ethnic, and socioeconomic changes in populations. 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). Below are examples of the important population research activities that these Institutes support.

#### **National Institute on Aging**

According to the U.S. Census Bureau, the number of people age 65 and 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 three-fold, to 19 million. To inform 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 of Demography of Aging, the NIA BSR Division also supports several large, accessible data

surveys. These surveys include a new study, the National Health and Aging Trends Study (NHATS), which has enrolled 8,000 Medicare beneficiaries with the goal of studying trends in late-life disability trends and dynamics. The study also includes a supplement to examine informal caregivers and their impact on the long-term care utilization of people with chronic disabilities. Another NIA survey, the Health and Retirement Study (HRS), has become one of the seminal sources of information to assess the health and socioeconomic status of older people in the U.S. Since 1992, the HRS has tracked 27,000 people, providing data on a number of issues, including the role families play in the provision of resources to needy elderly and the economic and health consequences of a spouse's death. HRS is so respected that the study is being replicated currently in 30 other countries, providing important data on how the U.S. compares with other countries whose populations are aging more rapidly. In March 2012, HRS posted genetic data collected voluntarily from over half of the HRS participants to dbGAP, the NIH's online genetics database. These data are now available for analysis by qualified researchers to track the onset and progression of diseases and disabilities affecting the elderly.

**Eunice Kennedy Shriver National Institute on Child Health and Human Development**

Since its establishment in 1968, the Eunice Kennedy Shriver NICHD Center for Population Research has supported research on population processes and change. As a result of the Institute's recent reorganization, this research is now housed in the Population Dynamics Branch. This branch supports research in three broad areas: demography, HIV/AIDs, other sexually transmitted diseases, and other reproductive health; and population health, with focus on early life influences and policy.

NICHD is the major supporter of the 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; the National Longitudinal Study of Youth, a multigenerational study of health and development; and the National Longitudinal Study of Adolescent Health (Add Health), tracing the effects of childhood and adolescent exposures on later health. NICHD supports the prompt and widespread release of demographic data collected with NIH and other Federal government funding through the Demographic Data Sharing and Archiving project.

One of the most important population research programs the NICHD supports is the Research Infrastructure for Demographic and Behavioral Population Science (DBPop). This program promotes innovation, supports interdisciplinary research, translates scientific findings into practice, and develops the next generation of population scientists, while at the same time providing incentives to reduce the costs and increase the efficiency of research by streamlining and consolidating research infrastructure within and across research institutions. DBPop supports research at 24 private and public research institutions nationwide, the focal points for the demographic research field for innovative research and training and the development and dissemination of widely used large-scale databases.

NIH-funded demographic research provides critical scientific knowledge on issues of greatest consequence for American families: marriage and childbearing, childcare, work-family conflicts, and family and household behavior. Demographic research is having a large impact in public health, particularly on issues such as infant and child health and development, and adolescent and young adult health, and health disparities. Research supported by the Population Dynamics

branch has revealed the critical role of marriage and stable families in ensuring that children grow up healthy, achieving developmental and educational milestones. Branch-supported researchers have published a number of recent findings, including a study, based on Add Health data, which concluded that women who are overweight or obese years during the transition from adolescence to adulthood are more likely to later deliver babies with a higher birth weight, putting the next generation at a higher risk of obesity-related health outcomes. In another published study, researchers using genetic and survey data from the Fragile Families and Child Well Being Study, found that post-partum depression was most likely among women with both at-risk genetic profiles and low educational levels.

### **National Center for Health Statistics**

Located within the Centers for Disease Control (CDC), the National Center for Health Statistics (NCHS) is the nation's principal health statistics agency, providing data on the health of the U.S. population and backing essential data collection activities. Most notably, NCHS funds and manages the National Vital Statistics System, which contracts with the states to collect birth and death certificate information. NCHS also funds a number of complex large surveys to help policy makers, public health officials, and researchers understand the population's health, influences on health, and health outcomes. These surveys include the National Health and Nutrition Examination Survey (NHANES), National Health Interview Survey (HIS), and National Survey of Family Growth. Together, NCHS programs provide credible data necessary to answer basic questions about the state of our nation's health. The wealth of data NCHS collects makes the agency an invaluable resource for population scientists.

Despite recent steady funding increases, NCHS continues to feel the effects of long-term funding shortfalls, compelling the agency to undermine, eliminate, or further postpone the collection of

vital health data. For example, in 2009, sample sizes in HIS and NHANES were cut, while other surveys, most notably the National Hospital Discharge Survey, were not fielded. In 2009, NCHS proposed purchasing only “core items” of vital birth and death statistics from the states (starting in 2010), effectively eliminating three-fourths of data routinely used to monitor maternal and infant health and contributing causes of death. Fortunately, Congress and the new Administration worked together to give NCHS adequate resources and avert implementation of these draconian measures. Also, funding from the Prevention and Public Health Fund has been an invaluable source of support for the agency since FY 2011, providing much needed funding to, for example, add components to NHANES, to purchase updated vital statistics data from the states, and to facilitate the implementation of electronic birth records in the all states. With funding from the NIH, the agency is also working to expedite the release of mortality data from the National Death Index. However, the progress NCHS has made is threatened if the agencies that it relies on for support (through funding from the HHS evaluation tap and via interagency agreements) continue to be cut.

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 2014 appropriations process proceeds.

## Written Testimony

### **FY14 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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President,

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**March 15, 2013**

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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 FY2014 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 1.35% of the National Institutes of Health's (NIH's) total FY2014 funding level.

Operating under the continuing resolution, NIDCR is funded at \$410,222,000 (after rescission and other adjustments). Sequestration will slash at least \$20,500,000 from this adjusted budget authority, bringing NIDCR to a funding level not realized since 2007, \$389.7 million. Needless to say, in addition to diminished grant opportunities that will only discourage young and talented researchers, NIDCR will not be able to keep up with the increasing rate of medical inflation. The six-month spending bill currently being considered by Congress will do little to cushion the blow of sequestration to NIDCR.

For NIDCR to realize its true potential, a viable solution is to ensure NIDCR receives its proper due of total NIH funding. The percentage of NIH funding that NIDCR receives has steadily declined over the years—even when NIH's budget doubled—from 1998 to 2011. During this period, NIDCR's percentage of total NIH funding decreased from 1.53% to 1.33%, its lowest percentage in a decade. Friends of NIDCR would welcome the opportunity to work with members of this Subcommittee to restore NIDCR funding to a percentage of total NIH funding that is appropriate. We realize this must be a gradual approach and the research performed by NIDCR justifies this approach. This is why Friends

of NIDCR recommends a modest increase in NIDCR's percentage of total NIH funding for FY2014 to 1.35%.

### **NIDCR: A Renown Leader in Research**

For 65 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 and research training, and by sharing science-based health information with the public and health care professionals.”*

NIDCR meets its mission by:

- Performing and supporting basic and clinical research;
- Conducting and funding research training and career development programs to ensure an adequate number of talented, well-prepared and diverse investigators is sustained;
- Coordinating and assisting relevant research and research-related activities among all sectors of the research community; and
- Promoting the timely transfer of knowledge gained from research and its implications to health professionals, researchers, and policy-makers; and on the overall well-being of our society.

In addition, NIDCR's Gold Standard Peer Review System ensures that taxpayers' dollars are being utilized in a wise, effective and productive manner.

### **NIDCR Research Benefits 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 (see below), and the presence of these biomarkers resulted in an early diagnosis of oral cancer 93 percent of the time. Moreover, in FY 2011, NIDCR began a large-scale study to identify the early genetic changes that drive the development of oral cancer. 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). Going forward, NIDCR will support research aimed at gaining a clearer take on HPV-related oral cancers, including their incidence, risk factors, natural history and biology.

**Salivary Diagnostics.** The promising prospect of using saliva as a diagnostic fluid to identify a number of emerging diseases, such as cancer, HIV/AIDS, and cardiovascular disease, is an example of the type of cutting-edge research being conducted and supported by NIDCR. Salivary Diagnostics, a non-invasive process, possesses advantages over traditional blood testing, including the absence of needles and the ability to be administered on-the-spot, yielding results in 10 minutes. It is an example of how NIDCR-funded scientists are close to moving their groundbreaking basic science discoveries into clinical care.

**Genome-wide Association Studies:** NIDCR is supporting the first genome-wide association studies, or "GWAS," on cleft lip/cleft palate and dental caries. This is being done in collaboration between epidemiologists, geneticists, informatics experts, and environmental scientists. The studies offer significant potential for understanding the molecular and genetic basis of cleft lip/cleft palate and dental caries with the goal of improving the ability to predict and manage them by providing the first comprehensive compilation of the biological instructions required to construct the middle region of the human face and to define the genetics that create its developmental disorders, according to NIDCR.

Moreover, NIDCR research benefits millions of Americans with:

- Periodontal Disease
- Chronic Dry Mouth
- Chronic Facial and Oral Pain, and
- Bone and Cartilage Regeneration

### **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; it 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.

**University of California, Los Angeles, School of Dentistry:**

*Healing of Craniofacial Defects using Adipose-derived Stem Cells.* Bone engineering using stem cells from adipose tissue (fat tissue) has enormous clinical potential for the treatment of congenital bone defects such as cleft palates. One of the most common craniofacial birth defects seen is the cleft palate with one in every 600 newborns being affected in each year in the U.S. Such defects may be able to be healed in the newborn using a combination of the newborn's own stem cells - derived from their fat - combined with specially designed scaffolds. Such a strategy, if successful, may also have applicability to other common craniofacial abnormalities in children thus decreasing the substantial financial burden imposed each year on the US medical system.

**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<sup>1</sup>, sequestration has taken effect. However, Friends of NIDCR maintains that investment in 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 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.<sup>2</sup> NIDCR-funded grants contribute to our nation's economy and keep scientists from looking abroad for work. FY2012 NIDCR-funded grants had a presence in 121

<sup>1</sup> "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](http://www.researchamerica.org/release_14march12_poll)

<sup>2</sup> *Ibid.*

congressional districts (often multiple awards for a congressional district) in 41 states and territories. 844 grants were awarded for FY12. This equates to 75 percent of NIDCR-funded research being distributed to grantees at universities, dental schools, and medical schools, primarily in the United States. Therefore, a significant portion of NIDCR-funded research occurs off the NIH campus and around the country. However, this nationwide NIDCR presence will surely decline with decreased investment in research.

### **Health Disparities Research Program**

Finally, through community-based disparities research funded by NIDCR, a difference is being made in meeting the health needs of our nation's low-income, underserved, and high-risk populations. Sadly, this need was made apparent with the tragic passing of 12-year-old Deamonte Driver who died from a tooth infection in 2007. NIDCR funds five centers that are conducting seven clinical trials aimed at reducing early childhood caries, improving the oral health of disadvantaged pregnant women, and increasing early detection of oral cancer.

### **RECOMMENDATION**

Eighty-five percent of Americans are concerned about stagnate funding for medical research.<sup>3</sup> 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 how saliva can be used to detect early indications of disease—or searching for breakthroughs to help our combat veterans—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 1.35% 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.

<sup>3</sup> "America Speaks," Poll Data Summary Volume 13, Research!America, <http://www.researchamerica.org/uploads/AmericaSpeaksV13.pdf>

Testimony of **Daniel Paul Perez**, President & CEO, **FSH Society, Inc.**  
 Telephone: (781) 275-7781, e-mail: [daniel.perez@fshsociety.org](mailto:daniel.perez@fshsociety.org) before the  
 United States House Appropriations Committee  
 Subcommittee on Labor, Health and Human Services, and Education  
 On the subject of **\$12 million FY2014 Appropriations for U.S. DHHS National Institutes of Health (NIH) Research Programs on Facioscapulohumeral Muscular Dystrophy (FSHD)**  
 March 15, 2013

Honorable Chairmen Rogers and Ranking Member Lowey, thank you for the opportunity to submit this testimony. I am Daniel Paul Perez, of Bedford, Massachusetts, President and CEO of the FSH Society, Inc. and an individual who has lived with facioscapulohumeral muscular dystrophy (FSHD) for 50 years. For hundreds of thousands of men, women, and children worldwide the major consequence of inheriting this 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 family constellations.

The National Institutes of Health (NIH) is the principal source of funding of research on Facioscapulohumeral Muscular Dystrophy (FSHD) currently at the \$6 million level. Over many years, this Committee has supported the incremental growth in funding for FSHD research. I am pleased to report that this modest investment has produced huge scientific returns.

### **1. Congress has made a major difference in muscular dystrophy**

I have testified many times before Congress. 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 muscular dystrophy. Congress is responsible for this success, through its sustaining support of the National Institutes of Health (NIH), and the enactment of the Muscular Dystrophy CARE

Act. I am testifying in order to document this success and call on Congress to continue the momentum of discovery you have set in motion.

Congress enacted The Muscular Dystrophy Community Assistance, Research and Education Amendments of 2001 (the MD-CARE Act, Public Law 107-84) on December 18, 2001. It was reauthorized in 2008 and new efforts are underway to reauthorize the MD-CARE Act as it will expire in 2013. We are hopeful that this reauthorization bill will receive the same overwhelming bi-partisan support enjoyed in earlier enactments.

## **2. Quantum leaps in our understanding of FSHD have occurred in past three years**

The past three 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.<sup>1</sup> 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."<sup>2</sup>
- Two months later, another paper was published that made a second critical advance in determining the cause of FSHD.<sup>3</sup> The research shows that FSHD is caused by the inefficient suppression of a gene that may be normally expressed only in early development.
- On January 17, 2012, an international team of researchers based out of Seattle discovered a gene called DUX4 required to develop chromosome 4 linked FSHD.
- 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.<sup>5</sup> This work was also supported by a NIH cooperative research center grant mandated by MD CARE Act.

- On July 13, 2012, a team of international 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.

I am proud to say that 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 National Institutes of Health, and the Muscular Dystrophy Association and other partners. This shows the power of the collaboration among funders, patient groups and researchers to advance the search for cures and treatments.

### **3. Remarkable progress in FSHD research and the need to keep moving forward**

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, by accelerating efforts in the following **five** areas:<sup>7</sup>

1. **Genetics / epigenetics**
2. **FSHD molecular networks**
3. **Clinical trial readiness**
4. **Model systems**
5. **Sharing**

We would be pleased to provide the Committee with detailed information on each of these areas. The pace of discovery and numbers of experts in the field of biological science and

clinical medicine working on FSHD are rapidly expanding. Many leading experts are now turning to work on FSHD not only because it is one of the most complicated and challenging problems seen in science, but because it represents the potential for great discoveries, insights into stem cells and transcriptional processes and new ways of treating human disease.

#### 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 exceedingly modest.

**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; as FY2012 actuals not available on-line as of March 12, 2013)

Fiscal Year	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012 <sup>e</sup>
All MD (\$ millions)	\$12.6	\$21	\$27.6	\$39.1	\$38.7	\$39.5	\$39.9	\$47.2	\$56	\$83	\$86	\$75	\$75
FSHD (\$ millions)	\$0.4	\$0.5	\$1.3	\$1.5	\$2.2	\$2.0	\$1.7	\$3	\$3	\$5	\$6	\$6	\$6
FSHD (% total MD)	3%	2%	5%	4%	6%	5%	4%	5%	5%	6%	7%	8%	8%

Despite the great success of the past two and a half years in the science of FSHD brought about by Congress we are concerned that the budget cuts required by the sequester are coming at a time when many of the FSHD research projects are ending. It is likely that new research projects will not be funded or existing programs will not be renewed. This is a perfect storm that could have devastating effects on FSHD research efforts. I served on the federal advisory committee MDCC for nine years until 2011. We have conveyed to the Executive Secretary of the MDCC our grave concern that the current portfolio of research on FSHD has a disproportionate number of FSHD grants near the end or in the last year of their grant cycles. While most are

competitively renewable this occurrence could not have happened at a worst time with sequestration making meat axe cuts across all federal agencies.

We request for FY2014, a doubling of the facioscapulohumeral muscular dystrophy (FSHD) research budget to \$12 million dollars. This will allow an expansion of the U.S. DHHS NIH Senator Paul D. Wellstone Muscular Dystrophy Cooperative Research Centers, an increase in research awards, expansion of post-doctoral and clinical training fellowships, and a dedicated center to design and conduct clinical trials on FSHD.

We are aware of the great pressures on the federal budget, but cutting the NIH budget and research funding for FSHD at this time would be the wrong decision. We have come so far with such modest funding. This is not the time to lessen our endeavor. 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.

Footnotes:

1. Lemmers, RJ, et al, A Unifying Genetic Model for Facioscapulohumeral Muscular Dystrophy *Science* 24 September 2010; Vol. 329 no. 5999 pp. 1650-1653
2. Kolata, G., Reanimated 'Junk' DNA Is Found to Cause Disease. *New York Times*, Science. Published online: August 19, 2010 <http://www.nytimes.com/2010/08/20/science/20gene.html>
3. Snider, L., Geng, L.N., Lemmers, R.J., Kyba, M., Ware, C.B., Nelson, A.M., Tawil, R., Filipova, G.N., van der Maarel, S.M., Tapscott, S.J., and Miller, D.G. (2010). Facioscapulohumeral dystrophy: incomplete suppression of a retrotransposed gene. *PLoS Genet.* 6, e1001181
4. Geng et al., DUX4 Activates Germline Genes, Retroelements, and Immune Mediators: Implications for Facioscapulohumeral Dystrophy, *Developmental Cell* (2012), doi:10.1016/j.devcel.2011.11.013
5. Jones TI, et al, Facioscapulohumeral muscular dystrophy family studies of DUX4 expression: evidence for disease modifiers and a quantitative model of pathogenesis. *Hum Mol Genet.* 2012 Oct 15;21(20):4419-30. Epub 2012 Jul 13.
6. Lemmers, RJ, et al, Digenic inheritance of an SMCHD1 mutation and an FSHD-permissive D4Z4 allele causes facioscapulohumeral muscular dystrophy type 2. *Nat Genet.* 2012 Dec;44(12):1370-4. doi: 10.1038/ng.2454. Epub 2012 Nov 11.
7. 2012 FSH Society *FSHD International Research Consortium*, held November 6, 2012 co-sponsored by DHHS NIH NICHD Boston Biomedical Research Institute Senator Paul D. Wellstone MD CRC for FSHD. To read the expanded summary and recommendations of the group see: <http://www.fshsociety.org/pages/sciConsortium.html>

**David M. Ratcliffe**

**Chairman of the Corporate Friends of CDC**

House Committee on Appropriations Subcommittee on Labor, Health and Human Services,

Education and Related Agencies

**Public Witness Hearing, Congressional Testimony**

Wednesday, March 13, 2013

Written Statement for the Record (3/15/13)

My name is David Ratcliffe, and I am the Co-Chairman of the Corporate Friends of the Centers for Disease Control and Prevention (CDC), alongside Co-Chairman, John Rice of General Electric. I am testifying in support of CDC's budget for fiscal year 2014 and requesting that the Chairman and his colleagues on the Labor, Health and Human Services, Education and Related Agencies Subcommittee Committee consider restoring CDC's budget authority to fiscal year 2010 levels. I am also asking the Committee to consider allowing more flexibility for the Director of the CDC with his annual budget.

Chairman Kingston, Ranking Member DeLauro, and distinguished Members of the Subcommittee, it is my honor to submit a statement on behalf of the Corporate Friends of CDC. My message to Congress is that, while cuts to the federal budget may be inevitable and indeed necessary, CDC should not be targeted for disproportionately large cuts. CDC is our nation's designated health protection agency and an operating division of the Department of Health and Human Services. We must protect CDC's core mission of securing Americans from health threats, saving American lives, and saving money by keeping Americans healthy.

As a federal agency, CDC cannot and does not advocate or lobby on its behalf. The Corporate Friends is a registered 501(c)4 corporation structured to provide advocacy and education efforts about CDC's significance to our nation's health and safety. As a former President and CEO of Southern Company, I fully support CDC's operation as vitally important to our nation's security. Much like our Department of Defense protects American's from military threats; CDC is committed to its job of protecting Americans from health, safety and security threats both foreign and domestic. Whether diseases start at home or abroad, are chronic or acute, curable or preventable, human error or deliberate attack, CDC and its collaboration with state

and local health departments are our first line of defense. CDC applies groundbreaking health and medical research and real-time emergency response to keep America healthy, safe, and secure.

Since 2011, I have had the privilege of working closely with one of Atlanta's most treasured resources, the CDC. The CDC is unique in that it is one of the only federal agencies headquartered outside of the Washington, D.C. beltway. This makes the connection to corporations and what CDC does even more evident. Atlanta is my hometown, along with 5 million other people, and CDC is a substantial contributor to employment, investment and tax base in Georgia, with almost \$940 million in payroll annually to Georgia, and over 8,000 employees, making it one of the state's top 15 employers.

I see firsthand that CDC's research science and outreach keeps employees and their families safe and healthy, while ensuring that our businesses can compete around the world in a safe, healthy environment. CDC is vital to a healthy national workforce and economy. CDC contributions expand well beyond Georgia, as more than 70 percent of CDC's funding goes to state and local agencies across the U.S. By doing so, CDC further sets the standard for action-oriented public health initiatives and research. CDC provides emergency preparedness and response 24/7 to any health threat. Through its efforts CDC has prevented 5-10 million cases of influenza, 30,000 hospitalizations, and about 1,500 deaths in the U.S. In the past few years, CDC has conducted more than 750 field investigations on health threats in the U.S. and in more than 35 countries. Whether through its global health initiatives or local foodborne illness investigations, the work of the CDC could not be more important. CDC's world-class work and importance to our nation's economic health and security is not lost on the voting public who

national polls, now, for many years have voted CDC as the most trusted agency of the federal government.

Therefore, I must express my concern for CDC's budget outlook for its fiscal year 2014. While CDC and all federal agencies operate under a Continuing Budget Resolution and sequestration, I ask that you give consideration to strengthening CDC during your fiscal year 2014 appropriations negotiations. CDC has already received more than \$750 million in cuts to its base appropriations since 2009, and I ask that you look to preserve base funding levels as a commitment to our nation's safety against current and unknown health threats. It is important for the Members of the Committee to understand that CDC's budget has been cut almost five percent, yet our nation's health threats continue to grow.

The current and future budgetary challenges and economic landscape make the need for a strong CDC greater than ever. Recession-driven cuts in federal, state, and local spending have reduced public health workers by about a fifth. The impact of the latest cuts for the second part of the fiscal year equal about \$350 million and provide even less flexibility for the CDC Director to improve the effectiveness of his budget. Americans and the American corporations, for whom I speak, want to know that they will be protected from a possible meningitis outbreak, E. coli threat, a whooping cough outbreak, chemical and biological terrorist threats, a new virus or other unknown epidemic. The snowballing impact of proposed cuts, from annual budgeting or sequestration, reduces the ability of the CDC to swiftly respond to problems.

Unless we can change proposed allocations and give the CDC director more flexibility to better use more limited resources, long standing core programs like Immunization Services across the country and Infectious Disease detection and response at CDC will be compromised. Prevention and public health are best buys, and in many cases can help reduce long-term health

costs and save taxpayer dollars. The world, our country and our national and global workforces are facing more drug resistance and emerging diseases, and protection against this is being compromised. Disease knows no borders and affects people anywhere and everywhere. We need CDC to protect the health of the world, and also the health of the economy. The CDC is the nation's defense department for health, working 24/7 to protect Americans from health safety and security threats that could negatively impact our bottom lines.

On behalf of the Corporate Friends of CDC, I am happy to be a resource to you all as you anticipate the 2014 budgeting process, so please do not hesitate to contact me.

**OUTSIDE WITNESS TESTIMONY  
OF STEVE CLIFTON, PRESIDENT  
NATIONAL COUNCIL OF SOCIAL SECURITY MANAGEMENT ASSOCIATIONS**

**Submitted to the House Committee on Appropriations  
Subcommittee on Labor, Health, and Human Services,  
Education, and Related Agencies**

On behalf of the National Council of Social Security Management Associations (NCSSMA), we respectfully request a minimum of \$12.3 billion for the Social Security Administration's (SSA) Limitation on Administrative Expenses (LAE) account in fiscal year (FY) 2014 funding. This level of funding is necessary to respond to the increased requests for assistance from the American public due to the aging of the baby boom generation and the economic downturn. Without adequate funding, SSA will be unable to provide the high-quality customer service Americans have come to expect and deserve.

SSA teleservice centers, hearing offices, program service centers, disability determination services (DDS), and the 1,200 field offices (FOs) are in critical need of adequate resources to address their growing workloads. The recommended FY 2014 funding level of no less than \$12.3 billion would allow SSA to cover inflationary increases, continue efforts to reduce hearings and disability backlogs, increase deficit-reducing program integrity work, and replace some critical staffing losses in SSA's components. It would also help to minimize the closure of additional field offices.

SSA is challenged by ever-increasing workloads, very complex programs to administer, and increased program integrity work with diminished staffing and resources. Despite SSA's enormous challenges,

SSA's FY 2012 appropriation for administrative funding through the LAE account was around \$300 million below the FY 2011 enacted level after rescissions from Carryover Information Technology funds. This funding level was over \$1 billion below the President's budget request and did not allow SSA to cover inflationary costs for fixed expenses. It resulted in significant reductions in the agency's vital services, including a continuation of the hiring freeze in most of SSA, closing all FOs to the public one-half hour earlier, the closing of FOs at noon on Wednesdays (effective January 2013), the consolidation of 41 FOs and the closure of 490 remote contact stations since FY 2010, suspension of mailing annual benefit statements to the public, and postponement of efficiency initiatives.

The need for resources in FOs is critical to provide vital services to the American public. SSA has lost approximately 9,100 federal and state employees since the end of FY 2010 and will have approximately the same number of employees in FY 2013 as it did in FY 2007. FO staffing has gone from 29,481 employees at the end of FY 2010 to 26,409 employees in February 2013—a 10.4 percent decrease. In the last two years, more than 600 SSA FOs have lost more than 10 percent of their staff and 16 percent of all SSA FOs have had a net attrition loss of over 20 percent.

Geographic staffing disparities will only increase as ongoing attrition spreads unevenly across the country. This leaves many offices significantly understaffed and without sufficient capacity to address workloads.

One of the greatest concerns for SSA is the huge increase in Retirement, Survivor, Dependent, Disability, and Supplemental Security Income (SSI) new claims and appeals. Since FY 2007, retirement and survivor claims are up 30 percent, and disability claims up 25 percent. This increase is driven by the economic downturn and by the nearly 80 million baby boomers who will be filing

for Social Security benefits by 2030—an average of 10,000 per day.

In FY 2012, disability claims receipts exceeded 3 million for the fourth successive year. Since FY 2008, the number of claims pending for a disability medical decision rose from 565,286 to 707,700 in FY 2012—an increase of 142,414, or 25.2 percent. Despite the fact disability receipts have exceeded 3 million for four successive years, the current staffing level for DDSs is 14,076, which is 2,117 (13.1 percent) below the level at the end of FY 2010. A continued hiring freeze in DDSs for FY 2013 will not allow SSA to complete as many disability claims as received.

SSA was making progress in addressing the enormous backlog of hearings cases, but resource issues have magnified the challenges. After December 2008, when the number of pending hearings rose to 768,540, the backlog was reduced for 19 straight months, to 694,417 in June 2010. However, pending hearings began to increase again and in February 2013 stood at approximately 832,000 cases. In FY 2012, 849,869 hearing requests were filed, which nearly matched the all-time high for hearing requests in FY 2011, an increase of over 45 percent since FY 2006. The number of disability claims pending is still not acceptable to the millions of Americans who depend on Social Security or Supplemental Security Income for their basic income, meeting health care costs, and supporting their families.

SSA FOs continue to serve a near record number of visitors. Each day, almost 182,000 people visit FOs and more than 445,000 people call SSA for assistance. Despite agency online service initiatives and the reduction of public service hours, 44.9 million visitors were served by FOs in FY 2012, which was approximately the same as in each of the previous three years. In addition, the SSA FO

busy rate to answer public telephone calls has increased from 7.4 percent in FY 2012 to 15.2 percent (through February 2013).

Program integrity initiatives save taxpayer dollars and are fiscally prudent in reducing the federal budget and deficit. To address program integrity, the President's FY 2013 SSA budget request included a \$1.024 billion request for the two most cost-effective tools to reduce improper payments—medical Continuing Disability Reviews (CDRs) and SSI redeterminations. The same SSA FO employees who answer telephone calls, take initial claim applications, and develop and adjudicate benefit claims, also process medical CDRs, which yield \$9 in lifetime program savings for every \$1 spent; and SSI redeterminations, which provide a return on investment of \$6 in program savings over 10 years for each \$1 spent, including Medicaid savings accruals. *If SSA were to receive the full \$1.024 billion requested by the President the estimated program savings over the next ten years would be \$8.1 billion.* However, as a result of the sequester and the current continuing resolution, SSA may not be able to accomplish these levels of program integrity workloads.

For millions of Americans, SSA is the face of the federal government. Backlogs and delayed services at SSA FOs result in inefficiencies and are a source of customer frustration. Last year, FOs received nearly 4,000 incidents of threat or violence, and there were over 500 incidents in the first three weeks of this year. Untimely services can be also economically disastrous to beneficiaries with disabilities who attempt to return to work and must report their work activity.

Without question, SSA would have used the President's proposed funding for FY 2013 of \$11.76 billion for the LAE account to address the growing workloads facing the agency. Projecting to FY

2014, we estimate SSA will require approximately \$300 million in additional funding just to address inflationary costs associated with items such as salaries, employee benefits, rent, and facility security. SSA would also need additional resources to address the backlog of post-eligibility work and medical CDRs. **By our estimates, this brings SSA's overall administrative funding needs to a minimum of \$12.3 billion for FY 2014.**

The effect of sequestration on FY 2013 SSA operations will result in a reduction of \$386 million from the current continuing resolution operating level of \$11.520 billion. Pending levels of initial disability claims could rise by over 140,000 claims; applicants may wait two weeks longer for initial disability decisions and nearly a month longer for disability hearing decisions; and staffing losses (attrition without replacement) of over 3,400 more employees are anticipated in FY 2013.

It is essential to preserve good service to the American public at SSA. SSA must be properly funded to ensure the efficient, accurate, and expeditious administration of this vital social program. We realize that the FY 2014 funding level outlined above is significant, particularly in this difficult federal budget environment. However, Social Security is the safety net of America and is facing unprecedented challenges due to the aging of the baby boomers and the economic downturn. The American public expects and deserves SSA's assistance. SSA needs proper resources to fulfill its stewardship responsibilities, process its core workloads, reduce the hearings backlog and accomplish critical program integrity workloads, which ensure accurate payments, save taxpayer dollars, and is fiscally prudent. We are confident this investment in SSA will benefit our entire nation. We sincerely appreciate your consideration of this request.



STATEMENT OF

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Dean, Tufts Clinical and Translational Science Institute  
Executive Director, Institute for Clinical Research and Health Policy Studies  
Tufts University and Tufts Medical Center, Boston, MA

ON BEHALF OF

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Society for Clinical and Translational Science, 2025 M St., NW, Suite 800, Washington, DC 20036

REGARDING

Fiscal Year 2014 (FY14) appropriations for clinical and translational Research and research training programs at National Institutes of Health (NIH), Agency for Healthcare Research and Quality (AHRQ), and related agencies

SUBMITTED TO

The House Labor, Health and Human Services, Education, and Related Agencies (LHHS)  
Appropriations Subcommittee

MARCH 15<sup>TH</sup>, 2013

JAC FY14 LHHS APPROPRIATIONS RECOMMENDATIONS

- Protect clinical and translational research and research training programs from devastating funding cuts through sequestration and deficit reduction activities.
- Provide \$32 billion for NIH, an increase of \$1.3 billion over FY12.
- Provide meaningful funding increases for AHRQ and related agencies that support clinical and translational research.
- Provide continued support for federal research training and career development activities such as the "K" and "T" awards programs.

Chairman Kingston, Ranking Member DeLauro, and distinguished members of the Subcommittee, thank you for the opportunity to submit written testimony on behalf of JAC.

#### THE JAC

JAC is comprised of organizations representing the clinical and translational research and research training community; the Association for Clinical Research Training, the Association for Patient-Oriented Research, Clinical Research Forum, and the Society for Clinical and Translational Science. These organizations are dedicated to improving the health of the public through clinical and translational research and to supporting this nation's research training and career development pipeline. JAC speaks with one voice on behalf of this community to advocate for adequate funding of clinical and translational research and research training programs at NIH, AHRQ, and related federal agencies like the Patient-Centered Outcomes Research Institute.

#### DEFICIT REDUCTION AND SEQUESTRATION

Our nation's investment in the full spectrum of biomedical research is an engine that drives economic growth while improving health outcomes for patients with chronic, costly, and life-threatening conditions. Research projects funded through NIH, AHRQ, and related agencies are conducted at academic health centers across the country. Federally-supported clinical and translational research activities have a meaningful economic impact on local communities, which includes high-quality job creation, in addition to forming a cornerstone of this nation's biotechnology industry. Translational research embraces the two poles of biomedical research, from bench-to-bedside and from clinical-trial-to-population. Cutting funding to NIH, AHRQ, and related programs would have direct and immediate negative consequences for the local communities that support clinical and translational research activities.

More troubling and problematic is the message that funding cuts to clinical and translational research programs would send to the next generation of researchers. Medical research activities are not a faucet that can simply be turned off and on with funding. When funding begins to dry up our best and brightest are faced with a strong disincentive to pursue a career in this field. It is difficult to justify a tremendous amount of training when a young investigator has slim chances of securing a federal grant to support their research. Currently, NIH cannot fund many promising meritorious grant submissions and only funds about 6% of all grant applications. Further, the average age for a researcher having their first grant funded is presently 42. If funding is cut, the pay line will drop further and the average age for securing a grant will rise. Compounding this situation is a very real threat to losing top research talent posed by biotechnology investments being made by several other countries. China alone plans to dedicate \$300 billion to medical research over the next five years; this amount is double the current NIH budget over the same period of time. Research is not beholden to language or culture and young investigators will gravitate towards any country that has the resources to support their promising research. Unless we provide a meaningful investment in clinical and translational research training programs over the coming years, our loss will be our competitors' gain. We will concede innovation in healthcare delivery and cutting-edge therapies to foreign biotech industries.

Most importantly, cutting funding to clinical and translational research programs will delay and jeopardize healthcare advances that would benefit patients managing serious and life-threatening medical conditions and cut healthcare costs. Federal programs focused on developing personalized medicine and patient-focused care are only just beginning to be implemented. If these programs are forced to confront reduced resources in their infancy, they may never be able to achieve their potential or accomplish their missions. A loss of funding for NIH, AHRQ, and

related agencies would seriously undermine the ongoing effort to bring this country's healthcare system in to the 21<sup>st</sup> century. Setbacks in this area would be felt by the patient community.

#### SUPPORT FOR CLINICAL AND TRANSLATIONAL RESEARCH ACTIVITIES

With the establishment of the Clinical and Translational Science Awards (CTSA) program in 2006, NIH began a commitment to supporting the full spectrum of research to bridge the gap between basic scientific discoveries and the bedside. In 2011, the CTSA Consortium reached its planned size of 60 medical research institutions located throughout the nation, linking them together to energize the discipline of clinical and translational science. The CTSA's have an explicit goal of improving healthcare in the United States by transforming the biomedical research enterprise to become more effectively translational.

Although the promise of the CTSA program is recognized both nationally and internationally, it has suffered from a lack of adequate funding. In 2006, 16 initial CTSA's were funded, followed by 12 in 2007, 14 in 2008, 4 in 2009, 9 in 2010, and 5 in 2011. Level funding at NIH curtailed the growth of the CTSA's, preventing institutions from fully implementing their programs and causing them to drastically alter their budgets after research had already begun. Without enough funding for CTSA's we risk jeopardizing new and existing research projects.

Comparative effectiveness research (CER) is the evaluation of the impact of different options that are available for treating a given medical condition for a particular set of patients. This broad definition can include medications, behavioral therapies, and medical devices, among other interventions, and is an important facet of evidence-based medicine. Both AHRQ and NIH have long histories of supporting CER, and the standards for research instituted by these agencies serve as models for best practices worldwide. Not only are these agencies experienced in CER, they are universally recognized as impartial and honest brokers of information.

Moreover, their approach is supplemental to, not duplicative of, that of the new Patient-Centered Outcomes Research Institute, and continued support is critical to ensuring this emerging area can flourish.

#### SUPPORT FOR RESEARCH TRAINING AND CAREER DEVELOPMENT PROGRAMS

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, not to reduce them. Career development grants are crucial to the recruitment of promising young investigators, as well as to the continuing education of established investigators. Reduced commitment to the K-12, K-23, K-24, and K-30 awards would have a devastating impact on our pool of highly trained clinical researchers. Even with the full implementation of the CTSA program, it is critical for institutions without CTSA to retain their K-30 Clinical Research Curriculum Awards, as the K-30s remain a highly cost-effective method of ensuring quality clinical research training. The JAC urges you to support the ongoing commitment to research training through adequate funding for T and K series awards.

Thank you for the opportunity to present the views and recommendations of the clinical research training community. Please contact JAC if you have any questions or if you would like any additional information.

COMMENTS OF

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ON BEHALF OF

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REGARDING

**Fiscal Year 2014 (FY14) Appropriations for the Centers for Disease Control and Prevention  
(CDC) and the National Institutes of Health (NIH)**

SUBMITTED TO

**The House Labor, Health and Human Services, Education, and Related Agencies (LHHS)  
Appropriations Subcommittee**

ON

**The 15<sup>th</sup> Day of March, 2013**

NAAF FY14 LHHS APPROPRIATIONS RECOMMENDATIONS

- **Protect medical research and patient care programs from devastating funding cuts through sequestration and deficit reduction activities.**
- **\$7.8 billion for CDC, an increase of \$1.7 billion over FY12.**
- **\$32 billion for NIH, an increase of \$1.3 billion over FY12.**

Chairman Kingston, Ranking Member DeLauro, and distinguished members of the Subcommittee, thank you for the opportunity to submit testimony on behalf of NAAF. It is my privilege to represent the great group of individuals affected by the autoimmune disease alopecia areata.

#### ABOUT THE FOUNDATION AND ITS RESEARCH

NAAF, headquartered in San Rafael, CA, 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 (NIAMS); 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.

At the Research Summit Dr. Angela Christiano of Columbia University, discoverer of the genetic basis of alopecia areata, presented her progress in genetics research. A joint analysis performed with an independent genome-wide association study (GWAS) of 1435 cases and 2032 controls resulted in the validation of previous GWAS targets and the identification of new associated genes. Some of these associated genes are unique to the hair follicle in alopecia areata. Dr. Christiano discussed targeting the IFN signature in the treatment of alopecia areata. She also discussed the genetic relationship between alopecia areata and other autoimmune diseases including the minimal overlap with psoriasis or vitiligo. This work greatly expands our understanding of the genetic architecture of this highly prevalent autoimmune disease.

Later this year the Proceedings of the Summit will be published in the *Journal for Investigative Dermatology (JID)*. The participants will be finalizing the goals for the next two years to be met by the following Alopecia Areata Research Summit in the fall of 2014. Those goals include:

#### Genetics:

- Execute combined association and linkage studies using 250 multiplex families from the Alopecia Areata Registry
- Utilize functional genomics with deep sequencing
- Develop network plot

- Analyze shared variants with related diseases including celiac disease, rheumatoid arthritis, type 1 diabetes; 5 loci shared between type 1 diabetes and alopecia areata
- Develop a biobank
- Determine if there is a genetic basis for disease subsets, i.e. alopecia areata patchy, alopecia areata totalis, alopecia areata universalis
- Increase alopecia areata samples to 10,000

#### Immunology:

- Study how to restore immune privilege
- Analyze the potential of targeting IL-15 pathway
- Identify the protolerance TCR signal; then target it pharmacologically
- Develop T cell receptor sequencing
- Complete biomarker studies

#### Animal Models:

- Identify and develop mouse and humanized mouse models
- Validate models
- Determine which model will be the best to replicate alopecia areata

#### Clinical:

- Finalize and validate Alopecia Areata Uniform Protocol
- Publish quality of life studies
- Publish incidence and prevalence studies
- Initiate burden of diseases studies
- Use pharmacogenomics to predict patient populations that will respond and which will get side effects
- Determine the attractive pathways for targeted therapy
- Continue collaborations with industry and government agencies to facilitate the regulatory path for alopecia areata treatments

### 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 two percent of the population, including more than five 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. We do not have known biomarkers at this time but an NIH-funded study is seeking to identify biomarkers.

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.

#### DEFICIT REDUCTION AND SEQUESTRATION

As you work with your colleagues in Congress on deficit reduction, budget, and appropriations issues please support the alopecia areata community by actively pursuing meaningful funding increases for critical medical research and healthcare programs. Our nation's investment in biomedical research, particularly through NIH, is an engine that drives economic growth while improving health outcomes for patients. NIH currently supports a modest, but integral research portfolio in alopecia areata. The research funded through this portfolio is conducted at academic health centers across the country, which has a direct impact on local economic activity. Further, while more work needs to be done, the commitment to NIH's alopecia areata research portfolio over the years has greatly increased our scientific understanding of the condition.

If federal funding for alopecia areata research is substantially reduced, the current effort to capitalize on recent advancements and develop treatment options will face a serious setback. Ongoing research projects will stall and critical new research projects will not be initiated.

In addition, reducing support for federal biomedical research efforts sends a powerful message to the next generation about our country's lack of commitment to this field. Many talented young people interested in biomedical research will seek other career paths. The damage done now to the research training and career development pipeline could last for decades and undermine this country's entire biomedical research industry. It should also be noted that the next generation of researchers will face increased competition for their talents from foreign competitors who are investing in their biomedical research infrastructure.

The alopecia areata community is very concerned that if healthcare programs endure significant funding cuts, patients will see few improvements in health and healthcare over the coming years.

#### CENTERS FOR DISEASE CONTROL AND PREVENTION

NAAF joins with other voluntary health organizations in requesting that you support CDC by providing an allocation of \$7.8 billion in FY14. This appropriation should include proportional funding increases for the various centers and programs at CDC, most notably the National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP).

The alopecia areata community could benefit greatly from an analysis of prevalence, incidence, and associated demographic information by CDC. Further, awareness programs could reach children who have not been diagnosed with the condition and who are struggling to understand what is going on with their bodies. Finally, healthcare professionals could benefit from education and awareness activities that would promote proper diagnosis of alopecia areata and appropriate intervention. To initiate new programs that have the potential to improve health outcomes for alopecia areata patients or patients dealing with other condition, CDC would require a meaningful infusion of additional resources. Without additional resources, CDC will be unable to support current programs and activities and forced to forego many emerging opportunities.

#### NATIONAL INSTITUTES OF HEALTH

NAAF joins with the broader public health community in requesting that you support NIH by providing an allocation of \$32 billion in FY14. This appropriation should include proportional funding increases for the various NIH Institutes and Centers, particularly NIAMS, the National Institute of Allergy and Infectious Diseases (NIAID), the National Center for Advancing Translational Research (NCATS), and the Office of the Director.

- NIAMS supports the bulk of alopecia areata research currently conducted through NIH. In order to capitalize on this research and further improve our scientific understanding of the condition, NIH requires additional resources to expand and advance the alopecia areata research portfolio. NIH is presently foregoing meritorious research opportunities and additional funding would allow more of these grants applications to be funded.
- NIAID—Innovative new research activities initiated through NIAID into alopecia areata would add-value to NIAID’s current research projects by leading to breakthroughs that could impact additional autoimmune conditions.
- NCATS—Clinical and translational research are of tremendous importance to the alopecia areata community. Expanding the federal commitment to NCATS would allow the Center to work more effectively with FDA to facilitate the development of treatment options for conditions that currently lack treatments with an FDA indication.
- OD—Due to the autoimmune and genetic components of alopecia areata, research in this area has a significant cross-cutting value. Innovative research activities initiated and coordinated by OD could improve our understanding of both autoimmune conditions and conditions with genetic components.

Thank you for your time and your consideration of these requests. Please contact me if you have any questions or if you would like any additional information.

TESTIMONY OF  
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**President and CEO**

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REGARDING  
**Fiscal Year 2014 (FY14) Appropriations for the Centers for Disease Control and  
Prevention (CDC) and the National Institutes of Health (NIH)**

SUBMITTED TO  
**The House Labor, Health and Human Services, Education, and Related Agencies (LHHS)  
Appropriations Subcommittee**

ON  
**The 15<sup>th</sup> Day of March, 2013**

NMF FY14 LHHS APPROPRIATIONS RECOMMENDATIONS

- **Protect medical research and patient care programs from devastating funding cuts through sequestration and deficit reduction activities.**
- **Provide \$7.8 billion for CDC**, an increase of \$1.7 billion over FY12, including proportional increases for the National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) and the National Center on Birth Defects and Developmental Disabilities (NCBDDD) to facilitate life saving awareness and education activities focused on early recognition and proper diagnosis of Marfan syndrome and related heritable connective tissue disorders.
- **Provide \$32 billion for NIH**, an increase of \$1.3 billion over FY12, including proportional increases for the National Heart, Lung, and Blood Institute (NHLBI); National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS); National Eye Institute (NEI); National Center for Advancing Translational Sciences (NCATS); Office of Rare Diseases Research (ORDR); Office of the Director (OD); and other NIH Institutes and Centers to facilitate adequate growth in the Marfan syndrome and related heritable connective tissue disorders research portfolio.

Chairman Kingston, Ranking Member DeLauro, and distinguished members of the Subcommittee, thank you for the opportunity to submit testimony on behalf of NMF. It is my honor to represent the estimated 200,000 Americans who are affected by Marfan syndrome or a related heritable connective tissue disorder.

#### ABOUT NMF

NMF is a non-profit voluntary health organization founded in 1981. NMF is dedicated to saving lives and improving the quality of life for individuals and families affected by the Marfan syndrome and related disorders. The Foundation has three major goals: 1) To provide accurate and timely information about the Marfan syndrome to affected individuals, family members, physicians, and other health professionals. 2) To provide a means for those with Marfan syndrome and their relatives to share in experiences, to support one another, and to improve their medical care. 3) To support and foster research.

#### ABOUT HERITABLE CONNECTIVE TISSUE DISORDERS

Marfan syndrome is a genetic disorder of the connective tissue that can affect many areas of the body, including the heart, eyes, skeleton, lungs and blood vessels. It is a progressive condition and can cause deterioration in each of these body systems. The most serious and life-threatening aspect of the syndrome is a weakening of the aorta. The aorta is the largest artery carrying oxygenated blood from the heart. Over time, many Marfan syndrome patients experience a dramatic weakening of the aorta which can cause the vessel to dissect and tear.

Aortic dissection is a leading killer in the United States, and 20% of the people it affects have a genetic predisposition, like Marfan syndrome, to developing the complication. Early surgical intervention can prevent a dissection and strengthen the aorta and the aortic valves, especially when preventive surgery is performed before a dissection occurs.

DEFICIT REDUCTION AND SEQUESTRATION

As you work with your colleagues in Congress on deficit reduction, budget, and appropriations issues please support the Marfan syndrome community by actively pursuing meaningful funding increases for critical medical research and healthcare programs. Our nation's investment in biomedical research, particularly through NIH, is an engine that drives economic growth while improving health outcomes for patients. NIH currently supports a meaningful research portfolio in Marfan syndrome coordinated through NIAMS and NHLBI. The research funded through this portfolio is conducted at academic health centers across the country, which has a direct impact on local economic activity. Further, while more work needs to be done, the commitment to NIH's Marfan syndrome and related disorders research portfolio over the years has greatly increased our scientific understanding of these conditions.

If federal funding for Marfan syndrome research is substantially reduced, the current effort to capitalize on recent advancements and develop treatment options will face a serious setback. Ongoing research projects will stall and critical new research projects, particularly new activities coordinated by NEI, NCATS, and ORDR will not be initiated.

In addition, reducing support for federal biomedical research efforts sends a powerful message to the next generation about our country's lack of commitment to this field. Many talented young people interested in biomedical research will seek other career paths. The damage done now to the research training and career development pipeline could last for decades and undermine this country's entire biomedical research industry. It should also be noted that the next generation of researchers will face increased competition for their talents from foreign competitors who are investing in their biomedical research infrastructure.

The Marfan syndrome community is concerned that if healthcare programs endure significant funding cuts, patients will see few improvements in health and healthcare over the coming years.

CENTERS FOR DISEASE CONTROL AND PREVENTION

NMF joins the other voluntary health groups in requesting that you support CDC by providing the agency with an appropriation of \$7.8 billion in FY14. Such a funding increase would allow CDC to undertake critical Marfan syndrome and related connective tissue disorders education and awareness activities, which would help prevent deadly thoracic aortic aneurysms and dissections.

In 2010, the American College of Cardiology and the American Heart Association issued landmark practice guidelines for the treatment of thoracic aortic aneurysms and dissections. NMF is promoting awareness of the new guidelines in collaboration with other organizations through a new Coalition known as “TAD”; the Thoracic Aortic Disease Coalition. The TAD Coalition is presently comprised of 10 organizations that are coordinating efforts to help promote the Guidelines to healthcare professionals and to raise public awareness of various aortic diseases and the associated risk factors.

The CDC would be an invaluable partner in the ongoing campaign to save lives and improve health outcomes by promoting the new Guidelines to healthcare providers and raising public awareness of risk factors. In this regard, we ask the Subcommittee encourage CDC to identify appropriate staff at the NCCDPHP and NCBDDD to participate in TAD Coalition activities. It is our hope that involving CDC in the activities of the TAD Coalition will lead to a lasting partnership and collaboration on critical outreach campaigns.

NATIONAL INSTITUTES OF HEALTH

NMF joins the broader public health community in requesting that you support NIH by providing the agency with an appropriation of \$32 billion in FY14. This modest 4% funding increase would ensure that biomedical research inflation does not result in a loss of purchasing power at NIH, critical new initiatives like the Cures Acceleration Network (CAN) are adequately supported, and that the Marfan syndrome research portfolio can continue to make progress.

**NHLBI**—Critical investment in research activities by NHLBI has greatly improved our scientific understanding of Marfan syndrome and related heritable connective tissue disorders. These breakthroughs have led to subsequent improvements in healthcare and treatment options.

**NIAMS**—The Marfan syndrome and related connective tissue disorders research portfolio at NIAMS has been crucial to the effort to improve the lives of individuals living with these conditions. The NIAMS research portfolio led the way in identifying many genetic factors for these conditions and still supports major advances in the pathophysiology of the disease.

**NEI**—Marfan syndrome is associated with eye problems and vision loss. However, we do not currently have a firm understanding of the link and NEI is only just beginning to initiate research projects in this area.

**NCATS**—The Office of Rare Diseases Research has long supported important Marfan syndrome research. Further, emerging programs at NCATS intended to ensure that scientific breakthroughs are translated to meaningful treatment options hold tremendous promise for the Marfan syndrome and heritable connective tissue disorders community.

Thank you for your time and your consideration of these requests. Please contact me if you have any questions or if you would like any additional information.

TESTIMONY OF  
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REGARDING  
**Fiscal Year 2014 (FY14) Appropriations for the Health Resources and Services Administration (HRSA), the Centers for Disease Control and Prevention (CDC), and the National Institutes of Health (NIH)**

SUBMITTED TO  
**The House Labor, Health and Human Services, Education, and Related Agencies (LHHS) Appropriations Subcommittee**

ON  
**The 15<sup>th</sup> Day of March, 2013**

PHA FY14 LHHS APPROPRIATIONS RECOMMENDATIONS

- 1. Protect medical research and patient care programs from devastating funding cuts through sequestration and deficit reduction activities.**
- 2. \$7 billion for HRSA, an increase of \$500 million over FY12.**
- 3. \$7.8 billion for CDC, an increase of \$1.7 billion over FY12, including a proportional increase for the National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP).**
- 4. \$32 billion for NIH, an increase of \$1.3 billion over FY12, including proportional increases for the National Heart, Lung, and Blood Institute (NHLBI); National Center for Advancing Translational Sciences (NCATS); Office of Rare Diseases Research (ORDR); Office of the Director (OD); and other NIH Institutes and Centers to facilitate adequate growth in the PH research portfolio.**

Chairman Kingston, Ranking Member DeLauro, and distinguished members of the Subcommittee, thank you for the opportunity to submit testimony on behalf of PHA. It is my honor to represent the hundreds of thousands of Americans who are affected by the devastating disease pulmonary hypertension (PH).

PHA has served the PH community for over 20 years. In 1990, three PH patients found each other with the help of the National Organization for Rare Disorders and shortly thereafter founded PHA. At that time, the condition was largely unknown amongst the general public and within the medical community; there were fewer than 200 diagnosed cases of the disease. Since then, PHA has grown into a nationwide network of over 20,000 members and supporters, including over 240 support groups across the country.

PHA is dedicated to improving treatment options and finding cures for PH, and supporting affected individuals through coordinated research, education, and advocacy activities. Since 1996, nine medications for the treatment of PH have been approved by the Food and Drug Administration (FDA), eight of those since 2001. These innovative treatment options represent important steps forward in the medical understanding of PH and the care of PH patients, but more needs to be done to end the suffering caused by this disease. PH remains a serious and life-altering condition.

PH is a debilitating and often fatal condition where the blood pressure in the lungs rises to dangerously high levels. In PH patients, the walls of the arteries that take blood from the right side of the heart to the lungs thicken and constrict. As a result, the right side of the heart has to pump harder to move blood into the lungs, causing it to enlarge and ultimately fail. Symptoms of PH include shortness of breath, fatigue, chest pain, dizziness and fainting.

PH can be idiopathic, and occur without a known cause, or be secondary to other conditions, such as HIV, scleroderma, lupus, blood clots, sickle cell, and liver disease. While PH impacts individuals of all races, genders, and ages, preliminary data from the Registry to Evaluate Early and Long Term Pulmonary Arterial Hypertension Disease Management (REVEAL Registry) suggests that women develop PH at a 4:1 ratio to men.

PH is a chronic condition that is costly in terms of quality of life and healthcare expenditures. The symptoms of PH are frequently misdiagnosed, leaving patients with the false impression that they have a minor pulmonary or cardiovascular condition. By the time many patients receive an accurate diagnosis, the disease has progressed to a late stage, which makes it difficult if not impossible to treat, even with drastic action such as a heart or lung transplant. While PH remains incurable with a poor survival rate, new treatment options are improving lives and enabling some patients to manage their condition for 20 years or longer.

I would like to extend my sincere gratitude to the Subcommittee for your historic support of PH programs at HRSA, CDC, and NIH. Thanks to your leadership, the PH research portfolio at NIH has advanced and improved our understanding of the disease, and

awareness of PH by the general public has led to earlier diagnosis and improved health outcomes for patients. Please continue to support PH activities moving forward.

#### DEFICIT REDUCTION AND SEQUESTRATION

Our nation's investment in biomedical research, particularly through NIH, is an engine that drives economic growth while improving health outcomes for patients. NIH supports a significant research portfolio in pulmonary hypertension with critical research activities conducted at academic health centers across the country. The federal commitment to this research portfolio has been the catalyst behind major breakthroughs that have improved our scientific understanding of PH and led to better health and healthcare for PH patients.

While meaningful progress has been made, PH remains a fatal condition and researchers across the country continue to work towards the goal of finding a cure. If federal funding for NIH is substantially reduced, the current effort to capitalize on recent advancements and improve treatment options will face a serious setback. Ongoing research projects, including those being conducted at academic health centers across the country, will stall and critical new research projects will not be initiated.

In addition, reducing support for federal biomedical research efforts sends a powerful message to the next generation about our country's lack of commitment to this field. Many talented young people interested in biomedical research will seek other career paths. Those who become the next generation of researchers will face increased competition for their talents from foreign competitors who are investing in their biomedical research infrastructure. As you work to make funding decision impacting discretionary programs, please provide a commitment of support and funding for NIH and other critical federal research programs.

Over the past 15 years, 9 therapies indicated to treat PH have been developed by industry and approved by FDA. PH is a chronic, disabling, and often fatal condition and the advent of current therapies has extended life and improved quality of life for individuals with the disease. However, the treatments are complex and come with significant side effect profiles. Moreover, current therapies do not completely restore affected individuals, which means that a life with PH can be difficult for both patients and caregivers.

More work is in progress in this area, but if healthcare programs endure significant funding cuts, PH patients may see few improvements. Funding cuts to discretionary health programs have the potential to drastically limit resources at FDA, undermining the agency's efforts to facilitate expeditious treatment development and potentially impair current oversight activities. Further, any cuts to the Centers for Medicare and Medicaid Services (CMS) have the potential to jeopardize access to care for PH patients by creating cost-driven barriers to available therapies. As you work to make funding decisions impacting discretionary programs, please provide appropriate support for FDA and please also ensure that CMS has sufficient resources.

As you work with your colleagues in Congress on deficit, budget, and appropriations issues please support the PH community by actively pursuing meaningful funding increases for critical medical research and healthcare programs.

#### HEALTH RESOURCES AND SERVICES ADMINISTRATION

PHA asks that you support HRSA by providing the agency with a meaningful funding increase of \$500 million in FY14. Such a funding increase would allow the agency to initiate important new activities such as partnering with the PH experts to improve the criteria for determining lung and heart-lung transplantation for PH patients. We ask for your leadership in encouraging HRSA, specifically the United Network for Organ Sharing, to engage in active and meaningful dialogue with medical experts at the REVEAL Registry. Such a dialogue has the potential to improve the methodology used to determine lung transplantation eligibility for PH patients and to improve survivability and health outcomes following a transplantation procedure.

#### CENTERS FOR DISEASE CONTROL AND PREVENTION

PHA joins other voluntary health groups in requesting that you support CDC by providing the agency with an appropriation of \$7.8 billion in FY14. Such a funding increase would allow CDC to undertake critical PH education and awareness activities, which would promote early detection and appropriate intervention for PH patients.

We are grateful to the Subcommittee for providing past support of PHA's Pulmonary Hypertension Awareness Campaign. We know for a fact that Americans are dying due to a lack of awareness of PH and a lack of understanding about the many new treatment options. This unfortunate reality is particularly true among minority and underserved populations and citizens in rural areas remote from medical centers with PH expertise. More needs to be done to educate both the general public and healthcare providers if we are to save lives.

To that end, PHA has utilized the funding provided through the CDC to 1) launch a successful media outreach campaign focusing on both print and online outlets 2) expand our support programs for previously underserved patient populations and 3) establish *PHA Online University*, an interactive curriculum-based website for medical professionals that targets pulmonary hypertension experts, primary care physicians, specialists in pulmonology/cardiology/rheumatology, and allied health professionals. The site is continually updated with information on early diagnosis and appropriate treatment of pulmonary hypertension. It serves as a center point for discussion among PH-treating medical professionals and offers Continuing Medical Education and CEU credits through a series of online classes.

Early diagnosis of PH and timely intervention with innovative therapies can significantly improve health outcomes for PH patients. In some instances, early intervention can mitigate the need for more drastic treatment and costly treatment options, like heart-lung transplantation. In order to promote early recognition and accurate diagnosis, PHA asks the Subcommittee to provide CDC with additional funding in FY14 so that important PH education and awareness activities can be initiated through NCCDPHP.

NATIONAL INSTITUTES OF HEALTH

PHA joins the public health community in requesting that you support NIH by providing the agency with an appropriation of \$32 billion in FY14. This modest funding increase would ensure that biomedical research inflation does not result in a loss of purchasing power at NIH, critical new initiatives like the Cures Acceleration Network (CAN) are adequately supported, and the PH research portfolio can continue to progress.

Less than two decades ago, a diagnosis of PH was essentially a death sentence, with only one approved treatment for the disease. Thanks to advancements made through the public and private sector, patients today are living longer and better lives with a choice of nine FDA approved medications. Sustained investment in basic, translational, and clinical research can ensure that we capitalize on recent advancement and emerging opportunities to speed the discovery of improved treatment options and cures.

Expanding clinical research remains a top priority for patients, caregivers, and PH investigators. We are particularly interested in establishing a pulmonary hypertension research network. Such a network would link leading researchers around the United States, providing them with access to a wider pool of shared patient data. In addition, the network would provide researchers with the opportunities to collaborate on studies and to strengthen the connections between basic and clinical science in the field of pulmonary hypertension research. Such a network is in the tradition of the NHLBI, which, to its credit and to the benefit of the American public, has supported numerous similar networks including the Acute Respiratory Distress Syndrome Network and the Idiopathic Pulmonary Fibrosis Clinical Research Network. We ask that you provide NHLBI with sufficient resources and encouragement to move forward with the establishment of a PH network in FY14.

We applaud the recent establishment of 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 CAN are critical to overhauling the translational research process and ensuring that more breakthroughs in basic research are developed into meaningful diagnostic tools and treatment options that directly benefit patients. In addition, new efforts like taking the lead on drug repurposing hold the potential to speed new treatment to patients, particularly patients who struggle with rare or neglected diseases. We ask that you support NCATS and provide adequate resources for the Center in FY14.

Thank you for your time and your consideration of our requests. Please contact me if you have any questions or if you require any additional information.

## **Lions Clubs International -- Labor, HHS, Education Priorities FY 2014**

**Statement for the Record of Wayne A. Madden  
President, Lions Clubs International (LCI)  
Before the U.S. House Subcommittee on Labor, HHS, Education, and Related Agencies  
March 15, 2013**

**For more information contact:**

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As the world's largest service organization with 1.35 million members worldwide and 345,000 members in United States, Lions Clubs International (LCI) is committed to major domestic sight initiatives, positive youth development and youth service programs in America's schools. Today we face great health and educational challenges, and we urge the House Subcommittee on Labor-HHS-Education to maintain funding levels for the following vital health and education programs: National Institutes of Health (NIH)/National Eye Institute (NEI); social and emotional learning initiatives at the U.S. Department of Education Office of Safe and Healthy Students; and drug prevention and anti-bullying programs at the U.S. Department of Health and Human Services.

### **NIH/National Eye Institute – Vision Health Recommendations**

LCI believes that vision loss is a major public health problem that increases healthcare costs and reduces productivity and quality of life for millions of Americans. Ever since Helen Keller

challenged Lions to become “knights of the blind in the crusade against darkness” nearly a century ago, we have been committed to serving our communities through projects designed to prevent blindness, restore eyesight and improve eye health and eye care for our neighbors in the U.S. and worldwide.

We also played an important role in the creation of the National Eye Institute, an agency created in 1968 as the nation’s lead Institute within the NIH to prevent blindness and save and restore vision of all Americans. LCI supports NEI-funded research resulting in treatments and therapies that save vision and restore sight, resulting in reduced healthcare costs and higher productivity. While we are cognizant of the nation’s current fiscal situation, Lions Clubs International is concerned that any reductions in NIH/NEI funding would result in fewer investigator-initiated research grants to save or restore vision. NIH research also serves an irreplaceable role in partnership with the private sector and charitable organizations.

Moreover, NEI has funded breakthrough research over the past ten years ranging from determining the genetic basis of eye disease to developing treatments that save and restore sight. Current NEI funding levels reflect little more than one percent of the \$68 billion annual cost of eye disease and vision impairment in the United States. NEI estimates that 38 million Americans age 40 and older experience blindness, low vision, or age-related eye disease, such as age-related macular degeneration, glaucoma, diabetic retinopathy, or cataracts. This number is expected to grow to 50 million by year 2020 as the “baby boomer” population ages and becomes at greater risk for aging eye disease.

Half of all blindness can be prevented through early intervention and treatment. Serious ocular conditions like amblyopia (lazy eye), strabismus (crossed eyes), nearsightedness and

farsightedness, can be treated and improved if diagnosed at an early stage. Early detection, diagnosis and treatment provide the best chance to improve these conditions in children.

LCI remains committed to providing charitable vision care, eyeglasses and hearing care services to needy and indigent people through our service clubs nationwide.

### **Hearing**

Lions Clubs International is committed to fighting hearing loss as well as blindness. Only a small percentage of Americans who experience hearing loss opt to use hearing aids. Thirty-six million Americans have hearing loss, and the 7 million Americans who cannot afford hearing aids are an underserved population. When people are not able to pay the high cost of quality hearing aids—which cost an average of \$3,600 each and are often not covered by insurance—they are left in silence, or with poor-functioning hearing aids.

Lions clubs across the country assist their neighbors with the high costs of hearing aids through the Affordable Hearing Aid Project (AHAP). AHAP's continuum of care model involves providing high-quality, low-cost hearing aids as well as services of hearing care professionals to conduct tests, fit the aids and provide follow-up care. Since 2009, 768 hearing aids have been provided to people who otherwise could not afford them. Federal support in this area would have significant public health dividends in difficult economic times.

### **Education/Social and Emotional Health Programs**

Federal programs that foster family and community engagement and promote successful life-skills and productive citizens have a special relationship with LCI and our Foundation. We

support sustained funding for education and health and human services programs in the following areas: early learning, social and emotional learning, military families, faith-based and community partnerships, anti-bullying, drug prevention, and service learning.

Lions Clubs International Foundation's (LCIF) youth development initiatives, known collectively as "Lions Quest," have been a prominent part of school-based K-12 programs since 1984. Fulfilling its mission to teach responsible decision-making, effective communications and drug prevention, Lions Quest has been involved in training more than 500,000 educators and other adults to provide services for over 12 million youth in programs worldwide, including 48 states in the U.S. LCIF grants up to \$2 million annually in supporting life skills training and service learning, and that funding is matched by local Lions, schools and other partners.

Lions Quest curricula incorporate parent and community involvement in the development of healthy and responsible young people in the areas of: life skills development (social and emotional learning), character education, drug prevention, service learning, bullying prevention, and reducing obesity in school-aged children. These Lions Quest programs provide strong evidence of decreased drug use, improved responsibility for students' own behavior, as well as stronger decision-making skills and test scores in math and reading. Further, Lions Quest programs help the federal government, particularly the Office of Safe and Healthy Schools, achieve its goals to promote drug-free and violence-free schools that promote the health and well-being of students across the country.

Lions Quest programs also address bullying, a major initiative of the U.S. Department of Health and Human Services. Safety starts in the classroom, and a key component of the Lions Quest program is to build a healthy and safe school climate which reduces bullying and other

discipline issues. Program curriculum encourages a culture of inclusion and respect that welcomes all students. Students are taught to show thoughtfulness and respect for their classmates and teachers. Support for federal programs to prevent violence and bullying in our schools through the Department of Health and Human Services and the Office of Safe and Healthy Schools are critical to the success of our youth.

Lions Quest has extensive experience with and recognition by Federal programs. Lions Quest Skills for Adolescence received a “Promising Program” rating from the U.S. Department of Education's Safe, Disciplined and Drug-Free Schools expert panel and a “Model” rating from the U.S. Department of Health and Human Services Substance Abuse and Mental Health Services Administration (SAMHSA).

Finally, LCI recommends Congressional support for social and emotional learning (SEL) programs that stimulate growth among schools nationwide through distribution of materials and teacher training, and to create opportunities for youth to participate in activities that increase their social and emotional skills. Not only do SEL curricula contribute to the social and emotional development of youth, but they also provide invaluable support to students' school success, health, well-being, peer and family relationships, and citizenship.

**About Wayne A. Madden, Lions Clubs International President**

Wayne A. Madden, of Auburn, Indiana, USA, was elected president of The International Association of Lions Clubs at the association's 95th International Convention, held in Busan, Korea, June 22-26, 2012.

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**TESTIMONY ON BEHALF OF THE  
FRIENDS OF NCBDDD ADVOCACY COALITION  
HOUSE COMMITTEE ON APPROPRIATIONS – SUBCOMMITTEE ON LHHS  
National Center on Birth Defects and Developmental Disabilities  
Centers for Disease Control and Prevention**

**Friends of NCBDDD Advocacy Coalition Contacts:**

- Co-Chair & Birth Defects Representative: Melissa Putman, Deputy Director, Federal Affairs, March of Dimes, mputman@marchofdimes.com, 202-659-1800
- Co-Chair & Disabilities Representative: Annie Acosta, Policy Advocate, The Arc, acosta@thearc.org, 202-783-2229
- Co-Chair & Blood Disorders Representative: Randy Fenninger, President, National Blood Clot Alliance, rfenninger@gmail.com, 202-257-6671

**The Friends of NCBDDD Advocacy Coalition is a collaboration of 25 organizations that support the extraordinary work of the Center for Disease Control and Prevention’s (CDC’s) National Center on Birth Defects and Developmental Disabilities (NCBDDD). We urge Congress and the Administration to maintain the integrity of the NCBDDD during these challenging budget times by providing level funding of \$145,524 million in Fiscal Year 2014. Ensuring stable, adequate funding and maintaining the current structure and programmatic focus represents a sound public investment that will continue to prevent birth defects and developmental disabilities and help people with disabilities and blood disorders live the healthiest life possible.**

Discretionary programs cannot continue to bear the brunt of efforts to reduce the deficit. Specifically, sequestration combined with reductions since fiscal year 2010 resulted in a \$6 million decrease for NCBDDD. This Center already operates on a lean budget and without adequate sustained funding many birth defects surveillance programs will be lost, services for people with disabilities will be diminished, and public health activities on behalf of people with blood disorders would be reduced, thus severely impacting NCBDDD's ability to track, monitor and develop public health interventions for these vulnerable populations.

### **The NCBDDD Public Health Mission**

Established by the U.S. Congress in 2000 (P.L. 106-310), the NCBDDD impacts the health of millions of our nation's most vulnerable citizens: infants and children, people with disabilities, and people with blood disorders. It is the only CDC Center whose mission focuses on these populations.

To achieve its mission, NCBDDD works to:

- Identify the causes and reduce the incidence of birth defects and developmental disabilities;
- Help children to develop and reach their full potential;
- Promote health and wellbeing among people of all ages with disabilities; and,
- Improve health outcomes for people with bleeding disorders such as thrombophilia, sickle cell disease and hemophilia.

Public health is defined as the science and art of preventing disease; promoting physical and behavioral wellness; supporting personal responsibility; and prolonging life in communities where people live, work and learn. Public health focuses on population level solutions to morbidity and improving health and wellness. Through practicing basic public health principles - surveillance, education, research and deploying interventions tailored to the needs of its specific vulnerable populations - NCBDDD is the only place in the federal government serving children and adults with birth defects, disabilities, and blood disorders utilizing a public health strategy. Specific examples of NCBDDD accomplishments in the areas of birth defects, disabilities, and blood disorders include:

**Birth Defects & Developmental Disabilities:**

- One in 33 babies in the United States is born with a birth defect and approximately 13% of children have a developmental disability. The NCBDDD funds surveillance, research and prevention activities aimed at helping us track, understand, and ultimately prevent these disorders.
- The success of NCBDDD programs have contributed to a 36% decline in neural tube defects, as well as significant advances in the identification of preventable risk factors for birth defects and improved screening, and early diagnosis and referral to early intervention for children with several disabilities.

**Disabilities:**

- Almost a third of US health care costs are associated with a disability, amounting to \$397.8 billion in 2006 alone. The NCBDDD funds surveillance, prevention, and health

promotion activities to improve the health and quality of life for people with disabilities and reduce health care spending.

- NCBDDD developed a surveillance system for numerous health indicators (e.g., smoking, obesity, blood pressure) for people with disabilities and increased the number of states/territories with access to current state-level disability and health surveillance data from 16 to 2011 to 50 in 2012.

**Blood Disorders:**

- Deep vein thrombosis (DVT) and pulmonary embolism (PE) affect 350,000 to 600,000 Americans every year and 100,000 people die as a result of a DVT or PE. Estimates of medical costs exceed \$10 billion annually. NCBDDD's bleeding disorders surveillance system has been updated and improved to collect additional information that will help us learn more about emergent issues, treatment, and complications.
- The Center increased hemophilia inhibitor screening by >50% in a pilot project within hemophilia treatment centers.

The Friends of NCBDDD Advocacy Coalition looks forward to working with Members of this Subcommittee to secure the resources needed to promote the health of infants, children and adults and enhance the potential for full, productive living.

**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

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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 2014, I would like to request \$67,422,000, for our Operations budget. 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 2013**

Fiscal Year	Deaf/Hard-of-Hearing Students				Hearing Students			Grand Total
	Undergrad	Grad RIT	MSSE	Sub-Total	Interpreting Program	MSSE	Sub-Total	
2007	1,017	47	31	1,095	130	25	155	1,250
2008	1,103	51	31	1,185	130	28	158	1,343
2009	1,212	48	24	1,284	135	31	166	1,450
2010	1,237	38	32	1,307	138	29	167	1,474
2011	1,263	40	29	1,332	147	42	189	1,521
2012	1,281	42	31	1,354	160	33	193	1,547
2013	1,269	37	25	1,331	167	31	198	1,529

**MSSE:** Master of Science in Secondary Education of Deaf/Hard of Hearing Students

**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. Applications for enrollment in FY 2013 were up 9% from the year before. In Fall 2012 (FY 2013), we attracted 1,529 students, the second largest enrollment in our history. Over the last seven years, our enrollment has increased 22%. For FY 2014, 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 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 have been placed in jobs commensurate with their education level (using the

Bureau of Labor Statistics methodology). Of our FY 2011 graduates (the most recent class for which numbers are available), 54% were employed in business and industry, 31% in education/non-profits, and 15% 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 more than 15,000 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 has significantly reduced equipment purchases and eliminated or reduced almost 40 positions – a workforce reduction of 6% in the midst of record enrollments. We have also reduced our budget by an average of 8% 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 30-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 2013, student tuition and fees increased by 49% to offset the rising costs of providing a state-of-the-art college education. Likewise, from FY 2006 to FY 2012, NTID raised almost \$19 million in support from individuals and organizations.

Our request of \$67,422,000 for Operations would help us balance our budget and reduce the damage we anticipate from sequestration. It is important to note that this request for FY 2014 is only 3.2% more than the FY 2011 operating appropriation and significantly reduced from our original request of \$73,819,000 (including \$2,000,000 for construction) submitted to the Department of Education in June 2012. Despite the measures we have taken to manage level funding for the past three years, the 5.1% reduction from sequestration would require us to make further cuts in the areas of equipment purchasing, interpreting and captioning, scholarship support, building maintenance, and, most importantly, in personnel and enrollment. If the 5.1% reduction stands, we will have to undertake a workforce reduction of up to 54 filled positions (about 10% of our current headcount). This reduction in staff could result in denying as many as 240 qualified deaf and hard-of-hearing students from enrolling each year. 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 request of \$67,422,000 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.

**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 2014 FEDERAL FUNDING PRIORITIES (Dollars in Thousands)**

<b>PROGRAM</b>	<b>FY 2014 REQUEST</b>
<b>National Institutes of Health (Total)</b>	<b>32,000,000</b>
National Children's Study	192,000
Common Fund	570,530
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
<b>Centers for Disease Control and Prevention (Total)</b>	<b>7,800,000</b>
National Center for Birth Defects and Developmental Disabilities	139,000
Birth Defects Research and Surveillance	22,300
Folic Acid Campaign	2,800
Section 317	720,000
Polio Eradication	126,400
Safe Motherhood Initiative	44,000
Preterm Birth	2,000
National Center for Health Statistics	162,000
<b>Health Resources and Services Administration (Total)</b>	<b>7,000,000</b>
Title V, Maternal and Child Health Block Grant	640,000
SPRANS- Infant Mortality and Preterm Birth	3,000
Heritable Disorders	13,300
Universal Newborn Hearing	18,660
Community Health Centers	1,580,000
Healthy Start	103,532
Children's Graduate Medical Education	317,500
<b>Agency for Healthcare Research and Quality (Total)</b>	<b>430,000</b>

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 2014 (FY14). The March of Dimes is a unique partnership of scientists, clinicians, parents, members of the business community and other volunteers affiliated with 51 chapters and 213 divisions in every state, the District of Columbia and Puerto Rico. 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 costs 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. In 2011, the nation's preterm birth dropped for the fifth consecutive year to 11.7 percent, giving thousands more infants a healthy start in life and saving billions in health and social costs. We believe one of the factors behind the decline was Congress's passage of the 2006 PREEMIE Act (P.L. 109-450), which brought the first-ever national focus to prematurity prevention. The Surgeon General's Conference on the Prevention of Preterm Birth created by the Act 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. The March of Dimes' FY14 funding requests regarding preterm birth are based on the recommendations from 2008 conference and the PREEMIE Act.

### **National Children's Study (NCS)**

The March of Dimes recommends \$192 million in FY 2014 for the National Children's Study to allow for roll-out of the main study with a science-based design and recruitment strategy. The NCS is the largest and most comprehensive study of children's health and

development ever planned in the U.S. When fully implemented, this study will follow 100,000 children in the U.S. from before birth until age 21. The data has the potential to transform our understanding of child health and development, and to lead to new forms of prevention and treatment for a multitude of conditions and diseases of childhood.

**Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)**

The March of Dimes recommends at least \$1,370 million for the NICHD in FY 2014. 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 invest 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 transdisciplinary science, which will facilitate the exchange of scientific ideas and lead 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 \$44 million for the Safe Motherhood program and re-instatement of the preterm birth sub-line at \$2 million, as authorized in the PREEMIE Act, to reflect current preterm birth research within the CDC.

**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 Act authorized preterm birth-related demonstration projects, which are aimed at improving education, treatment and outcomes for babies born preterm. Currently, HRSA is pursuing the Collaborative Improvement & Innovation Network (COIN) to Reduce Infant Mortality, which brings together infant mortality experts to share best practices and lessons learned. Through the COIN, state agencies are focusing on a range of interventions proven to reduce preterm birth and improve maternal and child health, including reducing elective deliveries before 39 weeks and implementing evidence-based smoking cessation initiatives. Expanding the COIN initiative nationwide will reduce preterm birth rates and infant mortality.

### **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. Additional federal resources are sorely needed to support research to discover the causes of all birth defects and for the development of effective interventions to prevent or at least reduce their prevalence.

### **CDC - National Center on Birth Defects and Developmental Disabilities (NCBDDD)**

For FY 2014, the March of Dimes requests funding of \$139 million for NCBDDD. We also encourage the Subcommittee to provide at least \$2.8 million to support folic acid education and \$22.3 million to support birth defects research and surveillance – a \$2 million increase from FY 2012 enacted levels. Allocating an additional \$2 million to birth defects research and surveillance will support genetic analysis of the research samples already obtained through the

NCBDDD's National Birth Defects Prevention Study—the largest case-controlled study of birth defects ever conducted. Further, allocating at least \$2 million to folic acid education will allow the CDC to sustain its effective education campaign aimed at reducing the incidence of spina bifida and anencephaly by promoting consumption of folic acid.

### **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 \$13.3 million for HRSA's heritable disorders program and the work of the Advisory Committee on Heritable Disorders in Newborns and Children, as authorized by the Newborn Screening Saves Lives Act (P.L. 110-204). In 2013, the United States will mark the 50th anniversary of newborn screening. The Heritable Disorders program plays a critical role in assisting states in the adoption of additional screenings, enhancing provider and consumer education and ensuring coordinated follow-up care.

### **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.

**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: FY2014 Budget, Department of Health and Human Services**

**March 15, 2013**

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 FY2014. ACP is the largest medical specialty organization and the second-largest physician group in the United States. ACP members include 133,000 internal medicine specialists (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 FY2014, 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, \$893,456,433 in discretionary funding, in addition to the \$305 million in enhanced funding through the Community Health Centers Fund;
- National Health Care Workforce Commission, \$3 million;
- Agency for Healthcare Research and Quality, \$430 million; and
- Sufficient funding of the Centers for Medicare and Medicaid Services, Operation and Management of Exchanges.

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 27 million Americans receiving access to health insurance, once the law is fully implemented. Current projections indicate there will be a shortage of up to 44,000 primary care physicians for adults, even before the increased demand for health care services that will result from near universal coverage is taken into account (Colwill JM, Cultice JM, Kruse RL. Will generalist physician supply meet demands of an increasing and aging population? *Health Aff (Millwood)*. 2008 May-Jun;27(3):w232-41. Epub 2008 Apr 29. Accessed at <http://content.healthaffairs.org/content/27/3/w232.full> on 14 January 2011.). 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](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 to help 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 of primary care production and training. The Section 747 program is the only source of federal training dollars available for general internal medicine, general pediatrics, and family medicine. For example, general internists, who have long been at the frontline of patient care, have benefitted from Title VII training models that promoted interdisciplinary training which helped prepare them to work with other health professionals, such as physician assistants, patient educators and psychologists. Without a substantial increase of funding, HRSA will not be able to carry out a competitive grant cycle for the third year in a row for physician training; the nation needs new initiatives relating to increased training in multi-professional care, the patient-centered medical home, and other new competencies required in our developing health system.

The College urges \$893,456,433 in appropriations for the **National Health Service Corps** (NHSC), the amount authorized for FY2014 under the ACA; this is in addition to the \$305 million in enhanced funding the Health and Human Services Secretary has been given the authority to provide to the NHSC through the Community Health Care Fund. Since enactment of the ACA, the NHSC has awarded over \$900 million 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 communities across the country. There are nearly three times the number of NHSC clinicians working in communities across America than there were four years ago, increasing Americans' access to health care. With field strength of nearly 10,000 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

must be sustained to help 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 more 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 policies. Members of the Commission have been appointed but have not been able to do any work, due to a lack of funding. The College believes the nation needs sound research methodologies embedded in its workforce policy to determine the nation's current and future needs for the appropriate number of physicians by specialty and geographic areas; the work of the Commission is imperative to ensure Congress is creating the best policies for our nation's needs.

The **Agency for Healthcare Research and Quality** (AHRQ) is the leading public health service agency focused on health care quality. AHRQ's research provides the evidence-based information needed by consumers, providers, health plans, purchasers, and policymakers to make informed health care decisions. The College is dedicated to ensuring AHRQ's vital role in improving the quality of our nation's health and recommends a budget of \$430 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 ensuring that sufficient funding is available for the **Centers for Medicare and Medicaid Services, Operation and Management of Exchanges** in order to become fully operational by 2014 and carry out their duties as necessary. Such funding will allow the federal government to administer the insurance exchange, as authorized by the ACA, if a state declines to establish an exchange that meets federal requirements. As of March 7, HHS has approved 24 states and the District of Columbia to fully or partially run their state's exchange, leaving 26 states which have not met approval or who have declined to run their own state exchange. If the Subcommittee decides to deny the requested funds, it may make it much more difficult for the federal government to organize a federally-facilitated exchange in those states, raising questions about where and how their residents would get 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 FY2014 appropriations process.

Written Testimony

House Appropriations Subcommittee on  
Labor, Health and Human Services, Education  
Fiscal Year 2014 Budget

Chairman Kingston and members of the committee:

I am Rosemary Ackley Christensen, Associate Professor Emerita, University of Wisconsin, Green Bay and currently living in Superior Wisconsin. I am an enrolled member of the Mole Lake Sokaogon Band of Wisconsin Ojibwe Lake Superior Indians. I have been an advocate for culturally based education and the teaching of Native American languages all of my life.

I strongly support the reauthorization of the Esther Martinez Native Language Programs under the administration for Native Americans in the Department of Health and Human Services. Please find it in your minds and hearts to reauthorize the program that provides education for our children in native language.

We are consistently told by our Elder scholars, those that speak our native language fluently and take the time to teach us important, life-formative teachings that help us to live life practicing the 3 r's of respect, reciprocity and relationship to all living things how our language forms us. Back in the eighties, Art Gabow, then chief of the Mille Lacs Band of Ojibwe, Minnesota said that *Ojibwemowin* (name of our language) is a gift to the *Anishinabeg* (name Ojibwe call ourselves) from *Gitchee Manitou*. He would tell the story that went with that statement teaching us through the story that our Ojibwe language is our culture and without Ojibwe there is no culture. It is a crucial and structural lesson. As an educator that worked in the k-12 system as a curriculum specialist/administrator, and later taught in university about American Indian studies, I worked on how to best infuse Tribal language into the educational system. I, of course, depended on Elders that spoke the language fluently to provide the teachings.

Years ago the New York Times Magazine (August 21, 2005) featured an article, "The Newest Indians" by Jack Hitt, pp36-41. It began with the statement that "More and more people are claiming to have discovered their indigenous ancestries. But what, exactly makes someone a Native American?" (p. 36) I was interested in the statement: "Language is an important vehicle of transmission of culture" says Angela Gonzales, a Hopi Indian and an assistant professor of sociology at Cornell University. "Some Tribes resist letting any outsiders even speak

their language. But that's why language is important. It's a great vehicle for the storage of important inaccessible cultural material. (p. 41)"

And in the seminal book by Donald L. Fixico, *The American Indian Mind in a Linear World: American Indian studies and Traditional Knowledge* (2003, Routledge, New York and London) he reminds us through the memories of various people what Boarding Schools did to Indian children, (quoting Ruben Snake, p. 87) "Not being allowed to speak one's native language was common throughout boarding schools." And in the book, *Original Instructions: Indigenous Teachings for a Sustainable Future* (Ed: Melissa K. Nelson, 2008, Bear and Company, Rochester, Vermont 05767) Nelson (p. 297) warns that "For Indigenous Peoples, when you lose languages, you lose land-based practices; when you lose natural resources and biodiversity, you lose cultural knowledge. ... Nature and culture are intimately entwined, not only for Native peoples but for all peoples."

I also draw attention to the book edited by Anne Waters, *American Indian Thought* (2004, Blackwell Publishing Ltd, 350 Main Street, Malden, MA 02148), chapter 22, "On Philosophical Discourse: Some Intercultural Musings" by Thurman Lee Hester, Jr. (pp. 263-267). The author speaks to the differences between Native philosophers and non-Native philosophers. "The fundamental difference is just one of many. Native American languages are often very different from European languages. Whether language is a reflection of philosophy, or philosophy a reflection of language—or both—linguistic difference almost certainly assures philosophical difference. Though these differences are part of what makes it difficult to communicate between Euro-American traditions and Native American traditions, they are also part of what makes it imperative that the communication take place. (264)

An Elder scholar I knew well said in a book he wrote with Louise Erdrich, "We are living two ways. Today our values are like the New York stock market, or better yet, we are on a roller coaster. We have partially lost our language, therefore we have partially lost our culture. We as Anishinaabe cannot teach our future generations our culture in English, because we cannot convey the true meaning of our culture in the English language. Anishinaabe culture and Anishinaabe language: one cannot exist without the other." (pp. 108, 109 in *Naawigiizis, The Memories of Center of the Moon*, Jim Clark of Mille Lacs, edited and with an introduction by Louise Erdrich, 2002, Birchbark Books by Farrar & Associates, 2115 West 21<sup>st</sup> Street, Minneapolis, MN 55405, 612 374-4023)

I think frequently about an Elder that was one of my important teachers, Jimmy Jackson, an Elder Ojibwe scholar that spoke his language fluently, and helped people with his teachings told a group of educators in the late eighties to help Indian families learn their language, if they, as educators wanted to ensure the children's success in school.

Others need to learn about Tribal languages as well. We that live on the continent called North America are reminded daily of Tribal languages. Sadly, many don't know the words they use and hear are from Tribal people that first called North America home. Many don't know that states such as Wisconsin, Minnesota, Michigan and the Dakotas for example are all native words as are the names for cities such as Milwaukee and Chicago and the big river, the Mississippi. Our Tribal languages are intertwined with the history and story of all Americans.



**March 15, 2013**

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**Federation of American Societies for Experimental Biology**  
 9650 Rockville Pike, Bethesda, MD 20814-3998 • [www.FASEB.org](http://www.FASEB.org)

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Testimony of the  
**Federation of American Societies for Experimental Biology**  
 On  
**FY 2014 Appropriations for the National Institutes of Health**  
 Submitted to the  
**House Committee on Appropriations**  
**Subcommittee on Labor, Health and Human Services, Education, and Related Agencies**  
**Representative Jack Kingston, Chairman**  
**Representative Rosa DeLauro, Ranking Member**

**The Federation of American Societies for Experimental Biology (FASEB) respectfully requests a fiscal year (FY) 2014 appropriation of no less than \$32 billion for the National Institutes of Health (NIH) to prevent further erosion of the nation's capacity for biomedical research and provide funding for additional grantees.**

As a federation of 26 scientific societies, FASEB represents more than 100,000 life scientists and engineers, making it the largest coalition of biomedical research associations in the United States. FASEB's mission is to advance health and welfare by promoting progress and education in biological and biomedical sciences, including the research funded by NIH, through service to its member societies and collaborative advocacy. FASEB enhances the ability of scientists and engineers to improve—through their research—the health, well-being, and productivity of all people.

Research funded by the National Institutes of Health (NIH) has produced an outstanding legacy, and American leadership in biomedical research has made us the envy of the world. Eighty-five percent of NIH funds are distributed through competitive grants to more than 300,000 scientists who work at universities, medical schools, and other research institutions in nearly every congressional district in the United States. NIH researchers developed the first screening test that reduced mortality from lung cancer, sponsored clinical trials to significantly reduce transmission of Human Immunodeficiency Virus from mother to child, uncovered the precise cause of more than 4,500 rare diseases, and completed a ten-year diet and exercise study showing how we can reduce the incidence of type 2 diabetes among high-risk people by more than 30 percent. Many of these advances arose from investigations designed to explain basic molecular, cellular, and biological mechanisms.

More recently, NIH has supported research that led to breakthroughs in:

- *Preventing Colon Cancer Deaths*: A study funded primarily by the National Cancer Institute found that removing polyps (abnormal growths) during colonoscopy can not only prevent colorectal cancer, but also reduce the chance of death from the disease by 53 percent. Colorectal cancer is one of the most common cancers in both men and women nationwide and colonoscopies can detect early-stage cancer before symptoms develop, allowing doctors to remove any polyps. Early detection is important because treatments are more likely to succeed if the disease is caught before it takes hold. This study provides strong evidence of the long-term benefit of removing polyps and supports continued screening for colorectal cancer in individuals over age 50.

- *Offering New Hope For Children With An Immunodeficiency Disorder:* Researchers supported by the National Human Genome Research Institute and the National Heart, Lung and Blood Institute discovered that gene therapy can safely restore immune function in children with severe combined immunodeficiency (SCID), a disorder that leaves patients susceptible to a wide range of infections because they cannot produce healthy white blood cells. Most children with SCID die by the age of two if left untreated. Previously available treatments relied on expensive enzyme replacement injections that had to be continued throughout the child's life. A clinical trial found that gene therapy using the patient's own stem cells and low-dose chemotherapy was effective in eliminating the need for enzyme replacement therapy and leading to long-term improved health. A second phase of the trial is now underway.
- *Repurposing Older Drugs to Treat Alzheimer's:* Bexarotene, a drug that has been available for ten years to treat skin cancer, rapidly reduced beta-amyloid levels in the brains of mice of all ages and shrank amyloid deposits known as plaques in most age groups. Abnormally high levels of beta-amyloid have been found in the brains of individuals with the most common, late-onset form of Alzheimer's disease. This NIH-funded study also found that Bexarotene restored cognition and memory in mice and improved the animals' ability to sense and respond to odors. Loss of smell is often a first symptom of Alzheimer's in humans.

### **Sustained Funding Is Critical in Order to Capitalize on New Scientific Opportunities**

The broad program of research supported by NIH is essential for advancing our understanding of basic biological functions, reducing human suffering, and protecting the country against new and

re-emerging disease threats. Biomedical research is also a primary source of new innovations in health care and other areas.

Exciting new NIH initiatives are poised to accelerate our progress in the search for cures. It would be tragic if we could not capitalize on the many opportunities before us. The development of a universal vaccine to protect adults and children against both seasonal and pandemic flu and development of gene chips and DNA sequencing technologies that can predict risk for high blood pressure, kidney disease, diabetes, and obesity are just a few of the research breakthroughs that will be delayed if we fail to sustain the investment in NIH.

As a result of our prior investment, we are the world leader in biomedical research. We should not abdicate our competitive edge. Without adequate funding, NIH will have to sacrifice valuable lines of research. The termination of ongoing studies and the diminished availability of grant support will result in the closure of laboratories and the loss of highly skilled jobs. At a time when we are trying to encourage more students to pursue science and engineering studies, talented young scientists are being driven from science by the disruption of their training and lack of career opportunities.

Rising costs of research, the increasing complexity of the scientific enterprise, and a loss of purchasing power at NIH due to flat budgets have made it increasingly competitive for individual investigators to obtain funding. In addition, the \$1.6 billion in cuts to NIH due to the sequestration mandated by the Budget Control act will exacerbate the current challenges facing the research community. Today, only one in six grant applications will be supported, the lowest rate in NIH history. Increasing the NIH budget to \$32.0 billion would provide the agency with an additional \$1.360 billion which could restore funding for R01 grants (multi-year awards to



**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 15, 2013*

*Submitted by: Athena Abdullah, JD, Director, Government Relations  
[aabdullah@paeaonline.org](mailto:aabdullah@paeaonline.org), 703-548-5538*

On behalf of the 170 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) 2014 appropriations for PA education programs that are authorized through Title VII of the Public Health Service Act. PAEA requests funding of at least \$264.4 million in FY 2014 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).

**Need for Increased Federal Funding**

Faculty development is one of the profession's critical needs. In order to attract the most highly qualified individuals to teaching, PA education programs must have the resources to train faculty in academic skills, such as curriculum development, teaching methods, and laboratory instruction. The challenges of teaching are broad and varied and include understanding different pedagogical theories, writing instructional objectives, learning and applying educational technology. Most educators come from clinical practice and these skills are essential to transitioning to teaching. Educators are a critical element of meeting the nation's demand for an increased supply of primary care clinicians.

Generalist training, workforce diversity, and practice in underserved areas are key priorities identified by HRSA. It is increasingly important that the health workforce better represents America's changing demographics, as well as addresses the issues of disparities in health care. PA programs have been

successful in attracting students from underrepresented minority groups and disadvantaged backgrounds. Studies have found that health professionals from underserved areas are three to five times more likely to return to underserved areas to provide care.

### **Physician Assistant Practice**

Physician assistants (PAs) are licensed health professionals who practice medicine as members of a team with their supervising physicians. PAs exercise autonomy in medical decision making and provide a broad range of medical and therapeutic services to diverse populations in rural and urban settings. In all 50 states, PAs carry out physician-delegated duties that are allowed by law and within the physician's scope of practice and the PA's training and experience. Additionally, PAs are delegated prescriptive privileges by their physician supervisors in all 50 states, the District of Columbia, and Guam. This allows PAs to practice in rural, medically underserved areas where they are often the only full-time medical provider.

### **Physician Assistant Education**

There are currently 170 accredited PA education programs in the United States – a growth of 23% in five years; together these programs graduate nearly 6,422 PA students each year. PAs are educated as generalists in medicine; their flexibility allows them to practice in more than 60 medical and surgical specialties. Forty percent of PA program graduates practice in primary care.

The average PA education program is 26 months in length. Typically, one year is devoted to classroom study and approximately 12 months is devoted to clinical rotations. The typical curriculum includes 340 hours of basic sciences and nearly 1,600 hours of clinical medicine.

As of today, approximately 60 programs are in the pipeline at various stages of development, moving toward accredited status. The growth rate in the applicant pool is even more remarkable. Since its inception

in 2001 until the most recent application cycle, CASPA grew from 4,669 applicants to nearly 19,000 applicants. In March 2009, there were a total of 12,216 applicants to PA education programs; as of March 2013, there were 18,900 applicants to PA education programs. This represents a 54% increase in Centralized Application Service (CASPA) applicants over the past five years.

The PA profession is expected to continue to grow as a result of the projected shortage of physicians and other health care professionals, the growing demand for professionals from an aging population, and the continuing strong PA applicant pool. 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.

The continued growth of the profession heightens the need for additional resources to help meet the challenges of recruiting qualified faculty, shortages of preceptors and clinical sites, and increasing the diversity of faculty and program applicants.

#### **Title VII Funding**

Title VII funding is the only opportunity for PA programs to apply for federal funding and plays a crucial role in developing and supporting PA education programs. Title VII funding fills a critical need for curriculum development and faculty development. Funding enhances clinical training and education, assists PA programs with recruiting applicants from minority and disadvantaged backgrounds, and funds innovative programs that focus on educating a culturally competent workforce. Title VII funding increases the likelihood that PA students will practice in medically underserved communities with health professional shortages. The absence of this funding would result in the loss of care to patients in underserved areas.

Title VII support for PA programs was strengthened in 2010 when Congress enacted a 15 percent carve out in the appropriations process for PA programs. This funding will enhance capabilities to train a growing PA workforce and is likely to increase the pool for faculty positions as a result of PA programs now being eligible for faculty loan repayment. Huge loan burdens serve as barriers for physician assistant entry into academia.

Here we provide several examples of how PA programs have used Title VII funds to creatively expand care to underserved areas and populations, as well as to develop a diverse PA workforce.

- One Texas program has used its PA training grant to support the program at a distant site in an underserved area. This grant provides assistance to the program for recruiting, educating, and training PA students in the largely Hispanic South Texas and mid-Texas/Mexico border areas and supports new faculty development.
- A Utah program has used its PA training grant to promote interprofessional teams — an area of strong emphasis in the Patient Protection and Affordable Care Act. 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.
- A South Carolina program has developed a model program that offers a two-year academic fellowship for recent PA graduates with at least one year of clinical experience. To further enhance

an evidence-based approach to education and practice, two specific evidence-based practice projects were embedded in the fellowship experience. Fellows direct and evaluate PA students' involvement in the "Towards No Tobacco" curriculum, aimed at fifth graders, and the PDA Patient Data experience, aimed at assessing health care services.

**Recommendations on FY 2014 Funding**

The Physician Assistant Education Association requests the Appropriations Committee to support funding for Title VII health professions programs at a minimum of \$264.4 million for FY 2014. This level of funding is crucial to support the nation's demand for primary care practitioners, particularly those who will practice in medically underserved areas and serve vulnerable populations. Additionally, we encourage support for a minimum of \$10 million to support PA education programs. We thank the members of the subcommittee for their support of the health professions and look forward to your continued support of solutions to the nation's health workforce shortage. We appreciate the opportunity to present the Physician Assistant Education Association's FY 2014 funding recommendation.

March 15, 2013

Submitted for the Record

Martha Nolan, Vice President of Public Policy, Society for Women's Health Research  
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 federal investment in biomedical research, specifically women's health and sex differences research, within the Department of Health and Human Services (HHS). We request that for fiscal year (FY) 2014, Congress fund the following agencies and the office of women's health programs at:

- **Agency for Healthcare and Research Quality (AHRQ) – \$430 million**
- **National Institutes of Health (NIH)-\$32 billion**
- **Office of Research on Women's Health (ORWH)-\$43.3 million**
- **HHS Office of Women's Health- \$34.7 million**
- **CDC Office of Women's Health- \$478,000**

SWHR is 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 sustained funding of a federal research agenda that is inclusive of biomedical and women's health research programs is absolutely essential if the U.S. is to meet the needs of its citizens, especially women. SWHR realizes that the federal government is focused on reducing our federal deficit; however, proper and sustained investment in health research will ultimately save valuable dollars that are currently wasted on inappropriate treatments and procedures.

Past investments in biomedical research propelled the U.S. into the position of world leader in biomedical research. These investments resulted in the mapping of the human genome and made

it possible for scientists to discover the biological and physiological differences between women and men. The study of how these differences impact health and medicine, known as sex based biology has been a fundamental part of SWHR's mission since its inception. This research confirms that biological sex plays an important role in disease susceptibility, prevalence, time of onset and severity. Sex differences are evident in cancer, obesity, heart disease, immune dysfunction, mental health disorders, and many other diseases. Medications can have different effects in woman and men, based on sex specific differences in absorption, distribution, metabolism and elimination. When translated into medical practice, this research will result in a personalized approach to medicine, which will transform medical practice in the U.S.

*National Institutes of Health-* In the past decade; NIH has faced a 20.8% decrease in buying power as a direct result of budgetary cuts. More than 83% of NIH funding is spent in communities across the nation, creating jobs at more than 3,000 universities, medical schools, teaching hospitals, and other research institutions in every state. The number of new grants funded by NIH has dropped steadily with declining budgets; and in 2012, the NIH Director, Francis Collins, reported that grant funding was at an all-time low of 20% .

A shrinking number of available grants put American scientists out of work. With a limited avenue to secure research funding, scientists will have little choice than to pursue opportunities outside of academic research, resulting in the loss of skilled bench scientists and researchers to countries like China, who continue to heavily invest in research. The U.S. desperately needs these researchers and scientist to meet the needs and challenges of an aging U.S. population.

**Innovation, which can take years to bear fruit, only occurs with continual research**

**investment.** It is estimated that U.S. health spending will account for nearly one-fifth of the U.S. economy by 2021. Given this timeframe, investments made today will just be coming onto the market. Rather than implementing across the board budget cuts that will limit future treatments, SWHR believes that Congress should invest in specific areas of cost savings that will lower the overall cost of healthcare, which is the largest driver of the federal deficit. Research into new and innovative strategies that are proven to prevent, treat, or cure chronic conditions is perhaps the single most cost effective strategy in reducing our federal deficit.

**SWHR recommends that Congress set, at a minimum, a budget of \$32 billion for NIH for FY 2014.** Further we recommend that NIH, with the funds provided, be mandated to report sex/gender differences in all research findings, including those studying a single sex but with explanation and justification. Additionally, NIH's mandate should be expanded 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.

*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 works in collaboration with NIH Institutes and Centers (IC's) to implement their programs and co-fund research that incorporates sex and gender differences into their ongoing studies. ORWH also 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 provides protected research time for junior faculty by pairing them with senior investigators in an interdisciplinary mentored environment. To date, over 490 scholars have been trained in 39 centers, and 80% of those scholars have been female. These centers have produced over 4,800 publications, and have been awarded 346 NIH research grants.
- 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. These programs have resulted in over 665 articles, reviews, abstracts, book chapters and other publications.
- The Advancing Novel Science in Women's Health Research (ANSWHR) program promotes innovative new concepts and interdisciplinary research in women's health research and sex/gender differences. ORWH partners with 23 NIH IC's, to broaden all areas of women's health and sex differences research.
- Administrative Supplements for Research on Sex and Gender Differences, is a new trans-NIH initiative to broaden the field of sex and gender differences research. It allows ORWH to leverage on-going grants by adding new dimension to the study.

**To allow ORWH's programs and research grants to continue make their impact on research and the public, Congress must direct that NIH continue its support of ORWH and provide it with a \$1 million dollar budget increase, bringing its FY2014 total to \$43.3 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 redress inequities in research, health care services, and education that have historically placed the health of women at risk. Without OWH's actions, the task of translating research into practice would 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 \$34.7 million for FY 2014.**

Under HHS, the agencies currently with offices, advisors or coordinators for women's health or women's health research include the Food and Drug Administration (FDA), Centers for Disease Control and Prevention (CDC), Agency for Healthcare Quality and Research (AHRQ), Indian Health Service (INS), Substance Abuse and Mental Health Services Administration (SAMHSA), Health Resources and Services Administration (HRSA). 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 offices that promote working in collaboration with other agencies, which shares much needed expertise while avoiding unnecessary duplication. SWHR recommends that they are sufficiently funded to ensure that these programs can continue and be strengthened in FY 2014.**

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.

Statement of  
Peter Polverini, DDS, DMSc  
President (2013-2014)  
American Association for Dental Research  
703-548-0066 email: [cfox@iadr.org](mailto:cfox@iadr.org)  
to the  
House Appropriations Subcommittee on  
Labor, Health and Human Services, Education, & Related Agencies  
on behalf of the  
National Institute of Dental and Craniofacial Research  
March 15<sup>th</sup>, 2013

**Introduction**

Mr. Chairman and members of the Subcommittee, I am Peter Polverini, Dean of the University of Michigan School of Dentistry and President of the American Association for Dental Research (AADR). My testimony is on behalf of AADR. I thank the subcommittee for this opportunity to testify about the exciting advances in oral health science and for your past support of research at the National Institutes of Health (NIH). It is that support that makes it possible for the National Institute of Dental and Craniofacial Research (NIDCR) to improve oral health with the research it funds. The investments we make today will make it easier to treat and prevent oral health diseases and disorders in the future. Therefore, I am requesting that NIDCR receive a funding level of \$450 million. My testimony will illustrate how scientific advances in oral health have benefited taxpayers, and explain some of the challenges that lie ahead.

**What Is The American Association for Dental Research?**

The AADR is a non-profit organization with more than 3,500 individual members in the United States, as well as 46 institutional members spread across 26 states. Its mission is to: 1) advance research and

increase knowledge for the improvement of oral health; 2) support and represent the oral health research community; and 3) facilitate the utilization and knowledge of research findings.

### **Why Is Oral Health Important?**

Maintaining good oral health throughout life is critically important to systemic health and overall quality of life. If oral diseases and poor oral conditions go untreated, it becomes difficult to eat, drink, swallow, smile, talk, and maintain proper nutrition. In spite of the dramatic improvements in oral health over the years, it is still a major concern. Americans spent \$108 Billion on dental expenditures in 2011, according to the Center for Medicare and Medicaid Services (CMS). 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. Tooth decay, or dental caries, is a very common disease where the minerals in the tooth structure are slowly dissolved out of the tooth to the point of cavitation – or a “cavity.” Untreated dental decay in primary teeth affects 20% of children aged 2 to 5, and 25% of children 6 to 11. Untreated dental decay in permanent teeth also affects 20 to 25% of adults, depending on the age bracket. Moreover, we know there are significant oral health disparities across racial, ethnic, and socioeconomic groups.

Scientists have discovered important linkages between gum disease, or periodontal disease, and heart disease, stroke, diabetes, and pancreatic cancer. The consequences of inflammation may be the common biologic factor explaining these linkages, but there are genetic factors as well. Further research is needed to understand these linkages, the potential for causal connections, and the effect of intervention or treatment of the oral diseases on systemic health.

### **Examples of Oral Health Research and Development:**

***National Dental Practice-Based Research Network** – 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, renamed *The National Dental Practice-Based Research Network (NDPBRN)*, is headquartered at the University of Alabama at Birmingham (UAB) 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. According to NIDCR Director Martha Somerman, D.D.S., Ph.D., a national coordinating center streamlines the network structure for greater financial and administrative efficiency.

**Human papillomavirus (HPV)** – HPV is frequently associated with cervical cancer. However, HPV is responsible for a rapidly growing type of oral cancer. According to Maura L. Gillison, MD, PhD, an oncologist and researcher at Ohio State University, rates of infection among men are about three times higher than among women. Oral cancers are likely to become the most common HPV-related cancer by 2020. The International Agency for Research against Cancer has acknowledged HPV as a risk factor for oropharyngeal cancer. Since not enough is known about HPV-related oropharyngeal cancers to enable potentially lifesaving interventions, NIDCR plans to support research intended to provide a clearer picture of HPV-related oral cancers including their incidence, risk factors, and natural history.

**Point of Care Diagnostics** –NIDCR is supporting studies aimed at providing early, point of care, detection of both oral and systemic conditions (e.g. oral cancer, pancreatic cancer, diabetes, cardiovascular disease). Point of care diagnostics are often more desirable than standard laboratory methods. Disease specific biomarkers found in saliva have recently provided important insights on human health. Saliva provides for noninvasive testing, potentially increasing the number of adverse health conditions detected at an early stage. Access to early diagnostic tests can save thousands of lives a year and can be conducted from home or mobile facilities reaching populations with limited access to health care. In

*order for the promise of salivary diagnostics to become a reality, there needs to be further research on the specific biomarkers that are thought to be associated with health or certain disease states.*

**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.*

**Health Disparities Research Program** - *Despite remarkable improvements in the oral health of the American population, not everyone in the nation has benefited equally. Oral, dental and craniofacial conditions remain among the most common health problems for low-income, racial/ethnic minority, disadvantaged, disabled, and institutionalized individuals across the life span. Dental caries, periodontal disease, and oral and pharyngeal cancer are of particular concern. The NIDCR Health Disparities Research Program supports studies that provide a better understanding of the basis of health disparities and inequalities, develops and tests interventions targeted to underserved populations; and explores approaches to the dissemination and implementation of effective findings to assure rapid translation into practice, policy and action in communities.*

**Chronic Pain** – *NIDCR is an active participant in trans-NIH work on chronic pain. The Interagency Pain Research Coordinating Committee (IPRCC) is a federal advisory committee created by the Department of Health and Human Services to enhance pain research efforts and promote collaboration across the*

*government, with the ultimate goals of advancing fundamental understanding of pain and improving pain-related treatment strategies.*

### **Challenges to Research**

Today's investments in basic research on the fundamental causes and mechanisms of disease will have a great impact on future advances in health care. Investments in NIDCR are needed to support research to define the genetic and environmental risk factors for CLP, as well as to improve care for children with these disorders. More work needs to be done in order to understand HPV-related cancers, especially oral cancers given their increasing prevalence. These are just a couple of the many research challenges confronting oral health scientists. We urge Congress to make science a national priority.

### **Fiscal Year 2014 Budget Request**

As you can see, Mr. Chairman, there are many research opportunities that need to be pursued in order to improve patient care. In order for Americans to have access to better oral health care, funding for NIH overall, and particularly NIDCR, should be more consistent. The budget sequestration, which went into effect March 1st, will have a devastating impact on science. Not only does it affect grants and cooperative agreements, but continuation awards will be reduced or in some cases not issued, thereby impeding ongoing research. New grants and cooperative agreements will likely be re-scoped, delayed, or canceled. These actions have direct implications on the health and safety of Americans. Moreover, the across-the-board cuts harm the prospects for lasting deficit reduction by stifling a significant driver of economic growth. We ask that you craft a solution that recognizes NIH as a critical national priority by providing at least \$32 billion in funding in the FY 2014 Appropriations bill, of which we recommend that NIDCR be appropriated \$450 million. Thank you for this opportunity to testify. We at AADR look forward to having the opportunity to work with the Congress and the Department of Health and Human Services to help build a strong and successful research enterprise.

# NACCHO

National Association of County & City Health Officials

*The National Connection for Local Public Health*

Statement of the  
**NATIONAL ASSOCIATION OF COUNTY AND CITY HEALTH OFFICIALS**

1100 17<sup>th</sup> St., NW, 7<sup>th</sup> Floor  
 Washington, DC 20036

Submitted for the record to the  
 Subcommittee on Labor, Health and Human Services, Education and Related Agencies  
 Committee on Appropriations  
 United States House of Representatives

**FY 2014 Funding for Programs at the Centers for Disease Control and Prevention**

**Contact:** Eli Briggs, Government Affairs Director  
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HHS Program (\$ in millions)	FY2012	NACCHO FY2014 Request
Prevention and Public Health Fund	1,000	1,000
CDC Public Health Emergency Preparedness Grants	643.1	715
CDC Community Transformation Grants	226.0	280
CDC Section 317 Immunization Program	620.2	720.0
CDC National Public Health Improvement Initiative	40.2	40.2
CDC Food Safety	27.1	44

The **National Association of County and City Health Officials** is the voice of the 2,800 local health departments across the country. These city, county, metropolitan, district, and tribal departments work every day to ensure the safety of the water we drink, the food we eat, and the air we breathe.

More than 180,000 health department staff across the country are responsible for programs that make it easier for people to be healthy. The nation's current financial challenges are compounded by those in state and local governments further diminishing the ability of local health departments to address community health and safety needs. Repeated rounds of budget

cuts and lay-offs continue to erode local health department capacity. Since 2008, local and state health departments have scaled back and eliminated programs that protect the public's health and cut more than 50,000 jobs. Sequester cuts will add to pressures on local health departments as federal cuts make their way down to the state and local level.

To help protect the public's health, we urge the Subcommittee to consider the following FY2014 funding request for programs at the Department of Health and Human Services (HHS) and Centers for Disease Control and Prevention (CDC):

***Prevention and Public Health Fund (HHS)***

***NACCHO Request: \$1 billion***

***FY2012: \$1 billion***

The Prevention and Public Health Fund (PPHF) is a dedicated federal investment in programs that prevent disease at the community level. The PPHF supports:

- Early and rapid detection of diseases and injury;
- Continuous quality improvement in public health practice;
- Community-based initiatives to stem the epidemic of preventable disease;
- Immunizations and innovative chronic disease grants to prevent and reduce the rising cost of health care for the leading causes of death; and
- Local and state public health workforce training.

***Public Health Emergency Preparedness***

**Center: Center for Public Health Preparedness and Response**

**Funding Line: State and Local Preparedness and Response Capability**

**Sub-line: Public Health Emergency Preparedness Cooperative Agreements (PHEP)**

**NACCHO request: \$715 million**

**FY2012: \$643 million (not including CDC Capacity)**

The Public Health Emergency Preparedness (PHEP) grant program 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. Local and state health departments work with federal officials, law enforcement, emergency management, health care, employers, schools, and religious groups to plan, train, and prepare for emergencies so that communities are ready. Local health departments protect the public in the following ways:

- They investigate, detect, and contain outbreaks of disease
- They educate the public about how to protect themselves; such as by wearing masks, drinking bottled water, or staying indoors.
- They dispense medications or vaccinations to slow the spread of illness.

***Chronic Disease Prevention***

**Center: Center for Chronic Disease Prevention and Health Promotion**

**Funding Line: Community Transformation Grants (CTG)**

**NACCHO Request: \$280 million**

**FY2012: \$226 million**

The CTG program provides resources for local communities to address heart attacks, strokes, cancer, diabetes, and other chronic diseases which contribute to the soaring cost of health care. Risk factors like obesity and smoking often lead to these diseases and conditions, which are responsible for 75% of all health care spending — 96 cents per dollar for Medicare and 83 cents

per dollar for Medicaid. CTG grantees are charged with a 5% reduction in 5 years of death and disability due to tobacco use, heart disease and stroke and the rate of obesity through nutrition and physical activity. The program seeks to improve the health of about 130 million Americans.

***Infectious Disease Prevention***

**317 Immunization Program**

**Center: National Center for Immunization and Respiratory Diseases**

**Funding Line: 317 Immunization Program**

**NACCHO Request: \$720 million**

**FY2012: \$620.2 million**

Local health departments vaccinate people in their communities, providing one of the most successful and cost-effective ways to prevent disease and death. Local health departments also have a responsibility for ensuring that the most vulnerable people in their communities receive protection from vaccines. 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 billing systems for immunization services at public health clinics to sustain high levels of vaccine coverage. Local health departments use innovative methods to increase vaccination rates, including “Vote and Vax” activities where voters receive immunizations at their polling places and conducting outreach to families to make sure kids are immunized and ready to attend school.

***Public Health Performance Improvement***

**Center: Center for Public Health Leadership and Support**

**Funding Line: National Public Health Improvement Initiative**

**NACCHO Request: \$40.2 million**

**FY2012: \$40.2 million**

The National Public Health Improvement Initiative provides funding to 74 state, tribal, local and territorial health departments to make changes and enhancements that increase the impact of public health services. NPHII strengthens health departments by providing staff, training, tools, and capacity-building assistance dedicated to establishing performance management and evidence-based practices for improved service delivery and better health outcomes.

***Food Safety***

**Center: Center for Emerging and Zoonotic Infectious Diseases**

**Funding Line: Food Safety**

**NACCHO Request: \$44 million**

**FY2012: \$27 million**

Foodborne illness affects 48 million Americans every year, resulting in 128,000 hospitalizations and 3,000 deaths. CDC's Food Safety program seeks to ensure food safety through surveillance and outbreak response. 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. 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 FY2014 Labor-HHS-Education Appropriations bill, NACCHO urges consideration of these recommendations for programs critical to protecting the public's health.**

**Friends of the Health Resources and Services Administration**

c/o American Public Health Association  
800 I Street NW  
Washington DC, 20001  
202-777-2513

Nicole Burda, Government Relations Manager

Testimony of the Friends of the Health Resources and Services Administration  
House Appropriations Subcommittee on Labor, HHS, Education and Related Agencies  
March 15, 2013

The Friends of HRSA is a non-profit and non-partisan coalition of more than 175 national organizations dedicated to ensuring that our nation's medically underserved populations have access to high-quality primary and preventive care. The coalition represents millions of public health and health care professionals, academicians and consumers invested in HRSA's mission to improve health and achieve health equity. **We recommend funding of at least \$7.0 billion for discretionary HRSA programs in fiscal year 2014.**

The recommended funding level takes into account the need to reduce the nation's deficit while prioritizing the immediate and long-term health needs of Americans. We are deeply concerned with the failure to avert the sequester that will cut over \$300 million from HRSA's FY 2013 discretionary funding. These cuts come on top of the 17 percent – or more than \$1.2 billion – reduction to HRSA's budget authority since FY 2010. HRSA's ability to prevent sickness, keep people healthy and treat illness or injury for millions of Americans will be severely compromised, by across-the-board cuts if the sequester is not reversed and the cuts restored. It is estimated that 7,400 fewer patients will have access to HRSA's AIDS Drug Assistance Program that provides life-saving HIV medications and about 25,000 fewer breast and cervical cancer screenings will be offered for poor, high-risk women, an important tool to reduce death rates, improve treatment options and greatly increase survival. Our recommended funding level is necessary to ensure HRSA is able to implement essential public health programs including training for public health and health care

professionals, providing primary care services through health centers, improving access to care for rural communities, supporting maternal and child health care programs and providing health care to people living with HIV/AIDS.

HRSA is a national leader in providing health services for individuals and families. HRSA's programs are carried out by about 3,100 grantees in every state and U.S. territory, working to improve the health of people who are primarily low-income, medically vulnerable and geographically isolated through access to quality services and a skilled health care workforce. The agency operates about 80 different programs, working to serve roughly 55 million Americans who are uninsured and more than 60 million Americans who live in communities where primary health care services are scarce. In addition to delivering much needed services, the programs provide an important source of local employment and economic growth in many low-income communities.

Our request 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, dentists, 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. For example, HRSA offers loan repayment and scholarships to nurses who work in areas experiencing critical shortages of nurses. This investment has increased the number of nurses working in communities with the greatest need by three fold – from about 1,000 to 3,000 – since 2008.

- Primary care programs support nearly 8,900 community health centers and clinics in every state and territory, improving access to preventive and primary care to more than 20 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 migrant and seasonal farm workers, homeless individuals and families and those living in public housing.
- Maternal and child health programs, including the Title V Maternal and Child Health Block Grant, Healthy Start and others, support a myriad of initiatives designed to promote optimal health, reduce disparities, combat infant mortality, prevent chronic conditions and improve access to quality health care for more than 40 million women and children. Maternal and Child Health Block Grants provide services to 6 out of every 10 women who give birth and their infants. Since Title V was established in 1935, the infant mortality rate has declined nearly 90 percent and contributed to a 51 percent decline in the U.S. child fatality rate from unintentional injuries since 1987. Today, MCH programs help assure that nearly 100 percent of 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

roughly 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 people living in rural areas where there are a shortage of health care services. The Office of Rural Health Policy serves as the Department of Health and Human Services' 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. Over the past 20 years, 25,000 individuals have been given a second chance at life from receiving blood cells, including bone marrow, blood and cord blood, given by living donors unrelated to their recipients.

We urge you to consider HRSA's role in strengthening the nation's health safety net programs and ensuring that vulnerable populations receive quality health services. By supporting, planning for and adapting to change within our health care system, we can build on the successes of the past and address new gaps that may emerge in the future. We advise that you to adopt our **FY 2014 request of \$7.0 billion for discretionary HRSA programs** to meet the public health needs and we thank you for the opportunity to submit our recommendation to the subcommittee.

## 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



*Submitted for the Record to the House Appropriations Subcommittee on  
 Labor, Health and Human Services, Education, and Related Agencies – March 15, 2013*

### FY 2014 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 order to allow for a new competitive cycle for physician primary care training grants. In addition, we recommend the Committee fund the Agency for Healthcare Research and Quality (AHRQ) at a base discretionary level of at least \$430 million for fiscal year 2013.**

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.

Members of both parties agree there is much that must be done to support primary care production and to nourish the development of a high quality, highly effective primary care workforce to serve as a foundation for our health care system. Providing strong funding for these programs is essential if we are to establish any such foundation.

***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 indispensable 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.

The Census Bureau projects that the US population will increase by 15.2% in the period of 2010 to 2025, and the population older than 65 will grow by 60%. Based on these projections, a recent study in the *Annals of Family Medicine* (Pettersen and Liaw, November/December 2012) estimates the number of primary care office visits will increase from 462 million in 2008 to 565 million in 2025, and by 2025 we will need nearly 260,687 practicing primary care physicians – 51,880 more than the current workforce. In this time of increasing primary care need, we urge you to recognize the importance of maintaining and expanding the pipeline of primary care production and training by supporting at least a \$71 million appropriation for the Primary Care Training and Enhancement program funded through the Labor-HHS-Education appropriations bill. This funding level is necessary to permit a competitive grant cycle for physician primary care training grants. Without additional funding, this will be the third year in a row there are insufficient funds to conduct a grant cycle. Funding for primary care training is an investment in the future restraint of health care spending, as well as in improved health outcomes.

As implementation of the Affordable Care Act proceeds, 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. Now is the time to ensure that critical funding for the Primary Care Training and Enhancement program takes place. We cannot allow the primary care pipeline to dry up.

Key advisory bodies such as the Institute of Medicine (IOM) and the Congressional Research Service (CRS) have also called for increased funding. The IOM (December 2008) pointed to the drastic decline in Title VII funding and described these health professions workforce training programs as "an undervalued asset." The CRS found that reduced funding to the primary care cluster has negatively affected the programs during a time when more primary care is needed (February 2008).

According to the Robert Graham Center, (Title VII's decline: Shrinking investment in the primary care training pipeline, October 2009), "the number of graduating U.S. allopathic medical students choosing primary care declined steadily over the past decade, and the proportion of minorities within this workforce remains low." Unfortunately, this decline coincides with a decline in funding of primary care training funding – funding that we know is associated with increased primary care physician production and practice in rural and underserved areas. The report goes on to say that "the nation needs renewed or enhanced investment in programs like Title VII that support the production of primary care physicians and their placement in underserved areas."

A recent study in the *Annals of Family Medicine* (Phillips and Turner, March/April 2012) stated that "Meeting this increased demand [for primary care physician production] requires a major investment in primary care training." The study continues, "Expansion of Title VII, Section 747 with the goal of improving access to primary care would be an

important part of a needed, broader effort to counter the decline of primary care. Failure to launch such a national primary care workforce revitalization program will put the health and economic viability of our nation at risk."

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 21<sup>st</sup> century.

The evidence is clear:

- "There is evidence from demonstration projects and international experience that preferential investment in primary care can reduce spending, particularly for inpatient and Emergency Department care." (Health Affairs, Mar-Apr 2009)
- "There is compelling evidence that health care outcomes and costs in the United States are strongly linked to the availability of primary care physicians. For each incremental primary care physician (PCP), there is 1.44 fewer deaths per 10,000 persons. Patients with a regular primary care physician have lower overall health care costs than those without one." (Council on Graduate Medical Education (COGME) December, 2010)
- Hospital readmission after discharge is often a costly failing of the U.S. health care system to adequately manage patients who are ill. Increasing the number of family physicians (FPs) is associated with significant reductions in hospital readmissions and substantial cost savings. (Robert Graham Center, 2011)

**We urge the Congress 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 in order to allow for a new competitive cycle for physician primary care training grants.**

***Agency for Health Care Research and Quality (AHRQ)***

Last year, 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.

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 \$430 million for fiscal year 2013.**



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*Protect, Prevent, Live Well*

Testimony of the American Public Health Association submitted for the record  
Georges C. Benjamin, MD, FACP, FACEP (E), Executive Director  
Concerning the fiscal year 2014 budgets for CDC and HRSA  
House Appropriations Subcommittee on Labor, HHS, Education and Related Agencies  
March 15, 2013

The American Public Health Association is the collective voice advocating for the public's health. As a diverse community of public health professionals, we've championed the health of all people and communities around the world for more than 140 years. We are pleased to submit our views regarding the FY 2014 budgets of the Centers for Disease Control and Prevention and the Health Resources and Services Administration. We urge you to take our recommendations into consideration as you move forward with writing the FY 2014 Labor-HHS-Education Appropriations bill.

**Centers for Disease Control and Prevention**

APHA believes that that Congress should support CDC as an agency – not just the individual programs that it funds. Given the challenges and burdens of chronic disease, the ongoing threat of an influenza pandemic, constant public health emergencies, new and reemerging infectious diseases and our many unmet public health needs and missed prevention opportunities – **we urge a funding level of \$7.8 billion for CDC's programs in FY 2014.** We are deeply disappointed with the failure to avert the sequester which will cut roughly \$300 million from CDC's FY 2013 funding. We urge you to work to reverse the sequester and restore these cuts to CDC's budget. This cut comes on top of the \$740 million reduction to CDC's budget authority in FY 2011. At the same time state and local health departments are operating on tight budgets and with a smaller workforce. Since 2008, more than 46,000 state and local

public health jobs have been lost. These cuts are simply not sustainable and will reduce the ability of CDC and its state and local grantees to investigate and respond to public health emergencies as well as food borne and infectious disease outbreaks.

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.

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 crisis 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 and ensuring the health and well being of the American public by helping to control asthma, protecting from threats associated with natural disasters and climate change and reducing exposure to lead and other environmental hazards. We encourage the subcommittee to provide adequate funding for NCEH programs 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 providing health services for individuals and families. Roughly 55 million Americans are currently uninsured and more than 60 million live in rural communities where primary health care services are scarce – the agency serves as a health safety net for the medically underserved and works to improve their health. To respond to these challenges, **APHA believes that the agency will require funding of \$7.0 billion for discretionary HRSA programs in FY 2014.**

The recommended funding level takes into account the need to reduce the nation's deficit while prioritizing the immediate and long-term health needs of Americans. We are deeply concerned with the failure to avert the sequester that will cut over \$300 million from HRSA's FY 2013 discretionary funding. These cuts come on top of the 17 percent or more than \$1.2 billion reduction to HRSA's budget authority since FY 2010. HRSA's ability to prevent sickness, keep people healthy and treat illness or injury for millions of Americans will be severely compromised, by across-the-board cuts if the sequester is not reversed and the cuts restored. Our recommended funding level is necessary to ensure HRSA is able to implement essential public health programs, including training for public health and health care professionals, providing

primary care services through health centers, improving access to care for rural communities, supporting maternal and child health care programs and providing health care to people living with HIV/AIDS. In addition to delivering much needed services, the programs provide an important source of local employment and economic growth in many low-income communities.

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, dentists, optometrists, physician assistants, mental and behavioral health professionals 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.
- Primary Care programs support nearly 8,900 community health centers and clinics in every state and U.S. territory, improving access to care for more than 20 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 programs, including the Title V Maternal and Child Health Block Grant, Healthy Start and others support a myriad of initiatives designed to promote optimal health, reduce disparities, combat infant mortality, prevent chronic conditions and improve access to quality health care for more than 40 million women and children, including children with special health care needs.

- HIV/AIDS programs provide assistance to states and communities most severely affected by HIV/AIDS. The programs deliver comprehensive care, prescription drug assistance and support services for more than half a million low-income people impacted by HIV/AIDS, which accounts for roughly 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 healthcare 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 programs improve access to care for people living in rural areas where there is a 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 only a fraction of federal spending and continued cuts to public health and prevention programs will not balance our budget, it 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.

**Written testimony by the Academy of Radiology Research on  
FY 2014 Appropriations for the National Institutes of Health  
Submitted March 15, 2013, 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 net positive increase for NIH and NIBIB in fiscal year (FY) 2014**

Thank you for providing the Academy of Radiology Research with the opportunity to submit testimony on fiscal year 2014 funding for the National Institutes of Health (NIH). The imaging research community deeply appreciates the Subcommittee's leadership in recommending an additional \$1 billion in NIH funding in fiscal year 2012. This represented a much-needed step in the right direction for medical research.

After the sequestration cut of 5.1% to the NIH in fiscal year 2013, the final appropriation for the agency will be approximately \$29.3 billion (assuming a relatedly flat FY2013 level). 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 an innovation economy.

NIH Director Francis Collins, M.D., Ph.D. recently stated before the Subcommittee on March 5 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 also important to note that NIH Directors did not wake up to a -5.1% sequester order on March 2 and are just now finding superfluous areas to trim, fat to cut, or duplication to eradicate. Directors and their staff have managed flat budgets, with eroding purchasing power, for the past decade. These reductions are to highly meritorious proposals.

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 flat budget caps, and begin reinvigorating medical research.

**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 other 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 been long known that diseased tissue has different mechanical properties than 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

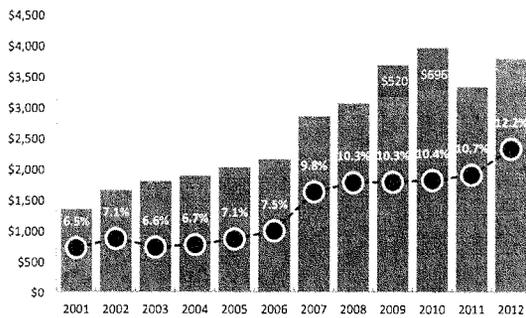
diseases including liver disease, breast cancer, prostate cancer, and many others can be detected at the earliest stages using MR elastography. Patients suspected of liver disease or cancer may think they are getting “an MRI.” However, at places like Mayo Clinic, the radiologists are likely using a new 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 expedite 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 FY2008 - FY2011. Of the 239 NIH Research, Disease and Condition Categorization (RCDC) codes at NIH, imaging projects were

**Total Amount of Grants Using Advanced Imaging Tools Produced by Radiology Research, and as a Percent of the total NIH Budget, 2001-2012**



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.

***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 and competitiveness 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 economic 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 \$70m increase for NIBIB in FY2014.



**Testimony of the National Indian Education Association**

**Native Education Appropriation Priorities  
Before the**

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

**Friday, March 15, 2013**

**B-2358 Rayburn House Office Building**

Chairman Kingston, Ranking Member DeLauro, and members of the Subcommittee, thank you for providing the National Indian Education Association (NIEA) the opportunity to submit written testimony on Native Education Appropriation Priorities. NIEA is grateful for this opportunity to provide testimony that may offer important insights regarding how the federal government can better uphold its trust responsibility and bring parity to Native education. NIEA has worked for decades to keep Native education moving toward educational equity and excellence.

Founded in 1970, NIEA's mission is to advance comprehensive educational opportunities for American Indians, Alaska Natives, and Native Hawaiians throughout the United States. We accomplish this by viewing education as an integrated system consisting of federal, tribal, public, and private partners who coordinate at the federal, state, local, and tribal levels. Our collective membership of educators, tribal leaders, researchers, school administrators, teachers, parents, and students stands over 2000 strong.

These education partners work together to ensure Native students have the same opportunity for effective learning and success as their non-Native peers. In support of this vision, NIEA also advocates for the inclusion of traditional Native languages, cultures, and values that enable Native learners to become contributing members of their communities and strengthen Native participation in education.

**STATE OF NATIVE EDUCATION**

Native education continues to be in nothing less than an ongoing state of emergency. Native children experience large disparities in academic achievement and educational attainment: reading and math scores are substantially lower than those of other groups and Native students face some of the lowest high school graduation rates in the country.<sup>i</sup> Fewer Native students enroll in college, and even fewer graduate.<sup>ii</sup> The situation is increasingly dire in Bureau of Indian Education (BIE) schools. During the 2010-2011 school year, the BIE's graduation rate stood at just 59 percent and barely one-third of students performed at proficient/advanced levels in language arts and mathematics.<sup>iii</sup>

The Administration recognizes the importance of having a specific, targeted approach to Native education programs focused on closing the achievement gap between Native and non-Native students. For example, the recently signed November 30, 2012 Memorandum of Agreement (MOA) between the BIE in the Department of the Interior, the Administration for Native Americans in the Department of Health and Human Services (HHS), and the White House Initiative on American Indian and Alaska Native Education in the Department of Education (ED) will ensure better agency cooperation and coordination to preserve and strengthen Native languages, culture, and education.

Without sustained funding for vital HHS and ED programs from Congress, it will be difficult to increase achievement rates among Native students and bring parity to Native education. NIEA understands the current fiscal climate. However, full funding is crucial to ensuring the following education programs are successful.

## **RECOMMENDATIONS**

### **Department of Education**

#### ***State-Tribal Education Partnership (STEP) Program: \$5 million***

The STEP program was appropriated roughly \$2 million dollars to five participating tribes in FY 2012 and 2013 under the Tribal Education Department appropriations. In order for this program to continue to succeed and thrive, it must receive its own line and authorization of appropriations. Collaboration between tribal education agencies and state education 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.

#### ***Impact Aid: \$1.36 billion***

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 the Native population in public schools, Native populations face reduced education funding because of this tax issue. Therefore, funding for Impact Aid must not be less than this requested amount. Furthermore, Impact Aid should be converted to a forward-funded program to eliminate the need for cost transfers and other funding issues.

#### ***Title VII (Indian Education Formula Grants): \$198 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 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.

***Native Hawaiian Education: \$34.18 million***

While the Kingdom of Hawaii once enjoyed the highest rates of literacy in the world, today Native Hawaiian educational attainment lags behind the general population. The Native Hawaiian Education program empowers innovative culturally appropriate programs to enhance the quality of education for Native Hawaiians.

Additionally, specific educational disparities were identified, and targeted for improvement. New grantees in Fiscal Year 2011 alone are estimated to provide educational programs to over 30,000 Native Hawaiian children and families. These programs strengthen the Native Hawaiian culture and improve educational attainment, both of which are correlated with positive economic outcomes.

***Alaska Native and Native Hawaiian-Serving Institutions: \$15.08 million***

This program assists Alaska Native and Native Hawaiian-Serving Institutions of Higher Education to improve their academic quality, institutional management, and fiscal stability. Alaska Natives and Native Hawaiians have significantly lower higher educational attainment rates than the national average. It is vital that Congress invest adequate funding for the institutions of higher education focused on serving Native peoples.

***Alaska Native Education Equity Assistance Program: \$35 million***

This assistance program funds the development of curricula and education programs that address the education needs of Alaska Native students, and the development and operation of student enrichment programs in science and mathematics. In 2011, the National Indian Education Study found that Native students continue to score significantly lower than their peers in reading and math in grades four and eight.

Further, the mathematics score disparity among American Indian and Alaska Native students and their non-Native counterparts is larger than in 2005. This funding is crucial to close this gap. Other eligible activities include professional development for educators, activities carried out through Head Start programs, family literacy services, and dropout prevention programs.

***Tribal Education Departments (TEDs): \$5 million***

This funding assists TEDs, who are uniquely situated at the local level to implement innovative education programs that improve Native education. TEDs are uniquely equipped to deliver education programs tailored to improve educational parity for Natives because tribes understand the programs and their effect on their children when a program succeeds.

TEDs would use this much-needed funding to develop academic standards, assess student progress, and create math and science programs that require high academic standards for students in tribal, public, and BIE schools. Tribes utilizing self-governance over education have been very successful because they understand the circumstances affecting their populations. Adequately funding TEDs would create the most return on federal dollars spent.

***Higher Education Act Programs - Strengthening TCUs: \$30 million***

Tribal Colleges and Universities, funded under Title III-A Sec. 316, which are truly developing institutions, are providing quality higher education opportunities to some of the most rural, impoverished, and historically underserved areas of the country. The goal of HEA-Title III programs is "to improve the academic quality, institutional management and fiscal stability of eligible institutions, in order to increase their self-sufficiency and strengthen their capacity to make a substantial contribution to the higher education resources of the Nation." The TCU Title III-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 global, competitive workforce. NIEA respectfully urges the Subcommittee to appropriate \$30 million in FY 2014 for HEA Title III-A section 316.

***Tribally Controlled Post-Secondary Career and Technical Institutions: \$10 million***

These funds are provided to United Tribes Technical College and Navajo Technical College to ensure Native students have the opportunity to continue their education. Natives are underrepresented in postsecondary education, and this funding ensures schools can provide certificate and other degree programs for Native students.

**Department of Health and Human Services**

***Head Start: Full funding for Head Start and Indian Head Start***

Head Start continues to play an instrumental role in Native education. This vital program combines education, health, and family services to model traditional Native education, which accounts for its success rate. It is now conventional wisdom that there is a return of \$7 to \$9 dollars for every single dollar invested in Head Start. However, current funding dollars provide less for Native populations as inflation and fiscal constraints increase.

Native partners, such as the Cherokee Nation, utilize these funds to operate a program that serves nearly 700 children and over 200 infants and toddlers in Early Head Start. In addition to employing 12 full-time teachers that specialize in Head start, the Tribe also contracts with over 50 teachers in regional public schools located in eastern Oklahoma. Native partners utilizing Head Start funds must be protected from any reductions as the program is already underfunded. Cuts would only reduce the number of children served

by the program. Therefore, NIEA requests full funding to ensure this highly successful program can help more Native people.

***Native Languages Preservation (Esther Martinez Program Grants): \$10 million***

Native language grant programs are the essential building blocks for saving Native languages and cultures, especially those that are at risk of disappearing in the next few decades. With adequate funding, Esther Martinez Program Grants support and strengthen Native American language immersion programs – including language nests, language survival schools, and language restoration programs – that preserve such languages and cultures.

In addition to protecting Native languages, these immersion programs have been shown to promote higher academic success for participating students in comparison with their Native peers who do not participate. This is critical for our Native youth, who have high school graduation rates far lower than their non-Native peers.

The HHS Budget should provide adequate funding for tribal governments to authorize programs and develop Native language instruction, curricula, and academic recognition in tribal and public education systems. HHS should recognize the barriers Native partners face in implementing language programs under state education agencies, such as exclusion from collaboration and consultation, and ensure technical assistance is provided where needed.

**CONCLUSION**

NIEA appreciates the opportunity to provide written comments on needed funding levels that will improve Native communities and protect Native education. With your support and through our continued collaboration, NIEA is hopeful that Congress and our federal partners will protect and strengthen programs and funding that ensures parity for our children and increase Native educational opportunities. With an educated citizenry, Native communities will have the opportunity to thrive and succeed in an increasingly competitive global marketplace.

For additional information, please contact Clint Bowers, NIEA Research and Policy Associate, at [cbowers@niea.org](mailto:cbowers@niea.org) or (202) 544.7290.

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<sup>1</sup> U.S. Department of Education, Institute of Education Sciences, National Center for Education Statistics, National Assessment of Educational Progress (NAEP), 2005, 2007, and 2009 National Indian Education Study.

<sup>ii</sup> US Census Bureau, American Community Survey 2005-2009 estimates.

<sup>iii</sup> Bureau of Indian Education, "Bureau-Wide Annual Report Card, 2010-2011."

**Testimony from the American Academy of Physician Assistants for Fiscal Year 2014 Appropriations  
Concerning HRSA's Title VII Health Professions Program**

Submitted by: Sandy Harding, MSW, Senior Director, Federal Advocacy  
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***Submitted for the Record to the House Appropriations Subcommittee on  
Labor, Health and Human Services, Education, and Related Agencies – March 15, 2013***

On behalf of the 90,000 clinically practicing physician assistants in the United States, the American Academy of Physician Assistants (AAPA) is pleased to submit comments on Fiscal Year 2014 appropriations for Physician Assistant (PA) educational programs that are authorized through Title VII of the Public Health Service Act. **AAPA respectfully request's the House Appropriations Committee to approve funding at existing levels for the Title VII health professions education program - \$264,400,000, with an allocation of 15% of the Primary Care Training and Enhancement program line for physician assistant training.**

Title VII Health Professions Programs are essential to placing health professionals in medically underserved communities. A study published in the *New York Times* has shown we are currently short 9,000 primary care physicians, and that number will grow to 65,000 primary care physicians in 15 years. According to the Health Resources and Services Administration (HRSA), an additional 31,000 health care practitioners are needed to alleviate existing professional shortages. Title VII funding encourages greater numbers of students to enter PA educational programs and to go into primary care, while increasing access to care for millions of Americans who live in medically underserved areas.

Federal support for Title VII is authorized through section 747 of the Public Health Service Act. **It is the only continuing federal funding available to PA educational programs.**

In 2012, 12 PA programs received \$2.3 million (5.9% of the total primary care medicine budget of \$38.9 million) in Title VII funding, which was directed to primary care education and training programs designed to prepare PAs for practice in urban or rural medically underserved areas. Additionally, these funds were directed to supporting programs that assist Veteran's in their transition into becoming PAs in the civilian workforce. **While the purview of the Title VII programs grant funding has expanded to include assisting returning combat veterans, the funds to PA programs from 2011 to 2012 has decreased by \$879,000.** More reductions to this budget will hurt new PA programs that need these funds to help with student recruitment, faculty development, and establishing clinical rotation sites.

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 demonstrates that PAs who have graduated from PA educational programs supported by Title VII are 67% more likely to be from underrepresented minority populations and 47% more likely to work in a rural health clinic than graduates of programs that were not supported by Title VII.**

Title VII programs are essential to the development and training of primary health care professionals and, in turn, provide increased access to care by promoting health care delivery in medically underserved communities. 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 2014.

#### **Overview of Physician Assistant Education**

The existing 170 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 340 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 graduation from an accredited PA program, physician assistants must pass a national certifying examination developed by the National Commission on Certification of Physician Assistants. To maintain certification, PAs must log 100 continuing medical education hours every two years, and they must take a recertification exam every six years.

### **Physician Assistant Practice**

Physician assistants (PAs) are licensed health professionals who practice medicine as members of a team with their supervising physicians. PAs exercise autonomy in medical decision making and provide a broad range of medical and therapeutic services to diverse populations in rural and urban settings. In all 50 states, PAs carry out physician-delegated duties that are allowed by law and within the physician's scope of practice and the PA's training and experience. Additionally, PAs are delegated prescriptive privileges by their physician supervisors in all 50 states, the District of Columbia, and Guam. This allows PAs to practice in rural, medically underserved areas where they are often the only full-time medical provider.

### **Critical Role of Title VII Public Health Service Act Programs**

In its February 2012 report to Congress, HRSA's Advisory Committee on Training in Primary Care Medicine and Dentistry wrote: *"The Title VII, section 747 grant programs have brought improvements in primary care education, faculty development, and workforce capacity. They have helped to identify and disseminate best practices to programs, accrediting bodies, and other stakeholders. These grants have permitted the development of innovative programs that benefit medical trainees throughout the country. Additionally, Title VII, section 747 grants are the foundation for programs that foster among academic leaders and trainees a sense of duty to provide care for underserved communities and populations."*

**Title VII programs are the only federal educational programs that are designed to address the supply and distribution imbalances in the health professions.** Since the establishment of Medicare, the costs of physician residencies, nurse training, and some allied health professions training have been paid through Graduate Medical Education (GME) funding; however, GME has never been available to support PA education. More importantly, GME was not intended to generate a supply of providers who are willing to work in the nation's medically underserved communities – the purpose of Title VII.

Furthermore, **Title VII programs seek to recruit students who are from underserved minority and disadvantaged populations, which is a critical step towards reducing persistent health disparities among certain racial and ethnic U.S. populations.** 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 physician assistants. 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 2014 Funding**

The American Academy of Physician Assistants urges members of the Appropriations Committee to consider the inter-dependency of all public health agencies and programs when determining funding for FY 2014. For instance, while it is critical, now more than ever, to fund clinical research at the National Institutes of Health (NIH) and to have an infrastructure at the Centers for Disease Control and Prevention (CDC) that ensures a prompt response to an infectious disease outbreak or bioterrorist attack, the good work of both of these agencies will go unrealized if the Health Resources and Services Administration (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 health care providers to be sure that disease outbreaks are reported, tracked, and contained.

Thank you for the opportunity to present the American Academy of Physician Assistants' views on FY 2014 appropriations concerning HRSA's Title VII Health Professions Program.

**Statement by the Ad Hoc Group for Medical Research on  
FY 2014 Appropriations for the National Institutes of Health  
Submitted March 15, 2013, 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 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, and population-based research conducted and supported by the National Institutes of Health (NIH).

We are deeply grateful to the Subcommittee for its long-standing and bipartisan leadership in support of NIH. These are difficult times for our nation and for people all around the globe, but we 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. Given the uncertainty surrounding the final FY 2013 appropriations and the President's FY 2014 budget request, we expect this statement to be only the beginning of an ongoing conversation between the Subcommittee and research stakeholders on the FY 2014 funding needs of NIH. At this time, the Ad Hoc Group recommends the highest possible funding level for NIH, and encourages the Subcommittee to stop the pernicious cuts to research funding that squander invaluable scientific opportunities, threaten medical progress and continued improvements in our nation's health, and jeopardize our economic vitality.

**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 a unique 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, and we are all enjoying longer, healthier lives thanks to the federal government's wise investment in this lifesaving agency. From the major advances – including a nearly 70 percent reduction in the death rate for coronary heart disease and stroke – to moving stories of personalized medicine – such as children with rare diseases like dopa-responsive dystopia, whose prognosis has been transformed from severely disabled to happy and healthy through genomic medicine – NIH's role in improving human health has been extraordinary. NIH research impacts the full spectrum of the human experience, resulting in a 40 percent decline in infant mortality over the past 20 years, as well as a 30 percent decrease in chronic disability among seniors. For patients and their families, NIH is the “National Institutes of Hope.”

NIH is the world's premiere 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. Another report, produced by Tripp Umbach, calculated a \$2.60 return on investment for every dollar spent on research at American medical schools and teaching hospitals.

### **Sequestration Threatens Scientific Momentum**

As patients, health care providers, and scientists we are deeply disturbed about the impact the 5 percent cut in NIH funding under sequestration in the current fiscal year will have on our ability to sustain the scientific momentum that has contributed so greatly to our nation's health and our economic vitality. But sequestration represents only the latest threat to the viability of this nation's medical research enterprise, following a decade when NIH has lost nearly one-fifth of its budget after inflation.

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 also 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. Appearing before this Subcommittee on March 5, NIH Director Francis Collins, M.D., Ph.D., said, "That's our seed corn. It has been the strength of America... the biomedical research community, their

creativity, their innovative instincts, and we're putting that at serious risk as we see this kind of downturn in the support for research.”

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. As Dr. Collins told this Subcommittee, other nations are “ramping up their support of biomedical research because they've read our playbook.” A 2012 report from the Information Technology and Innovation Foundation stated, “China, for example, has identified biotechnology as one of seven key strategic and emerging (SEI) pillar industries and has pledged to invest \$308.5 billion in biotechnology over the next five years. This means that, if current trends in biomedical research investment continue, the U.S. government's investment in life sciences research over the ensuing half-decade is likely to be barely half that of China's in current dollars, and roughly one-quarter of China's level as a share of GDP.... Other countries are also investing more in biomedical research relative to the sizes of their economies. When it comes to government funding for pharmaceutical industry-performed research, Korea's government provides seven times more funding as a share of GDP than does the United States, while Singapore and Taiwan provide five and three times as much, respectively.”

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 respectfully requests that NIH be recognized as an urgent national priority as the Subcommittee prepares the FY 2014 appropriations bill.

**Statement by the Association of American Medical Colleges on  
FY 2014 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 15, 2013**

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. This statement addresses four federal priorities essential in assisting medical schools and teaching hospitals to fulfill their missions of education, research, and patient care: the National Institutes of Health (NIH); the Agency for Healthcare Research and Quality (AHRQ); health professions education funding through the Health Resources and Services Administration (HRSA)'s Bureau of Health Professions; and 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 AAMC supports the recommendation of the Ad Hoc Group for Medical Research to recognize NIH as an urgent national priority in its FY 2014 Labor-HHS-Education Appropriations bill. Strengthening our nation's commitment to medical research, through robust funding of the NIH, is critical element to ensuring the health and well-being of the American people and our economy.

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' discretionary 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 \$400 million in base discretionary funding for the agency in FY 2013.

As the lead federal agency to improve health care quality, AHRQ's overall mission is to support research and disseminate information that improves the delivery of health care by identifying evidence-based medical practices and procedures. The Friends of AHRQ funding recommendation will allow AHRQ to continue to support the full spectrum of research portfolios at the agency, from patient safety to patient-centered health research and other valuable research initiatives. 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 2013.

This funding recommendation is necessary to ensure continuation of all Title VII and Title VIII programs at least at FY 2012 base discretionary levels, while also supporting promising initiatives such as the Pediatric Subspecialty Loan Repayment program 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 2010 alone, trained more than 50,000 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 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 program. This program provides critical federal graduate medical education support for children's hospitals to prepare the future primary care workforce for our nation's children and for pediatric specialty care. The AAMC has serious concerns about the president's plan to drastically reduce support for this essential program in FY 2013. At a time when the nation faces a critical doctor shortage, any cuts to funding that supports

physician training will have serious repercussions for Americans' health. We strongly urge restoration to the program's FY 2010 level of \$317.5 million in FY 2013.

**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 currently exceeds \$160,000, and typical repayment can range from \$300,000 to \$450,000. The Budget Control Act (BCA, P.L. 112-25) adds another \$10,000 to \$20,000 to total repayment as a result of eliminating graduate and professional in-school subsidies, effective July 1, 2012.

The AAMC opposes any rescissions from the National Health Service Corps (NHSC) Fund created under the Affordable Care Act (ACA, P.L. 111-142 and P.L. 111-152). 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. The AAMC further requests that any expansion of NHSC eligible disciplines or specialties be accompanied by a commensurate increase in NHSC appropriations so as to prevent a reduction of awards to current eligible health professions. Furthermore, the AAMC believes that such changes are best tested through the NHSC State Loan Repayment Program (SLRP), and that funds provided for this program should allow the states to define specialty and geographic shortages.

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 2013 spending bill.

**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) 2014 Budget for the National Institutes of Health  
 March 15, 2013**

[Elizabeth J. Kovacs, Ph.D., (708) 327-2477; [ekovacs@lumc.edu](mailto:ekovacs@lumc.edu)]

The American Association of Immunologists (AAI), the world's largest professional association of research scientists and physicians who are experts on the immune system, respectfully submits this testimony regarding appropriations for the National Institutes of Health (NIH) for Fiscal Year (FY) 2014. *AAI recommends an appropriation of at least \$32 billion for NIH for FY 2014* to enable NIH to support existing research projects, fund a limited number of outstanding new ones, and ensure that the brightest students and trainees are able to pursue careers in biomedical research in the United States.

**The Irreplaceable Role of NIH in Advancing Biomedical Research**

NIH grants support the work of most biomedical scientists.<sup>1</sup> The vast majority of AAI members who work in academia depend on NIH grants to support their research at universities, colleges and research institutions all around the country; many also teach the medical students and undergraduates who will be the next generation of physicians and researchers. Many AAI members who work in government are employed by the NIH; they depend on the NIH budget – as well as regular interaction with their private sector colleagues – to advance their work.<sup>2</sup> Our industry members, who generally do not receive NIH grants or awards, nonetheless depend on scientific discoveries that are generated by NIH-funded researchers to catalyze translational research or develop products. No matter where on the spectrum of biomedical science researchers may work, they know that NIH is the lynchpin to, and essential ingredient for, success.

NIH's irreplaceable role in our nation's biomedical research enterprise is indisputable among scientists. And the partnership between government-funded research and advancements in the private sector has never been more clear or more necessary: in a recent article in *Forbes*, three "current and former

leaders of major commercial and academic life science institutions” (Marc Tessier-Lavigne, Ph.D., P. Roy Vagelos, M.D., and Elias Zerhouni, M.D.)<sup>3</sup> compellingly argue that the “tiny” federal investment in NIH research has reaped “enormous benefits – human and economic” and that “continued investment in basic science is . . . key to our economic competitiveness. America remains the world’s leader in biotechnology and pharmaceutical discovery thanks to the strength of our research universities and other biomedical research institutions, which not only spawn countless biotechnology companies but also have attracted the R&D operations of most major pharmaceutical companies, which are keen to tap into our innovation.” Those who suggest that the private sector can or will fill the gap left by inadequate NIH funding miss the essential point made by these internationally recognized scientific leaders: NIH-funded research and NIH leadership provide the foundation upon which commercial discovery and development depend.

**Inadequate NIH Funding Threatens Human Health and U.S. Preeminence in Medicine**

America’s dominance in advancing basic biomedical research, discovering urgently needed treatments and cures, and “growing” brilliant young scientists has been unchallenged for more than fifty years. However, erosion of the NIH budget over the last decade has already led to the loss of grant funding among even the most highly qualified scientists, resulting in the closure of labs, the termination or interruption of important research, and the emigration of talented scientists to other countries that are investing heavily in their futures.<sup>4</sup> For those scientists who are willing and able to continue, securing funding increasingly consumes their time - time that should be devoted to research and to mentoring the nation’s future researchers, inventors and innovators. And in a relatively new discipline such as immunology, where knowledge is expanding exponentially and the potential for even greater success is palpable, this shrinking of federal resources is both alarming and a squandering of precious prior federal investment.

**The Immune System and Its Impact on Disease**

The functional immune system recognizes and attacks bacteria, viruses, and tumor cells inside the body. Many infectious agents, including influenza, HIV/AIDS, tuberculosis, malaria, and the common cold,

challenge - and sometimes overcome - the defenses mounted by the immune system, resulting in disease. A malfunctioning immune system can attack our normal body tissues, causing “autoimmune” diseases or disorders, including Type 1 diabetes, multiple sclerosis, rheumatoid arthritis, asthma, allergies, inflammatory bowel diseases, and lupus. The immune system also plays a role in many other diseases and conditions, including cancer, Alzheimer’s disease, obesity, Type II diabetes, and cardiovascular disease. Understanding the immune response is also crucial to developing protective vaccines against pathogens that might cause the next pandemic, man-made and natural infectious organisms (including plague, smallpox and anthrax) that could be used for bioterrorism, and environmental threats that could cause or exacerbate disease. Immunologists have made great progress in many of these areas, but solving key scientific questions that lead to prevention and cures cannot occur without investigator-initiated peer-reviewed research supported by a strong, adequately funded NIH.<sup>5</sup>

#### **Recent Immunological Advances and Their Promise for Tomorrow**

- **A potential cure for cancer?** NIH-funded scientists have demonstrated that they can remove a specific subset of immune cells (T lymphocytes) from individuals with cancer, genetically modify them in the laboratory to recognize the patient’s own cancer cells, and administer those cells to the patient. This personalized immunotherapy has induced complete and partial remissions in patients in a recent clinical experiment. Scientists have also shown similar techniques could induce cures in other types of cancer, including metastatic melanoma (a type of skin cancer), which is one of the ten most common cancers.<sup>6</sup>
- **A way to stop Alzheimer’s disease?** Alzheimer’s disease (AD) is a neurodegenerative disease of the brain that currently afflicts 5.4 million Americans, mostly over age 65.<sup>7</sup> While the cause of AD is unknown, researchers have recently found evidence of immune cells present in AD lesions, systemic alteration in the immune system of AD patients, and local inflammation in the brains of those with AD. Such recent discoveries are leading scientists to develop immune based therapies to treat AD patients,

including monoclonal antibodies which target AD plaques for destruction, and DNA based vaccines.

Such potential treatments are under development in many NIH-funded laboratories.

- ***New treatments for emerging zoonotic infectious diseases?*** Zoonotic infections (human infections acquired from a different animal species) include avian influenza, SARS, hantavirus, dengue virus, Nipah virus, and West Nile virus. Although the overall incidence remains low, these infections can have high mortality rates and emerge without warning, as evidenced by the 2012 hantavirus outbreak in Yosemite National Park and the severe West Nile virus season.<sup>8</sup> Developing preventive vaccines for these infections has proven difficult, and current treatments are limited. NIH-funded research on hantavirus and influenza A has shown an association between illness/death and an inappropriately strong immune response caused by an excessive release of cytokines (hormones of the immune system). Researchers are exploring whether limiting the inappropriate immune response during infection can reduce virus-induced illness and death.<sup>9</sup>

#### **The Importance of Sustained NIH Funding to Research, Scientists and Our Nation**

Despite strong Congressional support for biomedical research and NIH, fiscal pressures in recent years have resulted in flat or reduced NIH funding. After accounting for increases in biomedical research inflation, these budgets have eroded NIH's purchasing power by about 20% since 2003. Under sequestration, with its FY 2013 budget cut of about 5.1%, NIH's purchasing power will be further reduced. AAI is deeply alarmed about this funding reduction and believes it could irreparably harm ongoing research, weaken the U.S. biomedical research enterprise, and enable global competitors to recruit away our best scientists.

#### **Conclusion**

AAI thanks the members and staff of the subcommittee for their strong bipartisan support for biomedical research, and urges an appropriation of at least \$32 billion for NIH for FY 2014 to fund important ongoing research, strengthen the biomedical research enterprise, and support the thousands of scientists across the nation who devote their lives to finding the answers we need to prevent, treat, and cure disease.

<sup>1</sup> After a highly competitive peer review, NIH distributes most (more than 80%) of its \$30.7 billion budget to scientists who conduct research at approximately 2,500 universities, medical schools, and other research institutions across the United States. About 10% of its budget supports the work of the approximately 6,000 scientists who work in NIH's own laboratories. <http://nih.gov/about/>

<sup>2</sup> AAI is concerned that a federal policy limits the ability of government scientists to attend privately sponsored scientific meetings and conferences. [http://www.hhs.gov/travel/policies/2012\\_policy\\_manual.pdf](http://www.hhs.gov/travel/policies/2012_policy_manual.pdf) Government scientists contribute significantly to scientific advancement in our field. Information exchange among scientists from government, academia, industry and private research institutes is absolutely essential, and any barriers to the participation of government scientists undermine the best interests of science.

<sup>3</sup> Dr. Lavigne is President of The Rockefeller University and former Chief Scientific Officer for Genentech Inc.; Dr. Vagelos is Chairman of Regeneron Pharmaceuticals and Retired Chairman and CEO of Merck & Co., Inc.; and Dr. Zerhouni is President of Research and Development for Sanofi and former Director of NIH. "Legendary Drug Industry Executives Warn U.S. Science Cuts Endanger The Future," *Forbes* online (3/6/13) <http://www.forbes.com/sites/matthewherper/2013/03/06/drug-industry-greats-say-the-u-s-must-reverse-the-cuts-to-our-investment-in-science/>

<sup>4</sup> See "U.S. cuts could lead to brain drain in medicine." *The Baltimore Sun*, 2/23/13, [http://articles.baltimoresun.com/2013-02-23/news/bs-md-research-funding-20130221\\_1\\_nih-grants-researchers-head-first-grant](http://articles.baltimoresun.com/2013-02-23/news/bs-md-research-funding-20130221_1_nih-grants-researchers-head-first-grant). See also Atkinson, *et al.* 2012, "Leadership in Decline," The Information Technology and Innovation Foundation <http://www2.itif.org/2012-leadership-in-decline.pdf>

<sup>5</sup> 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.

<sup>6</sup> See Kalos *et al.* 2011, "T Cells with Chimeric Antigen Receptors Have Potent Antitumor Effects and Can Establish Memory in Patients with Advanced Leukemia," *Science Translational Medicine*, 3:95 <http://stm.sciencemag.org/content/3/95/95ra73.short>; Porter *et al.* 2011, "Chimeric Antigen Receptor-Modified T Cells in Chronic Lymphoid Leukemia," *N England J Med* 365:725-733 <http://www.ncbi.nlm.nih.gov/doi/full/10.1056/NEJMoa1103849>.

<sup>7</sup> See [http://www.alz.org/documents\\_custom/2012\\_facts\\_figures\\_fact\\_sheet.pdf](http://www.alz.org/documents_custom/2012_facts_figures_fact_sheet.pdf). The Alzheimer's Association estimates that up to 16 million people will have Alzheimer's by 2050. And the costs are staggering: "In 2012, the direct costs of caring for those with Alzheimer's... will total an estimated \$200 billion... Unless something is done, the costs of Alzheimer's in 2050 are estimated to total \$1.1 trillion (in today's dollars). Costs to Medicare and Medicaid will increase nearly 500 percent."

<sup>8</sup> See <http://www.cdc.gov/hantavirus/outbreaks/yosemite-national-park-2012.html> and <http://www.cdc.gov/ncidod/dvbid/westnile/index.htm>.

<sup>9</sup> See Teijaro *et al.* 2011, "Endothelial Cells Are Central Orchestrators of Cytokine Amplification during Influenza Virus Infection," *Cell* 146:980-991 <http://www.sciencedirect.com/science/article/pii/S009286741100941X>.

Written Statement of The Trevor Project  
Regarding Appropriations for Youth Mental Health  
Submitted to the House Committee on Appropriations, March 15, 2013



For further information, contact Elliot Kennedy, Government Affairs Counsel:  
Elliot.Kennedy@thetrevorproject.org

August 1, 2013

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

**Re: Oversight Hearing - Children's Mental Health**

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 mental health initiatives. We strongly encourage you to support our nation's youth by funding these vital programs:

- Increase and continue to fund SAMHSA Mental Health Programs: \$1.101 billion
- Continue to fund and reauthorize the Garrett Lee Smith Memorial Act, and increase funding by \$2 million to each program (\$44 million total, SAMHSA)
- Now is the Time Programs (Departments of Justice, Education, HHS):
  - Authorize \$150 million for the Comprehensive School Safety Program
  - Authorize \$80 million to help create safer and healthier school climates
  - Fully fund Project Aware - \$155 million (Department of Education, HHS)
- Continue to support and fund the Elementary and Secondary School Counseling Program (Department of Education): \$52.3 million
- Continue to fund and reauthorize the Runaway and Homeless Youth Act and increase funding to \$165 million (Department of Housing and Urban Development)
- Continue to fund the Prevention and Public Health Fund (Departments of Health and Human Services, SAMHSA):
  - Behavioral Health Screening and Integration with Primary Health - \$70 million
  - Public Health Workforce - \$45 million
- Restore and augment funding to the Centers for Disease Control and Prevention, Division of Adolescent and School Health: \$50 million

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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. The Trevor Project saves young lives through its free and confidential lifeline, a secure instant messaging service providing live help, in-school workshops, educational materials, online resources and advocacy. Recognized by the President as a Model of Pride, The Trevor Project has been an innovator in suicide prevention since 1998.

The recent tragic and senseless loss of life in Newtown, Connecticut, has highlighted the need for action to address the serious mental health concerns that continue to face our nation. President Obama has brought further attention to this critical issue through his “Now is the Time” Presidential plan,<sup>1</sup> which emphasizes the importance of both mental health care and safe schools as part of an effort to protect our youth and communities. We thank the Committee for taking a thorough look at the funding mechanisms that support our nation’s youth mental health programs, and we hope that this letter will identify the critical programs that exist to protect our most vulnerable youth.

While Congress has sought to increase access to appropriate mental health care in recent years through the passage of laws such as the Mental Health Parity and Addiction Equity Act and the Affordable Care Act, there unfortunately remain substantial barriers to accessing mental health care, particularly for young people.

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.<sup>2</sup> 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.<sup>3</sup> 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

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<sup>1</sup> THE WHITE HOUSE, NOW IS THE TIME: THE PRESIDENT’S PLAN TO PROTECT OUR CHILDREN AND COMMUNITIES BY REDUCING GUN VIOLENCE (2013).

<sup>2</sup> 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).

<sup>3</sup> 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).

populations such as LGBTQ young people, these negative outcomes can be exacerbated by prejudice, fear, and hate experienced in homes, schools, and communities.

Suicidality is closely associated with mental illness; more than 90 percent of those who die by suicide have a diagnosable mental disorder.<sup>4</sup> Therefore suicide prevention is an essential component of a comprehensive mental health system. Among young people ages 10 to 24, suicide is the second leading cause of death.<sup>5</sup> This issue is especially critical for LGBTQ youth populations. Research has shown that LGB youth are 4 times more likely to attempt suicide than their straight peers, and questioning youth are 3 times more likely.<sup>6</sup> Nearly half of young transgender people have seriously thought about taking their lives and one quarter report having made a suicide attempt.<sup>7</sup> While these statistics are tragic, it is important to remember that together we can prevent suicide through education and awareness.

The Trevor Project recommends the following appropriations to improve access to effective mental health care and reduce suicide risk for young people:

#### **Mental Health Block Grants (SAMHSA)**

SAMHSA operates the only federal programs dedicated to improving systems of care for youth in juvenile justice and special education programs. Through SAMHSA's block grant programs, states provide necessary services to youth and adults facing mental illness and addiction who would not otherwise be able to seek help and get treatment.

- Congress should allocate a minimum of \$1.101 billion in total FY 2013 funding for mental health programs to sustain and improve necessary initiatives.

#### **Garrett Lee Smith Memorial Act (S. 116) (SAMHSA)**

Suicide prevention programs for young people 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. Garrett Lee Smith funding currently supports suicide prevention programs in 40 states, 38 tribes, and 85 colleges.

<sup>4</sup> *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).

<sup>5</sup> 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).

<sup>6</sup> Laura Kann et al., *Sexual Identity Sex of Sexual Contacts, and Health-Risk Behaviors Among Students in Grades 9-12 – Youth Risk Behavior Surveillance, Selected Sites, United States, 2001-2009*, 60(SS07) MMWR 1 (2011), available at <http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6007a1.htm> (last visited Mar. 14, 2013).

<sup>7</sup> Arnold H. Grossman & Anthony R. D'Augelli, *Transgender Youth and Life-Threatening Behaviors*, 37(5) SUICIDE LIFE THREAT BEHAV. 527 (2007).

- Ensure the Suicide Prevention Resource Center that houses the National Best Practices Registry and also the evidence base in suicide prevention continues to be funded at \$5 million annually.
- Increase authorization for state and tribal programs to \$32 million annually, an increase of \$2 million.
- Increase authorization for higher education programs to \$7 million annually, an increase of \$2 million.

### **Now is the Time Programs (Departments of Justice, Education, Health and Human Services)**

The President's Now is the Time plan is a profound affirmation of this Administration's commitment to addressing 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.

- Authorize \$150 million for the Comprehensive School Safety Program. This valuable program will help ensure that every student feels supported and safe, by helping school districts hire 1,000 new school mental health professionals and resource officers.
- Authorize \$80 million to help schools create safer and healthier school climates through comprehensive emergency management, and new monitoring systems.
- Fully fund Project AWARE - \$155 million
  - Support innovative, state-based strategies for improving mental health training and responsiveness to mental health emergencies;
  - Put more trained teachers and mental health professionals on the ground;
  - Help school districts make sure students get the referrals they need;
  - 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.

### **Elementary and Secondary School Counseling Program (Department of Education)**

The Department of Education plays a vital role in ensuring that at-risk youth communities have consistent access to mental health services in schools. Congress should support these services through allocation of funding to new mental health in schools initiatives, as well as through a recommitment to programs that have already been successful.

- The Elementary and Secondary School Counseling Program is the **only** federal program that helps school districts put mental health professionals in schools. Congress should continue to fund this critical program at current levels (\$55.3 million).

### **Runaway & Homeless Youth Act (RHYA) (Department of Housing and Urban Development)**

An estimated 40 percent of all homeless youth are LGBTQ-identified, often because they are thrown out of their homes or face family rejection. Nearly 2/3 of these young people are likely to attempt suicide at least once. Funding for the RHYA has not significantly increased since 2008, despite a growing population desperately in need of the services provided by this Act. 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 fully fund the Runaway and Homeless Youth Act, providing \$165 million to help keep our vulnerable youth safe and healthy.

### **Prevention and Public Health Fund (Department of Health and Human Services)**

Preventative care results in better health outcomes, and it is cheaper and more cost effective than downstream alternatives. This is especially true for issues relating to mental health and suicide prevention. The Prevention and Public Health Fund represents an opportunity to recognize mental health as a public health issue, and to take meaningful action to give states the support services and infrastructure necessary to treat it as such.

- Congress should continue to fund Behavioral Health Screening and Integration with Primary Health (\$70 million), which in part goes towards expanding suicide prevention activities and screening for substance use disorders, and towards assisting communities with integrating primary care services into publicly-funded community mental health and behavioral health settings.
- Congress should continue to provide funding for the Public Health Workforce (\$45 million) to help communities train public health providers who will advance preventive medicine and improve the access to and quality of health services in medically underserved communities.

### **Division of Adolescent and School Health Funding (CDC)**

The Centers for Disease Control and Prevention (CDC)'s Division of Adolescent and School Health (DASH) provides crucial support services nationally. DASH helps administer the Youth Risk Behavior Surveillance System (YRBSS)—the only instrument utilized at the federal level to assess the health and education needs of middle and secondary school students in the United States. This survey collects important information about the health and well-being of our nation's youth, data that helps advocates and policymakers to make better-informed and more effective decisions on behalf young people.

- Congress should fully restore funding to DASH for \$50 million so that important data continue to be collected about at-risk youth and essential student health programs can continue.

### **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 mental health care for young people, and we urge the Committee to fully support 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](mailto:Elliot.Kennedy@thetrevorproject.org).

Sincerely,



Abbe Land  
Executive Director & CEO

**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 representing public health injury and violence prevention professionals engaged in building a safer, healthier America, 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 \$170.7 million in FY14 – an additional \$13 million for the Core Violence and Injury Prevention Program (VIPP) and an additional \$20 million for the National Violent Death Reporting System (NVDRS). Safe States Alliances also supports restoration of the CDC's Preventive Health and Health Services (Prevent) Block Grant to \$100 million.

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.<sup>1</sup> 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 injuries remain the leading cause of death for Americans ages one to 44.<sup>2</sup> As a result of injuries and violence, 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.<sup>2</sup> In a single year, injuries and violence will ultimately cost \$406 billion in medical costs and lost productivity.<sup>3</sup> In 2009, CDC estimates that injuries accounted for nearly half of all deaths among Americans from age

one to 44. This is more than deaths from non-communicable diseases and infectious diseases combined.<sup>4</sup>

At the federal level, the CDC Injury Center serves as the focal point for the public health approach to injury and violence prevention. Despite the enormous toll of injury and violence and the existence of cost-effective interventions, there is no dedicated and ongoing federal, state, or local funding to adequately respond to these problems. The CDC Injury Center only receives 2% of the CDC/ Agency for Toxic Substances and Disease Registry budget to address the significant burden of injuries and violence nationwide. In FY 2012, the total Injury Center budget was only \$137.7 million, down from \$147.8 million in FY 2010. The 5.1 percent cut imposed by sequestration further reduces the Injury Center's funding by an additional \$7 million. The net impact is a 12 percent cut to the Injury Center since FY 2010 and a funding level below FY 2000 levels.

Given its limited budget, the CDC Injury Center currently provides capacity building grants 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). ***With an additional investment of just \$13 million, the CDC Injury Center would be able to support injury and violence prevention programs in all states and territories, much as it does for other key public health issues.***

The National Violent Death Reporting System (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. NVDRS has enabled states to conduct evidence-informed violence prevention planning and implementation. CDC Injury Center currently funds 18 states to implement NVSRS. ***Safe States Alliance supports the President's proposal<sup>5</sup> to invest an additional \$20 million to expand NVDRS to all states.***

For more than 30 years, the Prevent Block Grant has remained an essential source of federal agencies to support state solutions to state health problems. The Prevent Block Grant allows each state to be autonomous and responsible to use its own district health priorities and needs. In FY 2011, more than 20 percent of the Prevent Block Grant was used by states to support injury and violence prevention and emergency medical services. According to a 2013 survey conducted by Safe States Alliance, 29 states reported receiving an average of \$329,000 from the Prevent Block Grant for injury and violence prevention efforts.<sup>6</sup> The Prevent Block Grant is a critical source of funding for SHD injury and violence prevention programs representing 9.4 percent of total funding in 2011. ***Safe States Alliance support restoration of the Prevent Block Grant at the \$100 million level.***

Safe States Alliance believes that all SHDs must have a comprehensive injury and violence surveillance and prevention programs, similar to other public health programs for chronic disease and infectious disease prevention. SHDs bring significant leadership to reduce injuries and injury-related health care costs by informing the development of public policies through data and evaluation; designing, implementing, and evaluating injury and violence prevention programs in cooperation with other agencies and organizations; collaborating with partners in health care and throughout the community; collecting and analyzing a variety of injury and

violence data to identify high-risk groups; disseminating effective practices, and providing technical support and training to injury prevention partners and local-level public health professionals. The following are examples of how SHDs have utilized the Core VIPP, NVDRS, and Prevent Block Grant to prevent injuries and protected the lives of Americans:

- An estimated 3,143 lives have been saved since 1998 as a result of CDC-funded smoke alarm installation and fire safety education programs in high-risk communities. In funded states, more than 487,800 smoke alarms have been installed in approximately 250,000 homes. High-risk homes that were targeted by the program included children age five and younger and adults age 65 and older.
- NVDRS data helped Oregon to develop and target suicide prevention programs for older adults. Almost 50% of men and 60% of women 65 years of age or older who died by suicide were reported to have a depressed mood before death. However, only a small proportion were receiving treatment for their depression when they died, suggesting screening and treatment for depression might have saved lives. In response to these findings, Oregon developed and is implementing a state Older Adult Suicide Prevention Plan to improve primary care integration with mental health services so suicidal behavior and ideation is diagnosed and older adults receive appropriate treatment.
- In response to the growing epidemic of prescription drug overdoses in Ohio, the Ohio Core VIPP and the Ohio Injury Prevention Partnership developed a multidisciplinary Prescription Drug Abuse Action Group (PDAAG). The group developed consensus-based recommendations for policymakers. In May 2011, the Ohio legislature passed a law containing many of the PDAAG policy recommendations including: licensure of pain

management clinics; in-office dispensing limits; Medicaid lock-in program; and Prescription Drug Monitoring Program changes.

- The Massachusetts Department of Public Health Injury and Violence Prevention Program (MDPH IVPP) worked in collaboration with partners to provide support and technical assistance to schools across the state to implement recent regulations on the identification and management of concussion in school sports during the 2011-2012 school year. To date, 262 school districts, 17 charter schools, and 31 private schools have confirmed they have put in place policies complying with the MDPH regulations. This represents 78% of the schools and school districts required to provide confirmation.

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 injury and violence prevention programs is a critical step to keep Americans safe and productive for the 21<sup>st</sup> century. Safe States Alliance would like to thank the Committee for consideration of this testimony.

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<sup>1</sup> National Research Council. *Injury in America: A Continuing Public Health Problem*. Washington, DC: The National Academies Press, 1985.

<sup>2</sup> 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>.

<sup>3</sup> 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>

<sup>4</sup> Centers for Disease Control and Prevention, National Center for Injury Prevention and Control. [online][accessed 2013 Feb 15]. Available from URL: [http://www.cdc.gov/injury/overview/leading\\_cod.html](http://www.cdc.gov/injury/overview/leading_cod.html).

<sup>5</sup> NOW IS THE TIME: The President's plan to protect our children and our communities by reducing gun violence. Washington, DC: White House; 2013.

<sup>6</sup> State of the States: 2011 Report. Atlanta, GA: Safe States Alliance; 2013.

**Eldercare Workforce Alliance FY2014 Outside Witness Testimony**  
Subcommittee on Labor, Health and Human Services, Education and Related Agencies  
Committee on Appropriations, United States House of Representatives

Written Testimony\*\* Regarding Funding Requests for Eldercare Workforce Programs  
of the Department of Health and Human Services

Submitted on March 15, 2013, on behalf of the Eldercare Workforce Alliance 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 28 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 2014, 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. We hope you will support a total of \$42.1 million in funding for geriatrics programs in Title VII and Title VIII of the Public Health Service Act and \$173 million in funding for programs administered by the Administration on Aging that support the vital role of family caregivers in providing care for older adults. Specifically, we recommend the following levels:

- **\$37.1 million for Title VII Geriatrics Health Professions Programs;**
- **\$5 million for Title VIII Comprehensive Geriatric Education Programs; and**
- **\$173 million for Family Caregiver Support Programs.**

Today's health care workforce is inadequate to meet the special needs of older Americans, many of whom

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*\*\*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.*

have multiple chronic physical and mental health conditions and cognitive impairments. It is estimated that an additional 3.5 million trained health care workers will be needed just to maintain the current level of access and quality. 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 importance is supporting the legions of family caregivers who 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 (AoA) programs that support family caregivers are so critical to ensure that there is a skilled eldercare workforce and knowledgeable, well-supported family caregivers available to meet the complex and unique needs of older adults.

Geriatrics health profession training programs are integral to ensuring that America's healthcare workforce is prepared to care for the nation's rapidly expanding population of older adults.

In light of current fiscal constraints, EWA specifically requests \$42.1 million in funding for the following programs administered through the Health Resources and Services Administration (HRSA) under Title VII and VIII of the Public Health Service Act.

**Title VII: Geriatrics Health Professions, Appropriations Request: \$37.1 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): The goal of this program is to promote the development of academic clinician educators in geriatrics. *Program Accomplishments*: In Academic Year 2010-2011, the GACA Program funded 68 full-time junior faculty awardees. These awardees provided interdisciplinary training in geriatrics to 38,392 health professionals in clinical geriatrics; provided interdisciplinary team training to 6,617 clinical staff in various geriatric clinical settings; and provided geriatric services to 57,364 geriatric patients who are underserved and uninsured patients in acute care, geriatric ambulatory care, long-term care, and geriatric consultation services settings. HRSA, through the Affordable Care Act (ACA), expanded the awards to be available to more disciplines. EWA strongly supports and requests adequate funding for future expansion. Currently, new awardees are selected only every five years and to meet the need for clinician educators in all disciplines, EWA believes that we need to invest more in the future in order to develop adequate numbers of faculty to provide this training. Specifically, these academic career development awards should be available to clinician educators annually. **EWA's FY 2014 request of \$5.5 million will support current GAC Awardees in their development as clinician educators.**
- Geriatric Education Centers (GEC): The goal of the Geriatric Education Centers is to provide quality interdisciplinary geriatric education and training to the health professions workforce, including geriatrics specialists and non-specialists. *Program Accomplishments*: In Academic Year 2010-2011, the 45 GEC grantees developed and provided 2,103 education and training offerings to health professions students, faculty, and practitioners related to care of older adults. Interdisciplinary education and training was provided to 10,703 interdisciplinary teams. The grantees provided education and training to 64,414 health professions students, faculty, and practitioners. The GECs provide much needed education and training. As part of the ACA, Congress authorized a supplemental grant award program that will train additional faculty through a mini-fellowship program. The program provides training to family caregivers and direct care workers. **Our funding request of \$22.7 million includes support for the core work**

**of 45 GECs and \$2.7 million awarded to 24 GECs that would be funded to undertake development of mini-fellowships under the supplemental grants program included in ACA.**

- Geriatric Training Program for Physicians, Dentists, (GTPD) and Behavioral and Mental Health Professions: The goal of the GTPD is to increase the number and quality of clinical faculty with geriatrics and cultural competence, including retraining mid-career faculty in geriatrics. *Program Accomplishments*: In Academic Year 2010-2011, 13 non-competing continuation grants were supported. A total of 54 physicians, dentists and psychiatry fellows provided geriatric care to 24,139 older adults across the care continuum. Geriatric physician fellows provided health care to 13,788 older adults; geriatric dental fellows provided health care to 4,834 older adults; and geriatric psychiatric fellows provided health care to 5,516 older adults. 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 in their disciplines. **EWA's funding request of \$8.9 million will support 13 institutions to continue this important faculty development program.**

**Title VIII Geriatrics Nursing Workforce Development Programs, Appropriations Request: \$5 million**

These programs, administered by the HRSA, are the primary source of federal funding for advanced education nursing, workforce diversity, nursing faculty loan programs, nurse education, practice and retention, comprehensive geriatric education, loan repayment, and scholarship.

- Comprehensive Geriatric Education Program: The goal of this program is to provide quality geriatric education to individuals caring for the elderly. *Program Accomplishments*: In Academic Year 2010-2011, 27 non-competing Comprehensive Geriatric Education (CGEP) grantees provided education and training to 3,645 registered nurses, 1,238 registered nursing students, 870 direct service workers, 569 licensed practical/vocational nurses, 264 faculty and 5,344 allied health professionals – totaling 11,930

professionals trained. This program supports additional training for nurses who care for the elderly; development and dissemination of curricula relating to geriatric care; and training of faculty in geriatrics. It also provides continuing education for nurses practicing in geriatrics.

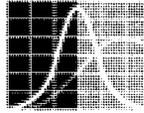
- Traineeships for Advanced Practice Nurses: Through the ACA, the Comprehensive Geriatric Education Program is being expanded to include advanced practice nurses who are pursuing long-term care, geropsychiatric nursing or other nursing areas that specialize in care of elderly.

**Administration on Aging: Family Caregiver Support, Appropriations Request: \$172.9 million**

- Family Caregiver Support Services: 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 at home for as long as possible. Request: \$154.5 million
- Native American Caregiver Support: 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. Request: \$6.4 million
- Alzheimer's Disease Support Services: 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. Request: \$9.5 million
- Lifespan Respite Care: Funds grants to improve the quality and access to respite care for family caregivers of children or adults of any age with special needs. Request: \$2.5 million

On behalf of the members of the Eldercare Workforce Alliance, we commend you on your past support for geriatric workforce programs and ask that you join us in expanding the geriatrics workforce at this critical time – for all older Americans deserve quality of care, now and in the future. Thank you for your consideration.


**APIC**

 Spreading knowledge.  
Preventing infection.\*

**SHEA**

 The Society for Healthcare  
Epidemiology of America

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**Testimony of**  
**the Association for Professionals in Infection Control and Epidemiology (APIC)**  
**and the Society for Healthcare Epidemiology of America (SHEA) to the U.S. House**  
**Appropriations Subcommittee on**  
**Labor, Health and Human Services, Education and Related Agencies on**  
**Fiscal Year 2014 Appropriations**  
**for the U.S. Department of Health and Human Services (HHS)**  
**March 15, 2013**

The Association for Professionals in Infection Control and Epidemiology (APIC) and the Society for Healthcare Epidemiology of America (SHEA) thank you for this opportunity to submit testimony on federal efforts to detect dangerous infectious diseases and protect the American public from healthcare-associated infections (HAIs). We ask that the Subcommittee support the following programs under appropriations for the Department of Health and Human Services. First, under the Centers for Disease Control and Prevention National Center for Emerging and Zoonotic Infectious Diseases: \$27.5

million for the National Healthcare Safety Network (NHSN) and the Prevention Epicenters Program; \$182.2 million for Core Infectious Diseases to include funding for Healthcare-Associated Infections, Antimicrobial Resistance, and the Emerging Infections Program (EIP). Additionally, we request \$34 million for the Agency for Healthcare Research and Quality (AHRQ) to reduce and prevent HAIs. This includes \$11.6 million in HAI research grants and \$22.4 million in HAI contracts including the Comprehensive Unit-based Safety Program (CUSP). Finally, we request \$500 million annually for the National Institutes of Health (NIH), National Institute of Allergy and Infectious Diseases' antibacterial and related diagnostics efforts by the end of FY 2014.

HAIs are among the leading causes of preventable death in the United States. In hospitals alone, CDC estimates that one in 20 hospitalized patients has an HAI, while over one million HAIs occur across healthcare settings annually.

In addition to the substantial human suffering, HAIs contribute \$28 to \$33 billion in excess healthcare costs each year. Fortunately several HAIs are on the decline as a result of recent advances in the understanding of how to prevent certain infections. In particular, bloodstream infections associated with indwelling central venous catheters, or "central lines," are largely preventable when healthcare providers use the CDC infection prevention recommendations in the context of a performance improvement collaborative. CDC recently reported a 41% reduction in central line-associated bloodstream infections in 2011, up from the 32% reduction reported in 2010. Now we have the opportunity to continue this momentum and extend it to other infections.

**Centers for Disease Control and Prevention (CDC)**

APIC and SHEA request **\$27.5 million for the National Healthcare Safety Network (NHSN) and the Prevention Epicenters Program**. These programs provide critical funding to detect dangerous multidrug-resistant organisms (MDROs) to protect patients and the public from disease and death associated with HAIs.

APIC and SHEA are strongly supportive of the Prevention Epicenters Program, a collaboration of CDC's Division of Healthcare Quality Promotion (DHQP) and academic medical centers that conduct innovative infection control and prevention research to address important scientific gaps regarding the prevention of HAIs, antibiotic resistance and other adverse healthcare events.

Consistent, high quality, scientifically sound and validated data are necessary to measure the true extent of the problem, develop evidence-based HAI prevention strategies, and to ensure that accurate data are available at the state and federal level for public reporting.

Funding for this program has been flat since FY 2010, despite the system's importance in our nation's efforts to monitor and prevent HAIs, and the increase in facilities reporting into the NHSN – from 3,000 in 2010 to nearly 12,000 in 2013.

APIC and SHEA request **\$182.2 million for Core Infectious Diseases to include funding for Healthcare-Associated Infections, Antimicrobial Resistance, and Emerging Infections Program**.

APIC and SHEA support the EIP as it helps states, localities and territories in detecting and protecting the public from known infectious disease threats in their communities while maintaining our nation's capacity to identify new threats as they emerge.

Further, ensuring the effectiveness of antibiotics well into the future is vital for the nation's public health, particularly when our current therapeutic options are now dwindling and research and development of new antibiotics is lagging. As noted in the recently released CDC *Vital Signs* report related to carbapenem-resistant Enterobacteriaceae (CRE), microorganisms are becoming more resistant to antimicrobials. Such resistance is one of the most pressing challenges facing healthcare providers and patients in the coming decade, so it is essential that the CDC maintain the ability to monitor organism resistance.

**Agency for Healthcare Research and Quality (AHRQ)**

APIC and SHEA request **\$34 million for AHRQ in FY 2014** to reduce and prevent HAIs. This total includes funding for HAI research grants to improve the prevention and management of HAIs, and HAI contracts including nationwide implementation of the Comprehensive Unit-based Safety Program (CUSP). Over the past decade, AHRQ has funded numerous projects targeting HAI prevention that have led to the successful reduction of central line-associated bloodstream infections (CLABSIs) in hospital intensive care units (ICUs) by 58% since 2001, representing up to 27,000 lives saved. In spite of this notable progress, there is a great deal of work to be done toward the goal of HAI elimination. SHEA and APIC are very pleased that AHRQ is expanding the

CUSP program to reach healthcare settings outside the ICU and to broaden the focus to address other types of infection.

**National Institutes of Health (NIH), National Institute of Allergy and Infectious Diseases (NIAID)**

APIC and SHEA request that at least **\$500 million annually be provided for NIAID's antibacterial and related diagnostics efforts** by the end of FY 2014. As part of this effort, we believe NIAID should invest at least \$100 million per year in the antibiotic-resistance focused clinical trials network that the Institute is currently establishing and should be operational by 2014. Although we applaud NIAID for establishing this new network, we believe the planned investment of \$10 million per year over the next 10 years will be insufficient to undertake the critical studies needed to address what are quickly becoming untreatable infections. We thank you for the opportunity to submit testimony and greatly appreciate this subcommittee's assistance in providing the necessary funding for the federal government to have a leadership role in the effort to eliminate HAIs.

**About APIC:** APIC's mission is dedicated to creating a safer world through prevention of infection. The association's more than 14,000 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.

**About SHEA:** Founded in 1980, SHEA works to achieve the highest quality of patient care and healthcare personnel safety in all healthcare settings by applying epidemiologic principles and prevention strategies to a wide range of quality-of-care issues. SHEA's membership of 2,000 represents all branches of medicine, public health, and healthcare epidemiology. SHEA members are committed to implementing evidence-based strategies to prevent HAIs and improve patient safety, and have scientific expertise in evaluating potential strategies to accomplish this goal.



**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 FY2014 Appropriations for the  
Low Income Home Energy Assistance Program (LIHEAP)  
March 15, 2013**

As the Subcommittee begins to develop the FY2014 Labor, Health and Human Services, Education, and Related Agencies appropriations bill, the Coalition of Northeastern Governors (CONEG) urges you to fund the Low Income Home Energy Assistance Program (LIHEAP) at the authorized level of \$5.1 billion but no less than \$4.7 billion in the core block grant program. The Governors appreciate the Subcommittee's continued support for LIHEAP, and recognize the difficult fiscal challenges facing Congress this year. However, the economic challenges facing the nation's low-income households have made this program more essential than ever. Adequate, predictable and timely federal funding is vital for LIHEAP to assist the vulnerable, low-income households who struggle to pay increased home energy bills. Therefore, we urge the Subcommittee to provide the FY2014 funds in a manner consistent with the LIHEAP statutory objective: "to assist low-income households, particularly those with the lowest incomes that pay a high proportion of household income for home energy, primarily in meeting their immediate home energy needs.

LIHEAP is a vital safety net for the most vulnerable citizens in every region of the nation: the elderly, disabled, and families with young children struggling to pay for the basic necessity of home energy. According to the National Energy Assistance Directors' Association (NEADA),

8.9 million households received heating and cooling assistance in FY2012. Nationwide, the majority of LIHEAP households have at least one member defined as “vulnerable,” and many of these households are not likely to benefit from the modest improvements in national economic and employment patterns. Moreover, approximately 20 percent of LIHEAP households contain at least one member who served this country in the military. LIHEAP is a resource that states across the country are able to use to assist vulnerable households in paying a portion of their heating bills in the cold winter months and a portion of their electricity bills for cooling in the hot months.

Households in the Northeast face some of the nation’s highest home heating bills due to the extended winter heating season and heating fuel prices that typically exceed national averages regardless of the fuel used. Recent trends in residential heating fuel prices suggest that low-income households in the Northeast will continue to experience a heavy energy burden. According to the recent Energy Information Administration (EIA) Winter Fuels Outlook, Northeast households are more likely to face higher natural gas prices than other regions of the nation. While delivered fuels, such as heating oil and propane, are used nationwide, Northeast households – more than any other region of the country – are dependent upon these expensive delivered fuels, particularly in the many areas where there is limited or no access to natural gas service. In the Northeast, 30 percent of households rely upon delivered fuels, and they account for approximately 80 percent of the homes nationwide that use home heating oil. When prices rise, these households are particularly vulnerable. 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.

According to EIA's current data, residential heating oil prices have been stable over the past two heating seasons, but at the historically high average price of approximately \$4.00 per gallon – a price that is almost 30 percent higher than the five year average price. At this price, and with the more typical winter temperatures experienced by the region, EIA anticipates that expenditures for heating oil this heating season could increase by 32 percent from last winter. In the past two years, the average price of residential heating oil in the Northeast has increased 43 percent – from an average of \$2.89 per gallon in February 2010 to an average of \$4.15 per gallon in February 2013. During the same period, the annual LIHEAP funding level has declined by 30 percent – from \$5.1 billion in FY2010 to approximately \$3.3 billion in FY2013.

LIHEAP is the foundation of efforts to provide immediate, meaningful assistance to low-income households, many living on modest, fixed incomes. Most LIHEAP assistance is targeted to households whose income is close to or below 150 percent of the federal poverty level, which for a two-person household is \$23,265 in 2013. These households spend a disproportionate amount of their income on home energy, often over three times more than non-low-income households. LIHEAP not only helps households better manage and pay home energy bills, it protects the health and safety of the elderly, young children and the disabled. Without adequate resources to pay home heating bills, these vulnerable households may resort to unsafe and dangerous heating sources such as ovens and space heaters. In the summer, these populations are particularly susceptible to heat-related illness and even death.

While LIHEAP funding has been reduced by more than 30 percent since FY2010, the need for the program continues to grow nationwide. States have faced significant challenges in trying to stretch scarce LIHEAP dollars as far as possible while still providing a meaningful benefit to those households most in need of assistance. States 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. Some Northeast states have also stretched their own limited budgets to provide supplemental LIHEAP funds or to leverage federal dollars. 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. The most recent funding reductions, coming as the heating season winds down and utility shut-off moratoriums expire, have created additional challenges. The potential result is a loss of funding for benefits to pay down arrearages, as well as inadequate staff to assist those households facing utility shut-offs to find alternative arrangements.

In summary, the CONEG governors appreciate the Subcommittee's continued support for LIHEAP, and urge you to fund the program at the authorized level of \$5.1 billion but no less than \$4.7 billion in the core block grant program for FY2014.



**Testimony of the National Nursing Centers Consortium Regarding  
Fiscal Year 2014 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 15, 2013**

*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 established under Title III of the Public Health Service Act.

NNCC is a 501(c)(3) member association of nonprofit, nurse-managed health clinics, sometimes called nurse-managed health centers or NMHCs. The Affordable Care Act (ACA) defines the term ‘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. The Nurse Managed Health Clinic Grant Program was created to provide NMHCs with a stable source of federal funding that would place them on footing similar to other safety-net providers. Although authorized, to date the Grant Program has received no appropriations.

### **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.<sup>i</sup> AAMC data also shows that American medical schools are not graduating enough doctors to meet this need. In fact, the number of family practice residencies across the nation has been in decline for the past 12 years, and medical schools have not filled available family practice residencies in the past 3 years.<sup>ii</sup> The Congressional Budget Office estimates the Medicaid expansion called for by the ACA will lead to 11 million new enrollees.<sup>iii</sup> 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 that state expanded its public coverage through health care reform legislation found that only 52% of internists in Massachusetts were accepting new patients and one out of every three family physicians was no longer accepting new patients.<sup>iv</sup> Another study completed one year later, found that the average wait time to see a physician in Boston was 49.6 days, the longest in the nation.<sup>v</sup>

NMHCs are primarily managed by nurse-practitioners which make up the fastest growing segment of primary care providers in the country. The number of NPs is expected to grow from 155,000 to 200,000 by the year 2020. Because of their growing numbers, policy makers 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.”<sup>vi</sup> 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.”<sup>vii</sup>

Along with the IOM, the National Governor’s Association (NGA) and the National Institute for Health Care Reform (NIHCR) have released reports identifying the greater use of nurse practitioners as a possible means of alleviating the pressure on the primary care workforce. The NGA report titled, “The Role of Nurse Practitioners in Meeting Increasing Demand for Primary Care,” was published in December of 2012. Published in February of 2013, the NIHCR research brief was titled, “Primary Care Workforce Shortages: Nurse Practitioner Scope-of-Practice Laws and Payment Policies.”

As safety-net providers, NMHCs offer medically underserved patients high quality primary care that is available regardless of the patient’s ability to pay. Because they already serve a high percentage of Medicaid patients, the clinics are perfectly positioned to fill the gaps in care that will result from the ACA’s proposed Medicaid expansion. However, because they often cannot meet the requirements for federally-qualified health center (FQHC) funding, many NMHCs are struggling financially. The NMHC Grant Program was created to place NMHCs on a similar footing with other safety-net providers by giving NMHCs an alternative source of federal funding.

In order 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 doing this will not only expand access but also lower the cost of

care. In addition to having lower labor costs, research shows that NMHCs cut costs by reducing unnecessary emergency room visits and hospitalizations.<sup>viii</sup>

*NMHCs Help Educate the Health Professionals of Tomorrow* – The main reason NMHCs have difficulty qualifying for FQHC funding is because many are affiliated with academic schools of nursing. Because academically-affiliated NMHCs operate under the jurisdiction of a university, most cannot meet FQHC governance requirements without breaking their academic connection and giving up their clinical programs. Ironically, however, these academic affiliations mean that the NMHC model emphasizes the workforce development that is so needed with the Medicaid expansion under the Affordable Care Act. NMHCs naturally serve as community-based clinical training sites for a diverse group of health profession students including registered nurses and advance practice nurses (mostly nurse practitioners), medical, pharmacy, dental, social work, public health, and other students.

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.<sup>ix</sup> 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.<sup>x</sup> 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. This data tells us two important things: 1) the contribution of NMHCs to workforce development is undeniable; 2) the ability of NMHCs to offer educational opportunities is greatly enhanced with increased funding.

In post-clinical focus groups students have reported being “overwhelmingly satisfied” with their experience in NMHC clinical rotations. Other feedback suggested that NMHCs are filling a gap in

nursing education by providing community-based experience not found in other clinical rotations.<sup>xi</sup> The IOM report on the future of nursing also specifically praised NMHC clinical programs for their emphasis on interprofessional education which is an important factor in future job satisfaction, and building a more flexible workforce.

Despite the benefits of NMHC clinical programs, NMHC leaders are often forced to abandon this important piece of the NMHC model in order 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.

**Request** - The 10 NMHC grants distributed in 2010 will expire this year if Congress does not move to appropriate funding to the program. For all the reasons mentioned above, NNCC respectfully requests an appropriation of \$20 million in fiscal year 2014 for the Nurse-Managed Health Clinic Grant Program, as authorized under Title III of the Public Health Service Act.

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<sup>i</sup>American Association of Medical Colleges (AAMC) Center for Workforce Studies.

<sup>ii</sup>American Association of Medical Colleges (AAMC) Center for Workforce Studies.

<sup>iii</sup>CBO. Estimates for the Insurance Coverage Provisions of the Affordable Care Act Updated for the Recent Supreme Court Decision. (July 2012). p 13. Retrieved on February 28, 2013 from <http://www.cbo.gov/sites/default/files/cbofiles/attachments/43472-07-24-2012-CoverageEstimates.pdf>.

<sup>iv</sup> Massachusetts Medical Society, "2008 Physician Workforce Study: Executive Summary," available at: [www.massmed.org/workforce](http://www.massmed.org/workforce).

<sup>v</sup> USA Today, "Wait Times to See Doctors are Getting Longer," available at: [http://usatoday30.usatoday.com/news/health/2009-06-03-waittimes\\_N.htm](http://usatoday30.usatoday.com/news/health/2009-06-03-waittimes_N.htm).

<sup>vi</sup> IOM, "the Future of Nursing: Leading Change, Advancing Health," page 1-2.

<sup>vii</sup> IOM, "the Future of Nursing: Leading Change, Advancing Health," page c-4.

<sup>viii</sup> Coddington, J. A. & Sands, L. P. Cost of health care and quality outcomes of patients at nurse-managed clinics. *Nurs Econ*, 26(2), 75-83. (2008).

<sup>ix</sup> Special survey of NMHCs funded under the ACA. Conducted by NNCC in 2011.

<sup>x</sup> 2012 NNCC member survey

<sup>xi</sup> Feedback from student focus groups conducted by the Institute for Nursing Centers in 2009

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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 15, 2013**

**SUMMARY: FUNDING RECOMMENDATIONS (in millions \$)**

<b>National Institutes of Health</b>	\$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
<b>Centers for Disease Control and Prevention</b>	<b>\$7,800</b>
National Institute for Occupational Safety & Health	\$293.6
Asthma Programs	\$25.3
Div. of Tuberculosis Elimination	\$243
Office on Smoking and Health	\$197.1
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 FY2014.**

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 FY2014.**

#### **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 \$197 million for the Office of Smoking and Health in FY2014.**

#### **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 FY2014 that funding for CDC's National Asthma Control Program be maintained at a funding level of at least \$25.3 million and that the National Asthma Control Program remain as a distinct, stand-alone program.**

#### **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 FY14 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 National Center for Sleep Disordered Research (NCSDR) at the NHLBI.

#### **TUBERCULOSIS**

Tuberculosis (TB) is the second leading global infectious disease killer, claiming 1.4 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 2014 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 FY2014, 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 2014, 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.

**Sandra M. Swain, MD, FACP**

**President  
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**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 Institutes of Health for FY 2014**

**March 15, 2013**

The American Society of Clinical Oncology (ASCO), the world's leading professional organization representing more than 30,000 physicians and other professionals who treat people with cancer, appreciates this opportunity to provide the following recommendations for Fiscal Year 2014 (FY 2014) funding:

- National Institutes of Health (NIH): \$30.9 billion
- National Cancer Institute (NCI): \$5.081 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 the clinical and translational research in the area of oncology that is critical to improving the lives of our citizens.

### **The Importance of Federal Cancer Research**

A recent study released by the Centers for Disease Control and Prevention shows that cancer deaths in the United States (US) are declining for all populations. Many of these advances in cancer prevention, detection, diagnosis, and treatment are due to federally supported cancer research. However, A strong, stable federal investment in research, prevention, and treatment is critical to continue the progress we are making for the 1.6 million individuals that are newly diagnosed with cancer every year.

ASCO thanks the subcommittee for its past investment in cancer research through the appropriations process and appreciates the unique effort required by the subcommittee in this challenging budget environment. While we recognize these fiscal difficulties, we must acknowledge that the current trajectory of cancer research funding is detrimental to future progress. ASCO calls on this subcommittee to renew the commitment to life-saving research.

As a direct result of the investment in cancer research, we understand more about cancers than at any point in human history. This understanding of cancer diseases at the molecular level has created unprecedented opportunities to slow the growth of cancer diseases. New treatments fight cancer by targeting specific subtypes of the hundreds of types of diseases that make up cancer. These treatments have led to meaningful results for millions of Americans diagnosed with cancer each year. *As a country we can be proud that two of three people in the US with cancer live at least 5 years after their diagnosis.* This is up from roughly one of two in the 1970s before the passage of the National Cancer Act. Since the 1990s, the nation's cancer death rate has dropped 18 percent, reversing decades of increases. Individuals with cancer are increasingly able to live active, fulfilling lives because of better symptom management and treatments with fewer adverse effects.

In order to continue this 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 cannot succeed alone. The NCI conducts high risk, high reward research that leads to great advancements in a way that private industry cannot. Progress in fighting cancer would be faster, more efficient, and more sustainable if funding were steady and sustained.

#### **Devastating Impact of the Sequester Cut to the NIH**

ASCO recognizes the budget crisis faced by Congress and all Americans, but NIH should not be a target for additional cuts over those already incurred this year. The five-percent cut to the budget of the NIH earlier this month, known as the sequester, will have a devastating and long-lasting impact on advances in biomedical research and the next generation of investigators in the US.

Under sequestration, when accounting for biomedical research inflation, the NIH budget will have decreased by twenty-three percent (\$6 billion) since FY 2003. This takes spending below FY 2001 levels. The sequester cuts will have far-reaching effects on biomedical research. One example, as you heard from Director Collins last week, the potential loss of young investigators is a great concern to the future of biomedical research in America. There are simply not enough grant funds at NIH to go around to all quality research proposals and new grant accrual suffers the most. *Currently, only about one in six quality grant applications are funded and under sequestration there is potential that 1,380 fewer grants could be funded.* Most researchers are now over the age of forty before receiving their first NIH grant award. This discourages bright, young scientists from entering the field of biomedical research and threatens the future workforce.

Not only is this bad health care policy, it is bad economic policy. United for Medical Research estimates that the sequester cut could lead to 20,500 fewer jobs across the country and a \$3 billion decrease in economic activity.

#### **Appropriations for FY 2014 for the National Institutes of Health**

The current appropriations level with sequester cuts sets an alarmingly low baseline for future funding. ASCO calls on this subcommittee to take action to ensure that NIH receives an increase that at least keeps pace biomedical research inflation in FY 2014. We join the community in respectfully requesting a minimum of \$30.9 billion for NIH including \$5.081 billion for NCI for FY 2014. Meaningful progress cannot be made if NIH funding does not keep pace with the annual increase in the cost of conducting biomedical research.

Research is a long-term process and without predictable funding, we cannot take advantage of exciting research opportunities already available. The NIH must have a sustained funding commitment in order to plan for multi-year projects. One such exciting project is The Cancer Genome Atlas (TCGA). TCGA was started as a pilot program in 2006 studying the genetic sequence of three cancer types. It has since expanded and is now identifying targets for treatment by deciphering the genetic code of twenty cancer types. This research identifies molecular targets that encourage drug development and with additional investment could be expanded across the

spectrum of disease. Cancer genomics also have begun to allow us to customize cancer treatment for patients to identify the most effective course of treatments.

Funding shortages have already stemmed the growth of such research, but without additional funding we risk losing this progress altogether.

### **Clinical Trials and Translational Research**

Dramatic trends in improved survival rates would not have been possible without clinical cancer research. Rigorous trials that test the safety and efficacy of new therapies in people is the engine that drives progress against cancer. Advances in technology and in our knowledge of how patient-specific molecular characteristics of the tumor and its environment fuel the growth of cancer have brought new hope to patients. Clinical trials are the key to translating cutting-edge laboratory discoveries into treatments that extend and improve the lives of those with cancer. Federal funding is an important component of the clinical trials system in the US and particularly important to fund research that industry is unlikely to pursue. This includes comparative effectiveness trials when multiple therapies exist, multi-modality trials that involve use of procedures, and ways to reduce dose of a therapy while preserving efficacy.

Many of these advances are outlined in ASCO's Clinical Cancer Care Advances report ([http://www.cancerprogress.net/pdf/CCA\\_2012.pdf](http://www.cancerprogress.net/pdf/CCA_2012.pdf)) updated annually. This year's Report features 87 studies, 17 of which the Report's editors have designated as major advances. It takes years of research effort to achieve advances that extend and/or improve quality of patients' lives. This progress would not be possible without patient volunteers, dedicated investigators, and substantial public and private research investment. In the US, the federally funded clinical trials system is essential to progress against cancer. The National Clinical Trials Network, sponsored by the NCI, involves approximately 3,100 institutions and places more than 20,000 patients into large clinical trials of promising treatments each year. Many of the significant developments presented in this document were a direct result of clinical research conducted by these cooperative groups involved in Network. Despite difficult economic times, preserving our nation's investment in cancer research is absolutely necessary to keep the momentum that brings better treatments to the growing number of people with cancer.

NIH-funded translational research and clinical trials have changed the standard of care in many cancers. The experience of pediatric cancers tells this story most dramatically. *In the 1950s, less than 10 percent of children with cancer were cured. Today, nearly 80 percent of children with cancer will survive their diseases.* Federally-funded clinical trials played the biggest role in this dramatic improvement. Clinical trials funded by NIH and NCI examine important questions that are not being investigated elsewhere, generate practice-changing information, and often recruit difficult to reach sub-populations.

Unfortunately, these trials are at risk, due to funding concerns that slow the launch and completion of trials. 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 these advances and the incredible scientific opportunities facing us, ASCO urges the NIH and NCI to focus more of its resources in the area of clinical trials and translational research. Specifically, ASCO would like to see an increase in funding for the National Clinical Trials Network. ASCO is very concerned that the federal funding situation is causing NCI to propose cutting accrual to clinical trials in order to make payments for the trials match actual research costs. These increases are well recognized as vital to the health of the research enterprise. NCI acknowledges that current payments are inadequate to cover the costs of conducting trials because of nearly a decade of virtually no change in payments. However, making them at the expense of new scientific opportunities also has long-term implications. 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.

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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 protect the US cancer research infrastructure.



## Statement of the American Academy of Family Physicians

### **Statement for the Record 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 2014**

**March 15, 2013**

The American Academy of Family Physicians (AAFP), representing 105,900 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 2014 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:

- At least \$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);
- \$122.2 million for the Office of Rural Health Programs (PHSA §§ 301, 330A, & 338J and §§ 711 and 1820(j), Title XVIII of the *Social Security Act* (SSA));
- At least \$305 million for the National Health Service Corps (PHSA § 338A, B, & I);
- \$120 million for the Primary Care Extension program (PHSA § 399V-1);
- \$3 million for the National Health Care Workforce Commission (ACA § 5101); and
- \$430 million for the Agency for Healthcare Research and Quality (PHSA § 487(d)(3), SSA §1142).

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The AAFP is one of the nation's largest medical organizations, representing family physicians, family medicine residents, and medical students nationwide. Founded in 1947, our mission has been to preserve and promote the science and art of family medicine and to ensure high-quality, cost-effective health care for patients of all ages.

#### **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.<sup>1</sup> 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 provide at least \$7 billion for HRSA in the FY 2014 appropriations 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. 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.<sup>2</sup> 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

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<sup>1</sup> Petterson, S, et al. Projecting US Primary Care Physician Workforce Needs: 2010-2015. *Ann Fam Med* 2012; vol.10 no. 6:503-509.

<sup>2</sup> 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.

VII-funded programs.<sup>3</sup> 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 given the increasing and aging population as well as the insured status of more people. These demographic trends will worsen family physician shortages. The AAFP urges the Committee to increase the level of federal funding for primary care training to at least \$71 million in FY 2014 to support the continuing work of grantees and allow for a new grant cycle.

**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 program authorized under Title VII, § 749A to increase primary care physician training capacity now administered by HRSA. 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 Teaching Health Center 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 2014 for planning grants.

**Rural Health Needs** – HRSA's Office of Rural Health focuses on key rural health policy issues and administers targeted rural grant programs. As the medical specialty most likely to enter rural practice, family physicians recognize the need to dedicate resources to rural health needs. A recent study found that medical school rural programs (RPs) 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 with greater

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<sup>3</sup> 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.

reliance on international medical graduates or unfocused expansion of traditional medical schools.<sup>4</sup> 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 2014.

**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 provides 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 AAFP recommends that the Committee provide at least the mandatory funding of \$305 million for the NHSC in FY 2014.

The AAFP has worked closely with HRSA to promote data-driven community health center expansion. The mapping tool developed and managed by the Robert Graham Center for Policy Studies in Family Practice and Primary Care identifies areas in greatest need for Federally Qualified Health Centers. Since the launch of the tool on July 1, 2010, the UDS Mapper has registered over 4,500 users and can be found at <http://www.udsmapper.org/about.cfm>.

#### **AGENCY FOR HEALTHCARE RESEARCH AND QUALITY (AHRQ)**

The mission of the Agency for Healthcare Research and Quality (AHRQ)—to improve the quality, safety, efficiency, and effectiveness of health care for all Americans—closely mirrors AAFP's own mission. AHRQ provides the critical evidence reviews that the AAFP and other physician specialty societies use to produce

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<sup>4</sup> 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.

clinical practice guidelines. AHRQ promotes evidence-based patient safety practices. In addition, AHRQ takes research results from NIH where they restrict research subjects to limit the variables in clinical research and brings the practical information to the practicing physicians who treat patients without those clinical restrictions. The AAFP asks that the Committee provide at least \$430 million for AHRQ in FY 2014.

**Primary Care Extension Program** – The AAFP supports AHRQ's Primary Care Extension Program to provide assistance to primary care physicians about evidence-based therapies and techniques so that they can incorporate them into their practice. As AHRQ develops more scientific evidence on best practices and effective clinical innovations, the Primary Care Extension Program will disseminate the information learned to primary care practices across the nation in much the same way as the federal Cooperative Extension Service provides small farms with the most current agricultural information and guidance. The AAFP recommends that the Committee provide \$120 million for the AHRQ Primary Care Extension program in FY 2014.

#### **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 \$3 million in FY 2014 so that this important Commission can begin this important work.

**UNITED TRIBES TECHNICAL COLLEGE**

3315 University Drive  
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 701-255-3285

David M. Gipp, President ([dmgipp@aol.com](mailto:dmgipp@aol.com))

FY 2014 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 15, 2013

For 44 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 provide for our core instructional programs.* The request of the UTTC Board for FY 2014 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 \$1.8 million above the FY 2012 level. These funds are awarded competitively and are distributed via formula.
- \$30 million as requested by the American Indian Higher Education Consortium for Title III-A (Section 316) of the Higher Education Act (Strengthening Institutions program). This is \$5 million above the FY 2012 enacted level.
- *Maintain Pell Grants at the \$5,635 maximum award level.*

SOME IMPORTANT FACTS ABOUT UNITED TRIBES TECHNICAL COLLEGE. We have:

- A dedication to providing an educational setting that takes a holistic approach toward the full spectrum of student needs – educational, cultural, and necessary life skills.
- Renewed unrestricted accreditation from the North Central Association of Colleges and Schools for the period July 2011 through 2021, including authority to offer all of our full programs on-line.
- Services including a Child Development Center, family literacy program, wellness center, area transportation, K-8 elementary school, tutoring, counseling and housing.
- A semester completion rate of 85%.
- A graduate placement rate of 77% (placement into jobs and higher education).
- A projected return on federal investment of 20-1 (2005 study).
- Over 45% of our graduates move on to four-year or advanced degree institutions.
- A current student body from 75 tribes who come mostly from high poverty, high unemployment tribal nations in the Great Plains; many students have dependents.
- 85% of undergraduate students receive Pell Grants.
- 26 Associate degree programs, 20 year certificates, and three bachelor degree programs (Elementary Education; Business Administration; and Criminal Justice).
- An expanding curricula to meet job-training needs for growing fields including law enforcement and health information technology. We have new short-term training programs for welding technology (in particular demand in ND because of the oil boom), electrical, energy auditing, and Geographic Information System technology.
- A dual-enrollment program targeting junior and senior high school students, providing them an introduction to college life and offering high school and college credits.
- A critical role in the regional economy. Our presence brings at least \$34 million annually to the economy of the Bismarck region. We have a workforce of 360 people.

- An award-winning annual powwow which last year had participants from 60+ tribes and international indigenous dance groups, drawing over 10,000 spectators.

#### FUNDING REQUESTS

Section 117 Perkins Base Funding. Funds requested under Section 117 of the Perkins Act above the FY 2012 level are needed to: 1) maintain 100 year-old education buildings and 50 year-old housing stock for students; 2) upgrade technology capabilities; 3) provide adequate salaries for faculty and staff (who have not received a cost of living increase for the past year and 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 educational programs. Very little of the other funds we receive may be used for core career and technical educational programs; they are competitive, often one-time supplemental funds which help us provide the services our students need to be successful. Our Perkins funding provides a base level of support (averaging over the past five years in excess of 40% of our core operating budget) while allowing the college to compete for desperately needed discretionary funds leading to additional resources annually for the college's programs and support services.

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. We would like to educate more students but lack of housing has at times limited the admission of new students. With the completion this year 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 rehabilitating the old buildings that now house students.

Pell Grants. We support maintaining the Pell Grant maximum to at least a level of \$5,635. This resource makes all the difference in whether most of our students can attend college. We are glad to learn of the February 6, 2013 report of the Congressional Budget Office that the Pell Grant program is currently financially healthy and can support full funding the maximum award levels for fiscal years 2013 and 2014.

#### GOVERNMENT ACCOUNTABILITY OFFICE REPORT

As you know, the Government Accountability Office (GAO) in March of 2011 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 represent on average over 40 percent of UTTC's core operating budget. These funds supplement, but do not duplicate, the 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. Therefore, UTTC actively seeks alternative funding to assist with curricula, deferred maintenance, and scholarship assistance, among other things

We reiterate that UTTC and other tribally-chartered colleges are not part of state educational systems and do not receive state-appropriated general operational funds for their Indian students. 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 and training at the postsecondary level—United Tribes Technical College and Navajo Technical College. Combined, these institutions received less than \$15 million in FY 2012 federal operational funds (\$8 million from Perkins; \$7 million from the BIE). That is a very modest amount for two campus-based institutions which offer a broad (and expanding) array of training opportunities.

UTTC offers services that are 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. Our students disproportionately possess more high risk characteristics than other student populations. We also provide services for the children and dependents of our students. Although BIE and Section 117 funds do not pay for remedial education services, we make this investment through other sources to ensure our students succeed at the postsecondary level.

Thank you for your consideration of our requests.

Susan M. Barman, 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 2014. This is necessary to prevent further erosion of research capacity and ensure a sustainable future.

The APS recognizes that the economic challenges facing the country demand that government resources be used judiciously. 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 maintaining U.S. leadership in the biomedical sciences.

**NIH funds outstanding science**

As a result of improved health care, Americans are living longer and healthier lives in the 21<sup>st</sup> century than ever before. However, chronic diseases such as heart failure, diabetes, respiratory disease and cancer continue to inflict a heavy burden in the United States and around the world.

A recent report from the World Health Organization showed that chronic, noninfectious diseases now cause more deaths globally than all other diseases combined. Additional economic and health challenges are on the horizon as the U.S. population ages and begins to require more health care. 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.

### **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 are being compounded by sequestration cuts. Scientists at all stages of their careers are struggling to maintain their research programs. However, this is particularly difficult for scientists in the early stages of their careers. To address this problem, the NIH has taken steps to foster the next generation of investigators including:

- Continuing its commitment to fund new investigators at approximately the same rate as established investigators.
- Creating a working group to examine future needs and make recommendations for ensuring a diverse and sustainable future biomedical workforce.

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 through the development of shared resources, infrastructure and expertise. The program currently serves institutions and researchers in 23 states and Puerto Rico.

The APS is a professional society dedicated to fostering research and education as well as the dissemination of scientific knowledge concerning how the organs and systems of the body work. The Society was founded in 1887 and now has nearly 11,000 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.

**National Psoriasis Foundation  
Written Testimony to the House Labor, Health and Human Services, Education, and  
Related Agencies (LHHS) Appropriations Subcommittee**

**Fiscal Year (FY) 2014 Psoriasis and Psoriatic Arthritis Research Funding for the  
Department of Health and Human Services: National Institutes of Health and Centers for  
Disease Control and Prevention**

**Submitted by: Dan Farrington, Chair, Board of Trustees  
National Psoriasis Foundation  
6600 SW 92nd Avenue, Suite 300, Portland, OR 97223  
Phone: (301) 951-1538 Email: DFarrington@farringtonlaw.com  
March 15, 2013**

**Introduction and Overview**

The National Psoriasis Foundation (the Foundation) appreciates the opportunity to submit written public witness testimony in support of \$1.2 million in fiscal year (FY) 2014 federal funding for the implementation of the psoriasis and psoriatic arthritis public health agenda at the National Center for Health Statistics (NCHS) within the Centers for Disease Control and Prevention (CDC). The Foundation is the largest psoriasis patient advocacy organization and charitable funder of psoriatic disease research worldwide, and exists to find a cure for psoriasis and psoriatic arthritis. Psoriasis, the nation's most prevalent autoimmune disease, affecting as many as 7.5 million Americans, is a noncontagious, chronic, inflammatory, painful and disabling disease for which there is no cure. It is a systemic disease that appears on the skin, most often as red, scaly patches that itch, can bleed and require sophisticated medical intervention. Up to 30 percent of people with psoriasis also develop potentially disabling psoriatic arthritis that causes pain, stiffness and swelling in and around the joints. There are other serious risks associated with psoriasis – for example, diabetes, cardiovascular disease, stroke and some cancers. Of serious concern is that beyond its terrible physical and psychosocial toll on individuals, psoriasis also costs the nation \$11.25 billion annually.

The Foundation works with the nation's research community and policymakers at all levels of government to advance policies and programs that will reduce and prevent suffering from psoriasis and psoriatic arthritis. In 2009, after examining existing scientific literature, clinical practice

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March 15, 2013*

and other components of psoriasis and psoriatic arthritis research and care, the Foundation's medical and scientific advisors recommended the creation of a federally-organized public health research program for psoriasis and psoriatic arthritis to collect the information necessary to address the key scientific questions in the study and treatment of psoriatic disease. Responding to this recommendation, recognizing the significant economic and social costs of psoriasis and psoriatic arthritis and acknowledging the sizeable gap in the understanding of these challenging conditions, in FY 2010, Congress provided \$1.5 million to CDC to commence an effort to identify what gaps exist. CDC has been an excellent steward of this federal funding, working diligently to develop a public health agenda for psoriasis while stretching these dollars over the course of three fiscal years.

Thanks to the initial Congressional appropriation, on February 12, 2013, the CDC released the first-ever public health agenda designed to address psoriasis and psoriatic arthritis. The agenda, entitled "*Developing and Addressing the Public Health Agenda for Psoriasis and Psoriatic Arthritis*," was developed by CDC in collaboration with clinical, biomedical and public health experts. Working in partnership, these experts identified gaps and developed a list of priorities to be addressed by future psoriasis and psoriatic arthritis research efforts. The identified priorities include:

- Improving the way psoriasis and psoriatic arthritis are diagnosed.
- Examining the relationship between other chronic diseases or comorbidities with psoriasis and psoriatic arthritis.
- Examining how people with psoriatic diseases access health care, the cost of their treatments and how the diseases impact their ability to work.
- Studying the effect of psoriasis and psoriatic arthritis on quality of life and other outcomes.

Investing in these priority areas of study will generate much-needed public health data that will help scientists understand the underlying questions about psoriatic diseases and how they affect

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a large population of people, and, in turn, this insight will help identify the most promising areas of new research to find better treatments and move the nation closer to a cure.

As such, we respectfully request that Congress continue to support this important initiative by appropriating \$1.2 million, in FY 2014, to enable the NCHS within the CDC to begin to answer the pressing questions identified in the psoriasis and psoriatic arthritis public health agenda. With FY 2014 funding, CDC researchers will be able to collect and analyze data that will help improve treatments and disease management, identify new pathways for future research and drug development and inform efforts to reduce the burden of disease on patients, their families and society in general.

**The Impact of Psoriasis and Psoriatic Arthritis on the Nation**

Psoriasis requires steadfast treatment and lifelong attention. People with psoriasis have significantly higher health care resource utilization, which costs more than that of the general population. As noted earlier, of serious and increasing concern is mounting evidence that people with psoriasis are at elevated risk for other serious, chronic and life-threatening conditions, including cardiovascular disease and diabetes. In addition, people with psoriasis experience higher rates of depression and anxiety, and they die four years younger, on average, than people without the disease.

Despite some recent breakthroughs, many people with psoriasis and psoriatic arthritis remain in need of effective, safe, long-term and affordable therapies to allow them to function without both physical and emotional pain. Due to the nature of the disease, patients often have to cycle through available treatments, and while there are an increasing number of methods to control the disease, there is no cure. Many of the existing treatments can have serious side effects and can pose long-term risks for patients (e.g., suppress the immune system, deteriorate organ function, etc.). The lack of viable, long-term methods of control for psoriasis can be addressed through a robust

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federal commitment to epidemiological, genetic, clinical and basic research. Research holds the key to improved treatment and diagnosis of psoriatic disease and eventually a cure.

**The Role of CDC in Psoriasis and Psoriatic Arthritis Research**

Despite our increased understanding of the autoimmune underpinnings of psoriasis and its treatments, there is a dearth of population-based epidemiology data on psoriatic disease. Broadly-representative population-based studies of psoriasis reflecting the full spectrum of disease are lacking and much-needed because there are still wide gaps in our knowledge and understanding of psoriatic disease. CDC's implementation of the psoriasis and psoriatic arthritis public health agenda will help to provide scientists and clinicians with critical information to further their understanding of (a) how early intervention can prevent or delay the development of comorbid conditions; (b) what factors can trigger flares and remissions; (c) some of the underlying causes of disease; (d) how differentiating lifestyle and other environmental triggers might lead to approaches that minimize exposure to these factors, thus reducing the incidence and severity of disease; and (e) best practice treatments, which would assist in improving patient care and outcomes, and in turn, help reduce health care costs.

**Psoriasis and Psoriatic Arthritis Research at NIH**

It has taken nearly 30 years to understand that psoriasis is, in fact, not solely a disease of the skin, but also of the immune system. Recently, scientists identified some of the immune cells involved in psoriasis, and over the last decade we have seen a surge in the understanding of these diseases, accompanied by new drug development. Scientists are poised, as never before, to make major breakthroughs; to facilitate such advancements, we need increased investment in the National Institutes of Health (NIH).

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Within the NIH, the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) is the principal federal government agency that supports psoriasis research. We commend NIAMS for its leadership role and very much appreciate its steadfast commitment to supporting and advancing psoriasis research. Additionally, we are pleased that research activities that relate to psoriasis or psoriatic arthritis also have been undertaken within other NIH institutes and centers; this work is critical given the myriad comorbidities of psoriasis, as noted earlier. We advocate a strong federal investment in genetic, immunological and clinical studies focused on understanding the mechanisms of psoriasis and psoriatic arthritis be funded and maintained.

Given the myriad factors involved in psoriatic disease and its comorbid conditions, the Foundation urges Congress to boost funding for NIH and NIAMS. We recognize the nation faces significant budgetary challenges; however, we believe an increased federal investment in biomedical research will help strengthen the economy and our understanding of psoriatic disease.

**Conclusion/Summary**

On behalf of the more than 7.5 million people with psoriasis and psoriatic arthritis, I thank the Subcommittee for the opportunity to submit written testimony regarding the FY 2014 investments we believe are necessary to ensure that our nation adequately addresses the needs of individuals and families affected by psoriatic disease. By allocating \$1.2 million to implement CDC's psoriasis and psoriatic arthritis public health agenda, Congress will help ensure that the nation makes progress in understanding the connection between psoriasis and its comorbid conditions, uncovering the biologic aspects of psoriasis and other risk factors that lead to higher rates of comorbid conditions and identifying ways to prevent and reduce the onset of comorbid conditions associated with psoriasis. Please feel free to contact the Foundation at any time; we are happy to be a resource to Subcommittee members and your staff.

Contact: Maggie Elehwany  
Vice President  
Government Affairs and Policy  
National Rural Health Association

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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 15, 2013***

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 2014 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 programs 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 are 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 choose what is most important for their own situation and then 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, preventative care services and many other health concerns. Due to the community nature of the grants and a focus on self-sustainability after the terms of the grant have run out – 85 percent of the Outreach Grantees continue to deliver services five full years after federal funding ended. Request: \$59.8 million.

**Rural Health Research and Policy** 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. These research centers provide the knowledge and the evidence needed for good policy making, both in the federal government and across the nation. Additionally, we urge the Subcommittee to include in report language instructions to the Office of Rural Health Policy to direct additional funding to the state rural health associations. The state associations serve to coordinate rural health activities at the state level and have a strong record of positive outcomes. Request: \$10.76 million.

**State Offices of Rural Health** are the state counterparts to the federal rural health research and policy efforts, and form the state infrastructure for rural health policy. They assist States in

strengthening rural health care delivery systems by maintaining a focal point for rural health within each State and by linking small rural communities with State and Federal resources to develop long term solutions to rural health problems. Without these funds, states would have diminished capacity to administer many of the rural health programs that are critical to access to care. State offices of rural health 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: \$10 million.

**Rural Hospital Flexibility Grants** fund quality improvement and emergency medical service projects for Critical Access Hospitals across the country. The BBA created this essential program to improve access to essential health care services by Critical Access Hospitals (CAHs), rural hospital networks and rural emergency medical services. A variety of factors may make it more difficult for many CAHs to do the types of quality improvement or information technology activities that they need to do. These grants allow statewide coordination and provide expertise to CAHs. Also funded in this line is the Small Hospital Improvement Program (SHIP), which provides grants to more than 1,500 small rural hospitals (50 beds or less) across the country to help improve their business operations, focus on quality improvement and to ensure compliance provisions related to health information privacy. Request: \$43.46 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: \$3.49 million.

**The Office for the Advancement of Telehealth** supports distance-provided clinical services and is designed to reduce the isolation of rural providers, foster integrated delivery systems through network development and test a range of telehealth applications. Long-term, telehealth promises to improve the health of millions of Americans, provide constant education to isolated rural providers and save money through reduced office visits and expensive hospital care. 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: \$12.3 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. Programs like the NHSC help to maximize the capacity of our health system to care for patients. The Patient Protection and Affordable Care Act provided additional funding to the NHSC through the HHS Secretary's Community Health Center fund. The 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.

**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 choose to practice in rural areas. Without this experience and support while in medical school, far fewer professionals would make the commitment to rural areas and facilities including Community Health Centers, Rural Health Clinics and rural hospitals. 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 individuals will have access to health care and rural American will have 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. This program's success has led to increased statutory authorizations, currently \$75 million. 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. Newly created under the Patient Protection and Affordable Care Act, this "grow-your-own" approach is one of the best and most cost-effective ways to ensure a robust rural workforce into the future. Request: \$4 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: \$35.6 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.

*Written Testimony of Alma Roberts, President, National Healthy Start Association – March 15, 2013  
House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related  
Programs*

Chairman Kingston, members of the Subcommittee, Healthy Start appreciates the opportunity to submit testimony to the Labor, Health and Human Services, Education, and Related Programs Subcommittee. Healthy Start is operated by the Maternal and Child Health Bureau at the Health Resources and Services Administration (HRSA) and funds a network of 105 community-based programs designed to reduce infant mortality and support disadvantaged pregnant women. Healthy Start programs, which are found in both urban and rural areas, focus on reducing infant mortality, the incidence of low-birthweight babies, as well as eliminating racial disparities in birth outcomes. Healthy Start programs serve women and families by providing outreach, home visits, case management, health education, depression screening and other effective approaches to ensure the birth of a healthy newborn child. We are requesting \$103.532 million for the Healthy Start program in the Fiscal Year 2014 Labor, Health and Human Services and Education and Related Agencies Appropriations bill, which is equal in amount to the funding level for FY2012.

In 1989, President George H.W. Bush, with the leadership of his Secretary of Health and Human Services Dr. Louis Sullivan, created the White House Task Force to Reduce Infant Mortality. The Task Force was asked to research disparities and to recommend interventions that could assist the nation in decreasing infant mortality rates. Federal Healthy Start was one of several funded activities recommended by the Task Force and was initiated as a five-year demonstration project. Originally, 15 urban and rural projects, in areas with infant mortality rates 1.5 to 2.5 times higher than the national average, were funded to implement innovative approaches to improve birth outcomes. Communities were charged with developing

community-based efforts to reduce infant mortality by 50% within the four year project period and to improve the health and welfare of women, infants, and their families. Healthy Start currently has 105 project sites across 39 states and has provided services to over 500,000 women, children and families in underserved urban and remote rural America.

Today, the community-based Health Start program sites have demonstrated great success in reducing infant mortality and the number of low-birthweight infants through the adoption of the following health care best practices:

- Preventive care/linkages to medical homes during preconception and interconceptional periods;
- Holistic and inclusive supportive services for women's health throughout their life course;
- In-home and clinic/in-center targeted services and care coordination for chronic diseases;
- Core services provided through evidence-based and promising home visitation practices;
- Core services provided through Community Health Workers and professional staff;
- Services that have the overarching goal of reducing perinatal disparities; and
- A means to access low cost, high quality health care options.

Continued investment in Healthy Start will reduce overall federal costs associated with the expensive medical treatments that low-birthweight infants require, as well as future spending on Medicaid, special education and a myriad of other social services that are needed for infants with special health care needs. Significant savings can accrue from enabling mothers to add a few ounces to a baby's weight before birth. An increase of 250 grams (approximately ½ pound) in birth weight saves an average of \$12,000 to \$16,000 in first year medical expenses. Prenatal interventions that result in normal birth (over 2500 grams or 5.5 pounds) save \$59,700 in medical expenses in the infant's first year. The long-term cost of low-birthweight infants include re-hospitalization, many other medical and social service costs and, when the child enters school, often large special education expenses. These public expenses can go on for a lifetime.

There are many factors we cannot control in determining whether a baby is born healthy. However, we can ensure that the federal government is fully committed to reducing the rates of infant mortality and low-birthweight rates. We look forward to working with you to achieve these goals. Once again, we respectfully request that the Subcommittee's support by providing \$103.5 million for the Healthy Start program in your Fiscal 2014 Labor, Health and Human Services, Education and Related Agencies Appropriations bill.

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**STATEMENT OF DR. RON SZYMUSIAK, PhD  
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**REGARDING FISCAL YEAR 2014 APPROPRIATIONS  
FOR THE NATIONAL INSTITUTES OF HEALTH, NATIONAL HEART,  
LUNG, AND BLOOD INSTITUTE, AND THE CENTERS FOR DISEASE  
CONTROL AND PREVENTION**

**SUBMITTED TO THE HOUSE ON LABOR, HEALTH AND HUMAN  
SERVICES, EDUCATION, AND RELATED AGENCIES  
APPROPRIATIONS SUBCOMMITTEE**

**MARCH 15<sup>th</sup>, 2013**

**SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2014:**

- **\$32 BILLION FOR THE NATIONAL INSTITUTES OF HEALTH (NIH), INCLUDING A PROPORTIONAL INCREASE FOR THE NATIONAL HEART, LUNG, AND BLOOD INSTITUTE**
- **FULL SUPPORT FOR THE NATIONAL CENTER ON SLEEP DISORDERS RESEARCH HOUSED AT THE NATIONAL HEART, LUNG, AND BLOOD INSTITUTE**
- **\$1 MILLION FOR SLEEP DISORDERS AWARENESS AND SURVEILLANCE ACTIVITIES AT THE CENTERS FOR DISEASE CONTROL AND PREVENTION**
- **IMPLEMENTATION OF THE 2011 NIH SLEEP DISORDERS RESEARCH PLAN**

Chairman Kingston and distinguished members of the Subcommittee, as you begin to craft the Fiscal Year 2014 (FY14) Labor-HHS-Education appropriation bill, the Sleep Research Society (SRS) is pleased to submit this statement for the record asking you to provide \$1 million in funding for sleep disorders awareness and surveillance at the Centers for Disease Control and Prevention (CDC), \$32 billion for NIH, including a proportional increase for the National Heart, Lung, and Blood Institute (NHLBI), 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 by a group of scientists in 1961 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 its reach into areas such as psychology, neuroanatomy, pharmacology, cardiology, immunology, metabolism, genomics, and healthy living. SRS recognizes the importance of educating the public concerning knowledge of sleep research activities and outcomes. Therefore, 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 maintaining 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 is needed to facilitate the continued growth and advancement in the sleep/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 and T & 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 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 and insomnia can worsen depression and anxiety. 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. It is important to fund NIH in FY14 so that we can continue these advancements in sleep and circadian research.

#### **CENTERS FOR DISEASE CONTROL AND PREVENTION**

CDC gathers important data on sleep disorders through their surveillance efforts. 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 provide CDC with an allocation of \$1 million for sleep awareness and surveillance activities in FY14 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 a plan in November of 2011 that highlights the implementation of pertinent sleep research goals to enable further advancements in the realm of sleep disorders and circadian rhythms. The plan identifies new opportunities for understanding the function of sleep that can inform individuals on healthier lifestyle choices. 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 FY14.

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.

**Phillip M. Gattone, President and CEO**  
**The Epilepsy Foundation of America**  
**Testimony – House Subcommittee on Labor-HHS-Education and Related Agencies**

Thank you, Chairman Kingston and Ranking Member DeLauro, for allowing me to testify on behalf of the more than 2.2 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 programs at the Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA), 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.

In October, 2012, the Epilepsy Foundation began a merger 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 became effective on January 1<sup>st</sup> and brings together the mission and assets of both organizations, including [www.epilepsy.com](http://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 it 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.

HRSA directs national health programs that improve the Nation's health by assuring equitable access to comprehensive quality health care for all. HRSA promotes a community-based system of services mandated for all children with special health care needs; supports programs that are designed to break down barriers to community living for people with disabilities; and provides primary health care to medically underserved people. The 2012 Institute of Medicine report also calls upon stakeholders like the Foundation and HRSA to identify needs and improve community services for underserved populations. We believe that Project Access is an important part of meeting that goal and fully support the work of HRSA to empower families in health decision making, promote medical home models, support access to health care, increase early health care screenings, and facilitate transition for youth to improved healthy and independent lives.

Project Access is a national effort which involves state agencies, physicians and other health care providers, families, schools, and community resources to implement demonstration projects in medically underserved areas to improve health care outcomes and access for children with epilepsy. Demonstration projects have been conducted in California, Washington, D.C., Wisconsin, New Jersey, Mississippi, Illinois, West Virginia, Alaska, Nevada, Wyoming, Washington, New Hampshire, Maine, Florida, New York and Oregon. These projects not only serve needs of an important public health condition like epilepsy, but can serve as a model for other chronic health conditions and disabilities.

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 and the Health Resources and Services

Administration. 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.

## Testimony for Submission

Julie M. Scofield  
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To the House Committee on Appropriations  
 Subcommittee on Labor, HHS, Education and Related Agencies for FY2014

The National Alliance of State and Territorial AIDS Directors (NASTAD) represents the nation's chief state health agency staff who have programmatic responsibility for administering HIV/AIDS and viral hepatitis healthcare, prevention, education and supportive service programs funded by state and federal governments. On behalf of NASTAD, we urge your support for increased funding for federal HIV/AIDS and viral hepatitis programs in the FY2014 Labor-Health-Education Appropriations bill, and thank you for your consideration of the following critical funding needs for HIV/AIDS and viral hepatitis programs in FY2014:

<b>Agency</b>	<b>Program</b>	<b>NASTAD Funding Request</b>
Health Resources and Services Administration	Ryan White Part B Base	\$463.8 million
Health Resources and Services Administration	Ryan White Part B ADAP	\$1.06 billion
Centers for Disease Control and Prevention	HIV Prevention by Health Departments	\$562.3 million
Centers for Disease Control and Prevention	Division of Viral Hepatitis	\$35 million

The HIV continuum of prevention to care begins with preventing HIV infections and when an individual is diagnosed, they are diagnosed early and linked to high quality care to achieve maximum health outcomes, which includes an undetectable viral load. Our domestic prevention efforts must match our commitment to the care and treatment of people who are living with HIV. To be successful, we must expand outreach, scale-up and consider new and innovative approaches to arrest the epidemic here at home. 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, and leading to fewer new HIV 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 \$2.4 billion Ryan White Program that provides health and support services to more than 500,000 people living with HIV/AIDS (PLWHA). NASTAD requests a minimum increase of **\$173.7 million** in FY2014 for state Ryan White Part B grants, including an increase of **\$42.2 million** for Part B and **\$131.5 million** for AIDS Drug Assistance Programs (ADAPs). With these funds states and territories provide care, treatment and support services to PLWHA, who need 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. State ADAPs provide medications to low-income uninsured or underinsured PLWHA. In FY2011, over 230,000 clients were enrolled in ADAPs nationwide. All states have reported to NASTAD a significant increase in the number of individuals seeking Part B and ADAP services. In FY2012, \$35 million was awarded to state ADAPs as emergency relief funding in order to alleviate waitlists for life-saving medications and other cost containment measures. It is imperative that this continues in FY2014 to avoid the creation of new waitlists and to ensure that care continues uninterrupted for ADAP clients.

#### **HIV/AIDS Prevention and Surveillance Programs**

Despite 30 years of combatting HIV in the United States, over 50,000 new infections occur annually. In 2011, 50,199 new individuals were diagnosed with HIV, of which an overwhelming 64% were among gay, bisexual and other men who have sex with men (MSM). In fact, new infections among MSM increased by 10% between 2010 and 2011. African Americans are still nearly nine times more likely than Whites to test positive for HIV and Latinos are nearly three times more likely. Between 2010 and 2011, the rate of new HIV infections among Asians increased by 22% in the US. African Americans accounted for 46% of all new US infections, while only accounting for 12.6% of the total US population. Latinos comprise 16% of the US population, but in 2011 accounted for 22% of all new infections in the US and dependent areas. When broken down by age, the only two age groups whose rate of infection has increased since 2008 are those between 20-24 and 25-29, accounting for nearly one-third of all new HIV infections in 2011. Even more startling, infection rates have dramatically increased among young Black gay men/MSM, who saw a 48% increase in new infections from 2006 to 2009 (CDC).

NASTAD requests an increase of **\$110 million** in FY2014 for CDC's flagship HIV prevention program, HIV Prevention by Health Departments program, which funds state and local health departments to provide the foundation for HIV prevention and control nationwide. By providing adequate resources to state and local health departments to scale up HIV prevention and surveillance programs, we will be closer to meeting the National HIV/AIDS Strategy (NHAS) goal of reducing new HIV infections by 25% by 2015. Health departments are the cornerstone implementers of federal public health policy and are essential to meeting the goals of the National HIV/AIDS Strategy to reduce the annual number of new HIV infections and reduce HIV-related health disparities. Despite the clear need to fund health departments for HIV prevention, this funding stream has seen steady decreases over the last several years.

HIV surveillance has been chronically underfunded in most jurisdictions for over a decade. As a result, many states cobble together their HIV surveillance programs with resources leveraged from other programs. Additional resources will allow improvements in core surveillance and expand surveillance for HIV incidence, behavioral risk and receipt of care information, including CD4 and viral load reporting. HIV surveillance data are the mechanism through which the success at achieving the goals of the NHAS will be measured. The completeness of national HIV surveillance activities is critical to monitor the HIV/AIDS epidemic and to provide data for targeting with greater precision the delivery of HIV prevention, care and treatment services.

#### **Viral Hepatitis Prevention Programs**

NASTAD requests an increase of **\$5.3 million** in FY2014 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 *HHS Action Plan for Viral Hepatitis*, and the CDC testing guidelines for baby boomers. In FY2012, DVH received \$10 million from the Prevention and Public Health Fund for the creation of a viral hepatitis screening initiative, which needs to continue in order to identify the 65 to 75% of people living with viral hepatitis who do not know their status. 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. This program provided an average award to states of \$94,000 in FY2012 to support a coordinator, leaving little to no money for the provision of public health services, such as public education and access to prevention services like testing and hepatitis A and B vaccinations. Even without funding for programmatic activities, coordinators were able to leverage existing infrastructure to administer nearly 90,000 tests nationwide in FY2011.

### **Prevention and Public Health Fund**

The Prevention and Public Health Fund tackles critical epidemics, such as HIV/AIDS and viral hepatitis. The fund is a unique opportunity to decrease health care spending related to HIV/AIDS treatment and care, and invest in viral hepatitis prevention and screening efforts. We encourage you to utilize the Prevention and Public Health Fund to support a broad testing and screening initiative that would include neglected diseases such as viral hepatitis in order to capture patients before they progress in their liver disease and increase costs to public healthcare systems, as well as HIV/AIDS prevention initiatives.

As you contemplate the FY2014 Labor, HHS and 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.

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 14<sup>th</sup>, 2013

**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 NATIONL 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 Professions Training programs address a critical national need. Persistent and severe staffing shortages exist in a number of the health professions, and chronic shortages exist for all of the health professions in our nation's most medically underserved communities. Furthermore, 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 FY14, 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 FY14, 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 FY14, 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 FY14, 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 FY14.*

## 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 FY14, 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 FY14, 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 OF WAYNE J. RILEY, M.D., M.P.H., MBA, FACP  
PRESIDENT  
AND  
CHIEF EXECUTIVE OFFICER**

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**PRESENTED BEFORE THE**

**HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN  
SERVICES, EDUCATION AND RELATED AGENCIES**

**SUMMARY OF FISCAL YEAR 2014 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. Wayne J. Riley, President and CEO of Meharry Medical College in Nashville, Tennessee. I have previously served as vice-president and vice dean for health affairs and governmental relations and associate professor of medicine at Baylor College of Medicine in Houston, Texas and as assistant chief of medicine and a practicing general internist at Houston's Ben Taub General Hospital. In all of these roles, I have seen firsthand the importance of minority health professions institutions and the Title VII Health Professions Training programs.

Mr. Chairman, time and time again, you have encouraged your colleagues and the rest of us to take a look at our nation and evaluate our needs over the next ten years. First, I want to say that it is clear that health disparities among various populations and across economic status are rampant and overwhelming. Over the next ten years, we will need to be able to deliver more

culturally relevant and culturally competent healthcare services. Bringing healthcare delivery up to this higher standard can serve as our nation's own preventive healthcare agenda keeping us well positioned for the future.

Minority health professional institutions and the Title VII Health Professions Training programs address this critical national need. Persistent and severe staffing shortages exist in a number of the health professions, and chronic shortages exist for all of the health professions in our nation's most medically underserved communities. Our nation's health professions workforce does not accurately reflect the racial composition of our population. For example, African Americans represent approximately 15% of the U.S. population while only 2-3% of the nation's healthcare workforce is African American.

There is a well established link between health disparities and a lack of access to competent healthcare in medically underserved areas. As a result, it is imperative that the federal government continue its commitment to minority health profession institutions and minority health professional training programs to continue to produce healthcare professionals committed to addressing this unmet need.

An October 2006 study by the Health Resources and Services Administration (HRSA), entitled "The Rationale for Diversity in the Health Professions: A Review of the Evidence" found that minority health professionals serve minority and other medically underserved populations at higher rates than non-minority professionals. The report also showed that; minority populations tend to receive better care from practitioners who represent their own race or ethnicity, and non-English speaking patients experience better care, greater comprehension, and greater likelihood of keeping follow-up appointments when they see a practitioner who speaks their language.

**Studies have also demonstrated that when minorities are trained in minority health profession institutions, they are significantly more likely to: 1) serve in rural and urban medically underserved areas, 2) provide care for minorities and 3) treat low-income patients.**

As you are aware, Title VII Health Professions Training programs are focused on improving the quality, geographic distribution and diversity of the healthcare workforce in order to continue eliminating disparities in our nation's healthcare system. These programs provide training for students to practice in underserved areas, cultivate interactions with faculty role models who serve in underserved areas, and provide placement and recruitment services to encourage students to work in these areas. Health professionals who spend part of their training providing care for the underserved are up to 10 times more likely to practice in underserved areas after graduation or program completion.

Institutions that cultivate minority health professionals have been particularly hard-hit as a result of the cuts to the Title VII Health Profession Training programs in fiscal year 2006 (FY06) and FY07 Funding Resolution passed earlier this Congress. Given their historic mission to provide academic opportunities for minority and financially disadvantaged students, and healthcare to minority and financially disadvantaged patients, minority health professions institutions operate on narrow margins. The cuts to the Title VII Health Professions Training programs amount to a loss of core funding at these institutions and have been financially devastating.

Mr. Chairman, I feel like I can speak authoritatively on this issue because I received my medical degree from Morehouse School of Medicine, a historically black medical school in Atlanta. I give credit to my career in academia, and my being here today, to Title VII Health Profession Training programs' Faculty Loan Repayment Program. Without that program, I would not be the president of my father's alma mater, Meharry Medical College, another historically black medical school dedicated to eliminating healthcare disparities through education, research and culturally relevant patient care.

**Minority Centers of Excellence:** COEs focus on improving student recruitment and performance, improving curricula in cultural competence, facilitating research on minority health issues and training students to provide health services to minority individuals. COEs were first established in recognition of the contribution made by four historically black health professions institutions (the Medical and Dental Institutions at Meharry Medical College; The College of Pharmacy at Xavier University; and the School of Veterinary Medicine at Tuskegee University) to the training of minorities in the health professions. Congress later went on to authorize the establishment of "Hispanic", "Native American" and "Other" Historically black COEs. *For FY14, 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 FY14, 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 FY14.*

### DEPARTMENT OF HEALTH AND HUMAN SERVICES

**Office of Minority Health:** Specific programs at OMH include:

- I) 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 its grant making authority. *For FY14, 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 FY14, 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.

**TESTIMONY OF DAVID CARLISLE, M.D.  
PRESIDENT AND CHIEF EXECUTIVE OFFICER**

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**PRESENTED BEFORE THE**

**HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND  
HUMAN SERVICES, EDUCATION AND RELATED AGENCIES**

**MARCH 14<sup>TH</sup>, 2013**

**SUMMARY OF FISCAL YEAR 2014 RECOMMENDATIONS:**

- 1) **PROVIDE FUNDING FOR THE HEALTH RESOURCES AND SERVICES ADMINISTRATION TITLE VII HEALTH PROFESSIONS 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 FY14, 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 FY14, 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 FY14, 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 FY14.*

## 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 FY14, 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 FY14, 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 access to quality care upon diagnosis. As you are aware, in many minority and underserved communities preventative care and research are inaccessible either due to distance or lack of facilities and expertise. As noted earlier, in just one underserved area, South Los Angeles, the number and distribution of beds, doctors, nurses and other health professionals are as parlous as they were at the time of the Watts Rebellion, after which the McCone Commission attributed the so-named 'Los Angeles Riots' to poor services - particularly access to affordable, quality healthcare. The Charles Drew University has proven that it can produce excellent health professionals who 'get' the mission - years after graduation they remain committed to serving people in the most need. But, the university needs investment and committed increased support from federal, state and local governments and is actively seeking foundation, philanthropic and corporate support.

Even though institutions like The Charles Drew University are ideally situated (by location, population, community linkages and mission) to study conditions in which health disparities have been well documented, research is limited by the paucity of appropriate research facilities. With your help, the Life Sciences Research Facility will translate insight gained through research into greater understanding of disparities and improved clinical outcomes. Additionally, programs like Title VII Health Professions Training programs will help strengthen and staff facilities like our Life Sciences Research Facility.

We look forward to working with you to lessen the huge negative impact of health disparities on our nation's increasingly diverse populations, the economy and the whole American community.

Mr. Chairman, thank you again for the opportunity to present testimony on behalf of The Charles Drew University. It is indeed an honor.

**WRITTEN TESTIMONY OF WAYNE J. RILEY, M.D., MPH, M.B.A.  
CHAIRMAN, BOARD OF DIRECTORS  
615-327-6904  
[wiriley@mmc.edu](mailto:wiriley@mmc.edu)**

**ASSOCIATION OF MINORITY HEALTH PROFESSIONS SCHOOLS**

**PRESENTED TO THE**

**HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN  
SERVICES, EDUCATION AND RELATED AGENCIES**

**Friday, March 14<sup>th</sup>, 2013**

**SUMMARY OF FISCAL YEAR 2014 RECOMMENDATIONS:**

- 1) **TITLE VII HEALTH PROFESSIONS TRAINING PROGRAMS:**
  - **\$24.602 MILLION FOR THE MINORITY CENTERS OF EXCELLENCE.**
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  - **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. Wayne J. Riley, Chairman of the Board of Directors of the Association of Minority Health Professions Schools (AMHPS) and the President and Chief Executive Officer of Meharry Medical College. AMHPS, established in 1976, is a consortium of our nation's twelve (12) historically black medical, dental, pharmacy, and veterinary 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 FY14, 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 FY14, 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 FY14, 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 FY14, 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 FY14.*

### 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 FY14, 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 FY14, 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.



**National AHEC  
Organization**

Connecting students to careers,  
professionals to communities,  
and communities to better health.

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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  
EXECUTIVE DIRECTOR  
NATIONAL AHEC ORGANIZATION  
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**REGARDING FISCAL YEAR 2014 APPROPRIATIONS  
FOR HRSA'S 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, 20123**

The members of the National AHEC Organization (NAO) are pleased to submit this statement for the record recommending \$33.145 million in FY 2014 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

**Testimony of the National AHEC Organization Concerning HRSA's Area Health Education Center (AHEC) Program**

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

**Testimony of the National AHEC Organization Concerning HRSA's Area Health Education Center (AHEC) Program**

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.

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.

- Primary Care services improve the health of the population, and therefore increase productivity of the U.S. workforce, while at the same time, contain costs within the US healthcare system. Primary care practitioners are the front-line in prevention of disease, providing cost savings in the United States healthcare system<sup>1</sup>.
    - 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
-

**Testimony of the National AHEC Organization Concerning HRSA's Area Health Education Center (AHEC) Program**

- In 2010, AHECs 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).

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.

- 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.
- AHECs via a cooperative agreement with HRSA are training 10,000 primary care providers throughout the county to address OIF/OEF/OND Veteran's mental health, substance abuse, traumatic brain injury and post-traumatic stress for those not utilizing the VA system

**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 2014 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 FY14, 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 FY14, 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.

**John Robitscher, CEO**  
**National Association of Chronic Disease Directors.**  
**Testimony – House Subcommittee on Labor-HHS-Education and Related Agencies**

Thank you, Chairman Kingston and Ranking Member DeLauro, for allowing me to testify on behalf of the National Association of Chronic Disease Directors (NACDD). Specifically, I want to express my support for increased funding for the key chronic disease programs which are all part of the National Center for Chronic Disease Prevention and Health Promotion at CDC.

NACDD is a non-profit public health organization which serves the chronic disease program directors of each state and U.S. jurisdiction and connects the more than 3,000 chronic disease practitioners across the country.

As the United States seeks ways to regain our economic footing and rebuild prosperity, we must remember that poor health of the population can exert tremendous force on employment rates, interest costs, and other tangible factors that ultimately affect our ability to maintain a strong global economic position. The primary driver of cost in healthcare is chronic disease. Public health chronic disease prevention and control, which is managed by state health departments, focuses on risk factors and diseases, links the clinical and community sectors, and is the key to addressing this epidemic.

Chronic disease not only affects health and quality of life, but is also a major driver of health care costs and has a related impact on business, such as absenteeism and presenteeism.

According to the Centers for Disease Control and Prevention (CDC), chronic disease accounts for approximately 75 percent of the nation's aggregate health care spending - or an estimated

\$5,300 per person in the U.S. annually. In terms of public insurance, treatment of chronic disease constitutes an even larger portion of spending - 96 cents per dollar for Medicare and 83 cents per dollar for Medicaid. Behavioral choices that result in an increased incidence of chronic disease are also extremely costly in terms of the affordability of health care coverage. According to the Partnership to Fight Chronic Disease, since 2000, health insurance premiums for employer-sponsored family coverage have increased by 87 percent. Health care costs for people with a chronic condition average \$6,032 annually - five times higher than for those without such a condition.

Nearly half (45 percent) of all Americans suffer from at least one chronic disease. More than two-thirds of all deaths are caused by one or more of five chronic diseases: heart disease, cancer, stroke, chronic obstructive pulmonary disease, and diabetes. More than one in four Americans have multiple chronic conditions, and evidence is growing that the presence of one chronic condition has a negative impact on the risk of developing others, particularly as people age. The nation's aging population, coupled with existing risk factors (tobacco use, poor nutrition, lack of physical activity) and medical advances, lead to the conclusion that these problems are only going to grow if they are not effectively addressed now.

A recent Milken Institute analysis determined that treatment of the seven most common chronic diseases, coupled with productivity losses, will cost the U.S. economy more than \$1 trillion annually. The same analysis estimates that modest reductions in unhealthy behaviors could prevent or delay 40 million cases of chronic illness per year.

As the American population ages and more people are categorized as “high risk” for multiple chronic diseases, it is important to recognize that an individual’s choices, as well as where they live, attend school, and work, have an impact. Risky behaviors such as poor diet, lack of physical activity, use of tobacco, and ignoring known risks, like family history, result in a dramatic increase in chronic conditions. While most people do not ignore their automobile’s “check engine light,” many routinely skip their own body’s preventive maintenance warnings; thus, making poor choices about their health. The result is a poor collective health quality in a country that spends much more on healthcare than anywhere else in the world.

State Public Health Chronic Disease Prevention and Control Programs, especially those that focus on critical, common risk factors (nutrition and physical activity, tobacco use) and related behaviors are a key link to improving our nation’s health. Programs focused on age groups (childhood obesity prevention, youth tobacco prevention, senior physical activity programs) are all needed to serve as an adjunct to clinical medicine. These programs provide the venues and opportunities to help make the healthy choice the natural choice and provide reinforcement for healthy messages provided in the course of clinical care. These programs are the difference between hearing “you should eat better and get more exercise” from one’s doctor once a year, and being in communities where healthy foods and opportunities for physical activity are the norm and part of one’s daily life. Mays and Smith noted in *Health Affairs* that a 10 percent increase in public health spending would yield a reduced mortality rate across all causes, as well as a greater reduction in heart disease, diabetes, and cancer.

Today, only a small fraction of the United States' governmental healthcare investment supports prevention and health promotion. States are implementing diverse, cost effective strategies that work for early detection of cancer, prevention and control of diabetes, reduction of heart disease, stroke and arthritis, and reduction of the disability associated with all of these conditions. The state success stories on NACDD's website are just the beginning. A substantial investment in the CDC, State Health Departments, and other HHS agencies must be made for a real impact. The investment needs to be such that every state in America has a full complement of evidence-based programs to promote health and fight chronic disease, as well as the necessary resources to coordinate these programs with related activities (Medicaid, CHIP, Exchanges). These programs must include increased resources for every state to address:

- Coordination and leadership of categorical programs
- Early Detection of Cancer and Cancer Survivorship Services
- Diabetes Prevention and Control (including prevention of kidney disease)
- Heart Disease and Stroke Prevention
- Healthy Community Programs (ACHIEVE, REACH, others)
- Tobacco Prevention and Control
- Arthritis Prevention and Control
- School Health and Oral Health Programs
- Healthy Aging - including Alzheimer's Disease
- Improving Physical Activity and Nutrition

Public health programs work to improve care, prevent disease, and prevent complications of disease. An investment in chronic disease prevention and control programs saves lives, improves quality of life and saves healthcare dollars.

Written Testimony Submitted to the House  
Labor, Health and Human Services, and Education Appropriations Subcommittee  
Regarding FY 2013 Funding for the Centers for Disease Control and Prevention and National  
Institutes of Health

Submitted by: Amy Verstappen, President and CEO, Adult Congenital Heart Association  
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**Introduction** - The Adult Congenital Heart Association (ACHA) – a national not-for-profit organization dedicated to improving the quality of life and extending the lives of adults with congenital heart disease (CHD) – is grateful for the opportunity to submit written testimony regarding Fiscal Year 2014 funding for congenital heart research and surveillance. **We respectfully request \$3 million for CHD surveillance at the Centers for Disease Control and Prevention (CDC) as well as additional CHD research at the National Heart, Lung and Blood Institute (NHLBI).**

**Adult Congenital Heart Disease** - Congenital heart defects are the most common group of birth defects occurring in nearly one percent of all live births, or 40,000 babies a year. These malformations of the heart and structures connected to the heart either obstruct blood flow or cause it to flow in an abnormal pattern. This abnormal heart function can be fatal if left untreated. In fact, congenital heart defects remain the leading cause of birth defect related infant deaths and premature death across the lifespan.

Many infants born with congenital heart problems require intervention in order to survive. Intervention often includes one or multiple open-heart surgeries; however, surgery is rarely a long-term cure. Children born with heart defects have a significantly decreased life expectancy. One in 10 won't survive to adulthood. Among those with the most complex heart defects, only half will make it to age 18.

The success of childhood cardiac intervention has created a new chronic disease – CHD. Thanks to the increase in survival, estimates suggest that there are more than 2 million people alive today

with CHD, more than half whom are adults, increasing at an estimated rate of 5% each year. Few congenital heart survivors are aware of their high risk of additional problems as they age, facing high rates of neuro-cognitive deficits, heart failure, rhythm disorders, stroke, and sudden cardiac death, and many survivors require multiple operations throughout their lifetime. 50% of all congenital heart survivors have complex problems for which life-long care from congenital heart specialists is recommended, yet fewer than 10% of adult congenital heart patients receive recommended cardiac care. Delays in care can result in premature death and disability. In adults, this often occurs during prime wage-earning years.

The public health burden of CHD has yet to be fully assessed. However, the limited available research suggests that medical costs associated with congenital heart defects are substantial. \$1.2 billion is the estimated lifetime cost for U.S. children born in a single year with one of four major heart defects. It is estimated that in 2009, the hospital cost for roughly 27,000 hospital stays for children treated primarily for CHD in the U.S. was nearly \$1.5 billion. In the same year, hospital costs for roughly 12,000 hospital stays of adults treated primarily for CHD was at least \$280 million. Investing in CHD surveillance and research will improve outcomes for CHD survivors, decreasing disability and improving productivity.

**ACHA** - ACHA serves and supports the more than one million adults with CHD, their families and the medical community—working with them to address the unmet needs of the long-term survivors of congenital heart defects through education, outreach, advocacy, and promotion of ACHD research. **In order to promote life-saving research and accessible, appropriate and quality interventions which, in turn, will reduce the public health burden of this chronic**

disease, ACHA advocates for adequate funding of CDC initiatives relating to CHD, and encourages funding within the NHLBI for CHD research.

**Federal Support for Congenital Heart Disease Research and Surveillance** - Despite the prevalence and seriousness of the disease, CHD data collection and research are limited and almost non-existent for the adult CHD population. In March of 2010, the first CHD legislation passed as part of *Patient Protection and Affordable Care Act (ACA)*.<sup>1</sup> The ACA calls for the creation of The National Congenital Heart Disease Surveillance System, which will collect and analyze nationally-representative, population-based epidemiological and longitudinal data on infants, children, and adults with CHD to improve understanding of CHD incidence, prevalence, and disease burden and assess the public health impact of CHD. It also authorized the NHLBI to conduct or support research on CHD diagnosis, treatment, prevention and long-term outcomes to address the needs of affected infants, children, teens, adults, and elderly individuals.

The National Center on Birth Defects and Developmental Disabilities included preventing congenital heart defects and other major birth defects in its recently published 2011-2015 Strategic Plan, specifically recognizing the need for understanding the contribution of birth defects to longer term outcomes (i.e., beyond infancy) and the economic impact of specific birth defects.

**The National Congenital Heart Disease Surveillance System at CDC** - As survival improves, so does the need for population-based surveillance across the lifespan. Funding to support the development of the National Congenital Heart Disease Surveillance System through both a pilot adult surveillance program, and the enhancement of the existing birth defects surveillance system

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<sup>1</sup> *Patient Protection and Affordable Care Act*, §10411(b).

will be instrumental in driving research, improving interventional outcomes, improving loss to care, and assessing health care burden. In turn, the National Congenital Heart Disease Surveillance System can serve as a model for all chronic disease states.

The current surveillance system is grossly inadequate. There are only 14 states currently funded by the CDC to gather data on birth defects, presenting limitations in generalizing the information across the entire population. Thus, there are significant inconsistencies in the methods of collection and reporting across the various state systems which limits the value of the data. Given the absence of population-based data across the lifespan, the data we do have excludes anyone diagnosed after the age of one, as well as those who are lost to care. It is this population, those lost to care are of greatest concern and most difficult to identify. Evidence indicates that those with CHD are at significant risk for heart failure, rhythm disorders, stroke, and sudden cardiac death as they age, requiring ongoing specialized medical care. For those who are lost to care, for reasons such as limited access to affordable or appropriate care or poor education about the need for ongoing care, they often return to the system with preventable advanced illness and/or disability. Population-based surveillance across the life span is the only method by which these patients can be identified, and, as a result, appropriate intervention can be planned. ACHA is currently working with the CDC to address these concerns through the National Congenital Heart Disease Surveillance System.

The FY2012 appropriations bill provided \$2 million to the CDC for surveillance of congenital heart defects. In spring 2012, the CDC funded three pilot adolescent and adult surveillance projects. The CDC states that the “purpose of this program is to provide support through CDC cooperative agreements for non-research activities to develop robust, population-based estimates of the prevalence of CHDs focusing on adolescents and adults, and better understand the

survival, healthcare utilization, and longer term outcomes of adolescents and adults affected by CHDs. The program is a pilot and designed as a learning collaborative effort between CDC and grantees with potentially unique and innovative approaches to monitoring CHDs among adolescents and adults.” In September 2012, the CDC convened an expert meeting to discuss future research priorities for CHD.

**ACHA requests that Congress provide the CDC \$3 million in FY 2014 to support data collection to better understand CHD prevalence and assess the public health impact of CHD. This level of funding will further support the pilot adolescent and adult surveillance projects and allow for further development of research priorities.**

Funding of Research Related to Congenital Heart Disease at NHLBI - Our nation continues to benefit from the single largest funding source for CHD research, the NHLBI. Yet, as a leading chronic disease, congenital heart research is significantly underfunded.

The NHLBI supports basic and clinical research to establish a scientific basis for the prevention, detection, and treatment of congenital heart disease. The Bench to Bassinet Program is a major effort launched by the NHLBI to hasten the pace at which heart research on genetics and basic science can be developed into new treatments across the life span for people with congenital heart disease. The overall goal is to provide the structure to turn knowledge into clinical practice, and use clinical practice to inform basic research.

**ACHA urges Congress to support the NHLBI in efforts to continue its work with patient advocacy organizations, other NIH Institutes, and the CDC to expand collaborative research initiatives and other related activities targeted to the diverse life-long needs of individuals living with congenital heart disease.**

**March 15, 2013**

**AMERICAN GERIATRICS SOCIETY**

**Written Testimony for the Subcommittee on Labor, Health and Human Services, Education and Related Agencies of the House Appropriations Committee**

**FY 2014 Appropriations for the Department of Health and Human Services**

- **Title VII Geriatrics Health Professions Programs**
  - **Title VIII Comprehensive Geriatric Education Nursing Program**
  - **The National Institute on Aging**
- 

Mr. Chairman and Members of the Subcommittee:

We submit this testimony on behalf of the American Geriatrics Society (AGS), a non-profit organization of over 6,000 geriatrics healthcare professionals dedicated to improving the health, independence and quality of life of all older Americans. As the Subcommittee works on its fiscal year (FY) 2014 Labor-HHS-Education Appropriations bill, we ask that you prioritize funding for the geriatrics education and training programs under Title VII and Title VIII of the Public Health Service Act and for research funding within the National Institute on Aging.

**We ask that the subcommittee consider the following recommended funding levels for these programs in FY 2014:**

- **\$37.1 million for Title VII Geriatrics Health Professions Programs**
- **\$5.0 million for Title VIII Comprehensive Geriatric Education Nursing Program**
- **\$1.4 billion for the National Institute on Aging**

While we recognize the fiscal challenges facing our nation, sustained and enhanced federal investments in these initiatives are essential to delivering higher quality, better coordinated and more cost effective care to our nation's seniors. We request that Congress provide the additional investments necessary to expand and enhance the geriatrics workforce, which is an integral

component of the primary care workforce, and to foster groundbreaking medical research so that our nation is prepared to meet the unique health care needs of the rapidly growing population of seniors.

**PROGRAMS TO TRAIN GERIATRICS HEALTH CARE PROFESSIONALS**

Our nation is facing a critical shortage of geriatrics faculty and health care professionals across disciplines. This trend must be reversed if we are to provide our seniors with the quality care they need and deserve. Care provided by geriatric health care professionals, who are trained to care for individuals who are the most complex and frail and who account for 80% of our Medicare expenditures, has been shown to reduce common and costly conditions that are often preventable with appropriate care, such as falls, polypharmacy, and delirium.

**Title VII Geriatrics Health Professions Programs (\$37.1 million)**

These programs support three initiatives: the Geriatric Academic Career Awards (GACAs), the Geriatric Education Center (GEC) program, and geriatric faculty fellowships. These are the only programs specifically designed to address the well-documented shortage of geriatrics health care professionals in the U.S. **We ask the subcommittee to provide a FY 2014 appropriation of \$37.1 million for Title VII Geriatrics Health Professions Programs.**

Our funding request breaks down as follows:

▪ **Geriatric Academic Career Awards (GACAs) (\$5.5 million)**

GACAs support the development of newly trained geriatric clinicians in academic medicine who are committed to teaching geriatrics in medical schools across the country. GACA recipients are required to provide training in clinical geriatrics, including the training of interdisciplinary teams of health care professionals. Our budget request of \$5.5 million would support GACA program awardees in their development as clinician educators.

*Program Accomplishments:* In Academic Year 2010-2011, the GACA program funded 68 full time junior faculty awardees. These awardees provided interdisciplinary training in geriatrics to 38,392 health professionals in clinical geriatrics; provided interdisciplinary team training to 6,617 clinical staff in various geriatric clinical settings; and provided geriatric services to 57,364 geriatric patients who are underserved and uninsured patients in acute care, geriatric ambulatory care, long-term care, and geriatric consultation services settings.

▪ **Geriatric Education Centers (GECs) (\$22.7 million)**

GECs provide grants to support collaborative arrangements involving several health professions, schools and health care facilities to provide multidisciplinary training in geriatrics, including assessment, chronic disease syndromes, care planning, emergency preparedness, and cultural competence unique to older Americans. Our funding request of \$22.7 million includes continued support for the core work of 45 GECs (\$20.0) and \$2.7 million to fund 24 GECs for the development of mini-fellowships under the supplemental grant program included in ACA.

*Program Accomplishments:* In Academic Year 2010-2011, the 45 GEC grantees developed and provided 2,103 education and training offerings to health professions students, faculty, and practitioners related to care of the older adult. Interdisciplinary education and training was provided to 10,703 interdisciplinary teams. The grantees provided education and training to 64,414 health professions students, faculty, and practitioners.

▪ **Geriatric Training for Physicians, Dentists, Behavioral/Mental Health Professions (\$8.9 million)**

This program is designed to train physicians, dentists, and behavioral and mental health professionals who choose to teach geriatric medicine, dentistry or psychiatry. The program

provides fellows with exposure to older adult patients in various levels of wellness and functioning, and from a range of socioeconomic and racial/ethnic backgrounds. Our funding request of \$8.9 million will allow 13 institutions to continue this important faculty development program.

*Program Accomplishments:* In Academic Year 2010-2011, 13 non-competing continuation grants were supported. A total of 54 physicians, dentists and psychiatry fellows provided geriatric care to 24,139 older adults across the care continuum. Geriatric physician fellows provided health care to 13,788 older adults; geriatric dental fellows provided health care to 4,834 older adults; and geriatric psychiatric fellows provided health care to 5,516 older adults.

**Title VIII Comprehensive Geriatric Education Nursing Program (\$5.0 million)**

The American health care delivery system for older adults will be further strengthened by federal investments in Title VIII Nursing Workforce Development Programs, specifically the comprehensive geriatric education grants, as nurses provide cost-effective, quality care. This program supports additional training for nurses who care for the elderly, development and dissemination of curricula relating to geriatric care, and training of faculty in geriatrics. It also provides continuing education for nurses practicing in geriatrics.

Additionally, under ACA, this program is being expanded to include advanced practice nurses who are pursuing long-term care, geropsychiatric nursing or other nursing areas that specialize in the care of older adults. Our funding request of \$5.0 million includes funds to continue the training of nurses caring for older Americans and offer traineeships to nurses under the program's expansion through the ACA.

*Program Accomplishments:* In Academic Year 2010-2011, 27 non-competing Comprehensive Geriatric Education (CGEP) grantees provided education and training to 3,645 registered nurses, 1,238 registered nursing students, 870 direct service workers, 569 licensed practical/vocational nurses, 264 faculty and 5,344 allied health professionals.

**RESEARCH FUNDING INITIATIVES - National Institute on Aging (\$1.4 billion)**

The NIA leads a broad scientific effort to understand the nature of aging and to extend the healthy, active years of life. Continued federal investments in scientific research, including comparative effectiveness initiatives, will ensure that the NIA has the resources to succeed in its mission to establish research networks, assess clinical interventions and disseminate credible research findings to patients, providers and payers of health care.

As a member of the Friends of the NIA, a broad-based coalition of more than 45 aging, disease, research, and patient groups committed to the advancement of medical research that affects millions of older Americans, **AGS asks that NIA receive \$1.4 billion in FY 2014.**

In closing, geriatrics is at a critical juncture, with our nation facing an unprecedented increase in the number of older patients with complex health needs. Strong support such as yours will help ensure that every older American is able to receive high-quality health care.

Thank you for your consideration.

**Prevent Blindness America**  
**Written Testimony to the House Appropriations**  
**Labor, Health and Human Services, Education,**  
**and Related Agencies Subcommittee**  
**Submitted by: Hugh Parry, President & CEO, Prevent Blindness America**  
**March 15, 2013**

**Funding Request Overview**

Prevent Blindness America appreciates the opportunity to submit written testimony for the record regarding fiscal year (FY) 2014 funding for vision and eye health related programs. As the nation's leading non-profit, voluntary health organization dedicated to preventing blindness and preserving sight, Prevent Blindness America maintains a long-standing commitment to working with policymakers at all levels of government, organizations and individuals in the eye care and vision loss community, and other interested stakeholders to develop, advance, and implement policies and programs that prevent blindness and preserve sight. Prevent Blindness America respectfully requests that the Subcommittee provide the following allocations in FY 2014 to help promote eye health and prevent eye disease and vision loss:

- Provide at least \$508,000 million to maintain vision and eye health efforts at the Centers for Disease Control and Prevention (CDC).
- Support the Maternal and Child Health Bureau's (MCHB) National Center for Children's Vision and Eye Health (Center).
- Provide at least \$640 million in FY 2014 to sustain programs under the Maternal and Child Health (MCH) Block Grant.
- Provide \$730 million to the National Eye Institute (NEI) in order to bolster efforts to identify the underlying causes of eye disease and vision loss, improve early detection and diagnosis, and advance prevention and treatment efforts.

### **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. Alarming, 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.”<sup>1</sup>

To curtail the increasing incidence of vision loss in America, Prevent Blindness America 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. In a time of significant fiscal constraints, 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 the loss of their livelihoods, all because of the loss of their vision.

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<sup>1</sup> “Vision Problems in the U.S.: Prevalence of Adult Vision Impairment and Age-Related Eye Disease in America,” Prevent Blindness America and the National Eye Institute, 2008.

**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 America 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.

Prevent Blindness America requests at least \$508,000 in FY 2014 to maintain vision and eye health efforts of the CDC. Adequate resources will allow the CDC to continue to address the growing public health threat of preventable chronic eye disease and vision loss among at-risk and underserved populations through increased coordination and integration of vision and eye health at state and local health departments, and through community health centers and rural services.

*Integrating Vision Health into Broader Disease Prevention and Health Promotion Efforts*

A cornerstone activity of the vision and eye health work at the CDC is its support and encouragement of efforts to better integrate state-level initiatives to address vision and eye disease by approaching vision health through other public health prevention, treatment, and research efforts. Vision loss is associated with a myriad of other serious, chronic, life threatening, and disabling conditions, including diabetes, depression, unintentional injuries, and behavioral risk factors such as tobacco use. Leveraging scarce resources and recognizing the numerous connections between eye health and other diseases, the CDC works to integrate and connect vision health initiatives to other state, local, and community health programs.

**Investing in the Vision of Our Nation's Most Valuable Resource – Children**

While the risk of eye disease increases after the age of 40, eye and vision problems in children are of equal concern. If left untreated, they can lead to permanent and irreversible visual loss and/or cause problems socially, academically, and developmentally. Although more than 12.1 million school-age children have some form of a vision problem, only one-third of all children receive eye care services before the age of six.<sup>2</sup>

In 2009, the MCHB established the National Center for Children's Vision and Eye Health (the Center), a national vision health collaborative effort aimed at developing the public health infrastructure necessary to promote eye health and ensure access to a continuum of eye care for young children.

The Center has established a National Advisory Committee to provide recommendations toward 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 a mechanism 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 America also requests at least \$640 million in FY 2014 to sustain programs under the MCH Block Grant. The MCH Block Grant enables states to expand critical

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<sup>2</sup> "Our Vision for Children's Vision: A National Call to Action for the Advancement of Children's Vision and Eye Health, Prevent Blindness America," Prevent Blindness America, 2008.

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 vital programs, preventive and systems building services needed to promote optimal health.

**Advance and Expand Vision Research Opportunities**

Prevent Blindness America calls upon the Subcommittee to provide \$730 million for the NEI to bolster its efforts to identify the underlying causes of eye disease and vision loss, improve early detection and diagnosis of eye disease and vision loss, and advance prevention and treatment efforts. Research is critical to ensure that new treatments and interventions are developed to help reduce and eliminate vision problems and potentially blinding eye diseases facing consumers across the country. 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 America, our Board of Directors, and the millions of people at risk for vision loss and eye disease, we thank you for the opportunity to submit written testimony regarding FY 2014 funding for the CDC's vision and eye health efforts, the MCHB's National Center for Children's Vision and Eye Health, and the NEI. Please know that Prevent Blindness America stands ready to work with the Subcommittee and other Members of Congress to advance policies that will prevent blindness and preserve sight. Please feel free to contact us at any time; we are happy to be a resource to Subcommittee members and your staff. We very much appreciate the Subcommittee's attention to – and consideration of – our requests.



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Fiscal Year 2014  
 U.S. House of Representatives, Committee on Appropriations  
 Subcommittee on Labor, Health and Human Services, and Education  
 Department of Health and Human Services

**Centers for Disease Control & Prevention**

*Increase overall CDC funding – \$7.8 billion*

- Healthy Communities Program – \$52.8 million
- Office on Smoking and Health – \$203.117 million
- Asthma programs – \$25.3 million
- Environment and Health Tracking Network – \$35 million
- Tuberculosis programs – \$243 million
- Influenza Planning and Response – \$159.6 million
- NIOSH – \$292.588 million (discretionary)
- Prevention and Public Health Fund – Please Protect the Fund

**National Institutes of Health**

*Increase overall NIH funding – \$32 billion*

- National Heart, Lung and Blood Institute – \$3.214 billion
- National Cancer Institute – \$5.296 billion
- National Institute of Allergy and Infectious Diseases – \$4.689 billion
- National Institute of Environmental Health Sciences – \$717.9 million
- National Institute of Nursing Research – \$151.178 million
- National Institute on Minority Health & Health Disparities – \$288.678 million
- Fogarty International Center – \$72.7 million

The American Lung Association is pleased to present our recommendations for Fiscal Year 2014 (FY14) to the Labor, Health and Human Services, and Education Appropriations Subcommittee.

The public health and research programs funded by this committee will prevent lung disease and improve and extend the lives of millions of Americans. Founded in 1904 to fight tuberculosis, the American Lung Association is the oldest voluntary health organization in the United States.

The American Lung Association is the leading organization working to save lives by improving lung health and preventing lung disease through education, advocacy and research.

**A Sustained Investment is Necessary**

Mr. Chairman, investments in prevention and wellness pay near- and long-term dividends for the health of the American people. **A recent study on the California tobacco control program published in *PLoS One* showed this amazing result: for every dollar the state spent on the program, it saved \$55 in healthcare costs.** In order to save healthcare costs in the long-term, investments must be made in proven public health interventions including tobacco control, asthma programs and TB infrastructure, particularly in light of recent sequestration cuts.

**Lung Disease**

Each year, close to 400,000 Americans die of lung disease. It is America's number three killer, responsible for one in every six deaths. More than 33 million Americans suffer from a chronic lung disease and it costs the economy an estimated \$106 billion each year. Lung diseases include: lung cancer, asthma, chronic obstructive pulmonary disease (COPD), tuberculosis, pneumonia, influenza, sleep disordered breathing, pediatric lung disorders, occupational lung disease and sarcoidosis.

**Improving Public Health and Maintaining Our Investment in Medical Research**

**The American Lung Association strongly supports increasing overall CDC funding to \$7.8 billion** in order for CDC to carry out its prevention mission and to assure an adequate translation of new research into effective state and local public health programs. The U.S. must also **maintain its commitment to medical research.** While our focus is on lung disease research, we support increasing the investment in research across the entire NIH.

**The Prevention and Public Health Fund**

The American Lung Association strongly supports the Prevention and Public Health Fund established in the Affordable Care Act and asks the Committee to **oppose any attempts to**

**divert or use the Fund for any purposes other than what it was originally intended.** The Prevention Fund provides funding to critical public health initiatives, like community programs that help people quit smoking, support groups for lung cancer patients, and classes that teach people how to avoid asthma attacks. The Prevention Fund paid for the very successful CDC media campaign, “Tips from Former Smokers.” Phase one of this campaign dramatically increased calls to quitlines and visits to [www.smokefree.gov](http://www.smokefree.gov), and phase 2 will launch in March.

### **Tobacco Use**

Tobacco use is the leading preventable cause of death in the United States, killing more than 443,000 people every year. Over 43 million adults and 1.9 million youth in the U.S. smoke. Annual health care and lost productivity costs total \$193 billion in the U.S. each year. Given the magnitude of the tobacco-caused disease burden and how much of it can be prevented, the CDC Office on Smoking and Health (OSH) should be much larger and better funded. Historically, Congress has failed to invest in tobacco control – even though public health interventions have been scientifically proven to reduce tobacco use. This neglect cannot continue if the nation wants to prevent disease, promote wellness and reduce healthcare costs. **The American Lung Association requests \$203.117 million be appropriated to OSH for FY14.**

### **Lung Cancer**

Over 370,000 Americans are living with lung cancer. During 2012, more than 226,000 new cases of lung cancer were diagnosed – roughly 14 percent of all cancer diagnoses. It is the leading cause of cancer deaths, with a five year survival rate of only 16.3 percent. In 2009, there were 87,694 lung cancer deaths in men and 70,387 in women. Although the number of deaths among men has plateaued, the number is still rising among women. African Americans are more likely to develop and die from lung cancer than persons of any other racial group. Lung cancer

receives far too little attention and focus. Given the magnitude of lung cancer and the enormity of the death toll, the American Lung Association strongly recommends that the NIH and other federal research programs commit additional resources to lung cancer. The National Lung Screening Trial showed promising results for a small segment of the population at high risk for developing lung cancer but more research must be done in order to see if others would similarly benefit. **We support a funding level of \$5.296 billion for the NCI and strongly urge more attention and focus on lung cancer.**

#### **Chronic Obstructive Pulmonary Disease (COPD)**

COPD is the third leading cause of death in the U.S. It has been estimated that 13.1 million patients have been diagnosed with some form of COPD and as many as 24 million adults may suffer from its consequences. In 2009, 133,965 people in the U.S. died of COPD. The annual cost to the nation for COPD in 2010 was projected to be \$49.9 billion. **We strongly support funding the NHLBI and its lifesaving lung disease research program at \$3.214 billion.** The American Lung Association also asks the Committee to continue its support of the NHLBI working with the CDC and other appropriate agencies to prepare a national action plan to address COPD, which should include public awareness and surveillance activities.

#### **Asthma**

Asthma is highly prevalent and expensive. More than 25 million Americans currently have asthma, of whom 7 million are children. Asthma prevalence rates are over 37 percent higher among African Americans than whites. Asthma is also the third leading cause of hospitalization among children under the age of 15 and is a leading cause of school absences from chronic disease. Asthma costs our healthcare system over \$50.1 billion annually and indirect costs from lost productivity add another \$5.9 billion, for a total of \$56 billion dollars annually. **The Lung**

**Association thanks this Committee for its support of the CDC's National Asthma Control Program and ask for an appropriation of \$25.3 million in FY14. In addition, we recommend that the NHLBI receive \$3.214 billion and the NIAID receive \$4.689 billion, and that both agencies continue their research investments in cures and treatments for asthma.**

### **Influenza**

Public health experts warn that 209,000 Americans could die and 865,000 would be hospitalized if a moderate flu epidemic hits the U.S., which may be made worse because of sequestration. To prepare for a potential pandemic, **the American Lung Association supports funding CDC's influenza planning and response efforts at \$159.6 million.**

### **Tuberculosis (TB)**

There are an estimated 10-15 million Americans who carry latent TB infection, and it is estimated that 10 percent of these individuals will develop active TB disease. In 2011, there were 10,528 cases of active TB reported in the U.S. While declining overall TB rates are good news, the emergence and spread of multi-drug resistant TB and totally-drug resistant TB also poses a significant public health threat. **We request that Congress increase funding for tuberculosis programs at CDC to \$243 million for FY14.**

### **Additional Priorities**

We strongly encourage improved disease surveillance and health tracking to better understand diseases like asthma. **We support an appropriations level of \$35 million for the Environment and Health Outcome Tracking Network. We also strongly recommend at least \$52.8 million in funding for CDC's Healthy Communities Program.** This program supports investments in communities to identify and improve policies and environmental factors influencing health and reduce the burden of chronic diseases.



AMERICAN  
SOCIETY FOR  
MICROBIOLOGY

*Public and Scientific Affairs Board*

*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 2014 Appropriation for the Centers for Disease Control and  
Prevention*

March 15, 2013

The American Society for Microbiology (ASM) is pleased to submit the following statement on the Fiscal Year (FY) 2014 appropriation for the Centers for Disease Control and Prevention (CDC). The ASM is the largest single life science organization in the world with approximately 37,000 members.

The CDC is the lead federal agency to prevent disease, injury, and disability and it must be adequately resourced for known and new public health threats. CDC partners with state and local health departments and global organizations and CDC medical personnel, scientists and other public health professionals respond to public health events 24/7 wherever needed. CDC experts react quickly to events here and abroad, ranging from foodborne illness outbreaks or previously unknown infectious pathogens, to the health crises following earthquakes or typhoons.

The ASM is very concerned that budgetary cuts are seriously eroding CDC's capabilities in key areas like surveillance, laboratory diagnosis, and control and prevention strategies. The budget constraints now in effect will prove deleterious to our Nation's public health system. Sequestration mandated cuts will certainly weaken or even eliminate important CDC activities. CDC officials have already announced probable decreases in grant award amounts and in numbers of new awards. Sequestration is expected to cut CDC support to states by more than \$200 million, which will unquestionably affect responses to disease outbreaks and other urgent public health problems.

Recent outbreak investigations point to the CDC's unique and multifaceted capabilities that are at risk under budget shortages. Last year, CDC personnel tracked the fungal meningitis linked to contaminated steroid injections, with over 700 cases and almost 50 deaths across 20 states. CDC's epidemiologists and laboratories investigated hantavirus infection among visitors to Yosemite National Park, bacterial infections in pediatric oncology patients in Colorado, the unprecedented outbreak of West Nile encephalitis in the Dallas/Fort Worth area. CDC also supported international efforts against infectious diseases, investigating cholera in Sierra Leone, anthrax in the Republic of Georgia, Marburg hemorrhagic fever in Uganda, and other outbreaks elsewhere. CDC funding is

critical to building and maintaining the expertise necessary to sustain CDC's rapid responses to public health threats in the US and worldwide.

As the Nation's public health agency, CDC continually faces challenges like microbial agents of infectious disease and other illnesses. One in six Americans gets sick each year from eating contaminated food; more than 1,000 foodborne outbreaks are reported to CDC officials annually. The CDC estimates that, each year in the United States, there are nearly 20 million new sexually transmitted diseases (STD) infections incurring lifetime medical costs of \$15.6 billion. Despite progress in treating HIV infection, significant challenges remain (e.g., in 2010, an estimated 12,200 new infections in people in the US aged 13-24; in 2011, 2.5 million people newly infected worldwide). Nearly 900,000 children in other countries still die each year from vaccine preventable diseases like rotavirus, hepatitis B, pneumococcal pneumonia, and meningitis. The U.S. has also witnessed a recent upsurge in vaccine-preventable diseases, with over 42,000 cases of pertussis (whooping cough) reported in 2012 alone and declared epidemics in several states. Globalization has meant fewer barriers to the spread of infectious diseases, making CDC's multi-talented programs even more essential. Human migration contributes considerably to the spread of disease: Each year, about 214 million people move across national borders, three quarter billion within their own countries, and nearly 3 billion travel by plane.

#### **CDC Funding Provides Rapid Response, Surveillance**

CDC has more than 15,000 employees and has personnel deployed to over 50 countries, trained to protect through health promotion, prevention of disease and disability, and preparedness. Such widespread, diverse expertise gives CDC its agility to detect and define an expansive array of threats and to respond quickly. The 2012-2017 strategic plan of CDC's National Center for Emerging and Zoonotic Infectious Diseases (NCEZID) underscores the complexities involved—one overall strategy, intended to “strengthen public health fundamentals,” directs CDC personnel to “advance and increase effectiveness of infectious disease laboratory science, surveillance, epidemiology, information technology, communications, and strategic partnerships.” The CDC budget directly support extensive surveillance, science based epidemiology, and other tools effective in combating disease.

CDC investigations vary from behind the scenes lab support for localized incidents to frontline responses in highly visible outbreaks. An example is CDC's current collaboration with the World Health Organization (WHO) to better understand a previously unknown respiratory virus, related to the SARS virus that emerged in China in 2002 and rapidly infected 8,000 worldwide. The new coronavirus, thus far called NCoV for novel coronavirus, causes severe lower respiratory disease. As of March 7, there were only 14 confirmed cases reported to WHO, with eight deaths, all among patients with ties to the Middle East, and thus far no cases have been identified in the United States. But CDC and other health organizations that have already faced fast moving outbreaks like SARS are concerned by similar evidence of human-to-human transmission and spread of the virus to other countries, especially given the conflicts and volatility currently engulfing the Middle East. CDC laboratories also are conducting tests on

patient specimens to isolate the new virus, as public health officials prepare to engage yet another communicable disease.

CDC regularly applies its scientific expertise and laboratory capabilities to investigate outbreaks both large and limited in scope, including these recent examples:

- CDC investigated more than 300 cases of swine-origin variant influenza virus that occurred last summer and fall across 9 midwestern and mid-Atlantic states. Most cases were in children who attended or exhibited swine at agricultural fairs, and a number of hospitalizations and one death occurred. This virus has acquired genetic material from the 2009 pandemic H1N1 virus, raising concerns about its pandemic potential. CDC and states have been working with 4-H clubs, USDA, and state agriculture agencies to address this emerging public health concern and reduce the risk for the upcoming fair season.
- CDC is collaborating with the US Department of Agriculture's Animal and Plant Health Inspection Service and state health departments to follow an outbreak of human *Salmonella typhimurium* infections linked to contact with pet hedgehogs. The outbreak strain had been rare, with only one to two cases reported via PulseNet (the national network for foodborne disease surveillance) annually since 2002. Since 2011, an increasing number of cases have been detected, with 14 in 2011, 18 in 2012, and two thus far in 2013.
- In August, CDC investigators and the FDA linked a multi-state outbreak of salmonellosis to contaminated cantaloupes from an individual farm, using pulsed field gel electrophoresis analysis of patient samples. There are over 2,700 serotypes of foodborne *Salmonella* bacteria, and advanced diagnostic tests used by CDC are essential in accurately pinpointing sources.
- In January, CDC summarized its foodborne surveillance for 2009-2010: 1,527 foodborne disease outbreaks reported, involving 29,444 cases of illness. Among the 790 events with a single confirmed pathogen, 42 percent were caused by norovirus, 30 percent by *Salmonella*.

CDC must also address the alarming rise of drug resistant pathogens, including Carbapenem Resistant Enterobacteriaceae (CRE). Multiple CDC networks, with input from state health departments, have detected increased cases over the past decade, warning of a potential “nightmare” scenario. CDC officials just released strongly worded reports on the pathogen’s “triple threat”: (1) resistant to all, or nearly all, available antibiotics; (2) causes a high mortality rate (40-50 percent); and (3) can transfer antibiotic resistance to certain other bacteria, even those normally benign. This is yet another example of the continuing threat of health care associated infections (HAIs).

Surveillance networks hosted by CDC collect data on a long list of diseases, using powerful computing and two way communication with thousands of public health partners. These help guide CDC strategy, providing another weapon against both emerging threats, like chikungunya virus or multidrug resistant tuberculosis, and longtime problems like foodborne illnesses. Last year, for instance, CDC surveillance identified a resurgence of WNV infections: By mid-December, there had been nearly

5,390 US cases reported from 48 states, the highest number since 2003. Since 1999, when WNV was first identified in the United States, CDC has tabulated more than 30,000 cases. With transfusion associated cases first reported in 2002, CDC and its partners implemented WNV screening of the US blood supply in 2003, preventing an estimated 3,000 to 9,000 transfusion related infections.

### **CDC Funding Protects, Promotes Public Health**

Using surveillance data, public education, and tools like vaccines, CDC strives to *prevent* illness and injury, being proactive well beyond reacting to disease outbreaks. To illustrate, although CRE is still limited in the United States, it is typically acquired within healthcare settings. This has prompted CDC to develop a CRE action plan, part of its ongoing education campaigns to both minimize drug resistance among pathogens and prevent costly healthcare associated infections (HAIs). In its latest progress report (February 2013), CDC listed successes against some types of HAIs using stringent infection control measures; for example, a 41 percent reduction in central line associated bloodstream infections since 2008. These CDC efforts embody the obvious: that prevention quite literally is more cost effective than finding a cure.

There are few public health measures as historically effective as immunization against communicable diseases. Both in the United States and elsewhere, CDC has been a major contributor, of personnel, vaccines, expert support systems, to national and global immunization campaigns like those against smallpox and polio. As of 2010, 85 percent of children aged 12-23 months were immunized against measles worldwide. Over the previous decade, measles deaths had been cut by 74 percent. In this country, CDC vigorously promotes vaccination against childhood infectious diseases, influenza, hepatitis, and more. It also evaluates new candidate vaccines through collaborations with medical schools and other federal agencies. Yet last year's outbreak of whooping cough, a vaccine preventable disease, is a reminder that US vaccination coverage is incomplete and that CDC education efforts must continue.

The ASM strongly urges that Congress increase the CDC budget in FY 2013 and FY 2014 and fund the CDC at the highest possible level.



American  
Alliance of  
Museums

**Testimony of  
Dr. Ford W. Bell, President  
American Alliance of Museums  
[www.aam-us.org](http://www.aam-us.org)  
House Committee on Appropriations Subcommittee on  
Labor, Health and Human Services, Education, and Related Agencies  
March 15, 2013**

Chairman Kingston, Ranking Member DeLauro, and members of the Subcommittee, thank you for allowing me to submit this testimony. My name is Ford Bell and I serve as President of the American Alliance of Museums. I request that the Subcommittee make a renewed investment in museums in FY14. We urge your support for \$38.6 million for the Office of Museum Services (OMS) at the Institute of Museum and Library Services (IMLS), its fully-authorized amount.

The Alliance is proud to represent the full range of our nation's museums – including aquariums, art museums, botanic gardens, children's museums, culturally specific museums, historic sites, history museums, maritime museums, military museums, natural history museums, planetariums, presidential libraries, science and technology centers, and zoos, among others – along with the professional staff and volunteers who work for and with museums. We are honored to work on behalf of the 17,500 museums nationwide that employ 400,000 people, and annually spend over \$2 billion on K-12 educational programming, receive more than 90 million visits from primary and secondary school students, and directly spend \$21 billion in their local economies.

IMLS is the primary federal agency that supports our 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. The 2012-2016 IMLS Strategic Plan lists clear priorities: placing the learner at the center of the museum experience, promoting museums as strong community anchors, supporting museums' stewardship of their collections, advising the President and Congress on how to sustain and increase public access to information and ideas, and serving as a model independent federal agency maximizing value for the American public. IMLS is indeed a model federal agency.

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 FY12 appropriation of \$30,859,000 – equal to President Obama's FY13 budget request – represents a nearly 15% decrease from the FY10 appropriation of \$35,212,000. The further 5% decrease resulting from sequestration will only make it even more difficult for OMS to help museums connect people to information and ideas. We urge the subcommittee to provide the full \$38.6 million for the IMLS Office of Museum Services.

Museums are essential in our communities for many reasons:



- Museums are 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, youth training, and job preparedness. They reach beyond the scope of instructional programming for schoolchildren by also providing critical teacher training. There is a growing consensus that whatever the new educational era looks like, it will focus on the development of a core set of skills: critical thinking, the ability to synthesize information, the ability to innovate, creativity, and collaboration. Museums are uniquely situated to help learners develop these core skills.
- Museums create jobs and support local economies. Museums serve as economic engines, bolster local infrastructure, and spur tourism. Both the U.S. Conference of Mayors and the National Governors Association have noted that cultural assets such as museums are essential to attracting businesses, a skilled workforce, and local and international tourism.
- Museums address community challenges. Many museums offer programs tailored to seniors, veterans, children with special needs, persons with disabilities, and more, greatly expanding their reach and impact. For example, some have programs designed specifically for children on the autism spectrum, some are teaching English as a Second Language, and some are working directly with Alzheimer's patients. Many museums facilitate job training programs, provide vegetable gardens for low-income communities, or serve as locations for supervised visits through the family court system. In 2012, more than 1,800 museums participated in the



Blue Star Museums initiative, offering free admission to all active duty and reserve personnel and their families from Memorial Day through Labor Day.

- Digitization and traveling exhibitions bring museum collections to underserved populations. Teachers, students, and researchers benefit when cultural institutions are able to increase access to trustworthy information through online collections and traveling exhibits. Most museums, however, need more help in digitizing collections.

Grants to museums are highly competitive and decided through a rigorous, peer-reviewed process. Even the most ardent deficit hawks view the IMLS grant-making process as a model for the nation. It would take approximately \$129 million to fund all the grant applications that IMLS received from museums in 2012 but, given the significant budget cuts, many highly-rated grant applications go unfunded each year:

- Only 31% of Museums for America/Conservation Project Support projects were funded;
- Only 19% of National Leadership/21<sup>st</sup> Century Museum Professionals/Sparks Ignition Grants for Museums/Connecting to Collections Implementation projects were funded;
- Only 61% of Native American/Hawaiian Museum Services projects were funded; and
- Only 33% of African American History and Culture projects were funded.

It should be noted that each time a museum grant is awarded, additional local and private funds are also leveraged. In addition to the required dollar-for-dollar match required of museums, grants often spur additional giving by private foundations and individual donors. A recent IMLS study found that



67% of museums that received Museums for America grants reported that their IMLS grant had positioned the museum to receive additional private funding.

Here are just two examples of how Office of Museum Services funding is used:

- The Telfair Museum in Savannah, Georgia was awarded a \$112,963 Museums for America grant in 2010 to begin a full-scale reinterpretation project on the subject of urban slavery in the city's past. The complete picture of this largely unstudied form of slavery in Savannah—a microcosm of the nation during this time—is told utilizing the Telfair's own historic assets and stories. In a good example of community leveraging, this project received support from the City of Savannah, Live Oak Libraries, Second African Baptist Church, and the National Trust for Historic Preservation.
- The Yale Peabody Museum of Natural History in New Haven, Connecticut was awarded a \$148,050 Museums for America grant in 2012 to support the Peabody Teachers Collaborative on Global Change (CGC), a professional development program for teachers in ecology and environmental science. The science literacy program serves several local school districts, particularly Title I school districts of New Haven and Hartford, and other districts in Connecticut. The project targets 48 schools and approximately 1,500 students, together with their families and communities. By making excellent use of the Museum's exhibits, particularly the world-renowned diorama halls, the program's impact is heightened for both teachers and students.

In closing, I would like to thank you once again for the opportunity to submit this testimony today.



AMERICAN  
SOCIETY FOR  
MICROBIOLOGY

*Public and Scientific Affairs Board*

*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 2014 Appropriation for the National Institutes of Health*

March 15, 2013

The American Society for Microbiology (ASM) is pleased to submit the following statement on the Fiscal Year (FY) 2014 appropriation for the National Institutes of Health (NIH). The ASM is the largest single life science organization in the world with more than 37,000 members.

The NIH supports research programs essential to public health and to stimulating valuable economic sectors in health care and biomedical sciences, and creating our future scientific workforce. The current fiscal impasse is alarming to the biomedical research community. NIH appropriations already had fallen short in recent years, with the Agency losing one-fifth of its purchasing power over the past decade. The budget sequestration now in effect would further cut NIH funding by over 5 percent in the current fiscal year, which actually would equal nearly 9 percent over the remaining FY 2013 period.

The ASM is very concerned by the probable fallout from this additional approximately \$1.6 billion decrease in NIH's FY 2013 funding, particularly when biomedical research should receive more, not less, federal support. NIH recently informed the scientific community that all grant awards currently being funded likely would receive less than their full FY 2013 commitment levels. Under sequestration, the Agency also will distribute fewer new awards. The most recent success rate of grant applications was already at a low 18 percent compared with 30 percent in 2003. In February, analysis by United for Medical Research (UMR) projected that sequestration of NIH funding could force the loss of 20,500 US jobs and \$3 billion in economic output. Sequestration decreases foreshadow the already grim scenario of an estimated \$900 billion in NIH spending cuts over the next ten years mandated under the Budget Control Act.

NIH funding jeopardizes the Nation's competitive edge in biomedicine and thus our economic success in the innovation dependent global marketplace. Budget cuts also will have a chilling effect on whether young Americans choose research careers, if those careers appear to lack professional and financial stability. It is generally agreed that the United States must attract and inspire, not discourage, the next generation of scientists. We urge Congress to also recognize that inadequate NIH funding would fail a national public health system faced with rising healthcare costs, as well as an aging and

increasingly diverse population. In 2011, national health spending reached an estimated \$2.7 trillion (17.9 percent of the GDP), a startling argument for those effective disease treatment and prevention approaches discovered through NIH funding.

The ASM strongly urges Congress to add additional funding for the NIH in FY 2013 and FY 2014 and fund the NIH at the highest possible level of funding.

### **NIH Funding of Biomedical Research is Essential to the Fight against Infectious Diseases**

Biomedical advances extend life expectancy and steadily improve our quality of life. Examples include HIV/AIDS studies transforming a fatal disease into a chronic condition through treatment, and the vaccine development responsible for dramatic global declines in diphtheria, polio, yellow fever, tetanus, and smallpox. Each year, three NIAID supported vaccines are now saving numerous children worldwide: pneumococcal vaccine, 826,000; Haemophilus influenzae type b vaccine, 386,000; and rotavirus vaccine, 435,000.

Despite lower mortality from communicable causes, infectious diseases persist as significant threats to public health. Detecting, preventing, and treating infectious diseases is a critical part of NIH's portfolio. In allocating resources, it is important to remember that NIH is the nation's primary federal supporter of basic, clinical, and translational research in medicine, generating diagnostics, therapeutics, prevention strategies, and surveillance tools that help lift the burden of infectious disease.

Health agencies in the United States periodically confront infectious diseases variously classified as newly emerging, reemerging/resurging, or deliberately emerging (bioterrorism), as well as pathogens increasingly resistant to drug therapy. In recent years, these so called emerging infectious diseases (EID) have included those caused by hantavirus, HIV, and highly virulent strains of *E. coli* and influenza viruses; rising numbers of dengue, listeriosis, and West Nile; and drug resistant forms of *Staphylococcus aureus*. In 2012 alone, emerging examples included a novel disease causing coronavirus initially reported in the Middle East and a variant influenza virus (H3N2v) that spread from swine to people in US farm communities. The media report this month (March) of a man infected with a deadly form of the tuberculosis pathogen, one considered to be "extensively drug-resistant" (XDR TB), is just the most recent reminder that we cannot afford to fall behind in our understanding of, and science based responses to, microbial pathogens and their host interactions. US health officials found his TB strain to be resistant to at least eight of the available standard drugs. Before being stopped at the US-Mexico border and placed in medical isolation, he had traveled through 13 countries over three months. XDR poses a major threat due to its frightening drug resistance.

Scientists funded by the NIAID consistently achieve advances against HIV/AIDS, malaria, tuberculosis, influenza, and other diseases significant to our health and economy. To illustrate their importance, NIAID supported these examples from the past year:

- Genetic changes in the salivary glands of mosquitoes infected with dengue virus might increase virus transmission, elucidating viral biology that must be understood to

develop countermeasures. There currently is no vaccine or drug treatment for dengue, which globally infects about 50 million to 100 million each year and has been reported in parts of the United States.

- Discovery of a toxin transport system in *S. aureus* suggests a new approach to drugs against a pathogen notorious for its ability to resist traditional antibiotics. Methicillin resistant staph (MRSA) is a leading cause of US hospital acquired infections, causing an estimated 18,000 deaths in 2005. In other research, genome sequencing of multiple strains of vancomycin resistant *S. aureus* gives scientific insight into pathogens resistant to an antibiotic of last resort.
- Universal flu vaccines against a wide range of virus strains are moving closer to reality with results from studies like those of human immune cells producing broadly neutralizing antibodies against flu viruses and those showing that a prime boost vaccine regimen can elicit “universal” antibody production. Several clinical trials of first generation universal vaccines are either under way or planned at NIAID’s Vaccine Research Center.
- Clinical trials demonstrated the most effective antiretroviral drug regimens to prevent HIV infection (pre-exposure prophylaxis, or PrEP); other research helped shape antiretroviral treatment for HIV infected individuals. Last August, NIAID awarded \$7.8 million in first year funding to universities and medical centers for basic research to identify new approaches in HIV vaccine design, part of a much larger HIV vaccine discovery effort.

The NIGMS has funded basic research on the structure and function of HIV, in search of new treatments, for more than 25 years. It is a partner with the National Science Foundation, the US Department of Agriculture and others in the Ecology and Evolution of Infectious Diseases (EEID) program, contributing expertise in basic research. Last year, NIGMS supported scientists developed a new improved CH-activation technique to add molecules to existing compounds, making it easier to tailor make new drugs; others reported on how iron uptake plays a role in bacterial invasion of host tissues.

We invest in NIH each year to expand our vital scientific knowledge, but also to create real world products that protect our communities. In February, for example, researchers launched early-stage clinical trials of two candidate vaccines against *Shigella* infection, which each year causes about 90 million cases of severe diarrheal illness and 108,000 deaths worldwide. Others are working toward broad spectrum antivirals effective against groups of pathogens, like that being developed against all enveloped viruses, including the Nipah, Ebola, HIV, influenza, and Rift Valley fever viruses. NIH also is supporting development of new technologies like nanoscience techniques to detect pathogens hidden deep in human tissue and genome sequencing to better track infectious disease outbreaks.

### **NIH Funding Stimulates Economic Sector, Workforce Expansion**

Biomedicine is big business—the US medical innovation sector employs 1 million US citizens, generates \$84 billion in wages and salaries, and exports \$90 billion in goods and services. Yet US industry performs only 17 percent of basic research, leaving most of the biomedical “foundation building” to federal responsibility. NIH is the largest funder of biomedical research in the world, including the research of 138 Nobel Prize winners. It contributes more than 80 percent of federal biomedical research funding in the United States. The NIH extramural program supports about 50,000 competitive research grants and 300,000 scientists and research personnel at more than 2,500 medical schools, universities, and other institutions throughout the country. Annual appropriations also support nearly 6,000 scientists working at the 27 NIH institutes and centers. The UMR analysis released in February reinforced the agency’s importance as an economic motive force. In 2012 alone, the NIH financed more than 402,000 jobs and \$57.8 billion in economic output nationwide.

Investment in NIH clearly reaps rewards well beyond improved public health. Since 2000, for example, NIGMS supported research has received 18 Nobel Prizes either in Chemistry or in Physiology or Medicine. In December, NIH proposed multiple initiatives to help strengthen both the US biomedical research enterprise and the Nation’s global competitiveness, designed “to support a research ecosystem that leverages the flood of biomedical data, strengthens the research workforce through diversity, and attracts the next generation of researchers.” To be successful, initiative strategies like enhanced training of graduate students and better management of “big data” through high performance computing will require sufficient funding increases.

NIH support for university research has long been a major factor in scientific and technological innovation in medicine. Unfortunately, the current fiscal scenario will force reductions in existing grants and likely fewer new awards going forward. Scientists at US universities are already reporting sequestration related setbacks to their planned research, casting doubt on both potential breakthroughs and student training programs. Stakeholders in biomedical research are concerned that among the research jobs at risk, younger scientists will be particularly affected. Undermining a future workforce generation is shortsighted, and the ASM fears subsequent negative impacts on new R&D discoveries, public health, and US global competitiveness.

The ASM urgently requests the Congress increase funding for the NIH and biomedical research.

**Testimony of the American College of Preventive Medicine  
Concerning Fiscal Year 2014 Appropriations**

*Submitted for the Record to the House Appropriations Subcommittee on  
Labor, Health and Human Services, Education, and Related Agencies – March 15, 2013*

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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 an increase of **\$5 million in FY 2014 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 that \$520 million be appropriated in FY 2014 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 in public health agencies and in other healthcare settings where improving the health of populations, enhancing access to quality care, and reducing the costs of medical care are paramount. As the body of evidence supporting the effectiveness of clinical and population-based interventions continues to expand, so does the need for specialists trained in preventive medicine.

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 medicine and public health*. Preventive medicine physicians possess critical knowledge in population and community health issues; disease and injury prevention; disease surveillance and outbreak investigation; and public health research. They are well versed in leading collaborative efforts to improve health that include stakeholder groups from all aspects of an issue—including community, industry, healthcare provider, academic, payer, and government organizations—in addressing both healthcare-related and social and behavioral determinants of health. Such diversity also illustrates the value preventive medicine physicians offer to many different sectors, industries, and organizations.

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 2013) currently supports only 49 preventive medicine residents across 9 residency training programs. An increase of \$5 million will allow HRSA to support nearly 60 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-fifth** of preventive medicine residents funded through HRSA programs are underrepresented 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 an increase of **\$5 million in FY 2014 for preventive medicine residency training under the public health and preventive medicine line item in Title VII of the Public Health Service Act.**

## Outside Witness Testimony

From the American Psychological Association

Regarding Fiscal Year 2014 Appropriations for

The Departments of Labor, Health and Human Services and Education

March 14, 2013

The American Psychological Association (APA) is the largest scientific and professional organization representing psychology in the US : membership includes more than 137,000 researchers, educators, clinicians, consultants and students. Through its divisions in 54 subfields of psychology and affiliations with 60 state, territorial and Canadian provincial associations, APA works to advance the creation, communication and application of psychological knowledge to benefit society and improve people's lives.

APA is very concerned that deficit reduction efforts to date—both actual and those under consideration—have relied almost exclusively on cuts to public health, health research, and other discretionary programs to balance the budget. Public health and health research programs have experienced three consecutive years of cuts. Under sequestration, these cuts will be even deeper. We urge this Committee to consider the critical role of the Public Health Service agencies in our nation's security, infrastructure and economic growth when making funding decisions.

As a member of the Centers for Disease Control and Prevention (CDC) Coalition, APA supports at least \$7.8 billion for CDC core programs in FY 2014. CDC programs play a key role in protecting Americans from public health threats and emergencies, and in reducing healthcare costs and strengthening the nation's health system. Funding for CDC in recent years has relied heavily on the Prevention and Public Health Fund and other fund transfers, and the agency has seen deep cuts to its budget authority. The Prevention and Public Health Fund was intended to supplement and not supplant

the base funding of our public health agencies and programs. APA urges the Committee to restore CDC's budget authority.

As a member of the Friends of the National Center for Health Statistics (NCHS), APA recommends \$162 million for the center in FY 2014, consistent with the President's request for FY 2012 and FY 2013. The data collected by NCHS 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, are essential to the nation's statistical and public health infrastructure. The Committee's leadership in securing stable funding has helped NCHS rebuild after years of underinvestment and stabilize the collection of essential health data.

APA applauds the NCHS's progress including questions related to sexual orientation in the National Health Interview Survey (NHIS), and urges that other federal surveys to follow suit. Still, there is slower progress toward inclusion of gender identity questions. APA urges the Committee to ensure that milestones established in the July, 2011 national data progression plan are met.

APA is pleased that the Committee has continued to designate specific funding for CDC's Prevention Research Centers (PRC) program, and urges the Committee to restore funding for the program to at least \$28 million in FY 2014, consistent with FY 2011 funding levels. The PRC network of community, academic, and public health partners makes significant research contributions that are essential to the focus on prevention that is critically needed to improve health in America.

Finally, APA asks the Committee to encourage the National Center on Injury Prevention and Control to increase research on the psychological impact of intimate partner and sexual violence in order to increase and improve evidence based interventions to support the recovery of women from the trauma of violence.

APA supports at least \$32 billion for the National Institutes of Health in FY 2014. This 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. NIH drives scientific innovation and develops new and better diagnostics, improved prevention strategies, and more effective treatments. NIH supports critical behavioral research on aging, memory, learning, child development, behavior change and maintenance, and prevention and treatment of many chronic and acute conditions. Just a few highlights:

--NIMH-supported research has shown that biomedical approaches to HIV prevention are most effective when they are combined with behavioral approaches. Behavioral research is needed more than ever to bolster medication adherence and treatment uptake, to document real-world decision-making processes associated with biomedical interventions, and to better understand potential unintended and/or undesired consequences of biomedical interventions.

--NICHD-supported research is examining the critical impact of stress in altering a child's developmental trajectories. Investment in additional longitudinal research is needed to understand the long-term impact of stress on mental health outcomes, cognitive, emotional and social development, including self-control, inhibitory response, executive functioning, attention, memory and learning skills and how those variables impact later adolescent health behaviors, childhood obesity and academic achievement.

--APA commends NIH for addressing the need for a more diverse biomedical and behavioral research workforce and is encouraged that NIH is examining the factors contributing to this disparity in funding success, including the role of bias in the peer review process, the process by which funding decisions are made, and training/mentoring and support programs for under-represented investigators across the pipeline and at critical career decision points. APA encourages the Committee to continue to press NIH to improve common data collected and measured across the biomedical and behavioral workforce, including those programs that track underrepresented students and investigators. Such

efforts will provide the much needed information and direction regarding what programs and initiatives are most successful at enhancing the diversity of the scientific workforce.

Turning to the Center for Mental Health Services, APA is 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 maintain level funding for the Minority Fellowship Program. This funding is urgently needed given the recent expansion of the program by granting eligibility to additional disciplines to participate.

APA strongly supports the work of SAMHSA's National Child Traumatic Stress Network (NCTSN) program and recommends increased support for the Network and its 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, the impact of war on military families, and other sources of trauma.

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.

In an effort to efficiently and effectively address the mental health issues facing our nation, APA strongly urges the Committee to invest in programs already established and currently serving the nation's needs to increase access to mental and behavioral health services and to increase the number of psychologists trained to provide those documented and needed mental and behavioral health services to those who need it throughout the country. APA urges Congress to fund the Health Resources and Services Administration's Graduate Psychology Education program (GPE) at \$4.5 million. This level represents a restoration to previously funded level for FY2003-2005 and would allow for 35-40 grants nationwide with over 900 eligible universities and hospitals. According to the President's Budget for FY 2010-2011 in that year alone the GPE Program enabled the addition of 620 doctoral level trainees to be trained through an interdisciplinary approach to provide mental and behavioral health services to approximately 46,000 underserved children, older adults, chronically ill persons, and victims of abuse and trauma including veterans and their families.

In addition, APA urges support of the programs funded under the Garrett Lee Smith Memorial Act at least at current appropriated levels. The suicide prevention programs authorized under the GLSMA and administered by the Substance Abuse and Mental Health Services Administration – State/Tribal, Campus, and the Technical Assistance Center – provide critical services to our youth population. Mental disorders account for nearly one-half of the disease burden for young adults in the United States, according to the *Journal of Adolescent Health's* January 2010 article, *Mental Health Problems and Help-Seeking Behavior among College Students*. Further, suicide is the second-leading cause of death for adolescents and young adults between the ages of 10 and 24 and results in 4,850 lives lost each year, according to the Centers for Disease Control and Prevention. Any federal efforts to provide needed services to this population should be supported by investing in the GLSMA programs.

APA appreciates the Committee's efforts on behalf of these programs.



March 15, 2013

Tom Myers  
General Counsel  
323-860-5259

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

Outside Witness Testimony, Submitted by Tom Myers,  
General Counsel, AIDS Healthcare Foundation

Dear Mr. Chairman Kingston:

AIDS Healthcare Foundation (AHF) hereby submits the following testimony and funding request in the amount of **\$2,422,178,000** for the Ryan White CARE Act for FY2014:

Consistent with goal number 4 of the National HIV/AIDS Strategy for the United States – “Achieving a More Coordinated Response to the HIV Epidemic in the United States” – appropriations for the Ryan White CARE Act (the “CARE Act”) in FY2014 presents a unique opportunity to harmonize the CARE Act with the Strategy’s three main goals:

1. Reducing New HIV Infections;
2. Increasing Access to Care and Improving Health Outcomes for People Living With HIV; and
3. Reducing HIV-Related Health Disparities.

Funding of the CARE Act at the requested level will allow the CARE Act to be harmonized with the changes in health care delivery to be brought about by the Affordable Care Act (“ACA”) to provide a more comprehensive and more effective response to the HIV epidemic in the U.S.

**The Current State And Trends Of The HIV/AIDS Epidemic In The United States Should Guide How To Harmonize The CARE Act With Health Care Reform And The National HIV/AIDS Strategy.**

While the future is always uncertain, and it is unclear exactly what the consequences of the ACA will be, there are a number of facts that can help determine necessary funding for the CARE Act:

- **There will be a need for a robust CARE Act, in its current form, for the foreseeable future.** The implementation of Medicaid expansion and insurance exchanges will be neither a quick nor complete process. Full-scale change is not set to begin until 2014, and even now, many states, including those with some of the largest HIV/AIDS populations such as Texas and Georgia— are delaying or foregoing participating in Medicaid expansion or setting up exchanges. As a result, the safety net that is the CARE Act will need to remain largely intact until this process is complete, and will need to be available for those states the do not fully implement the ACA.
- **Most Americans with HIV are not linked to or retained in HIV care.** Many American still do not know their HIV status, are not linked to HIV care, and are not retained in HIV care. In fact, a minority of all Americans with HIV are on antiretroviral treatment. Supporting access to and maintenance of care will be critical to ending the epidemic.
- **Neither Medicaid nor insurance exchanges may provide all the services currently available under the CARE Act.** The CARE Act understands that effectively treating a complex, chronic disease like HIV requires a number of

approaches, disciplines, and services. Insurance plans and Medicaid, in both of which people living with HIV are a small minority of participants, may not be organized with the needs of people living with HIV in mind, and may not offer the full range of services provided by the CARE Act.

- **20% of Americans with HIV are unaware of their status.** This group is thought unwittingly to be the source of 70% of all new infections. The HIV epidemic in the United States will not end until this group is made aware of their status, and are brought into care.
- **Treatment is Prevention.** One of the consensus emerging from the recent International AIDS Conference is that HIV treatment, which can reduce the chances of infection by up to 96%, is the most effective and the most cost effective way to prevent new infections. Getting people living with HIV into care, and keeping them adherent to treatment, will be the key to ending this epidemic.
- **The HIV Epidemic in the U.S. continues to trend South, and in Communities of Color.** Recent publications have documented and highlighted the enormous disparities in HIV rates and new infections in the South, and among communities of color. Addressing these disparities, in many States that have expressed a reluctance to implement the ACA, will be paramount in fighting the epidemic.

Given the above facts, in order to ensure that adequate care, treatment and prevention services are available to fully combat the HIV/AIDS epidemic in the United States, funding the Care Act at the requested level is required. Thank you for your

attention and support in this matter. We look forward to working with you to ensure that the CARE Act continues to be part of an effective, comprehensive program to end HIV/AIDS in America.

Sincerely,

Tom Myers  
AIDS Healthcare Foundation



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**Written Comments on the FY2014 Budget submitted to before the House Committee on  
Appropriations, Subcommittee on Labor, Health and Human Services, Education and  
Related Agencies**

**The Honorable Jack Kingston (R-GA), Chair and The Honorable Rosa DeLauro (D-CT),**

**Ranking**

**Friday, March 15<sup>th</sup>, 2013**

**SUMMARY REQUEST**

**National Institutes of Health overall funding \$32B**

NIH: National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) \$525M

**Health Resources and Services Administration**

Pediatric Subspecialty Loan Repayment Program \$5M

**Centers for Disease Control**

CDC Arthritis Program \$15M

The Arthritis Foundation is committed to raising awareness and reducing the unacceptable impact of arthritis, which strikes one in every five adults and 300,000 children, and is the nation's leading cause of disability. The Arthritis Foundation would like to provide recommendations for the Labor Health and Human Services (Labor HHS) Budget for Fiscal Year (FY) 2014.

Specifically, we would like to comment on three specific agencies of jurisdiction of the Labor HHS Appropriations Subcommittee: the National Institutes of Health (NIH) and in particular the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), the Health Services Resources Administration (HRSA) and the Centers for Disease Control (CDC).

**ARTHRITIS RELATED RESEARCH INVESTMENTS AT THE NATIONAL INSTITUTES OF HEALTH (NIH): FUNDING FOR THE NATIONAL INSTITUTE OF ARTHRITIS AND MUSCULOSKELETAL AND SKIN DISEASES (NIAMS)**

Research holds the key to preventing, controlling, and curing arthritis, the nation's leading cause of disability. The prevalence, impact and disabling pain continues to increase. 50 million Americans—one in five adults—have arthritis now. Within 20 years, the Centers for Disease Control and Prevention (CDC) estimates that 67 million adults or 25% of the population will have arthritis. Arthritis limits the daily activities of 21 million Americans and accounts for \$128 billion annually in economic costs. The National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) supports research into the causes, treatment, and prevention of arthritis and musculoskeletal and skin diseases. The critical research done at NIAMS improves the quality of life for people with arthritis and decreases the overall burden of the disease. **NIH funding should be allocated \$32B for FY 2014 and NIAMS should be funded at \$559M to fund critical research on arthritis and other related diseases at the Institute. Our NIH recommendations reflect , the minimum needed to sustain the current level of research and account for inflation.**

**HRSA PEDIATRIC SUBSPECIALTY LOAN REPAYMENT PROGRAM**

Juvenile arthritis is one of the most common childhood diseases, affecting more children than cystic fibrosis and muscular dystrophy. Currently, there are less than 250 board-certified practicing pediatric rheumatologists in the United States and about 90 percent of those are clustered in and around large cities. Pediatric rheumatology has one of the smallest numbers of doctors of any pediatric subspecialty. Of those children with juvenile arthritis, only one-fourth see a pediatric rheumatologist due to their scarcity. The other 75% of juvenile arthritis patients see either pediatricians (who tend not to be trained in how to care for juvenile arthritis) or adult rheumatologists, who aren't trained to deal with pediatric issues. Issues such as whether it's the stunted bone growth that can result from arthritis and its treatment, or the unwillingness of an adolescent to take his medicine. There are currently eleven states that do not have a single practicing pediatric rheumatologist and seven states with only one pediatric rheumatologist.

The Pediatric Subspecialty Loan Repayment Program was authorized by Section 5203 of the Affordable Care Act (ACA) in March 2010. The program would incentivize training and practice in pediatric medical subspecialties, like pediatric rheumatology, in underserved areas across the United States. The program would offer up to \$35,000 in loan forgiveness for each year of service for a maximum of three years. The program was authorized for \$30 million for FY 2010 through FY 2014, but has yet to be appropriated any funding. **The Arthritis Foundation urges Congress to allocate \$5 million dollars to fund the Pediatric Subspecialty Loan Repayment Program.**

**CENTER FOR DISEASE CONTROL: CDC ARTHRITIS PROGRAM**

The goal of the CDC Arthritis Program is to improve the quality of life for people affected by arthritis and other rheumatic conditions by working with states and other partners to (1) increase awareness about appropriate arthritis self-management activities, (2) expanding the reach of programs proven to improve the quality of life for people with arthritis and (3) decrease the overall burden of arthritis as well as its associated disability, work and activity limitations.

**The Arthritis Foundation requests that Congress provide a slight increase (\$2M) to expand the CDC Arthritis Program to \$15M for FY 2014.** These additional funds would allow the Program to expand to two additional states. Additional funding would allow the CDC Arthritis Programs to expand into ten new states. These state-based programs would (1) increase evidence based interventions, such as the Arthritis Foundation's Walk with Ease Program ([WWE](http://www.wwe.org)), into more communities; (2) reach diverse populations by funding partnership activities; and (3) support the OA Action Alliance, a coalition committed to elevating OA as a national priority. [www.oaactionalliance.org](http://www.oaactionalliance.org).

The Arthritis Foundation appreciates the opportunity to provide recommendations to the House Labor Health and Human Services Committee on recommendations for FY2014.

If you have questions about these comments, please don't hesitate to contact the Arthritis Foundation. Questions about HRSA requests—Kim Beer, Director, Government Relations, [kbeer@arthritis.org](mailto:kbeer@arthritis.org)/202.887.2918 or Maria Spencer, Director, Federal Affairs for NIH/CDC, [m Spencer@arthritis.org](mailto:m Spencer@arthritis.org)/202.887.2912

**Statement of K. Gus Kousoulas, PhD  
Director, Division of Biotechnology and Molecular Medicine  
Louisiana State University  
Director, LSU-Tulane NIH Center for Biomedical Research Excellence (COBRE)**

**Submitted to the House Appropriations Committee  
Subcommittee on Labor, Health and Human Services, and Education  
March 15, 2013**

Mr. Chairman and Members of the Subcommittee; thank you for the opportunity to submit this statement regarding FY 2014 funding for the National Institutes of Health's Institutional Development Award or "IDeA" Program. The IDeA program is supported 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<sup>1</sup> and LSU, and respectfully request that this committee recommend that the IDeA program be funded in FY 2014 at \$310 million.

The National Institutes of Health's (NIH) Institutional Development Award Program (IDeA) was established in 1993 to broaden the geographic distribution of NIH funding for biomedical and behavioral research. The IDeA program funds only merit-based, peer-reviewed research that meets NIH research objectives. The program fosters health-related research and enhances the competitiveness of investigators at institutions in 23 states and Puerto Rico. The program also serves unique populations, such as rural and medically underserved communities, in these states. The IDeA

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<sup>1</sup> Alabama, **Alaska**, **Arkansas**, **Delaware**, **Hawaii**, **Idaho**, Iowa, **Kansas**, **Kentucky**, **Louisiana**, **Maine**, **Mississippi**, **Montana**, **Nebraska**, **Nevada**, **New Hampshire**, **New Mexico**, **North Dakota**, **Oklahoma**, **Puerto Rico**, **Rhode Island**, **South Carolina**, **South Dakota**, Tennessee, Utah, **Vermont**, **West Virginia**, and **Wyoming**

States in **bold** letters are eligible for the IDeA program. All of the states listed above are also eligible for the EPSCoR program.

program has two key components: Centers of Biomedical Research Excellence (COBRE) and IDeA Networks of Biomedical Research Excellence (INBRE). **COBRE** programs build multi-disciplinary research centers with a thematic scientific focus. Junior investigators graduate from the program after they obtain NIH competitive funding on their own. **INBRE** programs enhance biomedical research capacity in primarily undergraduate institutions in alliance with LSU, as a major research institution in Louisiana. These two programs play complementary roles in developing research capability and human capital in biomedical fields in Louisiana and the rest of the IDeA states.

#### **Impact of the IDeA Program on Louisiana**

Louisiana leads all the EPSCoR/IDeA states in successfully competing for COBRE and INBRE grants. Ten different COBRE grants and one INBRE Center grant have been funded in the last 10 years totaling more than \$200 million dollars. The Louisiana INBRE is led by the LSU in Baton Rouge as the flagship institution, which coordinates the training of scientists from a number of primarily undergraduate institutions in Louisiana such as the University of Louisiana in Monroe, LSU-Shreveport, Southern University in Baton Rouge, Xavier University in New Orleans, and Louisiana-Tech University in Ruston. All other Louisiana universities participate in the INBRE program through the summer research program. These students and faculty are trained at major research facilities around the state including: LSU, Pennington Biomedical Research Center, Tulane Medical Center in New Orleans, and the LSU Health Sciences Centers in New Orleans and Shreveport. The INBRE program provides opportunities

via collaboration with all Louisiana-based COBRE programs, therefore creating a highly regarded network of life scientists throughout Louisiana.

The Louisiana success in COBRE funding has been focused on highly important areas of research of particular significance to the health of the citizens of Louisiana. These research areas include: (1) obesity and cardiovascular health (COBREs at Pennington Biomedical Research Center in Baton Rouge, LSU Health Sciences Center in New Orleans, and Tulane University in New Orleans); (2) cancer research (COBREs at Tulane University and LSU Health Sciences Center in Shreveport); (3) neurosciences (COBRE at LSU Health Sciences in New Orleans); (4) infectious disease research (COBRE at the LSU School of Veterinary Medicine and Tulane National Primate Research Center); (5) obesity and diabetes (COBRE at Pennington Biomedical Research Center in Baton Rouge); (6) aging research (COBRE at Tulane University); and (7) oral health (COBRE at the LSU School of Dentistry in New Orleans). Recently, special COBRE funding was awarded to Louisiana for the establishment of the Louisiana Clinical & Translational Science Center (LACaTS) involving all biomedical research and medical training programs in Louisiana working together to translate research findings to improve clinical care. Specifically, this collaborative network of scientists and clinicians focuses on the prevention, care and research of chronic diseases in the underserved population of Louisiana and the nation. This COBRE Clinical and Translational Research award (COBRE-CTR) is led by the Pennington Biomedical Research Center in Baton Rouge.

The COBRE and INBRE Project grants require the presence of senior mentors for junior investigators including students, postdoctoral fellows and junior faculty. The

COBRE and INBRE funding has been a key factor in the retention of well-funded investigators serving as principal investigators or mentors in each program.

Total economic impact for Louisiana stemming from the IDeA program is approximately \$300 million, when taking into account the presence of senior researchers that have been retained in Louisiana. This amounts to a total economic impact of \$600 million based on an economic impact multiplier of 2. Importantly, the IDeA funding has enabled the formation of a Louisiana-wide network of life scientists, opening up new collaborations and unsurpassed training opportunities for all students and faculty. The Louisiana Optical Network Initiative (LONI), funded by state funds, has enabled direct connectivity and communication among all COBRE and INBRE recipients through the INBRE-led access grid network; allowing remote training, sharing of seminar speakers and other training functions across Louisiana. IDeA funding has impacted the teaching and training of more than 1000 researchers and students in Louisiana.

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 thoughtful actions of this Subcommittee. This funding permitted the initiation of the COBRE and INBRE, which have been crucial to the success of the program. On behalf of the Coalition and LSU, I want to 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.

We request that this committee recommend the IDeA program be funded in FY 2014 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 COBRE Clinical and Translational Research (CTR) program, and provide for co-funding opportunities which allow researchers and institutions to merge with the overall national biomedical research community.

Over 22% of the Nation's population live in the EPSCoR/IDeA States, yet 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. And that is why the IDeA program is so important. It is helping to ensure that all regions of the country participate in biomedical research and education. Citizens from all states should have the opportunity to benefit from the latest innovations in health care, which are most readily available in centers of biomedical research excellence.

To put the value of the IDeA investment into perspective, the overall FY 2012 IDeA budget, \$276.48 million, is only 42% of the \$645.3 million in NIH funding that Johns Hopkins University alone, in a non-IDeA state, received in FY 2011. In FY 2011, the top seven states with NIH funding received over a \$1 billion each, and California alone received over \$3.5 billion. Given this, \$310 million for 23 states and Puerto Rico seems more than reasonable.

On behalf of the EPSCoR/IDeA Coalition, LSU and our partner institutions across Louisiana, I thank the Subcommittee for the opportunity to submit this testimony.



**Testimony of the American Nurses Association Regarding  
Fiscal Year 2014 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**

**August 1, 13**

Submitted by:

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The American Nurses Association (ANA) appreciates the opportunity to comment on Fiscal Year (FY) 2014 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 2014. Additionally, we respectfully request **\$20 million for the Nurse-Managed Health Clinics** authorized under Title III of the Public Health Service Act in FY 2014. While we recognize the reality of the sequester and the need to continue to cut the federal deficit, 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 2010-2020 state the expected number of practicing nurses will grow from 2.74 million in 2010 to 3.45 million in 2020, an increase of 712,000 or 26%.

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. According to Douglas Staiger, author of a New England Journal of Medicine study, the nursing shortage will "re-emerge" from 2010 and 2015 as 118,000 nurses will stop working full time as the economy grows.

Furthermore, as of January 1, 2011 Baby Boomers began turning 65 at the rate of 10,000 a day. 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.

The BLS projections explain a need for 495,500 replacements in the nursing workforce, bringing the total number of job openings for nurses due to growth and replacements to 1.2 million by 2020. 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.

#### **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.), including 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 48 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 2011-2012 survey, which included responses from over 1,600 students, stated that Title VIII programs played a critical role in funding their nursing education. The survey showed that 68 percent of the students receiving Title VIII funding are attending school full-time. Between FY 2005 and 2010 alone, the Title VIII programs supported over 400,000 nurses and nursing students as well as numerous academic nursing institutions, and healthcare facilities.

However, current funding levels are falling short of the growing need. In FY 2008 (most recent year statistics are available), the Health Resources and Services Administration (HRSA) was forced to turn away 92.8 percent of the eligible applicants for the Nurse Education Loan Repayment Program (NELRP), and 53 percent of the eligible applicants for the Nursing Scholarship program due to a lack of adequate funding. These programs are used to direct RNs into areas with the greatest need – including community health centers, departments of public health, and disproportionate share hospitals. Additionally according to the AACN *Title VIII Student Recipient Survey*, a record 58,327 qualified applicants were turned away due to insufficient clinical teaching sites, a lack of faculty, limited classroom space, insufficient preceptors and budget cuts.

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 2014.

#### **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 care 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 2014.**

Thank you for your time and your attention to this matter.

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March 15, 2013

**Testimony for the Record by Mary Lamielle, Executive Director  
National Center for Environmental Health Strategies  
for the Subcommittee on Labor, Health & Human Services, Education & Related Agencies  
United States House Committee on Appropriations**

The National Center for Environmental Health Strategies (NCEHS) thanks Chairman Kingston and Ranking Member DeLauro for the opportunity to present testimony. For twenty-nine years, NCEHS has focused on protecting the public health and improving the lives of people sick or disabled by chemical and environmental exposures. NCEHS is calling on the Subcommittee to fund efforts to address the medical, public health, disability, policy, and research needs of people disabled with chemical sensitivities or intolerances.

We are recommending two projects as follows:

1. Creation of an Interagency Working Group (or Committee) on Chemical Sensitivities charged with reviewing the limited existing federal policies and programs that address these issues and identifying a plan of action to address the medical, public health, disability, policy, and research needs. Such an effort was first recommended by the Expert Panel on Multiple Chemical Sensitivities convened by the Agency for Toxic Substances and Disease Registry in 1993. The effort would be coordinated by the National Institute on Disability and Rehabilitation Research (NIDRR) with broad

participation on the part of appropriate federal agencies, a number of which are aware of this proposal and supportive of the effort. The workgroup would convene one or more workshops focused on specific topics and invite interaction with impacted populations and other experts.

Department of Education, especially National Institute on Disability and Rehabilitation Research, \$500,000;

National Council on Disability \$100,000;

Centers for Disease Control and Prevention, National Center for Environmental Health \$100,000

2. Fund the creation of an Interdisciplinary Committee to develop and implement research on chemical sensitivities and for the construction and staffing of an Environmental Medical Unit (EMU), a hospital-based research facility, as recommended by multiple scientific and professional meetings and previously supported by Congress, to conduct “Studies of variation in susceptibility as manifested by chemical sensitivity/intolerances” as detailed in the Scientific Work Group Recommendation from the CDC National Conversation on Public Health and Chemical Exposures, [http://www.resolv.org/site-nationalconversation/files/2011/02/Scientific\\_Understanding\\_Final\\_Report.pdf](http://www.resolv.org/site-nationalconversation/files/2011/02/Scientific_Understanding_Final_Report.pdf), and *Recommendation 3.5 Improve understanding of individual susceptibility to chemical exposures* in the National Conversation’s Action Agenda <http://www.nationalconversation.us/action-agenda/chapter-3-science/chapter-3-additional-recommendations>.

National Institute of Environmental Health Sciences and Centers for Disease Control and Prevention: \$500,000 convene an Interdisciplinary Committee to develop a plan for construction and research agenda using an Environmental Medical Unit;

National Institute of Environmental Health Sciences: \$3.5 million for construction and operation of an EMU.

**RATIONALE FOR ACTION TO ADDRESS THE NEEDS OF PERSONS WITH CHEMICAL SENSITIVITIES OR INTOLERANCES:**

A significant numbers of civilians and Gulf War Veterans experience severe, debilitating, multi-system reactions and intolerances to a panoply of chemicals, over-the-counter and prescription medications, alcoholic and caffeinated beverages, and numerous other substances and products. The prevalence of chemical sensitivities or intolerances may be as high as 16% of the populations with those disabled by these conditions numbering up to 6% of Americans.

Funding is necessary to establish an interagency working group or committee on chemical sensitivities that would include agencies with responsibilities in these areas. The working group would examine the research, policy development, patient support, and public education necessary to meet the needs of affected populations. It should be charged with reviewing the current federal policies and programs, identifying the gaps in medical and disability research and policies, and making recommendations for further action to address such issues in a cohesive and systematic fashion. Federal participation should include but not be limited to the Centers for Disease Control and Prevention (CDC), the National Institute of Environmental Health Sciences (NIEHS), the National Institute on Disability and Rehabilitation Research (NIDRR) at the

Department of Education, the Department of Labor, and the National Council on Disability, among other agencies.

Funding is also necessary to create an Interdisciplinary Committee as recommended by the Action Agenda of the CDC's National Conversation on Public Health and Chemical Exposures Recommendation 3.5 and as described at the National Academy of Sciences Workshop "Biological Factors that Underlie Individual Susceptibility to Environmental Stressors, and Their Implications for Decision-Making," April 17-18, 2012.

Funding is also necessary for research concerning: (1) the possible health effects of exposure to low levels of hazardous chemicals, including chemical warfare agents and other substances; (2) individual susceptibility of humans to such exposures through an examination of genetic polymorphisms, and (3) the construction and use of an Environmental Medical Unit (EMU) as previously supported by Congress and underway in Japan to examine populations affected by toxicant-induced intolerances to determine the biomarkers and mechanisms by which to identify individual susceptibility so as to avoid placing such individuals in hazardous situations, detect affected individuals early in their illness, and provide prompt intervention.

Millions of Americans suffer daily due to the failure of the federal government to develop policies and programs to address the medical, public health, disability, policy, and research needs for people disabled with chemical sensitivities. Twenty years ago ATSDR convened an Expert Panel on Multiple Chemical Sensitivities to address these issues. In the intervening period federal agencies have failed to address these disabilities in a systematic and cohesive fashion.

Thank you for the opportunity to submit testimony.

**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 15, 2013**

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 \$445 million for Fiscal Year 2016 and \$27.3 million for the Department of Education's Ready To Learn program in Fiscal Year 2014.

Since 1967, the Corporation for Public Broadcasting has served as the steward of continuing federal appropriations for public television and radio. Today we are a system comprising more than 1,400 locally owned and locally operated public radio and television stations serving local 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 the only source of broadcast news, information and educational programming.

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, which amounts to approximately 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.

Federal money is the indispensable foundation upon which stations build and raise, on average, at least six times the amount they receive from the federal government. And 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 40 percent of their budget. While their communities do the best they can in terms of financial support, the fact is, without the federal appropriation these stations would cease to exist.

No matter what their size, all public media stations work for, and are accountable to, the people in the communities they serve. That connection is important because as stations acquire national programming, they also produce local content and services based on the needs of their respective communities.

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. Approximately 19% of CPB's funding is directed to the production or acquisition of programming, making CPB the largest single funder of content for children's programming such as *Sesame Street* and *Daniel Tiger's Neighborhood*; for public affairs programming such as *PBS NewsHour*, *Morning Edition* and *Frontline*; and for programming such as *Nova*, *Nature*, *American Experience*, StoryCorps and the films of Ken Burns.

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 (which represent African American, Latino, Asian American, Native American and Pacific Islander producers), 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.

In the past year, CPB provided support for Southern California Public Radio's launch of the "One Nation Media Project," which produces quality, multimedia journalism that engages a general audience while emphasizing topics that resonate authentically with multiethnic communities; the production of *America Revisited*, a three-part series by filmmaker Stanley Nelson on the history of African Americans; a documentary called *The Graduates* by filmmaker Bernardo Ruiz, which looks at the education challenges faced by Latino boys and girls; and *PARALYMPICS*, which introduces American audiences to high performing disabled athletes and the biomechanics of disabled sports.

For an investment of approximately \$1.35 per American per year, public broadcasting stations are able to train teachers and help educate America's children in school and at home; provide in-depth journalism that informs citizens about important 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**

CPB's mission is to facilitate the development of, and ensure universal access to, high-quality noncommercial programming and telecommunications services, and to strengthen and

advance public broadcasting's service to the American people. CPB does not own or operate public broadcasting stations, or govern the national public media organizations. As steward of these important funds, we ensure these monies are invested in stations that serve our communities and programs that help strengthen our civil society.

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 and a deeper engagement between the American people and the public service media organizations that serve them.

One example of a CPB investment that embodies each of the Three D's is our investment in education. Public broadcasting'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. Now, building upon our success in early childhood education, CPB is leading a national initiative to help communities address the high school dropout crisis called, "American Graduate: Let's Make It Happen." More than 75 public media stations located in 33 states with at-risk communities are working with more than 800 national and community-based partners to mobilize and bring together diverse stakeholders and community organizations; filling voids in information, resources and solutions; building and 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.

**CPB's Request for Appropriations**

Our FY 2016 request balances the fiscal reality facing our nation with the bare fact that stations are struggling to provide service to their communities in the face of shrinking non-federal revenues—a \$239 million, or 10.8 percent, drop between FY 2008 and FY 2011. Even with these challenges, public broadcasting contributes to American society in many ways that are worthy of greater federal investment. In FY 2016, CPB will continue to support a range of programming and initiatives through which stations provide a valuable and trusted service to millions of Americans.

CPB Base Appropriation (FY 2016): CPB requests a \$445 million advance appropriation for FY 2016, to be spent in accordance with the Public Broadcasting Act's funding formula. The two-year advance appropriation for public broadcasting, in place since 1976, is the most important part of the "firewall" that Congress constructed between federal funding and the programs that appear on public television and radio. President Gerald Ford, who initially proposed a five-year advance appropriation for CPB, said it best when he said that advance funding "is a constructive approach to the sensitive relationship between federal funding and freedom of expression. It would eliminate the scrutiny of programming that could be associated with the normal budgetary and appropriations processes of the government."

Ready To Learn (FY 2014): CPB requests that the U.S. Department of Education's Ready To Learn (RTL) program be funded at \$27.3 million, the same level as FY 2013. Mr. Chairman, education is the heart of public media. RTL is a partnership between the Department, CPB, PBS and local public television stations that leverages the power of digital television technology, the Internet, gaming platforms and other media to help millions of young children learn the reading and math skills they need to succeed in school. The partnership's work over

the past few years has demonstrably increased reading scores particularly among low-income children and is helping to erase the performance gap between children from low-income households and their more affluent peers. An appropriation of \$27.3 million in FY 2014 will enable RTL to develop tools to improve children's performance in math as well as reading and bring on-the-ground, station-convened early learning activities to more communities.

All told, the federal contribution to public media through CPB amounts to \$1.35 per American per year, and the return on investment to the American taxpayer can be measured in the numbers of children now ready to learn in school; through in-depth news and public affairs programming on the local, state, national and international level; unmatched, commercial-free children's programming; formal and informal educational instruction for all ages; or inspiring arts and cultural content.

Americans no longer sit back and experience appointment television or radio. They are on the move and public media is there with them, 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.

Mr. Chairman and members of the subcommittee, thank you again for allowing CPB to submit this testimony. On behalf of the public broadcasting community, including the stations in your states and those they serve, we sincerely appreciate your support.

**Testimony Submitted to the House Committee on Appropriations Subcommittee on  
Labor, Health and Human Services, and Education  
David H. Walker, M.D., President  
On behalf of the American Society of Tropical Medicine and Hygiene**

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The American Society of Tropical Medicine and Hygiene (ASTMH)—the principal professional membership organization representing, educating, and supporting scientists, physicians, clinicians, researchers, epidemiologists, and other health professionals dedicated to the prevention and control of tropical diseases—appreciates the opportunity to submit testimony to the House Labor, Health and Human Services, and Education Appropriations Subcommittee. The benefits of U.S. investment in tropical diseases are both humanitarian and diplomatic. With this in mind, we respectfully request that the Subcommittee fully fund the NIH and CDC in the FY 2014 LHHS appropriations bill in order to ensure a continued U.S. investment in global health and tropical medicine research and development, specifically:

**National Institutes of Health:**

- Malaria and neglected tropical disease (NTD) treatment, control, and research and development efforts within the National Institute of Allergy and Infectious Diseases (NIAID);
- Expanded focus on diarrheal disease within the NIH;
- Research capacity development in countries where populations are at heightened risk for malaria, NTDs, and diarrheal diseases through the Fogarty International Center (FIC); and
- Research on infectious diseases transmitted by ticks, fleas, and mosquitoes that occur within the borders of the U.S. as well as in tropical and subtropical regions abroad.

**The Centers for Disease Control and Prevention:**

- The Center for Global Health, which includes CDC's work in malaria and NTDs; and
- The National Center for Emerging & Zoonotic Infectious Diseases, which is responsible for protecting the U.S. from new and emerging infections spread by mosquitoes and ticks.

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**Return on Investment of U.S.-Funded Research**

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CDC and NIH play essential roles in R&D for tropical medicine and global health. Both agencies are at the forefront of the new science that leads to tools to combat malaria and NTDs. This research provides jobs for American researchers and an opportunity for the U.S. to be a leader in the fight against global disease, in addition to creating lifesaving new drugs and diagnostics to some of the poorest, most at-risk people in the world.

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**Tropical Disease**

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***Malaria and Parasitic Disease:*** Malaria remains a global emergency affecting mostly poor women and children; it is an acute, sometimes fatal disease. Despite being treatable and preventable, malaria is one of the leading causes of death and disease worldwide. Approximately every 30 seconds, a child dies of malaria—a total of about 800,000 under the age of 5 every year. The World Health Organization (WHO) estimates that one half of the world's people are at risk for malaria and that there are 108 malaria-endemic countries.

***Neglected Tropical Diseases:*** NTDs are a group of chronic parasitic diseases, which represent the most common infections of the world's poorest people. These infections have been revealed as the stealth reason why the “bottom billion”—the 1.4 billion poorest people living below the poverty line—cannot escape poverty, because of the effects of these diseases on reducing child growth, cognition and intellect, and worker productivity.

***Diarrheal disease:*** The child death toll due to diarrheal illnesses exceeds that of AIDS, tuberculosis, and malaria combined. In poor countries, diarrheal disease is second only to pneumonia as the cause of death among children under 5 years old. Every week, 31,000 children in low-income countries die from diarrheal diseases.

The United States has a long history of leading the fight against tropical diseases that cause human suffering and pose financial burden that can negatively impact a country's economic and political stability. Tropical diseases, many of them neglected for decades, impact U.S. citizens working or traveling overseas, as well as our military personnel. Additionally, some diseases such as dengue fever have been found in the U.S.

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#### **National Institutes of Health**

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**National Institute of Allergy and Infectious Diseases:** A long-term investment is critical to achieve the drugs, diagnostics, and research capacity needed to control malaria and NTDs.

NIAID is the lead institute for malaria and NTD research.

*ASTMH encourages the subcommittee to:*

- Increase funding for NIH to expand the agency's investment in malaria, NTDs, tick-borne infections, and diarrheal disease research and coordinate with other agencies to maximize resources and ensure development of basic discoveries into usable solutions;
- Specifically invest in NIAID to support its role at the forefront of these efforts to developing the next generation of drugs, vaccines, and other interventions; and
- Urge NIH to include enteric infections and neglected diseases in its RCDC process on the RePORT website to outline the work that is being done in these important research areas.

**Fogarty International Center:** Biomedical research has provided major advances in the treatment and prevention of malaria, NTDs, and other infectious diseases. These benefits, however, are often slow to reach the people who need them most. FIC works to strengthen research capacity in countries where populations are particularly vulnerable to threats posed by malaria, NTDs, and other infectious diseases. This maximizes the impact of U.S. investments and is critical to fighting malaria and other tropical diseases.

***ASTMH encourages the subcommittee to:***

- Allocate sufficient resources to FIC in FY 2014 to increase these efforts, particularly as they address the control and treatment of malaria, NTDs, and diarrheal disease.

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**The Centers for Disease Control and Prevention**


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**Malaria and Parasitic Disease:** Malaria has been eliminated as an endemic threat in the United States for over fifty years, and CDC remains on the cutting edge of global efforts to reduce the toll of this deadly disease. CDC efforts on malaria and parasitic disease fall into three broad categories: prevention, treatment, and monitoring/evaluation of efforts. The agency performs a wide range of basic research within these categories, such as:

- Conducting research on antimalarial drug resistance to inform new strategies and prevention approaches;
- Assessing new monitoring, evaluation, and surveillance strategies;
- Conducting additional research on malaria vaccines, including field evaluations; and
- Developing innovative public health strategies for improving access to antimalarial treatment and delaying the appearance of antimalarial drug resistance.

***ASTMH encourages the subcommittee to:***

- Fund a comprehensive approach to effective and efficient malaria and parasitic disease, including adequately funding the important contributions of CDC in malaria and parasitic disease at no less than \$18 million.

**Neglected Topical Diseases:** CDC currently receives zero dollars directly for NTD work outside of parasitic diseases; however, this should be changed to allow for more comprehensive work to be done on NTDs at CDC. CDC has a long history of working on NTDs and has provided much of the science that underlies the global policies and programs in existence today.

***ASTMH encourages the subcommittee to:***

- Provide direct funding to CDC to continue its work on NTDs, including but not limited to parasitic diseases; and
- Urge CDC to continue its monitoring, evaluation, and technical assistance in these areas as an underpinning of efforts to control and eliminate these diseases.

**Vector-Borne Disease Program (VBDP):** Through the VBDP, researchers are able to practice essential surveillance and monitoring activities that protect the U.S. from deadly infections before they reach our borders and to address problems of tick- and flea-transmitted infections such as Lyme disease and a dozen other infections, some of which are life-threatening within the U.S. The world is becoming increasingly smaller as international travel increases and new pathogens are introduced quickly into new environments. We have seen this with SARS, avian influenza, and now, dengue fever, in the United States. Arboviruses like dengue, and others, such as chikungunya, are a constant threat to travelers, and to Americans generally.

***ASTMH encourages the subcommittee to:***

- Ensure that CDC maintain these activities by continuing CDC funding for VBDP activities through the National Center for Emerging and Infectious Zoonotic Diseases.

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**Conclusion**

Thank you for your attention to these important U.S. and global health matters. We know Congress and the American people face many challenges in choosing funding priorities, and we hope you will provide the requested FY 2014 resources to those programs identified above that meet critical needs for Americans and people around the world. ASTMH appreciates the opportunity to share its expertise, and we thank you for your consideration of these requests that will help improve the lives of Americans and the global poor.



**FISCAL YEAR 2014 HOUSE APPROPRIATIONS COMMITTEE PUBLIC TESTIMONY**

**SUBMITTED BY THE TRAUMA CENTER ASSOCIATION OF AMERICA**

**FOR THE SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,**

**EDUCATION, & RELATED AGENCIES**

**MARCH 15, 2013**

**Introduction**

The Trauma Center Association of America (TCAA) thanks the Subcommittee for the opportunity to submit written testimony on Fiscal Year (FY) 2014 federal appropriations for trauma & emergency medical services system programs authorized under Sections 1201-4, 1211-32, 1241-46 and 1281-2 of the Public Health Service Act. Appropriate funding of these programs will help improve access to life-saving trauma care, prevent more trauma center closures and will pilot regionalized systems of emergency care to promote greater efficiency of emergency medical and trauma care. While we understand the fiscal challenges facing the Subcommittee, we urge you to prioritize limited federal funding toward life-saving trauma care for millions of victims of traumatic injury -- whether from mass shootings, falls, car crashes, or farm accidents. For the 45 million Americans who currently lack access to proximate life-saving trauma care -- such as the care provided to the victims of the Tucson and Aurora shootings-- and millions more Americans who rely upon an unstable trauma system, even within the context of reducing the budget deficit, we believe that federal funding for trauma care is a worthy and prudent investment in saving lives and returning victims of traumatic injury to productive futures.

**Background**

TCAA is a non-profit, 501(c)(6) association representing trauma centers and systems across the country committed to ensuring access to life-saving trauma services. The ability to deliver trauma care services -- comprehensive specialized treatment to victims of blunt force or penetrating injuries - within an hour of injury is critical to survival. Such traumatic injuries are a significant driver of health care costs. In fact, in the United States, approximately 35 million people are treated every year for traumatic injuries<sup>i</sup> -- which includes one hospitalization every 15 minutes. Traumatic injury is the leading cause of death under age 44<sup>ii</sup>. And, at an annual cost of \$67.3 billion, trauma is the 3<sup>rd</sup> most costly medical condition (behind heart disease (\$90.9b) and cancer (\$71.4b)).<sup>iii</sup> Yet, the federal investment in ensuring access to life-saving trauma care for all Americans is woefully lacking.

Key to the effective and efficient delivery of trauma care services are the existence of trauma centers and the highly specialized physicians, nurses and trauma teams who staff them. Trauma centers invest millions of dollars each year to ensure the immediate availability of up to 16 subspecialist physicians and significant supporting infrastructure. While costly, trauma care is highly effective. The risk of death for a severely injured trauma patient treated at Level I Center is 25% less than in a non-trauma center hospital. For those severely injured in motor vehicle crashes, initial triage to a non-trauma center increases the risk of death within the first 48 hours by at least 30%. In addition, recent studies have shown that while the number of violent attacks related to gunshots and stabbings have increased, the number of U.S. homicides are falling. In a December 2012 Wall Street Journal article, it was noted that the reported number of people treated for gunshot attacks has nearly doubled from 2001 to 2011 but that the percentage

of shooting victims dying was lowered. While the public often associates trauma care with car crashes or shootings, 38% of traumatic injuries are due to falls.

Trauma centers save lives every day for those fortunate enough to have access to them. Unfortunately, according to the Centers for Disease Control, nearly 45 million Americans lack access to a Level I or II trauma center within one hour of being injured -- that is equal to the populations of Arizona, New Mexico, Texas, Louisiana, Mississippi and Alabama combined. In addition, many centers struggle to keep their doors open -- from 1990-2005, 30% of trauma centers closed, with a disproportionate adverse impact on access for vulnerable populations.<sup>iv</sup> The primary reason for trauma center closure is a lack of funding.<sup>v</sup> Despite \$224 million in authorized funding under the Public Health Service Act to improve and ensure access to trauma care for one out of every ten Americans who need it each year, the Congress has yet to make access to life-saving trauma care a priority.

Equally essential is the development of trauma and regionalized EMS systems of care that ensure that severely injured or ill patients are transported to the right trauma center or hospital as appropriate in the right amount of time. Only 8 states have fully developed trauma systems and few areas of the nation have coordinated regionalized systems of emergency care, as called for by the IOM in its landmark 2006 study, *Emergency Medical Services: At the Crossroads*, which documented a fragmented and disjointed state of EMS in America.

News headlines of late have been filled with the stories of the horrific tragedies in Tucson, Aurora and Newtown. In Tucson, the survival and recovery of 13 of the 19 victims demonstrates the life-saving value of trauma care. The organized trauma care system in place in Tucson and Aurora -- from the EMS first responders to proximate trauma centers - played a significant role in the survival for many of the victims. Had these shootings occurred in the many

geographic regions of this nation where there is not proximate access to trauma care, the outcomes would likely have been very different.

Consider the events of January 2008 when a bus slid off a remote road and overturned in Mexican Hat, Utah. While responding heroically, first responders were hampered by bad weather and poor communications due to the remote location of the accident. The closest trauma center was 115 miles away, and victims had to be transported as far as 360 miles and up to 13 hours away after the accident to receive care at a trauma center -- not all survived due to lack of proximate access to trauma care. Beyond such large scale events, 33,000 people each year die in motor vehicle accidents; the risk of dying in a rural crash is 15 times higher than in urban areas.

**FY 2014 Funding Request:**

The immense economic pressures facing trauma centers that struggle to stay in operation are escalating. Lack of adequate funding is a significant factor in many trauma center closures. As aforementioned, 30% of trauma centers closed in a ten-year period, including the primary trauma hospital treating 848 trauma victims on 9/11. While new trauma centers are being created in a few areas of the nation where funding and reimbursement is sufficient, in many rural and some urban areas without adequate financial resources to support or maintain a trauma center, federal funding is essential to help prevent more closures and to improve access to trauma care where it is currently lacking. As noted by a Wall Street Journal article in May of 2010, federal investments in preparedness have primarily focused on "bioterrorism" and not on "blast attack terrorism" which is the most probable method of attack in the U.S. The provision of geographically dispersed competent trauma services is an essential federal function that relates directly to protecting the welfare of interstate travelers and commerce and driving economic development and infrastructure in medically underserved and economically stressed communities.

TCAA strongly urges the inclusion of \$28 million in the FY 2014 Labor-HHS-Education Appropriations bill, which would include funding for the following programs with a breakdown as follows:

- \$11 million for Trauma Care Center Grants
- \$11 million for Trauma Service Availability Grants
- \$3 million for Trauma Systems Planning Grant
- \$3 million for Regionalization of Emergency Care Pilots

### **Conclusion**

The "value" proposition for trauma care is well documented. The care provided by trauma centers, their specialist physicians and the supporting trauma team has a dramatic impact on subsequent quality of life and is delivered in a cost efficient manner. In fact, trauma center care is more cost effective than many other interventions, including dialysis for kidney failure. As the House Labor-HHS-Education Appropriations Subcommittee makes difficult choices and prioritizes the most prudent federal investments, TCAA urges funding to be included to implement the trauma and emergency medical services programs as contained in Sections 1201-4, 1211-32, 1241-46, and 1281-2 of the Public Health Service Act.

Thank you again for the opportunity to submit testimony. Please contact, Jennifer Ward, RN, BSN; President of the Trauma Center Association of America at (575) 525-9511, if you have any questions or need further information concerning TCAA's FY 2014 funding request.

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<sup>i</sup> National Trauma Institute. [www.nationaltraumainstitute.com](http://www.nationaltraumainstitute.com). San Antonio, TX.

<sup>ii</sup> Injury Prevention & Control: Trauma Care. [www.cdc.gov/traumacare](http://www.cdc.gov/traumacare). Centers for Disease Control and Prevention, Atlanta, GA.

<sup>iii</sup> Soni, A. Top 10 Most Costly Conditions among Men and Women, 2008: Estimates for the U.S. Civilian Noninstitutionalized Adult Population, Age 18 and Older. Statistical Brief #331. July 2011. Agency for Healthcare Research and Quality, Rockville, MD. [http://meps.ahrq.gov/mepsweb/data\\_files/publications/st331stat331.shtml](http://meps.ahrq.gov/mepsweb/data_files/publications/st331stat331.shtml).

<sup>iv</sup> Renee Yuen-Jan Hsia and Yu-Chu Shen. Rising closures of Hospital Trauma Centers Disproportionately Burden Vulnerable Populations. *Health Affairs*, 30, no.10 (2011): 1912-1920.

<sup>v</sup> *ibid*.

# TRANSPLANT ROUNDTABLE

**VIA HAND DELIVERY AND ELECTRONIC MAIL**

March 15, 2013

The Honorable Jack Kingston  
Chairman  
House L/HHS Appropriations Subcommittee  
Washington, D.C. 20515

The Honorable Rosa DeLauro  
Ranking Member  
House L/HHS Appropriations Subcommittee  
Washington, D.C. 20515

**Re: HRSA Organ Donation & Transplantation Funding for FY 2014**

Dear Chairman Kingston and Ranking Member DeLauro:

On behalf of the Transplant Roundtable, a coalition of organ transplant patients, professionals, and related organizations, the undersigned organizations offer our strong support for federal funding for the organ donation and transplantation programs run by the Division of Transplantation (DoT) within the Health Resources and Services Administration (HRSA). We applaud you for your many years of unwavering commitment to these programs and ask again for your assistance. While we recognize the serious challenges regarding the federal budget, it is critical that the federal government retain its strong commitment to these programs. As such, *we ask that you preserve, at a minimum, a level budget of \$24 million for these DoT programs from FY 2013 to FY 2014.*

The DoT serves a unique and irreplaceable function and *if discretionary funds are available, an increase in funding (i.e., \$3 million) for FY 2014 would make a huge difference and ultimately save lives.* DoT provides oversight and funding for the nation's organ procurement,

allocation, and transplantation system through the Organ Procurement and Transplantation Network (OPTN). It coordinates all organ and tissue donation activities and funds donation research. Further, through the National Living Donor Assistance Center (NLDAC), it provides funding for travel and subsistence expenses of living donors whose low income may otherwise prohibit them from donating. These and other programs funded through DoT are very worthy of additional federal investment as they produce a major return on this investment, year after year.

DoT reports that each day, an average of 79 people receive organ transplants; however, an average of 18 people die each day waiting for transplants that do not occur because of the shortage of donated organs. As of February 2013, the national patient waiting list for organ transplants contained more than 127,000 listings. The total number of transplants from January to November of 2012 was approximately 26,000, with nearly 13,000 donors during that same time period.

Congressional, agency and private sector support has resulted in transplantation that has saved and enhanced the lives of more than 600,000 people in the United States, helped to greatly reduce the number of deaths on the waiting list, and generated substantial savings to the Medicare program through foregone need for dialysis. As a country, we do very well in facilitating and providing these life-saving services, but we need sustained federal commitment and resources to continue this mission.

Your leadership has been exemplary over many years on transplantation and organ donation activities. On behalf of transplant patients and their families, we ask that you again champion federal organ donation and transplantation programs run through HRSA.

Sincerely,

Alliance for Paired Donation

American Association of Kidney Patients

American Association for the Study of Liver Diseases

American Society of Nephrology

American Society of Pediatric Nephrology

American Society of Transplantation

American Society of Transplant Surgeons

American Transplant Foundation

Association of Organ Procurement Organizations

Dialysis Patient Citizens

Eye Bank Association of America

NATCO, The Organization for Transplant Professionals

National Kidney Foundation

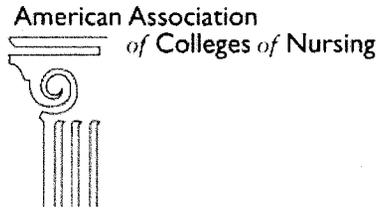
PKD (Polycystic Kidney Disease) Foundation

Renal Physicians Association

Texas Transplant Society

Transplant Recipients International Organization

United Network for Organ Sharing



**Testimony of the American Association of Colleges of Nursing Regarding  
Fiscal Year (FY) 2014 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 15, 2013**

Submitted by Suzanne Miyamoto, PhD, RN, Director of Government Affairs,  
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 over 720 schools of nursing that educate over 400,000 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 and researchers. AACN requests that nursing education, research, and practice are strongly supported in Fiscal Year (FY) 2014 through an investment of \$251 million for 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 for the Nurse-Managed Health Clinics (NMHCs) (Title III of the *Public Health Service Act*). These levels will ensure that our nation's nurses will be prepared to care for the growing number of patients requiring a complex range of healthcare services.

**Job Growth in the Nursing Workforce**

The demand for nurses is greater than previously anticipated. Last year, the Bureau of Labor Statistics (BLS) released their publication *Employment Projections for 2010-2020*, which anticipates

significant growth in the nursing workforce from 2.74 million in 2010 to 3.45 million in 2020. This upsurge in demand translates to 712,000 nurses, or an increase of 26%. The BLS further projects the need for 495,500 additional nurses to replace those soon to retire, bringing the total number of job openings for nurses due to growth and replacements to 1.2 million by 2020.

The aging of the nursing workforce and America's patients underscores this alarming projection. According to the *2008 National Sample Survey of Registered Nurses*, of the 2.6 RNs currently practicing in America, over one million are age 50 or older, and of these more than 275,000 nurses are over the age of 60. As this large segment of the workforce begins to retire, the nation will soon face a significant deficit in the number of experienced nurses available to provide services. Concurrent with the aging of the nursing workforce is the aging of America's Baby Boomer population. It is estimated that over 80 million Baby Boomers reached age 65 in 2011. As this population transitions into the nation's oldest generation, these citizens will continue to require more primary care services related to chronic illness treatment, medication management, and patient education. A significant investment must be made in the education of new nurses to provide the nation with the nursing services it requires.

### **Title VIII Nursing Workforce Development Programs**

For nearly five decades, 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 2005 and 2010 alone, the Title VIII programs supported over 400,000 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. Data from AACN's 2012-2013 enrollment and graduations survey show that nursing schools were forced to turn away 79,659 qualified applications from entry-level baccalaureate and graduate nursing programs in 2012 due primarily to faculty vacancies. 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 to the effectiveness of these programs in recruiting more students to the nursing profession and more importantly, practice in rural and underserved areas. The 2012-2013 survey, which included responses from over 1,100 students, revealed that 65% of respondents reported that Title VIII funding affected their decision to enter nursing school. The data also revealed that practicing in a community hospital or in an underserved community ranked among the respondents' top career choices after graduation.

Additionally, 74% of respondents stated that Title VIII funding allowed them to attend school full-time, as these loan and scholarship programs alleviated the financial burden that obligates many students to commit to their education only part-time. The Title VIII programs decrease the length of time needed to obtain their education, thus helping to ensure that students enter the workforce without delay. These efforts directly align with recommendations in the Institute of Medicine's

landmark report *Future of Nursing: Leading Change, Advancing Health* which states, “Nurses should achieve higher levels of education and training through an improved education system that promotes seamless academic progression.” Financial support from Title VIII programs ensure that more nurses are efficiently integrated into the workforce.

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 2014.***

#### **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. While other research is aimed at curing disease, nurse-researchers at NINR focus on the preventing these illnesses that threaten to exacerbate an already over-burdened healthcare system.

Additionally, NINR 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.

***AACN respectfully requests \$150 million for the NINR in FY 2014.***

**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 2014.***

AACN recognizes that the Subcommittee and Congress will need to make difficult decisions regarding appropriations for Fiscal Year 2014. 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 2014.



**Testimony of the Nursing Community Regarding  
Fiscal Year (FY) 2014 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 15, 2013**

*Submitted by Suzanne Miyamoto, Convener of the Nursing Community*

The Nursing Community is a forum comprised of 57 national professional nursing membership associations that builds consensus and advocates on a wide spectrum of healthcare and nursing issues surrounding practice, education, and research. These 57 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 2014, 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' *Employment Projections for 2010-2020*, the expected number of practicing nurses will grow from 2.74 million in 2010 to 3.45 million in 2020, an increase of 712,000 or 26%. The projections further explain the need for 495,500 replacements in the nursing workforce, bringing the total number of job openings for nurses due to growth and replacements to 1.2 million by 2020.

Two primary factors contribute to this overwhelming projection. First, America's nursing 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. Secondly, America's Baby Boomer population is aging. It is estimated that over 80 million Baby Boomers reached age 65 last year. 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 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 2010 alone, the Title VIII programs supported over 400,000 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 1,100 students, stated that the Title VIII programs played a critical role in funding their nursing education. The survey showed that 74% 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 2012-2013 enrollment and graduations survey show that nursing schools were forced to turn away 79,659 qualified applications from entry-level baccalaureate and graduate nursing programs in 2012, 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 2014.***

While we recognize the reality of sequestration and the need to continue to cut the federal deficit, we also firmly believe this request is necessary given the demand for nursing services is steadily on the rise.

**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 2014.***

#### **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 2014.***

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 2014 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	Hospice and Palliative Nurses Association
American Academy of Nursing	Infusion Nurses Society
American Assembly for Men in Nursing	International Association of Forensic Nurses
American Association of Colleges of Nursing	International Nurses Society on Addictions
American Association of Nurse Anesthetists	International Society of Psychiatric Nursing
American Association of Nurse Practitioners	National American Arab Nurses Association
American College of Nurse-Midwives	National Association of Neonatal Nurse Practitioners
American Nephrology Nurses' Association	National Association of Neonatal Nurses
American Nurses Association	National Association of Nurse Practitioners in Women's Health
American Organization of Nurse Executives	National Association of Pediatric Nurse Practitioners
American Psychiatric Nurses Association	National Black Nurses Association
American Society for Pain Management Nursing	National Nursing Centers Consortium
American Society of PeriAnesthesia Nurses	National Organization for Associate Degree Nursing
Association of Community Health Nursing Educators	National Organization of Nurse Practitioner Faculties
Association of periOperative Registered Nurses	Nurses Organization of Veterans Affairs
Association of Public Health Nurses	Oncology Nursing Society
Association of Rehabilitation Nurses	Pediatric Endocrinology Nursing Society
Association of Women's Health, Obstetric and Neonatal Nurses	Public Health Nursing Section, American Public Health Association
Commissioned Officers Association of the U.S. Public Health Service	Society of Urologic Nurses and Associates
Dermatology Nurses' Association	Wound, Ostomy and Continence Nurses Society
Gerontological Advanced Practice Nurses Association	



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Subcommittee on Labor, Health and Human Services, Education and Related Agencies  
 Committee on Appropriations  
 United States Senate, SD-131  
 Washington, DC 20510

### **Testimony on Behalf of the National Multiple Sclerosis Society**

Mr. Chairman and Members of the Committee, thank you for this opportunity to provide testimony regarding funding of critically important federal programs that impact those affected by multiple sclerosis. Multiple sclerosis (MS) is an unpredictable, often disabling disease of the central nervous system that interrupts the flow of information within the brain, and between the brain and body. Symptoms range from numbness and tingling to blindness and paralysis. The progress, severity, and specific symptoms of MS in any one person cannot yet be predicted, but advances in research and treatment are moving us closer to a world free of MS. Most people with MS are diagnosed between the ages of 20 and 50, with at least two to three times more women than men being diagnosed with the disease.

The National MS Society sees itself as a partner to the government in many critical areas. As we advocate for NIH research, we do so as an organization that funds over \$40 million annually in MS research through funds generated through the Society's fundraising efforts. And as we advocate for Lifespan Respite funding, we do so as an organization that works to provide some level of respite relief for caregivers. So while we're here to advocate for federal funding, we do it as an organization that commits tens of millions of dollars each year to similar or complementary efforts as those being funded by the federal government. Through these efforts, our goal is to see a day when MS has been stopped, lost functions have been restored, and a cure is at hand.

As Congress has not made any final decisions about the funding levels for FY2013 and also continues to re-examine possible alternatives to sequestration, we would like to take this time to remind the subcommittee about the importance of five key agencies/programs that have a direct impact on people living with MS as it discusses the FY2014 budget.

#### **Lifespan Respite Care Program**

Up to one quarter of individuals living with MS require long-term care services at some point during the course of the disease. Often, a family member steps into the role of primary caregiver

to be closer to the individual with MS and to be involved in care decisions. According to a 2011 AARP report, 61.6 million family caregivers provided care at some point during 2009 and the value of their uncompensated services was approximately \$450 billion per year—more than total Medicaid spending and almost as high as Medicare spending. Family caregivers allow the person living with MS to remain home for as long as possible and avoid premature admission to costlier institutional facilities.

Family caregiving, while essential, can be draining and stressful, with caregivers often reporting difficulty managing emotional and physical stress, finding time for themselves, and balancing work and family responsibilities. A 2012 National Alliance for Caregiving (NAC) survey of individuals providing care to people living with MS shows that on average, caregivers spend 24 hours a week providing care. Sixty four percent of caregivers were emotionally drained, 32% suffered from depression and 22% have lost a job due to caregiving responsibilities. In the broader caregiving community, it has been estimated that American businesses lose \$17.1 to \$33.36 billion each year due to lost productivity costs related to caregiving responsibilities.

The Lifespan Respite Care Program, enacted in 2006 under President Bush, provides competitive grants to states to establish or enhance statewide lifespan respite programs that better coordinate and increase access to quality respite care. Respite offers professional short-term help to give caregivers a break from the stress of providing care and has been shown to provide family caregivers with the relief necessary to maintain their own health and bolster family stability. With Lifespan Respite funding, state grantees have developed or enhanced statewide databases of respite care services, developed person-centered respite service options such as vouchers, and trained more volunteer and paid respite providers.

Perhaps the most critical aspect of the program for people living with MS is that Lifespan Respite serves families regardless of special need or age—literally across the lifespan. Much existing respite care has age eligibility requirements and since MS is typically diagnosed between the ages of 20 and 50, Lifespan Respite programs are often the only open door to needed respite services. The National MS Society asks that Congress preserve funding for the Lifespan Respite programs so that people with MS can remain at home, and family caregivers can remain productive members of the community and workforce and American businesses no longer suffer the monstrous financial impact caregiver strain currently has on them.

#### **National Institutes of Health**

We urge Congress to continue its investment in innovative medical research that can help prevent, treat, and cure diseases such as MS.

The NIH is the country's premier institution for medical research and the single largest source of biomedical research funding in the world. The NIH conducts and sponsors a majority of the MS related research carried out in the United States. Approximately \$122 million of FY 2011 and Recovery Act appropriations (the last available data) were directed to MS-related research. An invaluable partner, the NIH has helped make significant progress in understanding MS. NIH scientists were among the first to report the value of MRI in detecting early signs of MS, before symptoms even develop. Advancements in MRI technology allow doctors to monitor the progression of the disease and the impact of treatment.

Research during the past decade has enhanced knowledge about how the immune system works, and major gains have been made in recognizing and defining the role of this system in the development of MS lesions. These NIH discoveries are helping find the cause, alter the immune response, and develop new MS therapies that are now available to modify the disease course, treat exacerbations, and manage symptoms. Twenty years ago there were no MS therapies or medications. Now there are nine, with the two new oral medications now available and other new treatments in the pipeline. The NIH provided the basic research necessary so that these therapies could be developed. Had there been no federal investment in research, it's doubtful people living with MS would have any therapies available. The NIH also directly supports jobs in all 50 states and 17 of the 30 fastest growing occupations in the US are related to medical research or health care. More than 83% of the NIH's funding is awarded through almost 50,000 competitive grants to more than 325,000 researchers at over 3,000 universities, medical schools, and other research institutions in every state.

### **Centers for Medicare & Medicaid Services**

#### *Medicare*

Medicare is an extremely important program for many living with MS. It is estimated that over 20 percent of the MS population relies on Medicare as its primary insurer. The majority of these individuals are under the age of 65 and receive the Medicare benefit as a result of their disability. While sequestration excluded any cuts that would directly impact Medicare beneficiaries, the Society would like to remind Congress of the importance of having appropriate reimbursement levels for physicians to ensure participation in Medicare, promoting policies to allow access to diagnostics and durable medical equipment and discouraging overly burdensome cost-sharing for prescription drugs.

#### *Medicaid*

The National MS Society urges Congress to maintain funding for Medicaid and reject proposals to cap or block grant the program.

Medicaid provides comprehensive health coverage to over eight million persons living with disabilities, plus six million persons with disabilities who rely on Medicaid to fill Medicare's gaps. The latest statistics (which are pre-recession) show that about 5-10% of people with MS have Medicaid coverage. While that is a small figure, for these individuals, Medicaid is truly a safety net. The most recently available data (2007) reveals that the average annual direct and indirect (e.g. lost wages) cost for someone with MS in the U.S. is approximately \$69,000. After years of paying to manage their disease, some people with MS have spent the vast majority of their earnings and savings, making their financial situation so dire that they meet Medicaid's low income eligibility requirements.

Some policymakers have proposed capping or block granting Medicaid or more recently, placing a "per capita cap" whereby the federal government would limit each state to a fixed dollar amount per beneficiary. Any of these proposals would merely shift costs to states, forcing states to shoulder a seemingly insurmountable financial burden or cut services on which our most vulnerable rely. It could result in more individuals becoming uninsured, compounding the current problems of lack of coverage, overflowing emergency rooms, limited access to long-term services, and increased healthcare costs in an overburdened system. Also, by capping funds that

support home- and community-based care, the proposals would also likely lead to an increased reliance on costlier institutional care that contradicts the principles laid forth in the 1999 U.S. Supreme Court decision *Olmstead* and integrating and keeping people with disabilities in their communities.

While the economic situation demands leadership and thoughtful action, the National MS Society urges Congress to remember people with MS and all disabilities, their complex health needs, and the important strides Medicaid has made for persons living with disabilities particularly in the area of community-based care, and not modify the program to their detriment.

### **Social Security Administration**

The National MS Society urges Congress to provide \$12.3 billion for the Social Security Administration's (SSA) administrative budget.

Because of the unpredictable nature and sometimes serious impairment caused by the disease, SSA recognizes MS as a chronic illness or "impairment" that can cause disability severe enough to prevent an individual from working. During such periods, people living with MS are entitled to and rely on Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI) benefits to survive. People living with MS, along with millions of others with disabilities, depend on SSA to promptly and fairly adjudicate their applications for disability benefits and to handle many other actions critical to their well-being including: timely payment of their monthly benefits; accurate withholding of Medicare Parts B and D premiums; and timely determinations on post-entitlement issues, e.g., overpayments, income issues, prompt recording of earnings.

Providing \$12.3 billion would allow SSA to cover inflationary increases, continue efforts to reduce hearings and disability backlogs, increase deficit-reducing program integrity work, and replace some critical staffing losses in SSA's components. It would also help to minimize the closure of additional field offices. In the last two years, SSA closed a number of field offices due to limited resources. In many cases, applicants for benefits or those approaching retirement age who have questions about their eligibility or benefits have been forced to travel greater distances to visit a Social Security field office.

The disability backlog is also an area of serious concern. Since FY 2008, the number of claims pending for a disability medical decision rose from 565,286 to 707,700—an increase of 142,414, or 25.2 percent. Despite the fact that claims have exceeded three million for four successive years, the current staffing level for DDSs is 14,262, which is 1,107 (7.2 percent) below the level at the end of FY 2011, and 1,831 (11.3 percent) below the level at the end of FY 2010. SSA was making progress in addressing the enormous backlog of hearings cases, but resource issues have magnified the challenges. In June 2010, the number of pending hearings was down to 694,417 but by May 2012, it reached an all-time high of 823,828. Even with the dramatic increase in the volume of new hearing requests filed over the last few years, processing time has been reduced from 491 days in FY 2009 to 353 days in September 2012. If SSA does not receive adequate funding, this progress will regress and the disability hearings backlog will continue to mount, denying people with MS and other disabilities timely determinations and dispensing of benefits.

### **Food and Drug Administration**

The FDA is the United States' pre-eminent public health agency. Its role as the regulator of the country's pharmaceutical industry provides invaluable support and encourages vital progress for people living with MS and other diseases. In its capacity as the industry's regulator, the FDA ensures that drugs and medical devices are safe and effective for public use and provides consumers with confidence in new technologies. Because of the tremendous impact the FDA has on the development and availability of drugs and devices for individuals with disabilities, **the National MS Society requests that Congress provide adequate funding for FDA to complete its current mandates, which include developing a biosimilar approval pathway and appropriately implementing the Food and Drug Administration Safety and Innovation Act (FDASIA) of 2012.**

Advancements in medical technology and medical breakthroughs play a pivotal role in decreasing the societal costs of disease and disability. The FDA is responsible for approving drugs for the market and in this capacity has the ability to keep health care costs down. Each dollar invested in the life-science research regulated by the FDA has the potential to save upwards of \$10 in health gains. Breakthroughs in medications and devices can reduce the potential costs of disease and disability in Medicare and Medicaid and can help support the healthier, more productive lives of people living with chronic diseases and disabilities, like MS.

The approval of low-cost generic drugs saved the health care system \$140 billion in 2010 and nearly \$1 trillion over the past decade. However, recent funding constraints have resulted in a two year backlog of generic drug approval applications and could potentially cost the federal government and patients billions of dollars in the coming years. Similarly, FDA was tasked with creating a biosimilars approval pathway in 2010, which still needs to be finalized. This pathway is expected to allow a cheaper alternative for some biologic medications. The potential for these cost-saving medical breakthroughs and overall health care savings relies on a vibrant industry and an adequately funded FDA. Entire industries are working to enhance the lives of Americans with new medical devices and pharmaceuticals with tens of billions of dollars being spent annually by the NIH and industry in pursuit of new breakthroughs. The FDA has a comparatively small budget yet is charged with ensuring the safety and efficacy of these new products. User fee programs have been implemented in both in the fields of drugs and devices in order to enhance FDA's budget and review applications for novel treatments faster. Last year, Congress passed a reauthorization of this program, in FDASIA. Currently, however, both the FDA budget and user fees have been cut due to sequestration. This hole could negatively impact FDA's ability to perform its core functions and also have ramifications for new initiatives at the agency. In order to maintain the rigorous standards of the FDA, Congress must provide adequate funding for the agency.

### **Conclusion**

The National MS Society thanks the Committee for the opportunity to provide written testimony and our recommendations for FY2014 appropriations. The agencies and programs we have discussed are of vital importance to people living with MS and we look forward to continuing to working with the Committee to help move us closer to a world free of MS. Please don't hesitate to contact me with any questions.

**STATEMENT BY AMERICAN HEART ASSOCIATION**  
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**FY 2014 LABOR-HHS-EDUCATION APPROPRIATIONS: NIH, CDC, HRSA, AHRQ**

Although major progress has been made in the battle against cardiovascular disease (CVD) and stroke, CVD remains our nation's No. 1 and most costly killer of men and women, costing each year a projected \$313 billion in medical expenses and lost productivity. Stroke, alone, is our No. 4 killer, costing an estimated \$40 billion a year. Both remain major causes of disability.

Today, an estimated 83 million U.S. adults suffer from CVD and a recent study projects that by the year 2030, more than 40% of U.S. adults will live with CVD at a cost exceeding \$1 trillion annually. However, CVD and stroke research, prevention and treatment remain woefully underfunded and there is no steady stream of funding for the National Institutes of Health to mount a long-term, aggressive campaign against these terrible burdens on society.

The current federal budget dilemma makes a bad situation worse. The sequestration and funding the government under a continuing resolution endanger the health of tens of millions of CVD sufferers and threaten to undermine our struggling economy and global competitiveness. It is imperative that Congress provide stable and sustained funding for CVD and stroke research, prevention and treatment programs. The nation's physical and fiscal health are at stake.

**FUNDING RECOMMENDATIONS: INVESTING IN THE HEALTH OF OUR NATION**

Promising research that could stem the increase of heart disease and stroke risk factors remains unfunded. If Congress fails to capitalize on 50 years of progress, we will pay more in lives lost and health care costs. Our recommendations address the issues in a fiscally responsible way.

**Capitalize on Investment for the National Institutes of Health (NIH)**

NIH research helps prevent and cure disease, creates economic growth, fosters innovation, and preserves U.S. leadership in pharmaceuticals and biotechnology, and has transformed patient care. NIH is the primary funder of basic research – the starting point for all medical progress and an essential function of the Federal government that the private sector cannot fill.

NIH produces major returns on investment by developing new technologies that create good-paying jobs. In FY 2012, NIH created about 402,000 U.S. jobs and produced \$57.8 billion in economic activity. Each dollar NIH distributes in a grant returns \$2.21 in goods and services to the local community in just one year. Under sequestration, the NIH budget will be cut by 5% or \$1.6 billion, reducing its budget to 2007 levels, with an expected loss of 2,300 planned grants. Since NIH invests in every state and in 90% of congressional districts, 20,500 jobs will be lost and new economic activity will decline by \$3 billion. These cuts will compromise NIH's role as the world leader in medical research, delay treatments and cures as scientists are on the verge of breakthroughs, and dishearten early career investigators who may not return to science.

*American Heart Association Advocates:* We ask Congress to appropriate \$32 billion, same as our request last year, for NIH to restore sequester cuts, protect NIH from more cuts; and promote heart and stroke research. It will save lives, improve health, spur our economy and innovation.

**Enhance Funding for NIH Heart and Stroke Research: A Proven and Wise Investment**

Declining death rates from CVD and stroke are directly related to NIH research, with scientists on the cusp of discoveries that could lead to revolutionary 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 in stroke health care costs. Also, the Stroke Prevention in Atrial Fibrillation Trial 1 produced a 10-year net savings of \$1.27 billion.

**Cardiovascular Disease Research: National Heart, Lung, and Blood Institute (NHLBI)**

Although heart disease death rates have sharply fallen, there is still no cure for CVD and demand will only increase to find better ways for people to live healthy and productive lives with CVD. Stable and sustained NHLBI funding is essential to capitalize on investments that have discovered a gene variant linked to aortic valve disease; developed a new computer tomography scanner that provides better heart images with far less radiation; used genetics to identify and treat those at greatest risk of CVD; hastened drug development to reduce cholesterol and blood pressure; and created tailored strategies to treat, slow or prevent heart failure. Sustained funding will permit aggressive implementation of priority initiatives in the CVD strategic plan.

**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 severe physical and mental disabilities and emotional distress. In addition to the physical and emotional toll, stroke will cost a projected \$40 billion in medical expenses and lost productivity this year. And the future looks bleak. One study projects stroke prevalence will increase 25% over the next 20 years, striking more than 10 million individuals with direct medical costs rising 238% over the same time.

Stable and sustained NINDS funding is required to advance the nine top priorities in stroke prevention, treatment and recovery research. They include: accelerating translation of preclinical

animal models into clinical studies; preventing vascular cognitive impairment; expediting comparative effectiveness research trials; developing imaging biomarkers; expanding and integrating stroke trial networks; improving 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 2014.

### **Increase Funding for the Centers for Disease Control and Prevention (CDC)**

Prevention is one of the strongest tools in the fight against CVD and stroke. In our summary of prevention cost-effectiveness and value, we found, for example, comprehensive worksite health programs have shown a \$3.27 cut in medical costs for each dollar spent in the first 12-18 months. Yet, proven prevention strategies are not being implemented due to scarce funds. In addition to conducting research and evaluation and developing a surveillance system, the Division for Heart Disease and Stroke Prevention manages Sodium Reduction Communities and the Paul Coverdell National Acute Stroke Registry. Also, DHDSP, with the Centers for Medicare and Medicaid Services, implements Million Hearts™ to prevent 1 million heart attacks and strokes in 5 years.

The DHDSP also manages WISEWOMAN that serves uninsured and under-insured, low-income women ages 40 to 64. It helps them avoid heart disease and stroke by providing preventive health services, referrals to local health care providers – as needed – and lifestyle counseling and interventions tailored to risk factors to promote lasting behavior change.

*American Heart Association Advocates:* We join with the CDC Coalition in asking for \$7.8 billion for CDC's "core programs." AHA requests \$75 million for the DHDSPP and \$37 million for WISEWOMAN. Also, we advocate for \$35 million of the Prevention and Public Health Fund be allocated for Million Hearts™ to execute a national blood pressure educational campaign targeted at the 37 million Americans with uncontrolled 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, prompt CPR and defibrillation with an automated external defibrillator (AED) can more than double the chances of survival. Communities with comprehensive AED programs have survival rates approaching 40%, compared to the current less than 10%. HRSA's Rural and Community AED Program provides competitive grants to states to buy AEDs, strategically place them, and train lay rescuers and first responders in their use. Due to this effort, almost 800 patients were saved between August 1, 2009 and July 31, 2010. But limited resources allowed only 6% of applicants to be funded and only 8 states received funds in FY 2012.

*American Heart Association Advocates:* We ask for a FY 2014 appropriation of \$8.927 million to restore this life-saving AED program to FY 2005 levels when 47 states were funded.

**CONCLUSION**

Cardiovascular disease and stroke continue to inflict a deadly, disabling and costly toll on Americans. Our funding recommendations for NIH, CDC and HRSA will save lives and cut rising health care costs. We urge Congress to seriously consider our proposals that represent a wise investment for our nation and for the health and well-being of this and future generations.

Written Statement  
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Subcommittee on Labor, Health and Human Services, Education & Related Agencies  
In support of FY2014 Appropriations for the National Institutes of Health  
March 15, 2013

Mr. Chairman and Members of the Subcommittee, my name is Larry Swanson, Ph.D. I am the Milo Don and Lucille Appleman Professor of Biological Sciences at University of Southern California. Over the past 30 years my work has focused on the structure and organization of neural structures involved in motivated and emotional behaviors, as well as the development and wiring diagram of the nervous system more generally. This statement is in support of increased funding for the National Institutes of Health (NIH) for FY2014.

On behalf of the nearly 42,000 members of the Society for Neuroscience (SfN), thank you for your past support of neuroscience research at the NIH. SfN's mission is to advance the understanding of the brain and the nervous system; provide professional development activities, information and educational resources; promote public information and general education; and inform legislators and other policymakers.

This is an exciting time to be a part of the neuroscience field. Advances in understanding brain development, imaging, genomics, circuit function, computational neuroscience, neural engineering, and many other disciplines are leading to discoveries that were impossible even a few years ago. These will no doubt help us better understand and treat traumatic brain injury, Alzheimer's disease, Parkinson's disease, Down syndrome, schizophrenia, epilepsy, and post-traumatic stress disorder to name just a few. All told, there are more than 1,000 debilitating neurological and psychiatric diseases that strike over 100 million Americans each year, costing an estimated \$750 billion a year.

Now is the time to take advantage of scientific momentum, to pave the way for improved

human health, to advance scientific discovery and innovation, and to promote America's near-term and long-range economic strength. That requires robust investments in NIH that reverse the tide of stagnant and shrinking funding. These investments contribute to the economic growth of local communities in every state as part of the approximately 85 percent of the NIH budget that goes to funding extramural research. In 2012 alone, NIH supported more than 402,000 jobs and \$57.8 billion in economic output nationwide. Moreover, adequate funding will help preserve and expand America's role as a preeminent leader in biomedical research, supporting public and private institutions and fostering activity in the pharmaceutical, biotechnology, and medical device industries.

Seizing this moment can only happen if labs are able to pursue promising leads and innovative ideas can move forward. A constricted fiscal environment—compounded by sequestration—could stand in the way of that progress. It's impossible to say what breakthroughs will go undiscovered, but there is no doubt that this fiscal environment will result in delayed discoveries, with potentially huge opportunity costs for human health.

Last year, the Society stood with others in the research community in requesting at least \$32 billion for NIH. Today, the need is no less as the funding situation is even more precarious, and the Society urges Congress to reverse the current course and find ways to invest more in biomedical research. We urge Congress to act before sequestration takes full effect, further eroding the short and long-term capacity for discovery. 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.

### **Brain Research and Discoveries**

NIH-funded basic (also known as fundamental) research continues to be essential for

discoveries that will inspire scientific pursuit and medical progress for generations to come. Past NIH supported projects have helped neuroscientists make tremendous strides in diagnosing and treating neurological and psychiatric disorders. Given the long-term path of basic science and industry's need for shorter-term return on investment, private industry depends on federally-funded research to create a strong foundation for applied research. More than ever, it is important to support and fund research at levels from the most basic to translational.

The following are just two of the many basic research success stories in neuroscience emerging now thanks to strong historic investment in NIH and other research agencies:

*A New Model for Complex Brain Disease*

A new development from basic science shows tremendous potential for improving understanding of complex diseases such as Alzheimer's, which affects 5.4 million Americans and costs the United States \$200 billion in direct costs annually.

Traditionally, human disease is modeled by identifying and studying single gene mutations that run in families. Brain cells from mice genetically engineered to express this mutated gene can be studied to help illuminate the complex interactions that produce the disease.

Unfortunately for the ease of understanding these diseases, single gene mutations are not the only way to develop most diseases. With Alzheimer's disease, most cases are likely caused by mutations in many different genes. Thus, current models of Alzheimer's likely paint an incomplete picture of the disease.

New developments in stem cell technology are changing this picture. Stem cells are special cells that have the potential to become any other type of cell in the body. Due to advances in genetic engineering, scientists can now trick almost *any* cell into becoming a stem cell. This technique can be used to turn *skin* cells from patients with idiopathic Alzheimer's disease into

*brain* cells. These cells are ostensibly identical to the cells in that person's brain, complete with that person's unique genetic risk profile. Research with these cells could potentially help identify subgroups of patients who will respond differently to treatment in clinical trials.

For now, it is not clear whether the brain cells made from this technique are completely identical to the 70-year-old neurons in the brain of a patient with Alzheimer's disease. In addition, these cells are currently prohibitively difficult to create, making them unlikely to replace embryonic stem cells in other applications in the near future. Continued research funding will allow scientists to begin addressing these and other outstanding questions. This research exemplifies the powerful potential to apply basic research well beyond its original intent.

### ***The "Connectome"***

Current knowledge about the intricate patterns connecting brain cells (the "connectome") is extremely limited. Yet identifying these patterns and understanding the fundamental wiring diagram or architectural principles of brain circuitry is essential to understanding how the brain functions when healthy and how it fails to function when injured or diseased. Recent research suggests that some brain disorders, like autism and schizophrenia, may result from errors in the development of neural circuits. This research suggests a new category of brain disorders called "disconnection" syndromes.

Advanced technologies, along with faster and more data-efficient computers, now make it possible to trace the connections between individual neurons in animal models providing us with greater insight into brain dysfunction in mental health disorders and neurological disease. Scientists have already used these technologies to examine disease-related circuitry in rodent studies of Parkinson's disease. Their findings helped explain how a new treatment called deep brain stimulation works in people, and are being explored for treatments of other diseases.

**The Future of American Science**

As the subcommittee considers this year's funding levels, please consider that significant advancements in the biomedical sciences often come from young investigators. The current funding environment is taking a toll on the energy and resilience of these young people. America's scientific enterprise—and its global leadership—has been built over generations. Without sustained investment, we will quickly lose that leadership. 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.



**STATEMENT OF MICHAEL J. FITZPATRICK**

**EXECUTIVE DIRECTOR, NATIONAL ALLIANCE ON MENTAL ILLNESS**

**TO THE LABOR-HHS-EDUCATION SUBCOMMITTEE**

**COMMITTEE ON APPROPRIATIONS**

**U.S. HOUSE OF REPRESENTATIVES**

**REGARDING FY 2014 FUNDING FOR THE NATIONAL INSTITUTE OF MENTAL HEALTH (NIMH),  
THE SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION (SAMHSA) AND  
THE SOCIAL SECURITY ADMINISTRATION (SSA)**

**March 15, 2013**

Chairman Kingston and members of the Subcommittee, I am Mike Fitzpatrick, Executive Director of NAMI (National Alliance on Mental Illness). I am pleased today to offer NAMI's views on the Subcommittee's upcoming FY 2014 bill. NAMI is the nation's largest grassroots advocacy organization representing persons living with serious mental illnesses and their families. Through our 1,100 affiliates in all 50 states, we support education, outreach, advocacy and research on behalf of persons with serious mental illnesses such as schizophrenia, manic depressive illness, major depression, borderline personality disorder, severe anxiety disorders and major mental illnesses affecting children.

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

***The Impact of Sequestration on FY 2013 Funding for Mental Illness Research & Services***

Before detailing NAMI's recommendations for FY 2014, NAMI feels compelled to state for the record our concerns about the impact of the six month delay in enacting full year funding for



National Alliance on Mental Illness

agencies such as NIMH and SAMHSA, as well as the impact of the current across-the-board sequestration on these agencies.

- **Mental Illness Research** – Because of more than two-thirds of the NIMH budget is for ongoing multi-year studies, new research grants would face a cut as large as 20% in the current fiscal year – far above the 5% sequester. This will seriously undermine the capacity of NIMH to fund new research projects, including a proposed study on reducing shortening the duration between the onset of first break psychosis in schizophrenia and diagnosis and treatment. This is precisely the kind of research NIMH must be undertaking. We simply must do better at identifying psychosis earlier and intervening aggressively.
- **Mental Health Services** – It is projected that the sequester will result in an estimated 373,000 adults with serious mental illness and children with serious emotional disturbances going without treatment, leading to far costlier outcomes such as increased hospitalizations, involvement in the criminal justice system, and homelessness. As many as 8,900 homeless persons with serious mental illness would not get the vital outreach, treatment, housing, and support they need through the Projects for Assistance in Transition from Homelessness (PATH) program.

Mr. Chairman, beyond the immediate impact of sequestration in FY 2013, NAMI has enormous concerns about the impact of the current limitations on overall non-defense discretionary spending (NDD) put in place by the Budget Control Act of 2011. It is important to note that NDD is less than one-fifth of the overall federal spending, and less than 4.3% of GDP. Further, it is this category of spending that will amount to more than \$930 billion in deficit reduction over the coming decade – result being that NDD will be below what it was in the 1950s as a percent of GDP. In short, NDD simply cannot be cut any further if we as a nation want to maintain leadership in scientific research on serious mental illness and meet the basic needs of our most vulnerable citizens, including children and adults living with serious mental illness

***NIMH – Critical Investments Mental Illness Research***

It is critical for us to move beyond the current universe of palliative treatments for serious mental illness. Even with optimal care, some children and adults living with serious mental illness will not be able to achieve recovery (as defined as permanent remission). As NIMH Director Dr. Tom Insel has noted, consumers and families need rapid, effective treatments that target the core pathophysiology of serious mental illnesses and the tools for early detection. Mental illness research can develop new diagnostic markers and treatments, but this will require defining the pathophysiology of these illnesses. NIMH now has the research tools



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necessary. Now is the time to set an ambitious goal of finding cures to these extremely disabling illnesses. However, NIMH must have the resources it needs to support this critical research agenda.

While there was an increase in new and competing research project grants (RPGs) in FY 2012 (584), the long-term trend is not positive – increasing the NIMH “pay-line” to 22%. So long as strict limits on NDD remain in place and threats of sequestration loom, we are likely to see new RPGs decline and the “pay-line” at NIMH fall below 20%. As a nation, we cannot allow scientific opportunity and the search for new and breakthrough treatments for serious mental illness to pass us by.

The proposed NAPLS (North American Prodrome Longitudinal Study) initiative is a key example of this scientific opportunity. We now know that schizophrenia is a neurodevelopmental disorder and that by the time the behavioral symptoms appear it is often too late to significantly change the trajectory of the illness. The loss of cortical synapses in the brain begins long before the symptoms appear – the “prodrome” phase. NAPLS is designed to go upstream and identify risks and develop new interventions in this prodrome phase in order to dramatically shorten the duration between the prodrome and diagnosis and treatment. This is precisely the kind of breakthrough research that will get us beyond palliative treatment designed only to improve functioning. Further cuts to NDD and sequestration cannot be allowed to limit NIMH moving forward on scientific advance.

NAMI would also like to highlight a few of the critical ongoing studies that NIMH has been working on in 2012 and 2013. RAISE (Recovery After Initial Schizophrenia Episode) is the first ever large-scale trial exploring early and aggressive treatment integrating a variety of different therapies to reduce the symptoms and prevent the gradual deterioration of functioning that is characteristic in schizophrenia. Another critical project is Army STARRS (Study to Assess Risk and Resilience in Service Members), a joint Army-NIMH study of suicide and mental health among military personnel. It has already proved critical in identifying – as rapidly as possible – modifiable risk and protective factors related to mental health and suicide. It is also supporting the military's ongoing efforts to prevent suicide and improve soldiers' overall wellbeing.

***SAMHSA – Funding Must Focus on the Nation's Faltering Public Mental Health System***

Mr. Chairman, as a nation we are still in the process of assessing the full impact of the horrific events in Newtown, CT in December. From NAMI's perspective, what is clearly emerging is a consensus that there are significant gaps in the availability of mental health services and we



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must do more to intervene early to address the escalated risk of violence associated with untreated mental illness in general, and first break psychosis in particular. For example, we know that only 40% of people with serious mental illness have access to treatment in America today. Further, we know that even when mental health services are available, they are sometimes not the right ones and that often the very symptoms of a disorder such as schizophrenia prevent some from recognizing need for treatment.

Most importantly, over the years a robust body of research has been developed validating the evidence for effective mental health services that we know work. While these services exist in pockets across almost every state, they are difficult, if not impossible, to access in many communities. What are these services?

- Early identification and intervention of psychotic disorders,
- School based mental health services (in 50% of cases, symptoms appear by age 14),
- Services for individuals transitioning from childhood to adulthood – e.g. supported employment, supported education, case management, etc.
- Family education and support.
- Training for first responders – Mental Health First Aid & Crisis Intervention Training,
- Assertive Community Treatment (ACT)
- Acute inpatient beds, crisis stabilization programs,
- Supported housing
- Peer support

What is needed is for communities to invest in these evidence-based practices. In addition, SAMHSA must take more of a leadership role in guiding states and localities toward adopting these effective interventions. While SAMHSA programs such as the Mental Health Block Grant are only a small part of overall public mental health spending, they should nonetheless serve as a resource that guide state mental health agencies and local mental health systems toward filling gaps in services and more effectively targeting limited resources toward adults not now in treatment and early intervention for children and adolescents most at risk of first break psychosis.



A critical SAMHSA resource in guiding states toward this goal is the Mental Health Block Grant. Congress provided the Block Grant with a \$40 million increase between FY 2011 and 2012, increasing funding to its current level of \$459.8 million. Your colleagues in the Senate had proposed to boost the program by an additional \$20 million for FY 2013. NAMI urges you to continue this momentum ensure that states are able to address the more than \$4 billion in cuts that were made to overall public mental health agencies over the past 5 years AND address continuing gaps in services.

NAMI would also urge the Subcommittee to support other key SAMHSA programs targeted to serious mental illness experienced by children and adults including:

- The PATH Homeless Formula Grant program (funded in FY 2012 at \$64.8 million),
- The Children's Mental Health program (funded in FY 2012 at \$117.3 million),
- Continuation of the Primary Health and Behavioral Health Integration (funded in FY 2012 at \$65.8 million), and
- Suicide prevention activities at the Center for Mental Health Services under the Garrett Lee Smith Memorial Act (funded in FY 2012 at \$48 million).

#### ***Social Security's Administrative Budget***

Mr. Chairman, people with living with serious mental illness and other disabilities have been bearing the brunt of backlogs for disability claims and appeals at the Social Security Administration (SSA). Behind the numbers are individuals with disabilities whose lives have unraveled while waiting for decisions – families are torn apart; homes are lost; medical conditions deteriorate; once stable financial security crumbles; and many individuals die. For many years, SSA did not receive adequate funds for its mandated services. Between FY 2000 and FY 2007, the resulting administrative funding shortfall was more than \$4 billion. We thank this Subcommittee for its efforts to provide SSA with adequate funding for its administrative budget. Between 2008 and 2010, this Subcommittee provided SSA with the necessary resources to start meeting its service delivery needs. With this funding, SSA was able to hire thousands of needed new employees.

There can be no doubt that this additional staff greatly enhanced SSA program operations. Unfortunately, SSA has received virtually no increase in its LAE since 2010. In FY 2011, SSA's appropriation was a small decrease from the FY 2010 level and the FY 2012 appropriation was only slightly above the FY 2010 level. NAMI urges Congress to provide SSA with adequate resources to carry out all necessary program functions.



**Public and Outside Witnesses Hearing**

**Written Statement of**

**Chief Hank C. Clemmensen**

**President and Chairman of the Board**

*on behalf of the*

**Emergency Services Coalition for Medical Preparedness**

*presented to the*

**SUBCOMMITTEE ON  
LABOR, HEALTH AND HUMAN SERVICES,  
EDUCATION  
AND RELATED AGENCIES  
OF THE COMMITTEE ON APPROPRIATIONS**

**U.S. House of Representatives**

March 15, 2013

Thank you, Chairman Kingston, Ranking Member DeLauro, and the members of the subcommittee for the opportunity to testify on the importance of properly protecting first responders from the threat of bioterrorism and pandemic disease. I am Chief Hank Clemmensen of the Palatine Rural Fire Protection District in Inverness, Illinois and the President and Chairman of the Board of the International Association of Fire Chiefs (IAFC). The IAFC is also a member of the Emergency Services Coalition for Medical Preparedness. The Coalition consists of nearly 20 national organizations which represent all members of the public safety community – law enforcement, fire and emergency medical services, public health officials, emergency management officials, and public works employees. I thank the committee for its continued interest in our nation’s level of medical countermeasures and for the opportunity to represent the concerns of our nation’s first responders.

As we approach the 12<sup>th</sup> anniversary of the 9/11 terror attacks, the first responder community marks the sacrifice made by our men and women on that day. In the days and weeks following the attacks, our men and women continued to serve our nation courageously without regard to their personal health. We have learned many lessons from the 9/11 attacks as well as the anthrax attacks that followed in 2001. With Congress’ leadership and support, we have vastly improved preparedness and training in many areas, but there is still work to be done.

As a fire chief, I know my personnel will respond when called upon. If you ask if they will respond to a fire, the answer is “yes.” If you ask if they will respond to a medical emergency, the answer is “yes.” If you ask if they will respond to a pandemic or bio-attack, the answer is “yes.”

However, in recent years, numerous published studies have uncovered interesting questions and concerns held by first responders. *The Journal of Occupational and Environmental Health* published a recent study by Columbia University examining the factors associated with the

ability and willingness of essential workers to report for duty during a pandemic. The survey studied 1,103 workers from six essential workgroups in Nassau County, New York and found that although a substantial proportion of participants reported that they would be able (80%); much less would be willing (65%) to report for duty. In fact, only 49% of participants reported that they would both be willing and able to report for duty.

Other studies report similar trends. A study published in a 2007 issue of *Disaster Management & Response* surveyed paramedics to examine their concerns about responding to a pandemic. In this study, 80% of the respondents reported that they would not stay on duty without protective equipment or proper vaccination. If provided protective equipment, but not a vaccine, this rate decreased to 61% of the respondents who would not stay on duty. This study also reported that 91% of the respondents would stay on duty if they were provided protective equipment and proper vaccination. While that response rate is a good sign, it dramatically falls to a projected response rate of only 38% if the respondent fears their immediate family is not properly protected.

America's public safety officers will do everything we can to protect our communities, but we need Congress to do all it can to protect first responders and address a major gap in preparedness for a pandemic or bioterrorist attack. Currently, we only have surveys that suggest a potential lack of response, but we should not wait for an attack to provide absolute proof. Although the Pandemic and All-Hazards Preparedness Reauthorization Act (P.L. 113-5) has finally passed, I am concerned that unless this committee appropriates funding to support medical countermeasures specifically for first responders, a major gap will continue to exist in our preparedness efforts.

As such, the Coalition believes Congress should appropriate \$20 million for Fiscal Year 2014 to the Department of Health and Human Services' Office of the Assistant Secretary for Preparedness and Response (ASPR) to create pilot programs to protect emergency services providers and their households. Extending these protections to first responders and their families (those who live in their home) will improve preparedness and prevent first responders from infecting their families.

Additionally, in 2010, the Institute of Medicine recommended that the anthrax vaccine currently stored into the Strategic National Stockpile (SNS) be distributed on a *voluntary* basis to emergency service providers. This recommendation has yet to be acted on, meaning we will have a fully unprotected workforce until this program is enacted.

The SNS contains other products that can be put in the hands of emergency service providers and their households. The National Postal Model (NPM) utilizes postal workers who would volunteer to distribute antibiotics after a terrorist attack to reduce surges at dispensing points. The postal workers who volunteer in this capacity are provided Household Antibiotic Kits (HAKs) or med-kits. These kits are pre-positioned in their homes and provide protection for the postal worker and their family. This type of program should be extended to pre-position med-kits in the homes of first responders.

The Centers for Disease Control (CDC) and Prevention has conducted a Home Medkit Evaluation Pilot Study in St. Louis to examine households' abilities to maintain a med-kit as directed and preserve it for emergency use. This study found that out of 4,000 households, including first responders, corporate employees, and community health clinic staff, 97% of the respondents returned their med-kits intact. The study found that of the 1,535 first responders involved in the study, 99% returned their med-kits intact at the conclusion of the study. While

this is just one study, as a fire chief, I trust my personnel to maintain all other aspects of their personal protective equipment, and these home med-kits would be no exception.

Pre-positioning med-kits in the homes of first responders will address a critical time gap in preparedness planning. During an attack, if first responders are waiting for the release of medical countermeasures from the SNS to the state and then through public health agencies to responders, they have indicated through multiple studies less inclination to report for duty. This significant time lag in response is simply unacceptable. Pre-positioned home med-kits will facilitate faster response times and improved confidence and focus for our first responders.

Congress initially created the NPM through an appropriation of \$20 million. As a result, I ask this committee to make a similar appropriation of \$20 million in FY 2014 for the ASPR to complement the NPM by providing home med-kits to first responders in the five cities where the NPM is currently operational (Boston, Louisville, Minneapolis, Philadelphia, and San Diego). Additionally, I encourage this committee to task ASPR to use this appropriation to consider expanding the provision of home med-kits for first responders in other communities throughout the nation. Lastly, I encourage this committee to require ASPR to complete a study to identify the costs for providing pre-event medical protections to all of our nation's first responders who may be asked to mitigate a pandemic or act of bioterrorism.

First responders are rightfully assumed to be ready and willing to respond to emergencies – including pandemics and acts of bioterrorism. However, we do not send firefighters into a fire with ineffective protective equipment – similarly, we should not send them into a bioterrorist attack without the most basic of antibiotics. First responders' ability to fulfill their mission requires proper protection. Also, we must prevent the families of first responders from being infected by the first responders when they return home from work. Congress must address this

significant gap in preparedness and enhance first responders' ability to safely respond to a pandemic or bioterrorist attack.

On behalf of America's public safety leadership, I would like to thank you for the opportunity to address this important issue and provide this testimony. The Emergency Services Coalition for Medical Preparedness looks forward to working with Congress, the Administration, and state and local stakeholders to develop a medical countermeasures program that will protect America's first responders and their families. I look forward to answering any questions that you may have.

**ANSR****AMERICANS FOR NURSING SHORTAGE RELIEF****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**

*Submitted for the Record to the House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies - March 15, 2013*

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. Nurses work in a variety of settings, including primary care, public health, long-term care, surgical care facilities, schools, and hospitals. The March 2008 study, *The Future of the Nursing Workforce in the United States: Data, Trends, and Implications*, calculates a projected demand of 500,000 full-time equivalent registered nurses by 2025. According to the U.S. Bureau of Labor Statistics, due to the country's gaining population and increasing health needs, employment of registered nurses is expected to grow by 26 percent from 2010 to 2020 resulting in 711,900 new jobs. The Title VIII Nursing Workforce Education Programs will help fill these vacancies by supporting training programs designed to meet these health care needs.

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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

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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 21<sup>st</sup> century nurse workforce. For nearly 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 workforce 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 scholar-

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ships 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 2013. We look forward to working with the Subcommittee to prioritize the Title VIII programs in FY 2014 and the future.



**Written Testimony to the House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies**

**Submitted by: Robert Riggs, Chief Executive Officer  
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**FY 2014 Appropriations Recommendations:**

- Provide \$32 billion for the National Institutes of Health in Fiscal Year 2014, with corresponding increases to the National Institute of Arthritis, Musculoskeletal and Skin Disease, the National Heart, Lung and Blood Institute, the National Institute of Allergy and Infectious Diseases, and the National Institute of Minority Health and Health Disparities.
- The Committee recommendation for the National Institute of Arthritis, Musculoskeletal and Skin Disease to provide sustained investment in the Scleroderma research portfolio which has a proven success in providing insight to the medical and research community's understanding of the disease, as well as other connective tissue diseases.
- The Committee's encouragement of the National Heart, Lung and Blood Institute to expand research related to the pulmonary complications of Scleroderma patients with Systemic sclerosis.

**The Scleroderma Foundation:**

On behalf of the Scleroderma Foundation and the estimated 300,000 Americans impacted by the disease, I appreciate the opportunity to submit written testimony to the House Labor, Health and Human Services, Education and Related Agencies Appropriations Subcommittee regarding the Foundation's recommendations for Fiscal Year 2014 Appropriations for the Department of Health and Human Services. Given the work of this subcommittee to accommodate the crippling parameters of budget sequestration, long term deficit reduction and recent cuts to non-defense, discretionary spending, I greatly respect the Committee's continued

commitment in support of investments in medical research to enhance patient care and sustained funding support for health programs that benefit patients with rare, costly and difficult to treat diseases like Scleroderma.

Based in Danvers, Massachusetts, the Scleroderma Foundation is a non-profit, national organization committed to providing support to the thousands of patients and their families with the disease, promoting public awareness and education for medical professionals and the public about the condition, and supporting both federal and private research into finding the cause, treatment options and hopefully, a cure for Scleroderma and other connective tissue diseases.

With a network of 23 chapters, more than 150 support groups and a toll-free helpline for patients and their families, the Foundation strives to provide high quality support through peer counseling, physician referrals and educational information. The Foundation supports nearly \$1 million per year in research funding, providing seed money for new and established Scleroderma investigators. Determined by our Peer Research Review Committee of medical experts, this annual investment, which is the largest single expenditure of the Foundation, backs high quality and innovative research at universities, hospitals and laboratories.

**Scleroderma:**

Scleroderma is a rare, progressive disease that involves the hardening and tightening of the skin and connective tissues. Considered both a rheumatic and connective tissue disorder, patients experience an overproduction of collagen in the skin, tissue and underlying muscle (localized Scleroderma). Severe cases of Scleroderma also impact internal organs such as the heart, lungs, kidneys, intestines as well as internal systems and blood vessels (Systemic Scleroderma).

**Localized** Scleroderma primarily impacts the skin, but can also affect the associated tissue and muscles. In localized cases, thickened areas of skin appear lighter or darker than surrounding skin and can develop in patches, which is a type classified as "*morphea*."

Thickened skin can also appear in abnormally thick bands, or in a "*linear*" pattern on the arms,

legs or face (termed "*Scleroderma en coup de sabre*"). Most patients with the localized form of the disease improve over time, while a darkened skin appearance and localized muscle weakness, may remain permanently.

**Systemic Scleroderma** (SSc), which is experienced by approximately one-third of Scleroderma patients, affects the internal organs and systems, blood vessels, as well as the skin. In *limited cutaneous systemic sclerosis* or *CREST syndrome*, both the internal and external tightening occurs in strictly the face, hands, forearms, lower legs and feet and patients experience CREST symptoms. CREST symptoms include:

- **C**alcinosis, calcium deposits form in the connective tissues of the hands, face, abdominal area and arms.
- **R**aynaud's phenomenon, blood vessels in the hands, but also in the feet contract due to stress, anxiety or cold temperature appearing white or blue.
- **E**sophageal dysfunction, muscle weakness is experienced in the esophagus resulting in patients experiencing trouble swallowing or heartburn.
- **S**clerodactyly, rigid fingers caused by thickened or tight skin, cause patients difficulty in bending or straitening their digits.
- **T**eleangiectasia, the appearance of red spots in the hands and face.

*Diffuse cutaneous scleroderma* affects large areas of skin as well as the esophagus, gastrointestinal tract, lungs, kidneys, heart, and joints and occurs with a sudden onset. Given the impact of the fibrous collagen development and the long term impact within the associated internal organs, individuals with the diffuse form of Scleroderma often experience more serious long term patient prognoses and life threatening complications. These patients are at risk of developing pulmonary fibrosis or hypertension, heart issues such as cardiomyopathy, arrhythmia or myocarditis, kidney disease, and gastrointestinal issues in the esophagus and intestines. While Scleroderma can affect anyone regardless of age, race, ethnicity or gender, there is an increased incidence amongst women and minorities. Typically women are three times more likely to

experience Scleroderma and African Americans, Native Americans and other minority patient communities are more likely to be diagnosed with Systemic Scleroderma. In most cases, the localized form of the disease is more common to children and the average onset of the disease is between the ages of 25 and 55 years old.

Given the different types, unpredictable and sometimes swift progression of the disease, and its rarity, Scleroderma, like many other autoimmune diseases is difficult for medical practitioners to accurately diagnose. Diagnosis requires specialized tests and consultation with rheumatologists, dermatologists and other specialists depending on the disease progression. Furthermore, given the unique experience of each patient's disease progression, treatments are determined on a patient-by-patient basis depending on the experienced symptoms.

As there is no cure for the Scleroderma, physicians are left offering treatments which minimize the impact of the disease's progression and alleviate the symptoms. Skin softening agents, anti-inflammatory medication and exposure to heat, are used for typical skin and tissue symptoms. For patients experiencing the internal effects of the systemic class, physicians work to mitigate the long term impact of the disease on internal organs through specialized and personalized treatments. While researchers and medical experts have yet to determine the cause of Scleroderma, preliminary findings point to a susceptibility gene which indicates a predisposition likely tied to familial history of rheumatic disease. Scleroderma patients however rarely have relatives, either immediate or extended, who also have the disease.

**The Importance of Federal Investment in Scleroderma:**

Despite this Committee's likely limited 302 (b) allocation and efforts to reduce federal debt and deficit spending, federal funding for science and medical research at the National Institutes of Health has remained a bi-partisan, widely supported, critical national investment. As the Committee faces increased pressure due to the effects of budget sequestration, I urge your continued support of the historical commitment this Committee has made to providing adequate funding for the NIH.

In FY12 and the current fiscal year, the National Institutes of Health's estimated research portfolio for Scleroderma remains \$25 million and consists of grants funded predominantly at the National Institute of Arthritis, Musculoskeletal and Skin Disease (NIAMS) as well as through the National Heart, Lung and Blood Institute, the National Institute of Allergy and Infectious Diseases, and the National Institute of Minority Health and Health Disparities. Like many successful research portfolios, the proven success of the NIH supported Scleroderma portfolio, has provided translational knowledge into connective tissue diseases along with the medical community's increased understanding of Scleroderma.

The Committee's investment has provided hope to the millions of patients with diseases like Scleroderma which are difficult to diagnose, treat and currently without a cure. I know that within her lifetime, Scleroderma patients like Cynthia Cervantes, a high school junior that was afforded the opportunity to testify before this committee five years ago, will benefit from tangible advancements delivered through NIH findings.

As this Committee makes the difficult determination of discretionary spending, I urge your continued support of important health related research and patient care programs at NIH. Thank you again for providing the opportunity to submit written testimony on behalf of the Scleroderma Foundation.

**Testimony of the National Violence Prevention Network  
Concerning Fiscal Year 2014 Appropriations**

*Submitted for the Record to the House Appropriations Subcommittee on  
Labor, Health and Human Services, Education, and Related Agencies – March 15, 2013*

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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 2014 funding level to \$25 million to allow for nationwide expansion of the NVDRS program. FY 2013 NVDRS funding is \$3.5 million.

**BACKGROUND**

Each year, about 55,000 Americans die violent deaths. Suicide and homicide are the fourth and fifth leading causes of death for Americans of all ages. 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**. Six additional states; **Connecticut, Illinois, Maine, Minnesota, New York, and Texas** plus the **District of Columbia**, were previously approved for participation in the NVDRS, but were unable to join due to funding shortfalls. 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**

In January 2013, President Obama and Vice President Biden released, “Now Is The Time: The President’s Plan to Protect our Children and our Communities by Reducing Gun Violence.” Recognizing the utility of NVDRS in understanding violence, one of the major strategies in the report calls for an infusion of \$20 million for NVDRS to facilitate its nation-wide expansion.

The National Violence Prevention Network, a coalition of national organizations that advocate for national violence prevention programs, is supporting the Administration’s request by calling on Congress to provide \$25 million for NVDRS in FY 2014. As state funding is based on population and violent death rates, significant funding increases are necessary to incorporate larger states into the program. However, the cost of *not* implementing the program is much greater: without national expansion of the program, thousands of American lives remain at risk.

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 2014 NVDRS appropriation of \$25 million.

**Testimony of the Association of Public Television Stations (APTS) and  
the Public Broadcasting Service (PBS)  
Before the House Committee on Appropriations, Subcommittee on Labor, Health and Human  
Services, Education and Related Agencies**

On behalf of America's 361 public television stations, we appreciate the opportunity to submit testimony for the record on the importance of federal funding for local public television stations and PBS. We urge the Subcommittee to support level funding of \$445 million in two-year advance funding for the Corporation for Public Broadcasting in FY 2016, and level funding of \$27.3 million for the Ready To Learn program at the Department of Education in FY 2014.

**Corporation for Public Broadcasting—FY 2016 Request: \$445 million, two-year advance funded**

More than 40 years after the inception of public broadcasting, local stations and PBS continue to serve as the treasured educational and cultural institutions envisioned by their founders, reaching America's local communities with unique, essential and unsurpassed programming and services.

Local stations and PBS treat their audience as citizens rather than mere consumers, providing essential services to all Americans, not just the 18-49 year olds to whom advertisers hope to appeal to. We serve everyone, everywhere, every day, for free.

Public broadcasting serves the public good—in education, public affairs, public safety, the preservation of the national memory and celebration of the American culture, and many other areas—and richly deserves public support. The overwhelming majority of Americans agree. In a recent bi-partisan poll conducted by Hart Research Associates / American Viewpoint, 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 shows that Americans consider PBS to be the second most appropriate expenditure of public funds, behind only military defense.

Federal support for CPB and local public television stations has resulted in a nationwide system of locally owned and controlled, trusted, community-driven and community responsive media entities that form an incredibly successful public-private partnership. At an annual cost of about \$1.35 per year for each American, public broadcasting is a smart investment creating important economic activity while providing an essential educational and cultural service. Public media provides a 6 to 1 return on investment for every federal dollar. In addition, public broadcasting directly supports over 20,000 jobs, and the vast majority of them are in local public television and radio stations in hundreds of communities across America.

We seek federal funding for public broadcasting because we are part of the nation's public service infrastructure, just like public libraries, public schools and public highways.

Funding through CPB is absolutely essential to public television stations. Stations rely on the federal investment to develop local programming, operate their facilities, pay their employees and provide community resources on-air, online and on-the-ground. 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 broadcast source for these rural communities.

More than 70 percent of funding appropriated to CPB reaches local stations in the form of Community Service Grants. On average, federal spending 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 (and in a handful of instances, an even larger percentage) of their total budget. For all stations, this 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."

A 2007 GAO report concluded that these federal Community Service Grants are an irreplaceable source of revenue, and that "substantial growth of nonfederal funding appears unlikely." It also found that "cuts in federal funding could lead to a reduction in staff, local programming or services." In addition, a June 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.

Federal support combined with the advent of digital technology has created enormous potential for stations, allowing them to bring content to Americans in new, innovative ways while retaining our fundamental public service mission. Americans streamed 229 million videos across PBS' web and mobile platforms in January 2013 alone and in December 2012, 45% of all video minutes consumed on kids' internet sites were on PBSKIDS.org. Further, public television stations are now utilizing a wide array of digital tools to expand their current roles as educators, local conveners and vital sources of trusted information at a time when their communities need them most.

As the leading source of digital learning tools for America's preschool teachers and K-12 classrooms with resources to help build science, math and literacy skills, PBS and local stations make-up the nation's largest classroom. Local stations provide free, cutting edge, educational content for all Americans so that regardless of their family's income, children have access to safe, non-commercial media that has helped prepare 90 million American kids for success in school and has been proven to help close the achievement gap.

Stations are also responding to the needs of the 21st century classroom by expanding digital educational resources for teachers, students and parents alike. For example, stations and PBS are working together on PBS Learning Media, an online portal where educators can access standards-based, curriculum-aligned digital learning objects created from public television content as well as material from the Library of Congress, National Archives, and other contributors to the Department of Education's Learning Registry. Over 28,000 homeschooling families rely on PBS for instructive resources like PBS LearningMedia.

Stations are also building homegrown learning platforms like Maryland Public Television's Thinkport online system, which the state superintendent of schools has credited with helping raise Maryland's students to the top of the student achievement rankings nationwide.

In their role as community conveners, stations have been working to confront the dropout crisis in America's high schools. CPB developed the American Graduate initiative, a significant investment and partnership with local stations and their communities to address the daunting high school dropout problem. Stations are providing resources and services to raise awareness, coordinate action with community partners, and work directly with students, parents, teachers, mentors, volunteers and leaders to lower the drop-out rate in their respective communities.

Local public television stations have also embraced the opportunities of digital technology as a way to help address emergency response and homeland security issues in their communities. Stations like Las Vegas PBS have integrated their digital technology with local public safety officials to provide enhanced emergency communications that better aid the responders and provide citizens with needed information during a crisis. Vegas PBS is also the largest job trainer in Nevada, and this manifold mission of service is being emulated by public television stations nationwide.

Local public television stations serve as essential communications hubs in their communities providing unparalleled local coverage of news, current events, and state legislatures that encourages every American to become a more informed citizen. Public television is the place for real public affairs programming, real news, real history, real science, real art that makes us think, teaches us useful things, and inspires us to be a better, more sophisticated, more civilized, more successful people. We bring the wonders of the world – Broadway shows, the finest museums, the best professors and much more – to the most remote places in our country.

In order for our stations to continue playing this vital role in their communities, APTS and PBS respectfully request \$445 million for CPB, two-year advance funded for FY 2016.

Two-year advance funding is essential to the mission of public broadcasting. This longstanding practice, which was 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.

Public television's history of editorial independence has paid off in unprecedented levels of public trust—for the tenth consecutive year, the American people have ranked PBS as one of the most trusted national institutions. Advance funding and the firewall it provides is vital to maintaining this credibility among the American public.

In addition, local public broadcasting stations are able to 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.

Finally, the two-year advance funding mechanism also gives stations and producers the critical lead time needed to plan and produce high-quality programs. The signature series that demonstrate the depth and breadth of public television, like Ken Burns' *The Civil War* and Henry Hampton's *Eyes on the Prize*, take several years to produce. Ken Burns' documentary schedule is already planned through 2019, and it will educate the nation on subjects ranging from the Vietnam War to the history of country music.

The fact that stations know they will have funding to support projects like these in advance is critical for producers to be able to actively develop groundbreaking projects. 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.

The two-year advance funding is essential for stations as they continue to plan the production of the unparalleled programming and local services that educate, inspire, inform and entertain the American people in the unique way only public broadcasting can.

**Ready To Learn—FY 2014 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 math and reading skills of children between the ages of two and eight, especially those from low-income families. Federal support funds evidence-based television programs and digital content that teach key reading, math and STEM skills, effectively reaching our nation's children.

Together, CPB and PBS are collaborating with teams of math and literacy experts, technologists, education organizations, and producers, to design and test media that can help close the achievement gap. Numerous studies show that RTL content has a significant and positive effect on the educational lives of children who use it. For example, one study showed that children who watched the RTL-funded PBS series SUPER WHY! scored 46% higher on standardized tests than those who did not watch the show.

Pivoting off the success in literacy, public media has incorporated early math skills into RTL to help bridge the achievement gap by further innovating educational media content, educating kids inside and outside the classroom, and engaging local communities. Studies have already shown that using RTL content in low-income homes improves pre-school age kids' numerical sense skills. In addition to the content, new tools will be provided including a sophisticated progress tracking system that equips parents and educators with the means to measure student progress, in real time. RTL will continue to be rigorously evaluated for its

appeal and efficacy, so that the program can continue to offer America's youngest citizens the tools they need to succeed in school and in life.

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 \$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.

In FY 2013 the President's budget proposed consolidating Ready To Learn into a larger grant program. APTS and PBS are concerned that the consolidation of this program would end the ground-breaking educational impact that RTL has had on kids nationwide, and particularly those with limited access to other educational resources. Consolidation would deny RTL the benefits that come from the unique understanding of needs and relationship that local public media stations have with the communities they serve. At the same time, consolidation undermines PBS's ability to create television and online content on an economy of scale that results from producing once for national distribution through member stations who can tailor outreach to the demands 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 local-national 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.

Ready To Learn symbolizes the mission of public media and is a shining example of a public-private partnership as federal funds are leveraged to create the most appealing and impactful children's educational content that is supplemented by online and on-the-ground resources. Without the Ready To Learn 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.

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One hundred seventy million Americans regularly rely on public broadcasting -- on television, on the radio, online, and in the classroom -- because we provide them something they need that no one else in the media world provides: A place to think. A place to learn. A place to grow. A tool for the citizen. None of this would be possible without the federal investment in public broadcasting.

We request that Congress continue its commitment to this highly successful public-private partnership by continuing to provide level funding for the two-year advance of the Corporation for Public Broadcasting and the stand alone Ready To Learn Program.



**Written Testimony of Susan Savage, RDH, BSDH  
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 2014 Appropriations for the Department of Health and Human Services Impacting Oral Health

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On behalf of the American Dental Hygienists' Association (ADHA), thank you for the opportunity to submit testimony regarding appropriations for Fiscal Year 2014. 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 \$32 million for Title VII Program Grants to expand and educate the dental workforce; 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 \$10 million be appropriated; ADHA urges \$5 million for the CDC Oral Health Prevention and Education Campaign; ADHA urges funding sufficient so that all states have a school-based sealant program; ADHA urges at least \$25 million for oral health programming at CDC; ADHA urges \$20 million for Dental Health Improvement Grants. ADHA also urges funding of \$450 million for NIDCR.

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 an accredited dental hygiene education program 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 130,000 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. 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 2014**

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. ADHA recommends funding at a level of \$32 million for FY 2014.

**Alternative Dental Health Care Provider Demonstration Project Grants –  
Fund at a level of \$10 million in FY 2014**

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. Dental workforce expansion is one of many areas that need to be addressed as we move forward with efforts to increase access to oral health care services to those who are currently not able to obtain the care needed to maintain a healthy mouth and body. 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. Such new providers are already authorized in Minnesota and are under consideration in Connecticut, Vermont, Kansas, Maine, New Hampshire, Washington State and several other states. The stopgap FY2013 Labor, Health and Human Services 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. 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 \$10 million for FY 2014 to support these vital demonstration projects.

**Oral Health Prevention and Education Campaign –  
*Fund at a level of \$5 million in FY 2014***

A targeted national campaign led by the Centers for Disease Control to educate the public, particularly those who are underserved, about the benefits of oral health prevention could vastly improve oral health literacy in the country. While significant data has emerged over the past decade drawing the link between oral health and systemic diseases like diabetes, heart disease, and stroke, many remain unaware that neglected oral health can have serious ramifications to their overall health. Data is also emerging to highlight the role that poor oral health in pregnant women has on their children, including a link between periodontal disease and low-birth weight babies. ADHA advocates an allocation of \$5 million in FY 2014 for a national oral health prevention and education campaign.

**School-Based Sealant Programs –**

***Fund at a level sufficient to ensure school-based sealant programs in all 50 states***

Sealants have long-proven to be low-cost and effective in preventing dental caries (cavities), particularly in children. While most dental disease is fully preventable, dental caries remains the most common childhood disease, five times more common than asthma, and more than half of all children age 5-9 have a cavity or filling. The CDC noted that data collected in evaluations of school-based sealant programs indicates the programs are effective in stopping and preventing dental decay. Significant progress has been made in developing best practices for school-based sealant programs, yet most states lack well developed programs as a result of funding shortfalls. ADHA encourages the transfer of funding from the Public Health and Prevention Fund sufficient to allow CDC to meaningfully fund school-based sealant programs in all 50 states in FY 2014.

**Oral Health Programming within the Centers for Disease Control –**

***Fund at a level of \$25 million in FY 2014***

ADHA joins with others in the dental community in urging \$25 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 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 innovate new types of oral health programs and promote a data-driven approach to oral health programming. ADHA advocates for \$25 million in funding for grants to improve and support oral health infrastructure and surveillance.

**Dental Health Improvement Grants –**

***Fund at a level of \$20 million in FY 2014***

HRSA administered dental health improvement grants are an important resource for states to have available to develop and carry out state oral health plans and related programs. Past grantees have used

funds to better utilize the existing oral health workforce to achieve greater access to care. Previously awarded grants have funded efforts to increase diversity among oral health providers in Wisconsin, promote better utilization of the existing workforce including the extended care permit (ECP) dental hygienist in Kansas, and in Virginia implement a legislatively directed pilot program to allow patients to directly access dental hygiene services. ADHA supports funding of HRSA dental health improvement grants at a level of \$20 million for FY 2014.

**National Institute of Dental and Craniofacial Research –  
*Fund at a level of \$450 million in FY 2014***

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 \$450 million in FY 2014.

**Conclusion**

ADHA appreciates the difficult task Appropriators face in prioritizing and funding the many meritorious programs and grants offered by the federal government. In addition to the items listed, ADHA joins other oral health organizations in support for continued funding of the Dental Reimbursement Program (DRP) and the Community-Based Dental Partnerships Program established under the Ryan White HIV/AIDS Treatment and Modernization Act (\$14 million for FY 2014) as well as block grants offered by HRSA's Maternal Child Health Bureau (\$8 million for FY 2014). 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 through 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.

To: U.S. House Subcommittee on Labor, HHS, Education and Related Agencies Appropriations  
From: AcademyHealth, 1150 17<sup>th</sup> Street NW Suite 600, Washington DC 20036  
Re: FY 2014 Funding for Health Services Research & Health Data at AHRQ, NCHS, CMS, NIH

AcademyHealth is pleased to offer this testimony regarding the role of health services research in improving our nation's health and the performance of the health care and public health systems. 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 4,400 scientists and policy experts and 160 organizations that produce and use research to improve health and health care. We advocate for the funding to support health services research; a robust environment to produce this research; and its more widespread dissemination and use.

As medical research discovers for cures for disease, health services research discovers cures for the health system. This research diagnoses problems in health care and public health delivery and identifies solutions to improve outcomes for more people, at greater value. This research is used by patients, health care providers, public health professionals, hospitals, employers, and public and private payers to enhance consumer choice, improve patient safety, and promote high quality care.

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 into the merits of different policy options for delivery system transformation, patient-centered quality improvement, community health, and disease prevention offers

policymakers in both the public and private sectors the information they need to improve quality and outcomes, identify waste, eliminate fraud, increase efficiency and value, and promote personal choice.

Put plainly, health services research helps Americans get their money's worth when it comes 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.

In this regard, AcademyHealth was deeply troubled by the subcommittee's assault on health services research in the proposed FY 2013 Labor, Health and Human Services, Education and Related Agencies Appropriations Act last year—a move that went against the subcommittee's historic, bipartisan support of this work. AcademyHealth realizes the pressure Congress and the administration face to reduce the national debt. However, to virtually eliminate all funding for health services research—and terminate the lead agency responsible for it—is pennywise and pound foolish in the current fiscal environment. It won't generate significant budgetary savings, and it will drain the marketplace of new ideas that help policymakers realize real savings by understanding how best to control rising health care costs.

This year, we respectfully ask that the subcommittee instead consider the value of health services research and 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 2014 funding recommendations for agencies that support health services research and health data under the subcommittee's jurisdiction.

**Agency for Healthcare Research and Quality**

The Agency for Healthcare Research and Quality (AHRQ) is the federal health services research agency with the sole purpose of improving health care. AHRQ funds health services research and health care improvement programs in universities, medical centers, and research institutions 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 protocols that prevent medical errors and 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 an overall funding level of \$430 million for AHRQ in FY 2014.

**Centers for Disease Control and Prevention**

The 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 enhanced the agency's ability to 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 \$162 million for NCHS in FY 2014, put the agency on track to become a fully functioning, 21<sup>st</sup> Century, national statistical agency.

**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 2014. 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.

#### **Centers for Medicare and Medicaid Services**

Steady funding decreases for the Office of Research, Development and Information have hindered CMS's ability to meet its statutory requirements and conduct new research to strengthen public insurance programs, which together cover nearly 100 million Americans and comprise 45 percent of America's total health expenditures. As these federal entitlement programs continue to pose significant budget challenges for both federal and state governments, it is critical that we adequately fund research to evaluate the programs' efficiency and effectiveness and seek ways to manage their projected spending growth. AcademyHealth supports CMS's discretionary research and development budget to improve the effectiveness and efficiency of these programs.

In conclusion, the accomplishments of health services research would not be possible without the leadership and support of this subcommittee. We hope the subcommittee give strong consideration to our FY 2014 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 Lisa Simpson, President and CEO of AcademyHealth, at 202.484.1100 or [lisa.simpson@academyhealth.org](mailto:lisa.simpson@academyhealth.org).



# 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 2014 Budget**

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

Committee on Appropriations

U.S. House of Representatives

Washington, D.C.

Submitted by

Dr. Crispin Taylor, Executive Director, American Society of Plant Biologists

March 15, 2013

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 asks that the Subcommittee Members encourage increased support for plant-related research within NIH; 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, nutraceuticals, 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 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 our testimony on behalf of the American Society of Plant Biologists. For more information about ASPB, please see [www.aspb.org](http://www.aspb.org).

Dr. Crispin Taylor

Executive Director

American Society of Plant Biologists



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## Written Testimony for the House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies

### Fiscal Year 2014 Appropriations Funding Recommendations on Behalf of the GBS/CIDP Foundation, International

Submitted by: Ken Singleton, Executive Director  
GBS/CIDP Foundation International  
The Holly Building 104 1/2 Forrest Ave., Narberth, PA 19072  
(610) 667-0131, [ken.singleton@gsb-cidp.org](mailto:ken.singleton@gsb-cidp.org)

#### **FY 2014 Appropriations Recommendations:**

- For the **National Institutes of Health**, provide \$32 billion in Fiscal Year 2014, with proportional increases to the National Institute of Neurological Disorders and Stroke, the National Center for Advancing Translational Sciences, the National Institutes of Allergy and Infectious Disease and the Office of Rare Disease Research.
- The Committee recommendation for the **Centers for Disease Control and Prevention** to improve health outcomes for GBS and CIDP patients by promoting enhanced awareness and recognition activities in partnership with stakeholders.
- The Committee's commendation of **National Institute of Neurological Disorders and Stroke** research portfolio focused on disorders of the nervous system and encouragement to pursue expanded research focused on inflammatory disorders impacting the peripheral nervous system such as Guillain-Barré Syndrome, Chronic Inflammatory Demyelinating Polyneuropathy, and related conditions.
- The Committee's recommendation that the **Office of Rare Diseases Research** initiate research activities in peripheral nervous system disorders and express support for the **National Center for Advancing Translational Sciences** to pursue a GBS indication for current, off-label treatment options.



Chairman Kingston, Ranking Member DeLauro and Members of the Subcommittee, thank you for providing me with the opportunity to submit written testimony to the Labor, Health and Human Services, Education and Related Agencies Appropriations Subcommittee on behalf of the Guillain-Barré Syndrome (GBS)/Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) Foundation, International.

As a non-profit, 501(c)(3) organization, the GBS/CIDP Foundation, International advocates for research into prevention, access to affordable treatments and high quality patient care. Inspired by his experience with GBS, Bob and Estelle Benson founded the GBS/CIDP Foundation, International. Starting as a small support group for patients with GBS in 1980, the first support group meeting consisted of eight people in the Benson's dining room.

Over the past thirty years, the Foundation has expanded to over 30,000 members in 33 countries, offering support and assistance to ensure that patients with GBS, CIDP and associated disease variants are provided with proper diagnosis, treatment and support. In line with the founding principles of the Bensons, the mission of the Foundation remains to improve the quality of life for individuals and families worldwide affected by GBS, CIDP and 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.

**Guillain-Barré Syndrome and Chronic Inflammatory Demyelinating Polyneuropathy:**

GBS and CIDP are inflammatory, autoimmune disorders which affect the Peripheral Nervous System and the myelin insulation surrounding the sensory, motor or autonomic nerves. Patients with *Guillain-Barré Syndrome* experience a sudden onset of muscle weakness or paralysis over a few days, which presents through decreased reflexes in the arms and legs, low

blood pressure and in severe cases, trouble breathing or swallowing. While the cause is unknown, nearly half of cases occur after the patient experiences a viral or bacterial infection. Given the sudden and unexpected onset of GBS, patients require swift and costly treatments with hospitalization. Patients undergo plasma exchange (PE) and physician administered intravenous immune globulins (IVIg), which lessen the severity of the acute phase and accelerate patient recovery. An estimated three thousand to six thousand Americans develop GBS each year.

*Chronic Inflammatory Demyelinating Polyneuropathy* is the chronic form of GBS and patients with this disease experience a gradual onset which causes weakness and often a loss of reflexes. The associated disease variants describe the development of the disease which include “progressive,” developing a several year development, “recurrent,” consisting of multiple active episodes or “monophasic”, occurring in a single episode. The management of the disease requires systematic treatments with IVIg to ensure the best patient prognosis. Without proper diagnosis and treatment, the disease can progress and leave patients disabled. CIDP is extremely rare and occurs in one out of every 1.5 to 3 million Americans.

For both GBS and CIDP, costly biologic treatments are necessary and the only medical option for the management and treatment of these chronic and life threatening conditions. Some private health insurance companies which offer prescription drug coverage, have created a “specialty” or fourth tiered payment plan for high cost treatments like IVIg. Unlike other out of pocket requirements for traditional drug co-pays, which require patients to pay \$10- \$50, patients receiving drugs on this “specialty” tier are required to pay co-insurance for the treatment, sometimes up to 25-33%. For IVIg, this could over \$2,500 for a single treatment.

The high costs of these “specialty” tiers place a large financial burden on GBS and CIDP patients and their families, restrict patient access to medically necessary treatments and at times

force patients to go without vital, prescription drugs. The promise of federally supported medical advancements at the National Institutes of Health, into more effective treatments and lower cost treatments and hopefully one day a cure, are important to the thousands of patients impacted by these diseases each year.

**Federal Investment at NIH and CDC:**

The medical community has provided countless examples of the impact biomedical research has had on devastating and once terminal illnesses. Simple and small NIH grants from unknown, unestablished medical researchers have led to groundbreaking discoveries providing effective preventions and interventions, life-saving treatments and for some diseases, a cure. We cannot guarantee nor expect that if left to the private medical research and drug development sectors, these revolutionary developments would be made. Some disease like GBS, CIDP and the associated disease variants do not lend themselves to quick profit or a patient base large enough to bring about private investment. Some discoveries take the lifetime commitment of dedicated researchers that are not aimed at profits, but at people. Not aimed at fame, but of relieving human suffering.

It's not only the reason why the National Institutes of Health was established, but also why the federal investment in medical research is so highly respected and supported by the American public. The American people support the promise of what NIH discoveries can accomplish and the impact it could have on a mother or father with Alzheimer's disease, wife or husband struck by GBS or child with cancer. And they are proud to lead the world in medical innovation and the investment it brings about. But, as the funding our nation provides for medical research fails to keep pace with opportunity, this leadership role could be slipping through our grasp.

Reversing sequestration and the corresponding NIH cuts is imperative in our goal of maintaining the nation's status as the leader of groundbreaking biomedical health discoveries. The GBS/CIDP Foundation supports a \$32 billion request for fiscal year 2014 for the National Institutes of Health, with proportional increases to the National Institute of Neurological Disorders and Stroke (NINDS), the National Center for Advancing Translational Sciences (NCATS), the National Institutes of Allergy and Infectious Disease and the Office of Rare Disease Research (ORDR). This increase will allow for the possibility of an expanded research portfolio focused on inflammatory disorders of the nervous system at NINDS, ORDR to initiate research activities in peripheral nervous system disorders, and for NCATS to pursue a GBS indication for current, off-label treatment options through this Committee's support and encouragement.

Additionally, given the importance of accurate patient diagnosis for nervous system disorders and the swift administration of the correct treatments which supply the best patient prognosis, we respectfully request the subcommittee recommendation for the Centers for Disease Control and Prevention to promote enhanced awareness and recognition activities of GBS and CIDP, in partnership with stakeholders.

This subcommittee's past investment in biomedical research has provided hope to the millions of patients with rare diseases which are difficult to diagnose, treat and prevent. I respectfully urge your continued support of important health related research and patient care programs at NIH and CDC. Thank you again for providing me with the opportunity to submit written testimony on behalf of the thousands of GBS and CIDP patients and their families and the GBS/CIDP Foundation, International.

## Centers for Disease Control and Prevention (CDC) Coalition

C/o American Public Health Association 800 I Street NW Washington, DC, 20001 202-777-2514

Testimony of the CDC Coalition submitted for the record on March 15, 2013  
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.

The CDC Coalition believes that 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, constant public health emergencies, new and reemerging infectious diseases and other unmet public health needs – **we urge a funding of \$7.8 billion for CDC's programs in FY 2014**. We are deeply disappointed with the failure to avert the sequester which will cut roughly \$300 million from CDC's FY 2013 funding and we urge you to work to reverse cuts. These cuts come on top of the \$740 million reduction to CDC's budget authority in FY 2011. At the same time, state and local health departments are operating on tight budgets and with a smaller workforce, losing more than 46,000 public health jobs since 2008. These cuts are not sustainable and will reduce the ability of CDC and its state and local grantees to investigate and respond to public health emergencies as well as food borne and infectious disease outbreaks.

By translating research findings into effective intervention efforts, CDC has been a key source of funding for many of our state and local programs that aim to improve the health of communities. Federal funding through CDC 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 remains the nation's No. 1 killer. In 2010, over 597,000 people in the U.S. died from heart disease, accounting for nearly 25% of all U.S. deaths. More males than females died of heart disease in 2010 (307,384 compared to 290,305), while more females than males died of stroke that year (77,109 compared to 52,367). Stroke is the fourth leading cause of death and is a leading cause of disability. In 2010, about 129,000 people died of stroke (60% of them females), accounting for about 1 of every 19 deaths. CDC's Heart Disease and Stroke Prevention Program, WISEWOMAN, and the Million Hearts program are working improve cardiovascular health.

Cancer is the second most common cause of death in the United States. There are 1,660,290 new cancer cases and 580,350 deaths from cancer expected in 2013. According to the National Institutes of Health, in 2008 the overall cost for cancer in the U.S. was more than \$201.5 billion: \$77.4 billion for direct medical costs, \$124.0 billion for indirect mortality costs (cost of lost productivity due to premature death). 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.

Although more than 25.8 million Americans 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. CDC's Division of Diabetes Translation funds critical diabetes prevention, surveillance and control programs.

Arthritis is the most common cause of disability in the U.S., striking 50 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.

Over the last 20 years, obesity rates have dramatically increased and rates remain high. More than one third of adults are obese and 17% of children between the ages of 2-19 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 to develop other habits of healthy nutrition and activity.

An estimated 443,000 people die prematurely every year due to tobacco use. CDC's tobacco control efforts seek to prevent tobacco addiction in the first place, as well as help those who want to quit. We must continue to support these vital programs and reduce tobacco use in the United States.

According to CDC, only one out of three high school students participate in daily physical education classes and one in three children and adolescents are overweight or obese. And every year, more than 400,000 teen girls give birth and nearly half of all sexually transmitted diseases occur

in young people between the ages of 15 and 24. CDC plays a critical role in ensuring good public health and health promotion in our nation's schools.

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, 18 percent of who are undiagnosed. Also, the number of people living with HIV is increasing, as new drug therapies are keeping HIV-infected persons healthy longer and dramatically reducing the death rate. Prevention of HIV transmission is the best defense against the AIDS epidemic that has already killed 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. More than 19 million new infections occur each year. CDC estimates that STDs, including HIV, cost the U.S. healthcare system as much as \$17 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

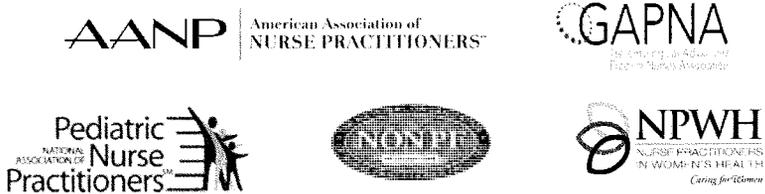
program. For every dollar spent on childhood vaccines to prevent thirteen diseases, \$10.20 is saved in direct and indirect costs. An estimated 20 million cases of disease and 42,000 deaths are prevented each year through timely immunization. Despite the incredible success of the program, it faces serious financial challenges.

Injuries are the leading causes of death for persons aged 1-44 years. Unintentional injuries and violence such as older adult falls, unintentional drug poisonings, child maltreatment and sexual violence accounts for over 35% of emergency department visits annually. Annually, injury and violence cost the U.S. approximately \$406 billion in direct and indirect medical costs including lost productivity. CDC's Injury Center works to prevent injuries and to minimize their consequences when they occur by researching the problem, identifying the risk and protective factors, developing and testing interventions and ensuring widespread adoption of proven prevention strategies.

One in every 33 babies born each year in the U.S. is born with one or more birth defects. Birth defects are the leading cause of infant mortality. Children with birth defects who survive often experience lifelong physical and mental disabilities. More than 50 million people in the U.S currently live with a disability, and 17 percent of children under the age of 18 have a developmental disability. The National Center on Birth Defects and Developmental Disabilities conducts programs to protect and improve health by preventing birth defects and developmental disabilities.

CDC's National Center for Environmental Health is essential to protecting and ensuring the health and well being of the American public 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 which has been cut by nearly 25 percent since 2010.

In order to meet the ongoing public health challenges outlined above, we urge you to adopt our **FY 2014 request of \$7.8 billion for CDC's programs.**



**Statement of the Nurse Practitioner Roundtable**

**Fiscal Year 2014 Appropriations for the Title VIII Nursing Workforce Development Programs, Nurse-Managed Health Clinics, and the National Institute of Nursing Research**

**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**

**March 15, 2013**

Chairman Kingston, Ranking Member DeLauro, and Subcommittee Members:

The Nurse Practitioner Roundtable is comprised of the five nurse practitioner associations representing the interests and concerns of more than 155,000 nurse practitioners (NPs) across the country. Our organizations advocate for the active role of NPs as providers of high-quality, cost-effective, comprehensive, patient-centered healthcare and their patients. NPs have been furnishing primary, acute and specialty healthcare to patients of all ages and walks of life for nearly half a century. They assess the health care needs of patients; order, perform, supervise, and interpret diagnostic tests; make diagnoses; and initiate and manage treatment plans including prescribing medications. They are the healthcare providers of choice for millions of patients. More than 70 percent of NPs are actively practicing as primary care providers throughout the country.

NPs work with organizations representing the rest of the advanced practice registered nurse (APRN) and general nursing community to support a strong federal investment in the Nursing Workforce Development programs, to secure authorized funding for Nurse-Managed Health Clinics, and fund research initiatives at the National Institute of Nursing Research (NINR) to ensure that a sufficient supply of the highest-quality nursing services is available to meet the nation's increasing need for effective and efficient healthcare.

### **The Growing Demand for Nurse Practitioners**

As millions of Americans enroll in expanded health insurance coverage in 2014, our nation will face a dramatically increased demand for health care providers at a time when many professions face shortages and increasing retirements. Policy makers recognize that NPs are essential to meeting the demand for primary care services for women, children, the uninsured and patients with special needs, yet we face a provider shortage that is projected to continue. A significant and sustained investment in the education of NPs is needed to produce the workforce required to meet our population's demands for health care services.

Nursing education programs are under increased pressure as Congress wrestles with reducing the federal deficit. The six-month continuing resolution (H.J. Res. 117) enacted last September extended funding for Title VIII nurse education programs at fiscal year 2012 levels, a reduction of more than four percent from 2011. These programs now face the uncertainty of sequestration, which could eliminate 645 training opportunities for advanced practice registered nurses.

Funding for Advanced Education Nursing in fiscal year 2012 totaled only \$64 million. This is

the only federal funding source for Nurse Practitioner education programs since they have no access to graduate medical education (GME) funds.

### **Title VIII Nursing Workforce Development Programs**

The Nursing Workforce Development programs authorized under Title VIII of the Public Health Service Act have provided the resources to help educate and prepare nurse practitioners and other qualified nurses to meet our nation's healthcare needs for nearly half a century. Title VIII programs reinforce nursing education from entry-level preparation through graduate study, and support the institutions that prepare NPs and other nurses to practice in rural and medically underserved communities. These are the only federal programs focused on filling the gaps in the workforce of health professionals unmet by traditional market forces and on producing a workforce capable of caring for the nation's increasingly diverse population.

Title VIII programs also address the serious need for more nursing and Nurse Practitioner faculty. Nursing schools were forced to turn away nearly 80,000 qualified applications from entry-level baccalaureate and graduate nursing programs in 2012, according to an AACN 2012-2013 enrollment and graduation survey, with faculty vacancies being a primary reason. The Title VIII Nurse Faculty Loan Program aids in increasing nursing school enrollment capacity by supporting students pursuing graduate education in exchange for their service as faculty for four years after graduation. The NP Roundtable urges you to provide \$251 million for the Nursing Workforce Development programs authorized under Title VIII of the Public Health Service Act in fiscal year 2014.

**Nurse-Managed Health Clinics**

Nurse-Managed Health Clinics (NMHCs) are health care delivery sites managed by Nurse Practitioners and other APRNs, staffed by an interdisciplinary team of healthcare providers that may include physicians, social workers, public health nurses, and therapists. These clinics are often associated with a school, college, university, or department of nursing, and occasionally with community health centers or independent nonprofit healthcare agencies.

NMHCs are particularly important threads in the nation's healthcare safety net, caring for patients in medically underserved areas including rural communities, Native American reservations, senior citizen centers, elementary schools, and urban housing developments. Treating populations that are among the most vulnerable to chronic illnesses, NMHCs are committed to the management and reduction of acute and chronic disease and creating healthier communities by providing primary care and other services, as well as counseling and educating patients and the community regarding health promotion and disease prevention. These clinics also serve as important clinical education training sites for NPs, other nursing students and health professionals. This is particularly important given the lack of clinical training sites that has been recognized as one of the barriers to nursing school enrollment. The NP Roundtable requests that you provide \$20 million for the Nurse-Managed Health Clinics authorized under Title III of the Public Health Service Act in fiscal year 2014.

**The National Institute of Nursing Research**

As one of the 27 Institutes and Centers at the National Institutes of Health (NIH), the National Institute of Nursing Research (NINR) funds research that provides the evidence-based

foundation for nursing practice. Nurse-scientists at NINR examine ways to innovate and improve care models to deliver safe, high quality health services in more cost-effective ways. NINR engages in research on improving the management of care for patients during illness and recovery, reducing the risks of disease and disability, promoting healthy lifestyles, enhancing the quality of life for those with chronic disease, and compassionately caring for individuals at the end of life. In addition, NINR provides critically needed faculty to support the education of the next generations of nurses and Nurse Practitioners; its training programs develop the nurse-researchers of the future, many of whom go on to serve as faculty in our nation's nursing schools. The NP Roundtable encourages you to provide \$150 million for the NINR in fiscal year 2014.

Nurse Practitioners recognize that controlling the growth of federal spending is a national priority, but they also know it is critical for Congress to provide sustained stable funding to maintain nurse practitioner education programs. Without a workforce of well-educated and clinically prepared NPs providing evidence-based care to those in need, our healthcare system will not be sustainable. The NP Roundtable respectfully urges you to provide for that workforce by committing \$251 million for the Title VIII Nursing Workforce Development programs, \$20 million for Nurse-Managed Health Clinics, and \$150 million for the National Institute of Nursing Research in fiscal year 2014.

American Association of Nurse Practitioners  
Gerontological Advanced Practice Nurses Association  
National Association of Nurse Practitioners in Women's Health  
National Association of Pediatric Nurse Practitioners  
National Organization of Nurse Practitioner Faculties



NATIONAL HISPANIC COUNCIL ON AGING

Yanira Cruz - President & CEO

*Working to improve  
the lives of Hispanic  
older adults and  
their families*

**Submitted by the National Hispanic Council on Aging (NHCOA)**

**Prepared for the House of Representatives Labor, Health and Human Services, Education and Related Agencies Appropriations Subcommittee**

**Addressing the Department of Health and Human Services, Administration on Aging FY 2014 Budget**

March 15, 2013

The Honorable Congressman Jack Kingston  
Chairman  
House of Representatives Appropriations Subcommittee – Labor, Health and Human Services,  
Education and Related Agencies Subcommittee  
2372 Rayburn House Office Building  
Washington, DC 20515

The Honorable Congresswoman Rosa DeLauro  
Ranking Member  
House of Representatives Appropriations Committee – Labor, Health and Human Services,  
Education and Related Agencies Subcommittee  
2413 Rayburn House Office Building  
Washington, DC 20515

Dear Chairman Kingston and Ranking Member DeLauro:

The National Hispanic Council on Aging (NHCOA)— the leading national organization working to improve the lives of Hispanic older adults, their families, and caregivers— thanks you for the opportunity to submit written testimony. Wisely investing in the future and implementing programs that will strengthen our country is a particularly daunting task given the limited resources and constraints at hand. Therefore, NHCOA recognizes the difficult decisions that lie ahead for your committee. We write to you today to express our support for the fiscally sensible programs created the Administration on Aging’s Older Americans Act programs. Specifically, we ask that you appropriate \$656 million for its congregate and home-delivered meal programs.

For more than 30 years, NHCOA has been a strong voice dedicated to ensuring our nation's Hispanic seniors—the fastest growing segment of the U.S.'s rapidly expanding aging population—enjoy healthy and happy golden years. Alongside its Hispanic Aging Network of nearly 40 community-based organizations across the country, NHCOA reaches thousands of Hispanics each year. NHCOA integrates research, policy, and practice to tackle the unique challenges Latino seniors face as they age, and by educating and empowering them to be better advocates for themselves. As an integral part of this mission, NHCOA incorporates a special focus on families and caregivers in all its programmatic priorities, recognizing the paramount importance of family in the Latino community.

Older Americans Act programs, implemented by the Administration on Aging, effectively serve older adults across the country, while also providing a wide variety of services that are flexible enough to meet the needs of every community. The Older Americans Act authorizes programs that train families to support their loved ones, put people back to work, put food on the table, reduce elder abuse, and help communities develop the policies they need to help their older adults age with dignity. Because of programs that provide basic necessities like Meals on Wheels, there are fewer older adults having to choose between putting food on the table or filling their prescription. As appropriators, your support is critical for the continued success of these life saving programs.

The population of Hispanic older adults, as well as the population of older adults in general, is growing rapidly. Every 7 seconds, today, and for the next 20 years, someone in the United States will turn 60. In terms of the Hispanic community, we have about three million Latino older adults. By 2050, that number will increase to 17 million. Moreover, the Hispanic community as a whole is projected to grow to 30% of the entire U.S. population by 2050. That

means nearly one-in-three people will be Hispanic. By 2019, the Latino senior population will become the largest non-White older adult population in the U.S.

Funding for the programs of the Older Americans Act has not grown to match this population increase. A reduction in funding will mean that fewer people will have access to home delivered meals, communities will have less funding to operate senior centers, and families will have less support in caring for their loved ones. These programs make a vital difference in communities across the country, but to keep effectively serving the growing population, an adequate level of funding is imperative.

Hispanics face a variety of challenges that make aging particularly difficult. Many Hispanic older adults have spent their lives in jobs that have not helped them prepare for their later years. Low-wage, physically-demanding jobs are all too common in the Latino community, and these jobs offer little in the way of health care and pension benefits. As a result, many Hispanics enter their golden years with little money saved and little or no previous access to health insurance. Cultural and linguistic differences are additional barriers to accessing needed services. All of these economic, physical, and social factors combined result in Hispanic older adults earning below average Social Security benefits, enduring chronic health problems at disparate rates, and having a harder time gaining access to needed services.

In 2011, an organization called Hispanics in Philanthropy released a study about the programs of the Older Americans Act and the difficulties those programs faced in serving Hispanic communities. The study found that many communities were unable to deliver the services and information necessary to help Hispanic older adults, despite being readily available. Many communities lack the financial resources to hire and train new workers to serve the rapidly

aging Hispanic population. Appropriating more money for Older Americans Act programs will allow communities to better serve their older adults and also to embrace their growing diversity.

NHCOA has worked and spoken with Hispanic older adults and their families across the country, and though the needs and concerns of the population are diverse, they were unified in their support for the Older Americans Act as a main vehicle to address the struggles of simply making ends meet. Every day, Hispanic older adults must decide what to sacrifice – food on the table, rent and utilities, or medications. Family members juggle multiple jobs to care for older adults in their families and are unaware of existing opportunities for caregiver training. Incidents of elder abuse are not reported because older adults do not know where to turn. Hispanic older adults also suffer disproportionately from chronic medical conditions like diabetes, are less likely to manage hypertension, and are significantly more likely to suffer from HIV/AIDS. Without sufficient funding, however, the Older Americans Act is not able to adequately address these problems.

Funding Older Americans Act programs is a wise investment in the future. Health management programs, which are proven effective at reaching Hispanic older adults, can keep minor health problems from becoming chronic, or even life threatening, conditions. The National Family Caregiver Support Program offers trainings and services that are flexible enough to meet the needs of every community. Elder abuse prevention programs have the potential to save lives. Through small investments that help older adults age in dignity, we can achieve real savings in more costly programs, such as Medicare and Medicaid. Furthermore, making an investment to train service providers on how to effectively work with a diversifying older adult population is a necessary preemptive measure and cannot happen at a better time.

NHCOA respectfully asks that your committee maintain or increase funding for Older Americans Act programs to help them meet the needs of the growing older adult population. This increased appropriation will not only allow communities to maintain the services and supports they already offer, but it will also improve their capacity to serve the rapidly growing population of U.S. Hispanic older adults.

Specifically, we ask for you to appropriate \$656 million to support the Administration on Aging's Congregate Nutrition Services and Home-Delivered Nutrition Services. These are programs that prevent the most vulnerable elders from going to sleep hungry. Of all racial and ethnic groups, Hispanics are the most likely to lack access to enough food. According to the Department of Agriculture, over one-in-four Hispanic households were food insecure in 2011. One of the older adults that NHCOA serves earns \$840 each from Social Security, her only source of income. However, her monthly rent is \$810, and nutrition services of the Older Americans Act are vital for her health. This situation is not uncommon, and it is one reason why nutrition services are so important for Hispanic older adults. Please consider the most vulnerable as you appropriate funds for FY2014.

Respectfully Submitted,



Dr. Yanira Cruz, Dr.PH  
President and CEO

**WRITTEN STATEMENT OF**

**Rebecca Morley**

**Executive Director**

**National Center for Healthy Housing**

**CDC's Healthy Homes and Childhood Lead  
Poisoning Prevention Program**

The Honorable Jack Kingston, Chairman  
Subcommittee on Labor, Health and Human Services, Education and Related Agencies  
Committee on Appropriations, US House of Representatives

The Honorable Rosa DeLauro, Ranking Member  
Subcommittee on Labor, Health and Human Services, Education and Related Agencies  
Committee on Appropriations, US House of Representatives

**March 15, 2013**

Thank you for the opportunity to discuss the nation's healthy homes and childhood lead poisoning prevention efforts and why the Centers for Disease Control and Prevention (CDC) program must be restored. In FY 2012, CDC funding for lead poisoning prevention was reduced from \$29 million to less than \$2 million. Health departments across the country have begun to shut down their lead poisoning prevention activities. We estimate that approximately 345 environmental public health positions have been eliminated. These positions include epidemiologists, data managers, nurse case managers, environmental health professionals and community health workers. Parents are unable to get the services they need to protect their children. The abatement and education programs at the U.S. Department of Housing and Urban Development and the U.S. Environmental Protection Agency will be unable to properly target their resources to the children and families who need them the most because CDC will be unable to carry out its surveillance mission, identify lead poisoned children, adequately fund and staff local and state health departments, and, most importantly, prevent poisoning in the first place.

I have worked in the field of childhood lead poisoning prevention for twenty years, beginning in the Office of Healthy Homes and Lead Hazard Control at HUD. Currently, I am the executive director of the National Center for Healthy Housing (NCHH). NCHH is a national non-profit organization dedicated to creating safe and healthy housing for children through practical and proven steps. Today, I also represent the National Safe and Healthy Housing Coalition, a group of over 150 organizations dedicated to creating safe and healthy homes for all people in the U.S. The country's strategy to eliminate childhood lead poisoning is articulated in the 2001 federal interagency strategy to address childhood lead poisoning, which I helped to write for the President's Task Force on Environmental

Health and Safety Risks to Children.<sup>1</sup> I have also published many articles on effective policies for addressing hazards in our nation’s housing and recently co-authored a book entitled “Safe and Healthy Homes: Research, Policy, and Practice.”

**Recommendation**

We urge Congress to restore CDC’s funding for the Healthy Homes and Lead Poisoning Prevention Program to \$29 million.

**Background on the CDC Lead Poisoning Prevention Program**

In FY 2011, CDC funded 35 states and localities to carry out five core functions:

1. Screen children for lead poisoning;
2. Track incidence and causes;
3. Inspect the home and other exposures and remove the environmental threat;
4. Publish guidance for clinical and public health practitioners for evidence-based case management; and
5. Provide education to the public and health care providers.

CDC leads the national lead poisoning primary prevention efforts. Between 2008 and 2010, primary prevention efforts helped reduce by 200,000 the number of children who have been exposed to lead—saving at least \$7.5 billion through avoided loss in IQ and associated reductions in lost lifetime productivity,<sup>2 3</sup> not to mention the pain and suffering endured by families with poisoned children. CDC

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<sup>1</sup> President’s Task Force on Environmental Health Risks and Safety Risks to Children. Eliminating Childhood Lead Poisoning: A Federal Strategy Targeting Lead-based Paint Hazards. Washington DC: U.S. Department of Housing and Urban Development and U.S. Environmental Protection Agency, February 2009.

<sup>2 3</sup> Nevin R, Jacobs DE, Berg M, Cohen J. 2008. Monetary benefits of preventing childhood lead poisoning with lead-safe window replacement, Environ Res 106: 410-419.

maintains a nationwide system for the collection and dissemination of data on lead poisoning cases; 46 states and DC report to CDC; these data are used to target activities for HUD, EPA and others.

### **Number of Children at Risk**

Today over 500,000 children<sup>4</sup> still need help each year from their CDC-funded health departments, and 12.3 million children have blood lead levels high enough to cause harm. All children residing in the 24 million homes with lead-based paint hazards remain vulnerable.<sup>5</sup> The adverse health effects of lead poisoning are well-known. In fact, the U.S. National Toxicology Program at the National Institutes of Health has published a new report showing the effects of lead are even more serious than previously thought.<sup>6</sup> Lead causes cognitive and behavioral problems, such as attention deficit hyperactivity disorder and many other health effects. African American children are nearly three times as likely to be lead poisoned as Caucasian children, and low-income children face double the risk.<sup>7</sup>

### **CDC's Effective Response**

CDC is the only agency that houses the information about where, how, and when children are poisoned. Between 1997 and 2008, NCEH's lead program served 850,000 children with dangerous blood lead levels. State and local health departments use CDC funding to identify and monitor the communities at greatest risk through their surveillance systems. They also provide local leadership on the prevention of childhood lead poisoning, for example by enforcing state and local lead poisoning prevention laws. These programs have been nearly eliminated as a result of cuts to the program that were made in fiscal

<sup>3</sup> Gould E. 2009. Childhood Lead Poisoning: Conservative Estimates of the Social and Economic Benefits of Lead Hazard Control. *Environ Health Perspect* 117:1162-1167

<sup>4</sup> In 2005-06, data from the National Health and Nutrition Examination Survey showed that an estimated 590,100 children 1-5 had blood lead levels  $\geq 5$   $\mu\text{g}/\text{dL}$ ; in 2007-08 that number increased to 646,400; in 2009-10 the number declined slightly to 442,000. Data from: National Performance Measures of Blood Lead in Children. Will Wheeler Presentation to the Advisory Committee on Childhood Lead Poisoning Prevention Nov 14, 2011

<sup>5</sup> Jacobs DE, Clickner RL, Zhou JL, Viet SM, Marker DA, Rogers JW, Zeldin DC, Broene P and W. Friedman. The Prevalence of Lead-Based Paint Hazards in U.S. Housing. *Environ Health Perspect* 110:A599-A606. Sept 13, 2002

<sup>6</sup> National Toxicology Program. Draft ntp monograph on health effects of low-level lead. October 14, 2011, National Institute Of Environmental Health Sciences, National Institutes Of Health, U.S. Department Of Health And Human Services

<sup>7</sup> Centers for Disease Control and Prevention, "Update: Blood Lead Levels—United States 1991-1994," *Morbidity and Mortality Weekly Report*, U.S. Department of Health and Human Services/Public Health Service, Vol 46, No. 7, Feb 21, 1997, p. 141-146 and erratum in vol 46, No. 26, p. 607, July 4, 1997. Also, Brody et al., Blood lead levels in the U.S. Population: Phase 1 of the third National Health and Nutrition Examination Survey, 1988 to 1991, *Journal of the American Medical Association* 272(4): 277-283, July 27, 1994 and Pirkle et al., The decline in blood lead levels in the United States, *Journal of the American Medical Association* 272(4):284-291, July 27, 1994

year 2012, placing millions of U.S. children and their families at risk. New studies show that children with very low levels of lead exposure (more than 500,000 in the U.S.) have lower academic achievement and are more likely to require expensive special education services. For every dollar spent on preventing lead exposure, the return is estimated to be over \$17. CDC funding paid for nurses, social workers, and environmental health professionals, assessments of the child's home and other sources of exposure, and referred property owners to remediation. The local programs also provide ongoing education and guidance to local officials, families, and health care providers to ensure that children receive appropriate care and, most importantly, prevent lead poisoning.

CDC's epidemiologists, blood lead laboratory proficiency program, and surveillance system are essential elements in monitoring and preventing lead poisoning. Without the CDC's resources to collect and analyze the surveillance data, no one will know when, where or how children are getting poisoned and literally millions of children will be unnecessarily poisoned in the decades to come. It was CDC's program that first identified lead-contaminated toys as a source of exposure,<sup>8</sup> and CDC was first on the scene to address lead poisoning among refugee families.<sup>9</sup> Internationally, CDC headed the emergency response to the lead epidemic in Nigeria, where hundreds of children have died from lead poisoning.<sup>10</sup>

### **Conclusion**

The CDC program has proven its cost effectiveness. It provides services that are critical for our nation's children and their parents. I urge Congress to restore funding for this program as a separate line item to the \$29 million level, allowing it to do its job protecting children from an entirely preventable condition.

<sup>8</sup> Toys and other consumer products recalled. See <http://www.cdc.gov/nceh/lead/Recalls/allhazards.htm>

<sup>9</sup> CDC Refugee lead poisoning prevention tool kit for refugees. See" [http://www.cdc.gov/nceh/lead/Publications/RefugeeToolKit/Refugee\\_Tool\\_Kit.htm](http://www.cdc.gov/nceh/lead/Publications/RefugeeToolKit/Refugee_Tool_Kit.htm)

<sup>10</sup> Dooyema CA, Neri A, Lo YC, Durant J, Daraan PJ, Swarthout T, Biya O, Gidado SO, Haladu S, Sani-Gwarzo N, Nguku PM, Akpan H, Idris S, Bashir AM, Brown MJ. Outbreak of Fatal Childhood Lead Poisoning Related to Artisanal Gold Mining in Northwestern Nigeria, 2010. *Environ Health Perspect*. 2011 Dec 20. [Epub ahead of print]

STATEMENT OF  
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ON BEHALF OF THE  
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FISCAL YEAR 2014 APPROPRIATIONS FOR THE  
NATIONAL INSTITUTES OF HEALTH

SUBMITTED TO THE  
HOUSE COMMITTEE ON APPROPRIATIONS  
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION,  
AND RELATED AGENCIES

MARCH 15, 2013

SUMMARY OF RECOMMENDATIONS FOR FY14:

- 1) \$32 BILLION FOR THE NATIONAL INSTITUTES OF HEALTH (NIH) AND A CORRESPONDING INCREASE TO THE NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASES (NIDDK)
- 2) CONTINUED SUPPORT FOR THE *GRANTS FOR RESEARCH IN GLOMERULAR DISEASES* INITIATIVE AND THE *ADVANCING CLINICAL RESEARCH IN PRIMARY GLOMERULAR DISEASES* PROGRAM AT NIDDK, AS WELL AS THE *NEPHROTIC SYNDROME STUDY NETWORK* AT THE OFFICE OF RARE DISEASES RESEARCH (ORDR)
- 3) EXPANSION OF THE FSGS/NS RESEARCH PORTFOLIO AT NIDDK, THE OFFICE OF RARE DISEASES RESEARCH (ORDR) AND THE NATIONAL INSTITUTE ON MINORITY HEALTH AND HEALTH DISPARITIES (NIMHD) BY FUNDING MORE RESEARCH PROPOSALS FOR PRIMARY GLOMERULAR DISEASE

Thank you for the opportunity to present the views of the NephCure Foundation regarding research on idiopathic focal segmental glomerulosclerosis (FSGS) and primary nephrotic syndrome (NS). NephCure is the only non-profit organization exclusively devoted to

fighting FSGS and the NS disease group. Driven by a panel of respected medical experts and a dedicated band of patients and families, NephCure works tirelessly to support kidney disease research and awareness.

NS is a collection of signs and symptoms caused by diseases that attack the kidney's filtering system. These diseases include FSGS, Minimal Change Disease and Membranous Nephropathy. When affected, the kidney filters leak protein from the blood into the urine and often cause kidney failure, which requires dialysis or kidney transplantation. According to a Harvard University report, 73,000 people in the United States have lost their kidneys as a result of FSGS. Unfortunately, the causes of FSGS and other filter diseases are poorly understood.

FSGS is the second leading cause of NS and is especially difficult to treat. There is no known cure for FSGS and current treatments are difficult for patients to endure. These treatments include the use of steroids and other dangerous substances which lower the immune system and contribute to severe bacterial infections, high blood pressure and other problems in patients, particularly child patients. In addition, children with NS often experience growth retardation and heart disease. Finally, NS caused by FSGS, MCD or MN is idiopathic and can often reoccur, even after a kidney transplant.

FSGS disproportionately affects minority populations and is five times more prevalent in the African American community. In a groundbreaking study funded by NIH, researchers found that FSGS is associated with two APOL1 gene variants. These variants developed as an evolutionary response to African sleeping sickness and are common in the African American patient population with FSGS/NS.

FSGS has a large social impact in the United States. FSGS leads to end-stage renal disease (ESRD) which is one of the most costly chronic diseases to manage. In 2008, the Medicare program alone spent \$26.8 billion, 7.9% of its entire budget, on ESRD. In 2005, FSGS

accounted for 12% of ESRD cases in the U.S., at an annual cost of \$3 billion. It is estimated that there are currently approximately 20,000 Americans living with ESRD due to FSGS.

Research on FSGS could achieve tremendous savings in federal health care costs and reduce health status disparities. For this reason, and on behalf of the thousands of families that are significantly affected by this disease, we encourage support for expanding the research portfolio on FSGS/NS at the NIH.

#### Encourage FSGS/NS Research at NIH

There is no known cause or cure for FSGS and scientists tell us that much more research needs to be done on the basic science behind FSGS/NS. More research could lead to fewer patients undergoing ESRD and tremendous savings in health care costs in the United States.

With collaboration from other Institutes and Centers, ORDR established the *Rare Disease Clinical Research Network*. This network provided an opportunity for the NephCure Foundation, the University of Michigan, and other university research health centers to come together to form the Nephrotic Syndrome Study Network (NEPTUNE). NEPTUNE is developing a database of NS patients who are interested in participating in clinical trials which would alleviate the problem faced by many rare disease groups of not having access to enough patients for research. **NephCure urges the subcommittee to continue its support for RDCRN and NEPTUNE, which has tremendous potential to facilitate advancements in NS and FSGS research.**

The NephCure Foundation is also grateful to NIDDK for issuing program announcements (PA) that serve to initiate grant proposals on primary glomerular disease. Two PAs that have recently been issued utilize the R01 and UM1 mechanisms to award funding for primary glomerular disease research. **NephCure recommends the subcommittee encourage NIDDK to continue to issue primary glomerular disease PAs.**

Due to the disproportionate burden of FSGS on minority populations, it is appropriate for NIMHD to develop an interest in this research. **NephCure asks the subcommittee to encourage ORDR, NIDDK and NIMHD to collaborate on research that studies the incidence and cause of this disease among minority populations. NephCure also asks the Subcommittee to urge NIDDK and the NIMHD to undertake culturally appropriate efforts aimed at educating minority populations about primary glomerular disease.**

Thank you for the opportunity to present the views of the FSGS/NS community. Please contact the NephCure Foundation if additional information is required.

STATEMENT OF LEE CLAASSEN  
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REGARDING FISCAL YEAR 2014 APPROPRIATIONS  
FOR THE CENTERS FOR DISEASE CONTROL AND PREVENTION  
AND NATIONAL INSTITUTES OF HEALTH

SUBMITTED TO THE HOUSE COMMITTEE ON APPROPRIATIONS;  
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,  
EDUCATION, AND RELATED AGENCIES

MARCH 15, 2013

**SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2014:**

- \$660,00 FOR THE IC EDUCATION AND AWARENESS PROGRAM AT THE CENTERS FOR DISEASE CONTROL AND PREVENTION
- \$32 BILLION FOR THE NATIONAL INSTITUTES OF HEALTH (NIH) AND PROPORTIONAL INCREASES ACROSS ALL INSTITUTES AND CENTERS
- SUPPORT FOR NIH RESEARCH ON IC, INCLUDING:
  - *THE MULTIDISCIPLINARY APPROACH TO THE STUDY OF CHRONIC PELVIC PAIN (MAPP) RESEARCH NETWORK*
  - RESEARCH ON IC IN CHILDREN

Thank you for the opportunity to present the views of the Interstitial Cystitis Association (ICA) regarding the importance of interstitial cystitis (IC) public awareness and research. ICA was founded in 1984 and remains the only nonprofit organization dedicated to improving the lives of those affected by IC. The Association provides an important avenue for advocacy, research, and education relating to this painful condition. Since its founding, ICA has acted as a voice for those living with IC, enabling support groups and empowering patients. ICA advocates for the expansion of the IC knowledge-base and the development of new treatments, including

investigator initiated research. Finally, ICA works to educate patients, healthcare providers, and the public at large about IC.

IC is a condition that consists of recurring pelvic pain, pressure, or discomfort in the bladder and pelvic region. It is often associated with urinary frequency and urgency. This condition may also be referred to as painful bladder syndrome (PBS), bladder pain syndrome (BPS), and chronic pelvic pain (CPP). It is estimated that as many as 12 million Americans have IC symptoms. Approximately two-thirds of these patients are women, though this condition does severely impact the lives of as many as 4 million men as well. IC has been seen in children and many adults with IC report having experienced urinary problems during childhood. However, little is known about IC in children, and information on statistics, diagnostic tools and treatments specific to children with IC are limited.

The exact cause of IC is unknown and there are few treatment options available. There is no diagnostic test for IC and diagnosis is made only after excluding other urinary/bladder conditions. It is not uncommon for patients to experience one or more years delay between the onset of symptoms and a diagnosis of IC. This is exacerbated when healthcare providers are not properly educated about IC and some patients suffer many years before they are diagnosed and empowered to attempt potential therapies.

The effects of IC are pervasive and insidious, damaging work life, psychological well-being, personal relationships, and general health. The impact of IC on quality of life is equally as severe as rheumatoid arthritis and end-stage renal disease. Health-related quality of life in women with IC is worse than in women with endometriosis, vulvodynia, and overactive bladder. IC patients have significantly more sleep dysfunction, and higher rates of depression, anxiety, and sexual dysfunction.

Some studies suggest that certain conditions occur more commonly in people with IC than in the general population. These conditions include allergies, irritable bowel syndrome, endometriosis, vulvodynia, fibromyalgia, and migraine headaches. Chronic fatigue syndrome, pelvic floor dysfunction, and Sjogren's syndrome have also been reported.

## **IC PUBLIC AWARENESS AND EDUCATION**

The IC Education and Awareness Program at the Centers for Disease Control and Prevention (CDC) is critical to improving public and provider awareness of this devastating disease, reducing the time to diagnosis for patients, and disseminating information on pain management and IC treatment options.

The IC program has utilized opportunities with charitable organizations to leverage funds and maximize public outreach. Such outreach includes public service announcements in major markets and the internet, as well as a billboard campaign along major highways across the country. The IC program has also made information on IC available to patients and the public through videos, booklets, publications, presentations, educational kits, websites, self-management tools, webinars, blogs, and social media communities such as Facebook, YouTube, and Twitter. For healthcare providers, this program has included the development of a continuing medical education module, targeted mailings, and exhibits at national medical conferences.

The CDC IC Education and Awareness Program also provides patient support that empowers patients to self-advocate for their care. Many physicians are hesitant to treat IC patients because of the time it takes to treat the condition and the lack of answers available. Further, IC patients may try numerous potential therapies, including alternative and complementary medicine, before finding an approach that works for them. For this reason, it is

especially critical for the IC program to provide patients with information about what they can do to manage this painful condition and lead a normal life.

*ICA recommends continued support for the CDC IC Education and Awareness Program and a specific appropriation of \$660,000 for fiscal year 2014. ICA also encourages continued support for the National Center for Chronic Disease Prevention and Health Promotion, which administers the IC program.*

## **RESEARCH THROUGH THE NATIONAL INSTITUTES OF HEALTH**

The National Institutes of Health (NIH) maintains a robust research portfolio on IC with the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) serving as the primary Institute for IC research. Major studies that have yielded significant new information include the RAND IC Epidemiology (RICE) study, which found that nearly 2.7-6.7 percent of adult women and 2 to 4 million men have symptoms consistent with IC. The IC Genetic Twin study found environmental factors, rather than genetic factors, to be substantial risk factors of developing IC. The Events Preceding Interstitial Cystitis (EPIC) study yielded linked non-bladder conditions and infectious agents to the development of IC in many newly-diagnosed IC patients. The findings of the EPIC study have been reinforced by a Northwestern University study which found that an unusual form of toxic bacterial molecule (LPS) impacts the development of IC as a result of an infectious agent. Finally, the Urologic Pelvic Pain Collaborative Research Network (UPPCRN) indicated promising results for a new therapy for IC patients.

Research currently underway also holds great promise to improving our understanding of IC and developing better treatments and a cure. The NIDDK Multidisciplinary Approach to the

Study of Chronic Pelvic Pain (MAPP) Research Network studies the underlying causes of chronic urological pain syndromes. The Specialized Centers of Research on Sex and Gender Factors Affecting Women's Health established by the Office of Research on Women's Health (ORWH) includes an IC component. Research on chronic pelvic pain is supported by the National Institute of Neurological Disorders and Stroke (NINDS) as well as the National Center for Complementary and Alternative Medicine (NCCAM). Additionally, the NIH investigator-initiated research portfolio continues to be an important mechanism for IC researchers to create new avenues for interdisciplinary research.

ICA also supports the National Center for Advancing Translational Sciences (NCATS), including the Cures Acceleration Network (CAN). Initiatives like CAN are critical to overhauling the translational research process and overcoming the research "valley of death" that currently plagues treatment development. In addition, drug repurposing and other efforts led by NCATS hold the potential to speed access to new treatment for patients. ICA encourages support for NCATS and the provision of adequate resources for the Center in fiscal year 2014.

*ICA recommends a funding level of \$32 billion for NIH in fiscal year 2014. ICA also recommends continued support the MAPP study administered by NIDDK, and the expansion of research focused on IC in children.*

Thank you for the opportunity to present the views of the interstitial cystitis community.

STATEMENT OF  
JANET HIESHETTER  
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ON BEHALF OF THE  
DYSTONIA ADVOCACY NETWORK

REGARDING FISCAL YEAR 2014 APPROPRIATIONS FOR THE  
NATIONAL INSTITUTES OF HEALTH

SUBMITTED TO THE  
HOUSE COMMITTEE ON APPROPRIATIONS  
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION,  
AND RELATED AGENCIES

MARCH 15, 2013

SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2014:

- \$32 BILLION FOR THE NATIONAL INSTITUTES OF HEALTH (NIH) AND PROPORTIONAL INCREASES ACROSS ITS INSTITUTES AND CENTERS
- CONTINUE TO SUPPORT THE *DYSTONIA COALITION* WITHIN THE RARE DISEASE CLINICAL RESEARCH NETWORK (RDCRN) COORDINATED BY THE OFFICE OF RARE DISEASES RESEARCH (ORDR) IN THE NATIONAL CENTER FOR ADVANCING TRANSLATIONAL SCIENCES (NCATS)
- EXPAND DYSTONIA RESEARCH SUPPORTED BY NIH THROUGH THE NATIONAL INSTITUTE ON NEUROLOGICAL DISORDERS AND STROKE (NINDS), THE NATIONAL INSTITUTE ON DEAFNESS AND OTHER COMMUNICATION DISORDERS (NIDCD) AND THE NATIONAL EYE INSTITUTE (NEI)

Dystonia is a neurological movement disorder characterized by involuntary muscle spasms that cause the body to twist, repetitively jerk, and sustain postural deformities. Focal dystonia affects specific parts of the body, while generalized dystonia affects multiple parts of

the body at the same time. Some forms of dystonia are genetic but dystonia can also be caused by injury or illness. Although dystonia is a chronic and progressive disease, it does not impact cognition, intelligence, or shorten a person's life span. Conservative estimates indicate that between 300,000 and 500,000 individuals suffer from some form of dystonia in North America alone. Dystonia does not discriminate, affecting all demographic groups. There is no known cure for dystonia and treatment options remain limited.

Although little is known regarding the causes and onset of dystonia, two therapies have been developed that have demonstrated a great benefit to patients and have been particularly useful to controlling patient symptoms. Botulinum toxin (e.g., Botox, Xeomin, Disport and Myobloc) injections and deep brain stimulation have shown varying degrees of success alleviating dystonia symptoms. Until a cure is discovered, the development of management therapies such as these remains vital, and more research is needed to fully understand the onset and progression of the disease in order to better treat patients.

#### DYSTONIA RESEARCH AT THE NATIONAL INSTITUTES OF HEALTH (NIH)

Currently, dystonia research supported by NIH is conducted through the National Institute of Neurological Disorders and Stroke (NINDS), the National Institute on Deafness and Other Communication Disorders (NIDCD), the National Eye Institute (NEI), and the Office of Rare Diseases Research (ORDR) within the National Center for Advancing Translational Sciences (NCATS).

ORDR coordinates the Rare Disease Clinical Research Network (RDCRN) which provides support for studies on the natural history, epidemiology, diagnosis, and treatment of rare diseases. RDCRN includes the *Dystonia Coalition*, a partnership between researchers,

patients, and patient advocacy groups to advance the pace of clinical research on cervical dystonia, blepharospasm, spasmodic dysphonia, craniofacial dystonia, and limb dystonia. The *Dystonia Coalition* has made tremendous progress in preparing the patient community for clinical trials as well as funding promising studies that hold great hope for advancing our understanding and capacity to treat primary focal dystonias. **DAN urges the subcommittee to continue its support for the *Dystonia Coalition*, part of the Rare Disease Clinical Research Network coordinated by ORDR within NCATS.**

The majority of dystonia research at NIH is conducted through NINDS. NINDS has utilized a number of funding mechanisms in recent years to study the causes and mechanisms of dystonia. These grants cover a wide range of research including the genetics and genomics of dystonia, the development of animal models of primary and secondary dystonia, molecular and cellular studies in inherited forms of dystonia, epidemiology studies, and brain imaging. **DAN urges the subcommittee to support NINDS in conducting and expanding critical research on dystonia.**

NIDCD and NEI also support research on dystonia. NIDCD has funded many studies on brainstem systems and their role in spasmodic dysphonia, or laryngeal dystonia. Spasmodic dysphonia is a form of focal dystonia which involves involuntary spasms of the vocal cords causing interruptions of speech and affecting voice quality. NEI focuses some of its resources on the study of blepharospasm. Blepharospasm is an abnormal, involuntary blinking of the eyelids which can render a patient legally blind due to a patient's inability to open their eyelids. **DAN encourages partnerships between NINDS, NIDCD and NEI to further dystonia research.**

In summary, DAN recommends the following for fiscal year 2014:

- \$32 billion for NIH and a proportional increase for its Institutes and Centers

- Support for the *Dystonia Coalition* within the Rare Diseases Clinical Research Network coordinated by ORDR within NCATS
- Expansion of the dystonia research portfolio at NIH through NINDS, NIDCD, NEI, and ORDR

#### THE DYSTONIA ADVOCACY NETWORK

The Dystonia Medical Research Foundation (DMRF) submits these comments on behalf of the Dystonia Advocacy Network (DAN), a collaborative network of five patient organizations: the Benign Essential Blepharospasm Research Foundation, the Dystonia Medical Research Foundation, the National Spasmodic Dysphonia Association, the National Spasmodic Torticollis Association, and ST/Dystonia, Inc. DAN advocates for all persons affected by dystonia and supports a legislative agenda that meets the needs of the dystonia community.

DMRF was founded over 33 years ago. Since its inception, the goals of DMRF have remained to advance research for more effective treatments of dystonia and ultimately find a cure; to promote awareness and education; and support the needs and well being of affected individuals and their families.

Thank you for the opportunity to present the views of the dystonia community, we look forward to providing any additional information.

**STATEMENT OF JANET LONG  
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**REGARDING FISCAL YEAR 2014 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, 2013**

SUMMARY OF FY14 RECOMMENDATIONS

- 1) \$32 BILLION FOR THE NATIONAL INSTITUTES OF HEALTH (NIH) AT AN INCREASE OF \$1 BILLION OVER FY 2012.**
- 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 2014.*

## **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 2014. US HAEA recommends an overall funding level of \$32 billion for NIH in fiscal year 2014 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.

**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 2014  
DEPARTMENT OF HEALTH AND HUMAN SERVICES APPROPRIATIONS**

**March 15, 2013**

SUMMARY OF FY14 RECOMMENDATIONS

- 1) **\$32 BILLION FOR THE NATIONAL INSTITUTES OF HEALTH (NIH) AT AN INCREASE OF \$1 BILLION OVER FY 2013. 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 again 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.

- o Since 2006, CDC epidemiologists have been working in conjunction with the Crohn's and Colitis Foundation of America 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 women 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.

**STATEMENT OF THE DIGESTIVE DISEASE NATIONAL COALITION  
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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 2014  
DEPARTMENT OF HEALTH AND HUMAN SERVICES APPROPRIATIONS**

**March 15, 2013**

SUMMARY OF FY14 RECOMMENDATIONS

- 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 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 CANCER SCREENING 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 33 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 FY14.

#### **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 1 out 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.

Mr. Chairman, much more can still be done to address the needs of the nearly 35 million Americans suffering from irritable bowel syndrome and other functional gastrointestinal disorders. The DDNC recommends that NIDDK increase its research portfolio on Functional Gastrointestinal Disorders and Motility Disorders.

### **DIGESTIVE DISEASE COMMISSION**

In 1976, Congress enacted Public Law 94-562, which created a National Commission on Digestive Diseases. The Commission was charged with assessing the state of digestive diseases in the U.S., identifying areas in which improvement in the management of digestive diseases can be accomplished and to create a long-range plan to recommend resources to effectively deal with

such diseases.

The DDNC recognizes the creation of the National Commission on Digestive Diseases, and looks forward to working with the National Commission to address the numerous digestive disorders that remain in today's diverse population.

**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.

**STATEMENT OF NANCY J. NORTON  
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**REGARDING FISCAL YEAR 2014 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, 2013**

- 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 FGIMDs, 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 2014.* 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 repurposing hold the potential to speed new treatment to patients. We ask that you support NCATS and provide adequate resources for the Center in FY 2014.

Thank you for the opportunity to present these views on behalf of the FGIMD community.

**THE AMERICAN SOCIETY OF NEPHROLOGY**

**WRITTEN TESTIMONY IN SUPPORT OF INCREASED  
FUNDING FOR THE NATIONAL INSTITUTES OF HEALTH (NIH) AND 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 15, 2013**

**EXECUTIVE SUMMARY**

The American Society of Nephrology (ASN) is dedicated to the study, prevention, and treatment of kidney disease, and the society's 14,000 plus members greatly respect your leadership and commitment to preventing illness, treating disease, and maintaining fiscal responsibility. Chronic kidney disease (CKD) currently affects up to 26 million, or 1 in 9, Americans, and more than 550,000 of them have irreversible kidney failure requiring life-sustaining treatment with regular dialysis therapies.

**The vast majority of research leading to advances in the care and treatment of adults and children afflicted with kidney disease is funded by the National Institutes of Health (NIH) broadly and the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) specifically. Any reduction in this funding would seriously reduce our ability to contain and reverse this disease, which costs Americans enormous suffering, lost productivity, and foreshortened spans of life.**

Examples of critical discoveries arising from NIH-funded research are numerous. For instance, investigative studies supported by NIH and NIDDK led to a groundbreaking discovery that helps explain racial/ethnic disparities that increase risks for kidney disease, which can lead to earlier detection and treatment. The recent finding that African Americans with two variants of the APOL1 gene are likely to experience faster decline in kidney function, and earlier initiation of hemodialysis than their peers without the gene, is a crucial step in understanding differences in kidney disease progression across different populations and how early interventions may improve their outcomes.

Scientists supported by NIH and NIDDK also identified mutations in two genes that help regulate blood pressure and salt balance in a rare, heritable disease that causes high blood pressure, or hypertension. Hypertension is a leading contributor to the development of kidney failure, so this finding may improve hypertension management in patients with kidney disease—possibly preventing kidney failure—and could lead to better therapies for controlling high blood pressure in the general patient population.

Moreover, funding from NIH and NIDDK enabled research that found that people with antibodies that target a protein [the phospholipase A2 receptor called PLAR2] on a specific kidney cell develop a kidney disorder, known as nephrotic syndrome that results in a harmful excess protein in urine. Future therapies that reduce PLAR2 antibody levels may help prevent people with nephrotic syndrome from progressing to kidney failure.

Dialysis is covered by Medicare regardless of a patient's age or disability status. Consequently, preventing kidney disease and advancing the effectiveness of therapies for kidney failure—starting with innovative research at NIDDK—would have a great impact at the highest level of costs within the Centers for Medicare and Medicaid Services. Perhaps most important, in human terms, the applied research will help prevent greater suffering among those who would otherwise progress to an even greater level of illness.

Sustained, predictable investment in research is the only way that scientific investigations can be effective and lead to new discoveries. With funding from NIH and NIDDK, scientists have been able to pursue cutting-edge basic, clinical, and translational research. While ASN fully understands the difficult economic environment and the intense pressure you are under as an elected official to guide America forward during these tough times, the society firmly believes that funding NIH and NIDDK is a

good investment to create jobs, support the next generation of investigators, and ultimately improve the public health of Americans.

**Several recent studies have concluded that federal support for medical research is a major force in the economic health of communities across the nation.**

It is critically important that the nation 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 NIH and 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 strongly recommends that the Fiscal Year 2014 Labor-HHS-Education Appropriations bill uphold its longstanding legacy of bipartisan support for biomedical research.

Should you have any questions or wish to discuss NIH, NIDDK, or kidney disease research in more detail, please contact ASN Manager of Policy and Government Affairs Rachel Shaffer at (202) 640-4659 or [rhaffer@asn-online.org](mailto:rhaffer@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 more than 14,000 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](http://www.asn-online.org).



**FY 2014 HOUSE APPROPRIATIONS COMMITTEE PUBLIC TESTIMONY**

**WRITTEN TESTIMONY OF MARGARET ANDERSON,  
EXECUTIVE DIRECTOR, *FASTERCURES***

**FOR THE SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,  
EDUCATION, AND RELATED AGENCIES**

March 15, 2013

Chairman Kingston, Ranking Member DeLauro, and members of the subcommittee, thank you for the opportunity to present my testimony on the critical importance of the federal investment in medical research at the National Institutes of Health (NIH).

I am Margaret Anderson, executive director of *FasterCures*, the Milken Institute's Center for Accelerating Medical Solutions. *FasterCures* is a nonprofit and nonpartisan organization focused on improving the medical research and development (R&D) 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, and patient advocacy groups – to catalyze transformative action that's focused on improving the medical research system to meet patients' needs.

At a time when scientific and technological advances have yielded and continue to promise remarkable breakthroughs, the ecosystem has yet to refine its ability to translate these advances into therapies that improve patient health.<sup>1</sup> But having an R&D enterprise that's functioning at peak performance is the only hope for one in three Americans suffering 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. Our ability to fully realize science's potential heavily depends on our national commitment to supporting medical research.

I am submitting this written testimony to urge the subcommittee to reaffirm our nation's commitment to medical research.

***Investing in the NIH yields enormous returns***

As you well know, federal investment in NIH-funded medical research over the past few decades has yielded enormous breakthroughs in understanding, preventing, diagnosing, and treating many diseases – advances such as the sequencing of the human genome, which is leading us closer to the age of precision medicine.

Here are just a few tangible examples of how NIH research has vastly improved our lives.

- Americans are living nearly 30 years longer than they did in 1900. 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.<sup>ii</sup>
- An investment of approximately \$5 per year for NIH heart disease research from each American has been key to reducing mortality from heart disease and stroke by more than 60 percent since 1970, with an economic return estimated at \$2.5 trillion per year.<sup>iii</sup>
- Meanwhile, \$7 a year per American supported HIV/AIDS research. A disease which once threatened to overrun our hospital systems is manageable today without hospitalization thanks to breakthroughs enabled by NIH, with total savings of \$1.4 trillion to date.<sup>iv</sup> Not

only have we developed effective therapies that are increasingly transforming the disease from a death sentence to a chronic condition, but also researchers are now closing in on a vaccine. Had we failed to invest in AIDS studies, millions more would have suffered and died.

- An investment of approximately \$9 per year for NIH cancer research from each American over the past 40 years<sup>v</sup> has doubled the survival rates for a number of cancers, and survivors enjoy a better quality of life.

***But much remains to be done***

At our recent Celebration of Science<sup>vi</sup> event held in September 2012, we witnessed scientific discovery literally unfold on the stage of the National Institutes of Health as scientists and patients told breathtaking stories of research triumph – a glimpse of how scientific discoveries have improved health and saved lives. It was remarkable.

We understand the biology of thousands of diseases, but only 250 have treatments available. So, while we need to celebrate the success stories in medical research that allow us to carry on our lives – be those successes through prevention, diagnostics, devices, or medical intervention – we have more work to do. We must ensure that we continue to have a robust flow of scientific discoveries that we can then translate into better health.

Today, our aging population faces unprecedented health challenges that threaten to send entitlement spending to unsustainable levels. Alzheimer's disease alone will cost an estimated \$1.1 trillion a year in 2012 dollars by 2050 (up from \$200 billion today) if we don't change its course.

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.

At *FasterCures*, we're more optimistic. Research *will* solve this challenge – and many others. But timing matters.

***NIH helps drive economic productivity and global competitiveness***

A continued investment in basic science is also key to our economic productivity and global competitiveness. An analysis on NIH's role in sustaining the economy<sup>vii</sup> found that:

- NIH supports nearly half a million jobs all across the country and remains the largest funder of life sciences research in the U.S.
- More than 80 percent of its budget directly funds “extramural” research performed by 325,000 scientists at more than 3,000 institutions in all 50 states and DC.
- In 2011, NIH research funding led to the creation of more than 400,000 new jobs, \$62 billion in new economic activity in the U.S., and 500 patent applications worldwide.

America still leads the world in scientific discovery, but China, India, Japan, the U.K., Singapore, and others are catching up quickly as they increase research budgets as much as 20 percent a year. China has pledged to devote \$308.5 billion just to biotechnology between 2012 and 2017, compared with a projected \$160 billion for all NIH programs.<sup>viii</sup>

- If present trends continue, China's financial commitment to biomedical research will be twice that of the US's in the next five years (and four times greater as a share of GDP);

- Growth in high-wage, high-skill jobs in the life sciences sector is flat-lining in the United States, while employment in other countries, like Germany and France, shows consistent growth;
- The U.S. accumulated a \$136.7 billion trade deficit in pharmaceutical products over the last decade, a period when many competitors realized increasing trade surpluses;
- The United States' share of global biopharmaceutical patents and overall industry output is shrinking, while China's continues to expand in these areas; and
- China already has more gene sequencing capacity than the entire United States and about one-third of total global capacity.

If we fail to make the investment now, we will not only lose our leadership in the global economy, we will also find young American scientists seeking more promising opportunities in other fields or in countries with a more robust medical research infrastructure.

Just as our nation has always sought to honor the commitments we made to veterans, we should also follow through on the implicit promises we made to the next generation of scientists. America's leaders told these students there is a great future in pursuing STEM education (science, technology, engineering, and math). Those who did, and then persevered through as much as 15 years of professional training, now find their opportunities are shrinking. As *FasterCures* founder Michael Milken noted, "unlike delaying construction of a bridge that can be resumed in a few years, if we lose a generation of scientists, there's no way to rebuild that human capital quickly."

***NIH research provides the foundation for biotechnology and pharmaceutical companies***

Improving and accelerating research and development requires all stakeholders in the medical research ecosystem to work together – including federal agencies, industry, academia, and patient groups. A majority of therapies have come to market because of national investments in science from agencies such as NIH.<sup>ix</sup>

Medical research at the NIH directly impacts the pharmaceutical research and development industry, with 90 percent of PhD scientists relying on NIH to support their research training and 74 percent of pharmaceutical and biotechnology companies having licensed patents from NIH-funded academic research.<sup>x</sup>

To provide additional context, I wanted to share anecdotes from two biopharma executives:

- Earlier this month, at a *FasterCures* and Friends of Cancer Research briefing on Capitol Hill, N. Anthony Coles, president and CEO of Onyx Pharmaceuticals, stressed that biotechnology and pharmaceutical companies depend solely on research funded by the NIH to understand human biology and disease origins, and that industry then takes this knowledge, advances the research, and moves it toward the delivery of medical products to patients.<sup>xi</sup>
- In November 2012, at our 4<sup>th</sup> annual Partnering for Cures conference, we heard from Mikael Dolsten, president of worldwide R&D for Pfizer, that, “even as one of the biggest biomedical R&D investors in the world, Pfizer cannot and should not go it alone.”

***We face a major paradox – the potential of science is greater than ever but the outlook for funding has never been bleaker***

As I wrote in *Science Translational Medicine*<sup>kii</sup> earlier this month, when it comes to supporting medical research, time is not on our side. The decisions we make today will have implications long into the future.

Committing less to our medical research infrastructure means that we are letting the possibility of a cure sit in a cupboard instead of pursuing its full potential to benefit patients, families, and communities. Allowing the opportunities presented by science to wither on the vine means the potential for transformational advances in health and medicine will remain untapped. Which initiative in science doesn't matter? Which disease isn't relevant to study? Which therapy won't be developed? Which young scientist will not make the discovery we are all counting on in the future?

The cost of inaction is unthinkable. We must act. Our future is at stake.

***In sum***

Increased funding for the NIH must be prioritized, for all of the reasons mentioned. Cuts today will have ripple effects for years to come. Our collective future is at stake.

There are many compelling reasons why *FasterCures* supports a continued strong investment in NIH. But the most primary and powerful reason we care for this vital agency lies at the core of our mission: It's about saving lives. There isn't a single person whose life has not been touched by disease. We all know someone who could use a faster cure.

We are at a critical inflection point in current discussions within the biomedical research enterprise about what actions need to be taken to push the science toward cures where possible. We need to take advantage of this moment and adequately fund our nation's medical research agency.

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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<sup>i</sup> Drug discovery and development: Understanding the R&D Process. [www.innovation.org](http://www.innovation.org)

<sup>ii</sup> Impact of NIH Research. [www.nih.gov/about/impact/health.htm](http://www.nih.gov/about/impact/health.htm)

<sup>iii</sup> Forbes: *Legendary Drug Industry Executives Warn U.S. Science Cuts Endanger The Future*. March 6, 2013 <http://www.forbes.com/sites/matthewherper/2013/03/06/drug-industry-greats-say-the-u-s-must-reverse-the-cuts-to-our-investment-in-science/>

<sup>iv</sup> Forbes: *Legendary Drug Industry Executives Warn U.S. Science Cuts Endanger The Future*. March 6, 2013 <http://www.forbes.com/sites/matthewherper/2013/03/06/drug-industry-greats-say-the-u-s-must-reverse-the-cuts-to-our-investment-in-science/>

<sup>v</sup> NCI Budget Information. <http://www.cancer.gov/aboutnci/servingpeople/nci-budget-information>

<sup>vi</sup> Celebration of Science. [www.celebrationofscience.org](http://www.celebrationofscience.org)

<sup>vii</sup> United for Medical Research: *NIH's Role in Sustaining the U.S. Economy*. <http://www.unitedformedicalresearch.com/wp-content/uploads/2012/07/NIHs-Role-in-Sustaining-the-US-Economy-2011.pdf>

<sup>viii</sup> United for Medical Research: *Leadership in Decline*. [http://www.unitedformedicalresearch.com/advocacy\\_reports/leadership-in-decline/](http://www.unitedformedicalresearch.com/advocacy_reports/leadership-in-decline/)

<sup>ix</sup> NIH: *NIH... Turning discovery into health*. [www.nih.gov/about/discovery/viewbook\\_2011.pdf](http://www.nih.gov/about/discovery/viewbook_2011.pdf)

<sup>x</sup> Economic Impact of NIH Funded Research, Burnham Institute for Medical Research Congressional Briefing, February 25, 2009.

<sup>xi</sup> *FasterCures*-Friends of Cancer Research Hill Briefing: *Cutting-Edge Science, Collaboration, and Sustained Funding Needed to Get New Medicines from Lab to Patient*. February 5, 2013. <http://www.fastercures.org/Programs/hill-briefings.php>

<sup>xii</sup> M. Anderson, No time to waste. *Sci. Transl. Med.* 5, 174ed3 (2013).



## National Health Council

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**Testimony of Myrl Weinberg, FASAE, CAE  
Chief Executive Officer, National Health Council  
Submitted to the House Appropriations Subcommittee on Labor, Health  
and Human Services, Education, and Related Agencies  
Regarding Fiscal Year 2014 Department of Health and Human Services Appropriations  
March 15, 2013**

Dear Chairman Kingston and Ranking Member DeLauro:

On behalf of the nation's leading patient advocacy organizations, thank you for the opportunity to submit testimony on the significance of funding for federal health research agencies and other programs that are designed to improve the health of our nation. As work begins on the Fiscal Year (FY) 2014 Labor-HHS appropriations bill, the NHC urges the Subcommittee to maximize funding for essential health programs, including those at the National Institutes of Health (NIH), Centers for Disease Control and Prevention (CDC), Health Resources and Services Administration (HRSA), Substance Abuse and Mental Health Services Administration (SAMHSA), and the Agency for Healthcare Research and Quality (AHRQ). We urge Congress to refrain from shying away from its longstanding commitment to serve people with chronic conditions, the individuals who use our health system on a daily basis.

The National Health Council (NHC) is the only organization of its kind that brings together all segments of the health care community to provide a united voice for the more than 133 million people living with chronic diseases and disabilities and their family caregivers. Made up of more than 100 national health-related organizations and businesses, its core membership includes the nation's leading patient advocacy organizations, which control its governance. Other members include professional societies and membership associations, nonprofit organizations

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with an interest in health, and major pharmaceutical, medical device, biotechnology, and insurance companies.

The NHC fully appreciates the challenging fiscal environment facing the country and your important role in guiding our nation through these complex and difficult times. The NHC recognizes that federal resources must be carefully allocated so as to ensure that such investments produce the greatest good for the American people.

In turn, let us not forget that federal support of health programs at HHS is moving us closer to making the impossible possible – saving medical expenses through effective prevention efforts and new treatments, and saving lives in the process.

The NHC and its member patient organizations cannot overstate that federal support of medical research, prevention programs, and health care delivery is vital to people living with chronic diseases and disabilities. As we depict in Figure 1, these services should not be considered in isolation, but rather serve as essential building blocks toward strengthening the collective health care system.

Investment in biomedical research is leading the discovery of biomarkers – physical signs or biological substances that indicate the presence of conditions such as **osteoarthritis**, one of the leading causes of disability in the elderly and the most common type of arthritis in the U.S., usually affecting middle-aged and older people. This type of research will advance our understanding of disease progression and earlier detection and aid in expediting clinical trials on novel treatments.

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Funds to pay for the study of rare or less common diseases will help to greatly improve our understanding of human health – and the more common conditions that burden us all. For example, research on **alpha-1 antitrypsin deficiency** – a disease affecting no more than 100,000 people – fueled new areas of investigation on COPD, a respiratory condition found in more than 12 million individuals.

The path to discovery supported by the federal government can result in cutting-edge, cost-effective programs. A widely-regarded NIH clinical trial on **diabetes** and subsequent translational research found that modest weight loss helped prevent type 2 diabetes for 58 percent of participants and positive results could be obtained for less than \$300 per person per year. These findings led to the creation of CDC's National Diabetes Prevention Program, which serves individuals with prediabetes in local communities across the country.

Research, prevention efforts, and programs that provide access to services and treatments each contribute importantly to enabling patients to manage their health. As baby boomers age, the prevalence of and deaths from diseases such as **Alzheimer's** and **heart disease** are projected to increase. Clearly, now is not the time to decrease our nation's investment in research that holds the key to the prevention, treatment, and cure of America's leading and most costly causes of death.

The NHC would be happy to provide the Subcommittee with numerous personal patient stories that demonstrate why appropriate funding of research, prevention, and health delivery programs is crucial to the millions of men, women, and children in this country living with chronic diseases and disabilities. We understand the difficulty you face in reaching consensus on

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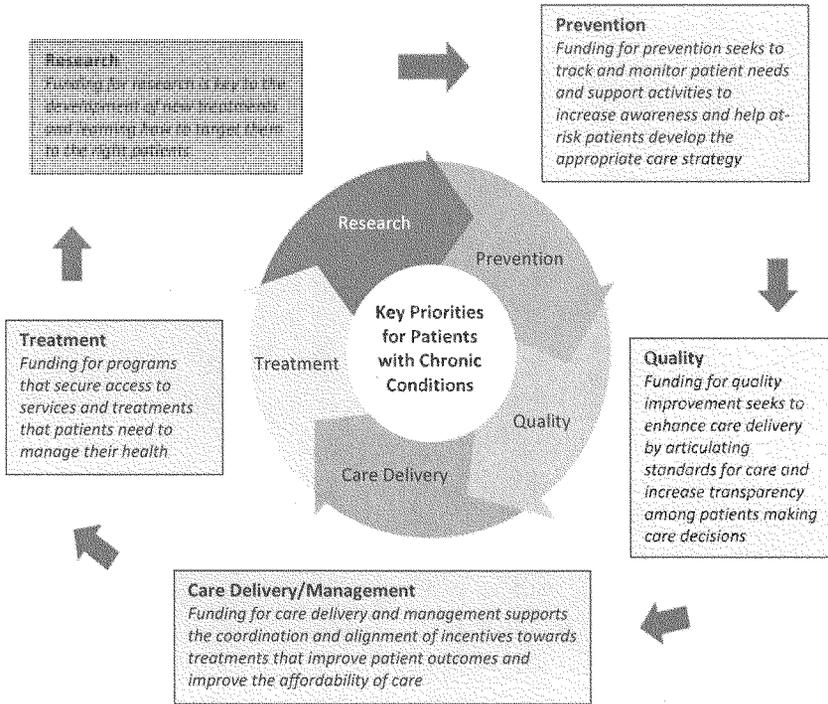
a funding level that balances the needs of our country with the needs of people with few or possibly no treatment options.

But how do you place a cost figure on people like Debra – a woman diagnosed with **chronic kidney disease** who, after many years of dialysis, underwent a successful kidney transplant that was made possible because of advancements based on federally funded research? She was able to give back to society as a volunteer at Walter Reed Army Medical Center, helping others confronted with organ failure to deal with the changes in their lives and remain positive.

If we fail to take aggressive and deliberate action now to appropriately fund essential health programs, we will pay a terrible cost later – both in terms of health care expenditures and human lives.

The NHC appreciates the opportunity to submit this written testimony to the Subcommittee. We understand that you face many hard decisions and again urge you to maximize funding for health programs that benefit people with chronic diseases and disabilities so that patients will be able to live longer, healthier, and more productive lives.

**Figure 1. Funding the Continuum of Care for Patients with Chronic Diseases and Disabilities**



**YOSEF REFAELI, Ph.D.**

**Associate Professor, Gates Center for Regenerative Medicine and Stem Cell Biology**

**CEO & Co-Founder, Taiga Biotechnologies**

**BRIAN TURNER Ph.D**

**President & Co-Founder, Taiga Biotechnologies**

Mr. Chairman and Members of the Subcommittee:

Thank you for the opportunity to submit written testimony regarding cell and protein therapies to help improve standards of care for bone marrow transplantation and provide the US government with a means for preparedness and countermeasure for nuclear exposures and radiological attacks. These therapies are vital to prepare our country for foreseen and unforeseen emergencies. Taiga Biotechnologies, Inc., a Colorado-based, privately held developer of novel therapies for complex diseases including cancers, infectious agents such as HIV and influenza, and hematologic conditions, in collaboration with the Charles C. Gates Center for Regenerative Medicine and Stem Cell Biology at the University of Colorado, is developing a technology that enables the rapid growth of adult blood stem cells (also called hematopoietic stem cells-HSC) from adult bone marrow or other non-embryonic sources. This proprietary technology can generate large numbers of cells that can be frozen and thawed while retaining their stem cell characteristics.

Taiga and the Gates Center's labs performed basic and proof-of concept research funded with peer reviewed Small Business Innovation Research (SBIR) grants from the NIH, and we have joined a consortium funded by the Defense Advanced Research Projects Agency (DARPA) to further develop some aspects of the Red Blood Cell Program. We are now in contact with the Biomedical Advanced Research and Development Authority BARDA division of countermeasures for radiological agents and preparedness regarding funding for clinical trials, development of a bank of ex vivo expanded HSCs as a countermeasure for a large scale/large casualty emergency, and a method by which irradiated individuals could use their own hematopoietic stem cells HSCs to reconstitute their immune systems. The specifics on the budget for these projects would be included in the prospective contract or grant awarded to Taiga/CU from BARDA, which is already a part of their approved budget.

**Background:** In the United States, there are currently a number of unmet medical needs regarding our nation's blood supply. Transfusion of red blood cells (RBC) is routinely used for many clinical and surgical applications with an average of 39,000 units of blood needed every day (data from 2004 indicate that 29 million units of blood were transfused in one year--source [www.aabb.com](http://www.aabb.com)).

Our nation's military reports that approximately half of all combat related casualties occur as a result of blood loss.

While the demand for red blood cells accelerates, our ability to maintain a safe and adequate blood supply has steadily decreased for three main reasons:

- First, the numbers of infectious agents shown to be transmitted through blood transfusions continuously increase;
- Second, the chronic use of Erythropoietin (Epo) has recently been associated with increased risk of developing erythroid leukemias, embolisms as well as cardiac complications; and,
- Finally, the performance of stabilized and recombinant hemoglobins and oxygen transporters (perfluorocarbons) has been disappointing, in some cases resulting in death.

In the area of transplantation, there are additional unmet medical needs. Widespread use of bone marrow cells has been radically limited by the numbers of cells that can be obtained from a single individual and the number of donors that “match” a particular patient. This lack of supply is accompanied by the major complication following standard bone marrow transplantation (BMT), which is susceptibility to infection while the immune system develops.

**Challenges for Traditional clinics:** One approach to mitigate the pressures on the blood supply was the development of a blood substitute. Most of these products have been based on hemoglobin, and as a group, have been designated as cell free hemoglobin-based blood substitutes (HBBS). A recent report that analyzed 16 independent clinical trials with HBBS, however, concluded that the use of such blood substitutes is associated with a significantly higher risk of death and heart attacks. Approaches to expand true adult stem cells have not been successful. Similarly, approaches to shorten the time for the immune system to develop following transplantation have made only modest improvements.

**Mass production of adult red blood cells and adult blood stem cells has been developed in Colorado:** Taiga is developing a technology that enables the rapid availability of adult blood stem cells (also called hematopoietic stem cells-HSC) from adult bone marrow or other non-embryonic sources. The proprietary technology can generate large numbers of cells that can be frozen and thawed while retaining their stem cell characteristics. Further, Taiga has recently used adult blood stem cells to generate fully mature red blood cells in the laboratory. The process used to generate adult human red blood cells in the lab involves a single step, requires 10-14 days, and yields >95% mature, enucleated red blood cells (RBCs). The resulting RBCs were able to rescue mice from lethal forms of anemia.

**Taiga's technologies provide several advantages over current technologies:** Taiga's ability to culture the adult blood stem cells in an almost indefinite manner enables us to generate mature RBCs in a continuous fashion from a defined source that can be carefully characterized and tested for safety. The RBCs our joint labs have been able to generate from Taiga's blood stem cell lines are fully enucleated and appear as adult RBCs. This ability to grow large numbers of adult blood stem cells may well expand the medical indications for a transplant and lower, or even remove the requirement of finding a "match."

Taiga's approaches have another advantage in that they use either adult bone marrow derived blood stem cells, cord blood or blood from healthy adults as a source. Hence, there are no Federal restrictions for research on human embryonic stem cells. Finally, Taiga is developing a protein treatment to allow successful engraftment following transplantation with a sub-optimal number of adult blood stem cells. In essence, this novel approach will enable bone

marrow transplants with fewer cells, such that a stock supply of cells can be used for more people. In addition, the medical complications and related costs associated with the delay in reestablishment of the patient's immune system can be significantly decreased with the use of this novel product. This treatment cuts the time to full immune system replacement (also called "hematopoietic reconstitution") in half. This protein treatment can be also be used prophylactically or therapeutically to prevent or cure bone marrow failure and/or acute radiation sickness (ARS).

**Conclusion:** For all the above reasons, Taiga Biotechnologies, Inc., in collaboration with the Charles C. Gates Center for Regenerative Medicine and Stem Cell Biology at the University of Colorado, feels uniquely qualified to help address the challenges faced by military and civilian planners to being fully prepared in the event of a catastrophic event. As such, we would appreciate the Subcommittee's support as we engage BARDA for both a grant to fund a Phase I/II clinical trial as well as a long-term contract to develop a strategic reserve of expanded and frozen human HSCs ready for transplantation at a 24 hours notice.

## Written Testimony

### **FY14 Funding: Bureau of Health Professions at the Health Resources Services Administration**

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 15, 2013**

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Mr. Chairman, Ranking Member, and distinguished Members of the Subcommittee, the members of the **Hispanic Dental Association (HDA)**, the leading voice for Hispanic oral health working for the elimination of oral health disparities, are requesting that FY2014 funding for the **Bureau of Health Professions at the Health Resources Services Administration (HRSA)** be appropriated at a recommended level of \$422 million. Of particular interest to HDA members are the **Health Professions Training for Diversity** and the **Oral Health Training Programs** at HRSA's Bureau of Health Professions. It is recommended that FY2014 funding for these two important programs be sustained at levels of \$70,361,000 and \$30,930,000, respectively.

#### **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 Health 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 pocketbook or wallet. Through these measures, the many misperceptions Hispanics have about oral health can be properly 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 at HRSA 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 socioeconomic, 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.

Health Professions and Diversity Program

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 2010-2011, grantees of the COE Program provided academic enrichment training to more than 3,500 URM students in health professions programs and 171 URM faculty. The SDS Program was just as effective. In academic year 2010-11, 50% of health professions graduates who received SDS funding entered service to medically underserved communities. This amount was five times the national average.

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. 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 firmly contend that HRSA programs help to address the need for diversity in health care professions and the need.

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 at the Health Resources Services Administration (HRSA) at a recommended level of \$422 million, and the Health Professions Training for Diversity and the Oral Health Training Programs at HRSA's Bureau of Health Professions at a recommended levels of \$70,361,000 and \$30,930,000, respectively, so that they can continue to meet the needs of reducing health disparities by increasing health care workforce diversity in our society.

Thank you for the opportunity to present our written testimony before the Subcommittee.



**COUNCIL ON SOCIAL WORK EDUCATION**

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**Testimony for Fiscal Year 2014  
Programs funded within 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 15, 2013

Submitted by  
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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).

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 is 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.

*Darla Spence Coffey, Council on Social Work Education, March 15, 2013*

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 2018, particularly for social workers specializing in the aging population and working in rural areas. In addition, the need for social workers specializing in mental health and substance use is expected to grow by almost 20 percent over the 2008-2018 decade.<sup>1</sup>

CSWE understands the difficult funding decisions Congress is faced with this year given the challenging budget climate. In these challenging times, it is my hope that the Committee will prioritize funding for health professions training in fiscal year (FY) 2014 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 \$520 million in FY 2014 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 the only 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. These programs also serve to increase minority representation in the health care workforce through targeted programs that improve the quality, diversity, and geographic distribution of the health professions workforce. The Title VII and Title VIII programs provide loans, loan

<sup>1</sup> U.S. Bureau of Labor Statistics. 2009. *Occupational Outlook Handbook, 2010-11 Edition: Social Workers*, <http://data.bls.gov/cgi-bin/print.pl/oco/ocos060.htm>. Retrieved March 28, 2012.

*Darlo Spence Coffey, Council on Social Work Education, March 15, 2013*

guarantees and scholarships to students, and grants to institutions of higher education and non-profit organizations to help build and maintain a robust health care workforce. Social workers and social work students are eligible for funding from the suite of Title VII health professions programs.

The Title VII and Title VIII programs were reauthorized in 2010, which helped to improve the efficiency of the programs as well as enhance efforts to recruit and retain health professionals in underserved communities. Recognizing the severe shortages of mental and behavioral health providers within the health care workforce, a new Title VII program was authorized in the *Patient Protection and Affordable Care Act* (P.L. 111-148). The **Mental and Behavioral Health Education and Training Grants** program would provide grants to institutions of higher education (schools of social work and other mental health professions) for faculty and student recruitment and professional education and training. The program received first-time funding of \$10 million in the final FY 2012 appropriations bill. **CSWE urges the Committee to maintain funding for this critically important program at \$10 million in FY 2014.** This is the only program in the federal government that is explicitly focused on recruitment and retention of social workers and other mental and behavioral health professionals.

### **SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION (SAMHSA) MINORITY FELLOWSHIP PROGRAM**

**CSWE urges the Committee to appropriate \$5.7 million for the MFP in FY 2014, which is equal to the FY 2012 enacted level.** 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. According to SAMHSA, minorities make up approximately one-fourth of the population, but only 10 percent of mental health providers come from ethnic minority communities. 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. SAMHSA makes

*Darla Spence Coffey, Council on Social Work Education, March 15, 2013*

grants to these six organizations, who in turn recruit minority doctoral students into the program from the six distinct professions.

Since its inception, 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 that are plaguing 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. Furthermore, a direct positive relationship exists between the numbers of ethnic minority mental health professionals and the utilization of needed services by ethnic minorities.<sup>2</sup>

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.

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<sup>2</sup> 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>.

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 15, 2013

Testimony: Corporation for Public Broadcasting and Department of Labor



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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.

Corporation for Public Broadcasting

In the CPB, NCAI supports an advanced FY 2015 appropriation of \$5 million for American Indian and Alaska Native radio stations. This \$5 million appropriation would come out of the FY 2014 advanced appropriation of \$445 million for the overall CPB budget.

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. In other words, Congress approves the FY 2015 funding level for CPB during the FY 2013 appropriations process. Thus, where the overall budget for the CPB in FY 2014 was \$445 million, Indian Country requests an advance appropriation of \$5 million to fund American Indian and Alaska Native radio stations for FY 2015.

Since 2011, the Native radio system has grown from 33 stations to 53 stations to provide service to more of Indian Country. CPB funding supports 30 of 53 Native

radio stations, which collectively reach more than eight percent of the American Indian and Alaska Native populations with free radio programming. These stations are funded through a variety of sources, including: individual donors, local businesses, CPB, tribal governments, and grants. Native-owned and operated radio stations are a model of local community service radio, serve as the primary and most consistent sole service providers of public safety information and cultural and linguistic preservation, and stand as an invaluable outlet for local news in tribal communities. Native radio stations employ at least 1,000 broadcasters, engineers, station staff, consultants, and other local community members.

Additionally, the Public Broadcasting Act directs CPB to utilize six percent of the appropriation for "projects and activities that will enhance public broadcasting." This funding supports the research, planning, professional development, and industry consultations that guide CPB's decision-making in other budget categories. Native Public Media and Koahnic Broadcast Corporation are capable to provide valued services to develop and maintain the Native radio system and are funded from the six percent allocation (currently amounting to \$1 million over two years). Native Public Media has assisted in filing for 51 new stations and secured construction permits for 38 of these new stations.

Native Public Media also provides education and training for tribal broadcasters in digital literacy, journalism, and community-based strategies that will broaden the impact of the Native radio system in unserved tribal communities across the United States. Koahnic Broadcast Corporation produces Native programming and content for radio broadcast and oversees Native Voice One - the distribution mechanism that utilizes satellite technology to deliver programming and content to Native radio stations and other affiliates across the United States. 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 53 tribal radio stations among this country's 566 federally recognized tribes illustrates the need for these services in Indian Country. This communications tool, though antiquated it may seem compared to other technologies available today, provides services of immense cultural significance.

### **Department of Labor**

*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. YouthBuild provides services to approximately 7,000 youth annually by re-engaging them in innovative alternative education programs that provide individualized instruction as they work towards earning either a GED or high school diploma, as well as fosters work skills so that youth can be competitive candidates in the job market. Youth participate in public construction projects while attending classes to obtain their high school diploma or GED.

YouthBuild reports that since it was established as a federal program in 1992, 120,000 YouthBuild students have built 22,000 units of affordable housing in low-income communities in 46 states and the District of Columbia. When the program was transferred from the Department of Housing and Urban Development to the Department of Labor in 2007, the 10 percent set-aside for rural and tribal programs was eliminated. Additionally, in 2011, due to a 28 percent cut in YouthBuild appropriations, over 18,000 applicants to YouthBuild programs were turned away.<sup>i</sup>

The YouthBuild program recruits youth that have been adjudicated, aged out of foster care, dropped out of high school, and others at risk of not having access to workforce training. In 2010,

4,252 youth participated in the program and had a completion rate of 78 percent. According to YouthBuild, 60 percent of those that completed the program were placed in jobs or further education.<sup>ii</sup> There are a number of tribal YouthBuild programs in several states, and at least four percent of YouthBuild participants are Native. Given the recent reduction in tribal YouthBuild programs, significant unemployment and housing challenges in Indian Country, and the growing Native youth population, it is essential that the 10 percent rural and tribal set-aside be restored.

***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.*** Reducing the education and employment disparity between Native people and other groups requires a concentrated effort that provides specific 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 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 the impact it has in Indian Country, as there are many more served by grantees that leverage WIA funding, along with other similar federally funded employment and training programs, through PL 102-477.

Any decrease in funding along with the looming discretionary cuts will be devastating and severely 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<sup>iii</sup>, 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<sup>iv</sup> and an average joblessness rate of nearly 50 percent<sup>v</sup>, the WIA Section 166 program is vital to helping reverse these trends.

Further, because the WIA Section 166 program 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 be maintained. 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, the WIA Section 166 program is the sole employment and training provider. Since 2003, the Workforce Investment Act (the Act) has been up for reauthorization; and over this ten-year period, the Act has not accounted for the population growth of tribal communities, nor the economic environment that has drastically changed. The Act authorizes the INAP to be funded at “not less than \$55 million,” but Section 166 is currently funded at approximately \$47 million. The Act 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 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.

### **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](mailto:aebarb@ncai.org) and Brian Howard, NCAI Legislative Associate, at [bhoward@ncai.org](mailto:bhoward@ncai.org) or Gerald Kaquatosh, NCAI fellow at [gkaquatosh@ncai.org](mailto:gkaquatosh@ncai.org).

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<sup>i</sup> See <https://youthbuild.org/research>.

<sup>ii</sup> *Ibid.*

<sup>iii</sup> US Census Bureau. Census 2000 Summary File 4, 2006-2010, 2009-2011 American Community Survey

<sup>iv</sup> U.S. Census. 2011 American Community Survey

<sup>v</sup> U.S. Department of Interior. Bureau of Indian Affairs. 2005 American Indian Labor Force Report

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### National Primate Research Centers Written Statement for the Record March 15, 2013

#### *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 2014 Funding for the National Institutes of Health Department of Health and Human Services**

The Directors of the eight National Primate Research Centers (NPRCs) respectfully submit this written testimony for the record to the House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies. The NPRCs appreciate the commitment that the Members of this Subcommittee have made to biomedical research through your support for the National Institutes of Health (NIH) and **recommends providing NIH with the highest possible funding level in fiscal year (FY) 2014.** Given the current uncertainty surrounding FY 2013 appropriations and the President's FY 2014 budget request, we expect this testimony to be only the beginning of an ongoing conversation between the Subcommittee and stakeholders about the FY 2014 funding needs of NIH. 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.

## NATIONAL PRIMATE RESEARCH CENTERS

The mission of the National Primate Research Centers 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 NPRCs are particularly concerned with the reduction of federal funds to support research, including the five percent cut in NIH funding under sequestration. The cuts harm our nation's ability to advance scientific discoveries that improve human health, bolster the economy, and help keep our nation globally competitive. Furthermore, the impact of sequestration has been compounded by ongoing funding constraints caused by ten years of flat NIH budgets, which have resulted in a loss of purchasing power and affected the ability of NIH-funded scientists to pursue promising new avenues of research. At the same time that scientists are facing these funding challenges, they are poised like 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.

Not only is NIH research essential to advancing health, it also plays a key economic role in communities nationwide. Approximately 84 percent of NIH funding is spent in communities across the nation,

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creating jobs at more than 2,500 research institutes, universities, teaching hospitals, and other institutions. NIH research also 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.

### **NPRCs' Contributions to NIH 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 technologies.

As a part of the NIH Office of the Director, the NPRCs see a great opportunity to 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. Also, as the National Center for Advancing Translational Sciences (NCATS) identifies new approaches to translating basic discoveries into treatments and therapeutics, the NPRC consortium will work with the new center to bring to the fore the central role of nonhuman primate research in developing, and ensuring the effectiveness of, new medical products and interventions. Finally, we continue to engage as a resource for the Clinical and Translational Science Award (CTSA) network to help clinical researchers increase their knowledge of and access to nonhuman primates as animal models.

Outlined below are a few of the overarching goals and priorities for the NPRCs, including specifics of how the NPRCs are striving to achieve these through programs and activities across the centers.

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**Advance Translational Research Using Animal Models** – Nonhuman primate models bridge the divide between basic biomedical research and implementation in a clinical setting. Currently, seven of the eight NPRCs are affiliated and collaborate with an NIH CTSA program through their host institution. Specifically, the nonhuman primate models at the NPRCs often provide the critical translational link between research with small laboratory animals and studies involving humans. As the closest genetic model to humans, nonhuman primates serve in the process of developing new drugs, treatments, and vaccines to ensure safe and effective use for the nation's public.

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. Major areas of research benefiting from the resources of the NPRCs include AIDS, avian flu, Alzheimer's disease, Parkinson's disease, autism, cardiovascular disease, diabetes, obesity, asthma, and endometriosis. To facilitate these and other studies, the NPRC have developed a resource of over 26,000 nonhuman primates, 70 percent of which are rhesus monkeys, the most widely used nonhuman primate for HIV research and a wide range of translational studies.

**Strengthen the Research Workforce** – The success of the federal government's efforts in enhancing public health is contingent upon the quality of research resources that enable scientific research ranging from the most basic and fundamental to the most highly applied. Biomedical researchers have relied on one such resource – the NPRCs – for nearly 50 years for research models and expertise with nonhuman primates. The NPRCs are highly-specialized facilities that foster the development of nonhuman primate animal models and provide expertise in all aspects of nonhuman primate biology. NPRC facilities and resources are currently used by over 2,000 NIH funded investigators around the country.

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The NPRCs are also supportive of students interested in the biomedical research at an early age. For example, the Yerkes NPRC supports a program that connects with local high schools and colleges in Atlanta, Georgia, and provides high school science students and teachers with summer-long internships to participate in research projects taking place at their center. Other NPRCs have similar programs that help develop a pipeline of aspiring science students and teachers.

### **The Need for Facilities Support**

The NPRC program is a vital resource for enhancing public health and spurring innovative discovery. In an effort to address many of the concerns within the scientific community regarding the need for funding for infrastructure improvements, the NPRCs support the continuation of a robust construction and instrumentation grant program at NIH. Animal facilities, especially primate facilities, are expensive to maintain and are subject to abundant “wear and tear.” The NPRCs are dependent on strong support for the P51 base grant program which is essential for the operational costs, and the C06 and G20 programs which support construction and renovation of animal facilities. Without proper infrastructure, the ability for animal research facilities, including the NPRCs, to continue to meet the high demand of the biomedical research community will be unsustainable.

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 highest possible funding for the agency in the FY 2014 appropriations bill.

**STATEMENT OF THE NATIONAL KIDNEY FOUNDATION  
30 EAST 33<sup>RD</sup> STREET NEW YORK, NY 10016**

**REGARDING FISCAL YEAR 2014 APPROPRIATIONS  
FOR THE CENTERS FOR DISEASE CONTROL AND PREVENTION  
CHRONIC KIDNEY DISEASE PROGRAM**

**SUBMITTED TO THE HOUSE COMMITTEE ON APPROPRIATIONS;  
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION,  
AND RELATED AGENCIES**

**March 15, 2013**

The National Kidney Foundation is pleased to submit testimony for the written record in support of the Centers for Disease Control and Prevention Chronic Kidney Disease Program.

We respectfully request \$2.2 million be provided for Fiscal Year 2014.

End Stage Renal Disease (ESRD), which requires dialysis or transplantation for survival, is the only disease-specific coverage under Medicare, regardless of age or other disability. At the end of 2010, the number of Americans with ESRD totaled more than 594,000, including 415,000 dialysis patients and almost 180,000 kidney transplant recipients. Complicating the cost and human toll is the fact that CKD is a disease multiplier; patients are very likely to be diagnosed with diabetes, cardiovascular disease, or hypertension (40% of ESRD patients had a diagnosis of diabetes). In 2010, CKD was present in 8.4% of Medicare beneficiaries but was responsible for 17% of Medicare expenditures.

Despite this tremendous social and economic impact, no national public health program focusing on early detection and treatment existed until FY 2006, when Congress provided \$1.8 million to initiate a Chronic Kidney Disease Program at the Centers for Disease Control and Prevention (CDC). Congressional interest regarding kidney disease education and awareness

also is found in Sec. 152 of the *Medicare Improvements for Patients and Providers Act of 2008* (MIPPA, P.L. 110-275), which directed the Secretary to establish pilot projects to increase screening for Chronic Kidney Disease (CKD) and enhance surveillance systems to better assess the prevalence and incidence of CKD. Cost-effective treatments exist to potentially slow progression of kidney disease and prevent its complications, but only if individuals are diagnosed before the latter stages of CKD.

The CDC program is designed to identify members of populations at high risk for CKD, develop community-based approaches for improving detection and control, and educate health professionals about best practices for early detection and treatment. **The National Kidney Foundation respectfully urges the Committee to maintain line-item funding for the Chronic Kidney Disease Program** for Fiscal Year 2014. Continued support will benefit kidney patients and Americans who are at risk for kidney disease, advance the objectives of Healthy People 2020 and the National Strategy for Quality Improvement in Health Care, and fulfill the mandate created by Sec. 152 of MIPPA.

The prevalence of CKD in the United States is higher than a decade earlier. This is partly due to the increasing prevalence of the related diseases of diabetes and hypertension. It is estimated that CKD affects 26 million adult Americans (1) and that the number of individuals in this country with CKD who will have progressed to kidney failure, requiring chronic dialysis treatments or a kidney transplant to survive, will grow to 712,290 by 2015 (2). Kidney disease is the 9<sup>th</sup> leading cause of death in the U.S. Furthermore, a task force of the American Heart Association noted that decreased kidney function has consistently been found to be an independent risk factor for cardiovascular disease (CVD) outcomes and all-cause mortality and that the increased risk is present with even mild reduction in kidney function. (3) Therefore

addressing CKD is a way to achieve one of the priorities in the *National Strategy for Quality Improvement in Health Care: Promoting the Most Effective Prevention and Treatment of the Leading Causes of Mortality, Starting with Cardiovascular Disease*.

CKD is often asymptomatic, a “silent disease,” especially in the early stages. Therefore, it goes undetected without laboratory testing. In fact, some people remain undiagnosed until they have reached CKD Stage 5 and literally begin dialysis within days. However, early identification and treatment can slow the progression of kidney disease, delay complications, and prevent or delay kidney failure. Accordingly, Healthy People 2020 Objective CKD–2 is to “increase the proportion of persons with chronic kidney disease (CKD) who know they have impaired renal function.” Screening and early detection provides opportunity for interventions to foster awareness, adherence to medications, risk factor control, and improved outcomes. Additional data collection is required to precisely define the incremental benefits of early detection on kidney failure, cardiovascular events, hospitalization and mortality. Increasing the proportion of persons with CKD who know they are affected requires expanded public and professional education programs and screening initiatives targeted at populations who are at high risk for CKD. As a result of consistent congressional support, the National Center for Chronic Disease Prevention and Health Promotion at CDC has instituted a series of projects that could assist in attaining the Healthy People 2020 objective. However, this forward momentum will be stifled and CDC’s investment in CKD to date jeopardized if line-item funding is not continued.

As noted in CDC’s *Preventing Chronic Disease: April 2006*, Chronic Kidney Disease meets the criteria to be considered a public health issue: (1) the condition places a large burden on society; (2) the burden is distributed unfairly among the overall population; (3) evidence exists that preventive strategies that target economic, political, and environmental factors could

reduce the burden; and (4) evidence shows such preventive strategies are not yet in place. Furthermore, CDC convened an expert panel in March 2007 to outline recommendations for a comprehensive public health strategy to prevent the development, progression, and complications of CKD in the United States.

The CDC Chronic Kidney Disease program has consisted of three projects to promote kidney health by identifying and controlling risk factors, raising awareness, and promoting early diagnosis and improved outcomes and quality of life for those living with CKD. These projects have included the following:

- (a) Demonstrating effective approaches for identifying individuals at high risk for chronic kidney disease through state-based screening (CKD Health Evaluation and Risk Information Sharing, or CHERISH).
- (b) Conducting an economic analysis by the Research Triangle Institute, under contract with the CDC, on the economic burden of CKD and the cost-effectiveness of CKD interventions.
- (c) Establishing a surveillance system for Chronic Kidney Disease. Development of a surveillance system by collecting, integrating, analyzing, and interpreting information on CKD using a systematic, comprehensive and feasible approach will be instrumental in prevention and health promotion efforts for this chronic disease. The CDC CKD surveillance project has built a basic system from a number of data sources, produced a report and created a website program consisting of information on preventing and controlling risk factors, the importance of early diagnosis, and strategies to improve outcomes. The website also provides links to a number of publications and reports. The

next steps include exploring state-based CKD surveillance data ideal for public health interventions through the state department of health.

We believe it is possible to distinguish between the CKD program and other categorical chronic disease initiatives at CDC, because the CKD program does not provide funds to state health departments. Instead, CDC has been making available seed money for feasibility studies in the areas of epidemiological research and health services investigation.

In summary, undetected Chronic Kidney Disease can lead to costly and debilitating irreversible kidney failure. However, cost-effective interventions are available if patients are identified in the early stages of CKD. With the continued expressed support of Congress, the National Kidney Foundation is confident a feasible detection, surveillance and treatment program can be established to slow, and possibly prevent, the progression of kidney disease. Thank you for your consideration of our testimony.

- (1) Josef Coresh, et al. "Prevalence of Chronic Kidney Disease in the United States," *JAMA*, November 7, 2007.
- (2) D.T. Gilbertson, et al., *Projecting the Number of Patients with End-Stage Renal Disease in the United States to the Year 2015*. *J Am Soc Nephrol* 16: 3736-3741, 2005.
- (3) Mark J. Sarnak, et al. Kidney Disease as a Risk Factor for the Development of Cardiovascular Disease: A Statement from the American Heart Association Councils on Kidney in Cardiovascular Disease, High Blood Pressure Research, Clinical Cardiology, and Epidemiology and Prevention. *Circulation* 2003; 108: 2154-69.

## EMERGENCY SERVICES COALITION ON MEDICAL PREPAREDNESS

Submitted by: Tim Stephens, Advisor to the Coalition on March 15, 2013

The Emergency Services Coalition for Medical Preparedness (ESCMP) recommends the establishment of pilot programs to "protect the protectors." These programs would be established in the Department of Health and Human Services, Assistant Secretary for Preparedness and Response (ASPR), complementing existing programs established for and with the US Post Office. A total of \$20 million would be appropriated, in addition to reallocation of materials and resources (if necessary) from existing medical countermeasure stockpiling programs.

This request is in support of the testimony of Chief Hank Clemmensen of the Palatine Rural Fire Protection District in Inverness, IL and the President and Chairman of the Board for the International Association of Fire Chiefs (IAFC). The IAFC and its members are the Nation's preeminent authority of the threat to local incident management capacity in large-scale events. The ESMCP (<http://www.emergencyservicescoalition.org/>) was formed in 2011 to represent the three million emergency services providers and provide a single voice regarding the "protection of the protectors," from chemical, biological, radiological and nuclear threats.

In 2008 the WMD Commission concluded that an act of bioterrorism was more likely than an act of nuclear terrorism. The Executive Director of the Commission recently stated "... our preparedness to respond to a major biological event is far less today than for a major hurricane."

These conclusions are supported by the annual reports issued by the Trust for America's Health ([www.tfah.org](http://www.tfah.org)), which document continuing deterioration in the capacities of the public health system, simultaneous with federal bioterrorism appropriations being cut consecutively for seven years.

These WMD Commission and TFAH description of public health capacity demonstrate the nation does not have sufficient capability to respond adequately to a large-scale biological event. The National Association of County and City Health Officials ([www.naccho.org](http://www.naccho.org)) has documented year on year local public health jobs lost due to the economic downturn of greater than 20% since 2008. Years of exercising and refining stockpile practices have yet to definitively demonstrate the ability to distribute medicines to the population in the less than 48 hours required by an large scale aerosolized anthrax attack.

The nation has not fully prepared and protected its emergency services personnel to ensure they can functionally mount a response to a large-scale event. Pre-event provision of protection for the protective services has been insufficient to ensure all providers can and will be able to respond.

This request for \$20 million for pilot program is consistent with the intent of the Pandemic and All Hazards Preparedness Act reauthorization, as signed this week by President Obama. The forward positioning of countermeasures in the workplaces and homes of the protectors is an overdue update of national policy. The programs are aligned with the statements made to the 112th Congress by the Chief Medical Officer of the Department of Homeland Security and the ASPR Principal Deputy.

Thank you for the opportunity to provide this input to the deliberation on our national security.



**Robert J. Beall, Ph.D.**  
President and Chief Executive Officer  
Cystic Fibrosis Foundation

On behalf of the Cystic Fibrosis Foundation 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 2014.

The Cystic Fibrosis Foundation remains significantly concerned about the impact of the recently-enacted sequester and other funding reductions on biomedical research and the health of the CF population. The Foundation requests the highest possible funding level for the National Institutes of Health, its National Center for Advancing Translational Sciences, and programs that provide access to health care in fiscal year 2014, in order to support continued scientific discoveries and promote the well-being of those living with this serious illness.

#### **Developing Cystic Fibrosis Treatments and a Cure through NIH Funding**

As the Committee considers its funding priorities for the coming fiscal year, we urge consideration of the critical role that NIH plays in the development of treatments for cystic fibrosis and other diseases and respectfully request increased funding for this vital agency.

NIH-funded advances like the mapping of the human genome and the development of high throughput screening were essential to the creation of Kalydeco™, a cystic fibrosis treatment approved in January 2012 and called "the most important drug of 2012" by *Forbes Magazine*. This breakthrough drug, developed by Vertex Pharmaceuticals in cooperation with the Cystic Fibrosis Foundation, is the first to treat the underlying cause of cystic fibrosis in those with a particular genetic mutation of CF that impacts about four percent of the CF population.

More exciting advancements are in the pipeline, as phase 3 clinical trials are underway to study a combination of Kalydeco and a new compound, VX-809. This combination would treat those with the most common CF mutation, comprising about 50 percent of those with CF in the United States.

Other NIH-funded research could be the key to future cystic fibrosis treatments, such as research conducted through NIH's pediatric liver disease consortium at the National Institute of Diabetes, Digestive, and Kidney Diseases (NIDDK), which helps researchers discover treatments for CF-related liver disease and other diseases that affect thousands of children each year.

NIH also issued two Requests for Applications (RFAs) last year that specifically target cystic fibrosis, one to study early lung disease and the other to study cystic fibrosis-related diabetes, both of which could lead to new scientific discoveries. The agency also invests in research at the University of Iowa that studies the effects of CF in both pig and ferret models. The ferret model in particular is expected to be uniquely informative of early events in CF-related diabetes and will compliment the ongoing work done through the NIDDK's RFA efforts.

CF-related genetic research also benefits from federal funding. Research into cystic fibrosis transmembrane conductance regulator (CFTR) folding and trafficking and CFTR protein structure is critical to the creation of new drugs that treat the underlying cause of the disease. The data that emerged from Kalydeco Phase 2 and 3 clinical trials provided proof that CFTR protein function modulation, the mechanism by which this drug targets the physiological defect in those with a particular CF mutation, is a viable therapeutic approach. More NIH-funded research is needed to understand the more than 1,000 other genetic mutations of CF.

Lastly, it is important to note that NIH funding benefits the economy, supporting more than 402,000 jobs and \$57 billion in economic output in 2012 according to a report by United for

Medical Research. Funding for NIH also attracts the next generation of promising researchers through programs like the National Research Service Awards (NRSAs). Robust funding for NIH promotes much-needed economic growth and supports the scientific progress that makes the United States the worldwide leader in biomedical research.

### **Advancing Innovation through Translational Science**

The Cystic Fibrosis Foundation strongly supports efforts to strengthen the field of translational science and urges the Committee to increase funding for the NIH's National Center for Advancing Translational Sciences (NCATS). NCATS' use of innovative methods and technologies to improve the development, testing and implementation of diagnostics and therapeutics improves the efficiency of the translation of basic scientific discoveries into new therapies and advances the search for cures.

Certain NCATS programs are integral to the center's success and merit special consideration. These include the Clinical and Translational Science Awards (CTSA), the Cures Acceleration Network (CAN) and the Therapeutics for Rare and Neglected Diseases (TRND) program, all designed to support clinical and translational research and transform the way in which it is conducted and funded. TRND in particular, inspired by the Cystic Fibrosis Foundation's Therapeutics Development Network of clinical research centers, is essential to the advancement of treatments for rare illnesses.

NCATS also emphasizes collaboration across sectors, promoting more efficient and innovative drug discovery and development. For example, the center is working with the Defense Advanced Research Projects Agency (DARPA) and the Food and Drug Administration (FDA) to design a tissue chip for drug screening. This chip, composed of diverse human cells and tissues, mimics how drugs interact with the human body. If successful, this chip 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.

Other significant collaborative projects include the Regulatory Science Initiative and the FDA-NIH Joint Leadership Council. As treatments like Kalydeco are developed to target specific genetic mutations and smaller populations, collaborative efforts between NIH, FDA and others in government, industry and academia will promote the swift advancement of therapies from the laboratory to the patients who need them most.

### **Promoting Access to Quality, Specialized Health Care**

The Cystic Fibrosis Foundation encourages robust funding for provisions of the Affordable Care Act (ACA) that ensure affordable access to quality, specialized health care for those with cystic fibrosis.

In order to receive the highest quality care, people with CF require treatment by a multidisciplinary team of providers who specialize in CF and practice at an accredited CF care center. Cystic fibrosis patients also need a variety of drugs and therapies to keep them healthy, many requiring 2-3 hours of treatment per day.

Cystic fibrosis is also an expensive disease. People with cystic fibrosis typically have medical costs 15 times greater than an average person. Unfortunately, the high cost of CF care is increasingly passed on to patients, placing a financial burden on those already struggling with a serious, chronic illness. Twenty five percent of CF patients in a recent survey reported that they have delayed or skipped medical care due to cost, and 31 percent said they skipped doses of medication or took less than prescribed due to cost concerns.

Affordable insurance that provides coverage for comprehensive, specialized care and medications allows those with CF to access the best treatment available for this difficult disease.

High co-payments, excessive co-insurance rates and unnecessary prior authorization requirements are burdensome barriers for those who need treatment to stay healthy.

We urge the Committee to provide sufficient funding for the ACA provisions that will help those with cystic fibrosis afford the care they need, including the expansion of the Medicaid program, the development of Health Insurance Marketplaces to ensure adequate and affordable coverage for high-quality, specialized cystic fibrosis care and the creation of Essential Health Benefits that include access to specialized CF care centers and medications and prevent overly burdensome barriers to needed treatments.

#### **About Cystic Fibrosis and the Cystic Fibrosis Foundation**

Cystic fibrosis is a rare genetic disease that causes the body to produce abnormally thick mucus that clogs the lungs and results in life-threatening infections. This mucus also obstructs the pancreas and stops natural enzymes from helping the body break down and absorb food.

The Cystic Fibrosis Foundation's mission is to find a cure for CF and improve the quality of life for those living with the disease. Through the Foundation's efforts, the life expectancy of a child with CF has doubled in the last 30 years and research to find a cure is more promising than ever. The Foundation's research efforts have helped create 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 our ongoing work to find a cure.

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Once again, we urge the Committee to increase funding for biomedical research at the National Institutes of Health and for programs that provide access to specialized health care in fiscal year 2014. We stand ready to work with the Committee and Congressional leaders on the challenges ahead. Thank you for your consideration.

Testimony of Anthony F. (Bud) Rock  
 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 15, 2013

**Seeking Support for the Following Agencies and Programs in FY 2014:  
 Institute of Museum and Library Services – Office of Museum Services  
 Department of Education – 21<sup>st</sup> Century Community Learning Centers  
 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 Chief Executive Officer of the Association of Science-Technology Centers (ASTC). My testimony addresses the importance of science, technology, engineering, mathematics (STEM), and health education, and will focus specifically on the fiscal year (FY) 2014 budgets for programs at three federal agencies over which your Subcommittee has jurisdiction: (1) the Office of Museum Services (OMS) at the Institute of Museum and Library Services (IMLS), which would have received \$30.859 million in funding under the FY 2103 budget request (the same amount as the FY 2012 estimated level); (2) the 21<sup>st</sup> Century Community Learning Centers (21<sup>st</sup> CCLC) program at the Department of Education (ED), which would have received \$1.152 billion under the FY 2013 budget request (the same amount as the FY 2012 estimated level); and (3) the Science Education Partnership Award (SEPA) program at the National Institutes of Health (NIH), which would have received \$20.3 million under the FY 2013 budget request (the same amount as the FY 2012 estimated level).

Our Request

On behalf of ASTC and the 383 science centers and museums we represent here in the United States, I urge the Subcommittee to continue its strong support for critical education programs within the Institute of Museum and Library Services, the Department of Education, and the National Institutes of Health as your work on the Labor, Health and Human Services, Education, and Related Agencies Appropriations Bill for fiscal year 2014 progresses. **Specifically, I urge you to do all you can to fully fund the Institute of Museum and Library Services' Office of Museum Services by providing the Congressionally-authorized level of funding, \$38.6 million, for fiscal year 2014. In addition, I encourage you to maintain robust funding for the Department of Education's 21<sup>st</sup> Century Community Learning Centers program and the National Institutes of Health's Science Education Partnership Award program for the same fiscal year.**

About ASTC and Science Centers

ASTC is a nonprofit organization of science centers and museums dedicated to providing quality educational experiences to students and their families as well as furthering public engagement with science among increasingly diverse audiences. It is imperative that we spark the interests of

our young people in all that the STEM fields have to offer, which is exactly why community-based science centers throughout the country are providing unique educational programs that excite, energize, and enrich our understanding of science and health and their many applications—often with support from IMLS, ED, and NIH, in addition to other federal agencies.

Science centers are unique places where visitors can discover, explore, and test ideas and, most importantly, learn how science and health impact their quality of life. Their offerings are varied, and include interactive exhibits, hands-on science experiences for children, professional development opportunities for teachers, and educational programs for adults.

ASTC now counts more than 600 members, including 481 operating or developing science centers and museums in 45 countries. Collectively, our institutions garner 95 million visits worldwide each year. Here in the United States, your constituents pass through science center doors more than 65 million times to participate in intriguing educational science activities and explorations of scientific phenomena. The most recent *Science and Engineering Indicators* (2012) generally affirms this data, offering that:

*Involvement with S&T outside the classroom in informal, voluntary, and self-directed settings—such as museums, science centers, zoos, and aquariums—is another indicator of the public's interest in S&T. By offering visitors the flexibility to pursue individual curiosity, such institutions provide a kind of exposure to S&T that is well-suited to helping people develop further interest. In the 2008 [General Social Survey], 61% of Americans indicated that they had visited an informal science venue during the previous year. About half (52%) said they had visited a zoo or aquarium, and more than one-quarter had visited a natural history museum (28%) or an S&T museum (27%).*

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 Chabot Space and Science Center in Oakland, the California Science Center in Los Angeles, the Connecticut Science Center in Hartford, the Museum of Arts and Sciences in Macon, Georgia, the Discovery Center of Idaho in Boise, and the Creative Discovery Museum in Chattanooga, Tennessee.

As part of its mission, ASTC works with these science centers and museums—small, large, and everywhere in-between—to educate and inform visitors on 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 including energy, the environment, infectious diseases, and space; increase understanding of important new technologies; and promote meaningful informed debate between citizens, scientists, policymakers, and the local community.

#### 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., 90% of our members offer school field trips, and we estimate that nearly 11 million children attend science centers and museums as part of those groups each year. Field trips, however, are just the beginning of what science centers and museums contribute to our country's educational infrastructure, as:

- 90% offer classes and demonstrations
- 89% offer school outreach programs
- 82% offer workshops or institutes for teachers
- 75% offer curriculum materials
- 71% offer programs for home-schoolers
- 56% offer after-school programs
- 41% offer programs that target senior citizens, and
- 39% offer youth employment programs.

#### The Importance of Federal Support for STEM Education

Along those lines—and 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. Reports like the National Academies' *Rising Above the Gathering Storm* (2005) and the President's Council of Advisors on Science and Technology's *Prepare and Inspire* (2010) have emphasized the need to attract and educate the next generation of American scientists and innovators, and have recommended that we increase our talent pool by vastly improving K-12 science and mathematics education. Clearly, in order to improve STEM education, we must draw on a full range of learning opportunities and experiences, including those in non-school settings.

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. Given the important role science centers and museums play in the education of both students and teachers, ASTC strongly supports—and greatly appreciates—the educational offerings provided by the Institute of Museum and Library Services, the Department of Education, and the National Institutes of Health.

Last year, the United States Conference of Mayors (USCM) recognized this important ties between science centers and museums and the federal government. At its 80<sup>th</sup> Annual Meeting, the USCM adopted a resolution calling on Congress and the President to fully fund federal

informal science education programs. The resolution also recognized the unique and essential role that American science centers play in providing math and science education for students of all ages while acknowledging the vital learning that goes on in science centers throughout the country.

#### 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. For years, science centers—and the communities they serve—have benefitted from competitively-awarded grants offered by IMLS.

Just last year, the Creative Discovery Museum in Chattanooga, Tennessee received an IMLS Museums for America grant to support its “Youth Spark Initiative,” a program that is designed to serve new audiences and expand the services the museum provides to the greater Chattanooga area. The overall goals of the initiative include serving the needs of adolescent youth (aged 11 to 16) through the museum experience; increasing participation of young people in museum programs; strengthening ties to youth by giving them a voice in the development of programs and future exhibits; assisting youth in achieving 21st century skills; bringing youth together from different parts of the community; and empowering teens to help the museum. Additionally, the museum will create a youth advisory board and develop a teen media collaborative.

**Funding for the IMLS Office of Museum Services reached a high in FY 2010, when it received \$35.212 million. The FY 2013 requested level of \$30.859 million—though equal to the amount available for FY 2012—reflected a \$4.353 million (12.4%) cut from the FY 2010 level.**

#### Department of Education

ED’s 21<sup>st</sup> Century Community Learning Centers program supports 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 21<sup>st</sup> 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.

As previously noted, more than half of ASTC’s science centers and museums offer after-school programs, which is especially noteworthy given that more than 15 million school-age children—including more than 1 million in grades K-5—are on their own after school. Research shows that kids who participate in such programs improved significantly in three major areas: feelings and attitudes, indicators of behavioral adjustment, and school performance. This translates to self-confidence and self-esteem, positive social behaviors, and accomplishment in school settings.

In 2010, the Scottsdale Unified School District’s Community Schools Department 21st CCLC was awarded a \$24,000 grant from the Arizona Department of Education in partnership with the

Arizona Science Center (another ASTC member). Funds are being used for STEM education at an elementary school, where a STEM club/camp will include family engagement, a full-day field trip to the Arizona Science Center, and club/camp instruction by the Science Center. The STEM club/camp pilot programs will assist Arizona 21st CCLC programs already committed to STEM during the day, and should significantly highlight STEM in the after-school program for students and their families.

**Funding for the 21<sup>st</sup> CCLC program has remained relatively constant since FY 2010, when it received \$1.166 billion in funding. The FY 2013 requested level of \$1.152 billion was equal to the amount available for FY 2012 and roughly the same amount available for FY 2011.**

#### National Institutes of Health

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 K-12 resources target state and national K-12 standards for STEM teaching and learning and are rigorously evaluated for effectiveness.

In 2009, the Maryland Science Center opened "Cells: The Universe Inside Us," with the support of the NIH's Science Education Partnership Award program. The exhibit employs the same telescopic technology used to view faraway planets and turns it inward on the human body, resulting in 4,000 square feet of space featuring dozens of interactive components and images never seen before by the public. At the science center, visitors embark upon a journey inside the body, illustrating how cells, the fundamental building blocks of life, are constantly growing and changing. The exhibition includes the latest research in cellular and molecular biology, and its relationship to human development, aging, and health.

**Funding for the SEPA program has also remained relatively constant in recent fiscal years. The FY 2013 requested level of \$20.3 million equaled the amount available for FY 2012, and reflects only a slight increase over the FY 2009, FY 2010, and FY 2011 levels.**

#### Conclusion

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 Institute of Museum and Library Services, the Department of Education, and the National Institutes of Health. I respectfully request that you allot the authorized level of \$38.6 million to fully fund IMLS and its Office of Museum Services for FY 2014, while providing robust FY 2014 funding for ED's 21<sup>st</sup> Century Community Learning Centers program and NIH's Science Education Partnership Award program. Thank you once again for your strong support for America's science centers and museums—and for the opportunity to present these views. I would be happy to respond to any questions or provide additional information as needed by the Subcommittee.

DATE: 15 March 2013

TO: Subcommittee on Labor, Health and Human Services, Education and Related Agencies  
Committee on Appropriations  
U.S. House of Representatives

FROM: Gerard M. Farrell, Executive Director,  
Commissioned Officers Association of the U.S. Public Health Service, Inc. (COA)  
8201 Corporate Drive, Suite 200, Landover, Maryland 20785

RE: Funding for the U.S. Public Health Sciences Track in FY 2014

The Commissioned Officers Association of the U.S. Public Health Service, Inc. (COA) asks that \$160 million be appropriated to support a congressionally-authorized (but unfunded) workforce program to recruit and train physicians, dentists, nurses, physician assistants, mental health experts and other public health professionals for public service careers in the USPHS Commissioned Corps. The program is called the United States Public Health Sciences Track and it resides in the U.S. Department of Health and Human Services. Its annual cost is estimated at \$160 million. The estimated cost is less than that of similar programs offered by the National Health Service Corps. Moreover, the Public Health Sciences Track offers a better payoff – more than double the required service time.

**Background and Rationale**

This program was authorized in Section 5315 of the Affordable Care Act (Public Law 111-148). Despite concerns and controversy surrounding other aspects of the law, there has never been, to our knowledge, any opposition to the Public Health Sciences Track expressed by any Member of

Congress. The authorizing language recognized the need to replenish and expand the USPHS Commissioned Corps and its active-duty force of 6,800 health professionals.

The Public Health Sciences Track means guaranteed jobs for all graduates. This is possible because there are thousands of unfilled positions, i.e., potential billets, for qualified clinicians who are willing to serve as uniformed public health professionals in Indian Country and in underserved urban and rural areas in nearly every state.

Equally important, USPHS officers are deployable on short notice in response to natural disasters and attacks from foreign and home-grown terrorists. When Hurricane Sandy struck last fall, a USPHS Captain commanded a contingent of 1,000 first responders - doctors, nurses, engineers and sanitarians - sent to New York, New Jersey, and Connecticut to lead and support recovery efforts. USPHS officers were also deployed in response to the mass killing of children in a Newtown, Connecticut, elementary school.

USPHS health professionals serve side-by side with Armed Forces personnel at home and abroad, on joint training missions, and even in forward operating bases in combat zones. USPHS psychiatric nurses have treated injured soldiers under fire in Afghanistan. USPHS psychologists and other mental health specialists have been detailed to the military to treat returning soldiers and Marines suffering from traumatic brain injury and post-traumatic stress disorder. The PHS Commissioned Corps is a public health and national security force multiplier.

The Public Health Sciences Track, as codified in Title 42, would provide for 850 annual scholarships for medical, dental, nursing, and public health students who commit to public service careers in the USPHS. This program would be the first dedicated pipeline into the USPHS Commissioned Corps.

The law would reserve ten slots at the Uniformed Services University of the Health Sciences (USUHS), which is the medical school and research institute for uniformed services personnel (Army, Navy, Air Force, and Public Health Service). The rest would be distributed among interested schools of medicine, dentistry, nursing, and public health, based on recommendations of the U.S. Surgeon General.

#### **Funding**

The authorizing language identified an existing source of funds. Support was to come from the Public Health and Social Services Emergency Fund. The law directed the DHHS Secretary to “transfer from the Public Health and Social Services Emergency Fund such sums as may be necessary” (Sec. 274). The transfer of funds never occurred, and that is why an appropriation is necessary. Even a small appropriation sufficient to support a pilot program at USUHS beginning in FY 2014 would be a critically important first step. It would keep the program alive.

For more information, COA Executive Director Jerry Farrell may be reached at the COA offices at 301-731-9080, ext. 211, or on his personal cell phone at 410-353-4513.

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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 15, 2013

Testimony on the Department of Health and Human Services

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INTRODUCTION

The National Congress of American Indians (NCAI) is the oldest and largest American Indian organization in the United States. Tribal governments cannot survive and prosper without healthy and strong tribal citizens. The United States Congress has shown a commitment to over 300 treaties and the federal trust responsibility through appropriations to programs that support the health and wellness of tribal communities. However, American Indians and Alaska Natives continue to experience chronically high rates of foster care, suicide, diabetes, and obesity.

Each year NCAI works with national and regional Indian organizations to develop budget recommendations and requests for each area of the federal budget. For this subcommittee, NCAI provides the recommendations below for some federal agencies under the Department of Health and Human Services (HHS) and fully supports the recommendations of the National Indian Child Welfare Association, National Indian Health Board, and National Indian Education Association.

**Substance Abuse and Mental Health Services Administration (SAMHSA)**

*Provide \$15 million to fund Substance Abuse and Mental Health Services Administration (SAMHSA) for Behavioral Health.* This SAMHSA grant program has been authorized to award grants to Indian health programs to provide the

following services: 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 their citizens.

*Support SAMHSA's Behavioral Health Tribal Prevention Grant program at \$40 million in FY 2014.* The Behavioral Health Tribal Prevention Grant will support behavioral health services that promote overall mental and emotion health, in particular substance abuse prevention and suicide prevention services. If funded, the grant program would be the only source of federal substance abuse and suicide prevention funding exclusively available to tribes.

*Provide a \$6 million tribal set-aside for American Indian suicide prevention programs under the Garrett Lee Smith Act.* Suicide has reached epidemic proportions in some tribal communities. The Garrett Lee Smith Memorial Act of 2004 is the first federal legislation to provide specific funding for youth suicide prevention programs, authorizing \$82 million in grants over three years through SAMHSA. Currently, tribes must compete with other institutions to access these funds. To assist tribal communities in accessing these funds, a line item for tribal-specific resources is necessary.

#### **Administration for Children and Families**

*Provide full funding for Head Start and Indian Head Start.* Head Start has been and continues to play an instrumental role in Native education. This vital program combines education, health, and family services to model traditional Native education, which accounts for its success rate. However, current funding dollars provide less for Native populations as inflation and fiscal constraints increase. It is now conventional wisdom that there is a return of at least \$7

for every single dollar invested in Head Start.<sup>1</sup> Therefore, Congress should fully fund Head Start and Indian Head Start to ensure this highly successful program serves more Native people.

***Provide \$10 million for Esther Martinez Program Native language preservation grants.***

Native language grant programs are essential to revitalizing Native languages and cultures, many of which are at risk of disappearing in the next decades. With adequate funding, Esther Martinez Program Grants support and strengthen Native American language immersion programs. In addition to protecting Native languages, these immersion programs have been shown to promote higher academic success for participating students in comparison to their Native peers who do not participate. This is critical for our Native youth, who have high school graduation rates far lower than their non-Native peers.

**Administration on Aging**

***Provide \$30 million for Parts A (Grants for Native Americans) and B (Grants for Native Hawaiians) of the Older Americans Act.*** Programs under Title VI of the Older Americans Act are the primary vehicle for providing nutrition and other direct supportive services to American Indian, Alaska Native, and Native Hawaiian elders. Approximately two-thirds of the Part A and Part B grants to tribes or consortia of tribes are for less than \$100,000. This funding level is expected to provide services for a minimum of 50 elders for an entire year. Yet, those tribes receiving \$100,000 typically serve between 200 and 300 elders. As such, many tribes are unable to meet the five-days-a-week meal requirement because of insufficient funding and are serving congregate meals only two or three days per week. Some Title VI programs are forced to close for a number of days each week, unable to provide basic services such as transportation, information and referral services, legal assistance, ombudsman, respite or adult day care, home

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<sup>1</sup> Mitra, D. (June 2011). "Pennsylvania's best investment: The social and economic benefits of public education." Philadelphia, PA: Education Law Center. Retrieved on January 8, 2013, from [http://www.elc-pa.org/BestInvestment\\_Full\\_Report\\_6.27.11.pdf](http://www.elc-pa.org/BestInvestment_Full_Report_6.27.11.pdf).

visits, homemaker services, or home health aide services. Rapidly increasing transportation costs also severely limit Title VI service providers' ability to deliver meals and related supportive services to home-bound Native elders at the current funding level. This funding should be significantly increased so that Native elders receive the care that they deserve.

*Provide \$8.3 million for the Native American Caregiver Support Program administered by the Administration on Aging and create a line-item for training for tribal recipients.* The Native American Caregiver Support Program under Part C of the OAA assists American Indian, Alaska Native, and Native Hawaiian families caring for older relatives with chronic illnesses. The grant program offers many services that meet caregivers' needs, including information and outreach, access assistance, individual counseling, support groups and training, respite care, and other supplemental services. However, this program cannot be effective if it is not adequately funded. It should be funded at \$8.3 million, with sufficient resources also allocated to address historically unmet tribal training needs.

*Create a tribal set-aside of \$2 million under Subtitle B of Title VII.* Subtitle B of Title VII of the Older Americans Act authorizes a program for tribes, public agencies, or non-profit organizations serving Native elders to assist in prioritizing issues concerning elder rights and to carry out related activities. While states have been funded at more than \$20 million per year under this program, tribes have never received appropriations for this purpose. Further, tribes have no additional source of mandatory federal funding for elder protection activities. As such, a \$2 million tribal set-aside should be created under Subtitle B to ensure that tribes have access to such funds at a comparable level to states.

*Provide \$3 million for national minority aging organizations to build the capacity of community-based organizations to better serve Native seniors.* Language and cultural barriers severely restrict Native elder access to federal programs for which they are eligible. Typically,

these senior Americans have limited access to and participation in programs such as Social Security, Medicare, and Medicaid. Funding is needed to build capacity for tribal, minority, and other community-based aging organizations to serve Native elders and enroll them in programs to which they are entitled. These efforts could include training tribal staff on expanding Native elders' access to Medicare, Medicaid, housing, congregate meals, and veteran benefits. Efforts could also include working with tribal leaders to leverage existing funds and programs to sustain support for elders. This funding is essential to strengthening local organizations in serving seniors.

### **National Institutes of Health**

Though NCAI is not requesting additional funding for the National Institutes of Health (NIH), we would like to protect current funding levels and highlight the significant negative impact the sequestration will have on many tribal governments and associate research and development projects. Of the major research institutes, the NIH stands to take the greatest hit in terms of total dollars lost at nearly \$2.4 billion. This could severely constrain research on diseases that cost tribal communities millions of dollars each year to treat, including: diabetes, cancer, and heart disease, amongst so many others. It will also affect the number of grants NIH awards each year, which may affect Native-focused funding mechanisms like the Native American Research Centers for Health (NARCH) funded by NIH. NCAI requests that the subcommittee work to protect research for and with tribal communities as these projects continue to inform policymaking decisions and highlight best practices for tribal programs and initiatives.

### **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](mailto:aebarb@ncai.org) and Terra Branson, NCAI Legislative Associate, at [tbranson@ncai.org](mailto:tbranson@ncai.org).

Testimony submitted before the House Appropriations Subcommittee on Labor, Health and Human Services, Education Fiscal Year 2014 Budget

Statement of Leslie Harper, Leech Lake Ojibwe

Director of Niigaane Ojibwemowin Immersion for the Leech Lake Band of Ojibwe

March 15, 2013

Gidanimikooninim, esteemed Committee Members. I greet you all and thank you for the opportunity to testify in support of the importance of our Native Languages, Culture-Based Education, and their connection to success for Native students. I will present testimony that describes, through our in-service field experience of the last nine years, the ways in which funding and public policy incongruence both supports *and* interrupts the transmission of educational content through the medium of our identified indigenous language of Ojibwe, and will reinforce needs that the proposed funding appropriation can meet. Currently we recognize a dual need to 1) Continue funding the Esther Martinez Initiative Native Language Programs under the Administration for Native Americans at the enacted amount of \$12 million annually; and, 2) Recommend that the language of the appropriation is amended to clearly state, “with no less than \$4 Million for immersion schools as defined by Esther Martinez Language Nest and Survival Schools Initiative in P.L. 109-394”.

My name is Leslie Harper, and I am an enrolled member of the Leech Lake Band of Ojibwe. I am the Director of the Niigaane Ojibwemowin Immersion school at Leech Lake in north-central Minnesota. Niigaane provides all academic content through the medium of Ojibwe language, and we are currently in our ninth year of operation. The Niigaane Ojibwemowin Immersion school was implemented as an extension of the community’s intent to provide continued transmission of Ojibwe language and lifeways, with the added cognitive benefits that are attained through bilingualism, which will improve academic performance and English language skills. Our school elicits local expertise in areas such as Ojibwe language lexicon, geography, and botany to collaboratively develop curriculum that situates the Niigaane student as an Ojibwe citizen

of the world, a student whose understandings contribute to the knowledge base of the entire world.

Niigaane operates within the Leech Lake Band of Ojibwe tribally-chartered Bureau of Indian Education Bugonaygeshig School at the Leech lake reservation in Minnesota. Niigaane curriculum focuses on presenting social and academic concepts from an Ojibwe frame of reference to which academic content area benchmarks are then applied, using an Ojibwe language and cultural base as a way to sustain values and mores while achieving the BIE's mandate to meet the achievement levels and all other Adequate Yearly Progress Indicators of the state in which our school is located.

Currently, the school includes Kindergarten through grade 6 with 35 students enrolled, and we have graduated out four students from our original Kindergarten entry cohort in 2005. The school has added a grade each year as students move from a lower grade to an upper grade. Students enter at Kindergarten, coming from English-speaking homes and communities with very little knowledge of Ojibwe language outside of basic greetings and perhaps the names of some common objects. Thus, Niigaane's primary intent is to utilize the consistent environment of a school setting as a path to renewal of language usage in the community. Students are introduced to Ojibwe as a second language, and instructed in Ojibwe for all subjects until grade three when English language class is introduced. Most subjects will continue to be presented in Ojibwe as the development of appropriate lexicon follows, along with an increasing amount of English language arts development.

The students who have graduated from our school to other regional English-medium schools are performing as well as, or better than, Minnesota's 7<sup>th</sup> and 8<sup>th</sup> grade students (all races and socio-economic statuses), on English language-medium assessments of academic achievement. These students have the added benefit of being functionally bilingual at an age much younger than the average Minnesota student. Research on multilingualism has long recognized that language learning produces higher-level cognitive functioning and higher-level social and cultural competence than does monolingualism. Our school requires a family to commit to volunteer at the school in order to improve our site and offerings, thus involving multiple generations of our people in our education site; only a few decades ago, our families were intimidated or

uninterested in participating in the public school educational sites because they did not reflect our Ojibwe community. This amazing turnaround results in up to 1000 hours per year of volunteer resources which we could not afford to purchase within the parameters of existing per-pupil funding. Reaching students at an earlier age with high-level language development, and in a linguistic- and culturally-relevant setting that honors our Ojibwe heritage as equal to any other world language of instruction, is positively benefiting our nation.

Niigaane faces a critical need to develop and train teachers to deliver the academic and social content of the curriculum that has been developed locally. It is imperative that the teaching teams are comprised of members who are highly proficient in speaking and writing the Ojibwe language in order to effectively deliver the language and content of the school site. As well, we are bound by state and federal monitor agencies to have the content delivered by a “Highly Qualified” teacher as per ESEA requirements, which state that the “Highly Qualified” teacher has an appropriate teacher college certification and state license to teach in the elementary setting.

However, current university elementary education training programs do not adequately address the needs of an Ojibwe-medium educational setting. Often, methods of delivery diverge from english-medium education due to differences in alphabet, syntax, lexicon, and socio-cultural context of content delivery. Therefore, internal/local determinations have been made by a local development team through maintenance of Elders Round Table discussions and a focus on elements of Culturally Based Education, on how to train the teachers to deliver the content to the students.

Thus, an extraordinary burden is placed on the Niigaane school site to additionally train the “Highly Qualified” teachers who come out of the teacher preparation colleges with little or no proficiency in the Language of Instruction: Ojibwe language, and little or no proficiency in the cultural and pragmatic context of the school site, the Leech Lake Reservation. The Niigaane school site must then seek extraordinary funding to train the teachers in language and cultural proficiency. Also, the Niigaane school site must recruit dedicated teachers who are willing to put in training time extraordinary to the usual four-year route of a college teacher prep program (summer work sessions, weekend development sessions).

Curriculum materials must be created locally, as currently, no publishing house provides a comprehensive set of elementary-age academic content materials created in the Ojibwe language. This requires extraordinary human resource (staffing, contractual) and financial resources to meet the needs of our Ojibwe language medium school.

All of these extraordinary resources can be described as barriers to implementation of our school, and require a great amount of time on the part of the local community to secure the resources necessary to revitalize and maintain our Ojibwe language and to provide our educational content through our Ojibwe language. The only federal funding source that is dedicated to the revitalization of our Ojibwe language is the Administration for Native Americans Esther Martinez Initiative, which has supported our school development and operations as local capacity-building initiatives for the past five years. Without this Language Survival School-specific funding available, we would not have been able to work to develop curricular items and assessments in the language of instruction at our site.

Assessments of our academic and social achievements must be developed in the language and context of Ojibwe immersion education, and accepted as valid and reliable indicators of progress toward any monitor status that we will encounter. Current academic assessments in English, which is a language other than the Language of Instruction, are not appropriate indicators of what the students are learning at the Ojibwe language immersion school site. However, the state monitors continue to tell us that our students must participate in the summative assessments of academic performance, in a language that is other than the language of instruction. We must investigate and determine appropriate public policy within the ESEA that responds to the needs of the citizens of our Leech Lake Nation for educational accountability in our Ojibwe language communities. We must therefore strengthen language that addresses Title III of the ESEA to encourage full medium of instruction in Native Languages and concomitant AYP calculations to support local definitions of Highly Qualified Teachers where the medium of instruction for content areas is in a Native Language (language other than English); and clarify Title I of the ESEA to treat Native American Immersion Schools and Schools using Native Language as a medium of instruction the same as schools in

Puerto Rico in order to provide assessments for accountability in the language of instruction where the medium of instruction is through a Native Language.

We feel that our locally determined route to language and culture revitalization through the medium of Ojibwe language immersion education for all academic and social contexts will benefit our nation far into the future by developing new members of the Ojibwe Nation who are grounded in Ojibwean ideals of citizenship. These benefits will extend to any context or community in which these Niigaane Ojibwe Immersion students - Ojibwe citizens - may find themselves, and will continue to positively contribute to the knowledge base of the world.

We have determined locally that our population will be well-served by Ojibwe-culturally based education, and we seek the funding support to continue to develop our efforts, and continued investigation into public policy and funding appropriations that support our efforts.

Miigwech weweni gaa'inendameg, thank you for your kind consideration.

**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 testify on behalf of the nation's 211 U.S. 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 FY2014 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. Accredited zoos and aquariums annually see more than 182 million visitors, collectively generate more than \$16 billion in annual economic activity, and support more than 142,000 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, 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 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, through its 2012 Museums for American grant, the Birmingham Zoo will support its Africa Zoo School program, which will serve 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. 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. Finally, the Beardsley Zoo used its 2011 Museums for America grant to continue its "Conservation Discovery Corps" teen program, a year-round informal science education program designed to provide diverse and economically challenged but environmentally aware

students with applied wildlife conservation training in the zoo and through field research.

Students were trained in conservation and education concepts that were applied through field expeditions and collaborations with scientists in research and habitat restoration activities to prepare them as zoo exhibit interpreters and teen Conservation Discovery Corps ambassadors.

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 FY2014 Labor, Health and Human Services, Education, and Related Agencies appropriations bill.

Thank you.

**Testimony for the Labor, Health and Human Services Appropriations Subcommittee  
Paulette Sullivan Moore, Vice President of Public Policy, National Network to End Domestic Violence  
U.S. House of Representatives  
Family Violence Prevention and Services Act and the Violence Against Women Act programs  
March 15, 2013**

Labor, Health and Human Services Chairman Kingston, Ranking Member DeLauro, Chairman Rogers, Ranking Member Lowey and distinguished members of the Appropriations Committee, thank you for this opportunity to submit 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 Vice President of Public Policy 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, their 2,000 member domestic violence and sexual assault programs, as well as the millions of victims they serve. Our direct connection with victims and victim service providers gives us a unique understanding of their needs and the vital importance of continued federal investments. I am submitting this testimony to request a targeted investment of **\$190.5 million** in Family Violence Prevention and Services Act (FVPSA) and Violence Against Women Act (VAWA) programs administered by the U.S. Department of Health and Human Services in the FY 2014 Budget (specific requests detailed below).

**Incidence, Prevalence, Severity and Consequences of Domestic and Sexual Violence.** The crimes of domestic and sexual violence are pervasive, insidious and life-threatening. Recently, the Centers for Disease Control and Prevention (CDC) released the first-ever National Intimate Partner and Sexual Violence Survey (NISVS) which found that domestic violence, sexual violence, and stalking are widespread. Domestic violence affects more than 12 million people each year. Nearly one in five women and one in seventy-one men has experienced rape in his or her lifetime. Nearly three in ten women and one in four men have experienced rape, physical, violence, or stalking in his or her lifetime. The CDC has estimated that 1,310,000 women in GA and 462,000 women in CT alone have experienced rape, physical violence, or stalking by an intimate partner in their lifetime.<sup>1</sup> The most heinous of these crimes is murder,

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and every day in the United States, an average of three women are killed by a current or former intimate partner.<sup>i</sup> The cycle of intergenerational violence is perpetuated as children are exposed to violence. Approximately 15.5 million children are exposed to domestic violence every year.<sup>ii</sup> One study found that men exposed to physical abuse, sexual abuse and adult domestic violence as children were almost 4 times more likely than other men to have perpetrated domestic violence as adults.

In addition to the terrible cost domestic and sexual violence have on the lives of individual victims and their families, these crimes cost taxpayers and communities. The cost of intimate partner violence exceeds \$5.8 billion each year, \$4.1 billion of which is for direct medical and mental health care services.<sup>iv</sup> Domestic violence costs U.S. employers an estimated \$3 to \$13 billion annually.<sup>v</sup>

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 its successes, VAWA and FVPSA should receive targeted investments in FY 14 in the Labor, Health and Human Services Appropriations bill.

**Family Violence Prevention and Services Act (FVPSA) (Administration for Children and Families) – \$140 million.** Since its passage in 1984 as the first national legislation to address domestic violence, FVPSA has remained the only funding directly for shelter programs. For more than 25 years, FVPSA has made substantial progress toward ending domestic violence. Despite the progress and success brought by FVPSA, a strong need remains for FVPSA-funded victim services.

There are more than 2,000 community-based domestic violence programs for victims and their children (approximately 1,500 of which are FVPSA-funded through state formula grants). These programs offer services such as emergency shelter, counseling, legal assistance, and preventative education to millions of adults and children annually and are at the heart of our nation's response to domestic violence. A recently released 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 indicated that, if shelters did not exist, the consequences for victims would be dire, including "homelessness, serious losses including children [or] continued abuse or death."<sup>vi</sup> Non-residential domestic violence services are also essential to addressing victims' needs. Such programs provide a wide variety of services to victims including counseling, child care, financial support, and safety planning. Without the counseling services she received from her local domestic violence program, one victim said, "I would not be alive, I'm 100 percent certain about that."<sup>vii</sup>

**The Increased Need for 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 to when they are escaping life-threatening violence. As increased training for law enforcement, prosecutors and court officials has greatly improved the criminal justice system's response to victims of domestic violence, there is a corresponding increase in demand for emergency shelter, hotlines and supportive services. Additionally, demand has increased as a result of the economic downturn, and victims with fewer personal resources become increasingly vulnerable. Since the economic crisis began, three out of four domestic violence shelters have reported an increase in women seeking assistance.<sup>viii</sup> As a result, shelters overwhelmingly report that they cannot fulfill the growing need for these services.

Just as demand is increasing, domestic violence programs are experiencing funding cuts or reductions from multiple sources. In NNEDV's funding survey, 69% of coalitions reported that domestic violence programs experienced overall funding decreases from Fiscal Year 2011 to Fiscal Year 2012. Additionally almost 80% of states reported that their programs were experiencing cuts or reduction in funding from county and city sources, and approximately 90% of states reported that their programs were seeing decreases in private donations.

Across the country, shelters are struggling to remain open, and non-residential programs are reducing their services and hours. Programs and coalitions have also been forced to lay off staff and/or to operate with unfilled positions. Since 2011, at least 19 local domestic violence programs across the country have been forced to close entirely. Victims suffer the consequences of these cuts, and are often left with no alternative other than returning to their abusers or becoming homeless. According to NNEDV's National Domestic Violence Counts Census Report, in one day in 2011, more than 67,000 victims of domestic violence received services, of which 35 percent found refuge in emergency shelters and transitional housing. Of the 23,632 victims in emergency shelter that day, more than 50 percent were children.<sup>ix</sup> However, on that same day, more than 10,500 requests for services by adults and children were unmet due to lack of funding. From October 2011 to September 2012, Georgia's 46 programs served over 30,000 victims, but in FY 12 GA programs had 3,390 requests for services that they could not meet due to lack of space. In the last fiscal year, the Connecticut Coalition Against Domestic Violence's 18 member programs provided services to 57,785 victims of domestic violence. Nationally, in FY '09, domestic violence programs funded by FVPSA provided shelter and non-residential services to over 1 million victims. Due to lack of capacity, however, an additional 167,069 requests for shelter went unmet. Furthermore, because of sequestration approximately 70,120 fewer victims will have access to FVPSA-funded domestic violence programs and shelters.

For those individuals who are not able to find safety, the consequences can be extremely dire, including continued exposure to life-threatening violence or homelessness. 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 at least \$140 million.

#### **ADDITIONAL REQUESTS**

**National Domestic Violence Hotline (Administration for Children and Families) - \$ 4.5 million.** For the past 15 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 (Centers for Disease Control and Injury Prevention) - \$6 million.** DELTA is one of the only sources of funding for domestic violence prevention work. The program supports statewide projects that integrate primary prevention principles and practices into local coordinated community responses that address and reduce the incidence of domestic violence. Currently, DELTA funds 56 Coordinated Community Response Coalitions nationwide. In the first three years that DELTA funded these projects, primary prevention activities in these communities increased ten-fold.

**Rape Prevention and Education (RPE) (Centers for Disease Control and Injury Prevention) - \$40 million.** This VAWA program administered through CDC strengthens national, state and local sexual violence prevention efforts and the operation of rape crisis hotlines. RPE funding provides formula grants 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. Despite its critical work, RPE has faced funding decreases since FY '06.

### **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 violence against women. We know that our nation is facing a difficult financial time and that there is pressure to reduce spending. Investments in these vital, cost-effective programs, however, help break the cycle of violence, reduce related social ills and will save our nation money now and in the future.

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- <sup>i</sup> 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.
- <sup>ii</sup> Bureau of Justice Statistics (2008). Homicide Trends in the U.S. from 1976-2005. U.S. Dept. of Justice.
- <sup>iii</sup> McDonald, R., et al. (2006). "Estimating the Number of American Children Living in Partner-Violence Families." *Journal of Family Psychology*, 30(1), 137-142.
- <sup>iv</sup> 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.
- <sup>v</sup> 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.
- <sup>vi</sup> 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.
- <sup>vii</sup> 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.
- <sup>viii</sup> *Mary Kay's Truth About Abuse*. Mary Kay Inc. (May 12, 2009).
- <sup>ix</sup> Domestic Violence Counts 2011: A 24-Hour census of domestic violence shelters and services across the United States. The National Network to End Domestic Violence. (Jan. 2012).

**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 15, 2013*

**TESTIMONY ON DEPARTMENT OF EDUCATION PROGRAMS**

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**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 to economic revitalization for both Indian Country and the nation as a whole. President Obama has repeatedly stressed 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.<sup>1</sup> 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.<sup>4</sup>

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.

#### **EDUCATION FUNDING REQUESTS FOR THE FY 2014 LABOR-HHS-EDUCATION BILL**

##### 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 2014. 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.

#### Impact Aid

- Provide \$1.395 billion for Impact Aid, Title VIII of the Elementary and Secondary Education Act (ESEA).

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 enrolling in public schools, Impact Aid provides essential funding for schools serving Native students. Therefore, funding for Impact Aid must not be less than this requested amount. 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.

#### 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. 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. Additionally, specific educational disparities were identified, and targeted for improvement. New grantees in FY 2011 alone are estimated to provide educational programs to over 30,000 Native Hawaiian children and families. These programs strengthen the Native Hawaiian culture and improve educational attainment, both of which are correlated with positive economic outcomes.

#### Tribal Education Departments

- Provide \$10 million to fund Tribal Education Departments.

Five million dollars should be appropriated to the Department of Education to support tribal education departments (TEDs). This funding assists TEDs, which are uniquely situated at the local level to implement innovative education programs that improve Native education. Because they are administered by tribes, TEDs are best equipped to deliver education programs tailored to improve education parity for Native students. TEDs would use this much-needed funding to develop academic standards, assess student progress, and create math and science programs that require high academic standards for students in tribal, public, and Bureau of Indian Education schools. Tribes

exercising self-governance over their citizens' education have been very successful because they better understand the circumstances of their populations and can develop initiatives that meet local needs. Adequately funding TEDs would create the most return on federal dollars spent.

Vocational Rehabilitation Services Projects for American Indians with Disabilities

- Increase Vocational Rehabilitation Services Projects 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.<sup>iii</sup> Of those American Indian and Alaska Native adults with a disability, 51 percent reported having fair or poor health.<sup>iv</sup> 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](mailto:aebarb@ncai.org) and Katie Jones, NCAI Legislative Associate, at [kjones@ncai.org](mailto:kjones@ncai.org).

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<sup>i</sup> National Indian Education Study 2011, NCES 2012-466. National Center for Education Statistics, Institute of Education Sciences, United States Department of Education.

<sup>ii</sup> School Year 2010-2011 Four-Year Regulatory Adjusted Cohort Graduation Rates, Department of Education.

<sup>iii</sup> Centers for Disease Control and Prevention. (2011). "Disability and Health". Retrieved on January 2, 2013, from <http://www.cdc.gov/ncbddd/disabilityandhealth/data.html>.

<sup>iv</sup> *Ibid.*



# NICWA

National Indian Child Welfare Association

**TESTIMONY REGARDING FY 2014 APPROPRIATIONS REGARDING DHHS PROGRAMS SERVING  
AMERICAN INDIAN AND ALASKA NATIVE CHILDREN**

**SUBMITTED TO: HOUSE COMMITTEE ON APPROPRIATIONS SUBCOMMITTEE ON LABOR,  
HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES**

**SUBMITTED BY: THE NATIONAL INDIAN CHILD WELFARE ASSOCIATION**

**MARCH 15, 2013**

**DHHS Title IV-B Subpart 2: Promoting Safe and Stable Families (PSSF)**

*Request: Increase FY 2014 appropriations for the discretionary component of this program to \$75 million (FY 2012 enacted \$63 million). This would increase the number of tribes eligible (currently 121) and increase allocations for eligible Indian tribes. Only tribes who are eligible for grants of \$10,000 or more under the statutory formula are eligible to apply.*

Data and background to justify requests

PSSF is one of only a few federal funding streams that can be used for services that prevent out-of-home placement and work to strengthen families where either the children are at risk of being placed or have been placed. These services form the foundation of all tribal child welfare programs and are critical to successful outcomes for their children and families. The funds are typically used to establish and operate integrated, preventive family preservation services and family support services for families at risk and/or in crisis. This funding is a particularly valuable tool for tribal child welfare because family preservation and family reunification work aligns

with traditional American Indian and Alaska Native (AI/AN) cultures and practices. Mainstream approaches to child welfare, which can often be in conflict with AI/AN ways of being and healing, often result in disproportionate placement of AI/AN children in state systems.

Anecdotes of successes of the federal investment in tribal programs

**From Tlingit & Haida Tribes:** Our Preserving Native Families (PNF)/ICWA department received a phone call from the Office of Children's Services (OCS) regarding concerns for two children and explained their concerns regarding the mother's behavior. OCS was preparing to go into the home for an initial investigation.

Our office did some research and learned that the mother was a TANF client. One of our supervisors made a call to our TANF program and asked if they would consider using a new assessment tool, created by the PNF department, to determine if the woman might be at risk for OCS involvement. The TANF worker agreed and based on the score, which was high, the TANF child welfare worker was able to engage the woman in PNF services quickly. OCS, pleased that PNF services were being offered, met with the woman who reported about the PNF services she was involved with. OCS determined that her children were safe and that the mother was actively engaging in prevention services with PNF. This mother only needed someone to reach out to her; she was in need of help, but did not know how to ask. This story is successful for two reasons; departments collaborated and a tribal family remains together today. It is Title IV-B Subpart 2 combined with BIA ICWA Title II funding that made this possible by providing the base levels of funding for Tlingit & Haida's PNF/ICWA department.

**SAMHSA Programs of Regional and National Significance (Circles of Care Children's Mental Health Grant Program)**

*Request: Continue FY 2014 appropriation for Programs of Regional and National Significance budget category at FY 2012 level of \$286 million. Funds for the Circles of Care program come out of this budget category (typically \$3 million per year).*

**Data and background to justify requests**

The Circles of Care Grant Program is the only children's mental health funding program exclusively available to tribes. It is the only source of federal funding that specifically supports the development of culturally competent children's mental health service delivery models in tribal communities, effective systemic reform and capacity building are otherwise impossible due to lack of designated funding.

The need for continued and increased Circles of Care funding is evidenced in available mental health data and the demonstrated and measured effectiveness of the program. For example, AI/AN youth experience post-traumatic stress disorder at higher rate than the national average,<sup>i</sup> struggle with alcohol use disorders at a higher rate than the general youth population,<sup>ii</sup> and have had the highest lifetime major depressive episode prevalence and the highest prevalence of a major depressive episode in the last year when compared to all other youth populations.<sup>iii</sup>

To date, Circles of Care has enabled 38 tribal grantee communities to develop culturally competent, community-based children's mental service delivery models. Circles of Care yields measurable long-term positive outcomes. These grants have significantly increased tribal community awareness of the issues that impact their children's mental health, facilitated community ownership and responses, and helped tribes to develop capacity through leveraging of tribal funds and creating new partnerships. Of those tribes that have graduated from the

Circles of Care program, nearly 1/3 have obtained direct funding through the Child Mental Health Initiative (CMHI) program, otherwise known as Systems of Care; others have been able to partner with other CMHI grantees to implement their models, and remaining graduated sites have secured other resources to implement their models to their best ability.

**SAMHSA Systems of Care Children’s Mental Health Grant Program**

*Request: Continue to fund this program in FY 2014 at the FY 2012 level of \$117 million. This competitive grant program allows eligible states, local governments and tribes to apply for and administer a children’s mental health services program (tribes at \$5–6 million per year).*

Data and background to justify requests

The current six-year tribal grantees are engaging local communities, youth, families, and private and public partners in collaborative partnerships to build sustainable children’s mental health programs and services. National aggregate data on six-year Systems of Care programs illustrate the success and continued need for Systems of Care program funding: 1) emotional and behavioral problems were reduced or remained stable for 89% of children and youth with co-occurring mental health and substance abuse diagnoses; 2) school performance improved or remained the same for 75% of children and youth served by the grant communities; and 3) almost 91% of children and youth with a history of suicide attempts or suicidal ideation improved or remained stable.<sup>iv</sup> Considering these positive outcomes and the behavioral health needs of tribal communities, continued six-year Systems of Care program funding is vital to tribes and their ability to design and implement successful children’s mental health programs, particularly because tribes remain ineligible for direct access to the Mental Health Block Grant and Medicaid funding.

Anecdotes of successes of the federal investment in tribal programs

**From Cherokee Nation:** Cherokee Nation's Behavioral Health Services had been working on various children's initiatives for eight years prior to receiving the SAMHSA Systems of Care (SOC) Expansion Planning Grant last year. During its one year as a SOC Expansion Planning grantee, Cherokee Nation accomplished more success in this arena than ever before. The funds were used as seed money to plan and lay the foundation for expanding and sustaining children's mental health. One concrete result of receiving these funds was Cherokee Nation's ability to assess and begin to revamp its children's mental health billing system. None of this could have been possible without the technical assistance (TA) resources provided, the guiding SOC philosophy, and systems-wide approach that created space for the larger Cherokee Nation and community coalitions to engage actively and benefit from the planning process and outcome. Cherokee Nation has since secured funding to begin implementing pieces of the strategic plan developed per the SOC Expansion Planning funding.

*For more information regarding this testimony, please contact NICWA Government Affairs Director David Simmons at [desimmons@nicwa.org](mailto:desimmons@nicwa.org)*

<sup>i</sup> Cooper, J.L., Masi, R., Dababnah, S., Aratani, Y., and Knitzer, K. (2007). Strengthening Policy to Support Children, Youth, and Families Who Experience Trauma. New York, NY: National Center for Children in Poverty, Mailman School of Public Health, Columbia University. Retrieved from [http://www.nccp.org/publications/pub\\_737.html](http://www.nccp.org/publications/pub_737.html)

<sup>ii</sup> Office of Applied Studies, Substance Abuse and Mental Health Services Administration (SAMHSA) (2007, January 19). Substance use and substance use disorders among American Indians and Alaska Natives. *The National Survey on Drug Use and Health Report*. Retrieved from <http://oas.samhsa.gov/2k7/AmIndians/AmIndians.cfm>

<sup>iii</sup> Urban Indian Health Institute, Seattle Indian Health Board (2012). *Addressing Depression Among American Indians and Alaska Natives: A Literature Review*. Seattle, WA: Urban Indian Health Institute. Retrieved from [http://www.uihi.org/wp-content/uploads/2012/08/Depression-Environmental-Scan-All-Sections\\_2012-08-21\\_ES\\_FINAL.pdf](http://www.uihi.org/wp-content/uploads/2012/08/Depression-Environmental-Scan-All-Sections_2012-08-21_ES_FINAL.pdf)

<sup>iv</sup> Duclos, C.W., Phillips, M. & LeMaster, P.L. (2004). Outcomes and Accomplishment of the circles of Care Planning Efforts. *American Indian Alaska Native Mental Health Research Journal*. Retrieved from [http://www.ucdenver.edu/academics/colleges/PublicHealth/research/centers/CAIANH/journal/Documents/Volume%2011/11\(2\)\\_Duclos Outcomes and Accomplishments\\_121-138.pdf](http://www.ucdenver.edu/academics/colleges/PublicHealth/research/centers/CAIANH/journal/Documents/Volume%2011/11(2)_Duclos Outcomes and Accomplishments_121-138.pdf)

**Written Testimony of George Vradenburg  
Chairman  
USAgainstAlzheimer's**

**Before the House Appropriations Subcommittee on Labor, HHS and Education**

**March 15, 2013**

On behalf of USAgainstAlzheimer's and the more than 5.4 million Americans suffering from Alzheimer's disease and their families, I thank you for this opportunity to provide testimony on the Fiscal Year 2014 Labor, HHS, Education and Related Agencies Appropriations spending bill.

The challenge before Chairman Kingston, Ranking Member DeLauro and your colleagues has never been greater. Our nation must confront structural debt, deficit and entitlement issues at the very same time our federal health care system will be absorbing tens of millions of new beneficiaries through a combination of baby boomers becoming eligible for Medicare and the expansion of Medicaid driven by the Affordable Care Act. Much of the burden associated with paying for the care of these Americans will be borne by the agencies funded under your bill.

A major driver of these healthcare costs that cannot be overlooked is the aging of our population. While the marked increase in the longevity of our population over the past century in particular should be celebrated as a national and international success story realized by our abilities to improve the public health and defeat or control a number of diseases and other causes of death, a ramification is that our people are living longer and thus placing tremendous pressures on our healthcare system. Alzheimer's disease and related dementia epitomizes the challenges posed by our aging population.

The only one of our leading causes of death that lacks any means of prevention or therapy able to delay onset or modify the symptoms of the disease, Alzheimer's poses a significant health and cost burden that will turn into an all-out crisis if not addressed in the near future. Today's more than 5 million victims in the U.S. are projected to more than triple by the mid-century point. The cost of caring for these patients today is \$200 billion annually, with about 70 percent or \$140 billion shouldered by Medicare and Medicaid. By 2050, the cost of the disease is estimated to exceed \$1 trillion annually.

The choice before our nation and your committee is not whether or not we will pay for Alzheimer's and scores of other diseases and conditions. The choice, rather, must be how we will pay for it: Will we commit to the research and innovation necessary to get ahead of this disease to develop effective therapies, treatments and care interventions that will improve health, lead to healthier and productive lives and reduce federal health care costs? Or will we continue down the path of ever-increasing spending on Alzheimer's care through nursing homes and other institutional costs and submit that tens of millions of Americans will have their lives ended by this disease?

When confronted with tough choices in the past, our nation has always opted for innovation despite the foreboding nature of challenges. When the Soviets beat us to space, we committed to beat them to the moon and we did so ahead of schedule. When diseases like cancer, heart disease and HIV/AIDS threatened our population, we committed aggressive research efforts

that have transformed preventive and treatment options for all of these diseases. The time is now to commit to a similar national crusade against Alzheimer's and dementia.

Congress and the Administration have already taken a significant step forward. In 2010, Congress passed the landmark National Alzheimer's Project Act that required the U.S. to develop a National Plan to Address Alzheimer's disease. Less than one year ago, the Administration released the first iteration of this plan that set as goal one preventing and effectively treating the disease by 2025. Achieving this goal will not be easy. Achieving this goal will be all but impossible if the appropriate resources – both federal and non-federal – are committed toward it.

Recognizing the funding constraints facing the committee, I offer the following three recommendations for your consideration:

- 1) **Your Committee must review how our government, particularly the National Institutes of Health, establishes research priorities.** Alzheimer's disease research remains woefully underfunded compared to the magnitude of the health and cost burden of this disease. Even with a helpful increase of \$50 million by the Administration last year, NIH funding for Alzheimer's research remains under \$500 million.<sup>1</sup> This amounts to about 1/3<sup>rd</sup> of 1 percent of the estimated \$140 billion spent on Alzheimer's care via Medicare and Medicaid. Were a business to have a \$140 billion problem yet spend less than \$500

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<sup>1</sup> See: [http://report.nih.gov/categorical\\_spending.aspx](http://report.nih.gov/categorical_spending.aspx)

million to fix it, it would not be a business very long. As the funder and overseer of the NIH budget, this committee has the opportunity and responsibility to set overarching priorities while at the same time respecting science and the peer review process and not micromanaging specific funding decisions. With NIH funding declining, the need for clear priorities has never been greater. I urge you to consider ways to drive NIH to prioritize the application of scarce resources to areas of greatest need.

- 2) **Beyond evaluating how priorities are set, we must advance innovative means to spur innovations in research and care.** A number of public-private partnerships whereby limited federal funding leverages a significantly larger sum of non-profit and private funds have been successfully deployed in areas of the government including the Department of Defense and intelligence community. NIH has been moving toward this direction via the Cures Acceleration Network (CAN), but that process has not been swift. I would encourage this committee to work with NIH and the National Center for Advancing Translational Sciences to stand up CAN and to provide additional guidance and direction, perhaps by focusing initial efforts toward a limited number of national priority diseases, like Alzheimer's, that are responsible for driving federal health care spending. To be as effective as other public-private partnerships, CAN must be a true partnership where investment decisions are made by experts, where partners have skin in the game, and where projects are goal-oriented, milestone-driven and time-bound.

**3) Ultimately, help ensure the nation achieves our national goal of preventing and treating Alzheimer's by 2025.** As noted, this goal will not be easy, but the research community believes strongly that it can be achieved if the necessary resources are applied to it. The United States has a storied history of setting and subsequently achieving ambitious goals when we commit our energies toward doing so. Stopping Alzheimer's disease and unlocking other mysteries of the brain can well be the moonshot for the first part of the 21<sup>st</sup> century. If we are successful, we have the potential to once again fundamentally transform human life and to defeat one of the most pressing diseases of our day. Achieving success requires a deep national commitment to this goal, and your committee plays a key role in establishing this foundation. I urge us to think big and to honor the legacy of the millions of victims of Alzheimer's disease by striving to prevent others from experiencing a similar fate.

Chairman Kingston and Ranking Member DeLauro, I thank you for your services and for affording me with this opportunity to share my thoughts, and I look forward to working with you to achieve our national goal of preventing and treating Alzheimer's by 2025.

**Submitted by**

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**Written Testimony for the Record**

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

Prepared by the Research Working Group of the Federal AIDS Policy Partnership – March 2013

Chairman Kingston, Ranking Member DeLauro, and members of the Committee, thank you for the opportunity to provide testimony on the National Institutes of Health (NIH) budget overall and for AIDS research in fiscal year 2014 (FY 2014). Tomorrow's scientific and medical breakthroughs depend on your vision, leadership, and commitment to robust NIH funding this year. To this end, the Research Working Group (RWG) urges this Committee to support—at minimum—a funding target of \$35.98 billion in FY14 to maintain the United States' position as the world leader in medical research and innovation.

Investments in health research via the NIH have paid enormous dividends in the health and wellbeing of people in the U.S. and around the world. NIH-funded HIV and AIDS research has supported innovative basic science for better drug therapies, evidence-based behavioral and biomedical prevention interventions, and vaccines that have saved and improved the lives of millions, and holds great promise for significantly reducing HIV infection rates and providing more effective treatments for those living with HIV/AIDS in the coming decade.

Despite these advances, the number of new HIV/AIDS cases continues to rise in various populations in the U.S. and around the world. There are over one million HIV-infected people in the U.S., the highest number in the epidemic's 31-year history; additionally over 50,000 Americans become newly infected every year. The evolving HIV epidemic in the U.S. disproportionately affects the poor, sexual and racial minorities, and the most disenfranchised and stigmatized members of our communities. However, with proper funding coupled with the promotion of evidence-based policies, we can capitalize on the ongoing scientific progress in prevention science, vaccines, and finding a cure for HIV, as well as addressing the comorbid illnesses such as viral hepatitis and tuberculosis that affect patients with HIV.

Major advances over the last few years in HIV prevention technologies—in particular with microbicides, HIV vaccines, circumcision, antiretroviral treatment as prevention, and pre-exposure prophylaxis (PrEP) using antiretrovirals—demonstrate that adequately resourced NIH programs can transform our lives. Federal support for AIDS research has also led to new treatments for other diseases, including cancer, heart disease, Alzheimer's, hepatitis, osteoporosis, and a wide range of autoimmune disorders. Over the years, the NIH has sponsored the evaluation of a host of vaccine candidates, some of which are advancing to efficacy trials. The successful iPrEx and HPTN 052

trials have shown the potential of antiretroviral drugs to prevent HIV infection. Moreover, increased funding will support the future testing of new microbicides and therapeutics in the pipeline via the implementation of a newly restructured, cross-cutting HIV clinical trials network that translates NIH-funded scientific innovation into critical quality-of-life gains for those most affected with HIV.

It is also essential to note that NIH-funded HIV pathogenesis and clinical research has contributed substantially to our understanding of potential curative approaches. These include, but are not limited to, therapeutic vaccines and other immune-system modulators, gene therapies, and drugs that can purge HIV from its various reservoirs in the body. These candidates, many of which are now being further explored in human studies, are the culmination of nearly three decades of steadfast public support for basic science and pilot-phase research—support that must continue if we are to end the epidemic once and for all.

Increased funding for the NIH in FY 2014 makes good bipartisan economic sense, especially in shaky times. Robust funding for the NIH overall will enable research universities to pursue scientific opportunity, advance public health, and create jobs and economic growth. In every state across the country, the NIH supports research at hospitals, universities, private enterprises, and medical schools. This includes the creation of jobs that will be essential to future discovery. Sustained investment is also essential to train the next generation of scientists and prepare them to make tomorrow's HIV discoveries. NIH funding puts 350,000 scientists to work at research institutions across the country. According to the NIH, each of its research grants creates or sustains six to eight jobs, and NIH-supported research grants and technology transfers have resulted in the creation of thousands of new, independent private-sector companies. Strong, sustained NIH funding is a critical national priority that will foster better health and economic revitalization.

Since 2003, funding for the NIH has failed to keep up with our existing research needs —damaging the success rate of approved grants and leaving very little money to fund promising new research. The real value of the increases prior to 2003 has been precipitously reduced because of the relatively higher inflation rate for the cost of research and development activities undertaken by the NIH. According to the Biomedical Research and Development Price Index, which calculates how much the NIH budget must change each year to maintain purchasing power, between FY 2003 and FY 2011, the cost of NIH activities increased by 32.8%. By comparison, the overall NIH budget increased by \$3.6 billion, or 13.4%, over FY 2003. So in real terms, the NIH has already sustained budget decreases of close to 20% over the past decade due to inflation alone. As such, any further cuts to NIH on top of sequestration will have the clear and devastating effects of undermining our nation's leadership in health research and our scientists' ability to take advantage of the expanding opportunities to advance health care. The race to find better treatments and a cure for cancer, heart disease, AIDS, and other diseases, and for controlling global epidemics like AIDS, tuberculosis, and malaria, all depend on a robust long-term investment strategy for health research at NIH.

In conclusion, the RWG calls on Congress to continue the bipartisan federal commitment towards combating HIV as well as other chronic and life-threatening illnesses by increasing funding for the NIH to \$35.98 billion in FY 2014, including funds for transfer to the Global Fund for HIV/AIDS, Tuberculosis and Malaria. A meaningful commitment to stemming the epidemic and securing the well being of people with HIV cannot be met without prioritizing the research investment at the NIH that will lead to tomorrow's lifesaving vaccines, treatments, and cures. Thank you for the opportunity to provide these written comments.

**Testimony of the American Academy of Pediatrics  
Concerning Fiscal Year 2014 Appropriations**

*Submitted for the Record to the House Appropriations Subcommittee on  
Labor, Health and Human Services, Education and Related Agencies*

March 15, 2013

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The American Academy of Pediatrics (AAP), a non-profit professional organization of 60,000 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 2014 and beyond. AAP urges all Members of Congress to put children first when considering short and long-term federal spending decisions.

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.

***America's children deserve better***

Twenty two percent of children in the United States now live in poverty – up from 17 percent in 2007. During this fragile economic time many families in the United States have seen their savings depleted and one or both parents lose their jobs. Such challenging economic conditions have impacted one group of Americans particularly hard: our children. 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.

Babies born in the United States are less likely to survive until their first birthday than those in 30 other industrialized nations. Of the world’s richest twenty-one nations, the United States comes in dead last in terms of overall health and safety of its children due to poor indicators on child health at birth, infant mortality rates, prevalence of low birth weight, child immunization rates for children aged 12 to 23 months, and deaths from accidents or injuries among people aged 0 to 19 years. America’s current generation of children is at risk of having shorter life expectancies than their parents. This is unacceptable. America’s children deserve better. As a nation we must rise above partisan politics and reclaim the health and well-being of our children through strong federal investments in programs that promote and protect the health of all children.

Unfortunately, we are not seeing children prioritized by Congress. Instead, the federal investment in America’s children has been disproportionately reduced. Discretionary programs that children rely on like the Special Supplemental Nutrition Program for Women, Infants and Children (WIC), the Title V Maternal and Child Health Services Block Grant, the Section 317 Immunization Program, and the Children’s Hospital Graduate Medical Education program are being cut through the sequestration process established through the *Budget Control Act of 2011* at a time when too many children are still caught in the clutches of poverty.

***Children's health care is not the cost driver of overall health care spending***

The United States continues to spend less on our children's health, education, and general welfare than most other developed nations in the world. Children under age 18 represent 30 percent of the total U.S. population, yet health care services for infants, children, and young adults are only 12 percent of total annual health care spending. Children, including those with special health care needs, make up more than 50 percent of all Medicaid recipients, but account for less than 25 percent of Medicaid costs.

By contrast, currently over two-thirds of Medicare expenditures are for beneficiaries with five or more chronic conditions, conditions like diabetes, arthritis, and hypertension that are largely preventable over the course of a lifetime. Strong and continued investments during childhood are critical to curbing the onset of chronic conditions that are growing health care costs.

Proposed cuts to prevention and public health initiatives, community health programs, and child safety net services are counterproductive to efforts to reduce government spending and control the deficit in the long-term.

***Children's programs are cost-effective and improve our nation's health and economy***

Every 1 dollar spent on the childhood vaccine series saves the healthcare system \$16.50 in future medical costs. Every 1 dollar spent on preventative services for a pregnant woman in the WIC program saves Medicaid up to \$4.20 by reducing the risk of pre-term birth and its associated costs. Every 1 dollar spent on high-quality home visiting programs saves up to \$5.70 as a result of improved prenatal health, decreased mental health and criminal justice costs, and fewer children suffering from abuse and neglect. Our nation's sickest and most vulnerable children rely on federal programs like these to support their physical and mental health needs. Reducing

funding for vital child health programs during a time when many families are still struggling financially will disproportionately hurt children.

The Administration for Children and Families, Centers for Disease Control and Prevention, Health Resources and Services Administration, and other agencies within the Department of Health and Human Services and the Department of Education provide essential services, research, and surveillance that help our nation's children grow into healthy and productive citizens.

Devoting adequate resources to federal health programs helps ensure children have safe and healthy food at home and school, homes and communities free of environmental toxins, and disaster preparedness and response systems that address their unique health needs. Federal funds support critical programs that address pressing public health challenges including: efforts to prevent infant mortality and birth defects; healthy child development; antimicrobial resistance and infectious diseases; emergency medical services for children; mental health and substance abuse prevention; tobacco prevention and cessation; unintentional injury and violence prevention; child maltreatment prevention; childhood obesity; environmental and chemical exposures; poison control; teen pregnancy prevention and family planning; health promotion in schools; and medical research and innovation.

Meeting our children's health needs also requires a robust pediatric workforce. Children are not just little adults. Pediatricians, including medical and surgical specialists, are trained to diagnose and treat the unique health care needs of children and adolescents. Unlike the adult population, our nation currently faces a shortage of pediatric subspecialists, resulting in many children with serious acute and chronic illnesses being forced to travel long distances – or wait several months

– to see a needed pediatric subspecialist. Federal support for pediatric workforce programs – Public Health Service Act Title VII health professions programs, Children’s Hospital Graduate Medical Education Program and the Pediatric Subspecialty Loan Repayment Program – is crucial to building the necessary supply of pediatricians to ensure all children, regardless of where they live or their insurance status, have access to timely and appropriate health care.

***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. At a time when states are facing unprecedented challenges with dwindling budgets yet rising demand for health services, federal investments in the public health infrastructure could not be more important. 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, 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 extraordinary 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 2014 and beyond. If we may be of further assistance please contact the AAP Department of Federal Affairs at 202-347-8600 or [aperencevich@aap.org](mailto:aperencevich@aap.org). Thank you for your consideration.



**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 PART D OF THE RYAN WHITE PROGRAM AT THE HIV/AIDS BUREAU**  
**OF THE HEALTH RESOURCES AND SERVICES ADMINISTRATION IN THE**  
**DEPARTMENT OF HEALTH AND HUMAN SERVICES**

**MARCH 15, 2013**

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 support of Part D of the Ryan White as part of the FY2014 Labor, Health and Human Services, Education, and Related Agencies appropriations measure.

**Ryan White Part D Funding Request**

Though each year the number of women, children and youth seeking primary medical care and support services from Ryan White Part D has increased, Ryan White Part D has been flat-funded in recent years. 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 support of Ryan White Part D Programs in FY 12. While the AIDS Alliance for Women, Infants, Children, Youth

& Families is grateful for this support, and understand that these are difficult economic times, we are requesting a **\$7.7 million increase for Ryan White Part D programs in FY 14.**

**Ryan White Part D Background and History**

A lifeline for women, infants, children and youth living with HIV and AIDS, Part D of the Ryan White Program provides family-centered primary medical care and support services to women, infants, children, and youth living with HIV/AIDS throughout the U.S. when payments for such services are unavailable from other sources. This model of care addresses the health care needs of persons living with HIV/AIDS in order to achieve optimal health outcomes. Ryan White Part D funding improves access to primary HIV medical care for HIV-infected women, infants, children, and youth through the provision of coordinated, comprehensive, culturally and linguistically competent services. Ryan White Part D serves over 90,000 women, children, youth, and families living with and affected by HIV and AIDS.

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 are 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 than 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. 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. A pivotal moment in the history of Part D occurred when researchers were able to prove the efficacy of AZT in preventing mother-to-child transmission of HIV from a federally funded clinical research protocol known as AIDS Clinical Trials Group study 076 (ACTG-076). 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. According to the CDC, as of 2010, one in four new HIV infections in the United States occurs 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. The unique systems of care created by Part D programs require additional support to maintain the comprehensive services women, infants, children, youth, and families need as care and treatment becomes more complex. Finding the right treatment regimen is a complex process, and drug resistance and treatment failure can occur over time. Furthermore, though significantly extending people's lives has been a great accomplishment, it has also required addressing other health problems that can arise, independent of HIV infection.

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. It will take time and extra effort to coordinate Ryan White and ACA integration.

#### **The Impact of Sequestration on Ryan White Part D**

Sequestration cuts will threaten life-saving HIV/AIDS care and prevention services provided by Ryan White Part D to women, infants, children and youth. Sequestration will aggravate existing racial and ethnic health disparities and increase the burden of disease for these populations, which are already vulnerable to the lingering effects of the recession. Sequestration will increase health care costs; decrease the number of HIV-positive pregnant women receiving

services to prevent mother-to-child transmission; and increase the number of infants born infected with HIV. These across the board cuts will impede this nation's ability to reduce the rate of new HIV infections, improve access to care and address the impact of HIV/AIDS on women, infants, children and youth.

### **Conclusion**

These are difficult economic times, and we recognize the considerable fiscal constraints Congress faces in allocating limited federal dollars. This increased funding of \$7.7 million in FY 14 will enable **Ryan White Part D programs to continue** to deliver life-saving HIV/AIDS care and treatment to their clients and avoid millions in wasted health care dollars treating individuals in late stages of illness or in inappropriate, higher cost settings. 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 they need.

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 14 appropriations bill. Should you have any questions, please do not hesitate to contact the Dr. Ivy Turnbull, Deputy Executive Director, at 202-835-8373 or [iturnbull@aids-alliance.org](mailto:iturnbull@aids-alliance.org).

Thank you.

### **References:**

1. Ryan White HIV/AIDS Program Living History Web site, *Part D: Women and Families in a Circle of Care*: [hab.hrsa.gov/livinghistory/programs/Part-D.htm](http://hab.hrsa.gov/livinghistory/programs/Part-D.htm).
2. Ryan White HIV/AIDS Program Living History Web site, Women and AIDS: [hab.hrsa.gov/livinghistory/issues/women\\_4htm](http://hab.hrsa.gov/livinghistory/issues/women_4htm).
3. Ryan White HRSA Care Action Newsletter: *Ryan White Providers Address HIV/AIDS Among African-American Women*: [hab.hrsa.gov/newspublications/careactionnewsletter/Sept2012.pdf](http://hab.hrsa.gov/newspublications/careactionnewsletter/Sept2012.pdf).
4. CDC. *HIV among women*. [Fact sheet]. 2011. Available at: [www.cdc.gov/hiv/topics/women/pdf/women.pdf](http://www.cdc.gov/hiv/topics/women/pdf/women.pdf).
5. U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), HIV/AIDS Bureau (HAB). *Going the distance: the Ryan White HIV/AIDS Program—20 years of leadership, a legacy of care*. 2010. Available at: [hab.hrsa.gov/data/biennialprogressrpts.html](http://hab.hrsa.gov/data/biennialprogressrpts.html).
6. [http://www.hivama.org/uploadedFiles/HIVMA/Policy and Advocacy/Ryan White Medical Providers Coalition Comments/FY13 RWMPC LHHS H Testmny March%202012.pdf](http://www.hivama.org/uploadedFiles/HIVMA/Policy%20and%20Advocacy/Ryan%20White%20Medical%20Providers%20Coalition%20Comments/FY13%20RWMPC%20LHHS%20H%20Testmny%20March%202012.pdf).

450 Midland Street  
Little Rock, Arkansas 72205

March 15, 2013

Sent Electronically

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

REQUEST: RE: 2014 Budget of Department of Health and Human Services –  
Do Not Fund DHHS Programs and Policies that Promote Deinstitutionalization of Persons  
with Severe Forms of Developmental Disabilities

AMOUNT OF FUNDING INVOLVED: UNKNOWN

Ladies and Gentlemen:

Thank you for this opportunity to provide information to the House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies. This letter is a request that Congress stop funding federal programs which use public funds to achieve dangerous public policies of deinstitutionalization of persons with severe forms of developmental disabilities.

I am the mother and co-guardian of an adult son, aged 44, who from birth has lived with the effects of severe brain injuries. John is a large, mobile and nonverbal man who functions on the level of a young toddler and who has slight or little awareness of danger. For many years our son's safe home has been a state-operated intermediate care facility for persons with mental retardation (ICF/MR). His care is beyond our reasonable capacities.

As Public Affairs Chairman, I represent Families and Friends of Care Facility Residents (FF/CFR), Arkansas' parent-guardian association. FF/CFR is an all-volunteer organization; we employ no lobbyist. I am authorized to write this letter in behalf of FF/CFR.

The following are examples of how government dollars are spent in the wrong way by the Department of Health and Human Services:

**1. Administration on Intellectual and Developmental Disabilities (DHHS-AIDD) - a federal agency operating with insufficient oversight**

Administration on Intellectual and Developmental Disabilities (AIDD) administers programs and grants created under Public Law 106-402, Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act). The DD Act was last reauthorized in 2000; there have been no hearings for families to object to the ways in which the programs and AIDD use federal funds. Through unchecked lobbying and litigation, and through funding of advocacy organizations with conflicts of interest (Arc), DD Act programs have used federal funds to undermine and eliminate institutional programs for persons with severe forms of cognitive-developmental disabilities. DHHS has been unresponsive to complaints from families of persons with severe forms of disabilities about AIDD policies and it has turned a blind eye to

the tragic results for many vulnerable persons when they are removed from their specialized, Medicaid-certified congregate care homes.

Congress should conduct hearings on the activities of AIDD, the DD Act programs and their national lobbying organizations. The groups' deinstitutionalization activities should not be funded.

**2. DHHS Incentive grants to encourage States to move away from providing institutional care – federal grants given without careful study of the consequences**

Generous DHHS incentive grants (e.g., Money Follows the Person, Balance Improvement Payment Plan and Community First Choice Option) are federal rewards to cash-strapped states to move away from providing institutional services for their most vulnerable citizens. Good public policies should be formulated with transparency, consultation with those who will be most affected, and, with careful studies when the consequences may be death, injury and suffering. DHHS incentive grants (increases in the states' FMAP funds) should be extended to institutional programs as well as to community programs or they should not be provided at all.

Please let me know if I may provide additional information. Thank you for your public service. Thank you for your attention and consideration.

Very truly yours,

/s/ Carole L. Sherman  
(  
(501) 680-5893 cell

Cc: Arkansas Congressional Delegation  
Families & Friends of Care Facility Residents

**Statement by United for Medical Research on  
FY 2014 Appropriations for the National Institutes of Health  
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 who have joined together to seek steady support in federal funding for the National Institutes of Health (NIH). We appreciate the opportunity to express our strong endorsement 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, an irreplaceable federal funder of basic research, and the source for extraordinary improvements in our health, longevity, and quality of life.

**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 seamless partnership between the 300,000 scientists funded by NIH, performing research at 2,500 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 MacroGenics CEO, Scott Koenig testified last year before this subcommittee, "The NIH is the nation's premier biomedical research agency and there is no private sector alternative for much of the basic research that NIH supports."

As a key player in the innovation ecosystem, 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.

### **NIH as an Economic Engine and the Impact of Sequestration**

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, NIH's loss of purchasing power is now over 20 percent. The grim reality of the March 1<sup>st</sup> sequester cut \$1.5 billion from the agency's budget and while it will take some time to fully realize the impact of a budget reduction of this magnitude, we are already beginning to see the effects.

Earlier this month, UMR released an update to our 2011 report on the economic impact of NIH's extramural research funding, "*An Economic Engine: NIH Research, Employment, and the Future of the Medical Innovation Sector.*" The new data shows that NIH funding directly and indirectly supported more than 402,000 jobs in 2012 alone and generated more than \$57.8 billion in new economic activity. Using the Department of Commerce's RIMS II model, the analysis detailed the output and employment effects of 2012 NIH extramural research funding by state, calculating the number of jobs supported in each state by NIH funding.

This new data clearly reiterates NIH's vital role in fueling economic growth in the health and life sciences industry. However, the report also illustrated the devastating impact of the sequester, estimating the loss of more than 20,500 jobs nationwide and a reduction of new economic

activity by \$3 billion. This underscores the urgent need to re-energize our support of biomedical research and this critical job sector by providing NIH with increased funding to mitigate the impact of the sequester and to counteract inflation.

### **NIH Provides Hope to Millions**

In addition to its strong contribution to the nation's economy, 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 future 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 generating 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 success serve to provide hope to millions of patients with unresolved diseases and conditions who continue to wait for the next generation of treatment or cure.

### **Global Competition and The Threat to the Next Generation of Innovators**

In an opinion piece published in the *Wall Street Journal*, financier Michael Milken, Chairman of FasterCures and founder of the Milken Institute, said, "[T]here is an important role for government in fostering basic science, which not only saves lives but also improves quality of life. Bioscience in particular provides sustained long-term benefits through job creation, increased productivity, lower health-care costs, longer working lives, process efficiencies and cheaper energy... The United States science ecosystem—defined by collaborations among public

agencies, for-profit companies, nonprofit organizations and academic research centers—still leads the world and provides benefits to every nation.” Indeed, longtime Congressional wisdom in investing federal dollars in NIH has yielded phenomenal dividends and made the U.S. the undisputed world leader in life science innovation.

A recent UMR report, *Leadership in Decline: Assessing U.S. International Competitiveness in Biomedical Research*, demonstrated that dominance is increasingly threatened as other nations emulate our model to fuel their own biomedical research enterprises.. 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. This is in stark contrast to American investment in biomedical research funding, which is now in decline. Just last week, three industry leaders, Marc Tessier-Lavigne, P. Roy Vagelos, and Elias Zerhoni, published an article in *Forbes* with the following grim prediction, “Today, China is challenging the US in the number of new biotechnology companies created annually. If we don’t keep up, pharmaceutical companies will eventually relocate their R&D operations to the new sources of innovation – just as they have relocated from Europe to the US over the past twenty years.” NIH Director Francis Collins has testified about the Beijing Genomics Institute (BGI) genomic sequencing center in Shenzhen, China, stating that, “The capacity of that one Chinese institution now surpasses the combined capacity of all genome sequencing centers in the United States.” Losing our competitive edge in biomedical research is a clear and present danger to the crucial economic contributions of our life sciences innovation ecosystem.

An even more ominous threat is the impact a reduced commitment to NIH will have on the next generation of our best and brightest scientists. As Sanofi President of R&D and former NIH Director Elias Zerhouni said in a February, 2013 interview with the *Washington Post*, “The most impacted are the young, new investigator scientists, who are coming into science, and will now abandon the field of science. There will be a generational gap created... [i]t will impact science for generations to come.” His views are echoed by NIH Director Collins, who testified before this subcommittee in early March, “That’s our seed corn. It has been the strength of America, the biomedical research community, their creativity, their innovative instincts, and we’re putting that at serious risk as we see this kind of downturn in the support for research.”

Simply put, the United States cannot afford to lose the human capital responsible for the medical innovations that produce the treatments and cures of tomorrow and fuel the economic output of the biosciences industry. If we do not reprioritize NIH and biomedical research, it will take decades to replenish the scientific talent and intellectual capacity that will be driven to other nations or away from promising research careers.

#### **NIH Should Remain a U.S. Priority**

Policymakers find themselves at a historic juncture where they must balance the need to preserve our fragile economic recovery in the short term, with the requirement to reduce federal debt over the long term. Our nation’s commitment to NIH addresses both of these issues – by preserving jobs needed to sustain our economic recovery – and by generating the discoveries that will bolster the nation’s economy for decades to come. Given its many economic, societal and health benefits, lawmakers on both sides of the aisle should make preserving NIH funding and preventing sequestration a top priority.

**Testimony of Stephen C. Shannon, DO, MPH, President and Chief Executive Officer,  
American Association of Colleges of Osteopathic Medicine, Concerning the Department of  
Health and Human Services Appropriations for Fiscal Year 2014**

*Submitted for the Record to the House Appropriations Subcommittee on Labor, Health and  
Human Services, Education, and Related Agencies*

March 14, 2013

On behalf of the American Association of Colleges of Osteopathic Medicine (AACOM), I am pleased to submit this testimony in support of vital funding for programs at the Health Resources Services Administration (HRSA), the National Institutes of Health (NIH), and the Agency for Healthcare Research and Quality (AHRQ) in fiscal year (FY) 2014. AACOM represents the administrations, faculty, and students of the nation's 29 colleges of osteopathic medicine at 37 locations in 28 states. Today, more than 21,000 students are enrolled in osteopathic medical schools. Nearly one in five U.S. medical students is training to be an osteopathic physician. **AACOM strongly supports funding of \$520 million for HRSA's Title VII and VIII programs under the Public Health Service Act; funding the HRSA Teaching Health Center Graduate Medical Education (THCGME) Development Grants at \$10 million minimally; sustainment of student scholarship and loan repayment programs for graduate and professional students at the U.S. Department of Education and opposition of any rescissions from the National Health Service Corps (NHSC) Fund created under the Affordable Care Act (ACA, P.L. 111-142 and P.L. 111-152); appropriating \$3 million to fund the National Health Care Workforce Commission; sufficient funding for the NIH; and appropriating \$430 million for the AHRQ.**

Title VII

The health professions education programs, authorized under Title VII of 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.

According to HRSA, an additional 33,000 health care practitioners are needed to alleviate existing health professional 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).** Strengthening the workforce has been recognized as a national priority, and the investment in these programs recommended by AACOM will help meet the demand facing this country for a well-trained, diverse workforce.

Teaching Health Centers Graduate Medical Education Program

HRSA's THCGME Program is the first of its kind to shift GME training to community-based care settings that emphasize primary care and prevention. It is uniquely positioned to provide much-needed primary care training in underserved populations. However, because the program

is the first of its kind, most community-based settings do not have existing infrastructures to provide this training. **AACOM strongly supports funding the THCGME Development Grants at \$10 million minimally**, which was the level of the FY13 President's budget request. This funding would allow potential THCGME training sites to develop the infrastructure needed to administer residency training programs.

#### National Health Service Corps

Approximately 50 million Americans live in communities with a shortage of health professionals, lacking adequate access to primary care. Through scholarships and loan repayment, the NHSC supports the recruitment and retention of primary care clinicians to practice in underserved communities. The self-reported average medical educational debt of graduates of colleges of osteopathic medicine (COMs) who borrowed to attend medical school increased from less than \$121,000 in 2000 to \$205,674 for 2012 graduates, with 91% of 2012 graduates reporting that they had medical education debt. Today, nearly 10,000 National Health Service Corps providers are providing primary care to approximately 10.4 million people at nearly 14,000 health care sites in urban, rural, and frontier areas. **AACOM strongly supports the preservation of student scholarship and loan repayment programs for graduate and professional students.** This critical funding works to address the primary care workforce shortage and advances innovative models of service, such as HRSA's Students to Service pilot program which provides loan repayment assistance to medical students in their last year of education in return for their commitment to practice.

#### Workforce Commission

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

issues. 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. **For these reasons, AACOM recommends that \$3 million be appropriated to fund the Commission.**

#### National Institutes of Health

Research funded by the National Institutes of Health (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 a sufficient level of funding 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.

#### Agency for Healthcare Research and Quality

AHRQ supports research to improve health care quality, reduce costs, advance patient safety, decrease medical errors, and broaden access to essential services. AHRQ plays an important role

in producing the evidence base needed to improve our nation's health and health care. The incremental increases for AHRQ's Patient Centered Health Research Program in recent years, as well as the funding provided to AHRQ in the American Recovery and Reinvestment Act of 2009 (ARRA), will help AHRQ generate more of this research and expand the infrastructure needed to increase capacity to produce this evidence. More investment is needed, however, to fulfill AHRQ's mission and broader research agenda, especially research in patient safety and prevention and care management research. **AACOM recommends \$430 million for AHRQ's base, discretionary budget.** 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.

Jan Fortney  
37 Yazoo Circle  
Maumelle, AR 72113

March 15, 2013

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

REQUEST: RE: 2014 Budget of Department of Health and Human Services –  
Do Not Fund DHHS Programs and Policies that Promote Deinstitutionalization of Persons  
with Severe Forms of Developmental Disabilities

AMOUNT OF FUNDING INVOLVED: UNKNOWN

Ladies and Gentlemen:

I am writing to have my comments submitted regarding State Protection and Advocacy Systems 2014 funding. Thank you for the opportunity to comment.

I am the mother and guardian of an adult daughter, age 37, 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. She lived at home with us until she was 18 ½ year old, when she seemed to need more activity in her life and independence. She has thrived at the Conway Human Development Center for over 18 years now, and we are very much still a part of her life.

I am a strong advocate for all individuals with developmental disabilities. I work with many other parents/guardians to support good public policies for people with developmental/intellectual disabilities. I am familiar with our State's Protection and Advocacy program, which was created under Public Law 106-402, the Developmental Disabilities Assistance and Bill of Rights Act of 2000 ("DD Act"), having served on Arkansas' Developmental Disabilities Council from 2004 through 2009. In Arkansas the P&A is called the Disability Rights Center (DRC).

I would like to bring to your attention activities of the P & A in Arkansas. DRC has publically and legally undermined the programs that support my daughter! Please consider the following examples:

- 1) June 22, 2010 – DRC held a press conference at the State Capitol asking our Governor to close the Booneville Human Development Center. Their press release said, "*On the eleventh anniversary of the Olmstead decision DRC calls for Governor Beebe to provide Arkansans with disabilities and their families with "a choice and a voice" in community placement options, and BHDC should be closed.*" Instead of trying to help make things better for those who "chose" to reside in the Booneville HDC, the DRC had an agenda to just close it! That's not really their decision!
- 2) In May, 2003, the Arkansas protection and advocacy system ("DRC") filed a class action lawsuit against our state's service system for people with developmental disabilities. The named-plaintiff, "Jane Doe," was a resident of the Conway Human Development Center and her legal guardian was not consulted by DRC. After named-plaintiff Jane Doe died, DRC brought a second class action lawsuit using named plaintiffs whose guardians had not been consulted. After the federal judge dismissed the second case, DRC brought a third lawsuit using two of the three named-plaintiffs from the second case. The third

suit did not seek class action status but as in the first two cases, the suit challenged Arkansas' admission and discharge policies to the Arkansas state-operated human development centers without support of residents or families of the centers. I received guardianship of my adult cognitively and physically disabled daughter through the court system; therefore, it should not be questioned by an entity that believes they know better than a parent or a judge!

*I object to the DRC using their federal funds in such a way, using public resources to bring class action lawsuits seeking to represent people that have been adjudicated incompetent without notice to their legal guardians and without an opportunity to opt out of the cases. I object to protection and advocacy systems use of litigation to eliminate and undermine congregate care programs.*

- 3) DRC played a role in the 2002 through 2009 DOJ investigation of the Conway Human Development Center (my daughter's home). DRC provided biased information in order to serve its own purposes of an agenda of closing Human Development Centers. All through the 6 week trial in 2010, which was dismissed in June of 2011, the DRC staff attorney was regularly quoted in the newspaper regarding their desire for closure of not only CHDC, but all of the state operated HDCs.

There are other examples. DRC tends to "stir the pot" to pit home and community based supporters and human development center/HDC supporters against each other. This policy is just wrong! DRC is supposed to be "supporting voices and choices" – ALL of them, not just the ones they deem proper choices! DRC has made it very clear that they will not support individuals that choose to live in an HDC.

The nation's service system for individuals with severe cognitive developmental disabilities has been weakened by the aggressive deinstitutionalization activities of P&A programs. These federally funded programs should not be able to use their funds to promote closure of safe homes for vulnerable individuals with DD, or to eliminate facilities which have been proven successful in caring for persons with severe and profound cognitive developmental disabilities.

Each year when the DRC asks for public comment on the upcoming year's goals and priorities, I have participated in the comment period. I don't see where the DRC publicly has in their goals and priorities that they want to downsize/close our state's publicly operated human development centers (HDCs). However, their actions show the obvious agenda of supporting sometimes an aggressive effort towards downsizing or even closing our HDCs.

Again, thank you for the opportunity to comment.

Respectfully submitted,

*Jan Fortney*

Jan Fortney  
Mother & Guardian of Kim

cc: Governor Mike Beebe  
Arkansas Congressional Delegation  
Families & Friends of Care Facility Residents  
National Parent-Guardian Network

983

Cheryl Felak, RN, BSN  
Because We Care – Beyond Inclusion  
5071 7<sup>th</sup> Ave NE  
Seattle, WA 98105

March 15, 2013

Sent Electronically

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

REQUEST: RE: 2014 Budget of Department of Health and Human Services –  
Do Not Fund DHHS Programs and Policies that Promote Deinstitutionalization of Persons  
with Severe Forms of Developmental Disabilities

AMOUNT OF FUNDING INVOLVED: UNKNOWN

Ladies and Gentlemen:

Thank you for this opportunity to provide information to the House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies. This letter is a request that Congress stop funding federal programs which use public funds to achieve dangerous public policies of deinstitutionalization of persons with severe forms of developmental disabilities.

I am the mother of a young adult (age 19), healthcare provider and advocate for people with developmental disabilities in support of a continuum of care service model. Our family needed to admit our son at age 15 to the Intermediate Care Facility for People with Intellectual Disabilities (ICF/ID) for not only his safety but for the health and safety of our family. Our son's care is beyond what could be provided safely in a community residential home.

Our son needs 24 hour awake care and maximum assistance with all personal care and activities of daily living. His care was manageable at home until his early onset pediatric dementia increased his episodes of mania and psychosis. The additional care needed to safely care for him with both a developmental disability and his mental health issues was impossible to manage. He had several prolonged hospitalizations for crisis stabilization. His care became a revolving door of crisis intervention and the health and safety of other family members was greatly compromised.

Since moving to the supportive community of the ICF/ID 4 years ago our son HAS NOT been hospitalized once. He is stable; he receives comprehensive care (daily nursing care, medical, dental, nutritional support, occupational therapy, behavior support, recreation, vocational training, etc) and he loves his home. The ICF/ID has safe staffing levels, lower staff turnover, specialized training – all which make this community the least restrictive for our son.

The following are examples of how government dollars are spent in the wrong way by the Department of Health and Human Services:

**1. Administration on Intellectual and Developmental Disabilities (DHHS-AIDD) - a federal agency operating with insufficient oversight**

Administration on Intellectual and Developmental Disabilities (AIDD) administers programs and grants created under Public Law 106-402, Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) . Three are programs funded with federal funds which are in direct conflict with The DD Act. Many families and advocates oppose this spending knowing programming is being driven by so-called advocacy organizations such as The Arc. The Arc opposes any form of congregate care regardless of what the experts, the families and caregivers of our most vulnerable citizens, desire for the safe, comprehensive, care for their loved ones. These programs go unchecked with little oversight or research which looks at objective criteria measuring quality of life and quality of care.

Congress should conduct hearings on the activities of AIDD, the DD Act programs and their national lobbying organizations. The groups' deinstitutionalization activities should not be funded.

**2. DHHS Incentive grants to encourage States to move away from providing institutional care – federal grants given without careful study of the consequences**

Generous DHHS incentive grants (e.g., Money Follows the Person, Roads to Community Living, Balance Improvement Payment Plan and Community First Choice Option) are federal rewards to cash-strapped states to move away from providing institutional services for their most vulnerable citizens. Good public policies should be formulated with transparency, consultation

with those who will be most affected, and, with careful studies when the consequences may be death, injury and suffering.

DHHS incentive grants should look at cost-effective, comprehensive, safe and accessible care and allow the individual to decide what "community" is to them.

**3. Closure of one of our States' ICF/IDs due to Advocacy by The Arc and Disability Rights Washington, the Protection and Advocacy Agency.**

One of our state's ICF/IDs was closed in 2011. Within 3 months of moving, one resident who had lived there safely for many years was dead. This man had PICA and DD and was moved to his "own" home with 24 hour staff. The staff put laundry detergent in a milk carton and left it on the counter. The man drank it. He spent about 2 agonizing weeks in the hospital then returned home. Within a day he developed breathing problems and the staff, not able to assess him, put him in the car and drove him to the hospital rather than calling 911. This man was dead upon arrival to the hospital.

The above is only one example. There have already been 2 more near death "accidents", several hospitalizations and other crisis among the 56 residents who were evicted from their home due to misplaced advocacy.

**4. Washington has passed legislation which denies those 21 and under to be admitted to the ICF/ID. For this age group there are no safe alternatives and the ICF/ID is an entitlement.**

**How was Washington able to pass this law? The Arc supported and advocated for “no children to be admitted” because “children should be at home.”**

I hope by writing a little about my family, it may be clear that for some children, the ICF/ID is the safe, appropriate environment for them. My son was 15 when he was admitted and it saved not only his life but my life too. His intense caregiving needs pushed my health to the very limits from which I have developed my own life long disability. In addition to my son’s hospitalizations, I have been hospitalized many times and have had to have multiple surgeries followed with complications due to injuries I sustained caring for him.

I cannot imagine what we would have done if this law had been passed prior to our son’s admission. When I brought this issue of no choice or options for our youth up with our then, Secretary of Social and Health Services, Susan Dreyfus, her response to me was “families still have a choice – they can send their child to a different state.” That is not a choice.

I would be more than happy to provide you with objective and evidence based research.

Very truly yours,

/s/ Cheryl Felak, RN, BSN  
Because We Care – Beyond Inclusion  
[www.becausewecare1.com](http://www.becausewecare1.com)  
(206) 5853-4141 cell

Cc: Washington Congressional Delegation

**Testimony of Clare Coleman, President & CEO  
National Family Planning & Reproductive Health Association**

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

**Re: Title X Family Planning Program  
(Department of Health and Human Services/Office of Population Affairs)**

**March 18, 2013**

**Summary:** Requesting \$327 million in funding for Fiscal Year (FY) 2014 for the national family planning program (Title X of the Public Health Service Act).

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My name is Clare Coleman; I'm the President & CEO of the National Family Planning & Reproductive Health Association (NFPRHA), a membership association representing the nation's family planning provider systems. A majority of NFPRHA's more than 500 members receive federal funding from Medicaid and through Title X of the Public Health Service Act, the only dedicated federally funded family planning program for the low-income and uninsured. These programs are a part of the nation's public health safety net,

and are at the forefront of efforts to reduce rates of unintended pregnancy and improve sexual and reproductive health outcomes.

NFPRHA requests that you make a significant investment in the Title X family planning program in the FY 2014 bill, by appropriating \$327 million. Title X sustained significant cuts – \$23.6 million -- in fiscal years 2011 and 2012, at a time when the need for publicly subsidized health care is growing. As a result of sequestration, it is estimated that the program will sustain an additional 5% – 9% cut. Cuts to Title X health systems have led to health center hours being cut and staff layoffs – which directly led to a sharp drop in the number of patients seen in the program in 2011, the last year for which federal data are available.

Title X-funded centers serve more than 5 million low-income women and men annually at nearly 4,400 health centers. Title X services help women and men plan the number and timing of pregnancies, helping to prevent nearly one million pregnancies a year, which would have likely resulted in 432,600 unintended births and 406,200 abortions. In addition to providing contraceptive services and supplies, Title X health centers provide preventive health services, education, and counseling. Title X assists with patient referrals

and helps coordinate care for individuals who traditionally have lacked access to routine care. The services provided at publicly funded health centers not only improve public health, they save billions of taxpayer dollars each year. In 2008, publicly funded family planning saved federal and state governments \$5.1 billion; services provided at Title X-supported centers accounted for \$3.4 billion in such savings in that same year alone. A recent estimate from the Brookings Institution found that expanding publicly funded family planning services would produce taxpayer savings of \$2 – \$6 for every dollar spent.

For more than 40 years, Title X has been a critical safety net for those living in under-resourced communities across the country. The \$23.6 million in cuts to Title X in FY 2011 and FY 2012 – a 7.4% loss of funding -- came after the largest growth of patients served by the Title X network in more than a decade, an increase of more than 170,000 women, men, and teens between 2008 and 2010. Unfortunately, the recent funding cuts have reversed this trend, and in just one year between 2010 and 2011, the program experienced a decline of more than 200,000 patients.

Today, safety-net providers deliver health care to many in need, and especially those in vulnerable populations, a role that will undoubtedly grow

when full ACA coverage expansion begins in 2014. Despite the proven cost savings and public support of Title X, the program is still under extreme pressure. A funding level of \$327 million would help to stabilize systems following the significant damage done by federal and state budget cuts over the last few years. This is essential -- if we do not stabilize the system now, this network of providers will not be available to serve those in need, including the millions of individuals who will gain health coverage through the ACA and will seek health care in the safety net.

Thank you for the opportunity to testify on the role of Title X in the public health safety net. NFPRHA stands ready to work with you to strengthen America's network of family planning providers and its role in helping to ensure that health care reforms are a success.

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