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DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES APPROPRIATIONS FOR 2012

HEARINGS

BEFORE A

SUBCOMMITTEE OF THE

COMMITTEE ON APPROPRIATIONS

HOUSE OF REPRESENTATIVES

ONE HUNDRED TWELFTH CONGRESS

FIRST SESSION

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

DENNY REHBERG, Montana, *Chairman*

JERRY LEWIS, California
RODNEY ALEXANDER, Louisiana
JACK KINGSTON, Georgia
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NOTE: Under Committee Rules, Mr. Rogers, as Chairman of the Full Committee, and Mr. Dicks, as Ranking Minority Member of the Full Committee, are authorized to sit as Members of all Subcommittees.

STEVE CRANE, KEVIN JONES, DONNA SHAHBAZ,
JOHN BARTRUM, SUSAN ROSS, and LORI BIAS,
Subcommittee Staff

PART 7

OUTSIDE WITNESS TESTIMONY

Printed for the use of the Committee on Appropriations

Part 7
Outside Witness Testimony

DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES APPROPRIATIONS FOR 2012

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National Association of State Comprehensive Health Insurance Plans

NASCHIP

April 4, 2011

The Honorable Denny Rehberg
Chairman
House Appropriations Committee-Labor, Health and Human Services, Education, and Related Agencies Subcommittee
2358 Rayburn House Office Building
Washington, DC 20515

The Honorable Rosa DeLauro
Ranking Member
House Appropriations Committee-Labor, Health and Human Services, Education, and Related Agencies Subcommittee
2413 Rayburn House Office Building
District of Columbia 20515

Dear Chairman Rehberg and Ranking Member DeLauro:

The National Association of State Comprehensive Health Insurance Plans (NASCHIP) appreciates the opportunity to submit testimony as you consider an FY 2012 Labor-HHS and Education Appropriations bill. NASCHIP represents the state high risk pools which were established by statute initially passed 10 years before the federal high risk pool program (PCIP) was created by the ACA, the Affordable Care Act. Our programs operate in 35 states including your states, Mr. Chairman and Ms. DeLauro. We serve more than 200,000 people providing them with insurance notwithstanding their preexisting conditions. This number reflects a 7 percent increase from 2009 levels which we consider a significant indicator of the value and necessity of our programs.

We are here to urge that you support a level of $75 million for the federal grant program for state high risk pool programs for FY 2012. This was the authorization level contained in our statute the State High-Risk Pool Funding Extension Act of 2006. This funding allows many states to provide means based premium subsidies to their citizens who might otherwise not be able to afford coverage.

We consider this level of funding the essential minimum for us to continue to do our work of providing a vital safety net to individuals who might otherwise be uninsured. For the current fiscal year, the federal grant program for state high risk pool programs has $55 million in available funding which represents only a fraction of the total costs of care for state high risk pools. In fact, total state pool expenses in 2009 were approximately $2.2 billion.

We were disappointed that the President only requested $44 million in funding for the federal grant program for state high risk pools in his FY 2012 budget proposal. It was based in part on an incorrect premise that as enrollments grow in the PCIP program it would lessen enrollment in our programs. The request also ignores the reality of increased enrollment into our programs in

National Association of State Comprehensive Health Insurance Plans

NASCHIP

2010. Only by receiving $75 million in funding for FY 2012 would we stand a chance of serving the individuals we need to serve.

The issues related to the PCIP program and either lower or higher than expected enrollments should have no bearing on the funding level we request. We have and will continue to work with Administration officials to improve enrollments in PCIP as we want to see this program succeed. However, the state high risk pools serve a growing population and are in need of continued funding. We urge you to include $75 million in your Labor-HHS and Education Appropriations bill for FY 2012.

Sincerely,

Amie Goldman
President
NASCHIP

National Association of State Comprehensive Health Insurance Plans
5775 Wayzata Blvd. Suite 910 ■ St. Louis Park, MN 55416

NAEVR
National Alliance For
Eye And Vision Research
Serving as Friends of the National Eye Institute

1801 Rockville Pike
Suite 400, Attn: James Jorkasky
Rockville Maryland 20852
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WRITTEN TESTIMONY IN SUPPORT OF INCREASED FISCAL YEAR (FY) 2012 FUNDING FOR THE NATIONAL INSTITUTES OF HEALTH (NIH) AND THE NATIONAL EYE INSTITUTE (NEI) LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES SUBCOMMITTEE OF THE U.S. HOUSE OF REPRESENTATIVES COMMITTEE ON APPROPRIATIONS
April 7, 2011

EXECUTIVE SUMMARY

NAEVR requests Fiscal Year (FY) 2012 NIH funding at $35 billion, which reflects a $3 billion increase over President Obama's proposed funding level of $32 billion. Funding at $35 billion, which reflects NIH net funding levels in both FY2009 and FY2010, ensures it can maintain the number of multi-year investigator-initiated research grants, the cornerstone of our nation's biomedical research enterprise. The vision community commends Congress for $10.4 billion in NIH funding in the American Recovery and Reinvestment Act (ARRA), as well as FY2009 and FY2010 funding increases that enabled NIH to keep pace with biomedical inflation after six previous years of flat funding that resulted in a 14 percent loss of purchasing power. FY2012 NIH funding at $35 billion enables it to meet the expanded capacity for research– as demonstrated by the significant number of high-quality grant applications submitted in response to ARRA opportunities–and to adequately address unmet need, especially for programs of special promise that could reap substantial downstream benefits, as identified by NIH Director Francis Collins, M.D., Ph.D. in his top five priorities. As President Obama has stated repeatedly, most recently during the 2011 State of the Union Address, biomedical research has the potential to reduce healthcare costs, increase productivity, and ensure the global competitiveness of the United States.

NAEVR requests that Congress increase NEI funding above the 1.8 percent proposed by the President–even if it does not fund NIH at $35 billion–since the proposed increase does not match biomedical inflation. In 2009, Congress spoke volumes in passing S. Res 209 and H. Res. 366, which designated 2010-2020 as *The Decade of Vision,* in which the majority of 78 million Baby Boomers will turn 65 years of age and face greatest risk of aging eye disease. This is not the time for a less-than-inflationary increase that nets a loss in the NEI's purchasing power, which eroded by 18 percent in the FY2003-FY2008 timeframe. NEI-funded research is resulting in treatments and therapies that save vision and restore sight, which can reduce healthcare costs, maintain productivity, ensure independence, and enhance quality of life.

THE BIPARTISAN NIH SUPPORT DISPLAYED AT THE HOUSE/SENATE SUBCOMMITTEES' MARCH 11/30 HEARINGS WITH SECRETARY SEBELIUS DEMONSTRATES THE VALUE OF INCREASED AND TIMELY APPROPRIATIONS

NAEVR was pleased to hear the level of bipartisan support expressed for NIH at the March 11 House and March 30 Senate LHHS Appropriations Subcommittee hearings with Department of Health and Human Services (DHHS) Secretary Kathleen Sebelius and was especially impressed by two sets of comments:

- Senate Ranking Member Richard Shelby (R-AL) cautioned against across-the-board cuts and urged Congress to sustain programs that are effective–where he cited NIH as "one of the most results-driven aspects of our entire federal budget." He added that "research conducted at NIH reduces disabilities, prolongs life, and is an essential component to the health of all Americans. NIH programs consistently meet their performance and outcomes measures, as well as achieve their overall mission." These comments are stated so well that NAEVR will not expand upon them, other than to cite vision examples in the next sections.

- Senator Barbara Mikulski (D-MD) noted that a government shutdown, NIH cuts, or delayed appropriations, individually or in combination, will have far-reaching consequences, especially for academic Institutions across the country which receive funding.

  To demonstrate that point, in late January 2011, NAEVR hosted 11 domestic and six international members of the Association for Research in Vision and Ophthalmology (ARVO) in Capitol Hill visits. They educated staff that a cutback to the FY2008 level would reduce NEI funding by $30-plus million and reduce the number of grants by 43–any one of which could hold the key to saving or restoring vision. The advocates also described the impact of delayed appropriations, in terms of continuity of research and retention of trained staff. If a department does not have bridge or philanthropic funding to retain staff while awaiting full funding of awards, it will need to let staff go, and that usually means a highly-trained person is lost to another area of research or an institution in another state, or even another country.

FY2012 NIH FUNDING AT $35 BILLION ENABLES THE NEI TO BUILD UPON THE IMPRESSIVE RECORD OF BASIC AND CLINICAL/TRANSLATIONAL RESEARCH THAT MEETS NIH'S TOP FIVE PRIORITIES AND WAS FUNDED THROUGH FY2009/2010 ARRA AND INCREASED "REGULAR" APPROPRIATIONS

NEI's research addresses the preemption, prediction, and prevention of eye disease through basic, translational, epidemiological, and comparative effectiveness research which also address the top five NIH priorities, as identified by Dr. Collins: genomics, translational research; comparative effectiveness; global health, and empowering the biomedical enterprise.

With respect to translational research, in June 2010, NEI hosted a *Translational Research and Vision* conference as the last of a series of NIH-campus based educational events recognizing its 40th anniversary (previous events addressed genetics/genomics, optical imaging, stem cell therapies, and the latest glaucoma research). In keynote comments, Dr. Collins recognized NEI as a leader in translational research. He specifically cited NEI's leadership in ocular genetics, noting that NEI has worked collaboratively with other NIH Institutes, especially the National Human Genome Research Institute (NHGRI) to elucidate the basis of eye disease and to develop treatments. As NEI Director Paul Sieving, M.D., Ph.D. has stated, one-quarter of all genes identified to date are associated with eye disease/visual impairment.

Dr. Collins also lauded the NEI's use of Genome-Wide Association Studies (GWAS) to determine the increased risk of developing age-related macular degeneration (AMD) from gene variants in the Complement Factor H (CFH) immune pathway, noting that "this was the first demonstration that GWAS is a useful tool to make the connection between gene variants and disease conditions." He added that, "Twenty years ago we could do little to prevent or treat AMD. Today, because of new treatments and procedures based on NIH/NEI research, 1.3 million Americans at risk for severe vision loss from AMD over the next five years can receive potentially sight-saving therapies."

With increased "regular" FY2009/2010 appropriations and ARRA funding, NEI has been able to build upon past research in two important areas:

Genetic Basis of AMD: In 2010, NEI initiated the International AMD Genetics Consortium, reflecting researchers on five continents who will be sharing and analyzing GWAS results to further elucidate the genetic basis of AMD. This may lead to new diagnostics and treatments for this leading blinding eye disease, growing in incidence with the aging of the population and with potential significant costs to the Medicare program.

Treatment of Diabetic Macular Edema: In May 2010, the NEI's Diabetic Retinopathy Clinical Research (DRCR) Network–a multi-center network dedicated to facilitating clinical research into diabetic retinopathy, diabetic macular edema, and associated conditions–reported results of a comparative effectiveness trial. The study confirmed that laser treatment for diabetic macular edema, when combined with injections of the Food and Drug Administration (FDA)-approved anti-angiogenic drug Lucentis, is more effective than laser treatment alone, the latter of which has been the standard of care for the past 25 years. With NIH's recent announcement of a new strategic plan to combat diabetes, led by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), this research is more important than ever within the larger context of NIH priorities. The current DRCR Network is a successor to several previous networks, all of which involved NEI-NIDDK collaboration. NEI's emphasis on diabetic retinopathy reflects the fact that it is the leading cause of vision loss in the working-age population and occurs with disproportionately greater incidence in the Hispanic population.

IF CONGRESS DOES NOT INCREASE FY2012 NIH FUNDING ABOVE THE PRESIDENT'S REQUEST, IT IS EVEN MORE VITAL TO IMPROVE UPON THE PROPOSED 1.8 PERCENT INCREASE FOR NEI

The NIH budget proposed by the Administration and finalized by Congress during the second year of the Congressionally-designated *Decade of Vision* should not contain a less-than-inflationary increase for the NEI due to the enormous challenges it faces in terms of the aging population, the disproportionate incidence of eye disease in fast-growing minority populations, and the visual impact of chronic disease (e.g., diabetes). If Congress is unable to fund NIH at $35 billion in FY2012 (NEI level of $794.5 million) and adopts the President's proposal, the 1.8 percent increase in funding must be increased to at least an inflationary level of 2.4 percent to prevent any further erosion in NEI's purchasing power. NEI funding is an especially vital investment in the overall health, as well as the vision health, of our nation. It can ultimately delay, save, and prevent health expenditures, especially those associated with the Medicare and Medicaid programs, and is, therefore, a cost-effective investment.

VISION LOSS IS A MAJOR PUBLIC HEALTH PROBLEM: INCREASING HEALTHCARE COSTS, REDUCING PRODUCTIVITY, DIMINISHING LIFE QUALITY

The NEI estimates that more than 38 million Americans age 40 and older experience blindness, low vision, or an age-related eye disease such as AMD, glaucoma, diabetic retinopathy, or cataracts. This is expected to grow to more than 50 million Americans by year 2020. The economic and societal impact of eye disease is increasing not only due to the aging population, but to its disproportionate incidence in minority populations and as a co-morbid condition of chronic disease, such as diabetes.

Although the NEI estimates that the current annual cost of vision impairment and eye disease to the US is $68 billion, this number does not fully quantify the impact of indirect healthcare costs, lost productivity, reduced independence, diminished quality of life, increased depression, and accelerated mortality. NEI's FY2010 baseline funding of $707 million reflects just a little more than one percent of this annual costs of eye disease. The continuum of vision loss presents a major public health problem, as well as a significant financial challenge to the public and private sectors.

NAEVR URGES CONGRESS TO FUND THE NIH AT $35 BILLION IN FY2012 WHICH WILL ENSURE THE MOMENTUM OF BREAKTHROUGH NEI-FUNDED VISION RESEARCH AND THE RETENTION OF TRAINED PERSONNEL

ABOUT NAEVR

The National Alliance for Eye and Vision Research (NAEVR) 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.

Testimony of Daniel Paul Perez, President & CEO, FSH Society, Inc.
Telephone: (781) 275-7781, e-mail: daniel.perez@fshsociety.org before the
United States House Appropriations Committee
Subcommittee on Labor, Health and Human Services, Education and Related Agencies on the Subject of FY2012 Appropriations for National Institutes of Health (NIH) Research on Facioscapulohumeral Muscular Dystrophy (FSHD) – April 7, 2011

Honorable Representative Rehberg, Mr. Chairman, Honorable Representative DeLauro, Ranking Member, Subcommittee members and members of the U.S. House Appropriations Committee, Subcommittee on Labor, Health and Human Services, Education and Related Agencies thank you for the opportunity to submit this testimony.

I am Daniel Paul Perez, of Bedford, Massachusetts, President & CEO of the FSH Society, Inc. and an individual who has lived with facioscapulohumeral muscular dystrophy (FSHD) for 48 years. FSHD is also known as facioscapulohumeral muscular disease, FSH muscular dystrophy and Landouzy-Dejerine muscular dystrophy. For hundreds of thousands of men, women, and children the major consequence of inheriting the most prevalent form of muscular dystrophy is a lifelong progressive and severe loss of all skeletal muscles. FSHD is a crippling and life shortening disease. No one is immune, it is genetically and spontaneously (by mutation) transmitted to children and it affects entire family constellations.

My testimony seeks to address the urgent need for NIH to redress and increase funding for research on FSHD.

A consortium of European partners known as Orphanet, led by the French government research agency, INSERM (Insitut National de la Santé et de la Recherche Medicale), that is comparable to the U.S. NIH, which includes both government and private members, has issued new epidemiology and prevalence data for hundreds of diseases that **ranks FSHD as the first and most prevalent muscular dystrophy.** The "Orphanet Series" report November 2010, "Prevalence of Rare Diseases" report can be found at internet web site: (http://www.orpha.net/orphacom/cahiers/docs/GB/Prevalence_of_rare_diseases_by_alphabetical_list.pdf). FSHD is presented as the third most prevalent muscular dystrophy in the Muscular Dystrophy Community Assistance, Research and Education Amendments of 2001 and 2008 (the MD-CARE Act). This new data changes the findings as listed in the MD-CARE Act. FSHD is 40 percent more prevalent than Duchenne muscular dystrophy (DMD), now recognized as the second most prevalent dystrophy.

Estimated Prevalence	**(Cases / 100,000)**
Facioscapulohumeral muscular dystrophy (FSHD)	7 / 100,000
Duchenne (DMD) and Becker dystrophy (BMD)	5 / 100,000
Steinert myotonic dystrophy (DM)	4.5 / 100,000

Figures from the online NIH database RCDC RePORT and the NIH Appropriations History for Muscular Dystrophy report provided by NIH/OD Budget Office & NIH OCPL show that from the inception of the MD CARE Act 2001, **funding has more than quadrupled from $21 million to $86 million in fiscal year 2010 (FY2010) for muscular dystrophy.** In FY2010, total muscular dystrophy funding grew by 3.6% ($3M / $83M) over the previous fiscal year.

Patients, professionals, and other parties interested in FSHD can contact us at FSH Society, Inc., BBRI R353, 64 Grove Street, Watertown, MA 02472 USA. Phone (617) 658-7878, fax (617) 658-7879, e-mail: solvefshd@fshsociety.org. Internet: http://www.fshsociety.org.

In FY2010, FSHD funding represented 7% of the NIH-wide muscular dystrophy budget ($6M / $86M). In the previous year, FSHD represented 6% of the total muscular dystrophy funding ($5M / $83M). **FSHD funding as a percentage of overall NIH muscular dystrophy funding has been level over the last nine years.**

National Institutes of Health (NIH) FSHD Funding & Appropriations

Sources: NIH/OD Budget Office & NIH OCPL & NIH RCDC RePORT

Fiscal Year	FSHD Research Dollars (in millions)	FSHD as a Percentage of Total NIH Muscular Dystrophy Funding
2006	$1.7	4%
2007	$3	5%
2008	$3	5%
2009	$5	6%
2010	$6	7%

We highly commend the NIH on the ease of use and the continued accuracy of the Research Portfolio Online Reporting Tool (RePORT) report "Estimates of Funding for Various Research, Condition, and Disease Categories (RCDC)" with respect to reporting projects on muscular dystrophy.

Now that FSHD has been established as the most prevalent muscular dystrophy, and in light of recent advances in research it makes no sense that FSHD remains the most underfunded dystrophy by the NIH and in the federal research agency system (CDC, DoD and FDA). Given FSHD's prevalence, disease burden, the overall percentage of funding of the muscular dystrophy research portfolio and major mechanistic breakthroughs on FSHD etiology in 2010 and 2011, we ask Congress to urge NIH to provide a catalyst for scientific opportunity in FSHD.

Inter-dystrophy funding changes and comparisons year after year clearly depicts that NIH FSHD funding needs to be increased and set right. Intra-dystrophy funding changes are misleading as a large change in a small number is still an anemic amount. In FY2010, the most prevalent muscular dystrophy, FSHD, received a one million dollar increase from NIH to $6 million, up 20 percent from $5 million. In FY2010, the second most prevalent, Duchenne (DMD/BMD) type, received a five million dollar increase from NIH to $38 million, up 15 percent from $33 million. In FY2010, the third most prevalent myotonic dystrophy (DM) type, received one million dollars less from NIH to $12 million down eight percent from $13 million. There is an obvious funding disparity as the first and third most prevalent dystrophies combined, each with major breakthroughs in the past two years, are receiving less than half of NIH funding that the second prevalent dystrophy with its disease causing gene being discovered 25 years ago.

The MD CARE Act mandates the NIH Director to intensify efforts and research in the muscular dystrophies, including FSHD, across the entire NIH. **It should be very concerning that: 1). in the last nine years muscular dystrophy has quadrupled to $86 million and that FSHD has remained on average at five percent of the NIH muscular dystrophy portfolio**; 2). FSHD, the most prevalent muscular dystrophy is far underrepresented based on percentage of overall NIH dystrophy funding given its prevalence and disease burden; and, 3). that both FSHD and DM have had extraordinary major breakthroughs in understanding the disease mechanism in the current and past fiscal years and NIH funding remains level in one and has declined in the other.

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Muscular Dystrophy Type	Rank By Prevalence	NIH Funding Dollars in Millions		Percentage of Total MD funding at NIH	
		FY2009	FY2010	FY2009	FY2010
FSHD	1	$5	$6	6%	7%
DMD/BMD	2	$33	$38	40%	44%
DM	3	$13	$12	16%	14%

Two major breakthroughs on FSHD occurred in FY2010 and FY2011 that make it urgent for the NIH to redress funding for FSHD. On August 19, 2010, a paper titled, *"A Unifying Genetic Model for Facioscapulohumeral Muscular Dystrophy" [Science 24 September 2010: Vol. 329 no. 5999 pp. 1650-1653]* was published online in the top-rated journal by a group of researchers who started their careers in FSHD research with post-doctoral fellowships from the FSH Society. This paper was a major breakthrough in understanding how FSHD works. It made the front page of the *New York Times* on the following day. The *Times* article *"Reanimated 'Junk' DNA Is Found to Cause Disease,"* quoted Dr. Francis Collins, a human geneticist and Director of the National Institutes of Health saying, "If we were thinking of a collection of the genome's greatest hits, this would go on the list." Dr. Collins went on to say, "Well, my gosh, ... here's a simple disease with an incredibly elaborate mechanism. To come up with this sort of mechanism for a disease to arise — I don't think we expected that." Professor David E. Housman, FSH Society Scientific Advisory Committee Chairman and a geneticist at Massachusetts Institute of Technology (M.I.T.), was quoted saying, "Scientists will now be looking for other diseases with similar causes, and they expect to find them. As soon as you understand something that was staring you in the face and leaving you clueless, the first thing you ask is, 'Where else is this happening?'"

Two months later, another paper was published that originated with seminal funding from the FSH Society that made a second critical advance in determining the cause of FSHD. *"Facioscapulohumeral Dystrophy: Incomplete Suppression of a Retrotransposed Gene"* was published in *PLoS Genetics,* October 28, 2010, that made a second critical advance in FSHD. The research shows that FSHD is caused by the inefficient suppression of a gene that may be normally expressed only in early development. The international team of researchers led by Stephen Tapscott, M.D., Ph.D., a member of the Hutchinson Center's Biology Division thinks that the work will lead to new approaches for therapy and new insights into human evolution of disease.

The international FSHD clinical and research community recently came together at the DHHS NIH Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) Boston Biomedical Research Institute Senator Paul D. Wellstone MD CRC for FSHD. Almost 90 scientists working on FSHD globally met at the 2010 FSH Society FSHD International Research Consortium, held October 21-22, 2010 to identify **areas of scientific opportunity in FSHD that need funding.** The summary and recommendations of the group state that given the recent developments in our definition of FSHD, that within one to two (1-2) years evidence-based intervention strategies, therapeutics, and trials need to be planned and conducted. Our immediate priorities should be to confirm that the DUX4 gene hypothesis is valid. Then we must understand the normal DUX4 function. Finally, we must understand the naturally occurring variability to enable us to manipulate the disease in our favor. We need to be prepared for this new era in the science of FSHD by accelerating efforts in the following ten areas:

1. Shareable Protocols;
2. Common and shareable materials and data by the whole community;
3. Corroborate and verify DUX4 finding;
4. FSHD alleles in context of population genetics need to be defined;
5. Biomarkers;
6. FSHD clinical evaluation scales/systems need be defined under one agreed standard;
7. Working Groups / animal and mouse model working group consortium;
8. Model systems for mechanistic, intervention work and advancement to clinical trials;

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9. Epigenetics / Genetics;
10. Clinical trials readiness.

To read the expanded summary and recommendations of the group please go to on-line file at: http://www.fshsociety.org/assets/pdf/IRCWorkshop2010WorkingConsensusOfPrioritiesGalley.pdf

It is impossible to justify the current low level of FSHD funding in the current context of muscular dystrophy budget at the NIH. We have worked hard with our scientific colleagues and member patients and families to build the corpus of knowledge to understand FSHD. We have made great progress in understanding our own disease. We have worked side by side with the NIH directors, program and legislative staff the whole distance to these remarkable discoveries. Still, there has been a confounding and recalcitrant lack of traction at NIH for funding in FSHD. Our request to the NIH – increase FSHD funding now!

NIH constantly reminds us that the NIH system of peer-review delivers the best science from investigator initiated grant applications, thus delivering quality science to the American tax-payer. NIH is receiving more and more grant applications on FSHD. As a non-profit volunteer health agency that funds breakthrough research based on peer-review mechanics and on a shoe-string compared to NIH, we appreciate the need for peer review, the need to fund the best science and also the need to recalibrate the process to ensure that pragmatic and necessary choices are being pursued in the advent of paradigmatic changes in a disease. We FSHD patients and fellow citizens appreciate this as tax-payers as well.

What it comes down to is -- the choice of "the best science" in a disease area and how this has been achieved. This is difficult to measure except in hindsight e.g. what hypotheses represent the best science. The Director of NIH said, set this down, take note, this is one of the ten greatest discoveries in human genomics and that we never expected diseases to be caused by unwanted RNA from reanimated junk DNA. The implications are enormous. FSHD has an incredibly elaborate mechanism that we did not expect. We now know that inadvertent expression of DUX4 from a stretch of reactivated "junk-DNA" causes muscle disease known as FSHD. It is clear that this type of research does not and has not done well in peer-review and it is obvious by the fact that funding is dwarfed. Looking back at the recent NIH Request For Proposals (RFAs) that covered FSHD we can see that all of the breakthrough D4Z4 DUX4 gene grant applications went unfunded by NIH. Perhaps the study sections need to be pulled apart and examined in the broader context of muscular dystrophy. Perhaps comparing Duchenne, Myotonic and FSHD is now much akin to determining the best science in computer science and biology combined. Computer science and biology seems an obvious apples to oranges comparison. We are saddened that the most brilliant work on FSHD was turned away by the NIH. It is crystal clear, if not completely black and white, that FSHD is not achieving the goals of parity in funding as set down in mandates set forth in the MD CARE Acts 2001/2008 and by the NIH Action Plan for the Dystrophies submitted to the Congress by the NIH.

As you know, we are impressed with the efforts of NIH staff and Muscular Dystrophy Coordinating Committee (MDCC) on behalf of the community of patients and their families with muscle disease and the research community pursuing solutions for all of us. We recognize in particular the efforts and hard work of the following NIH staff: **Story Landis, Ph.D.** and **John D. Porter, Ph.D. of** National Institute of Neurological Disorders and Stroke (NINDS); **Stephen I. Katz, M.D., Ph.D.** and **Glen H. Nuckolls, Ph.D.** and **Vittorio Satorelli, Ph.D.**, National Institute of Arthritis and Musculoskeletal and Skin Disease (NIAMS); **James W. Hanson, M.D.** and **Ljubisa Vitkovic, M.D., Ph.D.,** (NICHD).

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.

Patients, professionals, and other parties interested in FSHD can contact us at FSH Society, Inc., BBRI R353, 64 Grove Street, Watertown, MA 02472 USA. Phone (617) 658-7878, fax (617) 658-7879, e-mail: solvefshd@fshsociety.org. Internet: http://www.fshsociety.org.

We request this year in FY2012, immediate help for those of us coping with and dying from FSHD. **We ask NIH to fund research on facioscapulohumeral muscular dystrophy (FSHD) at a level of $35 million in FY2012.** In view of the tremendous breakthroughs in FSHD research that may rewrite genetics, we implore the NIH to immediately address the inadequacy in FSHD muscular dystrophy funding.

We implore the Appropriations Committee to request that the Director of NIH, the Chair, and Executive Secretary of the federal advisory committee MDCC to increase the amount of FSHD research and projects in its portfolios using all available passive and pro-active mechanisms and interagency committees.

We request that **NIH be more proactive in facilitating grant applications** (unsolicited and solicited) from new and existing investigators and through new and existing mechanisms, special initiatives, training grants and workshops – to bring knowledge of FSHD to the next level.

We ask NIH to consider **increasing the scope and scale of the existing DHHS U.S. NIH Senator Paul D. Wellstone Muscular Dystrophy Cooperative Research Centers (U54) to double or triple their size** – they are financially under-powered as compared to their potential. These centers have provided an excellent source of human biomaterials and are a catalyst for research, clinical research and training on muscular dystrophy. We ask NIH to develop funding mechanisms to help expand work from NIH Wellstone Centers outward to address needs and priorities of the scientific communities.

We ask NIH for **more than one Wellstone center solely dedicated to FSHD**. There needs to be one-half dozen groups with six to ten people solely working on FSHD across the U.S. to assure continuity in FSHD efforts.

We strongly support research discovery through the use of post-doctoral and clinical training fellowships -- a model that has worked very effectively for us. It produces results and progeny. Yet, NIH has only a few fellows in muscular dystrophy. We request that NIH issue **an RFA to exclusively fund 12 new post-doctoral fellows and four clinical fellows a year on an ongoing basis for the next five years on FSHD.** We ask that FSHD be the pilot dystrophy for such initiative.

We request that the Director of the **NIH initiate solely for FSHD an RFA for Specialized Centers (P50s)** to encourage multidisciplinary research approaches on the complexity of FSHD.

We request that the Director of the NIH redress the low level of funding in FSHD by issuing an **RFA exclusively for FSHD to allow it to be a prototype disease in the newly forming National Center for Advancing Translational Sciences.** This will help advance the translational science in FSHD and catalyze the development of novel diagnostics and therapeutics for FSHD.

We request that the Directors of the NIH develop, through **an RFA for FSHD, a central place where clinical trials can be designed and run on animal models of FSHD (mouse, dog, sheep, etc.).** It is cost prohibitive to have each U54, P01, P50 funding infrastructure to support these resources. We ask that FSHD be the proof-of-concept disease for such a facility.

Thanks to your efforts and the efforts of your Committee, Mr. Chairman, the Congress, the NIH and the FSH Society are all working to promote progress in FSHD. Our successes are continuing and your support must continue and increase.

Mr. Chairman, thank you for this opportunity to testify before your committee.

Patients, professionals, and other parties interested in FSHD can contact us at FSH Society, Inc., BBRI R353, 64 Grove Street, Watertown, MA 02472 USA. Phone (617) 658-7878, fax (617) 658-7879, e-mail: solvefshd@fshsociety.org. Internet: http://www.fshsociety.org.

STATEMENT BY THE AMERICAN HEART ASSOCIATION
RALPH L. SACCO, M.D., PRESIDENT
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FY 2012 APPROPRIATIONS FOR LABOR-HHS-EDUCATION
NIH, CDC, HRSA, AHRQ

Over the past 50 years, major progress has been made in the battle against heart disease, stroke and other forms of cardiovascular disease (CVD). Improved diagnosis and treatment have been remarkable—as has the survival rate. According to the National Institutes of Health (NIH), since the 1960s, 1.6 million lives have been saved that would have been lost to CVD. Americans can now expect to live on average 4 years longer due to the reduction in heart-related deaths.

Yet, one startling fact remains. Heart disease and stroke are still respectively the No. 1 and No. 3 killers in the U.S. Nearly 2,200 people die of CVD each day—one death every 39 seconds. CVD is a major cause of disability and costs our nation more than any disease—a projected $287 billion in medical expenses and lost productivity for 2007. Today, an estimated 83 million adults suffer from CVD. CVD risk factors such as obesity and high blood pressure are on the rise. At age 40, the lifetime risk for CVD is 2 in 3 for men and over 1 in 2 for women.

Moreover, a new study projects that more than 40% of adults in the U.S. will live with the consequences of CVD at a cost to exceed $1 trillion annually by the year 2030. The graying of Americans combined with the explosive growth in medical spending are the main drivers of increased costs. Our country is truly facing a crisis. Without prevention on a nationwide scale, managing CVD will be an enormous challenge. Clearly, there must be a greater emphasis on prevention and evidence-based approaches to healthy behaviors. This will require strategies to reach people where they live, work and play. Prevention must be an integral part of our toolkit to promote heart healthy and stroke-free habits and wellness at an early age.

Yet, in the face of these statistics, heart disease and stroke research, treatment and prevention programs remain woefully underfunded and funds for NIH is unpredictable for the continuity of effort needed for key advances to redefine disease, ramp up prevention and promote best care.

Given CVD is the No. 1 killer in each state and preventable and treatable risk factors continue to rise, many are surprised that the Centers for Disease Control and Prevention (CDC) invests on average only 16 cents per-person on heart disease and stroke prevention. Also, only 20 states are funded for WISEWOMAN—a proven heart disease and stroke prevention program that serves uninsured and under-insured low-income women with a high prevalence of CVD risk factors.

Where you live could also affect if you survive a very deadly form of heart disease—sudden cardiac arrest (SCA). Only 21 states received funding in FY 2010 for the Health Resources and Services Administration's (HRSA) Rural and Community Access to Emergency Devices Program designed to save lives from sudden cardiac death.

The American Heart Association applauds the Administration and Congress for providing hope to the 1 in 3 adults in the U.S. who live with CVD by wisely investing in the NIH and in the Prevention and Public Health Fund. These resources have provided a much needed boost to

improve our nation's physical and fiscal health. However, stable and sustained funding is critical for FY 2012 to advance heart disease and stroke research, prevention and treatment.

FUNDING RECOMMENDATIONS: INVESTING IN THE HEALTH OF OUR NATION

Heart disease and stroke risk factors continue to rise, yet promising research to stem this tide goes unfunded. Too many Americans die from CVD, while proven prevention efforts beg for resources for widespread implementation. Now is the time to boost research, prevention and treatment of America's No. 1 and most costly killer. If Congress fails to build on progress of the past half century, Americans will pay more in lives lost and higher health care costs. Our recommendations below address these issues in a comprehensive and fiscally responsible manner.

Summary of Recommendations

National Institutes of Health	$35.2 billion
National Heart, Lung, and Blood Institute	$3.514 billion
National Institute of Neurological Disorders and Stroke	$1.857 billion
Agency for Healthcare Research and Quality	$405 million
Centers for Disease Control and Prevention	$7.7 billion
WISEWOMAN	$37 million
National Center for Health Statistics	$162 million
Health Resources and Services Administration	
Rural and Community Access to Emergency Devices Program	$8.927 million

Capitalize on Investment for the National Institutes of Health (NIH)

NIH research has revolutionized patient care and holds the key to finding new ways to prevent, treat and even cure CVD, resulting in longer, healthier lives and reduced health care costs. **NIH invests resources in every state and in 90% of congressional districts. According to a 2008 study, the typical NIH grant paid the salaries of about 7 mainly high-tech full-time or part-time jobs in FY 2007. Further, every dollar that NIH distributes in a grant returns $2.21 in goods and services to the local community in one year.**

***American Heart Association Advocates*:** We advocate for a FY 2012 appropriation of $35 billion for NIH to capitalize on the investment to save lives, advance better health, spur our economy and spark innovation. NIH research prevents and cures disease, generates economic growth and preserves the U.S. role as the world leader in pharmaceuticals and biotechnology.

Enhance Funding for NIH Heart and Stroke Research: A Proven and Wise Investment

From 1997 to 2007, death rates for coronary heart disease and stroke fell nearly 28% and 45%, respectively. However, there is still much more to be done to improve the lives of heart disease and stroke patients—and more importantly to prevent CVD and stroke in the first place. Research will help lead the way. These mortality declines are directly related to NIH heart and

stroke research, with scientists on the verge of exciting discoveries that could lead to new treatments and even cures. For example, the biggest U.S. stroke rehabilitation study showed that patients who receive home physical therapy improve walking skills just as effectively as those treated in a program and that the progress continued up to one year post-stroke. NIH research has also demonstrated that over-zealous blood pressure lowering and combination lipid drugs did not cut cardiovascular disease in adult diabetics more than standard evidence-based care. Moreover, studies have defined the genetic basis of risky responses to vital blood-thinners.

In addition to saving lives, NIH-funded research can cut health care costs. For example, the original NIH tPA drug trial resulted in a 10-year net $6.47 billion reduction in stroke health care costs. Also, the Stroke Prevention in Atrial Fibrillation Trial 1 produced a 10-year net savings of $1.27 billion. Yet, in the face of such solid returns on investments and other successes, NIH still invests a meager 4% of its budget on heart research, and a mere 1% on stroke research.

Cardiovascular Disease Research: National Heart, Lung, and Blood Institute (NHLBI)
Even in the face of progress and promising research opportunities, there is no cure for CVD. As our population ages, demand will only increase to find better ways for Americans to live healthy and productive lives despite CVD. Stable and sustained funding is needed to allow NHLBI to build on investments that provided grants to use genetics to identify and treat those at greatest risk from heart disease; hasten drug development to treat high cholesterol and high blood pressure; and create tailored strategies to treat, slow or prevent heart failure. Other key studies include an analysis of whether maintaining a lower blood pressure than currently recommended further reduces risk of heart disease, stroke, and cognitive decline. This information is vital to manage the burden of heart disease and stroke. Sustained critical funding will allow for aggressive implementation of other initiatives in the NHLBI and cardiovascular strategic plans.

Stroke Research: National Institute of Neurological Disorders and Stroke (NINDS)
An estimated 795,000 people in this country will suffer a stroke this year, and more than 135,950 will die. Many of the 7 million survivors face severe physical and mental disabilities, emotional distress and huge costs—a projected $41 billion in medical expenses and lost productivity for 2007. A new study projects stroke prevalence will increase 25% over the next 20 years, striking more than 10 million individuals. Over the same time period, direct medical costs will rise 238%.

Stable and sustained funding is required for NINDS to capitalize on investments to prevent stroke, protect the brain from damage and enhance rehabilitation. This includes initiatives to: (1) determine if MRI brain imaging can assist in selecting stroke victims who could benefit from the clot busting drug tPA beyond the 3-hour treatment window; (2) assess chemical compounds that might shield brain cells during a stroke; and (3) advance stroke rehabilitation by studying if the brain can be helped to "rewire" itself after a stroke. Enhanced funding will also allow for proactive initiation and implementation of the NINDS' novel stroke planning process (a result of its Stroke Progress Review Group) to assess the stroke research field and develop priorities to advance the most promising prevention, treatment, recovery and rehabilitation research.

The American Heart Association Advocates: While AHA supports increased funding for the 18 institutes and centers that conduct heart and stroke research, including the National Institute of Diabetes, and Digestive and Kidney Diseases; and the National Institute on Aging, we have

specific funding recommendations for the NHLBI and the NINDS. AHA advocates for an FY 2012 appropriation of $3.514 billion for NHLBI; and $1.857 billion for NINDS.

Increase Funding for the Centers for Disease Control and Prevention (CDC)

Prevention is the best way to protect the health of all Americans and reduce the economic burden of CVD. Yet, effective prevention strategies and programs are not being implemented due to insufficient resources. The President's 2012 budget proposes a Coordinated Chronic Disease Prevention and Health Promotion Grant Program. AHA supports some consolidation of chronic disease programs, but with some important modifications and caveats. First, CDC must preserve the Division for Heart Disease and Stroke Prevention. A consolidation must ensure more predictable and adequate funding to all 50 states, including an annual share of the Prevention and Public Health Fund, with resources allocated by formula on the basis of burden, including cost, mortality, morbidity, and prevalence. These programs must be evidence-based and targeted, with a focus on capacity, evaluation and surveillance, including measurable outcomes and a higher level of accountability. To preserve the best elements of existing programs, funding should preserve evidenced-based outcomes work across the full spectrum of prevention and clinical care, including primary and secondary prevention, acute treatment, rehabilitation and continuous quality improvement (CQI). Each state must retain staff expertise to effectively address heart disease and stroke. State-based advisory groups of stakeholders from each constituency should be formed to help with plan implementation. A national advisory committee of constituencies should be created to foster stakeholder involvement. Matches, including in-kind, should be required when possible to build support in state health departments. Plans should use some funding for at least one program on common risk factors to consolidated diseases that can show a measurable, population-based impact. The rest of the funds should be spent on effective, evidence-based projects aimed at secondary prevention, acute treatment, rehabilitation, and CQI.

This CDC division administers WISEWOMAN that serves uninsured and under-insured low-income women ages 40 to 64 in 20 states. This program 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 their identified risk factors to promote lasting, healthy behavior modifications. From July 2008 to June 2010, WISEWOMAN reached more than 70,000 low-income women. During this time period, 89% of them had a least one risk factor and 28% had three or more risk factors for heart disease and stroke. However, more than 43,000 of these women participated in at least one lifestyle intervention session.

The American Heart Association Advocates: AHA joins with the CDC Coalition in advocating for $7.7 billion for the CDC's "core programs," including increases for the Division of Heart Disease and Stroke Prevention and WISEWOMAN. AHA recommends $37 million to expand WISEWOMAN to more states and serve more eligible women in already funded states. We join the Friends of the NCHS in asking for $162 million for the National Center for Health Statistics.

Restore Funding for Rural and Community Access to Emergency Devices (AED) Program

About 92% of sudden cardiac arrest (SCA) victims die outside of a hospital. But, prompt CPR and defibrillation, with an automated external defibrillator (AED), can more than double their chances of survival. Communities with comprehensive AED programs have reached survival rates of about 40%. HRSA's Rural and Community AED Program provides grants to states, competitively, to buy AEDs, train lay rescuers and first responders in their use and place AEDs

where SCA is likely to occur. From September 2007 to August 2008, 3,051 AEDs were bought and 10,287 people were trained. And, 795 patients were saved between August 1, 2009 and July 31, 2010. Requests for these AED grant dollars have exceeded the limited funds made available. For example, in FY 2009, less than 8% of the applicants were funded. Due to insufficient budgets, only 21 states received funds for this program in FY 2010.

***The American Heart Association Advocates*:** For FY 2012, AHA advocates restoring HRSA's Rural and Community AED Program to its FY 2005 level of $8.927 million.

Increase Funding for the Agency for Healthcare Research and Quality (AHRQ)

AHRQ develops scientific evidence to improve health care for Americans. AHRQ provides patients and caregivers with valuable scientific evidence to make the right health care decisions. AHRQ's research also enhances quality and efficiency of health care, providing the basis for protocols that prevent medical errors and reduce hospital-acquired infections, and improve patient confidence, experiences, and outcomes.

The American Heart Association Advocates: AHA joins Friends of AHRQ in advocating for $405 million for AHRQ to preserve its vital initiatives, boost the research infrastructure, spur innovation, nurture the next generation of scientists and help reinvent health and health care.

CONCLUSION

Cardiovascular disease continues to inflict a deadly, disabling and costly toll on Americans. Yet, our funding recommendations for NIH, CDC and HRSA outlined above will save lives and cut rising health care costs. The American Heart Association urges Congress to seriously consider our suggestions during the FY 2012 appropriations process. These proposed resources represent a wise investment for our nation and for the health and well-being of this and future generations.

UNITED TRIBES TECHNICAL COLLEGE
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FY 2012 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 and Senate Labor-HHS-Education and Related Agencies Appropriations Subcommittees

David M. Gipp, President

April 8, 2011

For 42 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 about half of our operating budget and provide for our core instructional programs.* The requests of the United Tribes Technical College Board for FY 2012 is for the following authorized Department of Education programs:

- *$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 2010 level and the President's requests for FYs 2011 and 2012. 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).

- *Maintain Pell Grants at the $5,550 maximum award level.*

AUTHORIZATION

United Tribes Technical College began operations in 1969. We realized that in order to more effectively address the unique needs of Indian people to acquire the academic knowledge and skills necessary to enter the work force we needed to expand our curricula and services. We were scraping by with small amounts of money from the Bureau of Indian Affairs, and so decided to work for an authorization in the Department of Education. That came about in 1990 when the Carl Perkins Act was reauthorized and it included specific authorization for what is

now called the Tribally Controlled Postsecondary Career and Technical Institutions program (Section 117). The Perkins Act has been reauthorized twice since then – in 1998 and in 2006, with Congress each time continuing the Section 117 Perkins program.

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, necessary life skills – thus enhancing chances for success.
- Services including campus security, a Child Development Center, a family literacy program, a wellness center, area transportation, a K-8 elementary school, tutoring, counseling, and family and single student housing.
- A semester completion rate of 80-90%.
- A graduate placement rate of 94% (placement into jobs and higher education).
- A projected return on federal investment of 20-1 (2005 study).
- Highest level of accreditation from the North Central Association of Colleges and Schools.
- Over 30% of our graduates move on to four-year or advanced degree institutions.
- A student body representing 87 tribes who come mostly from high-poverty, high unemployment tribal nations in the Great Plains; many students have children or dependents.
- 81% of undergraduate students receive Pell Grants, the highest percentage of Pell Grant recipients of any North Dakota college.
- 21 two-year degree programs, eight 1-year certificates, and 3 bachelor degree programs pending final accreditation this spring.
- An expanding curricula to meet job-training needs for growing fields including law enforcement, energy auditing and health information management. We have also broadened our online program offerings.
- A critical role in the regional economy. Our presence brings $31.8 million annually to the economy of the Bismarck region.
- A workforce of over 300 people.
- An award-winning annual powwow which last year had participants from 70+ tribes, featuring over 1500 dancers and drummers, and drawing over 20,000 spectators. We annually feature indigenous dance groups from other countries.

FUNDING REQUESTS

Section 117 Perkins Base Funding. Funds requested under Section 117 of the Perkins Act above the FY 2010 level are needed to: 1) maintain 100 year-old education buildings and 50 year-old housing stock for students; 2) upgrade technology capabilities; 3) provide adequate salaries for faculty and staff (who have not received a cost of living increase for the past two years and who are in the bottom quartile of salary for comparable positions elsewhere); and 4) fund program and curriculum improvements, including at least three four-year degree programs.

Acquisition of additional base funding is critical as UTTC has more than tripled its number of students within the past eight years while actual base funding, including Interior Department funding, have not increased commensurately (increased from $6 million to $8 million for the two programs combined). Our Perkins funding provides a base level of support while allowing the college to compete for desperately needed discretionary contracts and grants leading to additional resources annually for the college's programs and support services.

Title III-A (Section 316) Strengthening Institutions. We support Title III-A funding for tribal colleges. Among its statutorily allowable uses is facility construction and maintenance. We are constantly in need of additional student housing, including family housing. We work hard to cobble together various sources for housing construction. We would like to educate more students but lack of housing has at times limited the admission of new students. With the completion this past year of a new Science and Math building on our South Campus on land acquired with a private grant, we urgently need housing for up to 150 students, many of whom have families. New housing on the South Campus could also accommodate those persons we expect to enroll in a new police training program.

While UTTC has constructed three housing facilities using a variety of sources in the past 20 years, approximately 50 percent of students are housed in the 100-year-old buildings of the old Fort Abraham Lincoln, as well as in duplexes and single family dwellings that were donated to UTTC by the federal government along with the land and Fort buildings in 1973. These buildings require major rehabilitation. New buildings for housing are actually cheaper than trying to rehabilitate the old buildings that now house students.

Pell Grants. We support maintaining the Pell Grant maximum amount to at least a level of $5,550. As mentioned above, 81 percent of our students are Pell Grant-eligible. This program makes all the difference in the world of whether these students can attend college. We also support the continuation of appropriations to fund two scheduled award years per year, as this has helped many of our students shorten the time to obtain their degrees.

GOVERNMENT ACCOUNTABILITY OFFICE REPORT

As you know, the Government Accountability Office (GAO) in March of this year 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 Department of Education's Perkins Act for Tribally Controlled Postsecondary Career and Technical Institutions were among the programs listed in

the supplemental report of March 18. *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 about 46 percent of UTTC's core operating budget. The Perkins funds supplement, but do not duplicate, the BIE funds. *It takes both sources of funding to frugally maintain the institution.* In fact, 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 academic programming, deferred maintenance of its physical plant and scholarship assistance, among other things.

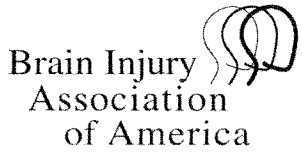
Secondly, as mentioned, UTTC and other tribally-chartered colleges are not part of state educational systems and do not receive state-appropriated general operational funds for their Indian students. The need for postsecondary career and technical education in Indian Country is so great and the funding 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 2010 federal funds ($8 million from Perkins; $7 million from the BIE). That is not an excessive amount of money for two campus-based institutions which offer a broad (and expanding) array of programs geared toward the educational and cultural needs of their students and toward job-producing skills.

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 to address the sociobehavioral, socioeconomic, and academic characteristics that pose problems. 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, UTTC must make this investment with our student population through other sources of funding to ensure they succeed at the postsecondary level.

Federal funding for American Indian/Alaska Native employment and training is barely one percent of the annual federal employment and training budget but has an enormous impact on the people and communities it serves.

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. We cannot continue operating without Carl Perkins funds. Thank you for your consideration of our requests.



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Creating a better future through brain injury prevention, research, education and advocacy

Brain Injury Association of America
Prepared for: Subcommittee on Labor, Health and Human Services, Education and Related Agencies
Re: CDC, HRSA – Department of Health and Human Services, NIDRR – Department of Education

Sarah C. D'Orsie
Director of Government Affairs
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April 8, 2011

The Honorable Denny Rehberg
Chairman
House Appropriations Subcommittee on Labor,
Health and Human Services, Education and Related Agencies
H-307 The Capitol
Washington, DC 20515

The Honorable Rosa DeLauro
Ranking Member
House Appropriations Subcommittee on Labor,
Health and Human Services, Education and Related Agencies
1016 Longworth House Office Building
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Dear Chairman Rehberg and Ranking Member DeLauro:

Thank you for the opportunity to submit this written testimony with regard to the FY 2012 Labor-HHS-Education appropriations bill. My testimony is on behalf of the Brain Injury Association of America (BIAA), our national network of state affiliates, and hundreds of local chapters and support groups from across the country.

In the civilian population alone every year, more than 1.7 million people sustain brain injuries from falls, car crashes, assaults and contact sports. Males are more likely than females to sustain brain injuries. Children, teens and seniors are at greatest risk.

Recently, we are seeing an increasing number of service members returning from the conflicts in Iraq and Afghanistan with TBI, which has been termed one of the signature injuries of the War. Many of these returning service members are undiagnosed or misdiagnosed and subsequently they and their families will look to community and local resources for information to better understand TBI and to obtain vital support services to facilitate successful reintegration into the community.

For the past 13 years Congress has provided minimal funding through the HRSA Federal TBI Program to assist States in developing services and systems to help individuals with a range of service and family support needs following their loved one's brain injury. Similarly, the grants to state Protection and Advocacy Systems to assist individuals with traumatic brain injuries in accessing services through education, legal and advocacy remedies are woefully underfunded. Rehabilitation, community support and long-term care systems are still developing in many States, while stretched to capacity in others. Additional numbers of individuals with TBI as the result of war-related injuries only adds more stress to these inadequately funded systems.

BIAA respectfully urges you to provide States with the resources they need to address both the civilian and military populations who look to them for much needed support in order to live and work in their communities.

With broader regard to all of the programs authorized through the TBI Act, BIAA specifically requests:

- **$10 million** (+ $4 million) for the Centers for Disease Control and Prevention TBI Registries and Surveillance, Brain Injury Acute Care Guidelines, Prevention and National Public Education/Awareness
- **$8 million** (+ $1 million) for the Health Resources and Services Administration (HRSA) Federal TBI State Grant Program
- **$4 million** (+ $1 million) for the HRSA Federal TBI Protection & Advocacy (P&A) Systems Grant Program

CDC – National Injury Center - The Centers for Disease Control and Prevention's National Injury Center is responsible for assessing the incidence and prevalence of TBI in the United States. The CDC estimates that 1.7 million TBIs occur each year and 3.4 million Americans live with a life-long disability as a result of TBI. In addition, the TBI Act as amended in 2008 requires the CDC to coordinate with the Departments of Defense and Veterans Affairs to include the number of TBIs occurring in the military. This coordination will likely increase CDC's estimate of the number of Americans sustaining TBI and living with the consequences.

CDC also funds states for TBI registries, creates and disseminates public and professional educational materials, for families, caregivers and medical personnel, and has recently collaborated with the National Football League and National Hockey League to improve awareness of the incidence of concussion in sports. CDC plays a leading role in helping standardize evidence based guidelines for the management of TBI and $1 million of this request would go to fund CDC's work in this area.

HRSA TBI State Grant Program - The TBI Act authorizes the HHS, Health Resources and Service Administration (HRSA) to award grants to (1) states, American Indian Consortia and territories to improve access to service delivery and to (2) state Protection and Advocacy (P&A) Systems to expand advocacy services to include individuals with traumatic brain injury. For the past thirteen years the HRSA Federal TBI State Grant Program has supported state efforts to address the needs of persons with brain injury and their families and to expand and improve services to underserved and unserved populations including children and youth; veterans and returning troops; and individuals with co-occurring conditions

In FY 2009, HRSA reduced the number of state grant awards to 15, in order to increase each monetary award from $118,000 to $250,000. This means that many states that had participated in the program in past years have now been forced to close down their operations, leaving many unable to access brain injury care.

Increasing the program to $8 million will provide funding necessary to sustain the grants for the 15 states currently receiving funding along with the three additional states added this year and to ensure funding for four additional states. Steady increases over five years for this program will provide for each state including the District of Columbia and the American Indian Consortium and territories to sustain and expand state service delivery; and to expand the use of the grant funds to pay for such services as Information & Referral (I&R), systems coordination and other necessary services and supports identified by the state.

HRSA TBI P&A Program - Similarly, the HRSA TBI P&A Program currently provides funding to all state P&A systems for purposes of protecting the legal and human rights of individuals with TBI. State P&As provide a wide range of activities including training in self-advocacy, outreach, information & referral and legal assistance to people residing in nursing homes, to returning military seeking veterans benefits, and students who need educational services.

Effective Protection and Advocacy services for people with traumatic brain injury is needed to help reduce government expenditures and increase productivity, independence and community integration. However, advocates must possess specialized skills, and their work is often time-intensive. A $4 million appropriation would ensure that each P&A can move towards providing a significant PATBI program with appropriate staff time and expertise.

NIDRR TBI Model Systems of Care - Funding for the TBI Model Systems in the Department of Education is urgently needed to ensure that the nation's valuable TBI research capacity is not diminished, and to maintain and build upon the 16 TBI Model Systems research centers around the country.

The TBI Model Systems of Care program represents an already existing vital national network of expertise and research in the field of TBI, and weakening this program would have resounding effects on both military and civilian populations. The TBI Model Systems are the only source of non-proprietary longitudinal data on what happens to people with brain injury. They are a key source of evidence-based medicine, and serve as a "proving ground" for future researchers.

In order to make this program more comprehensive, Congress should provide **$11 million** (+ $1.5 million) in FY 2011 for NIDRR's TBI Model Systems of Care program, in order to add one new Collaborative Research Project. In addition, given the national importance of this research program, the TBI Model Systems of Care should receive "line-item" status within the broader NIDRR budget.

We ask that you consider favorably these requests for the CDC, the HRSA Federal TBI Program, and the NIDRR TBI Model Systems Program to further data collection, increase public awareness, improve medical care, assist states in coordinating services, protect the rights of persons with TBI, and bolster vital research.

Sincerely,

Susan H Connors

Susan H. Connors, President/CEO
Brain Injury Association of America

Tri-Council for Nursing

Testimony of the Tricouncil for Nursing Regarding the Fiscal Year 2012 Appropriations for the Title VIII Nursing Workforce Development Programs
U.S. House of Representatives Subcommittee on Labor, Health and Human Services, Education and Related Agencies,
Department of Health and Human Services
April 11, 2011

The Tri-Council for Nursing, comprised of the American Association of Colleges of Nursing, the American Nurses Association, the American Organization of Nurse Executives, and the National League for Nursing, respectfully request $313.075 million for the Nursing Workforce Development programs authorized under Title VIII of the Public Health Service Act (42 U.S.C. 296 et seq.) in fiscal year (FY) 2012. This is the amount requested in the ***Recommended Funding Levels for the President's FY 2012 Budget.***

The Tri-Council is a long-standing nursing alliance focused on leadership and excellence in the nursing profession. This marks the thirteenth year of the nurse and nurse faculty shortages which have eroded the ability of the nursing profession to provide the highest quality of care that all patients rightfully desire and morally deserve. As the nation looks 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, a profession which the U.S. Bureau of Labor Statistics expects a 22 percent growth in employment through 2018.
In light of the severe economic challenges facing our country today, the Tricouncil urges the Subcommittee to focus on the larger context of building the nursing capacity needed to meet the increasing health care demands of our nation's population. This year, the first cohort of 79 million Baby Boomers began turning 65. With them has come the increased demand for health care and services of an aging population coupled with near epidemic growth in childhood obesity, diabetes and other chronic conditions in all parts of our country.

As our country struggles to regain its economic foot hold, the health care system has been virtually the only sector of the economy to steadily add jobs since 2001. This positive economic trend is expected to continue as the demand for nursing care in traditional acute care settings and expansion of non-hospital settings such as home care, and long term care will accelerate. The U.S. Bureau of Labor Statistics projects the need for new nurses at 581,500 in addition to hundreds of thousands who will be needed to replace experienced nurses who are expected to retire or leave the profession within the coming years. The Tricouncil is grateful to the Subcommittee for your past commitment to Title VIII funding and respectfully asks that FY2012 funding be able to support the reauthorization and expansions made to this title through the enactment of the *Patient Protection and Affordable Care Act (PPACA).* The nursing programs benefited not only from the current funding level at FY 2010 level of $243.872 but also received a-one-time infusion of $106.3 million in Recovery and Reinvestment Funds (ARRA).

Existing 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.), have helped build the supply and distribution of qualified nurses to meet our nation's healthcare needs since 1964. Over the last 47 years, the original programs and

newly added and expanded programs have addressed all aspects of supporting the workforce—education, practice, retention, and recruitment. They have bolstered nursing education at all levels, from entry-level preparation through graduate study, and provide support for institutions that educate nurses for practice in rural and medically underserved communities. The programs and funding recommendations are for the following:

- Advanced Nursing Education Grants (Sec. 811, Title VIII, PHSA)
- Nursing Workforce Diversity Grants (Sec. 821, Title VIII, PHSA)
- Nurse Education, Practice, Retention, and Quality Grants (Sec. 831, Title VIII, PHSA)
- Nurse Loan Repayment and Scholarship Programs (Sec. 846, Title VIII, PHSA)
- Nurse Faculty Loan Program (Sec. 846 A, Title VIII, PHSA)
- Comprehensive Geriatric Grants (Sec. 855, Title VIII, PHSA)

- **Advanced Education Nursing (AEN) Grants** (Sec. 811) support the preparation of RNS in master's and doctoral nursing programs. The AEN grants help to prepare our nation's nurse practitioners, clinical nurse specialists, nurse midwives, nurse anesthetists, nurse educators, nurse administrators, nurses in executive practice, public health nurses, and other nursing specialists requiring advanced nursing education.

The Tricouncil supports the President's Budget Request of $104.438 million for Advanced Education Nursing Grants.

- **Nursing Workforce Diversity Grants** (Sec. 821) prepare students from disadvantaged backgrounds to become nurses. This program awards grants and contract opportunities to schools of nursing for a variety of clinical training facilities to address nursing educational needs for not only disadvantaged students but also racial and ethnic minorities underrepresented in the nursing profession. Changes to this section under PPACA include consultation with the National Coalition of Ethnic Minority Nurse Associations to increase diversity within the profession.

The Tricouncil supports the President's Budget Request of $20 million for Nursing Workforce Diversity Grants.

- **Nurse Education, Practice, Retention, and Quality Grants** (Sec. 831, and Sec. 831 A) helps schools of nursing, academic health centers, nurse- managed health centers, state and local governments to strengthen nursing education programs. Changes to this section under PPACA created Sec. 831 A as a separated section for nurse retention grants.

Tricouncil supports the President's Budget Request of $59.773 million for the Nursing Education Practice and Retention Grants.

- **Nurse Loan Repayment and Scholarship Program** (Sec. 846, Title VIII, PHSA) provides grants to students that pay up to 85% of a student's loan in return for at least 3 years of service in a designated health shortage area. Changes to the program under PPACA, now make nursing students pursuing a graduate degree and who agree to serve as faculty for 2 years eligible for this program.

Tricouncil supports the President's Budget Request of $93.846 million for the Nurse Loan Repayment and Scholarship Programs.

- **Nurse Faculty Loan Program** (Sec. 846 A, Title VIII, PHSA) provides up to 85% of loan cancellation if the student agrees to a 4 year teaching commitment in a school of nursing. Changes to the program under PPACA now give funding priority to doctoral students, increase the loan amount for undergraduate, graduate and doctoral students and expands the program by creating a School of Nursing Student Loan Fund.

Tricouncil supports the President's Budget Request of $30 million for the Nurse Faculty Loan Program.

- **Comprehensive Geriatric Grants** (Sec. 855, Title VIII, PHSA provide support to nursing students specializing in care for the elderly. Changes to this section under PPACC include fellowships for short-term intensive courses on geriatrics and traineeships for individuals who are preparing for advanced nursing degrees in geriatric nursing, long-term care, gero-pyschiatric nursing or other nursing areas that specialize in the care of elderly populations.

Tricouncil supports the President's Budget Request of $5 million for the Comprehensive Geriatric Grants.

Our nation is faced with a burgeoning health care crisis that must be addressed on many fronts. Nurses, as the largest portion of the healthcare workforce are an important part of the solution to the crisis of cost, burden of disease, and access to quality care. To meet this challenge, the nursing shortage can be reversed through funding of proven Federal programs such as Title VIII. The Tricouncil respectfully requests your support of a funding level of $313.075 million for the Title VIII Nursing Workforce Development Programs in FY 2012.

Respectfully,

American Association of Colleges of Nursing
Kathleen Potempa, PhD, RN, FAAN
President
Geraldine "Polly" Bednash, PhD, RN, FAAN
Chief Executive Officer and Executive Director

American Nurses Association
Karen A. Daley, PhD, MPH, RN, FAAN
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Submitted on behalf of Tricouncil
by Jo Ann Webb, RN, MHA
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April 11, 2011

The Honorable Denny Rehberg
Chairman
House Appropriations Committee-Labor, Health and Human Services, Education, and Related Agencies Subcommittee
2358 Rayburn House Office Building
Washington, DC 20515

The Honorable Rosa DeLauro
Ranking Member
House Appropriations Committee-Labor, Health and Human Services, Education, and Related Agencies Subcommittee
2413 Rayburn House Office Building
District of Columbia 20515

Dear Chairman Rehberg and Ms. Delauro:

On behalf of NANASP, the National Association of Nutrition and Aging Services Programs, I thank you for providing an opportunity to submit testimony as you consider an FY 2012 Labor-HHS and Education Appropriations bill. NANASP is a national membership organization for persons across the country working to provide older adults healthful food and nutrition through community-based services. NANASP has 5 members from Montana including Eagle Shield Senior Citizens Center in Browning, Missoula Aging Services in Missoula, and Cascade County Meals on Wheels Program in Great Falls. NANASP has 15 members in Connecticut.

I am writing today to urge you to provide a much needed increase to President Obama's FY 2012 funding proposal for two major programs in the Older Americans Act: the senior nutrition programs and Community Service Employment for Older Adults.

The congregate and home-delivered (Meals on Wheels) nutrition programs and the Nutrition Services Incentive Program (NSIP) are the largest and most visible component of the Older Americans Act. Next year, the senior nutrition program celebrates its 40th anniversary of helping to keep millions of the vulnerable elderly healthy and independent in their homes and communities. This is a much more fiscally sound solution than having our seniors institutionalized because of the detrimental effects of hunger and malnutrition.

The President's budget proposes no increase for the senior nutrition programs in FY 2012. This is extremely alarming as these same programs were deemed worthy of increases for the past 5 fiscal years. The need for an increase in funding for meals for our seniors remains today. According to the Administration on Aging (AoA), flat funding for the nutrition programs means

that 36 million fewer home-delivered and congregate meals will be served in FY 2012 compared to FY 2010. These meals are especially critical for the health of the 58% of congregate and 60% of home-delivered meal participants who report that they receive the majority of their daily food intake from the nutrition program.

The second major program we ask you to consider for increased funding is the Community Service Employment for Older Adults, also known as the Senior Community Service Employment Program or SCSEP. Administered by the Labor Department, SCSEP provides part-time jobs to thousands of low-income seniors, about one-fourth of them working in senior nutrition and other programs serving the elderly. These disadvantaged and previously unemployed seniors earn the minimum wage as they re-enter the job market.

In FY 2012, the President's budget proposes to reduce the number of SCSEP participants by 25% below the FY 2008 level. SCSEP is the only federal job training program targeted for older workers, who continue to suffer in today's economy. While the current unemployment rate among older adults is lower than among younger workers, older workers are less likely to find new employment, and when they do find new jobs, their job search has taken longer. For example, nearly 30% of unemployed people aged 55+ were jobless for an entire year or more, a rate that exceeds that of all other age groups. Such a drastic cut in funding would not only eliminate over 22,000 job opportunities for older workers, but also take away 12 million hours of staffing for senior nutrition and other programs serving the community.

At NANASP we always say, "It is more than just a meal." Our programs provide much needed socialization for older adults and the link between nutrition and health is irrefutable. The senior nutrition and community service employment programs play a key role in health promotion and disease prevention. Our programs keep the very vulnerable elderly healthy, engaged, and independent and out of expensive long-term care institutions that are very costly to the Medicaid program. We hope you will strongly consider an increase in funding for the nutrition and community service employment programs in your Labor-HHS, Education Appropriations bill for FY 2012.

Respectfully Submitted,

Robert B. Blancato
Executive Director

Statement of the American Association for Geriatric Psychiatry
To the Subcommittee on Labor, Health and Human Services, and Education
Of the Committee on Appropriations
U. S. House of Representatives
On FY 2012 Appropriations for the Department of Health and Human Services
April 11, 2011

The American Association for Geriatric Psychiatry (AAGP) appreciates this opportunity to comment on issues related to fiscal year (FY) 2012 appropriations for mental health research and services. AAGP is a professional membership organization dedicated to promoting the mental health and well being of older Americans and improving the care of those with late-life mental disorders. AAGP's membership consists of geriatric psychiatrists as well as other health professionals who focus on the mental health problems faced by aging adults. Although we generally agree with others in the mental health community about the importance of sustained and adequate Federal funding for mental health research and treatment, AAGP brings a unique perspective to these issues because of the elderly patient population served by our members.

A National Health Crisis: Demographic Projections and the Mental Disorders of Aging
The aging of the baby boomer generation will result in an increase in the proportion of persons over 65 from 12.7 percent currently to 20 percent in 2030, with the fastest growing segment of the population consisting of age 85 and older. During the same period, the number of older adults with major psychiatric illnesses will more than double, from an estimated 7 million to 15 million individuals, meeting or exceeding the number of consumers in discrete, younger age groups.

Center for Mental Health Services
It is critical that there be adequate funding for the mental health initiatives under the jurisdiction of the Center for Mental Health Services (CMHS) within the Substance Abuse and Mental Health Services Administration (SAMHSA). While research is of critical importance to a better future, today's patients must also receive appropriate treatment for their mental health problems.

Evidence-based Mental Health Outreach and Treatment for the Elderly
AAGP was pleased that the final budgets for the last nine five years have included $5 million for evidence-based mental health outreach and treatment to the elderly, the only Federally funded services program dedicated specifically to the mental health care of older adults. AAGP is concerned that this program was eliminated in the President's FY 2012 budget proposal. It is critical that SAMHSA and CMHS ensure that, as they design programs to promote prevention and recovery from mental illness, the senior citizen cohort not be ignored. AAGP asks the Committee to restore the funding for this critical program as well as ensure that all of CMHS's programs assure a life-span approach by specifically including the older adult population as a targeted population.

Centers of Excellence for Depressive and Bipolar Disorders
PPACA also included authorization for a new national network of centers of excellence for depressive and bipolar disorders, which will enhance the coordination and integration of physical, mental and social care that are critical to the identification and treatment of depression

and other mental disorders across the lifespan. The work of these centers will help to disseminate and implement evidence-based practices in clinical settings throughout the country. AAGP strongly supports funding for the centers authorized by this legislation and is disappointed that the Administration has not recommended funding them. With respect to older adults, these centers would be able to focus on new models of care that integrate evidenced-based depression care into real world primary care and home care to improve the outcomes; specific combinations of medications and talk therapy that successfully treat depression and prevent relapse in older adults; specific clinical and biological factors that link depression and risk of Alzheimer's disease in some older depressed patients; and prevention of depression in older people at risk. AAGP recommends that these centers be funded at $10 million for FY 2012.

Preparing a Workforce to meet the Mental Health Needs of the Aging Population
In 2008, the Institute of Medicine (IOM) released a study of the readiness of the nation's healthcare workforce to meet the needs of its aging population. *The Re-tooling for an Aging America: Building the Health Care Workforce* called for immediate investments in preparing our health care system to care for older Americans and their families. AAGP is deeply grateful to this subcommittee and its House counterpart for providing, in the appropriations bill for FY 2010, funding for a follow-up study of the current and projected mental and behavioral healthcare needs for aging Americans. This study, which is now underway, will complement the 2008 IOM study in providing in-depth consideration of the mental health needs of geriatric and ethnic minority populations that were precluded by the broad scope of the earlier one.

Virtually all health care providers need to be fully prepared to manage the common medical and mental health problems of old age. In addition, the number of geriatric health specialists, including mental health providers, needs to be increased both to provide care for those older adults with the most complex issues and to train the rest of the workforce in the common medical and mental health problems of old age. The small numbers of specialists in geriatric mental health, combined with increases in life expectancy and the growing population of the nation's elderly, foretells a crisis in health care that will impact older adults and their families nationwide.

Already, there are programs administered by the Bureau of Health Professions in the HHS Health Resources and Services Administration (HRSA) administers that are aimed to help to assure adequate numbers of health care practitioners for the nation's geriatric population, especially in underserved areas. These are the only federal programs that seek to increase the number of faculty with geriatrics expertise in a variety of disciplines, and the breadth of the programs has been strengthened by provisions included in the Patient Protection and Affordable Care Act (PPACA).

The geriatric health professions program supports these important initiatives:

- The Geriatric Education Center (GEC) program provides interdisciplinary training for health care professionals in assessment, chronic disease syndromes, care planning, emergency preparedness, and cultural competence unique to older Americans. PPACA authorizes $10.8 million in supplemental grants for the GEC Program to support training in geriatrics, chronic care management, and long-term care for faculty in a broad array of health professions schools, as well as direct care workers and family caregivers. GECs receiving these grants

are required to develop and include material on depression and other mental disorders common among older adults, medication safety issues for older adults, and management of the psychological and behavioral aspects of dementia in all appropriate training courses.

- The Geriatric Training for Physicians, Dentists, and Behavioral and Mental Health Professionals (GTPD Program) provides fellows with exposure to older adult patients in various levels of wellness and functioning and from a range of socioeconomic and racial/ethnic backgrounds.
- The Geriatric Academic Career Awards (GACA) support the academic career development of geriatric specialists in junior faculty positions who are committed to teaching geriatrics in professional schools. PPACA expands the disciplines eligible for the awards. GACA recipients are required to provide training in clinical geriatrics, including the training of interdisciplinary teams of health care professionals.
- PPACA authorized a new Geriatric Career Incentive Awards Program in Title VIII of the Public Health Service Act for grants to foster great interest among a variety of health professionals in entering the field of geriatrics, long-term care, and chronic care management. This program was authorized for $10 million over three years.
- A new program, authorized by PPACA at $10 million for three years, will provide advanced training opportunities for direct care workers in the field of geriatrics, long term-care or chronic care management.

AAGP strongly supports increased funding for the existing programs, particularly as the disciplines included have been expanded, and funding to fully authorized levels for the new programs.

National Institutes of Health (NIH) and National Institute of Mental Health (NIMH)

With the graying of the population, mental disorders of aging represent a growing crisis that will require a greater investment in research to understand age-related brain disorders and to develop new approaches to prevention and treatment. Even in the years in which funding was increased for NIH and the NIMH, these increases did not always translate into comparable increases in funding that specifically address problems of older adults. For instance, according to figures provided by NIMH, NIMH total aging research amounts decreased from $106,090,000 in 2002 to $85,164,000 in 2006 (dollars in thousands: $106,090 in 2002, $100,055 in 2003, $97,418 in 2004, $91,686 in 2005, $85,164 in 2006).

The critical disparity between federally funded research on mental health and aging and the projected mental health needs of older adults is continuing. If the mental health research budget for older adults is not substantially increased immediately, progress to reduce mental illness among the growing elderly population will be severely compromised. While many different types of mental and behavioral disorders occur in late life, they are not an inevitable part of the aging process, and continued and expanded research holds the promise of improving the mental health and quality of life for older Americans. This trend must be immediately reversed to ensure that our next generation of elders is able to access effective treatment for mental illness. Federal funding of research must be broad-based and should include basic, translational, clinical, and health services research on mental disorders in late life.

AAGP believes that it is critical that NIH begin to invest increased funding in future evidence-based treatments for our nation's elders. Annual increases of funds targeted for geriatric mental

health research at NIH should be used to: (1) identify the causes of age-related brain and mental disorders to prevent mental disorders before they devastate lives; (2) speed the search for effective treatments and efficient methods of treatment delivery; and (3) improve the quality of life for older adults with mental disorders.

Participation of Older Adults in Clinical Trials

Federal approval for most new drugs is based on research demonstrating safety and efficacy in young and middle-aged adults. These studies typically exclude people who are old, who have more than one health problem, or who take multiple medications. As the population ages, that is the very profile of many people who seek treatment. Thus, there is little available scientific information on the safety of drugs approved by the Food and Drug Administration (FDA) in substantial numbers of older adults who are likely to take those drugs. Pivotal regulatory trials never address the special efficacy and safety concerns that arise specifically in the care of the nation's mentally ill elderly. This is a critical public health obligation of the nation's health agencies. Just as the FDA has begun to require inclusion of children in appropriate studies, the agency should work closely with the geriatric research community, health care consumers, pharmaceutical manufacturers, and other stakeholders to develop innovative, fair mechanisms to encourage the inclusion of older adults in clinical trials. Clinical research must also include elders from diverse ethnic and cultural groups. In addition, AAGP urges that Federal funds be made available each year for support of clinical trials involving older adults.

Study on NIH Funding for Mental Disorders among Older Adults

As little emphasis has been placed on the development of new treatments for geriatric mental disorders, AAGP encourages NIH to promote the development of new medications specifically targeted at brain-based mental disorders of the elderly. AAGP urges this Committee to request a GAO study on spending by NIH on conditions and illnesses related to the mental health of older individuals. NIH is already working to enhance cooperative activities among NIH Institutes and Centers that support research on the nervous system. A GAO study of the work being done by these institutes in areas that predominately involve older adults could provide crucial insights into possible new areas of cooperative research, which in turn will lead to advances in prevention and treatment for these devastating illnesses.

Conclusion

AAGP recommends:

- Increased funding for the geriatric health professions education programs under Title VII of the Public Health Service Act and full funding for new programs authorized by the PPACA;
- Funding to support clinical trials involving older adults;
- A GAO study on spending by NIH on conditions and illnesses related to the mental health of older individuals;
- $5 million in funding to continue evidence-based geriatric mental health outreach and treatment programs at CMHS;
- $10 million in funding for Centers of Excellence for Depressive and Bipolar Disorders.

Testimony of John R. Schreiber, M.D., M.P.H., 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) 2012 Budget for the National Institutes of Health
April 12, 2011

[John R. Schreiber, M.D., M.P.H.: (617) 636-8031; jschreiber@tuftsmedicalcenter.org]

The American Association of Immunologists (AAI), a not-for-profit professional association representing more than 7,000 of the world's leading experts on the immune system, appreciates having this opportunity to submit testimony regarding fiscal year (FY) 2012 appropriations for the National Institutes of Health (NIH). The vast majority of AAI members, whose crucially important discoveries help to prevent, treat and cure disease, depends on NIH funding to support their work.[1]

For more than fifty years, NIH has been envy of the world and has been instrumental in promoting science, better health, and discovery. Unlike many federal agencies, NIH distributes most of its funding to scientists working in all fifty states. In fact, about 80 percent of the $31.2 billion NIH budget is awarded to scientists working at research institutions throughout the United States, making NIH funding the foundation of our nation's biomedical research infrastructure and a key factor in local and national economic growth.[2] In addition to its positive economic impact on a community, NIH funding supports highly skilled jobs that focus on improving human health.[3] NIH funding also helps train the next generation of inventors and innovators, crucial to the nation's future job creation and pipeline of new therapeutics.

The role of the immune system

The immune system's job is to protect its human or animal host from a wide range of infectious and chronic diseases. When the immune system works, the host remains healthy. But many infectious diseases, including influenza, HIV/AIDS, malaria, tuberculosis, salmonella, and the common cold, challenge and sometimes overcome the defenses mounted by the immune system. And many chronic diseases, including cancer, diabetes, multiple sclerosis, rheumatoid arthritis, asthma, inflammatory bowel disease, and lupus, are either caused by - or due in large part to - an overactive (autoimmune) or underactive immune response.[4] Advances in immunological research have already yielded progress in preventing, diagnosing, and treating some of these diseases, but further progress depends on increased knowledge in the field of immunology.

A young and evolving discipline,[5] immunology has already answered many key questions and is now needed to explore urgent new challenges to community and global health, including understanding the human and animal immune response to: 1) pathogens that threaten to become the next pandemic, 2) man-made and natural infectious organisms that are potential agents of bioterrorism (including plague, smallpox, and anthrax),[6] 3) environmental threats, and 4) cancer. While researchers and public health professionals must respond quickly to these emergent threats, AAI believes that the best preparation is to support consistent, ongoing research rather than to "ramp up" research in times of emergency.[7]

Recent advances in immunological research

Immunological research has led to unprecedented medical advances in recent years, including new

treatments for lupus and malignant melanoma, and new vaccines against influenza and cervical cancer.

The value of vaccination against disease and the importance of continued research and evaluation cannot be overstated. Recent expansion of the influenza vaccine to all U.S. children "may induce herd immunity against influenza for older adults and has the potential to be more beneficial to older adults than the existing policy of preventing influenza by vaccinating older adults themselves." [8] A recent study has shown the efficacy of vaccinating older adults, whether healthy or with chronic diseases, against shingles, a painful blistering skin rash caused by the varicella-zoster virus, the virus that causes chickenpox.[9] Most recently, a new vaccine against rotavirus has greatly reduced hospital admissions in the United States in babies with infectious diarrhea and markedly decreased deaths in infants in the developing world.[10] Thousands of children will not die due to the results of immunology and infectious diseases research originally funded by the NIH on this killer virus.

Recently, immunologists have advanced the understanding of the exquisitely precise regulation of the immune system and are very hopeful that this understanding will allow for therapeutic manipulation of the immune system. This important discovery about immune-system regulation could lead to new approaches for the prevention and treatment of numerous autoimmune diseases, including lupus (systemic lupus erythematosus),[11] a serious chronic autoimmune disease affecting about 1.5 million Americans. Finally, new monoclonal antibodies (highly specific immune molecules) that block the immune response of people with autoimmune diseases (in which one's immune system attacks one's own body) show enormous promise in improving these debilitating diseases.

Sustaining NIH Funding in a Difficult Fiscal Climate

AAI greatly appreciates the strong, historical support of this subcommittee for biomedical research, from doubling the NIH budget (FY 1999 to FY 2003), to passing the Appropriations Acts for FY 2009 and 2010, to including in the American Recovery and Reinvestment Act of 2009 ("ARRA") a $10.4 billion supplemental appropriation for NIH.

As a result of this generous support, NIH has been able to fund many excellent, innovative projects with great promise for advancing human health, and to invest in the nation's research infrastructure. AAI - and the entire biomedical research community - are deeply grateful for this support and for the subcommittee's strong bipartisan commitment to advancing medical research. And yet, AAI comes to you this year deeply concerned about efforts to cut, rather than invest in, the NIH budget. Imminent advances may not come to fruition if the FY 2011 budget (which is not yet final) or the FY 2012 appropriations level is unable to support the current functional capacity at NIH (~$34.7 billion), made possible in large part by the prior support of this subcommittee. In addition, AAI remains concerned that investment in biomedical research continues unfettered by our global competitors, while our challenged budget makes it difficult for us to attract the best and brightest to these crucial scientific fields. The AAI funding recommendation for FY 2012 is premised on these concerns.

NIH Funding for FY 2012

AAI greatly appreciates the President's proposed increase for NIH for FY 2012 ($31.98 billion, or 2.4 percent increase over the regular FY 2010 appropriations level). More is required, however, for NIH to be able to support existing research projects and fund a reasonable number of excellent new ones. ***AAI therefore urges the subcommittee to provide NIH with a FY 2012 budget of $35 billion to enable***

NIH to maintain its current functional capacity and to provide a small funding boost (less than one percent) for important new research. Sustained funding, particularly in this challenging fiscal climate, would not only stabilize ongoing research projects and the overall research enterprise, but also inspire confidence in the system among many of our brightest young students who are considering (but due to such limited grant funding, are fearful to begin) careers in biomedical research.

NIH priorities for FY 2012

AAI believes strongly that the engine for biomedical innovation and discovery is individual investigator-initiated research. Researchers working in laboratories around the country, with their scientific collaborators around the world, are the best source of scientific advancement and progress. "Top-down" science, where government directives force the research in specified directions, is less likely to achieve the desired goals than funding the best, most promising, ripest grant applications.

AAI strongly supports the President's request for a $436 million increase in funding for individual research project grants (RPGs) that fund individual scientists. Unfortunately, this increase will only support approximately 43 additional RPGs. AAI notes that the President's budget includes $100 million to establish the Cures Acceleration Network (CAN). AAI recommends a significantly smaller appropriation for the first year of this start-up program, with the remainder going to support additional RPGs.

AAI supports the President's request for $300 million for the Global Fund to Fight AIDS, Tuberculosis, and Malaria – infectious diseases which devastate people and communities around the world.

AAI supports the President's proposed four percent increase for the Ruth Kirschstein National Research Service Awards, a long-needed training stipend increase for the young scientists who are the next generation of research leaders.

AAI urges this subcommittee to do all it can to reduce the time consuming, distracting, and unnecessary administrative burden that too often accompanies the receipt of government funds.

AAI continues to recommend that the NIH Common Fund (CF), which supports trans-NIH initiatives, not grow faster than the overall NIH budget so that individual researchers pursuing investigator-initiated approaches - who drive American scientific advancement – are not marginalized. The President's proposed increase of 2.4 percent is consistent with this recommendation.

AAI recommends strongly against an effort introduced in H.R. 1, the Full-Year Continuing Appropriations Act, 2011, to determine the size and number of NIH grants. Such a decision should be a scientific one made by NIH.

AAI supports the President's request for $1.538 billion for NIH Research, Management, and Services (RM&S) to fund the management, monitoring, and oversight of all research activities. Only through adequate funding of this account will NIH be able to supervise and oversee its large and complex portfolio.

The NIH Public Access Policy

AAI requests that the subcommittee require NIH to publicly report on the current and historical cost of the

NIH Public Access Policy ("Policy"), and to receive the response of private scientific publishers to this information. AAI continues to believe that the Policy duplicates publications and services which are already provided cost-effectively and well by the private sector, including not-for-profit scientific societies. AAI and other private sector publishers already publish - and make publicly available - thousands of scientific journals with millions of articles that report cutting-edge research funded by NIH and other entities. AAI urges that the subcommittee require NIH to partner with, rather than compete with, private publishers to enhance public access while addressing publishers' key concerns, including respecting copyright law and ensuring journals' continued ability to provide quality, independent peer review of NIH-funded research.

Conclusion

AAI thanks the subcommittee for its strong support for biomedical research, the NIH, and the biomedical researchers who devote their lives to scientific discovery and the prevention, treatment, and cure of disease.

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[1] AAI members work in academia, government, and industry. Many members receive grants from the National Institute of Allergy and Infectious Diseases, the National Cancer Institute, the National Institute on Aging, and the National Institute of Arthritis and Musculoskeletal and Skin Diseases, as well as other NIH Institutes and Centers.

[2] NIH funding supports "almost 50,000 competitive grants to more than 325,000 researchers at over 3,000 universities, medical schools, and other research institutions in every state and around the world." See http://www.nih.gov/about/budget.htm (3/9/11). According to NIH Director Francis Collins M.D., Ph.D., "every dollar that NIH gives out in a grant returns over $2.00 in investments in terms of economic goods and services that are produced within just one year." "Francis S. Collins," April 26, 2010, http://pubs.acs.org/cen/coverstory/88/8817cover.html.

[3] "[E]very grant that NIH gives creates seven high-quality, high-paying jobs that sustain American leadership in science." "Francis S. Collins," April 26,2010, http://pubs.acs.org/cen/coverstory/88/8817cover.html.

[4] The immune system works by recognizing and attacking bacteria and viruses inside the body and by controlling the growth of tumor cells. A healthy immune system can protect its human or animal host from illness or disease either entirely - by destroying the virus, bacterium, or tumor cell - or partially, resulting in a less serious illness. It is also responsible for the rejection response following transplantation of organs or bone marrow. The immune system can also malfunction, causing the body to attack itself, resulting in an "autoimmune" disease, such as Type 1 diabetes, multiple sclerosis, lupus or rheumatoid arthritis.

[5] Although the first vaccine (against smallpox) was developed in 1798, most of our basic understanding of the immune system has developed in the last 50 years, and the pace of discovery is rapidly increasing.

[6] To best protect against bioterrorism, scientists should focus on basic research, including working to understand the immune response, identifying new and potentially modified pathogens, and developing tools (including new and more potent vaccines) to protect against these pathogens.

[7] For example, to best protect against a pandemic, scientists should focus on basic research to combat seasonal flu, including building capacity, pursuing new production methods, and seeking optimized flu vaccines and delivery methods.

[8] Cohen SA, Chui K, Naumova E, "Influenza Vaccination in Young Children Reduces Influenza-associated Hospitalizations in Older Adults, 2002-2006," *Journal of the American Geriatrics Society*, 2011; 59(2):327-332.

[9] Tseng HF, Smith N, Harpaz R, Bialek SR, Sy LS, Jacobsen SJ, "Herpes zoster vaccine in older adults and the risk of subsequent herpes zoster disease," *Journal of the American Medical Association*, 2011 Jan 12; 305(2):160-166.

[10] Esposito DH, Tate JE, Kang G, Parashar UD, "Projected impact and cost-effectiveness of a rotavirus vaccination program in India, 2008," *Clinical Infectious Diseases*, 2011; 52 (2):171-177. Gagneur A, Nowak E, Lemaitre T, Segura JF, Delaperrière N, Abalea L, Poulhazan E, Jossens A, Auzanneau L, Tran A, Payan C, Jay N, de Parscau L, Oger E, "Impact of rotavirus vaccination on hospitalizations for rotavirus diarrhea: The IVANHOE study," *Vaccine*, 2011 March 25, doi:10.1016/j.vaccine.2011.03.035.

[11] Kim HJ, Verbinnen B, Tang X, Linrong L, Cantor H, "Inhibition of follicular T-helper cells by CD8+ regulatory T cells is essential for self tolerance," *Nature*, 2010 July 22; 467: 328-322.

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Before the House Appropriations Subcommittee on Labor, Health and Human Services, Education, and other Related Agencies
04/15/2011
Submitted for the Record

The Society for Women's health Research (SWHR) and the Women's Health Research Coalition (WHRC), is pleased to have the opportunity to submit the following testimony in support of ongoing federal funding for biomedical research—specifically sex differences and total women's health research--within the Department of Health and Human Services (HHS) at the National Institutes of Health (NIH), Centers for Disease Control and Prevention (CDC), and the Agency for Healthcare and Research Quality (AHRQ).

SWHR and WHRC believe that sustained funding for biomedical and women's health research programs conducted and supported across the federal agencies is absolutely essential if the U.S. is going to meet the health needs of women and men. **A well-designed and appropriately-funded federal research agenda does more than avoid dangerous and expensive "trial and error" medicine for patients—it advances the nation's research capability, continues growth in a sector with proven return on investment, and takes a proactive approach to maintaining America's position as world-wide leader in medical research, education, and development.**

SWHR and WHRC believe that sustained funding for biomedical and women's health research programs conducted and supported across the federal agencies is absolutely essential if the United States (U.S.) is to meet the health needs of women, and men, and advance the nation's research capability.

As President Obama stated in his State of the Union Address, investment in biomedical research "will strengthen our security, protect our planet, and create countless new jobs for our people". Proper investment in health research will save valuable dollars that are currently wasted on inappropriate treatments and procedures. Further, SWHR and WHRC want targeted research into sex differences that will help in determining targeted treatments that will help women and men to receive quality appropriate care.

SWHR, a national non-profit organization based in Washington DC, is widely recognized as the thought leader in research on sex differences and is dedicated to improving women's health through advocacy, education, and research. SWHR was founded in 1990 by a group of physicians, medical researchers and health advocates who wanted to bring attention to the myriad of diseases and conditions that affect women uniquely.

WHRC was established in 1999 by SWHR to give a voice to scientists and researchers from across the United States who shares SWHR's commitment to improving women's health research. WHRC now has more than 650 members, including leaders within the scientific and medical community from many of the country's leading universities and medical centers, voluntary health associations, pharmaceutical and biotechnology companies.

National Institutes of Health

Past Congressional investment for the NIH positioned the U.S as the world's leader in biomedical research and has provided a direct and significant impact on women's health research and the careers of women scientists over the last decade. In recent years, that investment has declined along with America's place as the Number 1 in biomedical research. These two facts are interrelated. Cutting NIH funding threatens scientific advancement, substantially delays cures becoming available in the U.S., and puts the innovative research practices and reputation that America is known for in jeopardy.

When faced with budget cuts, NIH is left with no other option but to reduce the number of grants it is able to fund. The number of new grants funded by NIH had dropped steadily with declining budgets, growing at a percent less than that of inflation since FY2003. Cuts to investments in biomedical research also negatively impact the economy. **A shrinking pool of available grants has a significant impact on scientists who depend upon NIH support to cover both salaries and laboratory expenses to conduct high quality biomedical research, putting both medical advancement and job creation at risk.** 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.

Reducing the number of grants available to researchers further decreases publishing of new findings and decreases the number of scientists gaining experience in research, both reducing a scientist's likelihood of achieving tenure in a university setting. New and less established researchers are forced to consider other careers, or take positions outside the U.S., and results in the loss of the skilled bench scientists and researchers so desperately needed to sustain America's cutting edge in biomedical research.

While the U.S. deficit requires careful consideration of all funding and investments, cutting relatively small discretionary funding within the NIH budget will not make a substantial impact on the deficit, but will drastically hamper the ability of the U.S. to remain the global leader in biomedical research. SWHR and WHRC recommend that Congress set, at a minimum, a budget that matches the Administration's request for a $1 billion increase for NIH for FY2012.

Study of Sex Differences

It has only been within the past decade that scientists have begun to uncover the significant biological and physiological differences between women and men and its impact health and medicine. Sex-based biology, the study of biological and physiological differences between women and men, has revolutionized the way that the scientific community views the sexes. Sex differences play an important role in disease susceptibility, prevalence, time of onset and severity and are evident in cancer, obesity, heart disease, immune dysfunction, mental health disorders, and many other illnesses. Medications can have different effects in woman and men, based on sex specific differences in absorption, distribution, metabolism and elimination. It is imperative that research addressing these important differences be supported and encouraged.

SWHR recommends that NIH, with the funds provided, report sex/gender differences in all research findings. Further, NIH should seek to expand its inclusion of women in basic, clinical and medical research to Phase I, II, and III studies. By currently only mandating sufficient female subjects in Phase III, researchers often miss out on the chance to look for variability by sex in the early phases of research, where scientists look at treatment safety and determine safe and effective dose levels for new medications. By mandating that sex differences research occur in earlier phases of clinical research studies, the NIH can continue to serve as a role model for industry research, as well as other nations. Only by gaining more information on how therapies work in women will medicine be able to advance toward more targeted and effective treatments for all patients, women and men alike.

Office of Research on Women's Health

The NIH's Office of Research on Women's Health (ORWH) serves as the focal point for coordinating women's health and sex differences research at NIH, advising the NIH Director on matters relating to research on women's health and sex differences research, strengthening and enhancing research related to diseases, disorders, and conditions that affect women; working to ensure that women are appropriately represented in research studies supported by NIH; and developing opportunities for and support of recruitment, retention, re-entry and advancement of women in biomedical careers. In September 2010, ORWH celebrated its 20th anniversary and unveiled a new strategic plan for

women's health and sex difference research, **Moving Into The Future With Dimensions and Strategies: A Vision For 2020 For Women's Health Research.**

BIRCWH and SCOR
The Building Interdisciplinary Research Careers in Women's Health (BIRCWH) and Specialized Centers of Research on Sex and Gender Factors Affecting Women's Health (SCOR) are two ORWH programs that benefit the health of both women and men through sex and gender research, interdisciplinary scientific collaboration, and provide tremendously important support for young investigators in a mentored environment.

The BIRCWH program, created in 2000, is an innovative, trans-NIH career development program that provides protected research time for junior faculty by pairing them with senior investigators in an interdisciplinary mentored environment. Each BIRCWH receives approximately $500,000 a year, most from the ORWH budget. **To date, 407 scholars have been trained in forty-one centers, and 80% of those scholars are female. The BIRCWH centers have produced over 1300 publications, 750 abstracts, 200 NIH grants and 85 awards from industry and institutional sources.**

SCORs, established in 2003, are designed to increase innovative, interdisciplinary research focusing on sex differences and major medical problems that affect women through centers that facilitate basic, clinical, and translational research. **Each SCOR program results in unique research and in 2010, resulted in over 150 published journal articles, 214 abstracts and presentations and 44 other publications.**

Additionally, ORWH has created several additional programs to advance the science of sex differences research and research into women's health. The Advancing Novel Science in Women's Health Research (ANSWHR) program, created in 2007, **promotes innovative new concepts and interdisciplinary research in women's health research and sex/gender differences**. The Research Enhancement Awards Program (REAP) supports meritorious research on women's health that otherwise would have missed the IC pay line.

In addition to its funding of research on women's health and sex differences research, ORWH has established several methods for dissemination information about women's health and sex differences research. ORWH created the Women's Health Resources web portal in collaboration (http://www.womenshealthresources.nlm.nih.gov) with that National Library of Medicine, to serve as a resource for researchers and consumers on the latest topics in women's health and uses social media to connect the public to health awareness campaigns.

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 $1 million dollar budget increase, bringing its FY2012 total to $43.9 million.**

Health and Human Services' Office of Women's Health
The HHS Office of Women's Health (OWH) is the government's champion and focal point for women's health issues. It works to redress inequities in research, health care services, and education that have historically placed the health of women at risk. Without OWH's actions, the task of translating research into practice would be only more difficult and delayed.

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, Centers for Disease Control and Prevention, Agency for Healthcare Quality and Research, Indian Health Service, Substance Abuse and Mental Health Services Administration, Health Resources and Services Administration, and Centers for Medicare and Medicaid Services. It is imperative that these offices are funded at levels which are adequate for them to perform their assigned missions, and are sustainable so as to support

needed changes in the long term. We ask that the Committee Report reflect Congress's support for these federal women's health offices, and **recommend that they are appropriately funded on a permanent basis** to ensure that these programs can continue and be strengthened in the coming fiscal year.

It is only through consistent funding that the OWH will be able to achieve its goals. The budgets for theses offices have been flat-lined in recent years, which results in effectively a net decrease due to inflation. Considering the impact of women's health programs from OWH on the public**, we urge Congress to provide an increase of $1 million for the HHS OWH, a total $34.7 million requested for FY2012.**

Centers for Disease Control and Prevention

SWHR supports the national and international work of the CDC, especially the work of CDC's Office of Women's Health (OWH). While SWHR is delighted that the CDC's OWH is now codified in statue, we are concerned that proposed cuts to the CDC budget by the Administration will significantly jeopardize programs that benefit women, leaving them with even fewer options for sound clinical information. Research and clinical medicine are still catching up from decades of a male-centric focus, and when diseases strike women, there remains a paucity of basic knowledge on how diseases affect female biology, a lack of drugs that have been adequately tested in women, and now even fewer options for information through the many educational outreach programs of the CDC.

The OWH within CDC is fundamental to promoting and improving the health, safety, and quality of life of women across their lifespan. The office led the CDC in the collaboration and development of text4baby, which sends free text messages on health and pregnancy issues, to pregnant women and new moms. In the year since its launch, over 135,000 subscribers have signed up for the service and millions of text messages have been sent. More than 300 outreach partners, including national, state, business, academic, non-profit, and other groups, help to promote the service.

With its small budget, the OWH actively participated with others in CDC, HHS, and the State Department in the early development of the Global Health Initiative, and routinely collaborates with other agencies to advance the knowledge and research into women's health issues. This year, OWH worked closely with HHS OWH on the development of the Action Agenda on Women's Health: Beyond 2010 and with NIH on the development of the research conference on Advances in Uterine Leiomyoma. SWHR and WHRC recommend that Congress provide the CDC OWH with a 1.06%increase for FY2012, bringing their total to $478,000.

Agency for Healthcare and Research Quality

The Agency for Healthcare Research and Quality's work serves as a catalyst for change by promoting the results of research findings and incorporating those findings into improvements in the delivery and financing of health care. Through AHRQ's research projects, lives have been saved. For example, it was AHRQ who first discovered that women treated in emergency rooms are less likely to receive life-saving medication for a heart attack. AHRQ funded the development of two software tools, now standard features on hospital electrocardiograph machines, which have improved diagnostic accuracy and dramatically increased the timely use of "clot-dissolving" medications in women having heart attacks. As efforts to improve the quality of care, not just the quantity of care, progress, findings such as these coming out of AHRQ reveal where relatively modest investments can offer significant improvement to women's health outcomes, as well as a better return on investment for scarce healthcare dollars.

While AHRQ has made great strides in women's health research, its budget has been dismally funded for years, though targeted funding increases in recent years for dedicated projects, including funds from the American Recovery and Reinvestment Act (ARRA), moved AHRQ in the right direction. ARRA funds more than doubled AHRQ's investment in patient-centered research relevant to women.

AHRQ is now supporting studies that examining comparative effectiveness in diabetes and breast cancer prevention in women, and comprehensive care for adults with serious mental illness.

With the ARRA funds, total investment in women's health increased from $52 million to $109 million, however, more core and sustained funding is needed to help AHRQ continue doing the research that helps patients and doctors make better medical decisions. Lack of investment in AHRQ will hinder advancements that will improve medical decision-making of doctors and patients and will result in improved health outcomes. Any decreased level of funding seriously jeopardizes the research and quality improvement programs that Congress mandates from AHRQ.

SWHR and WHRC recommend Congress fund AHRQ at $405 million for FY2012, an increase 2% over 2010 enacted levels .This investment ensures that adequate resources are available for high priority research, including women's health care, sex- and gender-based analyses, and health disparities—valuable information that can help to better personalize treatments, lower overall medical spending, and improve outcomes for female and male patients nationwide.

In conclusion, Mr. Chairman, we thank you and this Committee for its strong record of support for medical and health services research and its commitment to the health of the nation through its support of peer-reviewed research. We look forward to continuing to work with you to build a healthier future for all Americans.

Association of Rehabilitation Nurses
Written Testimony to the House Labor-Health and Human Services
Appropriations Subcommittee
Regarding Fiscal Year 2012 Nursing and Rehabilitation Related Funding
Submitted by: ARN President, Kathryn Doeschot MSN RN CRRN
(202) 230-5197 and jeremy.scott@dbr.com
April 13, 2011

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) 2012. ARN represents more than 5,700 Registered Nurses (RNs) who work to enhance the quality of life for those affected by physical disability and/or chronic illness. ARN understands that Congress has many concerns and limited resources, but believes that chronic illnesses and physical disabilities are heavy burdens on our society that must be addressed.

Rehabilitation Nurses and Rehabilitation Nursing

Rehabilitation nurses help individuals affected by chronic illness and/or physical disability adapt to their condition, achieve their greatest potential, and work toward productive, independent lives. They take a holistic approach to meeting patients' nursing and medical, vocational, educational, environmental, and spiritual needs. Rehabilitation nurses begin to work with individuals and their families soon after the onset of a disabling injury or chronic illness. They continue to provide support and care, including patient and family education, 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. These nurses base their practice on rehabilitative and restorative principles by: (1) managing complex medical issues; (2) collaborating with other specialists; (3) providing ongoing patient/caregiver education; (4) setting goals for maximum independence; and (5) establishing plans of care to maintain optimal wellness. Rehabilitation nurses practice in all settings, including freestanding rehabilitation facilities, hospitals, long-term subacute care facilities/skilled nursing facilities, long-term acute care facilities, comprehensive outpatient rehabilitation facilities, home health, and private practices, just to name a few.

With the *Affordable Care Act's* focus on creating a system that will increase access to quality care, emphasize prevention, and decrease cost, it is critical that a substantial investment be made in 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 (RNs) for individuals affected by chronic illness and/or physical disability.

According to the Health Resources and Services Administration (HRSA), in 2010, our healthcare workforce experienced a shortage of more than 400,000 nurses.[1] 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 to meet these new demands, but we are destined to fall short of these lofty goals if there are not enough nurses to facilitate change.

According to the U.S. Bureau of Labor Statistics, nursing is the nation's top profession in terms of projected job growth, with more than 581,500 new nursing positions being created through 2018.[2] These positions are in addition to the existing jobs that health care employers have not been able to fill. Educating new nurses to fill these gaping 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 $313.075 million in FY 2012 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

[1] http://bhpr.hrsa.gov/healthworkforce/reports/nursing/rnbehindprojections/4.htm
[2] http://www.bls.gov/oco/ocos083.htm#outlook

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 2012 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 interdisciplinary 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 $163 million in FY 2012 funding for NINR to continue its efforts to address issues related to chronic and acute illnesses.

Traumatic Brian Injury (TBI)

According to the Brain Injury Association of America, 1.7 million people sustain a traumatic brain injury (TBI) each year.[3] This figure does not include the 150,000 cases of TBI suffered by soldiers returning from wars in Afghanistan and conflicts around the world.

The annual national cost of providing treatment and services for these patients is estimated to be nearly $60 million in direct care and lost workplace productivity. Continued fiscal support of 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.

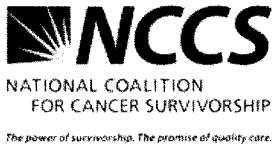
[3] http://www.biausa.org/living-with-brain-injury.htm

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 2012 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 2012 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 2012 funding levels detailed above, we believe the Subcommittee will be taking the steps necessary to ensure that our nation has a sufficient nursing workforce to care for patients requiring rehabilitation from chronic illness and/or physical disability.



Statement of Thomas P. Sellers, MPA
President & CEO
National Coalition for Cancer Survivorship
Regarding FY 2012 Appropriations for the National Institutes of Health
and Centers for Disease Control and Prevention
Submitted to the Subcommittee on Labor, Health and Human Services, Education
and Related Agencies
Committee on Appropriations
United States House of Representatives

It is my pleasure to submit this statement regarding fiscal year 2012 funding for the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC) on behalf of the National Coalition for Cancer Survivorship (NCCS) and the 12 million cancer survivors living in the United States. NCCS advocates for quality health care for survivors of all forms of cancer, and we believe the federal government should play a strong leadership role, through basic and clinical cancer research and delivery of survivorship services, to boost the quality of cancer care from diagnosis and for the balance of life. These research and survivorship programs should be conducted in partnership with private sector organizations.

In this statement, NCCS will focus on the need for a balanced program of basic, translational, and clinical research at the National Institutes of Health (NIH) and the National Cancer Institute (NCI) as well as the urgent need for Centers for Disease Control and Prevention (CDC) leadership to strengthen educational and informational services for survivors and improve access to cancer screening for the medically underserved.

Two recent reports – the *Annual Report to the Nation on the Status of Cancer, 1975-2007, Featuring Tumors of the Brain and Other Nervous System* and the *Morbidity and Mortality Weekly Report of March 11, 2011,* reporting on the number of cancer survivors in 2007 – provide a compelling portrait of the progress the nation has made in the fight against cancer, the work still to be done, and the pressing needs of millions of cancer survivors who are still in active treatment or living as long-term survivors.

The *Annual Report* notes that the incidence of cancer is decreasing; the decrease is statistically significant for women although not for men, because of a recent increase in prostate cancer incidence. The cancer death rates are decreasing for both sexes. The decreases in incidence and mortality are attributed to progress in cancer prevention, early detection, and treatment. Despite the overall progress, there are increasing incidence rates for some cancers and low survival for certain forms of cancer. For example, pediatric cancer incidence is increasing, although death rates are down. The survival from melanoma, pancreatic cancer, liver cancer, and many forms of malignant brain tumors remains much too short.

Those who do survive cancer experience a myriad of late and long-term effects. In the editorial note accompanying the *Morbidity and Mortality Weekly Report* that found almost 12 million American cancer survivors, CDC stressed the need for more research to identify those cancer survivors at risk of recurrence, second cancers, and the late effects of cancer and its treatment. CDC also recommended that special attention be paid to the burden of survivorship for the medically underserved and the older cancer survivor.

Recommendations for FY 2012 Funding

NCCS recommends smart, effective, and aggressive federal investments in initiatives to improve the quality of care and quality of life for cancer survivors. We recommend:

- A strong and sustained investment in NIH and NCI in FY 2012 to support basic, translational, and clinical research aimed at answering fundamental questions about cancer, advancing new and improved cancer treatments, identifying the side effects of cancer treatments, and strengthening interventions for the late and long term effects of cancer and treatment. No reductions should be made in NIH funding in FY 2012, in order to prevent interruption of both basic and clinical studies and to sustain the progress in cancer treatment that we are making through research.
- Steady progress in the overhaul of the NCI clinical trials system. The Institute of Medicine (IOM) has outlined a plan for modernizing the clinical trials system and eliminating inefficiencies, and NCI leaders have taken steps to implement the IOM recommendations. We urge completion of this reform effort, to guarantee that patients are willing to enroll in clinical research studies because they know they will be studies of high quality investigating important issues and treatments. An improved system will also ensure that research studies are efficiently completed and questions related to new treatments are answered without delay.
- A strong investment in survivorship research that will discover those at risk of late and long-term effects from cancer and treatment and appropriate interventions for those individuals.
- A sustained commitment to basic research aimed at detecting subtypes of cancer and contributing to the development of targeted, or personalized, cancer therapies.

- Maintenance of the federal cancer screening programs – including the breast and cervical cancer screening program and the colorectal cancer screening program – in a manner that will support services to medically underserved individuals and ensure early detection and diagnosis. The proposal to create a block grant of chronic disease programs should not include the screening programs, which do not lend themselves to effective administration through a block grant.
- A strong program of education and information regarding survivorship services for the 12 million cancer survivors living in the US. CDC has provided grant funding to support a survivorship resource center, and we urge that steps be taken to ensure that the services offered through the center reflect the latest knowledge about the problems of survivors and the most appropriate interventions. Morever, special populations, including the medically underserved and the elderly, should be provided adequate and appropriate information and services.

Federal research and survivorship programs have yielded better treatments and enhanced quality of life for millions of American cancer patients. These programs should be sustained through continued federal support so that the needs of a growing population of cancer survivors can be met.

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April 13, 2011

ARVO Written Testimony in Support of Increased FY12 Funding for the National Institutes of Health (NIH) and the National Eye Institute (NEI)

Submitted on behalf of the ARVO President, Mark Petrash, PhD

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

[About ARVO appears on last page.]

ARVO has two major requests:

1. **For Congress to fund NIH in FY12 at $35 billion.**

   This amount:

   — Is a $3 billion increase over the President's proposed budget;

   — Maintains NIH net funding levels from FY09 and FY10;

   —Ensures that NIH can maintain the number of multi-year investigator-initiated research grants.

2. **For Congress to make vision health a priority, and fund NEI in FY12 above the 1.8 percent proposed by the President.**

   —We request this even if Congress does not fund NIH at $35 billion.

   —Why? The proposed increase does not match biomedical inflation, and NEI already lost 20.1% purchasing power (2001 - 2011)*.

ARVO is also a member of the National Alliance for Eye and Vision Research, and supports their testimony. www.eyeresearch.org

Peer review eliminates budget excess

ARVO stands behind member John Ash, PhD, who stated the following in January 2011 ARVO Advocacy Day visits to Capitol Hill. "We understand the need for budget cuts, but *we should be cutting budgets similar to how U.S. citizens trim their household budgets, not across the board, but rather where there is waste and inefficiency.* **We challenge you to find another government agency that uses money more efficiently than the National Institutes of Health.**" Science funding decisions are awarded based on scientific merit and past progress. Grants are reviewed by peers, who make funding decisions based on the quality and impact of the proposed science. Progress is monitored annually, and excess budgets are trimmed during the peer review process.

Cost of vision impairment

Although the NEI estimates that the current annual cost of vision impairment and eye disease to the US is $68 billion, this number does not fully quantify the impact of indirect healthcare costs, lost productivity, reduced independence, diminished quality of life, increased depression, and accelerated mortality. NEI's FY2010 baseline funding of $707 million reflects just a little more than one percent of the annual costs of eye disease. The continuum of vision loss presents a major public health problem, as well as a significant financial challenge to the public and private sectors.

Congressional and Presidential support for biomedical research

In 2009, Congress spoke volumes in passing S. Res 209 and H. Res. 366, which designated 2010-2020 as *The Decade of Vision*, in which the majority of 78 million Baby Boomers will turn 65 years of age and face greatest risk of aging eye disease. This is not the time for a less-than-inflationary for a community that already lost 20.1% purchasing power in the past 10 years.*

Vision success and vision funding needs

Nearly 400 U.S.-based ARVO members, working at NEI-funded institutions, provided feedback in March 2011 to the NEI, in response to their request for feedback on their strategic plan.

Greatest vision achievements, since 2003

Below are the top three vision success stories, reported by members, in response to an ARVO survey about the NEI strategic plan. There were too many vision achievements to list them all.

Drug therapies for macular degeneration (AMD). Vision researchers developed a therapy to stop harmful, leaky blood vessel growth in patients with a form of AMD, called 'wet' AMD. The therapy was subsequently applied to stopping blood vessel growth at the front of the eye, following infection or injury, and to the back of the eye for stopping new blood vessel growth, associated with diabetes.

Gene therapies for eye disease. Vision researchers developed gene therapies for 3 retinal degenerative diseases (Leber congenital amaurosis, color blindness and retinitis pigmentosa). They also identified important genetic risk factors for age-related eye diseases, including age-related macular degeneration and glaucoma.

Cellular and molecular therapies. Vision researchers made important progress for repairing damage corneas and retinas with regenerative medical approaches. They also advanced medical research, to a point where rescuing visual function has been modeled, by turning genes on or off with light.

Impact of NIH and NEI-funded research. Research results in treatments and therapies that save vision and restore sight, which reduces healthcare costs, maintains productivity, ensures independence and enhances quality of life. As President Obama has stated repeatedly, most recently during the 2011 State of the Union Address, biomedical research reduces healthcare costs, increases productivity; and it ensures global competitiveness of the United States.

ARRA funding success stories

The vision community achieved great success for trans-NIH opportunities awarded with American Recovery and Reinvestment Act funding including:

- Using dancing dots to teach music to children.
- Delivering therapeutic agents that prevent multiple degenerative, aging eye diseases.
- Investigating color vision circuitry in the brain.

Cost effective vision funding needs

Less-than-inflationary budget increases will cost taxpayers more money in the long term. Prevention can save Medicare/Medicaid payments for vision care in the aging population, and in minority populations with disproportionate incidence of eye disease (glaucoma and diabetic retinopathy). NEI funding is a vital investment in overall health and vision health of our nation; it saves and prevents health expenditures. Vision retention allows people remain employed, reduces family burdens; and ultimately, it improves the safety of individuals and the entire community (driving safety being a prime example).

ARVO members expressed continued need for research support for the following areas and many additional areas (not covered).

- **Tools and markers for disease screening.**
  - —Identify inexpensive methods for detecting early disease, measuring disease progression and measuring responsiveness to treatments.
- **Improved therapies.**
  - —Understand factors that affect drug availability and side effects; and develop ways to improve availability of therapies in the eye.
- **Identify at risk groups and raise awareness.**
  - —Monitor trends and changes in the prevalence and incidence of eye conditions.
  - —Support development of educational tools to raise awareness and treatment compliance in high risk groups, (e.g. eye diseases with racial disparities or age disparities).
- **Aging eye disease.**
  - —Promote studies to treat common aging diseases (AMD, glaucoma, diabetic retinopathy, cataracts, etc.) with long-lasting, cost effective drugs.
  - —Understand environmental factors that make it more likely to develop eye disease, and educate people how to prevent eye disease.
- **Cornea.**
  - —Identify circumstances when corneal surgery should be delayed.
  - —Identify better ways to manage corneal transplantation rejection.

—Develop drugs to treat corneal problems without surgery.

—Understand normal corneal wound healing, so we can facilitate healing.

—Address complications with use of contact lenses and artificial corneas, such as corneal melting.

—Support studies to improve prevention of infection with contact lens and solution use.

- **Genetics.** Develop more rapid screening for disease genes, and develop additional gene therapies for eye disease.

- **Eye pain.** Understand the basis of eye pain, and develop therapies to treat it.

- **Metabolic syndrome.** Support studies on vision loss with obesity and metabolic syndrome, especially for aging eye diseases, which are on the rise in developed countries like the U.S.

- **Translational research.**

  —Support patient-based research, including development of therapies that benefit patients without surgical intervention.

  —Push clinical applications for innovative vision restoration technologies.

- **Comparative effectiveness.**

  —Support comparative effectiveness and comparative technology research, using clinical research tools that compare competing technologies/drugs for treating eye disease.

  —Re-examine affected populations to generalize/translate information about the cost-effectiveness of new interventions.

- **Glaucoma.**

  —Develop methods to monitor glaucoma before irreversible damage takes place, so treatment can be initiated before it is too late.

- **Brain and eye injury.** Better survival from traumatic brain and eye injuries (military and civilian) mean patients are living with difficult to treat symptoms. Vision research addresses battlefield and civilian needs to rapidly seal wound injuries and treat ocular and brain trauma earlier, so function is maintained. Without research, practitioners offer all sorts of unproven therapies after damage has happened. Such therapies are costly and possibly ineffective.

- **Children's vision.**

  —Find noninvasive ocular measurements that can be used in children.

  —Support outcomes and quality of life studies in children with ocular disease.

  —Find better ways to detect and treat eye movement disorders earlier, so vision is spared. Without early detection, the brain learns to erase images received by one eye, when the eyes are moving in a way the produces double vision.

- **Dry eye.** Develop better therapies for dry eye, as current therapies have limited success.

- **Eye infections.** Identify better ways to identify and treat drug resistant eye infections with antibiotics and anti-viral medications. Certain infections rapidly destroy eye tissues, within 24 hours.

- **Cataracts.** Identify cost-effective prevention of side effects from cataract removal.

- **Neural degeneration research collaborations.** Establish meaningful collaborations between glaucoma and other neural degeneration researchers, who currently work along independent paths, so shared therapeutic strategies can be developed.

  —Identify common, shared pathways between common eye and systemic diseases, and develop shared therapeutic targets.

About ARVO

ARVO is the world's largest international association of vision scientists (scientists who study diseases and disorders of the eye). About eighty percent of the United States members (>7,000 total) are supported by NIH grant funding. Vision science is a multi-disciplinary field, but the National Eye Institute is the only freestanding NIH institute with a mission statement that specifically addresses vision research. ARVO supports increased FY11 and FY12 NIH funding.

More Information

To find out more, please visit www.arvo.org/advocacy or contact Bobbie Ann Austin, PhD, ARVO Assistant Director of Science Program and Policy: baustin@arvo.org or 240-221-2901.

*Calculations were based solely upon annual biomedical research and development price index (BRDPI) and annual appropriated amounts. FY11 funding levels and FY11 BRDPI were not part of the calculation.

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Testimony of the National Rural Health Association (NRHA) Concerning HRSA's Programs Impacting Rural Health

Submitted for the Record to the House Appropriations Subcommittee on Labor, Health and Human Services, and Education - April 14, 2011

The National Rural Health Association (NRHA) is pleased to provide the Labor, Health and Human Services, Education and Related Agencies Appropriations Subcommittee with a statement for the record on FY 2012 funding levels for programs with a significant impact on the health of rural America.

The NRHA is a national nonprofit membership organization with more than 20,000 members that provides leadership on rural health issues. The Association's mission is to improve the health of rural Americans and to provide leadership on rural health issues through advocacy, communications, education and research. The NRHA membership consists of a diverse collection of individuals and organizations, all of whom share the common bond of an interest in rural health.

The NRHA is advocating for continued full funding for a group of rural health programs that assist many 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. Additional capacity that will be absolutely necessary with the addition of many newly insured Americans under the Patient Protection and Affordable Care Act. These programs have been successful in increasing access to health care in rural areas, helping communities create new health programs for those in need and training the future health professionals that will give care to rural America. With modest investments, these programs are able to evaluate, study, and implement quality improvement programs and health information technology systems.

While recognizing the constraints of the current economic and budgetary climate, we would like to remind you of the critical importance of these rural health programs and request modest increases to ensure that these programs do not lose any ground. Even small investments in these "rural health safety net" programs go a long way and generate big returns in rural communities. Cuts to these programs do more hard than good and in the long run the federal government will pay a much higher cost should these rural programs go away.

Some important rural health programs supported by the NRHA are outlined below.

Rural Health Outreach and Network Grants provide capital investment for planning and launching innovative projects in rural communities that later become self-sufficient. These grants are unique in the federal system as they allow the community to choose what is most important for their own situation and then build a program around that. These grants have led to projects dealing with obesity and diabetes, information technology networks, oral

screenings, preventive services, and many other health concerns. Due to the community nature of the grants and a focus on self-sustainability after the terms of the grant have run out - 85 percent of the Outreach Grantees continue to deliver services even five full years after federal funding had ended. **Request: $59.8 million**

Rural Health Research and Policy forms the federal infrastructure for rural health policy. Without these funds, rural America has no coordinated voice in the Department of Health and Human Services (HHS). In addition to the expertise provided to agencies such as the Centers for Medicare and Medicaid Services, this line item also funds rural health research centers across the country. These research centers provide the knowledge and the evidence needed for good policy making, both in the federal government and across the nation. Additionally, we urge the Subcommittee to include in report language instructions to the Office of Rural Health Policy to direct additional funding to the state rural health associations. The state associations serve to coordinate rural health activities at the state level and have a strong record of positive outcomes. **Request: $10.76 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 so critical to access to care. **Request: $10 million**

Rural Hospital Flexibility Grants fund quality improvement and emergency medical service projects for Critical Access Hospitals across the country. This funding is essential. CAHs are by definition small hospitals with fewer than twenty-five beds; they do not have the size, volume or the expertise to do the types of quality improvement or information technology activities that they need to do. These grants allow statewide coordination and provide expertise to CAHs. Also funded in this line is the **Small Hospital Improvement Program (SHIP),** which provides grants to more than 1,500 small rural hospitals (50 beds or less) across the country to help improve their business operations, focus on quality improvement and to ensure compliance provisions related to health information privacy. **Request: $43.46 million**

Rural and Community Access to Emergency Devices assists communities in purchasing emergency devices and training potential first responders in their use. Defibrillators double a victim's chance of survival after sudden cardiac arrest, which an estimated 163,221 Americans experience every year. **Request: $3.49 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.

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 NRHA is supporting the President's request, which will ensure that the NHSC has access to the additional dedicated funding through the CHC Fund. **Request: $173.2 million**

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. It has been estimated that nearly half of AHECs would shut down without federal funding. The success of this program was recognized through increased authorized levels in the Patient Protection and Affordable Care Act. **Request: $ 75 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 NRHA appreciates the support throughout the FY 2011 Continuing Resolution process and the opportunity to provide our recommendations for your fiscal year 2012 appropriations bill. Our request for continued funding for the rural health safety net is critical to maintaining access to high quality care in rural communities. We greatly appreciate the support of the Subcommittee and look forward to working with Members of Congress to continue making these important investments in rural health in FY 2012 and into the future.

AMERICAN NURSES ASSOCIATION

April 14, 2011

The Honorable Denny Rehberg
Chairman, Subcommittee on Labor, Health and Human Services
Committee on Appropriations
2358 Rayburn House Office Building
Washington, DC 20515

Dear Mr. Chairman:

I am writing on behalf of the American Nurses Association (ANA) to request the opportunity to provide public witness testimony before the Subcommittee on Labor, Health and Human Services. ANA is the only full-service national association representing Registered Nurses (RNs) in all practice and educational settings throughout the United States. 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.

ANA continues to be alarmed by the growing national shortage of RNs, which is being felt throughout the entire U.S. health system. The current U.S. nursing shortage is already having a detrimental impact on our health care system, and it is expected to grow to a 260,000 nurse shortfall by 2025. A shortage of this magnitude would be twice as large as any shortage experienced by this country since the 1960s.

ANA would greatly appreciate the opportunity to explore opportunities for the Federal government to address this growing shortage in testimony before your Subcommittee. Thank you for taking the time to consider this request, and please feel free to contact me at (301) 628-5098 or at rose.gonzalez@ana.org.

Sincerely,

Rose Gonzalez, MPS, RN
Director, Government Affairs

Testimony Submitted by the National Kidney Foundation
30 East 33rd Street, New York, NY
Labor, HHS, Education, and Related Agencies Appropriations Subcommittee
Support for Centers for Disease Control and Prevention

In 2008, the number of Americans with End Stage Renal Disease (ESRD), which requires dialysis or a kidney transplant to survive, reached 535,000. In that year alone, 110,000 progressed to ESRD. Medicare covers dialysis or transplantation regardless of age or other disability, the only disease-specific coverage under the program. Despite this social and economic impact, no national public health program focusing on early detection and treatment existed until FY 2006, when Congress provided $2 million for the first of five years of support to initiate a Chronic Kidney Disease Program at the Centers for Disease Control and Prevention (CDC). Treatments exist to potentially slow progression of kidney disease and prevent its complications, but only if individuals are diagnosed before the latter stages of Chronic Kidney Disease (CKD).

The CDC program will 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 restore line-item funding for the Chronic Kidney Disease Program in the CDC's Division of Diabetes Translation in the amount of $2,200,000. This would benefit kidney patients and Americans at risk for kidney disease, and advance the objectives of Healthy People 2020 and the National Strategy for Quality Improvement in Health Care.

The prevalence of Chronic Kidney Disease in the United States, when last measured, was higher than it was a decade earlier. This is partly explained by the increasing prevalence in this country of the related diseases of diabetes and hypertension. It is now 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). 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.

Despite the extent of the problem, CKD is an under-recognized and under-treated public health challenge in the United States. 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." One reason CKD is neglected is that it is often asymptomatic, especially in the early stages, and, therefore, laboratory testing is required to detect it. 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. Thanks to the interest that this Committee has expressed in CKD in the past, through directed appropriations, 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 restored.

The CDC Chronic Kidney Disease program has included three projects:

(a) Establishing a Surveillance System for Chronic Kidney Disease in the U.S
(b) Demonstration Project for Identifying Individuals at High-Risk for Chronic Kidney Disease in the U.S.
(c) The Research Triangle Institute, under contract with the CDC, has undertaken studies of the economic burden of CKD and the cost-effectiveness of CKD interventions.

Pursuant to the demonstration project, individuals at high risk for CKD have been screened in eight locations in four states. The goals of the demonstration project have been:

- **To educate providers and the public that simple tests can be used to identify CKD in the target population and to assess risk factors for intervention (obesity, hypertension, cardiovascular disease, lipid disorders, diabetes, and glycemic control)**
- **Evaluate if providers change practice patterns after being consulted by a person that went through the detection program**

The demonstration project should be replicated at eight sites in four additional states in order to confirm initial findings. If we fail to do so, we could be forfeiting the valuable insights that have been gained.

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. Because the CKD program does not provide funds to state health departments, we maintain it should be exempted from the changes in the structure and budget of the National Center for Chronic Disease Prevention and Health Promotion, at least until surveillance planning, and studies of detection feasibility and economic impact are completed.

Thank you for your consideration of this 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.

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Statement of Dr. Timothy Block, President and Founder, Hepatitis B Foundation
To the United States House Committee on Appropriations, Subcommittee on Labor, Health and Human Services, and Education
Highlighting the urgent need to address the public health challenges of chronic hepatitis B by strengthening programs at the Centers for Disease Control and Prevention, and the National Institutes of Health.

Mr. Chairman, my name is Dr. Timothy Block, and I am the President and Co-Founder of the Hepatitis B Foundation and its research institute, the Institute for Hepatitis and Virus Research. I also serve as the President of the Pennsylvania Biotechnology Center and am a professor at Drexel University College of Medicine. My wife Joan, and I, and another couple, Paul and Janine Witte, from Pennsylvania started the Hepatitis B Foundation 20 years ago to find a cure for this serious chronic liver disease and provide information and support to those affected.

Thank you for giving the Hepatitis B Foundation (HBF) the opportunity to provide testimony to the Subcommittee as you begin to consider funding priorities for Fiscal Year (FY) 2012. We are grateful to the Members of this Subcommittee for their interest and strong leadership for efforts to control and find cures for hepatitis B.

Today, the HBF is the only national nonprofit organization solely dedicated to finding a cure and improving the lives of those affected by hepatitis B worldwide through research, education and patient advocacy. Our scientists focus on drug discovery for hepatitis B and liver cancer, and early detection markers for liver cancer. HBF staff manages a comprehensive website which receives almost one million visitors each year, a national patient conference and outreach services. HBF public health professionals conduct research initiatives to advance our mission.

The hepatitis B virus (HBV) is the world's major cause of liver cancer – and while other cancers are declining, liver cancer is the fastest growing in incidence in the U.S. Without intervention, as many as 100 million worldwide will die from a HBV-related liver disease, most notably liver cancer. In the U.S., up to 2 million Americans have been chronically infected and more than 5,000 people die each year from complications due to HBV.

HBV is 100 times more infectious than the HIV/AIDS virus. Yet, hepatitis B can be prevented with a safe and effective vaccine. Unfortunately, for those who are chronically infected with HBV, the vaccine is too late. There are, however, promising new treatments for HBV. We are getting close to solutions but lack of sustained support for public health measures and scientific research is threatening progress. New research has confirmed that early detection and treatment significantly reduces health care costs, morbidity and mortality. The growing incidence of liver cancer, while most

other cancer rates are on the decline, represents examples of serious shortcomings in our system. In the U.S., 20,000 babies are born to mothers infected with HBV each year, and as many as 1,200 newborns will be chronically infected with the hepatitis B virus. More needs to be done to prevent new infections.

HHS INTERAGENCY WORKING GROUP ON VIRAL HEPATITIS

Last year, the Department of Health and Human Services put together an Interagency Working Group on Hepatitis to put together an Action Plan on Viral Hepatitis. This action plan will describe opportunities for HHS to respond to the 2010 Institute of Medicine (IOM) review of the viral hepatitis challenge in the United States and the IOM recommendations to prevent and build the capacity and collaborations essential for reducing the number of viral hepatitis infections and ameliorating the health and economic consequences of viral hepatitis among persons chronically infected. The Hepatitis B Foundation is very supportive of the efforts of the Working Group and is hopeful that its recommendations will result in actions to address the chronic underfunding of viral hepatitis prevention, research and outreach programs within the Department. We look forward to the release of the Hepatitis Action Plan in May of this year.

Mr. Chairman, as you know the two federal agencies that are critical to the effort to help people concerned with hepatitis B are: the Centers for Disease Control and Prevention (CDC), and the National Institutes of Health (NIH).

THE CENTERS FOR DISEASE CONTROL

CDC's Division of Viral Hepatitis (DVH), the centerpiece of the federal response to controlling, reducing and preventing the suffering and deaths resulting from viral hepatitis, is chronically underfunded. DVH is included in the National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention at the CDC, and is responsible for the prevention and control of viral hepatitis. DVH is currently (prior to finalization of the FY 2011 Continuing Resolution) funded at $19.8 million, approximately $6 million less than its funding level in FY 2003. In the President's FY 2012 budget proposal, DVH is funded at $25 million, an increase of $5.2 million. The HBF is very supportive of this increase and joins the hepatitis community in urging the Committee to fund the President's request for the Division of Viral Hepatitis.

The responsibility for addressing the problem of hepatitis should not lie solely with the Division. In view of the preventable nature of these diseases, the Hepatitis B Foundation feels that the National Center for Chronic Disease Prevention should also include a targeted effort focused on the prevention of chronic viral hepatitis which adversely impacts 5 million Americans. Specifically, we ask that the Committee include language urging the Center to help insure that the Prevention and Public Health Funds, particularly the Community Transformations Grants, are available to support viral hepatitis prevention projects.

1

Furthermore, there are 400 million people chronically infected with hepatitis B worldwide, with more than 120 million of these individuals in China. While hepatitis B transmission requires direct exposure to infected blood, worldwide misinformation about the disease has fueled inappropriate discrimination against individuals with this vaccine-preventable and treatable bloodborne disease. HBF urges the Committee to instruct the CDC to initiate global programs to increase the rate of vaccination, reduce mother -child transmission and promote educational programs to prevent the disease and to reduce discrimination targeted against individuals with the disease.

THE NATIONAL INSTITUTES OF HEALTH

We depend upon the NIH to fund research that will lead to new and more effective interventions to treat people with hepatitis B and liver cancer. The Hepatitis B Foundation joins with the Ad Hoc Group for Biomedical Research and requests a funding level of $35 billion for the National Institutes of Health in FY 2012.

We thank the Committee for their continued investment in the NIH. Sustaining progress in medical research is essential to the twin national priorities of smarter health care and economic revitalization. With additional investment, the nation can seize the unique opportunity to build on the tremendous momentum emerging from the strategic investment in NIH made through the 2009 American Recovery and Reinvestment Act (ARRA). NIH invested those funds in a range of potentially revolutionary new avenues of research that will lead to new early screenings and new treatments for disease.

In FY 2010, NIH spent approximately $70 million on hepatitis B funding overall including $4 million of onetime funding from the American Recovery and Reinvestment Act. It is estimated that in FY 2011 hepatitis B funding will return to the base level of $66 million. Additional funding could make transformational advances in research leading to better treatments for HBV. The Hepatitis B Foundation recommends that at a minimum, funding allocated for HBV research in FY 2012 be increased at the same rate recommended for NIH overall and, therefore, funded at $75.7 million.

The current leadership of the NIH has performed admirably with the limited resources they are provided; however, more is needed. While a number of cancers have achieved five-year survival rates of over 80 percent and the average five-year survival rate for all cancers has increased from 50 percent in 1971 to 66 percent, significant challenges still remain for other types of cancers, particularly the most deadly forms of cancer. In fact, nearly half of the 562,340 cancer deaths in 2009 were caused by eight forms of cancer with five-year relative survival rates of less than 50 percent: ovary (45.5%), brain (35.0%), myeloma (34.9%), stomach (24.7%), esophagus (15.8%), lung (15.2%), liver (11.7%), and pancreas (5.1%). It is no coincidence that cancers with significantly better five year survival rates, such as breast, prostate, colon, testicular, and chronic myelogenous leukemia, also have early detection tools, and in many cases, several effective

treatment options thanks to research programs championed and supported by Congress. By contrast, research into the cancers with the lowest five-year survival rates has been relatively under-funded, and as a result, these cancers have no early detection or treatment tools.

The Hepatitis B Foundation requests the establishment of a targeted cancers program at the National Cancer Institute (NCI) for the high mortality cancers. It should include a strategic plan for progress, an annual report from NCI to Congress, and a new grant program specifically focused on the deadly cancers. Additionally, the Hepatitis B Foundation urges a stronger focus on liver cancer and urges the funding of a series of Specialized Programs of Research Excellence (SPOREs) focused on liver cancer. While SPOREs currently exist for every other major cancer, none currently exist that are focused on liver cancer.

PREVENTION FUND

The Patient Protection and Affordable Care Act included the creation of a Prevention and Public Health Fund, to be used to reduce chronic disease rates and to address health disparities. To further clarify the intended use of these funds, earlier this year, the National Prevention, Health Promotion and Public Health Council that was established to advice on the use of these funds, released a report with recommendations. Included in the report were recommendations that "opportunities be expanded within communities and populations at greatest risk for diseases such as Viral Hepatitis B and C" and that there be an increased use of the "the most effective and highest impact evidence-based clinical preventive services and medications, such as screening and treatment for chronic viral hepatitis." Therefore, it is our view that insuring the Prevention Funds resources can be used for viral hepatitis prevention projects would help address this urgent need to help close the gap between diagnosis and access to care for hepatitis patients. We urge the Committee to include language in both the Office of the Secretary and the CDC's National Center for Chronic Disease Prevention to insure that Prevention Funds, specifically Community Transformation Grants, be eligible to viral hepatitis initiatives.

SUMMARY AND CONCLUSION

While the HBF recognizes the demands on our nation's resources, we believe the ever-increasing health threats and expanding scientific opportunities continue to justify higher funding levels for the CDC's Division of Viral Hepatitis and the National Institutes of Health.

Significant progress has been made in developing better treatments and cures for the diseases that affect humankind due to your leadership and the leadership of your colleagues on this Sub-committee. Significant progress has also similarly been made in the fight against hepatitis B. In conclusion, we specifically request the following for FY 2012:

- Fund the CDC's Division of Viral Hepatitis at $25 million;
- Language urging the HHS and the National Center for Chronic Disease Prevention to help

insure that the Prevention and Public Health Funds, particularly the Community Transformations Grants, are available to support viral hepatitis prevention projects.

- Initiate global programs at the CDC to increase the rate of vaccination, reduce mother -child transmission and promote educational programs to prevent the disease and to reduce discrimination targeted against individuals with the disease;

- Provide $35 billion for the National Institutes of Health, including a $9.7 million increase per year for hepatitis B research;

- Establish a targeted cancers program at the NCI; and

- Fund a series of Specialized Programs of Research Excellence (SPOREs) focused on liver cancer at the NCI.

The Hepatitis B Foundation appreciates the opportunity to provide testimony to you on behalf of our constituents and yours.

Thank you.

Working Together. Saving Lives.

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Walter Graham, Executive Director

STATEMENT

OF

THE UNITED NETWORK FOR ORGAN SHARING

PRESENTED

TO

THE UNITED STATES HOUSE OF REPRESENTATIVES

COMMITTEE ON APPROPRIATIONS

SUBCOMMITTEE ON LABOR,

HEALTH AND HUMAN SERVICES,

EDUCATION AND RELATED AGENCIES

BY

MARY ELLISON, ACTING EXECUTIVE DIRECTOR

APRIL 15, 2011

Mr. Chairman and Members of the Subcommittee, thank you for giving the United Network for Organ Sharing (UNOS) the opportunity to provide testimony as the Subcommittee begins to consider funding priorities for Fiscal Year (FY) 2012. My name is Mary Ellison and I am the Acting Executive Director of UNOS, the organization with the federal contract to coordinate the nation's organ transplant system, providing vital services to meet the needs of men, women and children awaiting lifesaving organ transplants. Based in Richmond, Va., UNOS is a private, nonprofit membership organization. UNOS members encompass every transplant hospital, tissue matching laboratory and organ procurement organization in the United States, as well as voluntary health and professional societies, ethicists, transplant patients and organ donor advocates.

Transplantation has saved and enhanced the lives of more than 450,000 people in the United States. It is the leading form of treatment for many forms of end-stage organ failure. With this success, however, has come increasing demand for donated organs. Living donation (transplanting all or part of an organ from a living person) has increased dramatically in the last few years, helping increase the number of transplants performed. In addition, UNOS has enacted a number of policies to encourage more efficient use of available organs, such as "splitting" livers from deceased donors to allow two recipients to be transplanted. The only long-term solution to the organ shortage, however, is for more people to agree to become organ donors. UNOS works closely with medical professionals to increase their understanding and support of the organ donation process.

Mr. Chairman, as you know the primary federal agency with jurisdiction over organ transplantation issues is the Health Resources Services Administration. However, as we will describe below, the Office of the Secretary and NIH also have important roles to play to help people in need of an organ transplant.

HEALTH RESOURCES SERVICES ADMINISTRATION

Even with advances in the use of living liver donors, the increase in the demand for organs needed for transplantation will continue to exceed the number available. The need to increase the rate of organ donation is critical. On April 11, 2011 there were 110,676 men, women and children on the national transplantation waiting list. Last year an average of 74 patients were transplanted each day; however a daily average of 18 patients died because the organ they needed did not become available in time to save them. HRSA's Division of Transplantation has a proven track record of successfully increasing the rate of organ donation with limited resources.

Recognizing the importance of this issue, Congress passed, and the President signed, the Organ Donation and Recovery Improvement Act of 2004 (P.L. 108-216) authorizing an increase of $25 million for organ donation activities in the first year, and such sums as necessary in following years, and yet, it was only last year that additional funding of $1 million has been provided to implement this legislation. To address these needs, UNOS recommends that the Division of Transplantation receive a $2 million increase in FY 2012, to allow the Division to more aggressively pursue program efforts to increase the supply of organs available for transplantation.

In addition, the shortage of organs for donation can be positively impacted by healthcare professionals, particularly physicians, nurse, and physician assistants that are frequently the first to identify and refer a potential donor. These professionals also have an established relationship with the family members

that weigh the option to donate their loved one's organs. In order to improve the knowledge and skills of the several key health professions, UNOS requests funding to develop curriculum and continuing medical education programs for targeted health professions. To launch a new five year effort to improve the competency of health professionals to help meet the goal of increasing the number or organs available for transplantation $450,000 is requested for the United Network for Organ Sharing (UNOS) to be made available from within the base funding of the Division of Health Professions based on the authority provided in Section 765 of Title VII to improve the workforce.

OFFICE OF THE SECRETARY

On March 3, 2008 the Department published a Request for information in the Federal Register to gather information to assist the Department to determine whether it should engage in a rulemaking with respect to vascularized composite allografts (VCAs). Three years later, the Department still has not finalized this decision. As it currently stands, the Food and Drug Administration has jurisdiction over VCA transplants, as they are currently defined as human tissue. However, as the numbers of these transplants are growing, finalizing the decisions associated with this issue and allowing HRSA's Division of Transplantation to have jurisdiction over VCA's will permit this category of transplants to benefit from the policy oversight and expertise of the Organ Procurement Transplant Network (OPTN).

Worldwide there have been more than two dozen limb transplants, a growing number of transplants of portions of the face, and a small number of transplants of other anatomical parts. Although the body parts vary significantly, they share important common characteristics with organ transplantation. As with organs, the VCA graft is subject to damage or death from the lack of blood flow and the need for revascularization is done through a surgical reconnection of blood vessels. Additionally, all the expertise and skills of health care professional trained to work with families, individuals and hospitals in the organ donation and procurement process are also needed in the donation and procurement of VCAs. All of these vital activities are already performed and overseen by the organ transplant community. Further, for 25 years the OPTN has overseen the processes and crafted policies to regulate them under federal contract. It therefore seems logical, efficient and will serve the best interests of patients and the nation's transplant system to bring VCAs under the umbrella of the OPTN.

UNOS urges the Office of the Secretary to take action on this decision, and issue the rule and begin the necessary process of amending the definition of human organs. This is especially critical given the recent activities of private entities that, lacking federal leadership, have begun taking the necessary steps to form registries for VCAs. As we learned over 20 years ago when the OPTN was established, it is crucial to have government oversight over registries such as this in order to establish fair and ethical distribution of body parts.

NATIONAL INSTITUTES OF HEALTH

Mr. Chairman, as you know, the National Institute of Allergy and Infectious Diseases has jurisdiction over transplantation research at the NIH. Recent research funded by NIAID has resulted in the development

of desensitization protocols related to kidney transplantation that have shown remarkable progress in helping allow the most vulnerable of patients live with a transplant. Up to 30% of the people on the renal transplant waiting list--without special intervention-- will likely never have the chance to receive a transplant due to an inability to find a compatible donor. These patients have become "sensitized" to human antigens (HLA) through pregnancy, transfusions, or prior transplants and therefore must wait significantly longer for a compatible donor. This added time on the wait list directly increases both their disease-related complications and mortality.

To improve access to transplantation for most these broadly sensitized patients, desensitization protocols have evolved to decrease the breadth and strength of their antibodies. Survival rates are excellent, equaling or exceeding the rates for kidney transplantation generally. It is reasonable to estimate that if these protocols were confirmed to be as safe and effective as early peer reviewed data has suggested, a large number of these long-suffering people could be successfully transplanted and removed from the waiting list each year. UNOS recommends that NIAID support a multi-center initiative with a companion data collection and analysis center to facilitate the use of this protocol at an increasing number of transplant centers across the country.

SUMMARY AND CONCLUSION

Mr. Chairman, again we wish to thank the Subcommittee for the opportunity to submit testimony and for your leadership in these difficult times. While UNOS recognizes the demands on our nation's resources, we believe the ever-growing waiting list for organs for transplantation, and the number of people that die every day just waiting for an organ, continue to justify higher funding levels for HRSA's Division of Transplantation

In conclusion, we specifically request the following for FY 2012:

- A $2 million increase for HRSA's Division of Transplantation;
- $450,000 from within the base funding of the Division of Health Professions to develop curriculum and continuing medical education programs for targeted health professions;
- Report Language urging the Office of the Secretary to finalize a decision to amend the definition of human organs to include vascularized composite allografts, and allow this category to come under the umbrella of the OPTN; and
- Report Language within the National Institute of Allergy and Infectious Disease to support a multi-center initiative focused on "desensitizing "patients previously found incompatible with most human organs.

STATEMENT

OF

THE NATIONAL HEALTHY MOTHERS, HEALTHY BABIES COALITION

PRESENTED

TO

THE UNITED STATES HOUSE OF REPRESENTATIVES

COMMITTEE ON APPROPRIATIONS

SUBCOMMITTEE ON LABOR,

HEALTH AND HUMAN SERVICES,

EDUCATION AND RELATED AGENCIES

BY

JUDY MEEHAN, CHIEF EXECUTIVE OFFICER

APRIL 15, 2011

Mr. Chairman and Members of the Subcommittee, thank you for giving the National Healthy Mothers, Healthy Babies Coalition (HMHB) the opportunity to provide testimony as the Subcommittee begins to consider funding priorities for Fiscal Year (FY) 2012. My name is Judy Meehan and I am the Executive Director of HMHB, an organization founded in 1981, prompted by the US Surgeon General's conference on infant mortality. Since it's founding, HMHB has become a recognized leader and resource in maternal and child health, reaching an estimated 10 million health care professionals, parents, and policymakers through its membership of over 100 local, state and national organizations.

Mr. Chairman, I would like to limit my testimony today to discuss an exciting program of HMHB, referred to as the text4baby program. This program is focused on improving the health outcomes of mothers and babies and demonstrating the potential of mobile health technology to reach underserved populations with critical health information. Of the 33 countries that the International Monetary Fund describes as "advanced economies" the United States now has the highest infant mortality rate according to data from the World Bank. In 1980, we were 13th and in 2000 we were 2nd. In the U.S. approximately 28,000 babies die before their first birthday, despite a volume of science around behaviors that improve a baby's chances for a healthy birth and opportunity to thrive. The text4baby program was launched to help address this problem.

Though the text4baby program has been wholly financed by generous funding from Johnson & Johnson, with technical and in-kind support from Voxiva and CTIA – The Wireless Foundation, we are hopeful that with your leadership, the Bureau of Maternal and Child Health can commit to helping us expand this program in two states where there is demonstrated and significant need. The Maternal and Child Health Block Grant program provides a flexible source of funding that allows States to target their most urgent maternal and child health needs. The program supports a broad range of activities including reducing infant mortality. HMHB recommends that funding from within the base of the block grant's Special Projects of Regional and National Significance (SPRANS) be provided to text4baby so that enrollment in this program could be expanded to targeted and special populations in Louisiana and Mississippi, the two states that have the worst infant mortality outcomes. Mr. Chairman, HMHB also recommends FY 2012 funding for the Maternal and Child Health Block Grant program of $695 million, an increase of $33 million or 5% above the level provided in the FY 2011 continuing resolution.

TEXT4BABY PROGRAM

Text4baby, a free mobile information service designed to promote maternal and child health, was developed to deliver evidence-based health information to the women who need it most: the 1.5 million women on Medicaid who give birth each year. While many of these women may lack access to the Internet and other sources of health information, the vast majority of them do have a cell phone, and a reported 80% of Medicaid beneficiaries are active texters. Text4baby provides pregnant women and new moms with information they need to take care of their health and give their babies the best possible start in life. Women who sign up for the service receive free SMS text messages each week, timed to their due date or baby's date of birth. Since its launch in February 2010, text4baby has enrolled over 157,000 users and delivered over 12 million evidence-based tips to help them women keep themselves and their babies healthy. That's a great start but it's not enough. Thanks to the grassroots efforts of more than 500 text4baby partners across the country, we are on track to achieve our goal of

bringing the service to 1 million moms by 2012 and delivering over 100 million timely and relevant health messages.

The text4baby program was developed in collaboration with the Centers for Disease Control and Prevention (CDC), Health Resources and Services, Administration (HRSA), American Academy of Pediatrics (AAP), and other experts. Text4baby messages cover topics like immunization, nutrition, smoking cessation, safe sleep, and the importance of early prenatal care. The content also connects women to services such as health insurance, childcare, and toll-free "quitlines" for assistance in becoming smoke- and drug-free. Text4baby has also delivered urgent infant product alerts at the request of the Food and Drug Administration and outbreak and immunization alerts at the request of CDC. Just last month, text4baby moms saw: "Breaking news! The American Academy of Pediatrics announced new car seat guidelines. Kids should now ride in rear facing-car safety seats until AGE 2."

EVALUATION OF THE PROGRAM

Mr. Chairman, we know that the program is effective. Over 96% of those enrolled in the program say they would refer a friend to the service. Also, preliminary data analysis indicates that text4baby is reaching the target audience: for example, analysis of enrollment data in Virginia showed that text4baby utilization is highest in zip codes with lower income levels and higher incidence rates of low birth weight babies. However, we also want to understand if and how text4baby is improving knowledge and changing behavior. There are currently six formal evaluations underway to examine text4baby's impact. The largest study, funded by the Department of Health and Human Services (HHS) and conducted by Mathematica Policy Research, is a mixed mode study and includes a mobile survey of text4baby users, focus groups, a community survey, electronic health record review, and interviews with key partners. This study will assess utilization of recommended care during prenatal and postpartum periods (considering things such as prenatal visits, postpartum visit, well-child visits, dental visits, and immunization); adherence to recommended health practices (such as breastfeeding and infant sleep position); and adoption of healthy behaviors (such as smoking cessation, healthy eating and exercise).

Even before the formal study results are in, we know that delivering over 12 million important evidence-based health tips to 157,000 individuals (and, by the end of next year, 100 million messages to 1 million moms) is an important national service.

EXPANDING THE PROGRAM

Glaring disparities in infant mortality exist within certain populations in the United States suggesting the need for a targeted expansion of the program. For example, babies born to African American mothers are most at risk with a rate of 13.5 deaths per 1,000 births. The States with the highest rates of infant mortality are Louisiana (10 babies per 1,000 died before their first birthday) and Mississippi (10.5 babies per 1,000 died before their first birthday). In order to demonstrate the full impact of text4baby, HMHB proposes a targeted outreach and support initiative in those two States. Specifically, HMHB proposes to leverage its great array of activities at the national, regional, state, and local level to meet the ultimate goal of seeing that every woman in Louisiana and Mississippi who is pregnant or a mother of a child less than one year enrolls in the service and receives the valuable health information she needs. This targeted outreach will include the development of state-wide

implementation teams, technical assistance in the way of event planning and media relations, fulfillment of requests for information, speakers and promotional materials, and support for local data and assessment activities. It will also include targeted outreach for African-American and Hispanic communities. HMHB's zip-code based analysis will allow tracking of the impact of targeted outreach activities with enrollment in real time.

MISSISSIPPI AND LOUISIANA STATISTICS

Since its launch in February 2010, text4baby has enlisted 1,276 users in Mississippi and over 2,768 users in Louisiana; however, in 2007, 46,491 babies were born in Mississippi and 66,301 babies were born in Louisiana. So, clearly, there is work to be done to increase enrollment in these states. Unfortunately, these two states are among the bottom in the Nation in terms of preterm births, low birth weight, and rates of death among children before their first birthday. They are also among the top in terms of smoking and obesity rates (see table below). These are two states in desperate need of a new way to receive information to help them care for their health and give their babies the best possible start in life.

	Mississippi	Louisiana	National
Preterm	18.3%	16.6%	12.7%
Low birth weight	12.3	11.2	8.2
IMR	10.5	10.0	6.7
Women smokers	21.9	22.1	19.6
Men smokers	27.2	25.1	19.6
Obesity in women	37.1	31.5	24.4

SUMMARY AND CONCLUSION

Mr. Chairman, again we wish to thank the Subcommittee for the opportunity to submit testimony and for your leadership in these difficult times. While HMHB recognizes the demands on our nation's resources, we believe the continuing decline of our nation's health and the increase in infant mortality justifies a targeted and specific effort. In conclusion, we specifically urge that funding from within the Maternal and Child Health Bureau's SPRANS program be made available for a targeted effort to increase program enrollment among disproportionately impacted populations in Louisiana and Mississippi, the two states with the worst overall outcomes. We also recommend that $695 million be provided in FY 2012 for the Maternal and Child Health Block Grant Program, an increase of $33 million or 5% over the FY 2011 continuing resolution.

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, 202-863-2512

The American Congress of Obstetricians and Gynecologists, representing 54,000 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 Rehberg, 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 outcomes through more research and better data, and we urge you to make this a top priority in FY12.

Research is critically needed to understand why our maternal and infant mortality rate remains comparatively high. Having better data collection methods and comprehensive maternal mortality reviews has shown maternal mortality rates in some states, such as California, to be higher than previously thought. States without these resources are likely underreporting maternal and infant deaths and complications from childbirth. Without accurate data, the full range of causes of these deaths remains unknown. Effective research based on comprehensive data is a key MOMS element to developing and implementing evidence-based interventions.

The President's budget for FY12 takes a positive first step towards this goal, including a $1 billion increase for NIH, and ACOG requests the Subcommittee build on these increases to sustain the investment for women's health. Please note that given the current fiscal climate, our requests are more conservative this year and do not reflect the actual need in the health community. ACOG asks for a 1.7% increase over FY10 to the NICHD within NIH to $1.352 billion, a 2.3% increase for HRSA to $7.65 billion, a 19% increase for CDC to $7.7 billion, and a 2% increase for AHRQ to $405 million.

Funding of research and programs in the following areas are vital to the MOMS Initiative:

Maternal Mortality Reviews at HHS

National data on maternal mortality is inconsistent and incomplete due to the lack of standardized reporting definitions and mechanisms. To capture the accurate number of maternal deaths and plan effective interventions, maternal mortality should be addressed through multiple, complementary strategies. ACOG recommends that HHS fund states in implementing maternal mortality reviews that would allow them to conduct regular reviews of all deaths within the state to identify causes, factors in the communities, and strategies to address the issues. Combined with adoption of the recommended birth and death certificates in all states and territories, CDC could then collect uniform data to calculate an accurate national maternal

mortality rate. Results of maternal mortality reviews will inform research needed to identify evidence based interventions addressing causes and factors of maternal mortality and morbidity.

ACOG urges Congress to provide $10 million to Health and Human Services to assist states in setting up maternal mortality reviews. ACOG also urges Congress to provide $50,000 to NIH to hold a workshop to identify definitions for severe maternal morbidity and $100,000 to HHS to develop a research plan to identify and monitor severe maternal morbidity.

Maternal/Child Health Research at the NIH
The *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) conducts the majority of women's health research. Despite the NIH's critical advancements, reduced funding levels have made it difficult for research to continue.

ACOG supports a 1.7% increase in funds over FY10 to $1.352 billion for the NICHD. A modest increase, these funds will assist the following research areas critical to the MOMS Initiative:

Reducing the Prevalence of Premature Births
There is a known link between pre-term birth and infant mortality, and women of color are at increased risk for delivering pre-term. NICHD is helping our Nation understand how adverse conditions and health disparities increase the risks of premature birth in high-risk racial groups, and how to reduce these risks. Prematurity rates have increased almost 35% since 1981, accounting for 12.5% of all births, yet the causes are unknown in 25% of cases. Preterm births cost the nation $26 billion annually, $51,600 for every infant born prematurely. Direct health care costs to employers for a premature baby average $41,610, 15 times higher than the $2,830 for a healthy, full-term delivery.

Additional research is critically needed to understand how we can drive down our prematurity rates and NICHD conducts the majority of this research. For example, a 2003 NICHD study showed that progesterone supplementation reduces preterm birth in a select group of women, paving the way for its widespread clinical use. Today, around 139,000 (3.3%) women are candidates for this therapy. Among these women, 22%, or about 30,500, are likely to have a recurrent preterm birth without this treatment. With treatment, about one third, or 10,000, of these preterm births can be prevented. The prevention of all 10,000 preterm births would result in direct medical cost savings of $334 million and total medical cost savings of $519 million. However, further studies are needed to determine if progesterone therapy can be designed to help prevent preterm delivery in other ways, including optimal preparation, dosage, and route of administration. The high cost of prematurity and past successful research at NICH highlights the need to sustain investments to reduce the rate of prematurity.

ACOG supports the Surgeon General's effort to make the prevention of pre-term birth a national public health priority, and urges Congress to allocate $1 million to NICHD to create a Trans-disciplinary Research Center on Prematurity to help streamline efforts to reduce pre-term births.

Obesity Research, Treatment and Prevention
Obese pregnant women are at higher risk for poor maternal and neonatal outcomes. Additional research and interventions are needed to address the increased risk for poor outcomes in obese

women receiving infertility treatment, the increased incidence of birth defects and stillbirths in obese pregnant women, ways to optimize outcomes in obese women who become pregnant after bariatric surgery, and the increased future risk of childhood obesity in their offspring.

ACOG is grateful to the NIH for making obesity a priority and initiating trans-disciplinary approaches to combat obesity. The recent release of the Strategic Plan for NIH Obesity Research offers some innovative and promising directions for obesity research, and sustained funding is critical to implement the plan.

Training Programs
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. The NICHD-coordinated Women's Reproductive Health Research (WRHR) Career Development program seeks to increase the number of ob-gyns conducting scientific research in women's health in order to address this gap. To date 170 WRHR Scholars have received faculty positions, and 7 new and competing WRHR sites were added in 2010.

Additional funding to add new sites can help sustain this low-dollar, large impact training program while at the same time shoring up the women's reproductive research workforce.

Maternal/Child Health Programs at CDC:
CDC funds programs that are critical to providing resources to mothers and children in need. Where NIH conducts research to identify causes of pre-term birth, CDC funds programs that provide resources to mothers to help prevent pre-term birth, and help identify factors contributing to pre-term birth and poor maternal outcomes.

ACOG supports a 19% increase in funds over FY10 to $7.7 billion to increase CDC's ability to bring prevention, treatment and interventions to more women and children in need, and to help enact some of the important provisions within health care reform. This funding will help the following programs important to the MOMS Initiative:

Electronic Birth Records and Death Records, National Center for Health Statistics (NCHS), National Vital Statistics System (NVSS)
NCHS is the nation's principal health statistics agency; it collects, analyzes and reports on data critical to all aspects of our health care system. NCHS collects state data needed to monitor maternal and infant health, such as use of prenatal care, and smoking during pregnancy. This data allows investigators to monitor maternal and child health objectives, and develop efficient prevention and treatment strategies.

Uniform consistent data from birth and death records is critical to conducting research and directing public programs to combat maternal and infant death. Only 75 percent of states and territories use the 2003-recommended birth certificates and 65 percent have adopted the 2003-recommended death certificate. The President recently issued a Memorandum to all departments and agencies encouraging expanded data collection on maternal mortality by using the 2003-US

standard birth certificate and updating to electronic systems, noting that until all states adopt the same data standards it will be difficult to formulate national maternal mortality ratios.

ACOG urges Congress to allocate $11 million for states to modernize their birth and death records systems to the 2003-recommended guidelines. It is a low cost that will yield enormous gains in CDC's ability to collect accurate data nationally and better direct medical research and best practice for physicians.

Safe Motherhood/Infant Health
2-3 women a day die from delivery complications. The Safe Motherhood Program supports CDC's work to identify and gather information on pregnancy-related deaths; collect and provide information about women's health and health behaviors around pregnancy; and expand the use of guidelines on preconception care into everyday practice and health care policy.

Safe Motherhood also tracks infant morbidity and mortality associated with pre-term birth. ACOG is concerned with recent trends particularly among rates of late pre-term births. Increased funding is needed for CDC to improve national data systems to track pre-term birth rates and expand epidemiological research that focuses especially on the causes and prevention of preterm birth and births at 37-38 weeks gestation.

ACOG urges Congress to include a 23.7% increase in funds to $55.4 million for Safe Motherhood, consistent with the President's FY11 budget.

Maternal/Child Health Programs at HRSA
HRSA delivers critical resources to communities to improve the health of mothers and children. ACOG urges a 2.3% increase in funds over FY10 to $7.65 billion to increase the scope of HRSA programs, ultimately bringing more resources to more mothers and children. This funding will help expand the following programs important to the MOMS Initiative:

Fetal Infant Mortality Reviews, Healthy Start Program
The U.S. infant mortality rate is again on the rise and is particularly severe among minority and low-income women. The infant mortality rate among African American women has been increasing since 2001 and reached 14.2 deaths per 1,000 births in 2004. There also has been a startling rise in infant mortality in the South in the past few years.

The Healthy Start Program through HRSA promotes community-based programs that focus on infant mortality and racial disparities in perinatal outcomes. These programs are encouraged to use the Fetal and Infant Mortality Review (FIMR) which brings together ob-gyn experts and local health departments to help solve problems related to infant mortality. Today more than 220 local programs in 42 states find FIMR a powerful tool to help solve infant mortality.

ACOG urges Congress to include $.5 million for Healthy Start Programs to include FIMR.

Maternal Child Health Block Grant (MCH)
The MCH is the only federal program that exclusively focuses on improving the health of mothers and children. State and territorial health agencies and their partners use MCH Block

Grant funds to reduce infant mortality, deliver services to children and youth with special health care needs, support comprehensive prenatal and postnatal care, screen newborns for genetic and hereditary health conditions, deliver childhood immunizations, and prevent childhood injuries.

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 programs for women with diabetes can reduce health costs by up to $5.19 by preventing costly complications in both mothers and babies. Studies also suggest that every $1 spent on smoking cessation counseling for pregnant women saves $3 in neonatal intensive care costs.

ACOG urges Congress to increase funding for MCH $700 million, a 5.74% increase over FY10.

Title X Family Planning

The Title X program provides contraceptive services, immunizations and other preventive health care, including screenings for STDs, HIV, breast cancer, cervical cancer, high blood pressure, and anemia to more than five million low-income men and women at more than 4,500 service delivery sites. These programs improve maternal and child health outcomes, prevent unintended pregnancies, and reduce the rate of abortions. 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 a 3.15% increase in funds for Title X to $327 million, consistent with the President's budget.

Best Practices and Comparative Effectiveness Research at AHRQ and CMS

There are glaring disparities in maternal outcomes among different ethnic and racial groups, particularly related to pre-term birth and maternal and infant mortality rates among African American women. For that reason, disparities research is a major tenant of ACOG's MOMS Initiative. Comparative effectiveness research has the capacity to greatly improve pre-term birth rates and maternal and infant mortality rates by testing the efficacy of prevention and treatment interventions on different populations.

Continued investment is also needed to fully update, maintain, and implement existing measures, and develop and test new quality measures. This work would be aided by additional support to establish regional quality improvement initiatives to research and pilot evidence-based quality improvement projects. Ohio, starting in 2007 with funding from CDC, established the multi-stakeholder Ohio Perinatal Quality Collaborative to improve maternal and infant health outcomes. The 21 OB teams in 25 participating hospitals have successfully decreased scheduled deliveries between 36 and 39 weeks gestation, in accordance with ACOG guidelines, and thus reducing costly pre-term births.

ACOG supports a 2% increase in funds for AHRQ to $405 million, consistent with the President's budget.

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 FY12.

AMERICAN NURSES ASSOCIATION

Testimony of the American Nurses Association Regarding
Fiscal Year 2012 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

April 15, 2011

Submitted by:
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The American Nurses Association (ANA) appreciates the opportunity to comment on Fiscal Year (FY) 2012 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 3.1 million registered nurses (RNs) 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. Registered nurses are fundamental to the critical shift needed in health services delivery, with the goal of transforming the current "sick care" system into a *true* "health care" system. RNs 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 support, development and deployment of this keystone profession is essential for any quality health reform plan to succeed. The ANA gratefully acknowledges this Subcommittee's history of support for nursing education. We also appreciate your continued recognition of the important role nurses play in the delivery of quality health care services, including Nurse-Managed Health Clinics (NMHCs).

The Nursing Shortage
A sufficient supply of nurses is critical in providing our nation's population with quality health care. Registered Nurses (RNs) and Advanced Practice Registered Nurses (APRNs) play an integral role in the delivery of primary care and help to bring the focus of our health care system back where it belongs—on the patient and the community. The current U.S. nursing shortage is already having a detrimental impact on our health care system, and it is expected to grow to a

260,000 nurse shortfall by 2025. 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.

As noted above, the nursing shortage is having a detrimental impact on the entire health care system. Numerous studies have shown that nursing shortages contribute to medical errors, poor patient outcomes, and increased mortality rates. A study published in the March 17, 2011 issue of the *New England Journal of Medicine* shows that inadequate staffing is tied to higher patient mortality rate. 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.

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.) support the supply and distribution of qualified nurses to meet our nation's healthcare needs. Over the last 46 years, Title VIII programs have addressed each aspect of the nursing shortages – education, practice, retention, and recruitment.

- Title VIII provides **the largest source of federal funding for nursing education**, offering financial support for nursing education programs, individual students, and nurses.
- These programs bolster nursing education at all levels, from entry-level preparation through graduate study.
- Title VIII programs favor institutions that educate nurses for practice in **rural and medically underserved communities.**
- In FY 2008, these programs provided loans, scholarships, traineeships, and programmatic support to **77,395 nursing students and nurses.**

The 107th Congress recognized the detrimental impact of the developing nursing shortage and passed the Nurse Reinvestment Act (PL 107-205). This law improved the Title VIII Nursing Workforce Development programs to meet the unique characteristics of today's shortage. These programs were also strengthened and reauthorized with the adoption of the Affordable Care Act. This achievement holds the promise of recruiting new nurses into the profession, promoting career advancement within nursing and improving patient care delivery. However, this promise cannot be met without a significant investment. **ANA strongly urges Congress to increase funding for Title VIII programs to a total of $313.075 million in FY 2012. This is also the amount requested in President Obama's FY 2012 Budget.**

Current funding levels are clearly failing to meet the need. In FY 2008 (most recent year statistics are available), the Health Resources and Services Administration (HRSA) was forced to turn away 92.8% of the eligible applicants for the Nurse Education Loan Repayment Program (NELRP), and 53% of the eligible applicants for the Nursing Scholarship program due to a lack of adequate funding. These programs are used to direct RNs into areas with the greatest need – including departments of public health, community health centers, and disproportionate share hospitals.

In 1973, Congress appropriated $160.61 million to Title VIII programs. Inflated to today's dollars, this appropriation would equal $818.08 million, more than three times the FY 2010 appropriation. Certainly, today's shortage is more dire and systemic than that of the 1970's; it deserves an equivalent response.

Title VIII includes the following program areas:
Nursing Education Loan Repayment Program & Scholarships: This line item is comprised of the Nurse Education Loan Repayment Program (NELRP) and the Nursing Scholarship Program (NSP). In FY 2010, the Nurse Education Loan Repayment Program and Scholarships received $93.8 million.

The NELRP repays up to 85 percent of a RN's student loans in return for full-time practice in a facility with a critical nursing shortage. The NELRP nurse is required to work for at least two years in a designated facility, during which time the NELRP repays 60 percent of the RN's student loan balance. If the nurse applies and is accepted for an optional third year an additional 25 percent of the loan is repaid.

The NELRP boasts a proven track record of delivering nurses to facilities hardest hit by the nursing shortage. HRSA has given NELRP funding preference to RNs who work in departments of public health, disproportionate share hospitals, skilled nursing facilities, and federally-designated health centers. However, lack of funding has hindered the full implementation of this program. In FY 2008, 92.8 percent of applicants willing to immediately begin practicing in facilities hardest hit by the shortage were turned away from this program due to lack of funding.

The NSP offers funds to nursing students who, upon graduation, agree to work for at least two years in a health care facility with a critical shortage of nurses. Preference is given to students with the greatest financial need. Like the loan repayment program, the NSP has been stunted by a lack of funding. In FY 2008, HRSA received 3,039 applications for the nursing scholarship. Due to lack of funding, a mere 177 scholarships were awarded. Therefore, 2,862 nursing students (94 percent) willing to work in facilities with a critical shortage were denied access to this program.

Nurse Faculty Loan Program: This program establishes a loan repayment fund within schools of nursing to increase the number of qualified nurse faculty. Nurses may use these funds to pursue a master's or doctoral degree. They must agree to teach at a school of nursing in exchange for cancellation of up to 85 percent of their educational loans, plus interest, over a four-year period. In FY 2010, this program received $25 million.

This program is vital given the critical shortage of nursing faculty. America's schools of nursing cannot increase their capacity without an influx of new teaching staff. Last year, schools of nursing were forced to turn away tens of thousands of qualified applicants due largely to the lack of faculty. In FY 2008, HRSA funded 95 faculty loans.

Nurse Education, Practice, and Retention Grants: This section is comprised of many programs designed to support entry-level nursing education and to enhance nursing practice. The

education grants are designed to expand enrollments in baccalaureate nursing programs, develop internship and residency programs to enhance mentoring and specialty training, and provide new technologies in education including distance learning. All together, the Nurse Education, Practice, and Retention Grants supported 42,761 nurses and nursing students in FY 2008. The program received $39.8 million in FY 2010.

Retention grant areas include career ladders and improved patient care delivery systems. The career ladders program supports education programs that assist individuals in obtaining the educational foundation required to enter the profession and to promote career advancement within nursing. Enhancing patient care delivery system grants are designed to improve the nursing work environment. These grants help facilities to enhance collaboration and communication among nurses and other health care professionals, and to promote nurse involvement in the organizational and clinical decision-making processes of a health care facility. These best practices for nurse administration have been identified by the American Nurse Credentialing Center's Magnet Recognition Program®. These practices have been shown to double nurse retention rates, increase nurse satisfaction, and improve patient care.

Nursing Workforce Diversity: This program provides funds to enhance diversity in nursing education and practice. It supports projects to increase nursing education opportunities for individuals from disadvantaged backgrounds - including racial and ethnic minorities, as well as individuals who are economically disadvantaged. In FY 2008, 85 applications were received for workforce diversity grants, 51 were funded. In FY 2010, these programs received $16 million.

Advanced Nursing Education: Advanced practice registered nurses (APRNs) are nurses who have attained advanced expertise in the clinical management of health conditions. Typically, an APRN holds a master's degree with advanced didactic and clinical preparation beyond that of the RN. Most have practice experience as RNs prior to entering graduate school. Practice areas include, but are not limited to: anesthesiology, family medicine, gerontology, pediatrics, psychiatry, midwifery, neonatology, and women's and adult health. Title VIII grants have supported the development of virtually all initial state and regional outreach models using distance learning methodologies to provide advanced study opportunities for nurses in rural and remote areas. In FY 2009, 5,649 advanced education nurses were supported through these programs. In FY 2010, these programs received $64.4 million.

These grants also provide traineeships for master's and doctoral students. Title VIII funds more than 60 percent of U.S. nurse practitioner education programs and assists 83 percent of nurse midwifery programs. Over 45 percent of the nurse anesthesia graduates supported by this program go on to practice in medically underserved communities. A study published in the *Journal of Rural Health* showed that 80 percent of the nurse practitioners who attended a program supported by Title VIII chose to work in a medically underserved or health profession shortage area after graduation.

Comprehensive Geriatric Education Grants: This authority awards grants to train and educate nurses in providing health care to the elderly. Funds are used to train individuals who provide direct care for the elderly, to develop and disseminate geriatric nursing curriculum, to train

faculty members in geriatrics, and to provide continuing education to nurses who provide geriatric care. In FY 2008, 6,514 nurses and nursing students were supported through these programs. In FY 2010, these grants received $4.5 million. The growing number of elderly Americans and the impending health care needs of the baby boom generation make this program critically important.

Nurse-Managed Health Clinics

A health care system must value primary care and prevention to achieve improved health status of individuals, families and the community. As Congress recognized through the passage of the Affordable Care Act (ACA) money, resources and attention must be reallocated in the health system to highlight importance of, and create incentives for, primary care and prevention. 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 money 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, sensible, cost-effective way to deliver primary health care services. These clinics are also used as clinical sites for nursing education. The nurse-managed care model is especially effective in disease prevention and early detection, management of chronic conditions, treatment of acute illnesses, health promotion, and more. Nurse Managed Health Centers (NMHCs) can also provide a medical home for underserved individuals as well as partnering with the Federal Government to reduce health disparities.

ANA was pleased to see that the Affordable Care Act (ACA) provided grant eligibility to Nurse-Managed Health Clinics (NMHCs) to support operating costs. ACA also authorized up to $50 million a year to support operating costs. **ANA strongly urges Congress to provide $20 million for the Nurse-Managed Health Clinics authorized under Title VIII of the Public Health Service Act in FY 2012 as recommended in President Obama's FY 2012 budget.**

CONCLUSION

While ANA appreciates the continued support of this Subcommittee, we are concerned that Title VIII funding levels have not been sufficient to address the growing nursing shortage. In preparation for the implementation of health care reform initiatives, which ANA supports, we believe there will be an even greater need for nurses and adequate funding for these programs is even more essential. 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. ANA asks you to meet today's shortage with a relatively modest investment of $313.075 million in FY 2012 for the Health Resources and Services Administration Nursing Workforce Development programs and $20 million for Nurse-Managed Health Clinics. Thank you.

Pancreatic Cancer Action Network
to the
House Subcommittee on Labor, Health and Human Services,
Education and Related Agencies
on behalf of the
National Institutes of Health FY 2012 Budget
April 15, 2011

Mr. Chairman and members of the Subcommittee:

My name is Julie Fleshman and I am submitting this testimony on behalf of the Pancreatic Cancer Action Network.

Founded in 1999, the Pancreatic Cancer Action Network is a nationwide network of individuals dedicated to advancing research, supporting patients and fostering hope for the families and loved ones affected by this disease.

The fourth leading cause of cancer-related death, pancreatic cancer struck more than 43,000 Americans last year, resulting in 36,800 deaths. The similarity of these statistics underscores its deadliness: indeed, most patients die within months of their diagnosis. The five-year survival rate is a meager six percent—a grim statistic that has changed little over the past 40 years. By comparison, the average five-year survival rate for all cancers is now 68 percent.

The fact that pancreatic cancer is so deadly should come as no surprise.

- There are no early detection tools, so by the time a definitive diagnosis is made, they have advanced disease that has spread to other organs, usually too late for effective treatment.

- Little is known about the risk factors associated with pancreatic cancer.

- Pancreatic cancer is difficult to diagnose since the symptoms are abdominal or back pain, weight loss, jaundice, loss of appetite, nausea, and diabetes—all of which could easily be misdiagnosed.

- Finally, pancreatic cancer has shown to be resistant to existing cancer treatments.

Dismal as the picture is today, unless something is done soon, it will only get worse. A recently published study in the *Journal of Clinical Oncology* predicts that the number of new pancreatic cancer cases will increase by 55 percent over the next two decades.

What do we need to do to change the course of this disease?

The answer is two-fold. First, there is no well-defined strategic plan in place to: advance the understanding of the biology of pancreatic cancer, its natural history and the genetic and environmental factors that contribute to its development; expand research on ways to screen and detect pancreatic cancer in much earlier stages; and launch innovative clinical trials to test targeted therapeutics and novel agents that will extend the survival and improve the quality of life of patients.

Second, there must be a robust and sustained commitment of resources. More to the point, the National Cancer Institute only devotes two percent of its total budget to research on pancreatic cancer.

Mr. Chairman, research is the only hope. We ask that you strongly urge the National Cancer Institute to put in place a strategic plan for pancreatic cancer research; strengthen and expand the Special Programs of Research Excellence for pancreatic cancer; and promote physician and public awareness.

Thank you.

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United States House of Representatives

Subcommittee on Labor, Health and Human Services, and Education of the Committee on Appropriations

Hearing on Department of Labor Job Training Programs

Testimony Submitted for the Record
National Skills Coalition

April 7, 2011

In a report issued in January 2011, the Government Accountability Office (GAO) wrote that "[f]ederally funded employment and training programs serve an important role in our society by helping job seekers enhance their job skills, identify job opportunities, and obtain employment."[1] This observation has been amply demonstrated by the substantial increase in demand for services during the recent economic downturn. Last year, more than 8 million U.S. jobseekers were served through programs funded under Title I of the Workforce Investment Act (WIA), a 234 percent increase in participation rates in just two years, while many more received training supported through other Department of Labor (DOL) programs such as Trade Adjustment Assistance (TAA) and the Registered Apprenticeship system. These programs have helped Americans get back to work: despite continued near-record high unemployment nationwide, more than 4.3 million WIA participants found jobs last year, and hundreds of thousands more received training and education that will help them prepare for new career opportunities.

However, these critical programs have come under attack in recent months. The House-passed Fiscal Year (FY) 2011 continuing resolution proposed $3.8 billion in funding cuts for DOL job training programs, including elimination of all Program Year (PY) 2011 appropriations for the WIA Adult, Dislocated Worker, and Youth funding streams—cuts the Appropriations committee characterized as "excess spending."[2] In addition, some lawmakers have suggested that federal job training and employment programs are duplicative or ineffective.[3] While the final CR negotiated by congressional leadership and the Obama administration ultimately rejected many of the unnecessary and unwise funding cuts under H.R. 1, we believe it is important to continue to address these issues as Congress begins to consider appropriations for FY 2012.

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[1] http://www.gao.gov/new.items/d1192.pdf
[2] http://appropriations.house.gov/_files/SummaryFiscalYear2011ContinutingResolutionCR.doc
[3] http://coburn.senate.gov/public//index.cfm?a=Files.Serve&File_id=9f1e1249-a5cd-42aa-9f84-269463c51a7d

Can "Carry-Over" Fund the Workforce System?

The WIA system has always been required, by statute, to obligate at least 80 percent of its funding each year. The system has been allowed to carry over not more than 20 percent of its unobligated funds for 2 additional years. Yet in its summary of program cuts under H.R. 1, the committee justified reductions in WIA formula funding by stating "These programs have significant carryover balances from prior year appropriations and have already received $1.5 billion in advance funding available for the current fiscal year," implying that the workforce system could have been sustained in PY 2011 through a combination of carryover and advanced funding. However, this assumption considers only "unexpended" funds – rather than the more accurate "unobligated" funds – and as a result significantly overstates the availability of such funds.[4] Much of this "carryover" is not really available, though it shows as "unexpended," as it is actually already obligated or encumbered, particularly at this time of increased demand for training services.

DOL reports that the national WIA system *carried over* $1.1 billion from PY 2009 to PY 2010.[5] This $1.1 billion nationwide does not include obligations. Expenditures are a very incomplete picture of money available in the workforce system. Training costs under WIA are often one- to two-year obligations, made to customers to fund tuition, books, fees, etc. However, training costs can't be reported as expenditures until the student can no longer receive a refund on the semester's tuition, the school has invoiced the service provider, and the payment is made. Wages and benefits for staff performing direct customer service at One-Stop Centers cannot be reported as expenditures until paid or accrued. Staffing costs or staffing commitments for the remainder of a program year cannot be reported as an obligation or as an expenditure. Contracts for services (such as IT development and maintenance, or customer support services such as child care) are obligations and not expenditures until billed by the vendor and paid by the provider. All state and local expenditures are reported quarterly, 45 days after a quarter ends. WIA dollars are reported as obligated or as accrued expenditures. Stating there is $1.1 billion *carried over* is like calling the bank for an account balance on June 30th, without accounting for outstanding checks.

Even accounting for just unexpended funds, though, this $1.1 billion figure represents only a 28 percent carryover of the total funds available for these programs in PY 2009. Local areas carried over just 21 percent of funds available in PY 2009—or about $600 million out of $2.8 billion. To suggest that the WIA system can function for an entire year on roughly one-quarter of its regular annual funding is profoundly unrealistic.

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[4] In a 2009 report the GAO wrote, "Labor's process for determining states' available funds considers only expenditures and does not consider the role of obligations in the current program structure... As a result, Labor's estimate of expenditure rates suggests that states are not spending their funds as quickly as they actually are. Labor's Office of the Inspector General has also noted that obligations provide a more useful measure for assessing states' WIA funding status if obligations accurately reflect legally committed funds and are consistently reported."

[5] http://www.doleta.gov/budget/docs/100930_WIA_SpendSum_byPgm_asof_110322_OUT.pdf

In FY 2008, when the WIA system lost $250 million through a rescission of "unexpended funds," $114 million (or nearly half—45 percent) of the $250 million rescission had to be taken from PY 2007 current year funds. The rescission was based on the notion that unexpended balances carried into PY 2007, would cover the rescission, but this proved to be incorrect. A 2008 NASWA survey found that with the exception of three states, all others needed waivers to use PY 2007 funds for the rescission, while nearly 75 percent of local areas had to use PY 2007 funds to pay for the rescission.[6] The carryover that appropriators now point to (based on amounts carried into PY 2010) is about the same amount as that carried into PY 2007—$1.1 billion. If history serves as a guide, this argues that the anticipated carryover at the end of PY 2010 will fall far short of amounts needed to carry the program through PY 2011.

As the committee begins consideration of FY 2012 appropriations for WIA, we strongly urge you to factor obligations and encumbrances into any assumptions regarding the availability of prior year funding to cover proposed reductions. We would also encourage the committee the bear in mind that formula funding under WIA Title I fell by nearly 30 percent in constant dollars between FY 2001-2010;[7] additional reductions in funding are unlikely to lead to meaningful savings when measured against the economic opportunities lost due to more than a decade of disinvestment.

Workforce Programs are Not Duplicative

In its January report, GAO found that there were 47 federally funded employment and training programs offered through nine different federal agencies, and indicated that 44 of those programs—including multipurpose block grant programs such as the Temporary Assistance for Needy Families (TANF)—overlapped with at least one other program in providing at least one similar service to a similar population. One area of particular focus was potential overlap between TANF and the Department of Labor's Wagner-Peyser Employment Service (ES) and Workforce Investment Act (WIA) Adult programs, with GAO noting that these programs can provide some of the same services to the same populations. GAO found that co-locating services and consolidating administrative structures between these three programs may increase efficiencies and reduce program costs, and recommended that the Departments of Labor (DOL) and Health and Human Services (HHS) work together to develop and disseminate information to support such efforts and investigate options to increase state and local incentives for pursuing such strategies.

While it is true that GAO identified some areas of potential overlap between various employment and training programs, it is important to note the report's conclusion that"[e]ven when programs overlap, the services they provide and the populations they serve may differ in meaningful ways."[8] Many of the workforce programs identified by GAO were created by

[6] Personal communication with NASWA staff, March 2011.
[7] http://www.nationalskillscoalition.org/resources/reports/tpib/nsc_tpib_wia_titlei.pdf
[8] http://www.gao.gov/new.items/d1192.pdf

Congress to address the unique needs of targeted populations. For example, nearly a quarter of all funding for employment and training in FY 2009 supported programs that provide services for disabled veterans and other individuals with disabilities. These individuals often face severe challenges entering into and succeeding in the labor market (only 17 percent of all individuals with disabilities were employed in January 2011) and often require highly-specialized services and equipment that cannot easily be provided through more general programs. Targeting resources to these and other at-risk populations maximizes the efficiency of federal investments by identifying barriers that prevent individuals from finding or keeping jobs, and helps ensure that these participants are not marginalized by programs tasked with serving a broader range of jobseekers.

It is certainly true that workforce programs could be better aligned and streamlined to ease access and service delivery for both workers and employers. The GAO makes a number of recommendations that would move the system toward better program alignment; many of these recommendations are already in place at the state and local levels, and multiple federal agencies are similarly focused on improving alignment, increasing efficiency, and streamlining services. These efforts would be greatly strengthened if Congress would take up long overdue reauthorizations of the WIA and TANF program. It is through the reauthorization process—not the appropriations process—that concerns about alignment, overlap, and increased efficiency should be addressed.

Workforce Programs are Effective

In addition to questions about overlap, some policymakers have questioned the effectiveness of federal workforce programs. These concerns are unfounded; research has consistently demonstrated that these programs are not only effective, but result in a significant return on investment for their customers and for society. In a 2010 analysis,[9] Christopher King at the University of Texas and Carolyn Heinrich at the University of Wisconsin-Madison concluded that the return on workforce investments is "particularly remarkable given [the] magnitude and intensity of workforce investments relative to size and complexity of barriers they address." King and Heinrich cite a 2008 study of workforce programs in Texas showing that every dollar invested in workforce services (including WIA programs, Temporary Assistance for Needy Families workforce services, veterans services, employment services and other programs) generated $1.63 for participants, $1.17 for taxpayers and $1.52 for society over five years.[10]

Extensive research demonstrates that individuals who receive services through the workforce system show positive outcomes for both employment and earnings gains. A 2008 DOL report found positive outcomes for WIA Adult program participants, stating "[T]he results… imply large and immediate impacts on earnings and employment for individuals who participate in

[9] http://www.utexas.edu/research/cshr/pubs/pdf/Heinrich and King - How Effective Are Workforce Development Programs.pdf
[10] http://www.spworkforce.org/docs/ROI_State_Rpt_TAWB_Rvd_August_12_08.pdf

the WIA Adult program...Those who obtained training services have lower initial returns, but they catch up to others within ten quarters, ultimately registering larger total gains," of more than $400 to $700 per quarter, and these gains held up over the 16 quarters studied.[11]

Another study conducted in 2005 found that WIA programs lead to positive employment and earnings gains for adults and dislocated workers. The authors concluded that WIA services, including training, are effective interventions for adults and dislocated workers (increasing employment by about 10 percentage points and average quarterly earnings by about $800 (in 2000 dollars), when measured in terms of net impacts on employment, earnings, and receipt of TANF for participants.[12]

Similarly, in his 2011 State of the State address, Mississippi governor Haley Barbour highlighted a study of the state's Workforce Enhancement Training Fund showing that graduates make $4,300 more per year than before that training, and argued that the improved, skilled workforce has been a reason companies like Toyota, GE Aviation, and others have created jobs in Mississippi.[13]

Conclusion

The budget and appropriations process are not the appropriate forum for addressing perceived inefficiencies in federal programs. Instead, as the committee begins the FY 2012 appropriations process, we would urge appropriators to work with the authorizing committees and federal agencies responsible for key workforce programs, including WIA and TANF, to ensure that scarce federal resources are being used to support evidence-based strategies that expand access to job training and related services for all U.S. workers and employers. We would be happy to work with the committee to identify those policies and strategies that would best support our nation's economic recovery and competitiveness goals.

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[11] http://wdr.doleta.gov/research/FullText_Documents/Workforce%20Investment%20Act%20Non-Experimental%20Net%20Impact%20Evaluation%20-%20Final%20Report.pdf

[12] http://wdr.doleta.gov/research/FullText_Documents/Net%20Impact%20Estimates%20for%20Services%20Provided%20through%20the%20Workforce%20Investment%20Act-%20Final%20Report.pdf

[13] http://www.governorbarbour.com/news/2011/jan/1.11.11%20Gov.%20Barbour's%20State%20of%20the%20State%20Address%20TEXT.pdf

April 13, 2011

The Honorable Denny Rehberg
Chairman
House Appropriations Committee-Labor, Health and Human Services, Education, and Related Agencies Subcommittee
2358 Rayburn House Office Building
Washington, DC 20515

The Honorable Rosa DeLauro
Ranking Member
House Appropriations Committee-Labor, Health and Human Services, Education, and Related Agencies Subcommittee
2413 Rayburn House Office Building
District of Columbia 20515

Dear Chairman Rehberg and Ranking Member DeLauro:

The Alliance of Information and Referral Systems (AIRS) thanks you for providing the opportunity to submit testimony as you consider an FY 2012 Labor-HHS, Education Appropriations bill. AIRS is the national voice of Information and Referral/Assistance (I&R/A) services and we provide a professional umbrella for over 1,200 I&R/A providers in both public and private organizations. Our primary purpose for submitting this testimony is to urge you not to cut Title IIIB funding of the Older Americans Act (OAA) as this provides federal funding to the **states** for I&R. President Obama's proposed FY 2012 budget emphasizes an increase in funding of $48 million for Title IIIB of the OAA.

Information and Referral brings people and services together. When people don't know where to turn, I&R /A is there for them. Last year, AIRS members answered more than **20 million** calls for help. Comprehensive and specialized I&R/A programs help people in every community and operate as a critical component of the health and human services delivery system. I&R/A organizations have databases of programs and services and disseminate information through a variety of channels to individuals and communities. People in search of critical services such as, food, shelter, child care, **work and job training**, mental health support often do not know where to begin. More often than not, I&R/A organizations provide the answers.

We encourage you to support a $48 million increase in funding for Title III of the Older Americans Act and at a very *minimum*, not cut funding for I&R/A services. Thank you for your consideration.

Respectfully Submitted,

Robert B. Blancato

Alliance of Information & Referral Systems

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Alliance for Aging Research
Testimony on FY 2012 National Institutes of Health Appropriations

Submitted to:
House Subcommittee on Labor, Health and Human Services,
Education and Related Agencies

Submitted by:
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April 15, 2011

Chairman Rehberg and members of the Subcommittee, for 25 years the not-for-profit Alliance for Aging Research 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 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 increased federal investment and focus to advance scientific discoveries to keep individuals healthier longer.

Research toward healthier aging has never been more critical for so many Americans. In January of 2011, the first of the baby boomers began turning age 65. 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, according to the U.S. Census Bureau. Late-in-life diseases such as type 2 diabetes, cancer, neurological diseases, heart disease, and osteoporosis are increasingly driving the need for healthcare services in this country. Many diseases of these aging are expected to become more prevalent as the number of older Americans increases. Preventing, treating or curing chronic diseases of the aging, is perhaps the single most effective strategy in reducing national spending on health care.

Consider that the number of Americans age 65 and older with Alzheimer's disease is projected to more than double by 2030. A report in the Journal of Clinical Oncology projected cancer incidence will increase by about 45% from 2010-2030, accounted for largely by cancer diagnoses in older Americans and minorities, and by 2030, people aged 65 and older will represent 70% of all cancer diagnoses in the U.S. Currently, the average 75-year old has three chronic health conditions and takes five prescription medications. Six diseases- heart disease,

stroke, cancer, diabetes, Alzheimer's and Parkinson's diseases – cost the U.S. over $1 trillion each year. In the absence of new discoveries to better treat and prevent osteoporosis, it is estimated to cost the U.S. $25.3 billion per year by 2025. According to an Alzheimer's Association report from 2010, research breakthroughs that slow the onset and progression of Alzheimer's disease could yield annual Medicare savings of $33 billion in 2020 and as much as $283 billion by 2050.

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 be the most effective way to postpone all of the physiological disorders of aging through manipulation of the aging rate itself. Researchers have formulated, and are beginning to pursue, new strategies 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 patients 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 the goal of adding healthy years to life, it cannot be achieved in a timely way without significant financial support. In stark contrast to the rapidly-rising costs of healthcare for the aging, we as a nation are making a miniscule, and declining, investment in the prevention, treatment or cure of chronic diseases of aging. Out of

each dollar appropriated to NIH only 3.6 cents goes toward supporting work of the NIA. Between FY 2003 and FY 2010, NIA-funded scientists saw a series of nominal increases and cuts that amounted to a 14.7 percent reduction in constant dollars. The November 11, 2010 issue of *Nature* notes that "[a]lthough the funding situation is tight all around for NIH-supported investigators, the NIA is in an exceptional predicament....As both the US and global populations age, the prevalence of chronic diseases such as cancer, heart disease and diabetes will also grow, along with neurodegenerative ailments....The NIA deals with age-related aspects of all of these."

An increase in funding for aging research is urgently needed to enable scientists to capitalize on the field's recent exciting discoveries. Advocates for age-related diseases like Alzheimer's disease and cancer in the past have called for Congressional appropriations of $2 billion annually in order to achieve major breakthroughs in treating and curing those diseases. Thus, a goal of $2 billion annually in federal funding for aging research on the basic underpinnings of aging over the next 3 to 10 years seems modest considering its great potential to lower overall disease risk (including Alzheimer's, cancer, and more) and add healthy years to life. For the NIA in particular, an increase in funding would enable flexibility in supporting high-quality grant proposals that fall within the 20th percentile of submitted grants. In recent years, the percent of grant applications receiving funding by the NIA has dropped precipitously and currently only the top 9% are being funded. This means that many valuable projects are being set aside due to budget constraints, and many talented scientists who might make major contributions to aging research are being dissuaded from making this their life's work.

In addition to increased resources, the field would also benefit greatly from the creation of a trans-NIH initiative that could improve the quality and pace of research that advances the understanding of aging, its impact on age-related diseases, and the development of interventions to extend human healthspan. The initiative would be most effective if it included the representatives from the National Institute on Aging (NIA) and the major-disease focused institutes that have some role in aging research such as the National Institute of Neurological Disorders and Stroke (NINDS), National Heart, Lung, and Blood Institute (NHLBI), National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), and the National Cancer Institute (NCI).

The field of aging research is poised to make transformational gains in the near future. 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 $35 billion in FY 2012 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 Silver 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.

The payoffs from such focused attention and investment would be large and lasting. Therapies that delay aging would lessen our healthcare system's dependence on the relatively inefficient strategy of trying to redress 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 2012 appropriations for the NIH and we would be happy to furnish additional information upon request.

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Fiscal Year 2012 Appropriations

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TESTIMONY OF THE AMERICAN ACADEMY OF PHYSICIAN ASSISTANTS
SUBMITTED TO THE
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES
COMMITTEE ON APPROPRIATIONS
UNITED STATES HOUSE OF REPRESENTATIVES
REGARDING FISCAL YEAR 2012 APPROPRIATIONS

April 15, 2011

On behalf of the nearly 80,000 clinically practicing physician assistants in the United States, the American Academy of Physician Assistants is pleased to submit comments on FY 2012 appropriations for Physician Assistant (PA) educational programs that are authorized through Title VII of the Public Health Service Act.

AAPA believes that the Title VII Health Professions Programs are essential to placing health professionals in medically underserved communities. According to the Health Resources and Services Administration, an additional 301,000 health care practitioners are needed to alleviate existing professional shortages. One of three health care professions providing primary medical care in the U.S., the PA profession is deemed by many economists to be among the fastest growing professions. Title VII will not only encourage greater numbers of students to enter PA educational programs; it will also help increase access to care for millions of Americans who live in medically underserved areas.

As a member of the Health Professions and Nursing Education Coalition (HPNEC), AAPA respectfully supports the coalition's request to fund Title VII health professions education program at the President's request of $449,454,000.

AAPA recommends that Congress continue its support to grow the PA primary care work force. The U.S. health care system will require a much-expanded primary health care workforce, both in the private and public health care markets. For example, the National Association of Community Health Centers' March 2009 report, *Primary Care Access: An Essential Building Block of Health Reform*, predicts that in order to reach 30 million patients by 2015, health centers will need at least an additional 15,585 primary care providers, just over one third of whom are non-physician primary care professionals.

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. Additionally, a study by the UCSF Center for California Health Workforce Studies found a strong association between physician assistants exposed to Title VII during their PA educational preparation and those who reported working in a federally qualified health center or other community health center.

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. Title VII funding is especially important for PA programs as it is the only federal funding available on a competitive application basis to these programs.

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 maintain funding to these important programs in FY 2011 at the President's request.

Overview of Physician Assistant Education
Physician assistant educational programs are located within schools of medicine or health sciences, universities, teaching hospitals, and the Armed Services. All PA educational programs are accredited by the Accreditation Review Commission on Education for the Physician Assistant.

The typical PA program consists of 26 months of instruction, and the typical student has a bachelor's degree and about four years of prior health care experience. The first phase of the program consists of intensive classroom and laboratory study. More than 400 hours in classroom and laboratory instruction are devoted to the basic sciences, with over 75 hours in pharmacology, approximately 175 hours in behavioral sciences, and nearly 580 hours of clinical medicine.

The second year of PA education consists of clinical rotations. On average, students devote more than 2,000 hours, or 50 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. During clinical rotations, PA students work directly under the supervision of physician preceptors, participating in the full range of patient care activities, including patient assessment and diagnosis, development of treatment plans, patient education, and counseling.

After graduation from an accredited PA program, physician assistants must pass a national certifying examination developed by the National Commission on Certification of Physician Assistants. To maintain certification, PAs must log 100 continuing medical education hours every two years, and they must take a recertification exam every six years.

Physician Assistant Practice
By design, PAs always practice in teams with physicians, extending the reach of medicine and the promise of improved health to the most remote and in-need communities in our nation. The PA profession's patient-centered, team-based approach reflects the changing realities of health care delivery and fits well into the patient-centered medical home model of care, as well as other integrated models of care management.

PAs practice in various medical setting across the country and in a recent survey conducted by the AAPA it is estimated that:

- Nineteen percent of all PAs practice in non-metropolitan areas where they may be the only full-time providers of care (state laws stipulate the conditions for remote supervision by a physician);
- 41 percent of PAs work in urban and inner city areas;
- 40 percent of PAs are in primary care;
- 44 percent of PAs worked in group practices or solo physician offices: and
- 80 percent of PAs practice in outpatient settings.

Nearly 300 million patient visits were made to PAs in 2009. PAs often provide autonomous medical care, have their own patient panels, and are granted prescribing authority in all 50 states.

Critical Role of Title VII Public Health Service Act Programs
Title VII programs promote access to health care in rural and urban underserved communities by supporting educational programs that train health professionals in fields experiencing shortages, improve the geographic distribution of health professionals, increase access to care in underserved communities, and increase minority representation in the health care workforce.

Title VII programs are the only federal educational programs that are designed to address the supply and distribution imbalances in the health professions. Since the establishment of Medicare, the costs of physician residencies, nurse training, and some allied health professions training have been paid through Graduate Medical Education (GME) funding. However, GME has never been available to support PA education. More importantly, GME was not intended to generate a supply of providers who are willing to work in the nation's medically underserved communities – the purpose of Title VII.

Furthermore, Title VII programs seek to recruit students who are from underserved minority and disadvantaged populations, which is a critical step towards reducing persistent health disparities among certain racial and ethnic U.S. populations. Studies have found that health professionals from disadvantaged regions of the country are three to five times more likely to return to underserved areas to provide care.

Title VII Support of PA Educational Programs

Federal support for Title VII is authorized through section 747 of the Public Health Service Act. It is the only federal funding available to PA educational programs. This funding is specifically targeted for primary care education and training programs and is designed to train PAs for practice in urban or rural medically underserved areas. The program is essential to the development and training of the nation's health workforce and is critical to providing continued health services to both underserved and minority communities. It also encourages PAs to return to these environments with the greatest need after they have completed their training, being one of the best recruitment tools to date.

Title VII was last reauthorized in 2010 under the Patient Protection and Affordable Care Act. Now there is a critical need to fund the Title VII program through the appropriations process to increase the supply, diversity, and distribution of PAs and primary care practitioners in medically underserved communities.

Support for educating PAs to practice in underserved communities is particularly important given the market demand for physician assistants. Without Title VII funding to expose students to underserved sites during their training, PA students are far more likely to practice in the communities where they were raised or attended school. Title VII funding is a critical link in addressing the natural geographic maldistribution of health care providers by exposing students to underserved sites during their training, where they frequently choose to practice following graduation. Currently, 36 percent of PAs met their first clinical employer through their clinical rotations.

Changes in the health care marketplace reflect a growing reliance on PAs as part of the health care team. Currently, the supply of physician assistants is inadequate to meet the needs of society, and the demand for PAs is expected to increase. A 2006 article in the Journal of the American Medical Association (JAMA) concluded that the federal government should augment the use of physician assistants as physician substitutes, particularly in urban Community Health Centers (CHCs) where the proportional use of physicians is higher. The article suggested that this could be accomplished by adequately funding Title VII programs. Additionally, the Bureau of Labor Statistics projects that the number of available PA jobs will increase 39 percent between 2008 and 2018.

Title VII funding has provided a crucial pipeline of trained PAs to underserved areas. Recognizing that the PA educational programs received significantly less funding than other programs in the cluster on primary care medicine and dentistry, the 111th Congress established a 15 percent set-aside for PA education within the section 747 cluster on primary care during reauthorization of the Title VII Programs.

Recommendations on FY 2012 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 2012. 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 2012 appropriations.

FY 2012

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COALITION FOR WORKFORCE SOLUTIONS

Coalition For Workforce Solutions-- Labor, HHS, Education Priorities FY 2012

Statement of Peter Kaiser
Chairman, Coalition for Workforce Solutions
Before the U.S. House Subcommittee on Labor, HHS, Education, and Related Agencies
April, 2011

I would like to thank Chairman Denny Rehberg, Ranking Member Rosa DeLauro and members of this distinguished Committee for the opportunity to provide this testimony on workforce spending priorities before the Labor, HHS, Education, and Related Agencies Subcommittee. I represent The Coalition for Workforce Solutions (CWS), a national organization exclusively representing employers, workforce development providers, vendors and service organizations that operate and utilize One-Stop Career Centers, Temporary Assistance for Needy Families initiatives, career and technical education programs and workforce investment services. Members of CWS are proud to play a role in our workforce system as it promotes economic growth while giving unemployed, underemployed and disadvantaged workers an opportunity to gain new skills.

Today, while the nation faces many complex challenges in light of mass layoffs and business realignments, the private sector is showing signs of recovery and businesses new and old need increased assistance in addressing their workforce needs. And our national network of WIA supported workforce services is in a unique position not only to train workers for economic recovery, but to match large and small employers with qualified workers in advanced manufacturing, health care, energy and other high-growth sectors. As the economy grows, our workforce system should be maintained and strengthened, not reduced or targeted for elimination.

As the Congress begins its deliberations on funding for FY 2012, we strongly urge you to restore funding for WIA and ensure our workforce development and job-training system continues its vital support for businesses of all sizes to create and retain jobs, provide needed skills and transition assistance to workers, and enhance economic growth through the private sector in thousands of communities around the country.

Our nation's workforce systems funded through WIA have become critical partners in regional economic development efforts -- from directly supporting efforts to recruit new businesses (by offering access to skilled workers and employment and training incentives), to saving money for local businesses as they begin to rehire workers. The programs also assist businesses to avert layoffs through skills upgrading, and support businesses that are closing or downsizing. These partnerships with employers and economic development services are critical to helping businesses survive and contribute to regional economic growth and prosperity. Now is not the time to take away these vital services when economic growth is paramount to our recovery and competitiveness.

WIA has experienced a 234 percent increase in demand for services since the onset of the recession and demand remains steady as the economy grows. It is easy to see why this is so: the one-stop system supported with WIA funds fosters community partnerships that drive job creation and economic recovery efforts while also providing vital labor market information, skills assessments, career guidance, counseling, employment assistance, support and training services to jobseekers and workers who need help in getting good jobs.

In every state and region, the workforce system addresses the needs of business so that local companies can remain competitive. By building relationships with community development organizations and local officials, businesses are provided with a collaborative network of support that is best-suited to the needs of employers. Only this system can provide businesses with the resources they can use to survive and thrive in this difficult economic time.

In fact, the workforce system is the *only system of its kind to engage employers and address the kind of compelling challenges that business face* in the following areas:

- Reducing turnover in entry level occupations in high growth industries such as health care through early immersion and career ladder programs.

- Finding the talent that advanced manufacturing companies need to compete by training workers in new skills and providing the next generation of workers a path to the modern workforce.

- Supporting economic development and business attraction activities so that new employers and manufacturers get assistance in determining local infrastructure, specific fits for training needs, and whatever it takes to be successful.

- Preparing youth in high demand IT careers as well as providing soft skills training, job search preparation, coaching and the life transforming skills that businesses need to develop a stable, high-quality workforce..

- Improving hiring efficiency such that employers improve their application conversion rate by 50% through collaborative partnerships with the workforce system that produce qualified candidates with the right skill-sets, dedication and motivation that employers need.

Businesses as well as jobseekers and workers benefit from WIA services. Research indicates that the workforce system produces a high return on investment. Last year, over 8 million job-seekers utilized the workforce system and over 4.3 million of them got jobs. While this is less than the normal 80 to 85 percent placement rate common in stronger economic times, the recent job environment had four (4) jobseekers for every one (1) vacancy. However, when jobs were simply not available, the system placed many of the unemployed in education and training programs that will lead to good new jobs.

The system is also effective. According to an Upjohn Institute Study, positive and statistically significant results were found for WIA Adult Program participants and for the Dislocated Worker Program. Furthermore, these employment and training services were shown to reduce reliance on public assistance. The average duration on TANF public assistance also was reduced by several percentage points for those participating in WIA or TANF welfare-to-work programs. One can conclude from a variety of studies that WIA training services raise employment rates and earnings while reducing reliance on TANF.

Many CWS members are private businesses that struggle everyday with budgets, so we can appreciate the need to make tough decisions. Since job creation is a priority for the Congress and since workers pay taxes and reduce pressure on public programs, maintaining support for the workforce system should remain a top priority. The workforce system is a critical partner in the nation's economic recovery as it trains and retrains workers to meet the demands of our changing economy. In our judgment, this system is essential to addressing the employment needs of the more than 14 million unemployed in this country -- we cannot afford to lose this valuable resource.

Nevertheless, this week Congress is considering an appropriations bill (HR 1473) that would reduce WIA's three state/local program sections by about $307 million below the FY 2010 levels enacted in Public Law 111-117. Overall, the bill provides about $2.8 billion for job-training state grants for adult employment, youth activities, and dislocated workers. The more than $1 billion in reductions to key job training and education programs equate to more than ten percent less than FY 2010 enacted levels.

While funding for Program Year 2011 is now set, the spending agreement covers only the first quarter of the next WIA program year ending September 30, 2011. Funding for the final three quarters will be contained in the FY 2012 appropriations.

Many WIA programs have received funding reductions in real dollar terms in recent years – these programs are significantly underfunded already relative to their mission. Congress should use the findings of duplication and overlap in workforce programs not to make further reductions but rather to work with the House Education and Workforce Committee to achieve better coordination and integration of services.

Despite the significant cuts in the latest CR, the bill represents substantial progress for thousands of jobseekers and employers across the country who informed their policymakers on the critical benefits of our workforce system. We are encouraged to see that Congress has rejected the severest cuts in H.R. 1 and we hope there is a more accurate picture emerging of how WIA programs help employers find qualified workers and train workers for new careers.

In short, CWS will work with Members of this Committee, the authorizing committees and other Members of Congress as they consider policies to better align planning and service delivery, and strengthen the overall system. As issues develop, there will be discussions about expectations for the future of the workforce system. Here are some issues of primary importance to CWS:

- Enhancing WIA accountability and driving high performance
- Empowering Workforce Investment Boards to play a strategic role that promotes coordination and integration of services across federally-funded systems
- Serving disadvantaged and underserved populations
- Sharing and promoting best practices throughout the system

CWS believes that WIA's core services and training have paid off in terms of higher employment *rates and improved earnings for dislocated workers, the unemployed and disadvantaged youth and adults*. As Members of the Committee examine the facts concerning WIA services, we trust that they will agree that the workforce system provides vital services to businesses and jobseekers. We strongly recommend that you support this system that provides such a unique role in today's economy. Thank you for your consideration of my testimony.

About Peter Kaiser

Peter Kaiser is a well-recognized expert in the field of Workforce Development with a career that spans 30 years as CEO of the Kaiser Group. Mr. Kaiser's basic interest in Training started in the United States Air Force and has continued to the present. He operates Kaiser Group's One-Stops, runs workshops, and is involved in national organizations to ensure the important presence of Workforce Development as part of the fabric of the United States in world competitiveness.

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AMERICAN ASSOCIATION OF
COLLEGES OF OSTEOPATHIC MEDICINE

OFFICE OF THE PRESIDENT

Testimony of Stephen C. Shannon, DO, MPH
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Concerning Department of Health and Human Services Appropriations for Fiscal Year 2012
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
House Committee on Appropriations
Submitted for the Record
April 15, 2011

On behalf of the American Association of Colleges of Osteopathic Medicine (AACOM), I am pleased to submit this testimony in support of increased funding in fiscal year (FY) 2012 for programs at the Health Resources Services Administration (HRSA), the National Institutes of Health (NIH), and the Agency for Healthcare Research and Quality (AHRQ). AACOM represents the administrations, faculty, and students of the nation's 26 colleges of osteopathic medicine at 34 locations in 26 states. Today, more than 19,000 students are enrolled in osteopathic medical schools. Nearly one in five U.S. medical students is training to be an osteopathic physician.

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 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 access to care, these needs strain an already fragile health care system. While AACOM appreciates the investments that have been made in these programs, we

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recommend increasing funding to $449.4 million, the same funding level requested by the President, in FY 2012 for the Title VII programs. Investment in these programs, including the Primary Care Training and Enhancement Program, the Health Careers Opportunity Program, and the Centers of Excellence, is necessary to address the primary care workforce shortage. Strengthening the workforce has been recognized as a national priority, and the investment in these programs recommended by AACOM will help meet the demand for a well-trained, diverse workforce that this country will witness as a result of health care reform.

Teaching Health Centers

The Teaching Health Center Graduate Medical Education Program (THCGME) is the first of its kind to shift graduate medical education (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 infrastructure to provide this training. AACOM strongly supports the President's budget request of $10 million to fund the THC Development Grants. This funding would allow potential THC 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 National Health Service Corps (NHSC) supports the recruitment and retention of primary care clinicians to practice in underserved communities. At the close of FY 2010, the NHSC provided a network of 7,500 primary health care professionals in 10,000 sites in underserved communities. However, this still fell approximately 20,000 practitioners short of fulfilling the need for primary care, dental and mental health practitioners in Health Professional Shortage Areas (HPSAs). Growth in HRSA's Community Health Center Program must be complemented with increases in the recruitment and retention of primary care clinicians to ensure adequate staffing, which the NHSC provides. AACOM supports the President's budget request of $418 million for this program. This includes $295 million from the Affordable Care Act (ACA) fund for the NHSC and $24.695 million in appropriated dollars for field placements and $98.7 million in appropriated dollars for recruitment.

National Institutes of Health

Research funded by the NIH leads to important medical discoveries regarding the causes, treatments, and cures for common and rare diseases, as well as disease prevention. These efforts improve our nation's health and save lives. To maintain a robust research agenda, further investment will be needed. AACOM recommends $32 billion in FY 2012 for the NIH. While the need is significantly greater, approximately $35.0 billion, anything less than the President's request will result in a reduction in real dollars dedicated to research.

With 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 supports the President's budget request of $131.002 million for NIH's National Center for Complementary and Alternative Medicine 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 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 $405 million in FY 2012 for AHRQ. This investment will preserve AHRQ's current programs while helping to restore its critical health care safety, quality, and efficiency initiatives.

AACOM is grateful for the opportunity to submit its views and looks forward to continuing to work with the Subcommittee on these important matters.

CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC) COALITION
C/o Don Hoppert, American Public Health Association 800 I Street, NW, Washington, D.C. 20001 (202) 777-2514

Testimony of the CDC Coalition
Concerning the Centers for Disease Control and Prevention's Budget for Fiscal Year 2012
House Appropriations Subcommittee on Labor, HHS and Education
Submitted for the Record, April 15, 2011

The CDC Coalition is a nonpartisan coalition of more than 140 organizations committed to strengthening our nation's prevention programs. Our mission is to ensure that health promotion and disease prevention are given top priority in federal funding, to support a funding level for the Centers for Disease Control and Prevention (CDC) that enables it to carry out its prevention mission, and to assure an adequate translation of new research into effective state and local programs. Coalition member groups represent millions of public health workers, clinicians, researchers, educators, and citizens served by CDC programs.

The CDC Coalition believes that Congress should support CDC as an agency – not just the individual programs that it funds. In the best judgment of the CDC Coalition – given the challenges and burdens of chronic disease, a potential influenza pandemic, terrorism, disaster preparedness, new and reemerging infectious diseases and our many unmet public health needs and missed prevention opportunities **– we believe the agency will require funding of at least $7.7 billion for CDC's "core programs" in FY 2012.** This request represents a 36 percent increase over FY 2011 and a 31 percent increase over the President's FY 2012 request. We are deeply disappointed with the more than $740 million in cuts to CDC's budget authority included in the proposed FY 2011 continuing resolution (CR). While CDC programs will receive significant new funding from the Prevention and Public Health Fund in fiscal year 2011, we are concerned that this funding would essentially supplant cuts made to CDC's budget authority. As you know the Prevention and Public Health Fund was intended to supplement and not supplant the base funding of our public health agencies and programs.

By translating research findings into effective intervention efforts, CDC has been a key source of funding for many of our state and local programs that aim to improve the health of communities. Perhaps more importantly, federal funding through CDC provides the foundation for our state and local public health departments, supporting a trained workforce, laboratory capacity and public health education communications systems.

CDC also serves as the command center for our nation's public health defense system against emerging and reemerging infectious diseases. With the potential onset of a worldwide influenza pandemic, in addition to the many other natural and man-made threats that exist in the modern world, the CDC has become the nation's—and the world's—expert resource and response center, coordinating communications and action and serving as the laboratory reference center. States and communities rely on CDC for accurate information and direction in a crisis or outbreak.

The Multiple Roles of CDC
CDC serves as the lead agency for bioterrorism and other public health emergency preparedness and must receive sustained support for its preparedness programs in order for our nation to meet future challenges. Given the challenges of terrorism and disaster preparedness, and our many unmet public health needs and missed prevention opportunities we urge you to provide adequate funding for state and local capacity grants. We ask the Subcommittee to ensure that our states and local communities

are prepared in the event of an act of terrorism or other public health threat this year and in future years. Unfortunately, this is not a threat that is going away.

Addressing the Leading Causes of Death and Disability

The President's FY 2012 budget proposes to consolidate a number of chronic disease programs within CDC. Members of the CDC Coalition are currently engaged in conversations with CDC and members of Congress to better understand what this consolidation will mean for the funding that is passed on to our state and local health and education agencies and the various programs our members have supported in the past. We look forward to working with Congress, the Administration and CDC to ensure that any effort to consolidate programs leads to the best health outcomes for the American people. We must ensure that CDC's National Center for Chronic Disease Prevention and Health Promotion has the resources it needs to assist our states and communities in their efforts to reduce the burden of chronic disease.

Heart disease remains the nation's No. 1 killer. In 2007, over 616,000 people in the United States died from heart disease, accounting for nearly 25% of all U.S. deaths. More women than men die of heart disease each year, and in 2007, females had higher rates of inpatient heart attack mortality than males. Stroke is the third leading cause of death and is a leading cause of disability. In 2007, stroke killed more than 135,000 people (61% of them women), accounting for about 1 of every 18 deaths.

Cancer is the second most common cause of death in the United States. There were an estimated 1,529,560 new cancer cases and 569,490 deaths from cancer in 2010. The financial cost of cancer is also significant. According to the National Institutes of Health (NIH), in 2008 the overall cost for cancer in the United States was more than $228.1 billion: $93.2 billion for direct medical costs, $18.8 billion for lost worker productivity due to illness, and $116.1 billion for lost worker productivity due to premature death.

Among the ways CDC is fighting cancer, is through funding the National Breast and Cervical Cancer Early Detection Program that helps low-income, uninsured and medically underserved women gain access to lifesaving breast and cervical cancer screenings and provides a gateway to treatment upon diagnosis. CDC also funds grants to states to develop Comprehensive Cancer Control (CCC) plans, bringing together a broad partnership of public and private stakeholders to set joint priorities and implement specific cancer prevention and control activities customized to address each state's particular needs.

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 United States. The total direct and indirect costs associated with diabetes were $178 billion in 2007. Preventive care such as routine eye and foot examinations, self-monitoring of blood glucose, and glycemic control could reduce these numbers.

Over the last 25 years, obesity rates have doubled among adults and children, and tripled in teens. Obesity, diet and inactivity are cross-cutting risk factors that contribute significantly to heart disease, cancer, stroke and diabetes. 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 addition in the first place, as well as help those who want to quit. We must continue to support these vital programs and reduce tobacco use in the United States.

Each day more than 3,900 young people initiate cigarette smoking. At the same time, according to CDC, only 3.8% of elementary schools, 7.9% of middle schools and 2.1% of high schools provide daily physical education or its equivalent for the entire school year. Almost 90% of young people do not eat the recommended number of servings of fruits and vegetables, while nearly 30% of young people are overweight or at risk of becoming overweight. And every year, almost 800,000 adolescents become pregnant and nearly 4 million teens are infected with a sexually transmitted disease. CDC plays a critical role in ensuring good public health and health promotion in our 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, 21 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 617,000 in the U.S. and dependant areas and is devastating populations around the globe.

The United States has the highest rates of sexually transmitted diseases (STDs) in the industrialized world. More than 19 million new infections occur each year, almost half of them among young people. CDC estimates that STDs, including HIV, cost the U.S. healthcare system as much as $15.3 billion annually. Over the past several years, significant ground has been lost in the fight against STDs. While syphilis was on the verge of elimination in the U.S. at the start of the decade, rates have increased by 114% since 2000. An adequate investment in STD prevention could save millions in annual health care costs in the future.

CDC and its National Center for Health Statistics collect 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. Adequate funding for these activities is essential for tracking America's health as a nation and developing targeted and appropriate public health policies and prevention interventions.

We must address the growing disparity in the health of racial and ethnic minorities. CDC is helping states address serious disparities in infant mortality, breast and cervical cancer, cardiovascular disease, diabetes, HIV/AIDS and immunizations. Our members are committed to ending the disparities and we encourage the Subcommittee to provide adequate funds for these efforts.

CDC oversees immunization programs for children, adolescents and adults, and is a global partner in the ongoing effort to eradicate polio worldwide. The value of adult immunization programs to improve length and quality of life, and to save health care costs, is realized through a number of CDC programs, but there is much work to be done and a need for sound funding to achieve our goals. Influenza vaccination levels remain low for adults. Levels are substantially lower for pneumococcal vaccination and significant racial and ethnic disparities in vaccination levels persist

among the elderly. In addition, developing functional immunization registries in all states will be less costly in the long run than maintaining the incomplete systems currently in place.

Childhood immunizations provide one of the best returns on investment of any public health program. For every dollar spent on seven vaccines recommended in the childhood series, $16.50 is saved in direct and indirect costs. An estimated 14 million cases of childhood disease and 33,000 deaths are prevented each year through timely immunization. Despite the incredible success of the program, it faces serious financial challenges.

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. Unintentional injury consistently remains the leading cause of death among young Americans ages 1-34 with 37.1 percent of unintentional fatal injuries caused by motor vehicle traffic fatalities. Conversely, violence related injuries are also substantial with homicide being the second leading cause of death for persons 15-24 years, while suicide is the 11th leading cause of death across all age groups. The consequences of these injuries can be far reaching from physical, emotional, financial turmoil to long term disability. CDC's Injury Center works to prevent unintentional and violence-related injuries to minimize the consequences of injuries when they occur by researching the problem; identifying the risk and protective factors; developing and testing interventions; ensuring widespread adoption of proven strategies and gathering data to assist states and communities to develop prevention programs and practices through the use of surveillance systems like the National Violent Death Reporting System.

One in every 33 babies born each year in the United States 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 at CDC conducts programs to protect and improve the health of children and adults by preventing birth defects and developmental disabilities; promoting optimal child development and health and wellness among children and adults with disabilities.

We also encourage the Subcommittee to provide adequate funding for CDC's Center for Environmental Health to revitalize environmental public health services at the national, state and local level and sustain current programs. These services are essential to protecting and ensuring the health and well being of the American public from threats associated with West Nile virus, climate change, terrorism, E. coli, lead-based paint and other hazards.

We appreciate the Subcommittee's past support for CDC programs in a climate of competing priorities. We thank you for considering our **FY 2012 request for $7.7 billion for CDC's "core programs."**

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
April 14, 2011

Funding Request Overview

Prevent Blindness America appreciates the opportunity to submit written testimony for the record regarding fiscal year (FY) 2012 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 2012 to help promote eye health and prevent eye disease and vision loss:

- Provide at least $3.23 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 additional resources for the National Eye Institute (NEI).

Introduction and Overview

Vision-related conditions affect people across the lifespan from childhood through elder years. Good vision is an integral component to health and well-being, affects virtually all activities of daily living, and impacts individuals physically, emotionally, socially, and financially. Loss of vision can have a devastating impact on individuals and their families. An estimated 80 million Americans have a potentially blinding eye disease, three million have low vision, more than one million are legally blind, and 200,000 are more severely visually blind. Vision impairment in children is a common condition that affects five to ten percent of preschool age children. Vision disorders (including amblyopia ("lazy eye"), strabismus ("cross eye"), and refractive error are the leading cause of impaired health in childhood.

Alarmingly, while half of all blindness can be prevented through education, early detection, and treatment, the NEI reports that "the number of Americans with age-related eye disease and the vision impairment that results is expected to double within the next three decades."[1] Among Americans age 40 and older, the four most common eye diseases causing vision impairment and blindness are age-related macular degeneration (AMD), cataract, diabetic retinopathy, and glaucoma.[2] Refractive errors are the most frequent vision problem in the U.S. – an estimated 150 million Americans use corrective eyewear to compensate for their refractive error.[3] Uncorrected or under-corrected refractive error can result in significant vision impairment.[4]

To curtail the increasing incidence of vision loss in America, Prevent Blindness America advocates sustained and meaningful federal funding for programs that help promote eye health and prevent eye disease, vision loss, and blindness; needed services and increased access to vision screening; and vision and eye disease research. We thank the Subcommittee for its consideration of our specific FY 2012 funding requests, which are detailed below.

Vision and Eye Health at the CDC: Helping to Save Sight and Save Money

The CDC serves a critical national 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:

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[1] "Vision Problems in the U.S.: Prevalence of Adult Vision Impairment and Age-Related Eye Disease in America," Prevent Blindness America and the National Eye Institute, 2008.
[2] Ibid.
[3] Ibid
[4] Ibid.

- 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.
- Integrate vision health with other public health strategies.

Integrating Vision Health into Broader Disease Prevention and Health Promotion Efforts

One of the cornerstone activities 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 other health problems 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.

To advance state-based vision health integration, CDC funds are supporting a joint effort between the New York State Department of Health and Prevent Blindness Tri-State, focused on integrating vision-related services at the state and local level. Working together, these partners are promoting vision loss prevention strategies within the State Department of Health. One initiative resulting from this partnership has been the launch of a statewide tobacco cessation media campaign highlighting the impact of smoking on potential vision loss. Other examples include state-based programs to prevent and reduce diabetes, including efforts to educate patients and health care providers of the relationship between diabetes and certain eye problems, such as diabetic retinopathy and cataracts. A similar effort has recently been initiated in Texas.

The goal of these integration efforts is to ensure that vision loss and eye health promotion are incorporated into all relevant local, state, and federal public health interventions, prevention and treatment programs, and other initiatives that impact causes of – and factors that contribute to – vision problems and blindness. By integrating efforts and coordinating approaches in this manner, federal and state resources will be used more efficiently, eye health problems and vision loss can be reduced, and the overall health and well-being of individuals and communities will be improved.

Identifying and Preventing Vision Problems through Community-Based Strategies

The CDC supports private sector efforts to develop and evaluate better ways to identify and treat individuals with potential eye disease, vision loss, and other ocular conditions. Among other efforts, CDC funding is currently supporting:

- A study to assess the overall effectiveness and costs associated with implementing an adult vision and eye health history and risk assessment/referral program. This study, being conducted by Johns Hopkins University, in partnership with Prevent Blindness Ohio, is working in collaboration with the Physician's Free Clinic in Columbus, Ohio and Akron Community Health Resources to investigate the best methods for identifying patients who need eye care services and providing linkages to follow-up care.

- An initiative spearheaded by Duke University and Prevent Blindness North Carolina to evaluate the benefit of pediatric and school-based vision screening. The project identified the need to ensure proper on-going training and education of pediatricians on vision screening. In collaboration with the American Board of Pediatrics, the project has developed maintenance of certification module to improve office-based preschool vision screening.

Data Collection

Understanding the breadth and depth of vision and eye health issues across the nation is paramount to ensuring appropriate allocation of resources and effective deployment of targeted interventions. Thus, the CDC supports programs and systems that collect, evaluate, and disseminate critical vision health data.

- The CDC developed the first optional Behavioral Risk Factor Surveillance System (BRFSS)[5] vision module, which collects state-based information on access to eye care and the prevalence of eye disease and eye injury. Early in 2011, the CDC will publish a report describing visual impairment as a serious public health issue affecting more than 2.9 million Americans. Unfortunately, in part due to insufficient funding, only 19 states currently use the vision module; this lack of broad adoption precludes the CDC, Congress, and other stakeholders from having the information they need to understand and address the full scope of vision loss and eye health problems facing the nation.

- CDC funding is supporting a joint endeavor between Duke University and Prevent Blindness America to conduct a systematic evidence review to describe the delivery systems of vision-related services and to identify new areas for policy evaluation or clinical research. This information will help identify the most at-risk populations and highlight gaps in care and service delivery to ensure that public and private resources are allocated to areas of greatest need.

To that end, Prevent Blindness America respectfully requests the Subcommittee provide a $3.23 million allocation for vision and eye health initiatives at the CDC. This level of investment will help the CDC sustain its efforts to address the growing public health threat of preventable vision loss among at-risk and underserved populations. FY 2012 resources will support strengthened state-based public health integration efforts to address vision and eye health and the development of additional evidence-based public health interventions that improve eye health among the nation's most at-risk and underserved.

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.[6]

[5] BRFSS is a state-based system of health surveys that collects information on chronic disease and injury.
[6] "Our Vision for Children's Vision: A National Call to Action for the Advancement of Children's Vision and Eye Health, Prevent Blindness America," Prevent Blindness America, 2008.

In 2009, the Maternal and Child Health Bureau established the National Center for Children's Vision and Eye Health, a national vision health collaborative effort aimed at developing the public health infrastructure necessary to promote eye health and ensure access to a continuum of eye care for young children. Prevent Blindness America is requesting on-going support for the National Center for Children's Vision and Eye Health.

With this support the Center, will continue to:

- Provide national leadership in the development of best practices and guidelines for public health infrastructure, national vision screening guidelines, and statewide strategies that ensure early detection, vision screening, and a continuum of vision and eye health care for children.

- Determine mechanisms for advancing state-based performance improvement systems, screening guidelines, and a mechanism for uniform data collection and reporting.

- Collaborate with states to develop and implement statewide strategies for vision screening, establish quality improvement strategies, and determine mechanisms for the improvement of data systems and reporting of children's vision and eye health services.

Advance and Expand Vision Research Opportunities

Prevent Blindness America calls upon the Subcommittee to provide additional support for the NEI to bolster its efforts to identify the underlying causes of eye disease and vision loss, improve early detection and diagnosis of eye disease and vision loss, and advance prevention and treatment efforts. Research is critical to ensure that new treatments and interventions are developed to help reduce and eliminate vision problems and potentially blinding eye diseases facing consumers across the country. In 2009, Congress commended the NEI's leadership in basic and translational research through H. Res. 366 and S. Res. 209 (111th Congress), which recognized NEI's 40 years as the National Institutes of Health (NIH) Institute that leads the nation's commitment to save and restore vision. The Resolutions also designated 2010-2020 as the *Decade of Vision* in recognition of the increasing health and economic burden of eye disease, mainly as a result of an aging population.

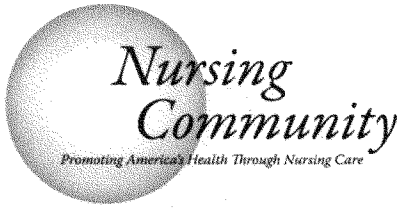
Through additional support, the NEI will be able to continue to grow its efforts to:

- Expand capacity for research, as demonstrated by the significant number of high-quality grant applications submitted in response to American Recovery and Reinvestment Act opportunities.
- Address unmet need, especially for programs of special promise that could reap substantial downstream benefits.
- Fund research to reduce healthcare costs, increase productivity, and ensure the continued global competitiveness of the United States.

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 2012 funding for the CDC's vision and eye health initiatives, 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.



Testimony of the Nursing Community Regarding
Fiscal Year 2012 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

Department of Health and Human Services

April 15, 2011

The Nursing Community is a forum for professional nursing organizations to collaborate on a wide spectrum of healthcare and nursing issues, including practice, education, and research. These 56 organizations are committed to promoting America's health through nursing care. Collectively, the Nursing Community represents over 850,000 Registered Nurses (RNs), Advanced Practice Registered Nurses (APRNs-including certified nurse-midwives, nurse practitioners, clinical nurse specialists, and certified registered nurse anesthetists), nurse executives, nursing students, nursing faculty, and nurse researchers. Together, our organizations work collaboratively to increase funding for the Nursing Workforce Development programs (authorized under Title VIII of the Public Health Service Act [42 U.S.C. 296 et seq.]), the National Institute of Nursing Research (NINR), and to secure authorized funding for Nurse-Managed Health Clinics so that American nurses have the support needed to provide high quality health care to the nation.

Nurses are involved in every aspect of health care, and if the nursing workforce is not strengthened, the healthcare system will continue to suffer. Currently, RNs comprise the largest group of health professionals with approximately 3.1 million licensed providers. Nurses offer essential care to patients as well as our nation's active duty military and veterans in a variety of settings, including hospitals, ambulatory care clinics, long-term care facilities, community or public health areas, schools, workplaces, and private homes. In addition, many nurses pursue graduate degrees to assume roles as advanced practice registered nurses who practice autonomously; become nurse faculty, nurse researchers, nurse administrators, and advanced public health nurses. Nurses also specialize in areas such as mental and women's health, pain management, hospice and palliative care, nephrology, oncology, rehabilitation, forensics, dermatology, urology, and care coordination. They are critical team members in all departments such as intensive and critical care, pediatrics, geriatrics, medical surgical, and operating rooms. RNs and APRNs hold a holistic view of health.

With the *Patient Protection and Affordable Care Act* [Public Law 111-148] (ACA) focus on creating a system that will increase access to quality care, emphasize prevention, and decrease cost, it is critical that a substantial investment be made in our RN and APRN workforce, in the scientific research that provides the basis for nursing practice, and in the safety-net facilities they operate.

In an article published in the July/August 2009 issue of *Health Affairs*, Dr. Peter Buerhaus, a noted health professions workforce analyst, and colleagues confirmed that although the economic recession has led to a temporary easing of the nursing shortage in some parts of the country, the overall shortfall in the number of nurses needed is expected to grow to 260,000 by the year 2025. Three major factors contribute to this growing demand for nursing care. First, over 275,000 practicing RNs are over the age of 60 according to the *2008 National Sample Survey of Registered Nurses*. When the economy rebounds, many of these nurses will seek retirement. Second, America's population is aging. Older Americans will seek more healthcare services creating an influx of consumers and necessitate the need for quality nursing care. Finally, the ACA will expand the number of individuals seeking care by 32 million.

Furthermore, in a report released by the Institute of Medicine and Robert Wood Johnson Foundation titled, *The Future of the Nursing: Leading Change, Advancing Health*, clear and evidence based guidance was provided on how to shape nursing's role in healthcare delivery as the system undergoes considerable changes. The report's key messages include:

- Nurses should practice to the full extent of their education and training; scope of practice limitations should be removed.
- Nurses should achieve higher levels of education and training through an improved education system that promotes seamless academic progression.
- Nurses should be full partners with other healthcare professionals in redesigning health care in the United States.
- Effective workforce planning and policy making require better data collection and an improved information infrastructure.

To achieve these goals, different levels of support will be needed for all nurses and each of the funding requests outlined below will help to meet not only the goals of the IOM report, but the larger national goals of access to high quality, cost effective care.

Addressing the Demand: 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.), helped build the supply and distribution of qualified nurses to meet our nation's healthcare needs since 1964. Over the last 47 years, these programs addressed all aspects of supporting the workforce— education, practice, retention, and recruitment. The Title VIII programs bolster nursing education at all levels, from entry-level preparation through graduate study, and provide support for institutions that educate nurses for practice in rural and medically underserved communities. Today, the Title VIII programs are essential to ensure the demand for nursing care is met. Between FY 2006 and 2009, the Title VIII programs supported over 347,000 nurses and nursing students as well as numerous academic nursing institutions, and healthcare facilities.

Results from the American Association of Colleges of Nursing's (AACN) *2010-2011 Title VIII Student Recipient Survey* included responses from 1,459 students who noted that these programs played a critical role in funding their nursing education. The survey showed that 80% of the students receiving Title VIII funding are attending school full-time. By supporting full-time students, the Title VIII programs are helping to ensure that students enter the workforce without delay. The programs also address the current demand for primary care providers. Nearly one third of

respondents reported that their career goal is to become a nurse practitioner. Approximately 80% of nurse practitioners provide primary care services throughout the United States. Additionally, the respondents identified working in rural and underserved areas as future goals, with becoming a nurse faculty member, a nurse practitioner, or a certified registered nurse anesthetist as the top three nursing positions for their career aspirations.

The Nursing Community respectfully requests $313.075 million for the Nursing Workforce Development programs authorized under Title VIII of the Public Health Service Act in FY 2012 as recommended in the President's FY 2012 budget proposal.

Building the Science: The National Institute of Nursing Research

As one of the 27 Institutes and Centers at the National Institutes of Health (NIH), the NINR funds research that establishes the scientific basis for quality patient care. Nurse researchers make significant advances in and contributions to health prevention and care. In addition, they work collaboratively as well as part of multidisciplinary research teams with colleagues from other fields and are vital in setting the national research agenda.

The Nursing Community respectfully requests $163 million for the National Institute of Nursing Research in FY 2012. Nursing research is an essential part of scientific endeavors to improve the nation's health. Knowledge of care across the lifespan is critical to the present and future health of the nation. Research funded at the NINR helps to integrate biology and behavior as well as design new technology and tools. At a time when healthcare needs are changing, nursing care must be firmly grounded in nursing science. The four strategic areas of emphasis for research at NINR are promoting health and preventing disease, eliminating health disparities, improving quality of life, and setting directions for end-of-life research.

The science advanced at NINR is integral to the future of the nation's healthcare system. Through grants, research training, and interdisciplinary 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 research fosters advances in nursing practice, improves patient care, and attracts new students to the profession.

Supporting Safety Net Facilities: Nurse-Managed Health Clinics

The ACA amended Sec. 330 of the Public Health Service Act to provide grant eligibility to Nurse-Managed Health Clinics (NMHCs) to support operating costs and authorized up to $50 million a year for this purpose. NMHCs are defined as a nurse-practice arrangement, managed by APRNs, 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, or independent nonprofit health or social services agency. Nurse-Managed Health Clinics successfully engage communities and address critical health needs for underserved populations.

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 2012 as recommended in the President's FY 2012 budget proposal.

NMHCs provide care to clients and patients in clinics located in places like public housing, on blighted urban streets, on Native American reservations, in rural communities, in senior citizen centers, in elementary schools, in storefronts, and even in churches. The services these clinics provide include primary care, health promotion, and disease prevention. Furthermore, NMHCs also act as important teaching and practice sites for nursing students.

The care provided in these sites directly contributes to positive health outcomes and savings in the long term. In one US city alone, nurses at an NMHC see their patients almost twice as frequently as other providers, and their patients are hospitalized 30% less and use the emergency room 15% less often than those of other healthcare providers. Providing funding for these centers is a direct investment in the specific health needs of localized communities.

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 $313.075 million in FY 2012 for the Title VIII Nursing Workforce Development programs, $163 million for the NINR, and $20 million for NMHCs will help ensure access to quality care provided by America's nursing workforce.

Members of the Nursing Community Submitting this Testimony

Academy of Medical-Surgical Nurses
American Academy of Ambulatory Care Nursing
American Academy of Nurse Practitioners
American Academy of Nursing
American Assembly for Men in Nursing
American Association of Colleges of Nursing
American Association of Critical-Care Nurses
American Association of Nurse Anesthetists
American Association of Nurse Assessment Coordinators
American College of Nurse Practitioners
American College of Nurse-Midwives
American Holistic Nurses Association
American Nephrology Nurses' Association
American Nurses Association
American Organization of Nurse Executives
American Psychiatric Nurses Association
American Society for Pain Management Nursing
American Society of PeriAnesthesia Nurses
Association of Community Health Nursing Educators
Association of periOperative Registered Nurses
Association of Rehabilitation Nurses
Association of State and Territorial Directors of Nursing
Association of Women's Health, Obstetric and Neonatal Nurses
Commissioned Officers Association
Dermatology Nurses' Association
Gerontological Advanced Practice Nurses Association
Hospice and Palliative Nurses Association
Infusion Nurses Society
International Association of Forensic Nurses
International Nurses Society on Addictions
International Society of Psychiatric Nurses
National Association of Clinical Nurse Specialists
National Association of Nurse Practitioners in Women's Health
National Association of Pediatric Nurse Practitioners
National Black Nurses Association
National Coalition of Ethnic Minority Nurse Associations
National Nursing Centers Consortium
National Organization of Nurse Practitioner Faculties
Nurses Organization of Veterans Affairs
Oncology Nursing Society
Public Health Nursing Section, American Public Health Association
Society of Urologic Nurses and Associates

American Association *of* Colleges *of* Nursing
ADVANCING HIGHER EDUCATION IN NURSING

Testimony of the American Association of Colleges of Nursing Regarding

Fiscal Year 2012 Appropriations for the Title VIII Nursing Workforce Development Programs, the National Institute of Nursing Research, Nurse-Managed Health Clinics, and the Capacity for Nursing Students and Faculty Program

U.S. House Appropriations Subcommittee on Labor, Health and Human Services, and Education

Department of Health and Human Services

April 15, 2011

The American Association of Colleges of Nursing (AACN) respectfully submits this testimony highlighting funding priorities for nursing education and research programs in Fiscal Year (FY) 2012. AACN represents 667 schools of nursing with baccalaureate and graduate nursing programs that educate over 337,000 students and employ more than 15,000 full-time faculty members. These institutions educate approximately half of our nation's Registered Nurses (RNs) and all of the Advanced Practice Registered Nurses (APRNs), nurse faculty, and researchers.

The programs outlined in this testimony play an integral role in continuing to shape, advance, and promote a professional nursing workforce to meet the needs of America's patients. An emphasis on two key components of the profession – education and research – will be necessary to sustain and enhance the quality of nursing care in the United States. The release of the landmark Institute of Medicine's (IOM) report, *The Future of Nursing: Leading Change, Advancing Health,* outlines specific priorities for the profession and identifies expanded federal support to meet the goals of preparing a more highly educated nursing workforce, removing barriers so all nurses can practice to the full scope of their education, and enabling nurses to serve as equal partners in the redesign of the healthcare system.

The ongoing reform of our healthcare system will continue to increase access to care, requiring a surge in the number of nurses and other health professionals. RNs and APRNs will be in high demand given the needs of an aging population, the increased complexity of care, and significant growth in the number of patients with chronic diseases. More specifically, the U.S. Bureau of Labor Statistics projects a demand on our delivery system that will necessitate the creation of 581,000 new positions by 2018, a 22% increase in the nursing workforce. Without increased attention to the challenges facing nursing education, schools of nursing will be unable to meet this demand, further jeopardizing access to quality care.

The current supply and demand of nurses demonstrates two distinct challenges. First, due to the present and looming need for health care by American consumers, the supply of nurses is not growing at a pace that will adequately meet long-term projections, including the demand for primary care provided by APRNs. This issue is further compounded by the number of nurses who will retire or leave the profession in the near future, ultimately reducing the nursing workforce. Currently, over

one million of the total 2.6 million practicing nurses are over the age of 50. More striking yet, over 275,000 RNs are over the age of 60 according to the *2008 National Sample Survey of Registered Nurses*.

Second, the supply of nurses nationwide is stretched thin due, in large part, to capacity barriers in schools of nursing. According to AACN, **67,563 qualified applications** were turned away from baccalaureate and graduate nursing programs in 2010, primarily due to budget constraints which impact the insufficient number of faculty, clinical sites, classroom space, and clinical preceptors. As the ability of most states to support the needs of higher education has decreased, federal support for nursing education has become even more critical. National reform goals cannot be met without an adequate number of nurses to provide the cost-effective and quality care associated with the nursing discipline.

Nursing Workforce Development Programs: A Proven Solution

For nearly fifty years, the Title VIII Nursing Workforce Development Programs (42 U.S.C. 296 et seq.) have supported hundreds of thousands of nurses and nursing students. Between FY 2006 and 2009, the Title VIII programs supported over 347,000 nurses and nursing students as well as numerous academic nursing institutions and healthcare facilities. As the largest source of dedicated funding for nursing, the Title VIII programs award grants to nursing education programs, as well as provide direct support through loans, scholarships, traineeships, and programmatic grants. The programs also favor institutions that educate nurses for practice in rural and medically underserved communities and help to develop a more diverse nursing workforce to meet the cultural healthcare needs of our nation's population. Additionally, programs funded through Title VIII contribute to the promotion of academic progression, a major goal highlighted in the IOM's *Future of Nursing* report.

Of specific interest to AACN, the Title VIII programs support future nurse faculty, a significant barrier to addressing the nursing care needs in the United States. The nurse faculty shortage has grown critical as the national vacancy rate is 6.9% for schools offering baccalaureate and graduate nursing programs according to an AACN *Survey on Vacant Faculty Positions for Academic Year 2010-2011*. Of those schools reporting vacancies, the number of positions left unfilled was 803. Regionally, schools of nursing are struggling to recruit and hire faculty. Compared to the North Atlantic (9.2%), Southern (9.5%), and Mid-Western (9.2%) regions of the country, the West Coast (11.7%) has the highest faculty vacancy rate.

Title VIII Effectiveness

The Nursing Workforce Development Programs are effective and meet their authorized mission. AACN's *2010-2011 Title VIII Student Recipient Survey* included responses from 1,459 students who noted that these programs played a critical role in funding their nursing education, which will ultimately help them to achieve future career goals. The students responding to the Title VIII survey have career aspirations that meet the direct needs of the healthcare system and the profession. Nearly one-third (32.8%) of the respondents reported that their career goal is to become a nurse practitioner. Given the demand for primary care providers, the Title VIII funds are helping to support the next generation of these essential practitioners. Moreover, the nurse faculty shortage continues to inhibit the ability of nursing schools to increase student capacity. Of the students who

responded to the survey, an additional 33.2% stated their ultimate career goal was to become nurse faculty. Providing support for Title VIII is the key to help schools expand student capacity, fill vacant nursing positions, and, in turn, improve healthcare quality.

Demand for Title VIII

While millions of Americans are struggling during this economic downturn and thousands of students need loans to finance their education, federal support is necessary. Nursing students depend on federal loans like Title VIII to pay for their education. AACN's *Title VIII Student Recipient Survey* also indicated that 73% of the undergraduate and 62.6% of the master's students responding to the question regarding funding for nursing education noted that they will pay for their education through federal loans. The average loan amount that students reported they would take (private/federal) to support their education was $19,336 for undergraduate students and $55,698 for master's students. These students also noted that the total amount they will pay for their education is $32,307 for undergraduates and $64,734 for master's. Given this information, it is interesting to note that 65.6% of the students reported that the amount of support they received from Title VIII was $3,000 or less in one fiscal year.

Over the last 47 years, Congress has used the Title VIII authorities as a mechanism to address past nursing shortages. When the need for nurses was great, higher funding levels were appropriated. For example, during the nursing shortage in the 1970's, Congress provided $160.61 million to the Title VIII programs in 1973. Adjusting for inflation to address the 38-year difference, $243.872 million (FY 2010 funding level) in 1973 dollars would be over $1 billion in current dollars.

AACN respectfully requests $313.075 million for the Nursing Workforce Development Programs authorized under Title VIII of the Public Health Service Act in FY 2012 as recommended in the President's budget proposal.

Nursing Research: Supporting Health Promotion & Disease Prevention

The National Institute of Nursing Research (NINR) is one of the 27 Institutes and Centers at the National Institutes of Health (NIH). As the nation's nucleus for nursing science, NINR funds research that establishes the scientific basis for health promotion, disease prevention, and high quality nursing care to individuals, families, and populations. Often working collaboratively with physicians and other researchers, nurse scientists are vital in setting the national research agenda. The four strategic areas of emphasis for research at NINR are:

- **Promoting Health and Preventing Disease**
  Presently, more than 1.7 million Americans die each year from chronic diseases. Nurse researchers focus on investigating wellness strategies to prevent these chronic diseases. A healthcare system that promotes prevention is a major focus of the new health reform law, and NINR is a leader in funding scientific research to discover optimal prevention methods.

- **Eliminating Health Disparities**
  Race, gender, socioeconomic status, ethnic origin, geography, and culture impact the health care of individuals and communities. NINR is committed to funding research that

investigates culturally appropriate interventions and care strategies focused on at-risk populations.

- **Improving Quality of Life**
  Disease prevention is a critical goal of nursing research. NINR is committed to funding research that assists individuals with managing their own health conditions, decreases adverse symptoms, and reduces the burden on caregivers.

- **Setting Directions for End-of-Life Research**
  Palliative care and respect for those at the end of their life is a critical part of treatment for serious and life-threatening illness. This care is provided alongside disease treatment to ease suffering and improve the quality-of-life for the patient. NINR seeks, through scientific research, to improve the understanding of the processes underlying palliative care efforts and develop effective strategies to optimize care across all patient populations.

NINR's FY 2010 funding level of $145.66 million is approximately 0.47% of the overall $31.247 billion NIH budget. Spending for nursing research is a modest amount relative to the allocations for other health science institutes and for major disease category funding. For NINR to adequately continue and further its mission, the institute must receive additional funding. Cuts in funding have impeded the institute from supporting larger comprehensive studies needed to advance nursing science and improve the quality of patient care.

With increased appropriations for NINR, more comprehensive, complex, and longitudinal studies could be funded in the critical areas listed below while maintaining their portfolio of current goals, projects, and priorities of the institute.

- Expand the scope of science in symptom management
- Global health
- Increase funding for scientist-initiated research applications
- Expand the translation, dissemination, and outreach of NINR generated research to bridge the gap between scientific evidence and clinical practice
- Evaluate the impact of nursing science on the health of the nation

Additionally, considering that NINR presently allocates 6% of its budget to training that helps develop the pool of nurse researchers, increased funding would support NINR's efforts to prepare faculty researchers desperately needed to educate new nurses. *AACN respectfully requests $163 million for the National Institute of Nursing Research in FY 2012.*

Nurse-Led Practice Models: Investing in Nurse-Managed Health Clinics

The *Affordable Care Act* amended Sec. 330 of the Public Health Service Act, allowing Nurse-Managed Health Clinics (NMHCs) to apply for grant funds to help cover the costs of operating these unique community-based settings. NMHCs are nurse-practice arrangements and are managed by APRNs who provide primary care or wellness services to underserved or vulnerable populations through clinics located in places like public housing, churches, Native American reservations, rural communities, senior citizen centers, elementary schools, and storefronts. Each of these clinics is associated with a school, college, university or department of nursing, federally qualified health center, or independent nonprofit health or social services agency, and serves as safety net of

providers for vulnerable populations. Moreover, NMHCs play a valuable role as teaching and practice sites for nursing students. *AACN respectfully requests $20 million for the Nurse-Managed Health Clinics authorized under Title III of the Public Health Service Act in FY 2012 as recommended in the President's budget proposal.*

Capacity Grants: Solutions to Grow Enrollment

According to AACN's latest enrollment and graduation survey, the major barriers to increasing student capacity in nursing schools are insufficient numbers of faculty, admission seats, clinical sites, classroom space, and clinical preceptors, as well as budget constraints. The *Capacity for Nursing Students and Faculty Program*, a section of the *Higher Education Opportunity Act of 2008*, offers capitation grants (formula grants based on the number of students enrolled/or matriculated) to nursing schools allowing them to increase the number of students. Schools of nursing continue to face budget cuts at the state level, and capacity grants are a proven method for meeting the needs of nursing education. *AACN respectfully requests $25 million for this program in FY 2012.*

Conclusion

AACN acknowledges the fiscal challenges facing this Subcommittee and Congress, but would be remiss in not highlighting the benefits of the aforementioned programs. Title VIII has a long and successful record of providing dedicated support for the nursing workforce. The National Institute of Nursing Research invests in developing the scientific basis for quality nursing care. Nurse-Managed Health Clinics provide services to the underserved and training and practice settings for nursing students. The *Capacity for Nursing Students and Faculty Program* would allow schools to increase student capacity.

To be effective in meeting the critical goals outlined in the IOM's report, *The Future of Nursing: Leading Change, Advancing Health*, and the larger health reform goals of the nation, these programs must receive additional funding. AACN respectfully requests **$313.075 million for Title VIII programs, $163 million for NINR, $20 million for Nurse-Managed Health Clinics, and $25 million for the** *Capacity for Nursing Students and Faculty Program* **in FY 2012.** Additional funding for these programs will assist schools of nursing to expand their educational and research programs, educate more nurse faculty, increase the number of practicing RNs, and ultimately improve the patient care provided in our healthcare system.

Written Testimony of Jeffrey Levi, PhD
Executive Director, Trust for America's Health
House Appropriations Subcommittee on Labor, Health & Human Services, Education and Related Agencies

My name is Jeff Levi, and I am Executive Director of Trust for America's Health (TFAH), a nonprofit, nonpartisan organization dedicated to saving lives by protecting the health of every community and working to make disease prevention a national priority. I am grateful for the opportunity to submit testimony to the Subcommittee regarding funding for key public health programs. As you craft the FY 2012 Labor, Health & Human Services, Education and Related Agencies (LHHS) appropriations bill, I urge you to include adequate funding for prevention and preparedness programs to promote America's health and preparedness for natural and manmade disasters. Moreover, as you work with the Department of Health and Human Services (HHS) to allocate funding from the Prevention and Public Health Fund (Fund), I urge you to support funding the long-term transformation of the nation's public health system.

CDC Funding
We are extremely concerned over the nearly $740 million cut to the Centers for Disease Control and Prevention (CDC) included in the FY 2011 Continuing Resolution (CR). The drastic nature of this cut will be extremely difficult to recover in FY2012, bringing the Agency back to FY2003 funding levels. These cuts will force the Agency to choose between vaccinating children against deadly, preventable illnesses, detecting foodborne outbreaks, and preventing death and injury from the next disaster. We urge you to restore the cuts made in FY2011, or at least protect CDC from further cuts and focus our investment on cost-effective public health and prevention programs.

The Prevention and Public Health Fund
The Patient Protection and Affordable Care Act (P.L. 111-148) (ACA) established the Prevention and Public Health Fund – the largest commitment to increasing support for prevention and public health in U.S. history. The Fund will provide $17.75 billion over the next 10 years to communities in every state across the country to invest in effective, proven prevention efforts. Already in FY2010, the Fund has invested $500 million to support state and local public health efforts to 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, reduce tobacco use, and help control the obesity epidemic. An additional $750 million has already been allocated for a variety of meaningful public health programs. In FY 2012, the Fund will provide an additional $1 billion to continue supporting prevention, wellness and public health activities.

The Fund was intended to supplement existing investments with the first-ever, reliable national funding stream for public health, while creating jobs, bending the cost curve, and prioritizing disease prevention. The Fund's mandatory status guarantees an ongoing commitment to prevention unprecedented in today's "sick care" system, and eliminating it, or using it to supplant existing programs, would be an enormous step backwards in our progress on cost containment, public health modernization, and wellness promotion. The Fund must be protected and implemented to keep Americans healthier and more productive, and reduce health care costs.

Community Transformation Grants
Community prevention is a central component of reducing healthcare costs, building the economy, and improving quality of life. The Affordable Care Act establishes the Community Transformation Grant (CTG) program, administered by the Centers for Disease Control and Prevention (CDC), to create healthier communities by implementing policy, environmental, and programmatic changes at the local level where children and families live, work, play, exercise, and learn. The program represents a critical opportunity to implement, evaluate, and disseminate evidence-based community preventive health activities to reduce chronic disease and address racial and ethnic disparities. This program will move us away from our current stove-piped approach to disease prevention and change the focus to innovative, cross-cutting approaches to reducing the risks that affect health and cause injury.

We recommend the Committee allocate $221 million, as proposed by the President, for the CTG program in FY2012, which would provide competitive grants to state and local government agencies, Indian tribes or tribal organizations, national networks of community-based organizations, and state and local non-profit organizations. Grants will be used for both community prevention capacity building and investing in targeted interventions to reduce the prevalence of the leading causes of death, associated risk factors and health disparities. Additionally, appropriated funding for FY 2012 for the CTG program should ensure that activities previously supported under the CDC's Racial and Ethnic Approaches to Community Health (REACH) and Healthy Communities programs, which are proposed for elimination, are integrated into and continue to be supported by CTG activities.

Chronic Disease
Tens of millions of Americans are suffering from preventable chronic diseases such as cancer, heart disease, and diabetes. President Obama has proposed consolidating disease specific budget lines into one competitive grant program called the Comprehensive Chronic Disease Prevention Program (CCDPP) at CDC. The proposed program would address the top five leading chronic disease causes of death and disability (heart disease, cancer, stroke, diabetes, and arthritis) and associated risk factors. If adopted, it would fund five components of activities intended to strengthen state-based coordination of chronic disease activities, improve program efficiencies, provide leadership and support for cross-cutting activities and enhance the effectiveness of chronic disease prevention and risk factor reduction. TFAH supports the concept behind CCDPP and recognizes the efficiencies that could be created by focusing on common risk factors for chronic disease and fostering collaboration and coordination with streamlined funding. However, we urge Congress to work with the President, the CDC, and others to ensure that the framework and funding for this proposal does not limit the ability to continue successful chronic disease prevention efforts.

The president proposed a total of $705 million in funding, which includes nearly $158 million from the Prevention Fund. We support this recommendation, although worry about the appearance of those funds being used to supplant some existing discretionary funding, with the caveat that Prevention Fund dollars be targeted towards new, transformative activities, such as funding to state health departments to build core chronic disease prevention capacity, rather than simply used to replace previous funds.

National Center for Environmental Health (NCEH)
Community environments can serve as barriers to healthy choices, or they can help promote healthy behaviors. The connection between our environment and our health begins with the design of our communities. CDC's Built Environment and Health Program would support Healthy Community

Design activities, previously funded from the general environmental health line. TFAH recommends a targeted budget item of $4 million for the Built Environment and Health initiative to enable CDC to support the training, tool development, and research translation to enable communities to make design changes that promote health, including rates of environmentally-mediated illness, chronic disease, and injury. CDC would support up to eight entities to conduct state-wide trainings on health impact assessment (HIA), conduct prospective HIAs, and support other policy interventions into transportation and community design decision-making. CDC would continue its partnerships with national organizations to develop and make tools and training available to other regions and non-health sectors. CDC will also improve surveillance, emphasize collaborative partnerships with planning and transportation organizations, and will work to leverage these funds and more fully integrate built environment activities within existing Health Promotion activities.

For over 30 years, CDC's Environmental Health Laboratory has been performing biomonitoring measurements--direct measurements of people's exposure to more than 450 toxic substances in the environment. This information helps public health officials to determine which population groups are at high risk for exposure and adverse health effects, assess public health interventions, and monitor exposure trends over time. The proposed $6,000 increase in the President's budget means that the Environmental Health Laboratory will continue to implement a quality assurance program for biomonitoring measurements produced by state biomonitoring grantees. **Additionally, TFAH recommends an additional $2.2 million per year for three years to enable the Division of Laboratory Sciences to work with the clinical laboratory community to obtain a standardized measurement process for several cardiovascular disease biomarkers.** Cardiovascular disease currently suffers from a highly variable quality and standard of care and contributes to health care spending. A reliable and trusted test for these biomarkers would help to address these problems.

Pandemic Influenza and Medical Countermeasures Enterprise

The recent H1N1 flu outbreak demonstrated how rapidly a new strain of flu can emerge and spread around the world. The sudden outbreak of this novel flu virus has tested the world's public health preparedness. H1N1 provided a real-world test that showed the strengths and vulnerabilities in the abilities of the United States and the rest of the world to respond to a major infectious disease outbreak. For FY2012 pandemic influenza activities, **TFAH recommends providing $160 million for CDC (which funds both seasonal and pandemic influenza activities), $45 million for the Food and Drug Administration (FDA), $33 million for National Institutes of Health, and $65 million for the Office of the Secretary (OS)**, as proposed in the President's budget to expand international and domestic surveillance and detection capabilities, including the identification of vaccine virus strains; identify emerging viruses with pandemic potential; accelerate research and development of rapid diagnostic tests; improve pandemic preparedness and response, as well as our ability to contain a potential pandemic; and support international efforts to strengthen vaccine manufacturing infrastructure, expand surveillance systems, and improve pandemic influenza preparedness and response capabilities.

The Biomedical Advanced Research and Development Authority (BARDA), within the office of the Assistant Secretary for Preparedness and Response (ASPR) was established in 2006 to jumpstart a new cycle of innovation in vaccines, diagnostics and therapeutics in order to combat emerging health threats, products that would not be developed in the private market without these investments. BARDA provides incentives and guidance for research and development of products to counter bioterrorism and pandemic flu and manages Project BioShield, which includes the procurement and advanced development of medical countermeasures for chemical, biological, radiological, and nuclear agents. BARDA has more than 25 product candidates in development, and BioShield has

helped build the stockpile of smallpox vaccine, radiation treatments, anthrax antitoxins, and botulism antitoxins. BARDA is also using unobligated H1N1 funds to support Centers of Innovation for Advanced Development and Manufacturing, which would allow for flexible manufacturing facilities, supported the development of H1N1 and H5N1 vaccine, has built domestic manufacturing surge capacity for flu, and has supported the opening of the nation's first cell-based influenza vaccine facility. **TFAH recommends providing $665 million for BARDA, within the Office of the ASPR, as a starting point to build toward higher levels of funding that must ultimately be allocated and sustained.** Funding will be targeted to countermeasure development in the high priority areas of anthrax, broad-spectrum antimicrobials, diagnostics, chemical nerve agents, next-generation influenza vaccines, and radiation countermeasures.

Public Health Emergency Preparedness

Through the Public Health Emergency Preparedness (PHEP) Cooperative Agreement, CDC distributes grants to 50 states, four metropolitan areas (New York City, Chicago, Los Angeles and Washington, DC) and eight U.S. territories for public health infrastructure and workforce upgrades to prepare for and respond to acts of terrorism, natural disasters, or infectious disease outbreaks. A major portion of this funding provides state and local health departments with the ability to create and sustain the public health workforce crucial to emergency preparedness and response. Preparing for future outbreaks will require predictable and ample long-**term funding for infrastructure, staffing, enhanced laboratory capacity, biosurveillance, and training. TFAH recommends providing $761.1 million for State and Local Preparedness and Response Capability**, equivalent to the FY2010 allocation. Funds enable CDC to help public health departments continue to develop the capabilities necessary to detect and respond to a public health emergency, as well as for technical assistance, research, measurement, and evaluation. The president's proposed decrease of $110 million to this program would be devastating to the nation's security. 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. The proposed cuts would result in the loss of thousands of front-line public health preparedness jobs and would eliminate the Chemical 1 Laboratory Program (10 states), the Career Epidemiology Field Officer Program (23 states), and all Preparedness and Emergency Response Learning Centers and Preparedness and Emergency Response Research Centers (17 states).

In the event of a major disease outbreak or bioterror attack, the public health and health care systems would be severely overstretched. The Hospital Preparedness Program (HPP), administered by ASPR, provides grants to all 50 states, D.C., and major cities and territories to develop health system preparedness capacity through the following priority areas: interoperable communication systems, bed tracking, personnel management, fatality management planning and hospital evacuation planning. During the past five years HPP funds have also been used to build surge capacity and decontamination capabilities and to conduct training, education, drills and exercises. HPP includes a particular focus on meeting the needs of at-risk populations. In recent years, the program has used funds to develop regional healthcare coalitions, which build a communitywide, coordinated approach to preparedness and develop relationships between hospitals, public health, and emergency response agencies. In its evaluation of the program, the Center for Biosecurity found that health system preparedness for medical disasters has improved significantly since the inception of the program.[1] However, the assessment also found that planning for catastrophic events remains in the early stages.

[1] *Hospitals Rising to the Challenge: The First Five Years of the U.S. Hospital Preparedness Program and Priorities Going Forward,* Center for Biosecurity at UPMC, March 2009. Accessed from: http://www.upmcbiosecurity.org/website/resources/publications/2009/2009-04-16-hppreport.html

Funding for HPP must be maintained to retain and build on the progress made in hospitals' ability to respond to a disaster. **TFAH recommends providing $417 million for the Hospital Preparedness Program.** Funds will enable the program to maintain recent momentum in building regional healthcare coalitions, developing capacity to respond to a mass casualty event, extend interoperable communications, and prepare the healthcare workforce for a disaster.

Global Disease Detection

Through integrated disease surveillance, prevention and control activities, CDC's Global Disease Detection (GDD) program aims to recognize infectious disease outbreaks faster, improve the ability to control and prevent outbreaks, and to detect emerging microbial threats, in support of the International Health Regulations. In collaboration with host countries and the World Health Organization, CDC has established seven GDD Regional Centers, which strengthen our capacity to detect and respond to infectious disease outbreaks before they reach American shores, such as respiratory syndromes, diarrheal diseases, food-borne illnesses, and zoonotic diseases. Funding also supports other capacities, such as training in field epidemiology and laboratory methods; pandemic influenza preparedness and response, including improving and expanding global surveillance networks, increasing virus isolation and epidemiological data collection through expansion of capacity; zoonotic disease research and containment; health communications; and laboratory systems.

TFAH recommends a $6 million increase for the GDD Program in FY 2012, which would add at least two new Regional Centers, and enhance capacity at two existing Regional Centers. Funding would bring Thailand, Kenya, China and Guatemala to full capacity, support Egypt, Kazakhstan, India, and South Africa as basic Centers and establish two new developing Centers. Significant cuts to the program, such as reverting to 2008 funding levels, would result in the loss of two existing Regional Centers and eliminate the startup of the newest regional center in South Africa. Establishing a Center requires years of negotiation, training, and nurturing of partnerships between CDC and local health and governmental officials. Closing a Center could result in that nation or region remaining closed to CDC for many years to come.

Conclusion

Investing in disease prevention is the most effective, common-sense way to improve health. It can help spare millions of Americans from developing preventable illnesses, reduce health care costs, and improve the productivity of the American workforce so we can be competitive with the rest of the world. Millions 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 prevention is essential to improving health in the United States, and high rates of disease will not change unless an adequate level of funding is provided to support public health and prevention efforts. At a time when today's children are in danger of becoming the first generation in American history to live shorter, less healthy lives than their parents, we need to get serious as a nation about our commitment to helping people stay healthy and not get sick in the first place. Rather than drastically cutting public health agencies, as was done in the FY2011 continuing resolution, we must invest in prevention and disease detection to prevent disease, disability, and death.

Mr. Chairman, thank you again for the opportunity to submit testimony on the urgent need to enhance federal funding for public health programs which can save countless lives and protect our communities and our nation.

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FY 2012 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 2012 federal appropriations for biomedical research, with an emphasis on appropriations for the National Institutes of Health (NIH). The Endocrine Society is the world's largest and most active professional organization of endocrinologists representing more than 14,000 members worldwide. Our organization is dedicated to promoting excellence in research, education, and clinical practice in the field of endocrinology. The Society's membership includes thousands of scientists and clinicians who receive federal support for their research and, in turn, contribute greatly to the nation's scientific and healthcare advances.

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 State's global preeminence in research and fostered the development of a biomedical research enterprise that is unrivaled throughout the world. As the world's largest supporter of biomedical research, the NIH competitively awards extramural grants and supports in-house research. However, with the continued decline in real dollars allocated to biomedical research each year by the federal government, the opportunities to discover life-changing cures and treatments have already begun to decrease.

Biomedical research funds allocated by the federal government support both basic and translational research, ensuring that the discoveries made in the laboratory become realistic treatment options for patients suffering from debilitating and life-threatening diseases. Diabetes is a devastating condition that affects an increasingly large number of Americans and requires a large proportion of the nation's health care spending. Almost 26 million people (8.3 percent of the US population) have diabetes, and the estimated cost of diabetes was $174 billion in 2007.[1]

No new diabetes medications would have been developed without federally supported basic and clinical research. The discovery of insulin and the collaborative research effort of basic and clinical scientists eventually led to the approval of a new class of medications for diabetes, essentially the first new treatments of diabetes in the past 80 years. Without the continued support of both basic and clinical research in diabetes, these medications would have never been developed. Now, with this broadened portfolio of treatments, it is possible to help most people with diabetes achieve optimal blood sugar control.

[1] Centers for Disease Control and Prevention. National Diabetes Fact Sheet, 2011.

Beyond the multitude of health benefits that result from NIH-funded research, national and local economies benefit from the dollars that flow out of NIH into the communities. Researchers in all 50 states and 90 percent of congressional districts receive funding from NIH, and these funds stimulate local economies through salaries and purchase of equipment, laboratory supplies, and vendor services. For instance, for each dollar of taxpayer investment, UCLA generates almost $15 in economic activity, resulting in a $9.3 billion impact on the Los Angeles region. The estimated economic impact of Baylor on the surrounding community in Houston is more than $358 million, generating more than 3,300 jobs.[2] The governors of 25 states acknowledged the economic impact that NIH-funded research has on their states in an April 2010 letter to House and Senate Budget Committee members. The letter states,

> But NIH is also an important national, regional, and local economic engine. Together, our states received more than $19 billion from the NIH last year for promising research efforts. NIH funding directly supports 350,000 jobs across the U.S. In our states, we see firsthand the world class research institutions and scientific teams enabled by NIH, as well as the indirect job benefits of laboratories needing space, supplies, services, and equipment. We are also deeply aware that NIH-funded discoveries are the basis of new companies and even new industries in our communities.

During a time of recession, investment in biomedical research makes sense because it leads to cures and treatments for debilitating diseases while at the same time generating significant economic activity for local communities throughout the country.

The Endocrine Society remains deeply concerned about the future of biomedical research in the United States without sustained support from the federal government. The Society strongly supports the continued increase in federal funding for biomedical research in order to provide the additional resources needed to enable American scientists to address the burgeoning scientific opportunities and new health challenges that continue to confront us. The Endocrine Society recommends that NIH receive at least $35 billion in FY 2012 to ensure the steady and sustainable growth necessary to continue building on the advances made by scientists and physicians during the past decade.

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[2] Federation of American Societies for Experimental Biology. *NIH Advocacy Slides: California, Texas.*

Funding for the Workforce Investment Act in Fiscal Year 2012 and Beyond

Statement by Harry J. Holzer

Professor of Public Policy, Georgetown University and Institute Fellow, Urban Institute

April 2011

I would like to share my thoughts on the Workforce Investment Act (WIA), and particularly on the levels at which it should be funded, in Fiscal Year 2012 and beyond. These thoughts reflect my nearly 30 years of research and writing on these issues as a labor economist, including a stint as Chief Economist of the U.S. Department of Labor.

There is little doubt among most labor market analysts that the growth of education and skills among American workers has not kept up with growth in the labor market demand for these skills in the past three decades (Goldin and Katz, 2008). In order for productivity gains to be widely shared among Americans, and for employers to be able to fill vacant jobs with highly productive workers, the skill levels of our workers will need to increase. And the skills that will be demanded in the labor market are not only those represented by BA or more advanced degrees from four-year colleges and universities, but also the "middle skill" categories in many sectors that include a wide range of education and training credentials beyond high school (Holzer and Lerman 2007; Holzer, 2010).

In order for the skills of American workers to rise in ways that meet our labor market demands, we need an *effective workforce development system* that is well-coordinated with our systems of secondary and postsecondary education. On their own, and without effective workforce programs, our institutions of higher education are unlikely to generate workers with the skills needed to meet our labor market needs. For one thing, the dropout rates at many such institutions (especially community colleges) are extremely high; large percentages of students leave without earning any kind of credential at all (Bailey et al., 2005). And, among those who complete a degree or certificate program, many do not attain good-paying jobs (Jacobson and Mokher, 2009).

At least partly, these outcomes reflect the fact that many institutions of higher education provide little in the way of career counseling or labor market services for students that would effectively point them towards good-paying jobs and careers (Jacobson and Mokher, op. cit.; Soares, 2009). And, perhaps due to their previous levels of education or their family situations, not all workers are able to attend or succeed at institutions of higher education; instead, many need some kind of job training that is targeted towards specific jobs and sectors of the market that do not require as much in the way of academic skills.[1] Also, while employers could provide more on-the-job

[1] These alternatives include apprenticeship programs in construction or other fields as well as a variety of certificate programs in the health services and information technology. Programs that train machinists and precision welders for advanced manufacturing are also frequently offered in non-college settings.

training to meet their skill needs, there are many reasons for why they often choose not to do so, especially for their non-professional and non-managerial employees.[2]

For all these reasons, *a strong workforce system remains critical to maintaining a labor market in which skilled workers are well-matched to the jobs that require and reward such skills.* Jobseekers often need assistance locating the best local jobs for which they are qualified; they might need counseling about how best to upgrade their skills and for what kinds of jobs and careers; and they might need funding for such training. Training resources also need to be directed towards sectors with good-paying jobs that are in high demand. Indeed, the core, intensive and training services provided at One-Stop centers around the country that are funded by WIA, especially Title I, do all of these things.

Unfortunately, the overall resources that fund our workforce system have declined dramatically over time, both in an absolute sense (adjusted for inflation) and especially relative to the size of our economy and workforce. Indeed, since 1980 WIA expenditures (compared to its predecessor programs, CETA and JTPA) have fallen by as much as 90 percent, while our economy has doubled in size and our workforce has grown by nearly half (Holzer, 2009). We now lag behind almost all other industrial countries in the share of our GDP that we devote to such efforts (O'Leary et al., 2004).

At the same time, the scope of employment services funded by WIA has risen dramatically, as the services have become more universal and the number of individuals receiving training has diminished. In fact, *in a nearly $15T economy with over 153 million workers, the roughly $2.8B now available (in FY 2011) in Title I formula funds provides about $18 per American worker* – much too small a sum to greatly affect the skills and employment outcomes of American workers in the aggregate.

Our national unwillingness to sufficiently fund our workforce system reflects, to some extent, a widespread belief that such expenditures are wasteful or ineffective. But the literature based on rigorous research of WIA programs does not bear out this point of view. Indeed, the most rigorous studies of programs funded under WIA (summarized in Heinrich and King, 2010) suggest that these modest investments are quite *cost-effective* on an individual basis, generating significantly higher earnings for those who receive them. This is particularly true of "sectoral" programs that target growing industries providing high-paying jobs, and often actively involve employers in the process of training workers to fill their jobs (Maguire et al., 2010; Roder and Elliott, 2011).

And the concerns that have been recently expressed over duplication across federally-funded employment programs are quite overblown. Estimates by the U.S. Government Accountability

[2] Employers are often unwilling to invest in general training for workers who might soon leave their firm or whose basic skills are questionable. Also, imperfections in information and the capital markets further constrain their ability or willingness to do so (Lerman et al., 2004).

Office (GAO) show that, while there are many employment and training programs scattered through the federal budget, they generally target towards very small and specific populations and expend very few resources in the aggregate. Overall, the need for such services among American workers far outstrips overall available funding.

Not all estimated training impacts have been as positive as they can be, and therefore our workforce systems still need to evolve and incorporate our growing understanding of what constitute "best practices." This is especially true for some of our least-skilled workers and for out-of-school youth.[3] Some of the most promising models, like "career pathways," need further development and rigorous evaluation. Workforce development efforts also need to be better integrated with the higher education and economic development programs of states, though some have made considerable progress on this front in recent years.

However, these improvements will likely not occur in a system that is effectively starved of needed resources. Instead, appropriate incentives (through better and simpler performance measures on formula funds) and technical assistance should be provided, along with the resources, to make sure that such improvements occur. Workforce innovations should be competitively funded and rigorously evaluated; and this continuously growing body of knowledge should then inform our workforce legislation and its funding of "best practices" in the field.

An appropriately funded education and workforce system that generates more knowledge about effective practices and adapts to labor market changes over time is what we should aspire to build time – not with ill-informed budget cuts but with sensible program adjustments and an adequate base of funding.

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[3] For instance, the most recent evaluations of the Job Corps show positive and cost-effective impacts that tend to fade over time for teens, though not for older youth (Schochet et al., 2008). Estimates of the impacts of youth funding under the Job Training Partnership Act (JTPA), the predecessor of WIA, were not positive (Orr et al., 1997), though we know little about their impact under WIA. And recent evaluations of training impacts for the hardest-to-serve populations have generated mixed results (Bloom and Butler, 2007).

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THE AD HOC GROUP FOR MEDICAL RESEARCH

Statement by the Ad Hoc Group for Medical Research on
FY 2012 Appropriations for the Department of Health and Human Services
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
April 15, 2011

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. The Ad Hoc Group appreciates the opportunity to submit this statement in support of enhancing the federal investment in biomedical, behavioral, and population-based research supported by the National Institutes of Health (NIH).

We are deeply grateful to the Subcommittee for its long-standing, bipartisan leadership in support of NIH. These are difficult times for our nation and for people all around the globe, but the affirmation of science is the key to a better future. To improve Americans' health and strengthen America's innovation economy, the Ad Hoc Group for Medical Research recommends $35 billion for NIH in fiscal year (FY) 2012.

The partnership between NIH and America's scientists, medical schools, teaching hospitals, universities, and research institutions continues to serve as the driving force in this nation's search for ever-greater understanding of the mechanisms of human health and disease. More than 83 percent of NIH research funding is awarded to more than 3,000 research institutions located in every state. These are funded through almost 50,000 competitive, peer-reviewed grants and contracts to more than 350,000 researchers.

The foundation of scientific knowledge built through NIH-funded research drives medical innovation that improves health and quality of life through new and better diagnostics, improved prevention strategies, and more effective treatments. NIH research has contributed to dramatically increased and improved life expectancy over the past century. A baby born today can look forward to an average life span of nearly 78 years – almost three decades longer than a baby born in 1900, and life expectancy continues to increase. People are staying active longer, too: the proportion of older people with chronic disabilities dropped by nearly a third between 1982 and 2005. Thanks to insights from NIH-funded studies, the death rate for coronary heart disease is more than 60 percent lower – and the death rate for stroke, 70 percent lower – than in the World War II era.

NIH research continues to create dramatic new research opportunities, offering hope to the millions of patients awaiting the possibility of a healthier tomorrow. For example, a new ability to comprehend the genetic mechanisms responsible for disease already is providing insights into diagnostics and identifying a new array of drug targets. We are entering an era of personalized medicine, where prevention, diagnosis, and treatment of disease can be individualized, instead of using the standardized approach that all too often wastes health care resources and potentially subjects patients to unnecessary and ineffective medical treatments and diagnostic procedures.

Peer-reviewed, investigator-initiated basic research is the heart of NIH research. These inquiries into the fundamental cellular, molecular, and genetic events of life are essential if we are to make real progress toward understanding and conquering disease. The application of the results of basic research to the detection, diagnosis, treatment, and prevention of disease is the ultimate goal of medical research. Clinical research not only is the pathway for applying basic research findings, but it also often provides important insights and leads to further basic research opportunities. Additional funding is needed to sustain and enhance basic and clinical research activities, including increasing support for current researchers and promoting opportunities for new investigators and in those areas of science that historically have been underfunded.

Ongoing efforts to reinvigorate research training, including developing expanded medical research opportunities for minority and disadvantaged students, continue to gain importance. For example, the volume of data being generated by genomics research, as well as the increasing power and sophistication of computing assets on the researcher's lab bench, have created an urgent need, both in academic and industrial settings, for talented individuals well-trained in biology, computational technologies, bioinformatics, and mathematics to realize the promise offered by modern interdisciplinary research.

To move forward, it will be essential to maintain the talent base and infrastructure that has been created to date. Large fluctuations in funding will be disruptive to training, to careers, long range projects and ultimately to progress. The research engine needs a predictable, sustained investment in science to maximize our return.

Further, NIH-supported research contributes to the nation's economic strength by catalyzing private sector growth and creating skilled, high-paying jobs; new products and industries; and improved technologies. Industries and sectors that benefit include the high-technology and high value-added pharmaceutical and biotechnology industries, among others. In particular, the NIH funds "enabling science" that explores and identifies discoveries at a point earlier than businesses often invest, stoking and sustaining the discovery pipeline.

The investment in NIH not only is an essential element in restoring and sustaining both national and local economic growth and vitality, but also is essential to maintaining this nation's prominence as the world leader in medical research. As Raymond Orbach, former Under Secretary for Science at the Department of Energy for President George W. Bush, noted in a recent editorial in *Science*, "Other countries, such as China and India, are increasing their funding of scientific research because they understand its critical role in spurring technological advances and other innovations. If the United States is to compete in the global economy, it too

must continue to invest in research programs." To succeed in the information-based, innovation driven world-wide economy of the 21st century, we must recommit to long-term sustained growth in medical research funding.

The ravages of disease are many, and the opportunities for progress across all fields of medical science to address these needs are profound. In this challenging budget environment, we recognize the painful decisions Congress must make. The community appreciates that this subcommittee always has recognized that discoveries gained through basic research yield the medical advances that improve the fiscal and physical health of the country. Strengthening the nation's commitment to medical research is the key to ensuring the future of America's medical research enterprise and the health of her citizens.

The Ad Hoc Group for Medical Research respectfully requests that NIH be recognized as an urgent national priority as the subcommittee prepares the FY 2012 appropriations bills.

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Protect. Prevent. Live Well.

Testimony of the American Public Health Association
Concerning the Public Health Service Budget for Fiscal Year 2012
Submitted to the House Appropriations Subcommittee on Labor, HHS, Education
April 15, 2010

The American Public Health Association (APHA) is the oldest and most diverse organization of public health professionals and advocates in the world dedicated to promoting and protecting the health of the public and our communities. We are pleased to submit our views on federal funding for public health activities in fiscal year (FY) 2012.

Recommendations for Funding the Public Health Service
APHA's budget recommendations for the Public Health Service includes funding for the Centers for Disease Control and Prevention (CDC), the Health Resources and Services Administration (HRSA), the Substance Abuse and Mental Health Services Administration (SAMHSA), the Agency for Healthcare Research and Quality (AHRQ), and the National Institutes of Health (NIH). Together all of these agencies play a critical role in keeping Americans healthy.

CDC
APHA believes that Congress should support CDC as an agency – not just the individual programs that it funds. In the best judgment of the CDC Coalition – given the challenges and burdens of chronic disease, a potential influenza pandemic, terrorism, disaster preparedness, new and reemerging infectious diseases and our many unmet public health needs and missed prevention opportunities – **we believe the agency will require funding of at least $7.7 billion for CDC's "core programs" in FY 2012.** This request represents a 36 percent increase over FY 2011 and a 31 percent increase over the President's FY 2012 request. We are deeply disappointed with the more than $740 million in cuts to CDC's budget authority included in the proposed FY 2011 continuing resolution (CR). While CDC programs will receive significant new funding from the Prevention and Public Health Fund in fiscal year 2011, we are concerned that this funding would essentially supplant cuts made to CDC's budget authority. As you know the Prevention and Public Health Fund was intended to supplement and not supplant the base funding of our public health agencies and programs.

The President's FY 2012 budget proposes to consolidate a number of chronic disease programs within CDC. APHA and other advocates are currently engaged in conversations with CDC and members of Congress to better understand what this consolidation will mean for the funding that is passed on to our state and local health agencies and the various programs our members have supported in the past. We look forward to working with Congress, the Administration and CDC to ensure that any effort to consolidate the programs leads to best health outcomes for the American people. We must ensure that CDC's National Center for Chronic Disease Prevention and Health Promotion has the resources it needs to assist our states and communities in their efforts to reduce the burden of chronic disease.

By translating research findings into effective intervention efforts, CDC has been a key source of funding for many of our state and local programs that aim to improve the health of communities. Perhaps more importantly, federal funding through CDC provides the foundation for our state and local public health departments, supporting a trained workforce, laboratory capacity and public health education communications systems.

CDC also serves as the command center for our nation's public health defense system against emerging and reemerging infectious diseases. With the potential onset of a worldwide influenza pandemic, in addition to the many other natural and man-made threats that exist in the modern world, the CDC has become the nation's—and the world's—expert resource and response center, coordinating communications and action and serving as the laboratory reference center. States and communities rely on CDC for accurate information and direction in a crisis or outbreak. This has been demonstrated most recently by CDC's quick response and ongoing investigation into human infections with H1N1 flu (swine flu) in the United States and internationally.

CDC's National Center for Injury Prevention and Control works to prevent unintentional and violence-related injuries to minimize the consequences of injuries when they occur by researching the problem; identifying the risk and protective factors; developing and testing interventions; and ensuring widespread adoption of proven strategies. We urge you to ensure the agency has the resources it needs to address these leading causes of death and disability.

We must address the growing disparity in the health of racial and ethnic minorities. CDC is helping states address serious disparities in infant mortality, breast and cervical cancer, cardiovascular disease, diabetes, HIV/AIDS and immunizations. APHA is committed to ending health disparities and we encourage the Subcommittee to provide adequate funds for these efforts.

We also encourage the Subcommittee to provide adequate funding for CDC's National Center for Environmental Health. We ask that the Subcommittee to continue its recent efforts to expand and enhance CDC's capacity to help the nation prepare for and adapt to the potential health effects of climate change by providing CDC with $15 million for climate change and health activities. Expanded funding would allow CDC to provide technical assistance, training and tools to help state and local health officials and improve coordination and integration of climate change across CDC. We also urge the Committee to closely evaluate the significant cut made to CDC's Healthy Homes/Lead Poisoning Prevention and the National Asthma Control programs in the president's budget to ensure these programs have adequate funding to provide states and localities with the funding they need to protect public health.

HRSA

We request an overall funding level of $7.65 billion for HRSA in FY 2012. This recommendation represents a 22 percent increase over FY 2011 and a 12 percent increase over the President's FY 2012 request. We believe this level of funding is the minimum amount necessary for HRSA to continue to meet the health care needs of the American public. Over the past several years, HRSA has received mostly level funding, undermining the ability of its successful programs to grow. Additionally we are deeply disappointed with the more than $1.2 billion in cuts made to the agency in the final FY 2011 Continuing Resolution and the potential negative consequences for public health. Our FY 2012 requested minimum level of funding will better allow the agency to carry out critical public health programs and services that reach millions of Americans, including training for public health and health care professionals, providing primary

care 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. However, much more is needed for the agency to achieve its ultimate mission of ensuring access to culturally competent, quality health services; eliminating health disparities; and rebuilding the public health and health care infrastructure.

HRSA operates programs in every state and thousands of communities across the country and is a national leader in providing health services for individuals and families. The agency serves as a health safety net for the medically underserved, including the 50 million Americans who were uninsured in 2009 and 50 million Americans who live in neighborhoods where primary health care services are scarce.

The $7.65 billion FY 2012 HRSA funding request is based upon recommendations provided by public health professionals to support HRSA programs including:

- Health Professions programs support the education and training of primary care physicians, nurses, dentists, optometrists, physician assistants, nurse practitioners, public health personnel, mental and behavioral health professionals, pharmacists, and other allied health providers; improve the distribution and diversity of health professionals in medically underserved communities; and ensure a sufficient and capable health workforce able to provide care for all Americans and respond to the growing demands of our aging and increasingly diverse population. In addition, the Patient Navigator Program helps individuals in underserved communities, who suffer disproportionately from chronic diseases, navigate the health system.
- Primary Care programs support more than 7,000 community health centers in every state and territory, improving access to preventive and primary care in geographically isolated and economically distressed communities. In addition, the health centers program targets populations with special needs, including migrant and seasonal farm workers, homeless individuals and families, and those living in public housing.
- Maternal and Child Health Flexible Maternal and Child Health Block Grants, Healthy Start and other programs provide services, including prenatal and postnatal care, newborn screening tests, immunizations, school-based health services, mental health services, and well-child care for more than 34 million uninsured and underserved women and children not covered by Medicaid or the Children's Health Insurance Program, including children with special needs.
- HIV/AIDS programs provide assistance to metropolitan and other areas most severely affected by the HIV/AIDS epidemic; support comprehensive care, drug assistance and support services for people living with HIV/AIDS; provide education and training for health professionals treating people with HIV/AIDS; and address the disproportionate impact of HIV/AIDS on women and minorities.
- Family Planning Title X programs provide reproductive health care and other preventive services for more than 5 million low-income women at over 4,500 clinics nationwide. These programs improve maternal and child health outcomes, prevent unintended pregnancies, and reduce the rate of abortions.
- Rural Health programs improve access to care for the 60 million Americans who live in rural areas. Rural Health Outreach and Network Development Grants, Rural Health Research

Centers, Rural and Community Access to Emergency Devices Program, and other programs are designed to support community-based disease prevention and health promotion projects, help rural hospitals and clinics implement new technologies and strategies, and build health system capacity in rural and frontier areas.

- Special Programs include the Organ Procurement and Transplantation Network, the National Marrow Donor Program the C.W. Bill Young Cell Transplantation Program, and National Cord Blood Inventory. Strong funding would facilitate an increase in organ, marrow and cord blood transplantation.

Greater investment is necessary to sufficiently fund HRSA services and programs that continue to face increasing demands. We urge you to consider HRSA's role in building the foundation for health service delivery and ensuring that vulnerable populations receive quality health services, while continuing to strengthen our nation's health safety net programs. 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.

AHRQ
We request a funding level of at least $405 million for AHRQ for FY 2012. This level of funding is needed for the agency to fully carry out its Congressional mandate to conduct, support, and disseminate research and translate research into knowledge and information that can be used to improve the health of all Americans. AHRQ focuses on improving health care quality, eliminating racial and ethnic disparities in health, reducing medical errors, and improving access and quality of care for children and persons with disabilities.

SAMHSA
APHA supports a funding level of $3.671 billion for SAMHSA for FY 2012. This funding level would provide support for substance abuse prevention and treatment programs, as well as continued efforts to address emerging substance abuse problems in adolescents, the nexus of substance abuse and mental health, and other serious threats to the mental health of Americans.

NIH
APHA supports a funding level of $35 billion for the NIH for FY 2012. The translation of fundamental research conducted at NIH provides some of the basis for community based public health programs that help to prevent and treat disease.

Conclusion
In closing, we emphasize that the public health system requires stronger financial investments at every stage. Successes in biomedical research must be translated into tangible prevention opportunities, screening programs, lifestyle and behavior changes, and other interventions that are effective and available for everyone. Without a robust and sustained investment in our nation's public health agencies, we will fail to meet the mounting health challenges facing our nation.

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

April 15, 2011

Written Testimony** Regarding Funding Requests for Eldercare Workforce Programs
of the Department of Health and Human Services

Submitted on behalf of the
Eldercare Workforce Alliance
By

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Mr. Chairman 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 2012, the Alliance** asks that you consider $54.9 million in funding for the geriatrics health professions and direct-care worker training programs that are authorized under Titles VII and VIII of the Public Health Service Act as follows:**

- **$46.5 million for Title VII Geriatrics Health Professions Programs**
- **$3.4 million for direct care workforce training; and**
- **$5 million for Title VIII Comprehensive Geriatric Education Programs**

Geriatrics health profession and direct-care worker 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.

***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.*

The Eldercare Workforce Alliance is a project of The Advocacy Fund.

The first of the baby boomers began to turn 65 this year. Within 20 years, one in five Americans will be over 65; 90 percent of those Americans will have one or more chronic conditions. Despite the growing need for services, there is a growing shortage of health professionals and direct-care workers with specialized training in geriatrics and an even greater shortage of the geriatrics faculty needed to train the entire workforce.

In 2008, the Institute of Medicine (IOM) issued a ground-breaking report, *Retooling for an Aging America: Building the Health Care Workforce,* which spotlighted these shortages and their impact on eldercare. The report called for an expansion of geriatrics faculty development awards to include additional professional disciplines, increased training for the direct-care workforce, and other efforts to create a healthcare workforce with adequate capacity to care for older adults. The Eldercare Workforce Alliance was established to encourage policy makers to act on the IOM's recommendations for addressing the eldercare workforce crisis.

The enactment of the Patient Protection and Affordable Care Act (ACA) was a historic moment for health care in this country. ACA makes important strides toward addressing the severe and growing shortages of health care providers with the skills and training to meet the unique health care needs of our nation's growing aging population.

ACA includes provisions from the *Retooling for an Aging America Act* (S. 245 and H.R. 468 in the 111th Congress), sponsored by Senator Kohl (D-WI) and Representative Schakowsky (D-IL). These provisions enhance existing and establish new geriatrics programs in an effort to build the capacity of the healthcare workforce needed to care for older adults, as recommended in the IOM report.

We very much appreciate the funding for the Title VII Geriatrics Health Professions programs that President Obama included in his FY 2012 budget. We urge you to appropriate adequate funds for geriatrics training programs in FY 2012 so that we can immediately begin to realize the health care workforce goals set forth in health reform. Specifically, the Eldercare Workforce Alliance requests $54.9 million in total funding for the following programs under Title VII and VIII of the Public Health Service Act:

Title VII Geriatrics Health Professions
Appropriations Request: $46.5 Million
Title VII Geriatrics Health Professions programs are the only federal programs that: (1) increase the number of faculty with geriatrics expertise in a variety of disciplines; and (2) offer critically important geriatrics training to the entire healthcare workforce.

- 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 2009-2010, GACA funded 84 non-competing continuation awards. GACA awardees provided approximately 60,000 health professionals with interdisciplinary geriatrics training. In turn, these trainees provided culturally competent quality health care to over 525,000 underserved and uninsured patients in acute care services, geriatric ambulatory care, long-term care, and geriatric consultation services settings.

  In 2010, HRSA expanded the awards to be available to more disciplines. EWA advocated for this expansion and we now want to ensure that there is adequate funding for this vital program. **Our request of $5.3 million, as reflected in the President's budget, includes necessary support for 68 Geriatric Academic Career Awardees, promoting the development of clinician educators.**

- Geriatric Education Centers (GEC): The goal of the Geriatric Education Centers is to provide quality interdisciplinary geriatric education and training to geriatrics specialists and non-specialists, including family caregivers and direct care workers.

  Program Accomplishments: In Academic Year 2009-2010, the GEC grantees provided clinical training to 54,167 health professional students and to 20,791 interdisciplinary teams in multiple settings.

  As part of the ACA, Congress authorized a supplemental grant award program that will train additional faculty through a mini-fellowship program. The program requires awarded faculty to provide training to family caregivers and direct care workers. **Our funding request of $22.7 million, as reflected in the President's budget plus $2.7 million for the supplemental grants, includes support for the core work of 45 GECs and for the 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, and Behavioral and Mental Health Professions: The goal of the GTPD is to increase the supply of quality and culturally competent geriatric clinical faculty and to retrain mid-career faculty in geriatrics. 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.

  Program Accomplishments: In Academic Year 2009-2010, 11 non-competing continuation grants were supported. Forty-nine physicians, dentists, and psychiatric fellows received support to provide geriatric care to 20,078 older adults across the care continuum. Geriatric physician fellows provided health care to 12, 254 older adults. Geriatric dental fellows provided health care to 4,073 older adults. Geriatric psychiatry fellows provided health care to 3,751 older adults.

  Our funding request of $8.5 million, as reflected in the President's budget, includes support for 13 institutions to continue this important faculty development program.

- Geriatric Career Incentive Awards Program: Congress has authorized this new program created through the ACA, which offers grants to foster greater interest among a variety of health professionals in entering the field of geriatrics, long-term care, and chronic care management. President Obama included $10 million in his FY 2012 budget to establish this awards program. **Our funding request of $10 million, as reflected in the President's budget, includes support for implementation of this new program.**

Title VII Direct-Care Worker Training Program
Appropriations Request: $3.4 million

Direct-care workers help older adults who need long-term services and supports including assistance with activities of daily living (e.g. eating, bathing, dressing, toileting). Expanded training opportunities for these essential workers are critical to ensuring an adequate geriatrics workforce. According to current employment projections, more than one million new direct care workers will be needed by 2018 in order to meet the growing need for care.

- Training Opportunities for Direct Care Workers: As part of the ACA, Congress approved an advanced training program for direct care workers, administered by HHS. Although President Obama's budget did not include this vital training program, EWA urges Congress to fund it in order to enhance direct care worker skills and knowledge, and thereby, improve the quality of care for older adults. **EWA's funding request of $3.4 million includes support to establish**

this unique grant program at community colleges as they look to increase the geriatrics knowledge and expertise of the direct care workforce.

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. 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.

  Program Accomplishments: In Academic Year 2009-2010, 27 CGEP grantees provided education and training to [suggest adding all of these together—total of x professionals in nursing, home health, as well as lay people] 3,030 Registered Nurses/Registered Nursing Students; 260 Advanced Practice Nurses; 221 Faculty; 110 Home Health Aides; 483 Licensed Practical/Vocational Nurses & LPN students; 730 Nurse Assistants/Patient Care Associates; 810 Allied Health Professionals and 929 lay persons, guardians, activity directors. The CGEP grantees provided 459 educational course offerings in the care of the elderly on a variety of topics to 6,846 participants.

- 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.

  Our funding request of $5 million, as reflected in the President's budget, includes funds that will continue the training of nurses caring for the elderly and offer 200 traineeships to nurses under the newly implemented traineeship program.

Without additional funds in these programs, we will fail to ensure that America's health care workforce will be prepared to care for older Americans. We understand that the Committee faces difficult budget decisions. However, we strongly believe that by investing in these programs, which create geriatrics faculty and offer the training that is needed to ensure a competent workforce, we will be delivering better care to America's older adults. Health care dollars will be saved from better care coordination and health outcomes, and the workforce will grow as more people are trained, recruited and retained in the field of geriatrics.

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.

Testimony Submitted for the Record to the Subcommittee on Labor, Health and Human Services, Education and Related Agencies on FY 2012 Appropriations for HIV/AIDS Programs

Submitted by the HIV Medicine Association
Andrea Weddle, Executive Director
aweddle@hivma.org

April 15, 2011

The HIV Medicine Association (HIVMA) of the Infectious Diseases Society of America (IDSA) represents more than 3,800 physicians, scientists and other health care professionals who practice on the frontline of the HIV/AIDS pandemic. Our members provide medical care and treatment to people with HIV/AIDS throughout the U.S., lead HIV prevention programs and conduct research to develop effective HIV prevention and treatment options. We work in communities across the country and around the globe as medical providers and researchers dedicated to the field of HIV medicine.

We appreciate the importance of addressing the fiscal challenges facing our nation, but the continued fragile state of the economy makes it imperative to set priorities to ensure that our nation has a strong health care safety-net, effective programs for preventing infectious diseases like HIV and a robust scientific research agenda.

The U.S. investment in HIV/AIDS programs has revolutionized HIV care globally making HIV treatment one of the most effective medical interventions available. A vibrant research agenda and rapid public health implementation of scientific findings have transformed the HIV epidemic, reducing morbidity and mortality due to HIV disease by nearly 80 percent in the U.S. Implementation of health care reform and the Administration's plans for a National HIV/AIDS Strategy offer promise for making significant progress in reducing the impact of the domestic HIV epidemic. However, their success will depend on maintaining adequate investments in the health care safety net, and in prevention, public health and research programs. The funding requests in our testimony largely reflect the consensus of the Federal AIDS Policy Partnership (FAPP), a coalition of HIV organizations from across the country, and are estimated to be the amounts necessary to sustain and strengthen our investment in combatting HIV disease.

Health Care Reform

We strongly support at a minimum the President's FY2012 request level for health care reform programs supported with discretionary funding under the Patient Protection and Affordable Care Act (ACA), in particular: health workforce education and training programs under Titles VII and VIII of the Public Health Service Act (PHSA); health care quality improvement programs, and Medicaid demonstration programs.

If we are to succeed in improving the quality and efficiency of our health care delivery system, 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 "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 $760.5 million in fiscal year 2011 with at least an increase of $65.8 million over the FY2010 level for Part C.

Part C of the Ryan White Program funds comprehensive HIV care and treatment -- services that are directly responsible for the dramatic decreases in AIDS-related mortality and morbidity over the last decade. On average it costs $3,501 per person per year to provide the comprehensive outpatient care and treatment available at Part-C funded programs, including lab work, STD/TB/Hepatitis screening, ob/gyn care, dental care, mental health and substance abuse treatment, and case management. Part C funding covers 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 Ryan White Program generally is under-funded and Part C of the program is disproportionately and severely under-funded. The Centers for Disease Control and Prevention estimate that there are more than 1.1 million persons living with HIV/AIDS and approximately 240,000, or almost 1 in 4, of these individuals receive services from Part C medical providers. Of the 240,000 patients, approximately 1 out of 3 is uninsured, and 2 out of 3 are underinsured.

While the patient caseload in Part C programs has been rising, funding for Part C has effectively decreased due to flat funding and funding cuts at the clinic level. Part C programs expect a continued increase in patients due to higher diagnosis rates and economic -related declines in insurance coverage. During this economic downturn people with HIV across the country are relying on Part C comprehensive services more than ever. As a result of consistently increasing caseloads and limited funding, Part C clinics are taking dramatic steps that adversely impact their ability to serve patients, including:

1. Limiting primary care services
2. Discontinuing critical services such as laboratory monitoring
3. Suffering eviction from institutional-based clinic sites
4. Laying off staff
5. Operating only 4 days/week

The HIV medical clinics funded through Part C have been in dire need of increased funding for years, but new pressures are creating a crisis in communities across the country. An increase in funding is critical to prevent additional staffing and service cuts and ensure the public health of our communities.

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Center for Disease Control and Prevention's (CDC) National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP)

HIVMA strongly urges total FY2012 funding of **$1.953 billion for the CDC's NCHHSTP,** an increase of $834.1 million over the FY2010 level, including increases of: **$515.3 million for HIV prevention and surveillance**, **$20.2 million for viral hepatitis** and **$85.9 million for Tuberculosis prevention**.

Every nine and a half minutes a new HIV infection happens in the U.S. with more than 60 percent of new cases occurring among African Americans and Hispanic/Latinos. Despite the known benefit of effective treatment, 21 percent of people living with HIV in the U.S. are still not aware of their status and as many as 36 percent of people newly diagnosed with HIV progress to AIDS within one year of diagnosis.

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. The CDC estimates that the 56,300 new HIV infections each year in the U.S. may result in $56 billion in medical care and lost productivity costs.

We appreciate that the President proposed a $68.8 million increase for HIV prevention at the CDC, and at a bare minimum we strongly urge the Committee to at least meet this request.

Finally, we strongly support adequate funding for science-based, comprehensive sex education programs. We are pleased that the FY2011 Continuing Resolution provides $109 million for the Teen Pregnancy Prevention Program, which focuses on reducing the risks of pregnancy and sexually transmitted diseases through proven and successful models. We urge the Committee to support opportunity to adopt report language supporting true, comprehensive sex education that promotes healthy behaviors and relationships for all young people, including lesbian, gay, bisexual, and transgender youth, including an explicit focus on prevention of HIV and other STDs.

CDC-Tuberculosis

Tuberculosis is the major cause of AIDS-related mortality worldwide and the second leading infectious disease killer. Congress passed landmark legislation in the Comprehensive Tuberculosis Elimination Act of 2008 to shore up state TB control programs, to enhance U.S. capacity to address drug-resistant tuberculosis; and to develop new drugs, diagnostics and vaccines.

State budget cuts have hit local TB control programs hard, and the CDC Division of TB Elimination has seen some budget reductions in the last two fiscal years. Our ability to respond to TB within our own borders is being compromised as a result. We must do better. Finally, we

are beginning to see exciting new tools to combat tuberculosis after decades of little or no productive research and development in this area. We have an exciting new diagnostic that can diagnose drug-susceptible and drug-resistant TB very quickly. There are a number of new drugs in clinical trials for both drug resistant and drug-susceptible TB. There are promising new TB vaccine candidates being tested. Now, resources are needed more urgently than ever to follow through on this research and development now in progress and to ensure that these new tools reach the public health officials on the ground that need them.

We respectfully fiscal year 2012 funding for the CDC Division of TB Elimination at a level of $231 million.

CDC-Viral Hepatitis

Funds are urgently needed to provide core public health services and to track chronic cases of hepatitis. Hepatitis is a serious co-infection for nearly one-third of our HIV patients. We strongly urge you to **boost funding for viral hepatitis at the CDC by $20.2 million over the FY2010 level million for a total funding of $40 million**.

Agency for Health Care Quality and Research (AHRQ)

HIVMA urges the Committee to provide $2.2 million, a $200,00 increase over the FY 2010 level for the HIV Research Network (HIVRN), the only significant HIV work being done at AHRQ. The HIVRN is a consortium of 18 HIV primary care sites co-funded by AHRQ and HRSA to evaluate health care utilization and clinical outcomes in HIV infected children, adolescents and adults in the US. The Network analyzes and disseminates information on the delivery and outcomes of health care services to people with HIV infection. These data help to improve delivery and outcomes of HIV care in the U.S. and to identify and address disparities in HIV care that exist by race, gender, and HIV risk factor. The HIVRN is a unique source of information on the cost and cost-effectiveness of HIV care in the U.S. at a time when data on comparative cost and effectiveness of health care is particularly needed to inform health systems reform and the development and implementation of a National HIV/AIDS Strategy.

National Institutes of Health (NIH) – Office of AIDS Research

HIVMA strongly supports an increase of at least $4 billion over the FY2010 level for all research programs at the NIH, including at least a $400 million increase for the NIH Office of AIDS. This level of funding is vital to sustain the pace of research that will improve the health and quality of life for millions of Americans.

Our past investment in a comprehensive portfolio was responsible for the dramatic gains that we made in our HIV knowledge base, gains that resulted in reductions in mortality from AIDS of nearly 80 percent in the U.S. and in other countries where treatment is available. Gains that also helped us to reduce the mother to child HIV transmission rate from 25 percent to nearly 1 percent in the U.S. and to very low levels in other countries where treatment is available.

With only one in four research applications receiving funding, the pipeline for critical discoveries and HIV scientists has been dwindling and our role as a leader in biomedical research is at serious risk. A continued robust AIDS research portfolio is essential to sustain and to accelerate our progress in offering more effective prevention technologies; developing new and less toxic treatments; and supporting the basic research necessary to continue our work developing a vaccine that may end the deadliest pandemic in human history. The sheer magnitude of the number of people affected by HIV– more than one million people in the U.S.; more than 33 million people globally – demands a continued investment in AIDS research if we are going to truly eradicate this devastating disease. We believe a high priority should be research to discover novel prevention strategies, to improve available treatment strategies, to aid prevention and to maximize the benefits of antiretroviral therapy, especially in the populations disproportionately affected by HIV in the U.S. and in resource-limited settings.

Historically, our nation has made significant strides in responding to the HIV pandemic here at home and around the world, but we have lost ground in recent years, particularly domestically, as funding priorities have shifted away from public health and research programs. We appreciate the many difficult decisions that Congress faces this year, but urge you to recognize the importance of investing in HIV prevention, treatment and research now to avoid the much higher cost that individuals, communities and broader society will incur if we fail to support these programs. We must seize the opportunity to limit the toll of this deadly infectious disease on our planet and to save the lives of millions who are infected or at risk of infection here in the U.S. and around the globe.

Testimony of Geoffrey Canada, President/CEO, Harlem Children's Zone & President, Harlem Children's Zone Promise Academy Charter Schools & Angela Glover Blackwell, Founder and CEO, PolicyLink to the House Committee on Appropriations, Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

April 15, 2011

Thank you for this opportunity to support comprehensive services for poor children and the US Department of Education's (ED) Promise Neighborhoods program which we believe will break the cycle of generational poverty for hundreds of thousands of poor children.

Like the work at the Harlem Children's Zone® (HCZ®), the Promise Neighborhoods program has already begun to transform the odds for entire communities. High-achieving schools are at the core of Promise Neighborhoods, but it is not only about creating a successful school. It is about programs for children from birth through college and career, supporting families and rebuilding community. Doing this changes the trajectory of an entire community.

In the mid-1990s it became clear to the HCZ team that despite heroic efforts at saving poor children, success stories remained the exception. Our piecemeal approach was of limited value against a perfect storm of problems and challenges. So the HCZ Project was created in Central Harlem to work with kids, their families and their community. Starting with one building, HCZ has grown to 97 blocks. Last year, the HCZ Project served 15,508 clients including 8,838 youth and 6,670 adults. HCZ, Inc., which includes the HCZ Project plus our Beacon Centers and Preventive Foster Care programs, served 23,556 clients including 10,541 youth and 13,015 adults.

Now, over a decade later, the Children's Zone® model is working. Parents are reading more to their children. Four year olds are ready for kindergarten. Students are closing the black-white achievement gap in several subjects. Teenagers are graduating from high school and this school year, over 600 of them who attended traditional public schools are in college. HCZ helps parents file for taxes including the Earned Income Tax Credit (EITC) and last tax season, families collectively received over $8M.

HCZ's theory of change is embodied in the application of all of the following five principles:

- Serve an entire neighborhood comprehensively and at scale.
- Create a pipeline of high-quality programs that starts from birth and continues to serve children until they graduate from college. Provide parents with supports as well.
- Build community among residents, institutions, and stakeholders, who help to create the environment necessary for children's healthy development.
- Evaluate program outcomes; create a feedback loop that cycles data back to management for use in improving and refining program offerings; and hold people accountable.
- Cultivate a culture of success rooted in passion, accountability, leadership, and teamwork.

The HCZ® model is not cheap. On average, HCZ spends $5,000 per child each year to ensure children's success. For far less money than is already spent, just on incarceration, we can educate,

graduate our children, and bring them back to our communities ready to be successful, productive citizens. We think the choice is obvious.

HCZ's achievements are not magic. They are a result of hard work and a comprehensive effort.

This same type of hard work and comprehensive effort is happening in countless communities across the country. To provide a sense of the level of interest in the Promise Neighborhoods program, when the Department of Education offered the first round of planning grants in FY10's budget, over 339 communities competed for just 21 grants. Additionally, over 100 of these communities scored over 80, leading Secretary of Education Arne Duncan to note that there would have been more grants if resources were available.

Just 7 months later, these communities are going strong. For example:

Buffalo, New York

The Buffalo Promise Initiative, which is led by M&T's Westminster Foundation, is collaborating with the John R. Oishei Foundation, Read to Succeed Buffalo, the City of Buffalo, Buffalo Public Schools, United Way of Buffalo and Erie County, Catholic Charities, Buffalo Urban League, and the University at Buffalo to serve 11,000 residents in a one-square mile, low-income neighborhood. The Buffalo Promise Initiative is a vital counterpoint to the challenges brought about in Buffalo due to a shift away from industrially focused jobs, a shrinking population, and increasing poverty. A comprehensive approach is blooming, addressing the needs and hopes of children and their families in a changing Buffalo.

Indianola, Mississippi

The Indianola Promise Community (IPC) is located in Indianola, Mississippi, in the heart of the Mississippi Delta and the birthplace of musician B.B. King. The Delta Health Alliance is the lead agency for this unique public policy initiative. The Indianola Promise Community unites healthcare, education, community, and faith-based services to provide Indianola residents the chance to realize their promise as active members and leaders in their town and neighborhoods. The Delta Health Alliance has teamed up with a number of non-profit organizations and government agencies, including the local school district, the municipal government, Mississippi State University, the county hospital, and the Children's Defense Fund, to develop a comprehensive collaborative with the ability to take on a number of pressing challenges.

Although Indianola has a number of obstacles to overcome, leaders from all aspects of the community have joined together to make the IPC a success. The Delta Health Alliance is integrating more than a dozen of their preexisting services and adding new programs and new partners into a robust set of resources. The goal is to create a set of integrated services for children and their families. The IPC engages with all community service providers to prevent the duplication of resources and highlight service gaps. Community members also serve on the Steering Committee that oversees the work of the project.

Northern Cheyenne Reservation

The rich and deep history of the Northern Cheyenne community and their commitment to engage their members is apparent in their plans to develop a thriving Promise Neighborhood for their community. The Promise Neighborhood is located on the Northern Cheyenne Reservation and the surrounding communities of Colstrip and Ashland in southeast Montana. The land is sprawling, approximately 700 square miles, and approximately 7,300 people live within the Neighborhood.

The Boys and Girls Club of Northern Cheyenne Nation (BGCNCN), the Promise Neighborhood lead partner, believes in "systemic, collaborative, strengths-based and culturally appropriate approaches" to youth and community development that will comprehensively address the disadvantages that the community faces.

The Boys and Girls Club has established relationships with local communities, and thus is an excellent lead partner for this initiative. All of the primary institutions that serve young people in the area are involved in collaborating during this planning year. The Promise Neighborhood has the full support of the Northern Cheyenne government, local schools and agencies, Chief Dull Knife College, and a number of nonprofits. All are working together to specifically create and implement in- and out-of-school strategies and services that will support the academic achievement, healthy development, cultural awareness and connectedness, and college and career success of the Neighborhood's children. Some of the BGCNCN's programs for youth include a Native American Mentoring Program, a diabetes prevention program, leadership groups, and a computer lab. The planning phase has brought these groups together to begin a more concerted effort to assess and develop a pipeline of programs that will benefit the youth and community.

San Antonio, Texas

The Eastside Promise Neighborhood in San Antonio, Texas is led by the United Way and has a strong partnership with the City of San Antonio. San Antonio Mayor Julián Castro and other community leaders are major supporters of the initiative. The Promise Neighborhood initiative is part of the City's larger plan to support the struggling Eastside, including the development of affordable housing, education, environment, and other supports, and developing a strategic framework that speaks to the community's core problems.

The Promise Neighborhood initiative, with its set of partners like the San Antonio Independent School District, Family Service Association, Housing Authority, City Year, Trinity University, San Antonio for Growth on the Eastside (SAGE), and the Urban Land Institute, is working hard to coordinate the supports and resources in the neighborhood to activate their collective vision for community transformation. The planning and coordination of resources going into the community as a part of the Promise Neighborhood initiative fits into the City's broader *Eastside Reinvestment Plan* aiming to shift away from siloed and uncoordinated services on the Eastside.

Because parents are a key element to their children's success, Eastside Promise Neighborhood has a commitment to parental engagement and capacity- building through focus groups, community meetings during which the community shapes the agenda, and parentally-focused career and empowerment groups through initiatives like the United Way's Family-School-Community Partnership.

This asset-based approach and vision ensures more efficient and effective use of neighborhood talent, resources, rich opportunities for young people through high quality neighborhood schools and engaged parents, and a solid physical infrastructure including high-quality housing in the neighborhood to support the community. The community looks to be on the right path toward stabilizing and empowering the Eastside to *stay, grow, graduate and … stay.*

To support all of the Promise Neighborhoods' efforts, HCZ, PolicyLink and the Center for the Study of Social Policy joined together to create the Promise Neighborhoods Institute at PolicyLink (PNI). Supported solely by private philanthropic dollars, PNI provides communities with a system of support, resources, and information to help them in local Promise Neighborhoods efforts. PNI is already supporting 38 Promise Neighborhoods—including 21 funded by the US Department of Education. PNI has three goals:

- Ensure the 21 federal planning grantees are successful and transition to implementation.
- Support an additional 17 communities in their planning efforts and transition to implementation.
- Foster a national learning network that enable communities to learn from their peers and leverage resources in order to significantly improve the educational and developmental outcomes of children and youth in the nation's most distressed communities.

To accomplish these goals, PNI offers:

- Site visits designed to assess community need and implement a comprehensive and personalized package of technical assistance services that help communities learn, make systemic, organizational and programmatic improvements and achieve measurable and sustainable results.
- Promise Neighborhood Network conferences to share best practices.
- Trainings on topics such as how to attract funding and talk to the media.
- Webinars and discussions moderated by experts in the field.
- A website —PromiseNeighborhoodsInstitute.org—featuring in-depth resources and tools.

Since its launch, PNI has:

- Developed a rich menu of technical assistance that is based on what works.
- Grown a robust community of practice that is being accessed by more than 2,000 people.
- Implemented a feedback loop to continually refine city, county, state, and federal public policy and philanthropic approaches.
- Mobilized neighborhood leaders to advocate for integrated neighborhood revitalization investments to become the norm in solving some of the nation's most intractable problems affecting poor children and families.

In the current planning phase, Promise Neighborhoods are getting ready to apply for full implementation. They are developing strategic business plans to estimate revenues and cover costs. Part of this includes the development of data systems for how they will track and evaluate data to make sure that they can document success, and catch and deal with challenges. In addition, they are developing powerful partnerships with schools and with organizations and agencies so they can provide children and families with the supports and services that are needed for success from cradle to college and career. We look forward to continuing to work with the Promise Neighborhoods

grantees and others as they transition from planning to implementation. And, we look forward to seeing the results of their efforts.

We urge the Committee to support Promise Neighborhoods with resources for new sites to engage in planning, and for robust support for implementation in communities across the country. Thank you for your consideration. If you should need additional information about The Promise Neighborhoods program please contact Judith Bell from PolicyLink (Judith@policylink.org) or Katie Shoemaker at HCZ (kshoemaker@hcz.org).

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HOWARD UNIVERSITY

PRESENTED TO THE

HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES

APRIL 15, 2011

SUMMARY OF FISCAL YEAR 2012 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) **PROPORTIONAL SUPPORT FOR THE NATIONAL INSTITUTES OF HEALTH'S NATIONAL CENTER ON MINORITY HEALTH AND HEALTH DISPARITIES.**

3) **SUPPORT FOR MINORITY HEALTH RESEARCH INFRASTRUCTURE AT THE NATIONAL INSTITUTES OF HEALTH.**

   - **PROPORTIONAL FUNDING FOR RESEARCH CENTERS FOR MINORITY INSTITUTIONS.**
   - **PROPORTIONAL FUNDING FOR THE NATIOANL INSTITUTE ON MINORITY HEALTH AND HEALTH DISPARITIES.**

4) **$65 MILLION FOR THE DEPARTMENT OF HEALTH AND HUMAN SERVICES' OFFICE OF MINORITY HEALTH.**

5) **$235 MILLION FOR THE DEPARTMENT OF EDUCATION'S SUPPORT FOR HOWARD UNIVERSITY, INCLUDING THE HOWARD UNIVERSITY HOSPITAL.**

Mr. Chairman and members of the subcommittee, thank you for the opportunity to present my views before you today. I am Dr. Eve Higginbotham, Senior Vice-President and Executive Dean for Howard University Health Sciences. I am the senior health official at Howard, with responsibilities for our College of Medicine, College of Dentistry, College of Pharmacy, Nursing, and Allied Health, Louis Stokes Health Sciences Library, and the Howard University Hospital. Howard University is the only Historically Black College or University (HBCU) with so many aspects of the health sciences housed at one institution. For that reason, we are poised to continue to impact the education of minorities and others dedicated to improving the health of all Americans.

Mr. Chairman, I want to welcome you to this new role of leading the L-HHS Subcommittee. Howard University Health Sciences has made historic contributions to the reduction of health disparities, and it is because of programmatic activity like the Title VII Health Professionals Training programs that we are able to 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 HUHS 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 professions 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), 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 FY12, funding for the Title VII Health Professions Training programs must at the very least be maintained, 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 FY12, 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 FY12, I recommend a funding level of $22.133 million for HCOPs.***

NATIONAL INSTITUTES OF HEALTH

Research Centers at Minority Institutions: The Research Centers at Minority Institutions program (RCMI), currently administered by the National Center for Research Resources, has a long and distinguished record of helping our institutions develop the research infrastructure necessary to be leaders in the area of health disparities research. Although NIH has received unprecedented budget increases in recent years, funding for the RCMI program has not increased by the same rate. ***Therefore, the funding for this important program grow at the same rate as NIH overall in FY12.***

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 the Centers of Excellence program. ***For FY12, I recommend funded increases proportional with the funding of the over NIH.***

DEPARTMENT OF HEALTH AND HUMAN SERVICES

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. ***For FY12, I recommend a funding level of $65 million for the OMH.***

DEPARTMENT OF EDUCATION

Howard University Academic, Research, and Hospital Support: The Department of Education maintains support for Howard University's academic programs, research programs, construction activities, and the Howard University Hospital. Howard University has played a historic role in providing access to postsecondary educational opportunities for students from traditionally underrepresented backgrounds, especially African Americans. For this reason, and others, Howard is supported annually with a federal appropriation. The direct federal appropriation accounts for approximately 50 percent of the Howard University's operating costs, including nearly $29 million for the operation of the Howard Hospital—a staple of care for residents in Northwest Washington, D.C. **In FY12, an appropriation of $235 million is suggested to continue the vital programs and services which we provide.**

Mr. Chairman, please allow me to express my appreciation to you and the members of this subcommittee. With your continued help and support, Howard University's Health Sciences can help this country to overcome health disparities. Congress must be careful not to eliminate, paralyze or stifle programs that have been **proven to work**. HUHS seeks to close the ever widening health disparity gap. If this subcommittee will give us the tools, we will continue to work towards the goal of eliminating that disparity everyday.

Thank you, Mr. Chairman, and I welcome every opportunity to answer questions for your records.

WRITTEN TESTIMONY OF WAYNE J. RILEY, M.D., MPH, M.B.A.
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ASSOCIATION OF MINORITY HEALTH PROFESSIONS SCHOOLS

PRESENTED TO THE

HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES

APRIL 15, 2011

SUMMARY OF FISCAL YEAR 2012 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) **PROPORTIONAL SUPPORT FOR THE NATIONAL INSTITUTES OF HEALTH'S NATIONAL CENTER ON MINORITY HEALTH AND HEALTH DISPARITIES.**
3) **SUPPORT FOR RESEARCH INFRASTRUCTURE AT THE NATIONAL INSTITUTES OF HEALTH.**
   - **PROPORTIONAL FUNDING FOR RESEARCH CENTERS FOR MINORITY INSTITUTIONS.**
   - **PROPORTIONAL FUNDING FOR THE NATIOANL INSTITUTE ON MINORITY HEALTH AND HEALTH DISPARITIES.**
4) **$65 MILLION FOR THE DEPARTMENT OF HEALTH AND HUMAN SERVICES' OFFICE OF MINORITY HEALTH.**
5) **$65 MILLION FOR THE DEPARTMENT OF EDUCATION'S STRENGTHENING HISTORICALLY BLACK GRADUATE INSTITUTIONS PROGRAM.**

Mr. Chairman and members of the subcommittee, thank you for the opportunity to present my views before you today. I am Dr. Wayne J. Riley, 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 schools. The members are two dental schools at Howard University and Meharry Medical College; four schools of medicine at The Charles Drew University, Howard University, Meharry Medical College, and Morehouse School of Medicine; five schools of pharmacy at Florida A&M University, Hampton University, Howard University, Texas Southern University, and Xavier University; and one school of veterinary medicine at Tuskegee University.. 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 want to welcome you to this new role of leading the L-HHS Subcommittee. 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), 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 FY12, funding for the Title VII Health Professions Training programs must at the very least be maintained, 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 FY12, 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 FY12, I recommend a funding level of $22.133 million for HCOPs.***

NATIONAL INSTITUTES OF HEALTH

Research Centers at Minority Institutions: The Research Centers at Minority Institutions program (RCMI), currently administered by the National Center for Research Resources, has a long and distinguished record of helping our institutions develop the research infrastructure necessary to be leaders in the area of health disparities research. Although NIH has received unprecedented budget increases in recent years, funding for the RCMI program has not increased by the same rate. ***Therefore, the funding for this important program grow at the same rate as NIH overall in FY12.***

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 the Centers of Excellence program. ***For FY12, I recommend funded increases proportional with the funding of the over NIH.***

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. ***For FY12, 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 FY12, an appropriation of $65 million is suggested to continue the vital support that this program provides to historically black graduate institutions.**

Mr. Chairman, please allow me to express my appreciation to you and the members of this subcommittee. With your continued help and support, AMHPS' member institutions and the Title VII Health Professions Training programs and the historically black health professions schools can help this country to overcome health disparities. Congress must be careful not to eliminate, paralyze or stifle the institutions and programs that have been **proven to work**. The Association seeks to close the ever widening health disparity gap. If this subcommittee will give us the tools, we will continue to work towards the goal of eliminating that disparity everyday.

Thank you, Mr. Chairman, and I welcome every opportunity to answer questions for your records.

TESTIMONY OF M. ROY WILSON, M.D.
CHAIRMAN, BOARD OF DIRECTORS

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PRESENTED BEFORE THE

HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES

APRIL 15, 2011

SUMMARY OF FISCAL YEAR 2012 RECOMMENDATIONS:

1) **PROVIDE FUNDING FOR THE HEALTH RESOURCES AND SERVICES ADMINISTRATION TITLE VII HEALTH PROFESSISONS TRAINING PROGRAMS, INCLUDING:**
   - **$24.602 MILLION FOR THE MINORITY CENTERS OF EXCELLENCE**
   - **$22.133 MILLION FOR THE HEALTH CAREERS OPPORTUNITY PROGRAM.**
2) **PROVIDE FUNDING FOR THE NATIONAL INSTITUTES OF HEALTH (NIH), SPECIFICALLY:**
   - **PROPORTIONAL INCREASE FOR THE NATIONAL INSTITUTE ON MINORITY HEALTH AND HEALTH DISPARITIES (NIMHD)**
   - **SUPPORT THE NATIONAL CENTER FOR RESEARCH RESOURCES:**
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 FY12, 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 FY12, 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 FY12, an increase proportional to NIH's increase is recommended for NIMHD to support these critical activities.***

Research Centers At Minority Institutions: RCMI at the National Center for Research Resources (NCRR) has a long and distinguished record of helping institutions like The Charles Drew University develop the research infrastructure necessary to be leaders in the area of translational research focused on reducing health disparities research. Although NIH has received some budget increases over the last five years, funding for the RCMI program has not increased by the same rate. ***Therefore, the funding for this important program grow at the same rate as NIH overall in FY12.***

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 FY12, I recommend a funding level of $65 million for OMH to support these critical activities.***

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 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 FY12, 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 JOHN E.MAUPIN, D.D.S., MBA
PRESIDENT

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PRESENTED TO THE

HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES

SUMMARY OF FISCAL YEAR 2011 RECOMMENDATIONS:

1) FUNDING FOR THE 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) FUNDING FOR THE NATIONAL INSTITUTES OF HEALTH'S NATIONAL INSTITUTE ON MINORITY HEALTH AND HEALTH DISPARITIES.

3) PROPORTIONAL INCREASE FOR NATIONAL CENTER ON RESEARCH RESOURCES' 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. John E. Maupin, President of Morehouse School of Medicine (MSM) in Atlanta, Georgia. I have previously served as President of Meharry Medical College, executive vice-president at Morehouse School of Medicine, director of a community health center in Atlanta, and deputy director of health in Baltimore, Maryland. In all of these roles, I have seen firsthand the importance of minority health professions institutions and the Title VII Health Professions Training programs.

I want to say that minority health professional institutions and the Title VII Health Professionals Training programs address a critical national need. Persistent and sever staffing shortages exist in a number of the health professions, and chronic shortages exist for all of the health professions in our nation's most medically underserved communities. Furthermore, our nation's health professions workforce does not accurately reflect the racial composition of our population. For example while blacks represent approximately 15% of the U.S. population, only 2-3% of the nation's health professions workforce is black. Morehouse is a private school with a very public mission of educating students from traditionally underserved communities so that they will care for the underserved. Mr. Chairman, I would like to share with you how your committee can help us continue our efforts to help provide quality health professionals and close our nation's health disparity gap.

There is a well established link between health disparities and a lack of access to competent healthcare in medically underserved areas. As a result, it is imperative that the federal government continue its commitment to minority health profession institutions and minority health professional training programs to continue to produce healthcare professionals committed to addressing this unmet need.

An October 2006 study by the Health Resources and Services Administration (HRSA), entitled "The Rationale for Diversity in the Health Professions: A Review of the Evidence" found that minority health professionals serve minority and other medically underserved populations at higher rates than non-minority professionals. The report also showed that; minority populations tend to receive better care from practitioners who represent their own race or ethnicity, and non-English speaking patients experience better care, greater comprehension, and greater likelihood of keeping follow-up appointments when they see a practitioner who speaks their language. **Studies have also demonstrated that when minorities are trained in minority health profession institutions, they are significantly more likely to: 1) serve in rural and urban medically underserved areas, 2) provide care for minorities and 3) treat low-income patients.**

As you are aware, Title VII Health Professions Training programs are focused on improving the quality, geographic distribution and diversity of the healthcare workforce in order to continue eliminating disparities in our nation's healthcare system. These programs provide training for students to practice in underserved areas, cultivate interactions with faculty role models who serve in underserved areas, and provide placement and recruitment services to encourage students to work in these areas. Health professionals who spend part of their training providing care for the underserved are up to 10 times more likely to practice in underserved areas after graduation or program completion.

Given the historic mission, of institutions like MSM, to provide academic opportunities for minority and financially disadvantaged students, and healthcare to minority and financially disadvantaged patients, minority health professions institutions operate on narrow margins. The slow reinvestment in the Title VII Health Professions Training programs amounts to a loss of core funding at these institutions and have been financially devastating.

Mr. Chairman, I feel like I can speak authoritatively on this issue because I received my dental degree from Meharry Medical College, a historically black medical and dental school in Nashville, Tennessee. I have seen first hand what Title VII funds have done to minority serving institutions like Morehouse and Meharry. I compare my days as a student to my days as president, without that Title VII, our institutions would not be here today. However, Mr. Chairman, since those funds have been slowly replenished, we are standing at a cross roads. This committee has the power to decide if our institutions will go forward and thrive, or if we will continue to try to just survive. We want to work with you to eliminate health disparities and produce world class professionals, but we need your assistance.

Minority Centers of Excellence: COEs focus on improving student recruitment and performance, improving curricula in cultural competence, facilitating research on minority health issues and training students to provide health services to minority individuals. COEs were first established in recognition of the contribution made by four historically black health professions institutions (the Medical and Dental Institutions at Meharry Medical College; The College of Pharmacy at Xavier University; and the School of Veterinary Medicine at Tuskegee University) to the training of minorities in the health professions. Congress later went on to authorize the establishment of "Hispanic", "Native American" and "Other" Historically black COEs. ***For FY12, 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. 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 FY12, I recommend a funding level of $22.133 million for HCOPs.***

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. ***For FY12, I recommend a funding increase proportional to any increase given to the NIH for the NIMHD.***

Research Centers at Minority Institutions: The Research Centers at Minority Institutions program (RCMI), currently administered at the National Center for Research Resources, has a long and distinguished record of helping our institutions develop the research infrastructure necessary to be leaders in the area of health disparities research. Although NIH has received unprecedented budget increases in recent years, funding for the RCMI program has not increased by the same rate. ***Therefore, the funding for this important program grow at the same rate as NIH overall in FY12.***

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Office of Minority Health: Specific programs at OMH include: 1) Assisting medically underserved communities with the greatest need in solving health disparities and attracting and retaining health professionals; 2) Assisting minority institutions in acquiring real property to expand their campuses and increase their capacity to train minorities for medical careers; 3) Supporting conferences for high school and undergraduate students to interest them in health careers, and 4) Supporting cooperative agreements with minority institutions for the purpose of strengthening their capacity to train more minorities in the health professions. The OMH has the potential to play a critical role in addressing health disparities, and with the proper funding this role can be enhanced. ***For FY12, 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 offices, initiate endowment campaigns, and support numerous other institutional development activities. ***In FY12, 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 and the Title VII Health Professions Training programs can help this country to overcome health and healthcare disparities. Congress must be careful not to eliminate, paralyze or stifle the institutions and programs that have been **proven to work**. MSM and other minority health professions schools seek to close the ever widening health disparity gap. If this subcommittee will give us the tools, we will continue to work towards the goal of eliminating that disparity as we have since our founding day.

Thank you, Mr. Chairman, and I welcome every opportunity to answer questions for your records.

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 2012 RECOMMENDATIONS:

1) **FUNDING FOR THE 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) **PROPORTIONAL FUNDING INCREASE FOR THE NATIONAL INSTITUTES OF HEALTH'S NATIONAL INSTITUTE ON MINORITY HEALTH AND HEALTH DISPARITIES.**

3) **PROPORTIONAL FUNDING INCREASE 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. Wayne J. Riley, President and CEO of Meharry Medical College in Nashville, Tennessee. I have previously served as vice-president and vice dean for health affairs and governmental relations and associate professor of medicine at Baylor College of Medicine in Houston, Texas and as assistant chief of medicine and a practicing general internist at Houston's Ben Taub General Hospital. In all of these roles, I have seen firsthand the importance of minority health professions institutions and the Title VII Health Professions Training programs.

Mr. Chairman, time and time again, you have encouraged your colleagues and the rest of us to take a look at our nation and evaluate our needs over the next ten years. I took you seriously and came here prepared to offer my best judgments. First, I want to say that it is clear that health disparities among various populations and across economic status are rampant and overwhelming. Over the next ten years, we will need to be able to deliver more culturally relevant and culturally competent healthcare services. Bringing healthcare delivery up to this higher standard can serve as our nation's own preventive healthcare agenda keeping us well positioned for the future.

Minority health professional institutions and the Title VII Health Professions Training programs address this critical national need. Persistent and severe staffing shortages exist in a number of the health professions, and chronic shortages exist for all of the health professions in our nation's most medically underserved communities. Our nation's health professions workforce does not accurately reflect the racial composition of our population. For example, African Americans represent approximately 15% of the U.S. population while only 2-3% of the nation's healthcare workforce is African American.

There is a well established link between health disparities and a lack of access to competent healthcare in medically underserved areas. As a result, it is imperative that the federal government continue its commitment to minority health profession institutions and minority health professional training programs to continue to produce healthcare professionals committed to addressing this unmet need.

An October 2006 study by the Health Resources and Services Administration (HRSA), entitled "The Rationale for Diversity in the Health Professions: A Review of the Evidence" found that minority health professionals serve minority and other medically underserved populations at higher rates than non-minority professionals. The report also showed that; minority populations tend to receive better care from practitioners who represent their own race or ethnicity, and non-English speaking patients experience better care, greater comprehension, and greater likelihood of keeping follow-up appointments when they see a practitioner who speaks their language. **Studies have also demonstrated that when minorities are trained in minority health profession institutions, they are significantly more likely to: 1) serve in rural and urban medically underserved areas, 2) provide care for minorities and 3) treat low-income patients.**

As you are aware, Title VII Health Professions Training programs are focused on improving the quality, geographic distribution and diversity of the healthcare workforce in order to continue eliminating disparities in our nation's healthcare system. These programs provide training for students to practice in underserved areas, cultivate interactions with faculty role models who serve in underserved areas, and provide placement and recruitment services to encourage students to work in these areas. Health professionals who spend part of their training providing care for the underserved are up to 10 times more likely to practice in underserved areas after graduation or program completion.

Institutions that cultivate minority health professionals have been particularly hard-hit as a result of the cuts to the Title VII Health Profession Training programs in fiscal year 2006 (FY06) and FY07 Funding Resolution passed earlier this Congress. Given their historic mission to provide academic opportunities for minority and financially disadvantaged students, and healthcare to minority and financially

disadvantaged patients, minority health professions institutions operate on narrow margins. The cuts to the Title VII Health Professions Training programs amount to a loss of core funding at these institutions and have been financially devastating.

Mr. Chairman, I feel like I can speak authoritatively on this issue because I received my medical degree from Morehouse School of Medicine, a historically black medical school in Atlanta. I give credit to my career in academia, and my being here today, to Title VII Health Profession Training programs' Faculty Loan Repayment Program. Without that program, I would not be the president of my father's alma mater, Meharry Medical College, another historically black medical school dedicated to eliminating healthcare disparities through education, research and culturally relevant patient care.

Minority Centers of Excellence: COEs focus on improving student recruitment and performance, improving curricula in cultural competence, facilitating research on minority health issues and training students to provide health services to minority individuals. COEs were first established in recognition of the contribution made by four historically black health professions institutions (the Medical and Dental Institutions at Meharry Medical College; The College of Pharmacy at Xavier University; and the School of Veterinary Medicine at Tuskegee University) to the training of minorities in the health professions. Congress later went on to authorize the establishment of "Hispanic", "Native American" and "Other" Historically black COEs. ***For FY12, 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. 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 FY12, I recommend a funding level of $22.133 million for HCOPs.***

NATIONAL INSTITUTES OF HEALTH (NIH)

Research Centers at Minority Institutions: The Research Centers at Minority Institutions program (RCMI) at the National Center for Research Resources has a long and distinguished record of helping our institutions develop the research infrastructure necessary to be leaders in the area of health disparities research. Although NIH has received unprecedented budget increases in recent years, funding for the RCMI program has not increased by the same rate. ***Therefore, the funding for this important program grow at the same rate as NIH overall in FY12.***

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 FY12, I recommend that this Institute's funding grow proportionally with the funding of the NIH.***

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Office of Minority Health: Specific programs at OMH include:

1) Assisting medically underserved communities with the greatest need in solving health disparities and attracting and retaining health professionals,
2) Assisting minority institutions in acquiring real property to expand their campuses and increase their capacity to train minorities for medical careers,
3) Supporting conferences for high school and undergraduate students to interest them in health careers, and
4) Supporting cooperative agreements with minority institutions for the purpose of strengthening their capacity to train more minorities in the health professions.

The OMH has the potential to play a critical role in addressing health disparities. ***For FY12, 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 FY12, 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.

Friends of NCBDDD Advocacy Coalition
In Support of the National Center on Birth Defects and Developmental Disabilities

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

Statement of
Friends of NCBDDD at CDC Advocacy Coalition
[National Center on Birth Defects and Developmental Disabilities]

Chair: E. Clarke Ross, D.P.A., Policy In Context Consulting
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April 15, 2011

Statement Attachments:
1. **Friends of NCBDDD Advocacy Coalition Statement (2 pages)**
2. **NCBDDD at CDC – Facts and Figures (2 pages)**
3. **NCBDDD at CDC – Focus on Public Health-Social Impact-Safety Net Need of the Populations served (2 pages)**

Friends of NCBDDD Advocacy Coalition
In Support of the National Center on Birth Defects and Developmental Disabilities

National Center on Birth Defects and Developmental Disabilities (NCBDDD) at CDC: 10 Years of Accomplishment

The Friends of NCBDDD Advocacy Coalition recommends that Congress provide **at least $144 million in FY 2012** to sustain the vital programs and activities funded by NCBDDD. Furthermore, we call on Congress to ensure any program modifications do no harm for children and adults currently served by the Center and that funds intended to directly benefit the targeted populations not be diverted.

CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) works to prevent birth defects and developmental disabilities and help people with disabilities and blood disorders live the healthiest life possible. It is the only CDC Center whose primary mission is focused on birth defects, disability and blood disorders. 2011 marks the 10th year of the Center's accomplishments.

NCBDDD impacts millions of our nation's most vulnerable: infants and children, people with disabilities, and people with blood disorders. During times of increasing fiscal constraint, NCBDDD is committed to finding strategic approaches to support and strengthen core public health activities for these vulnerable and underserved populations. Public health is the science and art of preventing disease and disability, promoting physical and behavioral wellness, supporting personal responsibility, and prolonging life in communities where people live, work, and learn. Building upon the latest science and evidence-based research, the Center has identified key priorities to these populations to ensure continued public health advancements are made, as well as demonstrating sound returns on investments.

Child Health and Development - Assuring Child Health
Division of Birth Defects and Developmental Disabilities
Success in this NCBDDD program area includes rapidly translating research findings into prevention strategies that prevent birth defects and developmental disabilities, focusing attention on the importance of early care and special intervention services for children born with a birth defect or developmental disability, and supporting parents in helping their children grow into healthy, safe, productive members of society.

Health and Development for People with Disabilities - Improving the Health of People with Disabilities
Division of Human Development and Disability
This spectrum of NCBDDD activities promotes healthy development and reduces health disparities across the life course for persons with or at risk of disability. Program goals include: Improving the health and developmental outcomes for children, improving the quality of life and life expectancy for people with disabilities, and eliminating health disparities faced by persons of all ages living with disabilities.

Friends of NCBDDD Advocacy Coalition
In Support of the National Center on Birth Defects and Developmental Disabilities

Public Health Approach to Blood Disorders
Division of Blood Disorders
The history of NCBDDD activities in this area includes bleeding and clotting disorders, hemoglobinopathies and blood product safety. The future of blood disorders is predicated on building upon our past successes and expanding our public health activities to begin addressing the most prevalent, costly, and debilitating bleeding and clotting disorders.

Companion Documents:

NCBDDD at CDC – Facts and Figures

CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD)
Focus on Public Health-Social Impact-Safety Net Need of the Populations Served

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Friends of NCBDDD Advocacy Coalition

In Support of the National Center on Birth Defects and Developmental Disabilities

NCBDDD at CDC – Facts and Figures

NCBDDD can provide program performance data and social determinants of illness and disability data upon request. Some of these essential data are provided below.

Assuring Child Health

Health Impact

- Birth defects are a leading cause of death in the first year of life and can result in lifelong disability.
- Congenital heart defects occur in 1% of all births and are the leading cause of death attributable to birth defects.
- NCBDDD data indicate that about 1 in 110 children in the US have an autism spectrum disorder (ASD).

Economic Impact

- Birth defects have accounted for more than 139,000 hospital stays during a single year, resulting in $2.6 billion in hospital costs.
- Medical costs associated with congenital heart defects are substantial. $1.2 billion is the estimated lifetime cost for US children born in a single year with one of four major heart defects.
- Recent studies have estimated that the lifetime cost to care for an individual with an ASD is $1-3 million.

Improving the Health of People with Disabilities

Health Impact

- More than 50 million Americans —about 1 in 5— report having some level of disability.
- Obesity rates for children and adults with disabilities are 38 percent and 57 percent higher than rates for children and adults without disabilities.
- About 40% of adults with a disability rated their own health as fair or poor compared to only about 10% of adults without a disability.
- Smoking rates for people with disabilities are about 62% higher than for people without disabilities.

Economic Impact

- A 2009 study co-authored by CDC researchers found that almost 27% of US adult health care spending was associated with disability, amounting to $397.8 billion in 2006 alone.
- People with disabilities are 2.5 times more likely than people without disabilities to report not getting the medical care they needed because of cost.

Friends of NCBDDD Advocacy Coalition

In Support of the National Center on Birth Defects and Developmental Disabilitie

Protecting the Health of People with Blood Disorders

Health Impact

- Deep Vein Thrombosis (DVT) affects about 2.5 million U.S. adults. Pulmonary embolism (PE) is known as the silent killer with sudden death occurring in about one-quarter of people who have a PE. New DVT/PE events occur in 350,000 to 600,000 people each year, at least 100,000 of whom die. Risk factors for DVT/PE include: obesity, immobility, recent hospitalization, and history of inherited clotting disorders.
- Von Willebrand Disease (VWD) affects up to 1 million Americans, in particular women. Because it is typically not diagnosed, VWD can result in ongoing problems and often costly and inappropriate treatment, such as unnecessary hysterectomies.
- People with Sickle Cell Disease (SCD) are estimated to have a life expectancy that is 30 years shorter than the average American.

Economic Impact

- Blood disorders impose high costs on the U.S. health care system, including up to $10 billion per year from DVT/PE.
- SCD affects about 100,000 people in the US and health care costs exceed $1 billion per year.
- Hemophilia, directly affects perhaps 20,000 people, with an average cost of care of over $100,000 per year, and a total impact on the health care system in excess of $3 billion per year.

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Friends of NCBDDD Advocacy Coalition

In Support of the National Center on Birth Defects and Developmental Disabilities

CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD)
Focus on Public Health-Social Impact-Safety Net Need of the Populations Served

The Friends advocacy coalition calls on Congressional appropriators and the Administration to continue to focus the Center's programs on outcomes that affect positive public health, positive social impact, and the safety net purpose. These include:

Assuring Child Health

- Decrease or eliminate birth defects and developmental disabilities occurring due to known causes.
- Improve longer term outcomes of children with birth defects, autism, and other developmental disabilities, and eliminate racial/ethnic disparities in these outcomes.
- Identify preventable risk factors of birth defects and developmental disabilities, and develop appropriate interventions to reduce these risks.
- Increase early identification and intervention for infants and young children with disabling conditions.
- Mediate the impact of poverty on developmental outcomes for young children.

Improving the Health of People with Disabilities

- Change individual health behaviors to improve health in children, youth, and adults with disabilities.
- Improve health care access and screening for children, youth, and adults with disabilities.
- Reduce the incidence of secondary conditions by increasing health promotion and wellness interventions for children and adults with disabilities.
- Improve public health surveillance systems to track the health, development, and participation of persons with disabilities across the life course.
- Implement fully the Section 4302 "Patient Protection and Affordable Care Act" intent, expectations, and requirements in "Understanding Health Disparities: Data Collection and Analysis" including "disability status" as well as Section 5307 "Cultural Competency, Prevention, and Public Health" including "individuals with disabilities training."

Friends of NCBDDD Advocacy Coalition
In Support of the National Center on Birth Defects and Developmental Disabilities

Public Health Approach to Blood Disorders

- Improve the life expectancy of people with Sickle Cell Disease
- Reduce the morbidity and mortality related to bleeding disorders in women.
- Reduce the incidence of DVT/PE, and prevent related mortality and serious morbidity.
- Prevent emerging morbidities of people with bleeding disorders.

Positive Outcomes

These outcomes should positively affect several social impact goals to improve the life situation of persons with disabilities and other challenges. These include:

- Seamless, positive, and helpful transitions from one of life's stages to the next stage in life, such as the transition from high school to adulthood and work.
- Promotion and support of independent living in the community – a community participation that encourages and promotes self-direction.
- Continued coordinated efforts to assist parents and consumers make informed medical and life decisions.
- Focused activities with the goal of reducing the severity of disability.

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Written Testimony Submitted to the House
Labor, Health and Human Services, and Education Appropriations Subcommittee
Regarding FY 2012 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 non-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 2012 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 approximately 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.

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. The success of childhood cardiac intervention has created a new chronic disease – CHD. Thanks to the increase in survival, of the nearly 2 million people alive today with CHD, more than half 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 less 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.

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 National Institutes of Health (NIH) for CHD research. ACHA continues to work with federal and state policy makers to advance policies that will improve and prolong the lives of those living with CHD.

ACHA is also a founding member of the Congenital Heart Public Health Consortium (CHPHC). The CHPHC is a group of organizations uniting resources and efforts to prevent the occurrence of CHD and enhance and prolong the lives of those with CHD through targeted public health interventions by enhancing and supporting the work of the member organizations. Representatives of federal agencies serve in an advisory capacity. In addition to ACHA, the Alliance for Adult Research in Congenital Cardiology, American Academy of Pediatrics, American College of Cardiology, American Heart Association, March of Dimes Foundation, National Birth Defects Prevention Network, and the National Congenital Heart Coalition are all members of the CHPHC.

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 2004, the NHLBI convened a working group on CHD, which recommended developing a research network to conduct clinical research and establishing a national database of patients.

In March of 2010, the first CHD legislation passed as part of *Patient Protection and Affordable Care Act* (ACA).[1] 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. These provisions included in the ACA were originally in the *Congenital Heart Futures Act* (H.R. 1570/S.621, 111th Congress), which garnered bi-partisan support in both the House and Senate and was championed by Senators Richard Durbin (D-IL) and Thad Cochran (R-MS), Representative Gus Bilirakis (R-FL) and former Representative Zack Space (D-OH).

Recently, the National Center on Birth Defects and Developmental Disabilities included preventing congenital heart defects and other major birth defects, in it's 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

[1] *Patient Protection and Affordable Care Act*, §10411(b).

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 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, that is 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.

ACHA requests that Congress provide the CDC $3.0 million in FY 2012 to support data collection to better understand CHD prevalence and assess the public health impact of CHD. This level of funding will support a pilot adult surveillance system and allow for the enhancement of the existing birth defects surveillance system.

Funding of Research Related to Congenital Heart Disease at NIH

Our nation continues to benefit from the single largest funding source for CHD research, the NIH. 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.

Summary

Thank you for the opportunity to highlight this important disease. We know that you face many difficult funding decisions for FY 2012 and hope that you consider addressing the life-long needs of those with CHD. By making an investment in the research and surveillance of CHD, the return will be seen through reduced health care costs, decreased disability and improved productivity in a population quickly approaching 2 million.

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

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Outside Witness Testimony
House Appropriations Subcommittee on Labor/HHS/Education and Related Agencies

FY 2012 FUNDING REQUESTS

Department of Health and Human Services
Workforce Commission and associated centers
Health Resources and Services Administration (HRSA)
Title VII primary care cluster (Section 747 of Public Health Service Act (PHS))
Teaching Health Center development grants (Section 749A. of PHS Act)
Rural Physician Training Grants (Section 749B. of PHS Act)
Agency For Healthcare Research And Quality (AHRQ)
Agency funding
Primary Care Extension Program (Section 399W of PHS Act)

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Dear Mr. Chairman,

On behalf of the Council of Academic Family Medicine (CAFM), we are pleased to submit testimony on behalf of several programs under the jurisdiction of the Health Resources and Services Administration (HRSA) and the Agency for Healthcare Research and Quality (AHRQ). 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.

Members of both parties agree there is much that must be done to support primary care production and nourish the development of a high quality, highly effective primary care workforce to serve as a foundation for our health care system. Providing strong funding for these programs is essential to the development of a robust workforce needed to provide this 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 indispensible funding for the training of primary care physicians. With each successive reauthorization, Congress has modified the Title VII health professions programs to address relevant workforce needs. The most recent authorization directs the Health Resources and Services Administration (HRSA) to prioritize training in the new competencies relevant to providing care in the patient-

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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.

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, Oct., 2009), "the number of graduating U.S. allopathic medical students choosing primary care declined steadily over the past decade, and the proportion of minorities within this workforce remains low." Unfortunately, this decline coincides with a decline in funding of primary care training funding – funding that we know is associated with increased primary care physician production and practice in underserved areas. 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."

Title VII has a profound impact on states across the country and is vital to the continued development of a workforce designed to care for the most vulnerable populations and meet the needs of the 21st century. Attached are just a few examples of the impact Title VII has across the country in states like Idaho, Montana, New York, North Dakota, Massachusetts, Washington, and Wyoming. Included are examples of opportunities lost through a lack of robust funding for the program.

We urge the Congress to appropriate at least $140 million for the health professions program, Primary Care Training and Enhancement authorized under Title VII, Section 747 of the Public Health Service Act in fiscal year 2012 as requested in the President's budget.

Rural Physician Training Grants
"Rural Physician Training Grants," Title VII Section 749B of the Public Health Service Act, were developed to increase the supply of rural physicians by authorizing grants to medical schools which establish or expand rural training. The program would provide grants to produce rural physicians of all specialties. It would help medical schools recruit students most likely to practice medicine in underserved rural communities, provide rural-focused training and experience, and increase the number of medical graduates who practice in underserved rural communities.

According to a July, 2007 report of the Robert Graham Center (*Medical school expansion: An immediate opportunity to meet rural health care needs*), data show that although 21 percent of the U.S. population lives in rural areas, only 10 percent of physicians practice there. The Graham Center study describes the educational pipeline to rural medical practice as "long and complex." There are multiple tactics needed to reverse this situation, and this grant program includes several of them. Strategies to increase the number of physicians practicing in rural areas include "increasing the number of rural-background students in medical school, selecting the "right" students and giving them the "right" content and experiences to train them for rural practice." This is exactly what this grant program is designed to do.

We request the Committee provide the fully authorized amount of $4 million in FY 2012 for Title VII Section 749B Rural Physician Training Grants.

Teaching Health Centers
Teaching Health Centers (THC) are community health centers or other similar venues that sponsor residency programs and provide residents with their ambulatory training experiences in the health center. This training in the community, rather than solely at the hospital bedside is one of the hallmarks of family medicine training.

However, payment issues have always caused a tension and struggle between the hospital, which currently receives reimbursement for residents it sponsors when they train in the hospital, and programs that require training in non-hospital settings. This program is designed to provide residency programs and community health centers grant funding to plan for a transition in sponsorship, or the establishment of new programs. There are already 11 community-based entities from states across the country that have committed to train 44 primary care residents, demonstrating early success in this program.

We are pleased that THC's operations are currently funded through a mandatory appropriations trust fund of $230 million over five years, and it is essential that these important centers continue to be funded through this mandatory appropriation. Despite the positive impact that family medicine and other primary care residency training programs have on those community-based entities that initiate them, a multitude of challenges make it clear that many of these entities would have difficulty doing the same without adequate and predictable financing. Converting this program to discretionary funding also would deter other entities from making the business decisions necessary to expand residency training (e.g., securing commitments from key stakeholders to agree to train new or additional residents, applying for accreditation if not already part of an eligible consortia, and hiring new faculty) since funding over the next few years would be subject to the annual appropriations process.

Teaching Health Center Development Grants
If this program is to be effective, there must be funds for the planning grants to establish newly accredited or expanded primary care residency programs. Teaching Health Center Development Grants are important to help establish these innovative programs.

We recommend the Committee appropriate the full authorized amount for the new Title VII Teaching Health Centers development grants of at least $10 million for fiscal year 2012.

AHRQ
Research related to the most common acute, chronic, and comorbid conditions that primary care clinicians care for on a daily basis is lacking. Research in these areas is vital because the overall health of a population is directly linked to the strength of its primary health care system. 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 key to helping 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, introduce and disseminate new discoveries into real life practice, and how to maximize appropriate care. Ample funding for AHRQ can help researchers address these problems confronting our health system today.

We recommend the Committee fund AHRQ at a level of at least $405 million for fiscal year 2012

Primary Care Extension Program
The Primary Care Extension Program was modeled after the successful United States Agriculture Extension Service. This program, under Title III of the Public Health Service Act, is designed to support and assist primary care providers with the adoption and incorporation of techniques to improve community health. As the authors of an article describing this concept (JAMA, June 24, 2009) have stated, "To successfully redesign practices requires knowledge transfer, performance feedback, facilitation, and HIT support provided by individuals with whom practices have established relationships over time. The farming community learned these principles a century ago. Primary care practices are like small farms of that era, which were geographically dispersed, poorly resourced for change, and inefficient in adopting new techniques or technology but vital to the nation's well-being."

Congress agreed with the authors that "practicing physicians need something similar to the agricultural extension agent who was so transformative for farming," and authorized this program at $120 million for FY 2011 and 2012.

We recommend the Committee fund the Primary Care Extension program at the authorized level of $120 million for fiscal year 2012.

Title VII Testimonials from the field

WWAMI (a partnership between the University of Washington School of Medicine and the states of Wyoming, Alaska, Montana, and Idaho): Title VII grants have helped fund over 30 faculty positions across the states of Washington, Wyoming, Alaska, Montana, and Idaho. These grants have helped fund the development of areas of scholarship for residency programs in Montana, assisted in the training of fellows that became Residency Directors at other programs, and funded faculty development programs delivered with televideo to rural areas in Wyoming. *Ardis Davis MSW, Teaching Associate*

The University of Buffalo: The School of Medicine is dependent upon Title VII funding to support nationally recognized training, recruitment, and retention of primary care clinicians to serve the poor and underserved. This funding includes programs that recruit minorities, train medical students and post graduate trainees, and assist in faculty development. They also are vital to help build clinical competencies for addressing health disparities for the poor and underserved. Another Title VII grant allowed the University of Buffalo to implement a training program designed to help students learn how to care for patients with disabilities. *Andrew Symons MD, MS, Vice Chair for Medical Student Education, Department of Family Medicine*

Boston University School of Medicine: Title VII grants have allowed us to do a lot of things in our department that we wouldn't otherwise have been able to do. One of the outcomes of FaMes (Family Medicine Student Track) is the number of students matching family medicine from Boston University in the past three years has almost doubled. *Joanne Wilkerson MD, MSc, Associate Director of Predoctoral Education, Department of Family Medicine*

University of Colorado, Denver: Most recently we were able to use a Title VII grant to develop a program of required service learning experiences where students provide health education in rural communities and share their experience as a medical student with rural youth to encourage them to enter health careers. Each year this program reaches about 6500 rural residents including about 3500 children. *David Gaspar, Chair, Director of Medical Student Education, Department of Family Medicine*

Dartmouth Medical School: As a result of a Title VII grant, we have embedded advanced communication skills training in our 3rd year medical school curriculum in Shared Decision Making with such success that it has become integral to the medical school curriculum, and begun a mentoring program matching 30 new rural community family doctors with students who would not have had this exposure without this grant. *Cathleen Morrow MD, Predoctoral Director, Associate Professor, Department of Community and Family Medicine*

North Dakota School of Medicine and Health Science: Title VII grants have enabled the school to provide equal education to students at distant sites through the development of video conferencing and computer services and has provided services and training at rural sites across the state. *Gwen Halaas, MD, MBA, Senior Associate Dean*

University of Massachusetts Medical School: A Title VII grant resulted in enhanced curriculum and training in quality improvement and patient safety for all our medical students in each of their four years, and for our residents in Family Medicine, Medicine and Pediatrics. In addition, we created a new Quality Scholars faculty development program for primary care faculty interested in becoming resident and student mentors and advocates for quality improvement in their practice sites. The new quality improvement focus is now integrated into the ongoing training programs so that the impact of the grant will continue for many years to come. *Daniel Lasser, MD, MPH, Professor and Chair, Department of Family Medicine and Community Health*

University of Massachusetts Medical School: Title VII grants have supported the development of community based curriculum at Federally Qualified Community Health Center training sites designed to provide and enhance skills necessary to be competent and comfortable caring for underserved populations. Our residency graduates are five times more likely to select positions working with underserved populations for their careers. *Stacy Potts, MD, Residency Director for the UMass Worcester Family Medicine Residency Program*

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 – April 15, 2011

The members of the Health Professions and Nursing Education Coalition (HPNEC) are pleased to submit this statement for the record in support of the fiscal year (FY) 2012 budget request of **$762.5 million for the health professions education programs authorized under Titles VII and VIII of the Public Health Service Act and administered through the Health Resources and Services Administration (HRSA)**. HPNEC is an informal alliance of more than 60 national organizations representing schools, programs, health professionals, and students dedicated to ensuring the health care workforce is trained to meet the needs of the country's growing, aging, and diverse population. For a complete list of HPNEC members, visit http://www.aamc.org/advocacy/hpnec/members.htm.

As you know, the Title VII and VIII health professions and nursing programs provide education and training opportunities to a wide variety of aspiring health care professionals, both preparing them for careers in the health professions and helping bring health care services to our rural and underserved communities. An essential component of the health care safety net, the Title VII and Title VIII programs are the only federal programs designed to train health care providers in interdisciplinary settings to meet the needs of the country's special and underserved populations, as well as increase minority representation in the 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.

Authorized since 1963, the Title VII and Title VIII education and training programs are designed to help the workforce adapt to the evolving health care needs of the ever-changing American population. In an effort to renew and update Titles VII and VIII to meet current workforce challenges, the programs were reauthorized in 2010—the first reauthorization in the past decade. Reauthorization not only improved the efficiency of the Title VII and Title VIII programs, but also laid the groundwork for innovative programs with an increased focus on recruiting and retaining professionals in underserved communities.

HPNEC is keenly aware of the difficult decisions facing the Subcommittee as it works to improve the nation's fiscal health. We appreciate the Subcommittee's longstanding support of the Title VII and Title VIII programs, as well as bipartisan recognition that a strong health care workforce is essential to the continued health and prosperity of the American people, particularly in the face of the critical disparity between the supply of practicing health care providers and the increasing demand for care. According to HRSA, over 33,000 additional health practitioners are needed to alleviate existing professional shortages. Destabilizing funding for the Title VII and Title VIII programs would reduce education and training support for primary care physicians, nurses, and other health professionals, exacerbating shortages and further straining the nation's already fragile health care system.

Failure to fully fund the programs would jeopardize activities to train professionals across all disciplines to coordinate care for the nation's expanding elderly population; limit training opportunities for providers to meet the unique needs of the nation's sick and ailing children; severely impact the distribution of professionals practicing in rural and underserved communities; and hinder efforts to recruit and retain a diverse and culturally competent workforce. To ensure the health care workforce is equipped to address these issues, a strong commitment to the Title VII and Title VIII programs is essential.

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The existing Title VII and Title VIII programs can be considered in seven general categories:

- The **Primary Care Medicine and Oral Health Training** programs, now authorized separately, provide for the education and training of primary care physicians, physician assistants, and dentists, to improve access and quality of health care in underserved areas. Two-thirds of all Americans interact with a primary care provider every year. Approximately one-half of primary care providers trained through these programs go on to work in underserved areas, compared to 10 percent of those not trained through these programs. The *General Pediatrics*, *General Internal Medicine,* and *Family Medicine* programs provide critical funding for primary care training in community-based settings and have been successful in directing more primary care physicians to work in underserved areas. They support a range of initiatives, including medical student training, residency training, faculty development and the development of academic administrative units. These programs also enhance the efforts of osteopathic medical schools to continue to emphasize primary care medicine, health promotion, and disease prevention, and the practice of ambulatory medicine in community-based settings. Recognizing that all primary care is not only provided by physicians, the primary care cluster also provides grants for *Physician Assistant* programs to encourage and prepare students for primary care practice in rural and urban Health Professional Shortage Areas. 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 areas far removed from health professions schools, the **Interdisciplinary, Community-Based Linkages** cluster provides support for community-based training of various health professionals. These programs are designed to provide greater flexibility in training and to encourage collaboration between two or more disciplines. These training programs also serve to encourage health professionals to return to such settings after completing their training. The *Area Health Education Centers (AHECs)* provide clinical training opportunities to health professions and nursing students in rural and other underserved communities by extending the resources of academic health centers to these areas. AHECs, which have substantial state and local matching funds, form networks of health-related institutions to provide education services to students, faculty and practitioners. *Geriatric Health Professions* programs support geriatric faculty fellowships, the Geriatric Academic Career Award, and Geriatric Education Centers, which are all designed to bolster the number and quality of health care providers caring for our older generations. Given America's burgeoning aging population, there is a need for specialized training in the diagnosis, treatment, and prevention of disease and other health concerns of older adults. The *Mental and Behavioral Health Education and Training Programs* help mitigate the growing shortages of mental and behavioral health providers by providing grants for training social workers, child and adolescent mental health professionals, and paraprofessionals working with children and adolescents. They also provide grants to doctoral, internship, and postdoctoral programs through the Graduate Psychology Education program, which supports interdisciplinary training of psychology students with other health professionals for the provision of mental and behavioral health services to underserved populations (i.e., older adults, children, chronically ill, and victims of abuse and trauma, including returning military personnel and their families), especially in rural and urban communities.

- The purpose of the **Minority and Disadvantaged Health Professionals Training** programs is to improve health care access in underserved areas and the representation of minority and disadvantaged health care providers in the health professions. *Minority Centers of Excellence* support programs that

seek to increase the number of minority health professionals through increased research on minority health issues, establishment of an educational pipeline, and the provision of clinical opportunities in community-based health facilities. The *Health Careers Opportunity Program* seeks to improve the development of a competitive applicant pool through partnerships with local educational and community organizations. The *Faculty Loan Repayment and Faculty Fellowship* programs provide incentives for schools to recruit underrepresented minority faculty. The *Scholarships for Disadvantaged Students* make funds available to eligible students from disadvantaged backgrounds who are enrolled as full-time health professions students.

- The **Health Professions Workforce Information and Analysis** program provides grants to institutions to collect and analyze data on the health professions workforce to advise future decision-making on the direction of health professions and nursing programs. The *Health Professions Research and Health Professions Data* programs have developed a number of valuable, policy-relevant studies on the distribution and training of health professionals, including the Eighth National Sample Survey of Registered Nurses, the nation's most extensive and comprehensive source of statistics on registered nurses. In conjunction with the reauthorization of the Title VII programs and in recognition of 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 data and information on the health workforce for the nation.

- The **Public Health Workforce Development** programs are designed to increase the number of individuals trained in public health, to identify the causes of health problems, and respond to such issues as managed care, new disease strains, food supply, and bioterrorism. The *Public Health Traineeships and Public Health Training Centers* seek to alleviate the critical shortage of public health professionals by providing up-to-date training for current and future public health workers, particularly in underserved areas. *Preventive Medicine Residencies*, which receive minimal funding through Medicare GME, provide training in the only medical specialty that teaches both clinical and population medicine to improve community health. The Title VII reauthorization reorganized this cluster to include 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 services in areas where these types of professionals are in short supply. The *Public Health Workforce Loan Repayment Program* provides loan repayment for public health professionals accepting employment with Federal, state, local, and tribal public health agencies.

- The **Nursing Workforce Development** programs under Title VIII provide training for entry-level and advanced degree nurses to improve the access to, and quality of, health care in underserved areas. These programs provide the largest source of federal funding for nursing education, providing loans, scholarships, traineeships, and programmatic support that, between FY 2006 and 2009, supported over 347,000 nurses and nursing students as well as numerous academic nursing institutions, and health care facilities. Health care entities across the nation are experiencing a crisis in nurse staffing, caused in part by an aging workforce and capacity limitations within the educational system. Each year, nursing schools turn away tens of thousands of qualified applications at all degree levels due to an insufficient number of faculty, clinical sites, classroom space, clinical preceptors, and budget constraints. At the same time, the need for nursing services and licensed, registered nurses is expected to increase significantly over the next 20 years. The *Advanced Education Nursing* program awards grants to train a variety of advanced practice nurses, including nurse practitioners, certified nurse-midwives,

nurse anesthetists, public health nurses, nurse educators, and nurse administrators. *Workforce Diversity* grants support opportunities for nursing education for students from disadvantaged backgrounds through scholarships, stipends, and retention activities. *Nurse Education, Practice, and Retention* grants are awarded to help schools of nursing, academic health centers, nurse-managed health centers, state and local governments, and other health care facilities to develop programs that provide nursing education, promote best practices, and enhance nurse retention. The *Loan Repayment and Scholarship Program* repays up to 85 percent of nursing student loans and offers full-time and part-time nursing students the opportunity to apply for scholarship funds. In return these students are required to work for at least two years of practice in a designated nursing shortage area. The *Comprehensive Geriatric Education* grants are used to train RNs who will provide direct care to older Americans, develop and disseminate geriatric curriculum, train faculty members, and provide continuing education. The *Nurse Faculty Loan* program provides a student loan fund administered by schools of nursing to increase the number of qualified nurse faculty.

- The loan programs under **Student Financial Assistance** support financially needy and disadvantaged medical and nursing school students in covering the costs of their education. The *Nursing Student Loan* (NSL) program provides loans to undergraduate and graduate nursing students with a preference for those with the greatest financial need. The *Primary Care Loan* (PCL) program provides loans covering the cost of attendance in return for dedicated service in primary care. The *Health Professional Student Loan* (HPSL) program provides loans covering the cost of attendance for financially needy health professions students based on institutional determination. The NSL, PCL, and HPSL programs are funded out of each institution's revolving fund and do not receive federal appropriations. The *Loans for Disadvantaged Students* program provides grants to health professions institutions to make loans to health professions students from disadvantaged backgrounds.

By improving the supply, distribution, and diversity of the nation's health care professionals, the Title VII and Title VIII programs not only prepare aspiring professionals to meet the country's workforce needs, but also help to improve access to care across all populations. The multi-year nature of health professions education and training, coupled with unprecedented existing and looming 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 of the immense fiscal pressures facing the Subcommittee, we respectfully urge support for **$762.5 million** for the Title VII and VIII programs, a commitment essential not only to the development and training of tomorrow's health care professionals but also to our nation's efforts to provide needed health care services to underserved communities. We forward to working with Members of Congress to prioritize the health professions programs in FY 2012 and into the future.

Statement for the Record to the House Committee on Appropriations
Concerning the Bill to Fund the Departments of Labor, Health and Human Services, and Education, and Related Agencies Appropriations for FY 2012

April 15, 2011

The American Academy of Family Physicians representing 97,600 family physicians, residents, and medical students nationwide, is pleased to submit this statement for the record in support of our funding priorities for inclusion in the fiscal year 2012 appropriations bill.

The AAFP urges the House Appropriations Subcommittee on Labor, Health and Human Services, and Education to make a robust FY 2012 investment in our nation's primary care physician workforce in order to ensure that it is adequate to provide efficient, effective health care delivery addressing access, quality and value.

We recognize the difficult decisions which our nation's budgetary pressures present and remain confident that wise federal investment will help to transform health care to achieve optimal, cost-efficient health for everyone. Specifically, we recommend that the Committee provide the Health Resources and Services Administration and the Agency for Healthcare Research and Quality with the FY 2012 funding levels called for in the President's budget request.

HEALTH RESOURSES AND SERVICES ADMINISTRATION
HRSA is the federal agency chiefly responsible for improving access to health care services for Americans who are uninsured, isolated or medically vulnerable. HRSA's mission also calls for a skilled health workforce, and the AAFP supports their efforts to train the necessary primary care physician workforce. Primary care physicians will serve as a strong foundation for a more efficient and effective health care system.

The AAFP recommends that the Committee provide at least $449.5 million for all of the Health Professions Training Programs authorized by Title VII of the Public Health Service Act and administered by the Health Resources and Services Administration (HRSA) as requested in the President's FY 2012 budget.

Within that line, we urge you to provide at least:

- **$140 million for Health Professions Primary Care Training and Enhancement authorized under Title VII, Section 747 of the Public Health Service Act;**
- **$10 million for Teaching Health Centers development grants authorized by Title VII, Section 749A; and**
- **$4 million for Title VII, Section 749B Rural Physician Training Grants.**

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Title VII Health Professions Training Programs
As the only medical specialty society devoted entirely to primary care, the AAFP appreciates this Committee's commitment to a strong primary care physician workforce. We are concerned that a failure to provide adequate funding for the Title VII, Section 747, the Primary Care Training and Enhancement (PCTE) program, would destabilize ongoing efforts to increase education and training support for family physicians, exacerbating primary care shortages and further straining the nation's health care system.

Title VII, Section 747 primary care training grants to medical schools and residency programs have for decades helped to increase the number of physicians who select primary care specialties and work in underserved areas. A study published in the *Annals of Family Medicine* on the impact of Title VII training programs on community health center staffing and national health service corps participation found that physicians who work with the underserved in CHCs and NHSC sites are more likely to have trained in Title VII-funded programs.[1] Title VII primary care training grants are vital to departments of family medicine, general internal medicine, and general pediatrics; strengthen primary care curricula; and 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 of the populace. These demographic trends will cause primary care physician shortages to worsen. We urge the Committee to increase the level of federal funding for primary care training to reinvigorate medical education, residency programs, as well as academic and faculty development in primary care to prepare physicians to support the patient centered medical home.

Teaching Health Centers
The AAFP has long called for reforms to graduate medical education programs in order 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, Section 749A to increase primary care physician training capacity now administered by HRSA.

Federal financing of graduate medical education has led to training which occurs mainly in hospital inpatient settings in spite of the fact that most patient care is delivered outside of hospitals in ambulatory settings across the nation. The Teaching Health Center program provides resources to any qualified community based ambulatory care setting that operates a primary care residency program including Federally Qualified Health Centers or Federally Qualified Health Centers Look Alikes, Rural Health Clinics, Community Mental Health Centers, a Health Center operated by the Indian Health Service, or a center receiving Title X grants.

We were pleased that the *Patient Protection and Affordable Care Act* authorized a mandatory appropriations trust fund of $230 million over five years to fund the operations of Teaching Health Centers. However, if this program is to be effective, there must be funds for the planning grants to establish newly accredited or expanded primary care residency programs.

Rural Health Needs
Another important HRSA Title VII grant program is the Rural Physician Training Grants program to help medical schools to recruit students most likely to practice medicine in rural communities. This modest program authorized by Title VII, Section 749B will help provide rural-focused training

[1] 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;6(5):397–405.

and experience and increase the number of recent medical school graduates who practice in underserved rural communities.

National Health Service Corps
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 practitioners 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 Government Accountability Office (GAO-01-1042T) described the NHSC as "one safety-net program that directly places primary care physicians and other health professionals in these medically needy areas." Currently most of the more than 7 million people who rely on NHSC clinicians for their health care needs would not have access to care without the NHSC.

Since its inception in 1972, the NHSC has helped place 37,000 primary care health professionals in underserved communities across the country, many of whom remain in these areas following the completion of their service. According to the FY 2009 Health Resources and Services Administration Budget Justification, over 75 percent of the clinicians placed by the NHSC in underserved areas continued to serve in their position for at least one year after the completion of their service obligation.

Today, there are over 9,000 vacancies at NHSC approved sites across the country with more added every day, yet funding is inadequate to fill all of these needed slots.

The AAFP recommends that Committee provide at least the President's requested level of $418.5 million for the National Health Service Corps for FY 2012 to include $295 million in funds made available for NHSC operations, scholarships and loan repayments by the *Affordable Care Act*.

AGENCY FOR HEATLHCARE RESEARCH AND QUALITY
The mission of the Agency for Healthcare Research and Quality (AHRQ)—to improve the quality, safety, efficiency, and effectiveness of health care for all Americans—closely mirrors the AAFP's own mission. AHRQ is a small agency with a huge responsibility for research to support clinical decision-making, reduce costs, advance patient safety, decrease medical errors and improve health care quality and access. Family physicians recognize that AHRQ has a critical role to play in patient-centered outcomes research also known as comparative effectiveness research.

Patient-Centered Outcomes Research
AHRQ's investment in patient-centered outcomes research will help Americans make the informed decisions we must make to focus on paying for quality rather than quantity. By determining what has limited efficacy or does not work, this important research can spare patients from tests and treatments of little value. Today, patients and their physicians face a broad array of diagnostic and treatment options without the scientific evidence needed to know what procedure or which drug is most likely to succeed or how best to time a given therapy. AHRQ is supporting research to answer those questions so that physicians and their patients can make the choices about care that are most likely to succeed. AHRQ also supports the essential research into the prevention of medical errors and reducing hospital-acquired infections.

Medical Liability Demonstrations
Solving the professional medical liability has long been one of the AAFP's highest priorities. Although the medical liability demonstrations announced by AHRQ in FY 2010 are quite modest, we support the effort to find alternatives to the current medical tort system.

Primary Care Extension Program
The AAFP supports the Primary Care Extension Program to be administered by AHRQ to provide support and assistance to primary care providers about evidence-based therapies and techniques so that providers can incorporate them into their practice. As AHRQ develops more scientific evidence on best practices and effective clinical innovations, the Primary Care Extension Program will disseminate them 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 information and guidance.

The AAFP recommends that the Committee provide at least $405 million for AHRQ in FY 2012. In addition, we ask that the Primary Care Extension program receive the authorized level of $120 million in FY 2012.

Testimony on Behalf of the March of Dimes Foundation
House Committee on Appropriations - Subcommittee on Labor, Health and Human Services, and Education

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 2012 (FY12).

The March of Dimes was founded in 1938 by President Franklin D. Roosevelt to support research to prevent polio. Today, the Foundation aims to improve the health of women, infants and children by preventing birth defects, premature birth, and infant mortality through scientific research, community services, education and advocacy.

The March of Dimes is a unique partnership of scientists, clinicians, parents, members of the business community and other volunteers affiliated with 51 chapters and 213 divisions in every state, the District of Columbia and Puerto Rico. Additionally, in 1992, the March of Dimes extended its mission globally and now operates through partnerships in 33 countries on four continents.

The March of Dimes is aware that the current fiscal environment necessitates restrictions on federal funding increases and program expansions. However, it is our hope that these budgetary limitations will not put at risk our vital mission on which affected families rely. Therefore, the March of Dimes recommends the following funding levels for programs and initiatives that are essential investments in maternal and child health.

PRETERM BIRTH

In 2008, one in eight infants was born preterm (before 37 weeks). Preterm birth is the leading cause of newborn mortality (death within the first month) and the second leading cause of infant mortality (death within the first year). In 2009, the National Center for Health Statistics (NCHS) reported that the primary reason for the higher infant mortality rate in the United States compared to other high resource countries is the greater percentage of preterm births - 12.4 percent in the U.S. compared to 5.5 percent in Ireland. But survival alone does not necessarily result in good health for these infants. Among those who survive, one in five faces health problems that persist for life. Prematurity-related conditions include cerebral palsy, intellectual disabilities, chronic lung disease, blindness and deafness. A comprehensive report published by the Institute of Medicine in 2007 estimated that preterm births cost the U.S. more than $26 billion in 2005 alone, with costs climbing each year.

As a result of legislation enacted in 2006 (P.L. 109-450), the U.S. Surgeon General sponsored a conference in 2008 of more than 200 of the country's foremost experts that convened for two days to develop a strategy to address the costly and serious problems of preterm birth. The meeting resulted in an action plan that included several overarching themes and recommendations. Among the most important were the enhancement of biomedical and epidemiological research and strengthening our nation's data resources that document the health status of pregnant women and their infants. The Foundation's funding requests regarding preterm birth are based on these recommendations.

National Institutes of Health

The March of Dimes commends members of the Subcommittee for their continuing support of the National Children's Study (NCS). **For FY12, the Foundation supports the President's funding recommendation of $193.9 million for the NCS and we urge the Subcommittee to support this recommendation as well.** The NCS is the largest and most comprehensive study of children's health and development ever planned in the United States. The 37 "vanguard centers" have recruited nearly 3,000 participants thus far and more than 650 children have been born into the study. When fully implemented, this study will follow a representative sample of 100,000 children in the United States from before birth until age 21. The data from this important study will help scientists at universities and research organizations across the country and around the world identify precursors of diseases and develop new strategies for treatment and prevention. Specifically, the first data generated by the NCS will provide information concerning disorders of birth and infancy, including

preterm birth and its health consequences. The Foundation remains committed to supporting a well-designed NCS that promotes research of the highest quality and asks the Subcommittee to do the same.

***Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD)**
For FY12, the March of Dimes recommends at least $1.352 billion for the NICHD. This $23 million increase compared to the FY10 enacted level will enable NICHD to expand its support for preterm birth-related research through the Maternal-Fetal Medicine Units, Neonatal Research Network, and Genomic and Proteomic Network for Preterm Birth Research. In addition, it will allow for planning grants to begin establishing a network of integrated trans-disciplinary research centers, as recommended by the Institute of Medicine report and the aforementioned 2008 Surgeon General's Conference. The causes of preterm birth are multi-faceted and necessitate a coordinated and collaborative approach integrating many disciplines. These trans-disciplinary centers would serve as a national resource for investigators to design and share new research approaches and strategies to comprehensively address preterm birth.

Centers for Disease Control and Prevention - Preterm Birth
The National Center for Chronic Disease Prevention and Health Promotion's Safe Motherhood Program works to promote optimal reproductive and infant health. In 2009, CDC created a robust research agenda to prevent preterm birth by improving derivation of accurate data to understand preterm birth; developing, implementing and evaluating prevention methods; and conducting targeted etiologic and epidemiologic studies. **For FY12, the March of Dimes recommends a $6 million increase in the CDC's preterm birth budget compared to the FY10 enacted level (for a total of $8 million) to strengthen our national data systems and to expand preterm birth research as authorized by the PREEMIE Act (P.L. 109-450).**

Centers for Disease Control and Prevention - National Center for Health Statistics
The National Center for Health Statistics' (NCHS) vital statistics program collects birth and death data that are used to monitor the nation's health status, set research and intervention priorities, and evaluate the effectiveness of existing health programs. It is imperative that data collected by NCHS be comprehensive and timely. Unfortunately, a quarter of the states and territories lack the capacity to use the most recent (2003) birth certificate format and only two-thirds have adopted the most recent (2003) death certificate format. **The March of Dimes supports the President's recommendation to provide $162 million – a $23 million increase over the FY10 enacted level – for the NCHS in FY12 and urges the Subcommittee to support this recommendation in both the bill language and in the accompanying committee report as well.**

Health Resources and Services Administration - Healthy Start
The Maternal and Child Health Bureau's Healthy Start Program is a collection of community-based projects focused on reducing infant mortality, low birth weight, and racial disparities in perinatal outcomes among high-risk populations by strengthening local health systems and resources. Communities with Healthy Start programs have seen significant improvements in perinatal health outcomes. **The March of Dimes supports the President's recommendation to provide $105 million (level funding) for Healthy Start in FY12 and urges the Subcommittee to support this recommendation as well.**

BIRTH DEFECTS
According to the Centers for Disease Control and Prevention, an estimated 120,000 infants in the U.S. are born with major structural birth defects each year. Genetic or environmental factors, or a combination of both, can cause various birth defects; yet the causes of more than 70 percent are unknown. Many birth defects result in childhood and adult disability that require costly, lifelong treatments and special care. Additional federal resources are sorely needed to support research to discover causes of all birth defects and for the development of effective interventions to prevent or at least reduce their prevalence.

CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD)
The NCBDDD conducts programs to protect and improve the health of children by preventing birth defects and developmental disabilities and by promoting optimal development and wellness among children with disabilities. **For FY12, the March of Dimes requests at least $144 million for NCBDDD. In addition, we encourage the Subcommittee to allocate an additional $5 million specifically to support birth defects research and surveillance and an additional $2 million specifically to support folic acid education. A source for this $7 million in additional funding could be the Prevention and Public Health Fund.** Investing in the work of the NCBDDD will promote wellness and preventive strategies aimed at children, reduce health disparities, and enable CDC to more effectively support transition to adulthood for children with lifelong disabilities.

Allocating an additional $5 million to 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 – would be a sound investment. This analysis would enable researchers to begin the work needed to translate their findings into effective birth defects intervention and treatment programs. The study has already yielded rich results. In 2009 alone, 29 articles regarding risk factors for birth defects - for example maternal diabetes, obesity, use of certain medications, and smoking - were published in medical and health journals. In addition, this investment would make possible the continuation of NCBDDD's state-based birth defects surveillance grant program. Surveillance is the backbone of the public health network and its support should be a Subcommittee priority. Because of the current fiscal situation facing many states, funding for state-based surveillance systems is in jeopardy and requires increased federal support to ensure the survival of essential birth defects surveillance programs.

Allocating an additional $2 million to NCBDDD will allow the CDC to expand its effective national education campaign aimed at reducing the incidence of spina bifida and anencephaly by promoting consumption of folic acid. Since the institution of fortification of U.S. enriched grain products with folic acid, the rate of neural tube defects has decreased by 26 percent. However, CDC estimates that up to 70 percent of neural tube defects could be prevented if all women of childbearing age consumed 400 micrograms of folic acid daily. To raise awareness among women of childbearing age and thereby increase the use of folic acid, NCBDDD's national education campaign must be expanded.

The March of Dimes is very concerned about the Administration's recommendation that the NCBDDD's budget lines be consolidated into three categories: Child Health and Development, Health and Development for People with Disabilities, and Public Health Approach to Blood Disorders. As proposed, the Birth Defects and Developmental Disabilities budget line would be renamed Child Health and Development and existing sub-categories would be eliminated (e.g. Birth Defects, Fetal Alcohol Syndrome, Folic Acid). While the March of Dimes recognizes and supports program flexibility for CDC management, we are concerned that the title "Child Health and Development" fails to make clear the overall purpose of the programs covered, masking the urgency and importance of the need for ongoing support from Congress. **We urge the Subcommittee to modify the Administration's proposal by retaining the term "Birth Defects" as a sub-line with the category "Child Health and Development." We believe this adjustment is needed to ensure that the content of these essential programs to reduce birth defects is clearly articulated.**

NEWBORN SCREENING
Newborn screening is a vital public health activity used to identify genetic, metabolic, hormonal and functional disorders in newborns so that treatment can be provided. 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 successfully managed. Across the nation, state and local governments are experiencing significant budget shortfalls. Because of this fiscal pressure, discontinuing screening for certain conditions or postponing the purchase of necessary technology is a serious threat that, if left unresolved, will put infants at risk of permanent disability or even death. **For FY12, an additional $5 million for HRSA's heritable disorders program, as authorized by the**

Newborn Screening Saves Lives Act (P.L. 110-204), is necessary to increase support for state efforts to improve screening, enhance counseling, and increase capacity to reach and educate health professionals and parents about newborn screening programs and follow-up services.

OTHER

Agency for Health Research and Quality (AHRQ)

AHRQ supports research to improve health care quality, reduce costs and broaden access to essential health services. **For FY12, the March of Dimes recommends $405 million total - a 2 percent increase over the FY10 enacted level** - for AHRQ to continue its important work, including the development and dissemination of maternal and pediatric quality measures and comparative effectiveness research. Moreover, with the historic enactment of health reform last year, AHRQ's research is needed more than ever to build the evidence-base that will be used to improve health and health care coverage.

Health Resources and Services Administration - Maternal and Child Health Block Grant

Title V of the Social Security Act, the Maternal and Child Health Block Grant, supports a growing number of community-based programs (e.g. home visiting, respite care for children with special health care needs, and supplementary services for pregnant women and children enrolled in Medicaid and the State Children's Health Insurance Program), but federal support has not kept pace with increased enrollment and demand for these services. **For FY12, the March of Dimes recommends $700 million for the Maternal and Child Health Block Grant - $38 million more than the FY10 enacted level.**

CDC National Immunization Program

Infants are particularly vulnerable to infectious diseases, which is why it is critical to protect them through immunization. In 2008, the national estimated immunization coverage among children 19-35 months of age was 76 percent. The CDC's National Immunization Program supports states, communities and territorial public health agencies through grants to reduce the incidence of disability and death resulting from vaccine-preventable diseases. **The March of Dimes is requesting $685 million in FY12 for the National Immunization Program.**

CDC Polio Eradication

Since its creation as an organization dedicated to research and services related to polio, the March of Dimes has been committed to the eradication of this disabling disease. **The March of Dimes is requesting $102 million in FY12 for the CDC's Polio Eradication Program.** Level with the FY10 enacted level and $10 million less than the President's FY12 request, this funding would allow CDC to continue its immunization activities in the remaining endemic and high-risk countries in Africa and Asia and interrupt polio transmission in these regions.

Closing

Thank you for the opportunity to testify on the federally-supported programs of highest priority to the March of Dimes. The Foundation's volunteers and staff in every state, the District of Columbia and Puerto Rico look forward to working with Members of this Subcommittee to secure the resources needed to improve the health of the nation's mothers, infants and children.

MARCH OF DIMES
FY 2012 FEDERAL FUNDING PRIORITIES
(Dollars in Millions)

PROGRAM	FY 2010 FUNDING	MARCH OF DIMES REQUEST
National Institutes of Health (Total)	31,089	35,000
National Children's Study	193.8	193.9
Common Fund	544	556.9
National Institute of Child Health and Human Development	1,329	1.352
National Human Genome Research Institute	516	524.8
National Center on Minority Health and Disparities	212	214.6
Centers for Disease Control and Prevention (Total)	6,475	7,700
Birth Defects Research & Surveillance	21.342	26.342
Folic Acid Campaign	3.1	5.1
Immunization	559	685
Polio Eradication	102	102
Preterm Birth (Safe Motherhood)	2	8
National Center for Health Statistics	139	162
Health Resources and Services Administration (Total)	7,483	7,650
Maternal and Child Health Block Grant	662	700
Newborn Screening	10	15
Newborn Hearing Screening	19	19
Community Health Centers	2,146	2,560
Healthy Start	105	105
Agency for Healthcare Research and Quality (Total)	397	405

Testimony of the

Association of Maternal & Child Health Programs (AMCHP)

to the

House of Representatives Committee on Appropriations,
Subcommittee on Labor, Health and Human Services and Education,
Health Resources and Services Administration (HRSA),
Maternal & Child Health Bureau (MCHB)

by

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I have never been more proud to call myself a Montanan than on the day of the first clinic we attended.

- Angela Haddick *(Helena, MT)*

Chairman Rehberg and distinguished subcommittee members:

On behalf of the Association of Maternal & Child Health Programs (AMCHP), I am pleased to submit testimony describing AMCHP's request for $700 million in funding for Fiscal Year 2012 for the Title V Maternal and Child Health Services block grant, a 5% increase over Fiscal Year 2010. The Maternal and Child Health (MCH) Services Block Grant supports a wide range of programs that meet state and locally determined needs. In 2008, over 40 million individuals were served by maternal and child health programs supported through the MCH Services Block Grant.

AMCHP did not develop this request lightly and our members are very cognizant of the many important and urgent discussions about reducing the federal deficit and government spending. However, we strongly contend that with the recent economic downturn and increased need to provide services to vulnerable populations a $700 million request is worthy of serious consideration by the Committee.

The MCH Services Block Grant provides support and services to millions of American women, infants and children, including children with special health care needs. It has been proven a cost effective, value-based, and flexible funding source used to address the most pressing and unique needs of each state. States and jurisdictions use the MCH Services Block Grant to design and implement a wide range of maternal and child health programs that meet national and state needs. Although specific initiatives may vary among the 59 states and jurisdictions, all of them work 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
- Facilitate the development of comprehensive, family-centered, community-based, culturally competent, coordinated systems of care for children with special health care needs.

The MCH Services Block Grant improves the health of America's women and children by:

- **Supporting programs that work.** The MCH Services Block Grant earned the highest program rating by the Office of Management and Budget's (OMB) Program Assessment Rating Tool (PART). OMB found that MCH Services Block Grant funded programs helped to decrease the infant mortality rate, prevent disabling conditions, increase the number of children immunized, increase access to care for uninsured children, and improve the overall health of mothers and children. Reduced MCH Services Block Grant funding threatens the ability of these programs to carry on this work. Our results are available to the public through a national website known as the Title V Information System. Such a transparent system is remarkably rare for a federal program and we are proud of the progress we have made in demonstrating results.
- **Addressing the growing health needs of women, children and families.** As states face economic hardships and face limits on their Medicaid and CHIP programs, more women and children seek care and preventive services through MCH Services Block Grant funded programs. Resources are needed to reduce infant mortality, provide a range of preventive health and early intervention services to those in need, improve oral health care, reach more children and youth with special health care needs, and reduce racial disparities in health care.
- **Supporting and integrating other federally funded programs** such as Community Health Centers, Healthy Start, WIC, CHIP and Medicaid. The MCH Services Block Grant helps identify areas of need in a state and works with all state and federal programs to complement health care services and promote disease prevention for women, children, and families.

To help illustrate the importance of MCH Services Block Grant funding I would like to share Allyson's story. Allyson is a young girl from Helena, Montana who was helped by Montana's MCH Services Block Grant supported programs.

Allyson is a bright, bubbly 15 month old from Helena with a beautiful smile and lots of attitude. However, this was not always the case: in 2009 she was born with a cleft lip and palate. If left untreated this condition would have led to a number of painful and costly health problems, including issues with feeding, hearing loss, oral health, and speech.

Allyson's mother Angela vividly remembers the shock, disappointment and fear that washed over her when the doctor informed her of her newborn daughter's condition. One of the first questions she asked was "can we stay here in Montana?" fearing that the only available resources to help her daughter might be located far from their family and friends in Denver or Seattle.

Fortunately, Montana's Children's Special Health Service (CSHS), a division of the Montana Department of Health, supports cranio-facial clinics using MCH Services Block Grant funds. Allyson received high quality care from a variety of health professionals working in these clinics including cranio-facial/plastic surgeons, speech therapists, pediatric dentists, orthodontists, dental hygienists, audiologists, pediatricians, geneticists, and social workers. Early treatment saved Allyson and her family a great deal of pain

and suffering, reduced their future medical costs, and allowed Allyson to continue to grow into a healthy and energetic member of her community.

Without MCH Services Block Grant funding these Montanan professionals would not have been available to Allyson and her family: the expense of just one of these services normally would have made them out of reach of Allyson's family, much less the combined costs. Montana's CSHS clinics not only help children born with cleft lips, but help hundreds of children with a wide range of acute and complicated medical conditions including: cystic fibrosis, diabetes, metabolic disorders, endocrine disorders, and epilepsy/neurological disorders. Nationwide, MCH Services Block Grant funded services like these touch over 1,944,766 million children and their families.

With a smiling and happy daughter today, Angela will tell you that she is truly amazed at how much the CHSH clinics accomplished for her family, and for the people of Montana. As she has stated "I have never been more proud to call myself a Montanan than on the day of the first clinic we attended."

The MCH Services Block Grant supports a similar network in every state and none of this could happen without the MCH Services Block Grant. We hope that all our nation's citizens are as proud as Angela because of the work of MCH Services Block Grant supported programs and professionals.

America has made huge strides in advancing the health of women and children but our country faces huge challenges in improving maternal and child health outcomes and addressing the needs of vulnerable children. On the sentinel measures of how well our society is doing to protect women and children we compare badly to other industrialized countries. Today, the United States ranks 30th in infant mortality rates and 41st in maternal mortality. Sadly, every 18 minutes a baby in America dies before his or her first birthday and each day in America we lose 12 babies due to a Sudden Unexpected Infant Death. There are places in this country where the African-American infant mortality rate is double, and in some places even triple, the rate for whites. Preventable injuries remain the leading cause of death for all children. Nationwide we still fail to adequately screen all young children for developmental concerns, and childhood obesity has reached epidemic proportions threatening to reverse a century of progress in extending life expectancy to our nation's very future.

Without adequate funding MCH Services Block Grant programs will be overwhelmed by the mismatch between state needs and available resources. AMCHP members ask for your leadership in making the important decision to fund the MCH Services Block Grant at $700 million for FY 2012. State maternal and child health programs have a long track record of demonstrating our positive impact on MCH outcomes and are fully accountable for the funds that we receive. Maintaining vital funding for the MCH Services Block Grant is an effective and efficient way to support our nation's women, children, and families.

In closing Mr. Chairman and distinguished members, I ask you to imagine with me an America in which every child has the opportunity to live until his or her first birthday; a nation where our federal and state partnership has effectively moved the needle on our most pressing maternal and child health issues such as infant mortality. Imagine all American parents being as proud as Allyson's mom. Imagine a day when we are celebrating significant reductions or even the total elimination of health disparities by creatively solving our most urgent maternal and child health challenges.

The MCH Services Block Grant aims to do just that using resources effectively to improve the health of all of America's women and children. Supporting the MCH Services Block Grant is a cost-effective investment in our nation's future. We appreciate you support and leadership in funding it at $700 million for Federal Fiscal Year 2012. Thank you.

Stephanie Bruch

Friends of the Health Resources and Services Administration (HRSA)

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Testimony of the Friends of the HRSA
Concerning the Health Resources and Services Administration's Budget for Fiscal Year 2012
House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
Submitted for the Record
April 13, 2011

The Friends of HRSA is a non-profit and non-partisan alliance of more than 180 national organizations, collectively representing millions of public health and health care professionals, academicians and consumers. The coalition's principal goal is to ensure that HRSA's broad health programs have continued support in order to reach the populations presently underserved by the nation's patchwork of health services.

HRSA operates programs in every state and territory and thousands of communities across the country and is a national leader in providing health services for individuals and families. The agency serves as a health safety net for the medically underserved, including the 50 million Americans who were uninsured in 2009 and 60 million Americans who live in neighborhoods where primary health care services are scarce. **To respond to these challenges, it is the best professional judgment of the members of the Friends of HRSA that the agency will require an overall funding level of at least $7.65 billion for fiscal year (FY) 2012.** This recommendation represents a 22 percent increase over FY 2011 and a 12 percent increase over the President's FY 2012 request.

While we recognize the reality of the current fiscal climate, our request of $7.65 billion represents the minimum amount necessary for HRSA to continue to meet the health care needs of the American public. Anything less will undermine the efforts of HRSA programs to improve access to quality health care for millions of our neediest citizens. Additionally, the Friends of HRSA coalition members remain concerned about the deep cuts made to the agency in the final FY2011 Continuing Resolution and the negative consequences for public health. Therefore, the requested minimum level of funding for FY2012 is essential to allow the agency to carry out critical public health programs and services that reach millions of Americans, including training for public health and health care professionals, providing primary care services through community 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. However, much more is needed for the agency to achieve its ultimate mission of ensuring access to culturally competent, quality health services; eliminating health disparities; and rebuilding the public health and health care infrastructure.

Our $7.65 billion FY 2012 HRSA funding request is based upon recommendations provided by coalition members to support HRSA programs including:

- Health Professions programs support the education and training of primary care physicians, nurses, dentists, dental hygienists physician assistants, nurse practitioners, public health personnel, mental and behavioral health professionals, optometrists, pharmacists, and other allied health providers; improve the distribution and diversity of health professionals in medically

underserved communities; and ensure a sufficient and capable health workforce able to provide care for all Americans and respond to the growing demands of our aging and increasingly diverse population. In addition, the Patient Navigator Program helps individuals in underserved communities, who suffer disproportionately from chronic diseases, navigate the health system.

- Primary Care programs support community health centers operating in more than 8,000 communities in every state and territory, improving access to cost-effective and high-quality primary and preventive care in rural and urban underserved areas . In addition, the Health Centers program targets the country's most vulnerable populations, including migrant and seasonal farm workers, homeless individuals and families, and those living in public housing.
- Maternal and Child Health Flexible Maternal and Child Health Block Grants, Healthy Start and other programs provide services, including prenatal and postnatal care, newborn screening tests, immunizations, school-based health services, mental health services, and well-child care for more than 34 million uninsured and underserved women and children not covered by Medicaid or the Children's Health Insurance Program, including children with special needs.
- HIV/AIDS programs provide assistance to metropolitan and other areas most severely affected by the HIV/AIDS epidemic; support comprehensive care, drug assistance and support services for people living with HIV/AIDS; provide education and training for health professionals treating people with HIV/AIDS; and address the disproportionate impact of HIV/AIDS on women and minorities.
- Family Planning Title X programs provide reproductive health care and other preventive services for more than 5 million low-income women at over 4,500 clinics nationwide. These programs improve maternal and child health outcomes, prevent unintended pregnancies, and reduce the rate of abortions.
- Rural Health programs improve access to care for the 60 million Americans who live in rural areas. Rural Health Outreach and Network Development Grants, Rural Health Research Centers, Rural and Community Access to Emergency Devices Program, and other programs are designed to support community-based disease prevention and health promotion projects, help rural hospitals and clinics implement new technologies and strategies, and build health system capacity in rural and frontier areas.
- Special Programs include the Organ Procurement and Transplantation Network, the National Marrow Donor Program the C.W. Bill Young Cell Transplantation Program, and National Cord Blood Inventory. Strong funding would facilitate an increase in organ, marrow, and cord blood transplantation.

Greater investment is necessary to sufficiently fund HRSA services and programs that continue to face increasing demands. We urge you to consider HRSA's role in building the foundation for health service delivery and ensuring that vulnerable populations receive quality health services, while continuing to strengthen our nation's health safety net programs. 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 appreciate the Subcommittee's hard work in advocating for HRSA's programs in a climate of competing priorities. The members of the Friends of HRSA thank you for considering our **FY 2012 request for $7.65 billion for HRSA in the FY 2012 Labor, Health and Human Services, Education, and Related Agencies Appropriations bill** and are grateful for this opportunity to present our views to the Subcommittee.

Written Testimony on behalf of
The American Brain Coalition

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Submitted to the United States House of Representatives
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

Fiscal Year 2012

Appropriations for the Department of Health and Human Services
April 15, 2011

Federal Funding for Brain Research

What Is The American Brain Coalition?

The American Brain Coalition (ABC) is a non-profit organization that brings together people with disabling brain disorders, the families of those that are affected, and the professionals that research and treat diseases of the brain. The mission of the ABC is to reduce the burden of brain disorders, and advance the understanding of the brain.

Thank You for Your Support

The American Brain Coalition would like to thank the Members of this Subcommittee and the House for its ongoing support for the National Institutes of Health. The 1990's Decade of the Brain, highlighted Congressional commitment to brain research and allowed for tremendous medical progress. Past funding provided the opportunity for a substantial number of grants and infrastructure projects to move forward and enhance our understanding of an array of physical and mental health concerns. Progress in the fields of addiction, alcoholism, Parkinson's disease and stroke were already made by scientists funded through NIH, and there is more yet to come. Scientists are inspired to do more research and patients suffering from debilitating neurological and psychiatric disorders are given hope because of your past support.

Today's Research: Hope for the Future

Today's research is the foundation for tomorrow's breakthroughs. The federal government's investment in research must be sustained in order to translate today's scientific findings into further bedside treatments, and the ABC supports NIH in its entirety. Recent discoveries, such as those listed below, are a direct result of robust funding for the NIH.

Post-Traumatic Stress Disorder (PTSD) was once thought to be a psychological condition seen in soldiers returning from war who were thought to be "weak". Recognition of PTSD as a legitimate disorder whose occurrence was not tied to weakness came with evidence that it resulted from clear changes in brain structure and function. It is currently treated with a combination of talk therapy, exposure therapy, cognitive behavior therapy, and neuropsychiatric drugs. With a recent spike in the incidence of PTSD amongst veterans returning from Afghanistan and Iraq, we must look to the future and improved treatments. PTSD occurs in about 11-20% of veterans of the Iraq and Afghanistan wars[1], and they need assistance and hope. Potential treatment advances include exploring an optimal time to begin exposure therapy after a trauma or using hydrocortisone to increase cortisol levels and prevent or reduce symptoms.

[1] U.S. Department of Veterans Affairs, How Common is PTSD? Accessed at: http://www.ptsd.va.gov/public/pages/how-common-is-ptsd.asp

Multiple Sclerosis affects 400,000 Americans, and every week 200 more are newly diagnosed[2]. It is a devastating autoimmune disease with neurological effects that may begin with blurred vision and can progress to partial or full paralysis and cognitive impairments such as memory difficulties. Current treatment for MS is a variety of drugs that reduce the number of flare-ups and may slow disease progression. Imaging techniques also help track disease progression and assist in predicting the onset of new symptoms. But there is no cure. Looking to the future, genetics research is important, along with immunosuppressant drugs and stem cell research. These stem cells could be injected to potentially stimulate the growth of glial cells, which produce myelin—the protective nerve covering destroyed in MS.

Other advancements include:

- The identification of stroke treatment and prevention methods
- The discovery of a new class of anti-depressants that produce fewer side effects than their predecessors
- The creation of new drugs to help prevent epileptic seizures
- The expansion of treatments for the psychotic symptoms of schizophrenia

Research Improves Health and Fuels the Economy

A federal investment in NIH contributes to the nation's economic strength by creating skilled, high-paying jobs, new products and industries, and improved technologies. Research provides hope to the 1 in 3 Americans suffering from brain disorders, while maintaining America's global reputation for medical innovation and progress, in pharmaceuticals and biotechnology. Three-quarters (76%) of Americans say that it is important for the U.S. to be a global leader in scientific research, according to a Research!America poll[3]. Research is an economic engine for states, creating jobs for those employed in university laboratories from high-level scientists to janitorial services.

Improving the diagnoses, treatment, and cures for neurological and psychiatric diseases saves the U.S. economy money. For example, 5 million Americans suffer from Alzheimer's disease today, and the cost of caring for these people is staggering. Medicare expenditures are $91 billion each year, and the cost to American businesses exceeds $60 billion annually, including lost productivity of employees who are caregivers. As the baby boom generation ages and the cost of medical services increases, these figures will only grow. Treatments that could delay the onset and progression of the disease by even five years could save $50 billion in healthcare costs each year. Research funded by the NIH is critical for the development of such treatments. The cost of investing in NIH today is minor compared to both current and future healthcare costs.

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[2] Society for Neuroscience *Brain Research Success Stories* Multiple Sclerosis, Accessed at http://www.sfn.org/skins/main/pdf/brss/BRSS_Multiple_Sclerosis.pdf

[3] Research!America, America Speaks, Poll Data Summary Volume 11, Accessed http://www.researchamerica.org/uploads/AmericaSpeaksV11.pdf

New and Exciting Advocacy Efforts

The brain research community—including researchers, doctors, patients, health systems, pharmaceutical and biotechnology companies—are rallying around "The Next Frontier: One Mind on Brain Research" event on May 23-25 being organized by former Congressman Patrick Kennedy. The event is meant to unite these groups and create a roadmap for brain research over the next decade. Exciting discoveries are waiting in the wings for future support. Advancements in genetics, stem cell research, and imaging could coalesce into vast improvements in diagnosis and treating neuropsychiatric disorders. The quality of life for millions of Americans could be changed forever; those suffering and those caring for loved ones.

Recommendation

The American Brain Coalition is requesting at least $32 billion for FY 2012, as recommended by the President, although the actual need is much greater, falling at around $35 billion.

There is still much work to be done to uncover the mysteries of the brain. FY 2012 provides Congress with the opportunity to renew its past commitment to health funding as a national priority.

Thank you for the opportunity to submit this written testimony.

National Coalition for Osteoporosis and Related Bone Diseases
Before the
House Appropriations Subcommittee on
Labor, Health and Human Services, Education and Related Agencies
April 15, 2011

Mr. Chairman and Members of the Committee:

The National Coalition for Osteoporosis and Related Bone Diseases (Bone Coalition) would like to take this opportunity to thank you all for your continued visionary support of the National Institutes of Health -- the nation's biomedical research agency. Because of your past efforts and your appreciation of the potential and value of medical research, new scientific opportunities are being pursued that hold potential for better diagnosis, treatment, prevention and eventually cures for diseases such as osteoporosis, osteogenesis imperfecta, Paget's disease of bone, and a wide range of rare bone diseases.

RECOMMENDATION:

The National Coalition for Osteoporosis and Related Bone Diseases joins with hundreds of health and medical organizations of the Ad Hoc Group for Medical Research Funding in urging the Committee to provide an appropriation of $35 billion in FY 2012 for the National Institutes of Health. This increase will create substantial opportunities for scientific and health advances, while also providing key economic scientific support in communities across the nation.

Organized in the early 1990s, the Bone Coalition is dedicated to increasing federal research funding for bone diseases through advocacy and education. Five leading national bone disease groups comprise the Bone Coalition: two professional societies, the American Academy of Orthopaedic Surgeons and the American Society for Bone and Mineral Research; and three voluntary health organizations, the National Osteoporosis Foundation, the Osteogenesis Imperfecta Foundation, and the Paget Foundation for Paget's Disease of Bone and Related Disorders.

Osteoporosis and related bone diseases are omnipresent—affecting people of all ages, ethnicities, and gender. These diseases profoundly alter the quality of life and constitute a tremendous burden to patients, society and the economy—causing loss of independence, disability, pain and death. The annual direct and indirect costs for bone and joint health care are $849 billion – 7.7 percent of the U.S. gross domestic product.

- ***Osteoporosis*** is a bone-thinning disease in which the skeleton can become so fragile that the slightest movement, even a cough or a sneeze can cause a bone to fracture. About 10 million Americans already have the disease, and another 34 million people have low bone density, which puts them at risk for osteoporosis and bone fractures. According to estimated figures, osteoporosis was responsible for more than 2 million fractures in 2005, including hip, spine, wrist, and other fractures. The number of fractures due to osteoporosis is expected to rise to more than 3 million by 2025. Approximately 1 in 2 women and up to 1 in 4 men over age 50 will break a bone because of osteoporosis, and

an average of 24 percent of hip fracture patients age 50 and older will die in the year following their fracture. Individuals with certain diseases are at higher risk of developing osteoporosis. For example: diabetes patients are at increased risk for developing an osteoporosis-related fracture; cancer patients are at increased risk because many cancer therapies, such as chemotherapy and corticosteroids, have direct negative effects on bone; and certain cancers, including prostate and breast cancer, may be treated with hormonal therapy, which can cause bone loss.

- ***Osteogenesis imperfecta,*** or "brittle bone disease," is an inherited genetic disorder characterized by fragile bones which fracture easily, often from no apparent cause. A severely affected child begins fracturing before birth. Hundreds of fractures can be experienced in a lifetime, as well as hearing loss, short stature, skeletal deformities, weak muscles and respiratory difficulties. As many as 50,000 Americans may be affected by this disease.

- ***Paget's disease of bone*** is a geriatric disorder that results in enlarged and deformed bones in one or more parts of the body. Excessive bone breakdown and formation can result in bone which is structurally disorganized, resulting in an overall decrease in bone strength and an increase in susceptibility to bowing of limbs and fractures. Pain is the most common symptom. Other complications include arthritis and hearing loss if Paget's disease affects the skull. Paget's disease of bone affects 1 ½ to 8 percent of older adults depending on a person's age and where he or she lives. Approximately 700,000 Americans over the age of 60 are affected.

Past investments in NIH by your Committee have paid dividends for patients in the many advances in the bone research field, and these investments have had significant impact on public health. In just one example, researchers have recently discovered that bisphosphonate drugs commonly prescribed for osteoporosis and Paget's disease significantly reduce death rates by preventing fractures among older adults, producing mortality rates five times lower than those over 60 taking no bone medications. Years of basic research by NIH established the scientific foundation for development of this type of medication now producing significant results.

And while progress to date has clearly been impressive, there is still no cure for osteoporosis, osteogenesis imperfecta, Paget's disease or numerous other diseases and conditions that affect the skeleton. Depending on the disease, the opportunity to build on recent discoveries for new treatments, cures and preventive measures has never been greater. With that in mind, the Coalition has identified the following areas where further intensive investigation is warranted:

Office of the NIH Director: The Coalition urges the Director to work with all relevant Institutes to enhance interdisciplinary research leading to targeted therapies for improving the density, quality and strength of bone for all Americans. More scientific knowledge is needed in a number of key areas involving bone and muscle, fat, and the central nervous system. Research is also urgently needed to improve the identification of populations who might require earlier treatment because they are at risk of rapid bone loss due to a wide range of conditions or diseases: obesity, diabetes, chronic renal failure, cancer, HIV, conditions that affect absorption of nutrients or medications, or addiction to tobacco, alcohol or other opiates. The Coalition encourages NIH to

develop a plan to expand genetics and other research on rare bone diseases, including: osteogenesis imperfecta, Paget's disease of bone, fibrous dysplasia, osteopetrosis, fibrous ossificans progressiva, melorheostosis, X-linked hypophosphatemic rickets, multiple hereditary exostoses, multiple osteochondroma, Gorham's disease, and lymphangiomatosis.

National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS): The Coalition urges support for research into the pathophysiology of bone loss in diverse populations. The information gained will be critical in developing targeted therapies to reduce fractures and improve bone density, quality and strength. Efforts are needed to determine appropriate levels of calcium and vitamin D for bone health at different life stages. Research is also needed in assessing bone microarchitecture and remodeling rates for determining fracture risk, anabolic approaches to increase bone mass, novel molecular and cell-based therapies for bone and cartilage regeneration, and discerning the clinical utility of new, non-invasive bone imaging techniques to measure bone architecture and fragility. Support for studies on the molecular basis of bone diseases such as Paget's disease, osteogenesis imperfecta and other rare bone diseases should also be a priority.

National Cancer Institute (NCI): The Coalition urges investigations on how to repair bone defects caused by cancer cells. Translational research is also needed to understand the impact of metastasis on the biomechanical properties of bone and the mechanisms by which bone marrow and tumor derived cells can influence metastatic growth, survival and therapeutic resistance.

National Institute on Aging (NIA): The Coalition encourages research to better define the causes of age-related bone loss and fractures, reduced physical performance and frailty, including identifying epigenetic changes, with the aim of translating basic and animal studies into new therapeutic approaches. Critical research is also needed on changes in bone structure and strength with aging, and the relationship of age-related changes in other organ systems. The prevention and treatment of other metabolic bone diseases, including osteogenesis imperfecta, glucocorticoid-induced osteoporosis, and bone loss due to kidney disease should also be priority research areas.

National Institute of Child Health and Human Development (NICHD): The Coalition urges research in the new, emerging field of metabolic disease and bone in children and adolescents, especially childhood obesity, anorexia nervosa and other eating disorders. Research is also needed on what the optimal Vitamin D levels should be in children to achieve bone health, and the implications of chronic or seasonal Vitamin D deficiency to the growing skeleton. Development and testing of therapies and bone building drugs for pediatric patients are also a pressing clinical need. The committee is encouraged by results thus far from the Bone Mineral Density in Childhood Study (BMDCS) that will serve as a valuable resource for clinicians and investigators to assess bone deficits in children and risk factors for impaired bone health. However the committee is concerned that without further funding to continue the study, there will be inadequate data on bone development in adolescents and different ethnic groups. Therefore the committee encourages NIH to extend the study and to explore research that will lead to better understanding and prevention of osteopenia and osteoporosis.

National Institute of Dental and Craniofacial Research (NIDCR): The Coalition urges continued research support on the effects of systemic bone active therapeutics on the craniofacial

skeleton, including factors predisposing individuals to osteonecrosis of the jaw, as well as new approaches to facilitate bone regeneration. The Coalition commends NIDCR for its longstanding intramural program on fibrous dysplasia.

National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK): The Coalition encourages support for research on the relationship between Vitamin D and morbidity and mortality in chronic kidney disease. Research is also needed on the value of anti-resorptive therapies, the link between renal insufficiency and diabetic bone disease, the differences in calcification of blood vessels, the mechanisms of metastasis of renal cell carcinoma, and diseases that occurs in patients with end stage chronic renal disease on hemodialysis.

National Institute of Neurological Disorders and Stroke (NINDS): The Coalition encourages research support into the pathophysiology of spinal cord, brachial plexus, and peripheral nerve injuries in order to develop targeted therapies to improve neural regeneration and functional recovery.

National Institute of Biomedical Imaging and Bioengineering (NIBIB): The Coalition encourages critical research to advance our ability to treat bone diseases and disorders through bone imaging, as well as managing the loss of bone and soft tissue associated with trauma by advancing tissue engineering strategies to replace and regenerate bone and soft tissue.

Centers for Disease Control and Prevention

On another front, prevention is of major concern to the Coalition. As the population ages and the ranks of senior citizen Baby Boomers expand, the annual cost of acute and long-term care for osteoporosis, alone, is projected to increase dramatically from $19 billion annually to more than $25 billion by 2025. Without significant intervention now, chronic diseases such as osteoporosis will overwhelm efforts to contain health care costs. Thanks to medical research better diagnosis, prevention and screening strategies and treatment therapeutics are now available to address the growing problem of osteoporosis.

The recent HHS report, "Enhancing Use of Clinical Preventive Services Among Older Adults: Closing the Gap," calls attention to the potential of preventive measures for osteoporosis. The report shows new data outlining critical gaps with a high percentage of women on Medicare reporting never having received osteoporosis screenings. Yet, as the report states, studies have proven that osteoporosis screening using hip scans and follow-up management can reduce hip fractures by 36 percent. In 1999 alone, Medicare spent more than $8 billion to treat injuries to seniors, with fractures accounting for two-thirds of the spending.

The Coalition, therefore, urges the Director of the Centers for Disease Control to develop an education and outreach plan in consultation with the patient and medical community to begin laying the ground work to address osteoporosis on a public health basis.

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Testimony of the International Myeloma Foundation Regarding Fiscal Year 2012 Appropriations for Myeloma Cancer Programs

April 13, 2011

The International Myeloma Foundation (IMF) appreciates the opportunity to submit written comments for the record regarding fiscal year (FY) 2012 funding for myeloma cancer programs. The IMF is the oldest and largest myeloma foundation dedicated to improving the quality of life of myeloma patients while working toward prevention and a cure.

To ensure that myeloma patients have access to the comprehensive, quality care that they need and deserve, the IMF advocates ongoing and significant federal funding for myeloma research and its application. The IMF stands ready to work with policymakers to advance policies and programs that work toward prevention and a cure for myeloma and for all other forms of cancer.

Myeloma Background
The second most common blood cancer worldwide, multiple myeloma (or myeloma) is a cancer of plasma cells in the bone marrow. It is called "multiple" myeloma because the cancer can occur at multiple sites in multiple bones. Each year approximately 20,000 Americans are diagnosed with myeloma and 10,000 lose their battle with this disease.

Although the incidence of many cancers is decreasing, the number of myeloma cases is on the rise. Once a disease of the elderly, it is now being found in increasing numbers in people under the age of 65. The 2009 President's Cancer Panel Report suggests that much of the increase in cancer incidence is being caused by environmental toxins. To give just one example supporting this hypothesis, a recently published study in *The Journal of Occupational and Environmental Medicine*, suggests a link between blood cancers like myeloma and exposure to the toxic dust at Ground Zero.

In recent years significant gains have been made, extending myeloma patients' lives and improving their quality of life. Furthermore, progress begun in myeloma is already helping patients with other blood cancers and even solid tumors. It is important to maintain that momentum.

- There is no cure for myeloma.
- Remissions are not always permanent.
- Additional treatment options are essential.

Living with the disease, myeloma patients can suffer debilitating fractures and other bone disorders, severe side effects of certain treatments, and other problems that profoundly affect their quality of life, and significantly impact the cost of their health care.

Sustain and Seize Cancer Research Opportunities

Myeloma research is producing extraordinary breakthroughs – leading to new therapies that translate into longer survival and improved quality of life for myeloma patients and potentially those with other forms of cancer as well. Myeloma was once considered a death sentence with limited options for treatment, but today myeloma is an example of the progress that can be made and the work that still lies ahead in the war on cancer. Many myeloma patients are living proof of what innovative drug development and clinical research can achieve – sequential remissions, long-term survival, and good quality of life. Our nation has benefited immensely from past federal investment in biomedical research at the National Institutes of Health (NIH) and the IMF advocates $35 billion for NIH in FY 2012.

A study in the *Journal of Clinical Oncology* projects that the number of new cancer cases diagnosed each year will jump 45% over the next 20 years. In multiple myeloma an even greater increase (57%) is projected, and we are already seeing increasing diagnoses in patients under age 65, including patients in their 30s, in what was once a rare disease of the elderly.

While a number of cancers have achieved 5-year survival rates of over 80% since passage of the National Cancer Act of 1971, significant challenges still remain for other cancers. In fact, **nearly half of the 562,490 cancer deaths in 2010 were caused by just eight forms of cancer with 5-year survival rates of 45% or less – one of which is myeloma.** Yet, myeloma and these other cancers have historically also received the least amount of federal funding. As we have seen mortality rates of diseases such as breast cancer, prostate cancer, AIDS, and childhood leukemia greatly reduced through targeted, comprehensive, and well-funded programs that have led to earlier detection and superior forms of treatment, so too must we shine a brighter light on myeloma and the other seven deadly cancers to achieve this same goal for them. The IMF urges Congress to allocate $5.740 billion to the National Cancer Institute (NCI) in FY 2012 to continue our battle against myeloma.

Boost Our Nation's Investment in Myeloma Prevention, Early Detection, and Awareness

As the nation's leading prevention agency, the Centers for Disease Control and Prevention (CDC) plays an important role in translating and delivering at the community level what is learned from research. Therefore, the IMF advocates $6 million for the Geraldine Ferraro Blood Cancer Program. Authorized under the Hematological Cancer Research Investment and Education Act of 2002, this program was created to provide public and patient education about blood cancers, including myeloma.

With grants from the Geraldine Ferraro Blood Cancer Program, the IMF has successfully promoted awareness of myeloma, particularly in the African-American community and other underserved communities. IMF accomplishments include the production and distribution of more than 4,500 copies of an informative video which addresses the importance of myeloma awareness and education in the African-American community to churches, community centers, inner-city hospitals, and Urban League offices around the country, increased African-American attendance at IMF Patient and Family Seminars (these seminars provide invaluable treatment information to newly

diagnosed myeloma patients), increased calls by African-American myeloma patients, family members, and caregivers to the IMF's myeloma Hotline, and the establishment of additional support groups in inner city locations in the United States to assist underserved areas with myeloma education and awareness campaigns. Furthermore, the more than 90 IMF-affiliated patient support groups in the U.S. also made this effort their main goal during Myeloma Awareness Week in October 2005.

An allocation of $6 million in FY 2012 will allow this important program to continue to provide patients – including those populations at highest risk of developing myeloma – with educational, disease management and survivorship resources to enhance treatment and prognosis.

Additionally, the IMF is concerned about the consolidation plan for chronic disease programs at the CDC outlined in the President's FY 2012 budget. This would be a substantial change in the chronic disease program where the Geraldine Ferraro Blood Cancer Program is currently housed. While we agree that there are health issue areas that share risk factors such as healthy eating and maintaining an active lifestyle that make sense to consolidate, unfortunately those are not risk factors for myeloma. We urge the CDC to maintain the programs like the Geraldine Ferraro Blood Cancer Program as a stand-alone program which would cease to exist under the proposed consolidation plan.

Conclusion

The IMF stands ready to work with policymakers to advance policies and support programs that work toward prevention and a cure for myeloma. Thank you for this opportunity to discuss the FY 2012 funding levels necessary to ensure that our nation continues to make gains in the fight against myeloma.

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ANSR AMERICANS FOR NURSING SHORTAGE RELIEF

Testimony of the Americans for Nursing Shortage Relief (ANSR) Alliance
Regarding Fiscal Year 2012 Appropriations for
Nursing Workforce Development Programs

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

April 15, 2011

The undersigned organizations of the ANSR Alliance greatly appreciate the opportunity to submit written testimony regarding fiscal year (FY) 2012 appropriations for the Title VIII Nursing Workforce Development Programs at the Health Resources and Services Administration (HRSA) and 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 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 Alliance, therefore, urges Congress to:

- **Appropriate $313 million in funding for Nursing Workforce Development Programs under Title VIII of the Public Health Service Act at the Health Resources and Services Administration (HRSA) in FY 2012.**
- **Appropriate $20 million in FY 2012 for the Nurse Managed Health Clinics as authorized under Title III of the Public Health Service Act.**

The Nursing Shortage

Nursing is the largest health care profession in the United States. According to the National Council of State Boards of Nursing, there were nearly 3.780 million licensed RNs in 2009. Nurses and advanced practice nurses (nurse practitioners, nurse midwives, clinical nurse specialists, and certified registered nurse anesthetists) work in a variety of settings, including primary care, public health, long-term care, surgical care facilities, and hospitals. 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, employment of registered nurses is expected to grow by 22 percent from 2008 to 2018, much faster than the average for all occupations and, because the occupation is very large, 581,500 new jobs will result. Based on these scenarios, the shortage presents an extremely serious challenge in the delivery of high quality, cost-effective services, as the nation looks to reform the current healthcare system. Even considering only the smaller projection of vacancies, this shortage still results in a critical gap in nursing service, essentially three times the 2001 nursing shortage.

The Desperate Need for Nurse Faculty

Nursing vacancies exist throughout the entire health care system, including long-term care, home care and public health. Even the Department of Veterans Affairs, the largest sole employer of RNs in the U.S., has a nursing vacancy rate of 10 percent. In 2006, the American Hospital Association

reported that hospitals needed 116,000 more RNs to fill immediate vacancies, and that this 8.1 percent vacancy rate affects hospitals' ability to provide patient care. Government estimates indicate that this situation only promises to worsen due to an insufficient supply of individuals matriculating in nursing schools, an aging existing workforce, and the inadequate availability of nursing faculty to educate and train the next generation of nurses. At the exact same time that the nursing shortage is expected to worsen, the baby boom generation is aging and the number of individuals with serious, life-threatening, and chronic conditions requiring nursing care will increase. Consequently, more must be done today by the government to help ensure an adequate nursing workforce for the patients/clients of today and tomorrow.

A particular focus on securing and retaining adequate numbers of faculty is essential to ensure that all individuals interested in – and qualified for – nursing school can matriculate in the year that they are accepted. The National League for Nursing found that in the 2009-2010 academic year,

- 42 percent of qualified applications to prelicensure RN programs were turned away.
- One in four (25.1 percent) of prelicensure RN programs turned away qualified applicants.
- Four out of five (60 percent) of prelicensure RN programs were considered "highly selective" by national college admissions standards, accepting less than 50 percent of applications for admission.

Aside from having a limited number of faculty, nursing programs struggle to provide space for clinical laboratories and to secure a sufficient number of clinical training sites at health care facilities.

ANSR supports the need for sustained attention on the efficacy and performance of existing and proposed programs to improve nursing practices and strengthen the nursing workforce. The support of research and evaluation studies that test models of nursing practice and workforce development is integral to advancing health care for all in America. Investments in research and evaluation studies have a direct effect on the caliber of nursing care. Our collective goal of improving the quality of patient care, reducing costs, and efficiently delivering appropriate health care to those in need is served best by aggressive nursing research and performance and impact evaluation at the program level.

The Nursing Supply Impacts the Nation's Health and Economic Safety

Nurses make a difference in the lives of patients from disease prevention and management to education to responding to emergencies. Chronic diseases, such as heart disease, stroke, cancer, and diabetes, are the most preventable of all health problems as well as the most costly. Nearly half of Americans suffer from one or more chronic conditions and chronic disease accounts for 70 percent of all deaths. In addition, increased rates of obesity and chronic disease are the primary cause of disability and diminished quality of life.

Even though America spends more than $2 trillion annually on health care -- more than any other nation in the world -- tens of millions of Americans suffer every day from preventable diseases like type 2 diabetes, heart disease, and some forms of cancer that rob them of their health and quality of life. In addition, major vulnerabilities remain in our emergency preparedness to respond to natural, technological and manmade hazards. An October 2008 report issued by Trust for America's Health, entitled "Blueprint for a Healthier America," found that the health and safety of Americans depend on the next generation of professionals in public health. Further, existing efforts to recruit and retain the public health workforce are insufficient. New policies and incentives must be created to

make public service careers in public health an attractive professional path, especially for the emerging workforce and those changing careers.

The Institute of Medicine report, *Hospital-Based Emergency Care: At the Breaking Point*, notes that nursing shortages in U.S. hospitals continue to disrupt hospitals operations and are detrimental to patient care and safety. Hospitals and other health care facilities across the country are vulnerable to mass casualty incidents themselves and/or in emergency and disaster preparedness situations. As in the public health sector, a mass casualty incident occurs as a result of an event where sudden and high patient volume exceeds the facilities resources. Such events may include the more commonly realized multi-car pile-ups, train crashes, hazardous material exposure in a building or within a community, high occupancy catastrophic fires, or the extraordinary events such as pandemics, weather-related disasters, and intentional catastrophic acts of violence.

Since 80% of disaster victims present at the emergency department, nurses as first receivers are an important aspect of the public health system as well as the healthcare system in general. The nursing shortage has a significant adverse impact on the ability of communities to respond to health emergencies, including natural, technological and manmade hazards.

Summary

The link between health care and our nation's economic security and global competitiveness is undeniable. Having a sufficient nursing workforce to meet the demands of a highly diverse and aging population is an essential component to reforming the health care system as well as improving the health status of the nation and reducing health care costs. To mitigate the immediate effect of the nursing shortage and to address all of these policy areas, **ANSR requests $313 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 2012.**

List of ANSR Member Organizations:

Academy of Medical-Surgical Nurses
American Academy of Ambulatory Care Nursing
American Academy of Nurse Practitioners
American Academy of Nursing
American Association of Critical-Care Nurses
American Association of Nurse Anesthetists
American Association of Nurse Assessment Coordinators
American Association of Nurse Executives
American Association of Occupational Health Nurses
The American College of Nurse-Midwives
American College of Nurse Practitioners
American Organization of Nurse Executives
American Psychiatric Nurses Association
American Society for Pain Management Nursing
American Society of PeriAnesthesia Nurses
American Society of Plastic Surgical Nurses
Association for Radiologic & Imaging Nursing
Association of Community Health Nursing Educators

Association of Pediatric Hematology/Oncology Nurses
Association of periOperative Registered Nurses
Association of State and Territorial Directors of Nursing
Association of Women's Health, Obstetric & Neonatal Nurses
Citizen Advocacy Center
Dermatology Nurses' Association
Developmental Disabilities Nurses Association
Emergency Nurses Association
Infusion Nurses Society
International Association of Forensic Nurses
International Nurses Society on Addictions
International Society of Nurses in Genetics, Inc.
Legislative Coalition of Virginia Nurses
National Association of Clinical Nurse Specialists
National Association of Hispanic Nurses
National Association of Neonatal Nurses
National Association of Neonatal Nurse Practitioners
National Association of Nurse Massage Therapists
National Association of Nurse Practitioners in Women's Health
National Association of Orthopedic Nurses
National Association of Pediatric Nurse Practitioners
National Association of Registered Nurse First Assistants
National Black Nurses Association
National Council of State Boards of Nursing
National Council of Women's Organizations
National Gerontological Nursing Association
National League for Nursing
National Nursing Centers Consortium
National Nursing Staff Development Organization
National Organization for Associate Degree Nursing
National Organization of Nurse Practitioner Faculties
National Student Nurses' Association, Inc.
Nurses Organization of Veterans Affairs
Pediatric Endocrinology Nursing Society
Preventive Cardiovascular Nurses Association
RN First Assistants Policy & Advocacy Coalition
Society of Gastroenterology Nurses and Associates, Inc.
Society of Pediatric Nurses
Society of Trauma Nurses
Women's Research & Education Institute
Wound, Ostomy and Continence Nurses Society

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Cystic Fibrosis Foundation
...adding tomorrows every day

Robert J. Beall, PhD, President and Chief Executive Officer
Cystic Fibrosis Foundation
(800) FIGHT CF, www.cff.org

On behalf of the Cystic Fibrosis Foundation and the 30,000 Americans with cystic fibrosis (CF), we are pleased to submit the following testimony with our requests for Fiscal Year 2012 Labor, Health and Human Services, and Education Appropriations

ABOUT CYSTIC FIBROSIS

Cystic fibrosis is a life-threatening genetic disease for which there is no cure. People with CF have two copies of a defective gene, known as CFTR, which causes the body to produce abnormally thick, sticky mucus that clogs the lungs and results in fatal lung infections. The thick mucus in those with CF also obstructs the pancreas, making it difficult for patients to absorb nutrients from food.

Since its founding, the CF Foundation has maintained its focus on promoting research and improving treatments for CF. More than 30 drugs are now in development to treat CF; some treat the basic defect of the disease, while others target its symptoms. Through the research leadership of the Cystic Fibrosis Foundation, people with CF are living into their 30s, 40s and beyond. This improvement in the life expectancy for those with CF can be attributed to research advances and to the teams of CF caregivers who offer specialized care. Although life expectancy has improved dramatically, we continue to lose young lives to this disease.

The promise for people with CF lies in research. In the past six years, the Cystic Fibrosis Foundation has invested over $1 billion in its medical programs of drug discovery, drug development, research, and care focused on life-sustaining treatments and a cure for CF. A greater investment is necessary, however, to accelerate the pace of discovery and development of CF therapies.

SUSTAINING THE FEDERAL INVESTMENT IN BIOMEDICAL RESEARCH

This Committee and Congress are to be commended for their support for biomedical research through the years. It is vital that we continue to sufficiently fund the NIH, so that it can capitalize on scientific advances and maintain the momentum generated by the doubling of funds and the infusion from the American Recovery and Reinvestment Act (ARRA). These increases in funding brought a new era in drug discovery that has benefited all Americans.

Cutting discretionary health spending by 13.5 percent, as has been proposed, would halt this progress. Deep cuts would have a detrimental effect on the fight against many of our most serious diseases, stifle scientific opportunities, and result in high-wage job loss in all 50 states. In 2007, NIH grants and contracts created and supported more than 350,000 jobs across the United States, an important contribution to the American economy.

We urge this Committee and Congress to maintain robust investment in biomedical research at the NIH so it can fund critical research today that will provide the care and cures of tomorrow.

STRENGTHENING CLINICAL RESEARCH AND DRUG DEVELOPMENT

The Cystic Fibrosis Foundation has been recognized for its unique research approach, which encompasses everything from basic research through Phase 4 post-marketing monitoring of drug safety, and has created the infrastructure required to accelerate the development of new CF therapies. As a result, we now have a pipeline of more than 30 potential therapies that are being examined to treat people with CF.

One such treatment is VX-770, a drug being developed by Vertex Pharmaceuticals that was discovered in collaboration with CFF. This promising therapy targets the physiological defect that causes CF in patients with a particular type of genetic mutation, as opposed to only addressing symptoms of the disease. In late February 2011 we learned that Phase 3 clinical trial data of VX-770 showed profound improvements in lung function and other health measures in CF patients, and a New Drug Application is expected to be submitted to the FDA for review later this year. This new treatment is a direct result of the Foundation's innovative research agenda, advancing from bench to bedside through the Foundation's research program which speeds the creation of new CF therapies.

The Foundation is a leader in creating a clinical trials network to achieve greater efficiency in clinical investigation. Because the CF population is small, a higher proportion of people with the disease must partake in clinical trials than in most other diseases. This unique challenge prompted the Foundation to streamline our clinical trials processes. As a result, research conducted by the Foundation is more efficient than ever before and we are a model for other disease groups.

While the CF Foundation has made great progress in creating a more efficient drug development process for cystic fibrosis, still more needs to be done for other rare diseases, many of which have no treatments available. The federal government has the opportunity to make a real difference in this regard, and we are hopeful that the Committee will direct the national health agencies to encourage all investigators and institutions receiving federal funding to advance novel methodologies and mechanisms for translating basic research into therapies that can benefit patients.

Advancing Translational Science

The CF Foundation strongly urges this Committee and Congress to support funding for NIH's proposed National Center for Advancing Translational Sciences (NCATS), which will house the Institutes' existing translational science programs while establishing and providing a more focused, integrated, and systematic approach for linking basic discovery to therapeutic development.

The existing programs to be housed under NCATS are integral to translating basic science into treatments and will benefit from funding for the new center. These programs include Clinical and Translational Science Awards (CTSA), discussed in further detail below, and the newly authorized Cures Acceleration Network (CAN), both designed to transform the way in which clinical and translational research is conducted and funded. The Therapeutics for Rare and Neglected Diseases (TRND) program will also be

housed in the new center. NIH Director Collins has specifically cited the Cystic Fibrosis Foundation's Therapeutics Development Network (TDN), which plays a pivotal role in accelerating the development of new treatments for cystic fibrosis patients, as an exemplar for TRND's innovative therapeutics development model.

The Foundation's investment in pharmaceutical and biotech companies can also serve as a model for the new center's overall mission. NCATS, like CFF, will promote public-private partnerships and convene cross-sector collaborations between industry, government, academia, and others to advance drug development, as well as provide services and resources for high throughput screening, assay development, and preclinical modeling. Prioritizing these initiatives through a standalone center at NIH has the potential to greatly accelerate the development of drugs for diseases that have historically received little pharmaceutical industry attention. In addition, integrating translational science programs from throughout NIH into one center will help bring greater efficiency to the Institutes' pursuit of this important research. Once again, we applaud NIH Director Collins for spearheading NCATS and look forward to working with him as this new initiative is implemented.

Clinical and Translational Science Awards (CTSA)

The CTSA program, soon to be housed in NCATS, encourages novel approaches to clinical and translational research, enhances the utilization of informatics, and strengthens the training of young investigators. Key to the success of CTSAs is the parallel maintenance of infrastructure support for Clinical Research Centers (CRC). Without a mechanism to offset clinical research costs, young investigators or Principle Investigators (PIs) studying rare diseases for which there is limited funding will not be able to continue to conduct clinical research. It is important that all NIH institutes recognize that there is a significant cost associated with the conduct of well designed and safe clinical trials, and not all of these costs can be borne by the CTSAs. Congress should direct the NIH to cover costs that used to be borne by the General Clinical Research Centers (GCRCs) through individual research grants.

Support should also be directed toward the continuation and expansion of research networks, such as NIH's pediatric liver disease consortium at the National Institute of Diabetes, Digestive, and Kidney Diseases (NIDDK). This successful collaboration is helping researchers discover treatments not only for CF liver disease but for other diseases that affect thousands of children each year.

SUPPORTING DRUG DISCOVERY

The Cystic Fibrosis Foundation's clinical research is fueled by a vigorous drug discovery effort comprised of early stage translational research into successful treatments for this disease. Several research projects at the NIH will expand our knowledge about the disease, and could eventually be the key to controlling or curing cystic fibrosis.

Opportunities in Animal Models

The Cystic Fibrosis Foundation is encouraged by the NIH's investment in a research program at the University of Iowa to study the effects of CF in a pig model. The program, funded through research awards from both the National Heart, Lung, and Blood

Institute (NHLBI) and the Cystic Fibrosis Foundation, bears great promise to help make significant developments in the search for a cure. While a company has been established to produce the animals, the infrastructure and extensive animal husbandry required to keep the animals alive and conduct research on them is available at few academic institutions. Such barriers have greatly limited widespread adoption of these valuable research tools. We urge additional funding to create a common facility that would enable researchers from multiple institutions to conduct research with these models.

Understanding CFTR Folding and Trafficking

The data that emerged from the VX-770 Phase 2 and 3 clinical trials, discussed above, is proof that the way in which this drug targets the physiological defect that causes CF, called CFTR protein function modulation, is a viable therapeutic approach. However, this exciting data was obtained from patients with a specific CF mutation which affects only approximately 4 percent of CF patients. More research is needed to understand other genetic mutations, the most common of which is called F508del. F508del causes multiple negative effects, including misfolding and poor activation properties of the CFTR protein. We encourage the Committee to increase investment in genetic research that can help scientists to better understand the F508del mutation. This will facilitate CF drug discovery and has the potential to benefit not just those with cystic fibrosis, but also those with other protein misfolding diseases.

Personalized Medicine

Strong federal and private investment in research is bringing personalized medicine into the forefront. As we gain a deeper understanding of many diseases and their accompanying genetic profiles, we understand the great challenge of personalizing therapies. While exciting and promising for patients, it is also expensive, complex, and scientifically challenging. For instance, CF doctors are facing difficulties in delivering appropriate care to CF patients, as insurance providers will not cover certain combinations of medicines that clinicians have found are effective for cystic fibrosis in particular when there is no formal clinical data to support it. This puts patients in a difficult position, as these clinical trials are expensive and unlikely to be performed by pharmaceutical companies, especially for treatment of a small, targeted population. As such we urge the Committee to provide sustained federal investment in personalized medicine, to help move this burgeoning field forward and advance exciting scientific discoveries.

SUPPORTING GREATER ACCESS TO QUALITY HEALTH CARE

We are making remarkable strides in our fight against cystic fibrosis, but people who live with it face greater obstacles each year, as high medical costs can prevent them from accessing appropriate medical care. Health care for a CF patient costs $64,000 per year on average, 15 times more than that of the average person. Because of high costs, nearly a quarter of CF patients delay getting medical care or skip treatments their providers recommend to enhance and lengthen their life.

The Foundation sees some promise in a number of provisions in the new health care reform law that increase access to health insurance coverage for those with rare and chronic diseases, a critical tool in decreasing out of pocket costs for patients. These provisions include those allowing children to remain on their parents' insurance until they are 26; prohibiting insurance companies from denying or rescinding coverage based on a pre-existing condition; banning annual and lifetime caps on coverage; and the expansion of Medicaid eligibility.

The new law is not perfect, however, and we are concerned that while the provisions listed above will ensure continuity of coverage and greater access to care for those with CF and other chronic diseases, more must be done to reduce the financial burden so many families face in affording their care, especially in these challenging economic times.

While we urge Congress to explore new options to help make care more affordable and reduce shifting costs to patients, we ask that provisions that have the potential to provide desperately needed relief to people with cystic fibrosis be retained, and that they are sufficiently funded so that those with rare and chronic diseases can access the care they need.

In addition, the Foundation wishes to applaud the formation of the Patient Centered Outcomes Research Institute (PCORI) and urges the Committee to support this important entity. PCORI, a private non-profit institute created by the Patient Protection and Affordable Care Act, will support and direct research that gives patients, doctors, and others the information they need make informed decisions about the most effective and appropriate methods for preventing and treating health conditions. The CF Foundation has had great success in improving quality of care for cystic fibrosis patients through the development and administration of a comprehensive patient registry and the collection of comprehensive data on outcomes and practice patterns for use in comparative effectiveness research, and we are confident that dedicating a national institute to such pursuits will improve care for all Americans.

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The Cystic Fibrosis Foundation has devoted our own resources to developing treatments through drug discovery, clinical development, and clinical care. Several of the drugs in our pipeline show remarkable promise in clinical trials and we are increasingly hopeful that these discoveries will bring us even closer to a cure. However, sufficient investment in basic science, translational science, clinical research, and drug development programs at NIH is needed to continue these successes not only for CF but for all rare diseases. Additionally, funding for programs that promote access and quality of care will help achieve a greater quality of life for those living with chronic diseases like cystic fibrosis.

We urge the Committee to consider these factors as you craft the Fiscal Year 2012 Labor, Health and Human Services, and Education Appropriations legislation, and stand ready to work with NIH and Congressional leaders on the challenging issues ahead. Thank you for your consideration.

5

STATEMENT FROM THE

AMERICAN GERIATRICS SOCIETY

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

HOUSE APPROPRIATIONS COMMITTEE
UNITED STATES HOUSE OF REPRESENTATIVES

ON TITLE VII GERIATRICS HEALTH PROFESSIONS PROGRAMS, TITLE VIII COMPREHENSIVE GERIATRIC EDUCATION NURSING PROGRAM & THE NATIONAL INSTITUTE ON AGING

APRIL 15, 2011

Mr. Chairman and Members of the Subcommittee:

We are writing 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 begins to work on its fiscal year (FY) 2012 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.**

Continued Federal investments are needed to support the training of the health 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. While we fully recognize the fiscal challenges facing our nation, we also recognize that sustained and enhanced federal investments in these initiatives are essential to delivering higher quality and better coordinated care to our nation's seniors.

We ask that the subcommittee consider the following recommended funding levels for these programs in FY 2012:

- **$46.5 million for Title VII Geriatrics Health Professions Programs**
- **$5 million for Title VIII Comprehensive Geriatric Education Nursing Program**
- **$1.4 billion for the National Institute on Aging**

Summarized and broken down below are the American Geriatrics Society's funding priorities in these areas for FY 2012.

PROGRAMS TO TRAIN GERIATRICS HEALTH CARE PROFESSIONALS

This year, the first wave of baby boomers turn 65, signaling the start of a significant demographic shift in America's population. According to the Institute of Medicine's (IOM) ground-breaking 2008 report, *Retooling for an Aging America: Building the Healthcare Workforce*, America's health care workforce is woefully ill-prepared to care for the growing and unprecedented number of seniors, especially those with multiple chronic and complex medical conditions.

Our nation is facing a critical shortage of geriatrics faculty and health care professionals across disciplines. At the same time, the Title VII and VIII geriatrics programs under the Public Health Service Act have remained essentially level-funded since FY 2007 and in each subsequent year the geriatrics programs have received an even smaller percentage of funding provided to Title VII and VIII programs.

This trend must be reversed if we are to provide our seniors with the quality care they need and deserve. AGS believes it is critical that Congress increase the percentage of Title VII and VIII funding that is devoted to supporting increasing the capacity of America's health care workforce to care for older adults. Care provided by geriatric health care professionals, who understand the most complex cases and the most frail elderly, has shown to reduce those common and costly conditions that are often preventable with appropriate care, such as falls, polypharmacy, and delirium.

Title VII Geriatrics Health Professions Programs ($46.5 million)

Funding for Title VII Geriatrics Health Professions Programs is a proven investment in ensuring that older adults receive high quality health care now and in the future. These programs support three initiatives: the Geriatric Academic Career Awards (GACAs), the Geriatric Education Center (GEC) program, and

geriatric faculty fellowships, the only programs specifically designed to address the evident shortage of geriatrics health care professionals in the U.S. Strong and sustained investments are important to reversing the chronic under-funding of these essential programs at a time when our nation is facing a critical shortage of geriatrics health care professionals across disciplines. **We ask the subcommittee to provide a FY 2012 appropriation of $46.5 million for Title VII Geriatrics Health Professions Programs.**

Our funding request of $46.5 million breaks down as follows:

- **Geriatric Academic Career Awards (GACAs) ($5.3 million)**
  GACAs support the development of newly trained geriatric physicians in academic medicine who are committed to teaching geriatrics in medical schools across the country. GACA recipients are required to provide training in clinical geriatrics, including the training of interdisciplinary teams of health care professionals. Under ACA, GACAs have been expanded to a variety of new disciplines beyond physicians, including those in nursing, social work, psychology, dentistry, and pharmacy. AGS has long advocated for this change. We must now ensure that there is adequate funding to meet the increased demand given the greater number of disciplines eligible for the award. A budget of $5.3 million would support 68 awardees at $78,000 per award.

  Program Accomplishments: In Academic Year 2009-2010, there were 84 non-competing continuation awards. GACA awardees provided interdisciplinary training in geriatrics training to about 60,000 health professionals. These awardees provided culturally competent quality health care to over 525,000 underserved and uninsured patients in acute care services, 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. Under ACA, Congress authorized $10.8 million over three years for a supplemental grant award program that will train additional faculty through an intensive short-term fellowship program and also requires faculty to provide training to family caregivers and direct-care workers. Our funding request of $22.7 million includes continued support for the core work of 45 GECs and for up to 24 GECs to be funded to undertake the work through the supplemental grant program.

  Program Accomplishments: In Academic Year 2009-2010, the GEC grantees provided clinical training to 54,167 health professional students and to 20,791 interdisciplinary teams in multiple settings.

- **Geriatric Training Program for Physicians, Dentists, and Behavioral and Mental Health Professions ($8.5 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 $8.5 million will allow 13 institutions to continue this important faculty development program.

  Program Accomplishments: In Academic Year 2009-2010, 11 non-competing continuation grants were supported. Forty-nine physicians, dentists, and psychiatric fellows provided geriatric care to

20,078 older adults across the care continuum. Geriatric physician fellows provided health care to 12,254 older adults. Geriatric dental fellows provided health care to 4,073 older adults. Geriatric psychiatry fellows provided health care to 3,751 older adults.

- **Geriatric Career Incentive Awards Program ($10 million)**
  This is a new grant award program created under ACA to foster greater interest among a variety of health professionals in entering the field of geriatrics, long-term care, and chronic care management. AGS supports the President's FY 2012 request of $10 million to implement this new program.

Title VIII Comprehensive Geriatric Education Nursing Program ($5 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. Increasing funding for the nursing comprehensive geriatric education program would be highly cost-effective. This program supports additional training for nurses who care for the elderly, development and dissemination of curricula relating to geriatric care, and training of faculty in geriatrics. It also provides continuing education for nurses practicing in geriatrics.

Under the new health reform law, this program is being expanded to include advanced practice nurses who are pursuing long-term care, geropsychiatric nursing or other nursing areas that specialize in the care of older adults. Our funding request of $5 million includes funds to continue the training of nurses caring for older Americans and offers 200 traineeships to nurses under this newly expanded program.

Program Accomplishments: In Academic Year 2009-2010, 27 CGEP grantees provided education and training to 3,030 Registered Nurses/Registered Nursing Students; 260 Advanced Practice Nurses; 221 Faculty; 110 Home Health Aides; 483 Licensed Practical/Vocational Nurses & LPN students; 730 Nurse Assistants/Patient Care Associates; 810 Allied Health Professionals and 929 lay persons, guardians, activity directors. The CGEP grantees provided 459 educational course offerings in the care of the elderly on a variety of topics to 6,846 participants.

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. Robust medical research in aging is critical to the development of medical advances which will ultimately lead to higher quality and more efficient health care. 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 2012.** Alternatively, in light of our nation's immediate budget constraints, we request that that the NIA be funded at no less than $ 1.29 billion, as requested in the President's FY 2012 budget.

According to the Congressional Research Service, in FY 2003, NIH reached the peak of its purchasing power from regular appropriations when Congress completed a five-year doubling of the NIH budget. In each year since then, NIH's buying power has declined because its annual appropriations have grown at a lower rate than the inflation rate for medical research.

Essentially flat funding of NIH since 2003 has additionally led to declining numbers of young investigators choosing research careers, given the scarcity of funding to support their career development. We must provide the resources and tools to support the next generation of investigators and expand the pool of clinical researchers focused on advancing aging research.

The ongoing Federal commitment to investments in science, research, and technology lead to cutting-edge breakthroughs in medicine and improved patient care. AGS urges Congress to maintain this commitment in FY 2012 and beyond, so that we may continue to advance medicine to improve the quality of care of our nation's older adults and the long-term goals of health reform can be fully achieved.

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.

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United States House Appropriations Subcommittee on Labor, Health and Human Services, and Education

Public Witness Testimony for the Record Regarding FY 2012 funding levels for programs of interest to U.S. colleges and schools of pharmacy

AACP and its member colleges and schools of pharmacy appreciate the continued support of the U.S. House of Representatives Appropriations Subcommittee on Labor, Health and Human Services, and Education. Our nation's 124 accredited colleges and schools of pharmacy are engaged in a wide-range of programs supported by grants and funding administered through the agencies of the Department of Health and Human Services (HHS) and the Department of Education. We also understand the difficult task you face annually in your deliberations to do the most good for the nation and remain fiscally responsible to the same. AACP respectfully offers the following recommendations for your consideration as you undertake your deliberations.

US DEPARTMENT OF HEALTH AND HUMAN SERVICES SUPPORTED PROGRAMS AT COLLEGES AND SCHOOLS OF PHARMACY

Agency for Healthcare Research and Quality (AHRQ)

AACP supports the Friends of AHRQ recommendation of $405 million for AHRQ programs in FY12.

Pharmacy faculty are strong partners with the Agency for Healthcare Research and Quality (AHRQ).

- Vincent J. Willey, Associate Professor at the University of the Sciences in Philadelphia, was appointed to the Comparative Effectiveness Research Pharmacy Workgroup.
- AHRQ Effective Healthcare programs including the Center for Education and Research on Therapeutics (CERTs) and the Developing Evidence to Inform Decisions about Effectiveness (DEcIDE) support pharmacy faculty researchers focused on improving the effectiveness of healthcare services.
- Researcher faculty at The University of Arizona College of Pharmacy's Center for Health Outcomes and PharmacoEconomic Research, support the Arizona CERT and its mission to improve therapeutic outcomes and reduce adverse events caused by drug interactions and drugs that prolong the QT interval, especially those affecting women. Researchers determined that certain drug combinations increased the risk of death. Published research from this CERT includes the 2010 *Women's Health Research: Progress, Pitfalls and Promise*, for the Institute of Medicine and a comparison study on the US Department of Veterans Affairs drug-drug interactions compared to two standard compendia. #U18 HS17001

- Almut G. Winterstein, University of Florida, has received a two-year $482,000 award from the Agency for Healthcare Research and Quality for "Comparative Safety and Effectiveness of Stimulants in Medicaid Youth with ADHD." #5R01HS018506-02
- Sean D. Sullivan, University of Washington, received a $2.45 million grant from AHRQ to implement the multidisciplinary Mentored Clinical Scientist Comparative Effectiveness Research Career Development (K12) Program in collaboration with research partners at Group Health Research Institute, the Fred Hutchinson Cancer Research Center, and the Veterans' Administration Health Services Research and Development Center of Excellence. #1K12HS019482-01
- Daniel C. Malone, University of Arizona, received a three-year grant from AHRQ for $1.25 million, to evaluate awareness of CER guides by pharmacists and physicians and identify critical skills needed to use these reviews to support and encourage safe and effective prescribing of medications. #1R18HS019220-01

Centers for Disease Control and Prevention (CDC)

AACP supports the CDC Coalition recommendation of $7.7 billion for CDC core programs in FY12 and the Friends of NCHS recommendation of $162 million for the National Center for Health Statistics.

The educational outcomes of a pharmacist's education include those related to public health. When in community-based positions, pharmacists are frequently providers of first contact. The opportunity to identify potential public health threats through regular interaction with patients provides public health agencies such as the CDC with on-the-ground epidemiologists. Pharmacists support the public health system through risk identification of patients seeking medications associated with preventing and treating travel-related illnesses. Pharmacy faculty are engaged in CDC-supported research in areas such as immunization delivery, integration of pharmacogenetics in the pharmacy curriculum and inclusion of pharmacists in emergency preparedness. Information from the National Center for Health Statistics (NCHS) is essential for faculty engaged in health services research and for the professional education of the pharmacist.

- Katie J. Suda, faculty member at the University of Tennessee, was supported by CDC funding to conduct a national analysis of outpatient anti-infective prescribing patterns. She also prepared a continuing education program in partnership with the CDC entitled, "Weighing in on Antibiotic Resistance: Community Pharmacists Tip the Scale," featured on the CDC Web site: http://www.cdc.gov/getsmart/specific-groups/hcp/ce-course.html. The program details the CDC's Get Smart program, focused on decreasing the amount of unnecessary antibiotics in the community.
- Grace Kuo, Associate Professor of Clinical Pharmacy at the University of California San Diego, founded PharmGenEd™, an evidence-based pharmacogenomics education program designed for pharmacists and physicians, pharmacy and medical students, and other healthcare professionals and is supported by funding from CDC. #IU38GD000070

Health Resources and Services Administration (HRSA)

AACP supports the Friends of HRSA recommendation of $7.65 billion for FY12.

HRSA is a federal agency with a wide-range of policy and service components. Faculty at colleges and schools of pharmacy are integral to the success of many of these. Colleges and schools of pharmacy are the administrative units for interprofessional and community-based linkages programs including geriatric education centers and area health education centers.

Pharmacy faculty research issues related to rural health delivery. Student pharmacists benefit from diversity program funding including Scholarships for Disadvantaged Students.

Office of Pharmacy Affairs

AACP recommends a program funding of $5 million for FY12 for the Office of Pharmacy Affairs.

AACP member institutions are actively engaged in Office of Pharmacy Affairs (OPA) efforts to improve the quality of care for patients in federally-qualified health centers and entities eligible to participate in the 340B drug discount program. The success of the HRSA Patient Safety and Clinical Pharmacy Collaborative is a direct result of past OPA actions linking colleges and schools of pharmacy with federally-qualified health centers. The result of these links has been the establishment of medical homes that improve health outcomes for underserved and disadvantaged patients through the integration of clinical pharmacy services. The Office of Pharmacy Affairs would benefit from a direct line-item appropriation so that public-private partnerships aimed at improving the quality of care provided at federally qualified health centers can be sustained and expanded.

Office of Telehealth Advancement

Technology is an important component for improving healthcare quality and maintaining or increasing access to care. Colleges and schools of pharmacy utilize technology to increase access to care, improve care quality and to increase the reach of education to student and practicing pharmacists.

- Keri H. Naglosky, Marcia M. Worley, Timothy P. Stratton and Randall D. Seifert University of Minnesota, received a $63,000 grant for their study, "Pilot Study to Determine the Effectiveness of Pharmacist Provided MTM Using Face-to-Face and TeleMTM in the Treatment of Long-Haul Drivers with Hypertension Department of Transportation Classifications Stage 1, 2 and 3."
- Leigh Ann Ross and Sarah Fontenot, faculty at the University of Mississippi, work with The Delta Health Alliance on many projects including its HRSA telehealth grant and as members of the HRSA Patient Safety Collaborative, receiving the Clinical Pharmacy Services Improvement Award in 2010. Five Delta hospitals have telemedicine capabilities as a result of its funding and 86,083 individuals received medical or health education services during the 2009-2010 fiscal year. #H2AIT16626

Poison Control Centers

HRSA grant funding supports the management of ten of the 57 poison control centers by pharmacy faculty.

- In 2010, the Maryland Poison Center, headed by Bruce Anderson, faculty at the University of Maryland, answered ~36,000 human exposure calls, ~2,000 animal exposures and ~25,000 requests for poison or drug information and over 70% of the human exposure calls were managed on site, avoiding treatment at a health care facility. This year, Paul Starr, also at the University of Maryland, was recognized for his 20 years as a certified specialist in poison information. #H4BHS15526

Bureau of Health Professions (BHPr)

AACP supports the Health Professions and Nursing Education Coalition (HPNEC) recommendation of $762.5 million for Title VII and VIII programs in FY12.

AACP member institutions are active participants in BHPr programs. Two colleges of pharmacy are current grantees in the Centers of Excellence program (Xavier University School of Pharmacy). This program focuses on increasing the number of underserved

individuals attending health professions institutions. Colleges and schools of pharmacy are also part of Title VII interprofessional and community-based linkages programs including Geriatric Education Centers and Area Health Education Centers. These programs are essential for creating the educational approaches necessary for the Institute of Medicine's recommendations of improving quality through team-based, patient-centered care and serve as valuable experiential education sites for student pharmacists.

- Gayle A. Hudgins, faculty at the University of Montana, was awarded an ARRA supplement of $132,446 from HRSA, Bureau of Health Professions, for equipment to enhance training for health professionals.

Food and Drug Administration (FDA)

AACP recommends a funding level of $3.7 billion for FDA programs in FY12.

The FDA sees the colleges and schools of pharmacy as essential partners in assuring the public has access to a healthcare professional well versed in the science of safety. Pharmacy faculty partner with the FDA to improve the drug manufacturing process through the National Institute for Pharmaceutical Technology and Education (NIPTE) and increase the science-base for decisions regarding drug and device safety and effectiveness.

- Dianne M. Cappelletty, Associate Professor at The University of Toledo, was recently appointed to serve on the advisory committee to the Division of Anti-Infective and Ophthalmology Products.
- James E. Polli, University of Maryland, received $1,099,990 from the FDA for "Pharmacokinetic Studies of Epileptic Drugs: Evaluation of Brand & Generic Antiepileptic Drug Products in Patients."
- Michael J. Pikal, University of Connecticut, is a recipient of $19,899 from the FDA-supported National Institute of Pharmaceutical Technology and Education (NIPTE) for Qbd Lyophilized Protein Parenteral Manufacturing Processes
- A team of researchers led by Dr. Margaret O. James, professor and chair of medicinal chemistry at the University of Florida College of Pharmacy, has discovered that the chemical triclosan hinders an enzyme linked to the metabolism of estrogen and future research may show its relationship in pregnancy complications.

National Institutes of Health (NIH)

AACP supports the Ad Hoc Group for Medical Research recommendation of $34.7 billion for FY12.

Pharmacy faculty are supported in their research by nearly every institute at the NIH. The NIH-supported research at AACP member institutions spans the research spectrum from the creation of new knowledge through the translation of that new knowledge to providers and patients. In 2010, pharmacy faculty researchers received more than $358 million in grant support from the NIH. AACP member institutions are concerned, as are other health professions education organizations, of the need to increase the number of biomedical researchers.

- At the University of California, San Francisco, Kathleen M. Giacomini and co-lead Deanna L. Kroetz received $15.1 million in funding over the next five years from the NIH for research into the genetics behind membrane transporters and a branch project from that research that will focus on the genetic factors that determine responses to the anti-diabetic drug, metformin in African American patients with type 2 diabetes. #2U19GM061390-11

- Michael J. Katovich, faculty at the University of Florida, was awarded a $2.5 million, five-year award from the National Heart, Lung and Blood Institute for "ACE2 in Vascular Endothelial Function." #2R01HL056921-15
- Alice M. Clark and Ameeta K. Agarwal, University of Mississippi, received $388,221 from the National Institute of Allergy and Infectious Diseases to study New Drugs for Opportunistic Infections. #5R01AI027094-21
- John J. Lawrence, faculty at The University of Montana, received $1,713,300 from NIH to study "Differential Modes of Cholinergic Transmission onto Cellular Hippocampal Targets." #1R01NS069689-01A1
- Eugene D. Morse, the University at Buffalo, received two grants: $952,000 in funding for, "Clinical Pharmacology Quality Assurance and Quality Control" funded by the National Institute of Allergies and Infectious Diseases/Division of AIDS and $2.3 Million for, "Clinical Pharmacology Lab from NIH to Promote HIV Research in Africa." #272200800019C-4-0-1
- Jordan K. Zjawiony and Charles L. Burandt, the University of North Carolina, received $71,500 from the NIH to study Chemistry and Pharmacology of Newly Emerging Psychoactive Plants-Year 2. #5R03DA023491-02

US DEPARTMENT OF EDUCATION SUPPORTED PROGRAMS AT COLLEGES AND SCHOOLS OF PHARMACY

AACP supports the President's request for:

1. **Pell Grant maximum be maintained at $5550**
2. **Gaining Early Awareness and Readiness for Undergraduate Programs (GEAR UP) should be funded at $3.23 million**

AACP recommends a funding level of $160 million for the Fund for the Improvement of Post Secondary Education (FIPSE).

The Department of Education supports the education of healthcare professionals by:

- assuring access to education through student financial aid programs;
- supporting educational research allows faculty to determine improvements in educational approaches; and
- maintaining the oversight of higher education through the approval of accrediting agencies.

AACP actively supports increased funding for undergraduate student financial assistance programs. Admission to into the pharmacy professional degree program requires at least two years of undergraduate preparation. Student financial assistance programs are essential to assuring colleges and schools of pharmacy are accessible to qualified students. Likewise, financial assistance programs that support graduate education are an important component meeting our nation's need for scientists and educators.

Infectious Diseases Society of America's (IDSA)
Statement Concerning Fiscal Year 2012 Funding at the Department of Health and Human Services, the Centers for Disease Control and Prevention, and National Institutes of Health

Submitted to the House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies

April 15, 2011

The Infectious Diseases Society of America (IDSA) appreciates this opportunity to speak in support of federal efforts to prevent, detect and respond to infectious diseases in the United States and abroad as part of the Fiscal Year (FY) 2012 funding cycle. IDSA represents more than 9,300 infectious diseases physicians and scientists devoted to patient care, prevention, public health, education, and research. Our members care for patients of all ages with serious infections, including meningitis, pneumonia, tuberculosis (TB), antibiotic-resistant bacterial infections such as methicillin-resistant *Staphylococcus aureus* (MRSA) and drug-resistant gram-negative bacterial infections, and emerging infections like the 2009 H1N1 influenza virus.

Although IDSA supports strong funding levels for infectious diseases efforts within each federal agency, the growing crisis in antibiotic resistance that is occurring in the United States (US) and globally has led IDSA to focus our testimony this year on funding for this issue alone.

The Antibiotic Resistance Crisis

The past approaches our society has employed to manage antibiotic development and their uses are now failing. Bacterial infections are becoming increasingly resistant to existing antibiotics, and, ironically, as the number of patients succumbing to these infections rises, the number of new antibiotics in development is plummeting. Remarkably, in 1990, there were nearly 20 pharmaceutical companies with large antibiotic research and development (R&D) programs. Today, alarmingly, there are only two large companies with strong and active programs, and only a small number of companies have more limited programs. As a nation, we have an obligation to our children and grandchildren to create a sustainable global antibiotic R&D enterprise that will produce these precious drugs in perpetuity and to invest in new ways to protect their effectiveness once approved.

The discovery of antibiotics in the 1930s fundamentally transformed the way physicians care for patients, shifting their approach from a focus on diagnosis without means to intervene to a treatment-focused approach that saves lives. Seven decades of medical advances enabled by antibiotics are now seriously threatened. Without effective antibiotics, diverse fields of medicine will be severely hampered, including surgery, the care of premature babies, cancer chemotherapy, care of the critically ill, and transplantation medicine, all of which are feasible only in the context of effective antibiotic therapy.

The antibiotic pipeline is bare particularly for drugs needed to address antibiotic-resistant bacteria. Collectively, highly problematic antibiotic-resistant organisms are summarized by the ESKAPE mnemonic: *Enterococcus, Staphylococcus, Klebsiella, Acinetobacter, Pseudomonas,* and *ESBL* (*Enterobacter* and *E. coli*). These bacteria have developed defenses that permit them to escape the actions of available antibiotics. The ESKAPE pathogens are currently the most

important causes of the antibiotic resistance crisis in the US and other developed countries. Such pathogens also are spreading through developing countries, which already are experiencing significant public health problems from extreme drug-resistant and pan drug-resistant TB and HIV/AIDS.

We are at risk not only from health care-associated and community-acquired antibiotic-resistant infections, but from threats (bioterrorism, pandemics) that could affect our nation's security. The longer we wait to invest in and implement solutions the harder and more expensive it will be to solve these problems. The time to act is *now*. On April 7, 2011, IDSA issued a new policy paper entitled "Combating Antimicrobial Resistance: Policy Recommendations to Save Lives" (http://cid.oxfordjournals.org/content/52/suppl_5/S397.full.pdf) to address this global public health and national security threat through policy strategies in eight broad areas of focus. (See Table 2 in that paper for a comprehensive list of IDSA supported funding recommendations, which we are unable to fully describe in this testimony.) The US Government must act immediately to: 1) adopt economic incentives and support other collaborative mechanisms to address the antibiotic market failure by rekindling antibiotic R&D; 2) create new regulatory approaches to facilitate the clinical development of antimicrobials; 3) more effectively coordinate federal antimicrobial resistance efforts; 4) enhance antimicrobial resistance surveillance and data collection; 5) strengthen activities to prevent and control antimicrobial resistance; 6) strengthen investments in antimicrobial-focused research; 7) strengthen investment in development and utilization of rapid molecular diagnostics for infectious diseases; and 8) eliminate non-judicious antibiotic use in agriculture and other settings.

In particular, investments for antibiotic resistance activities within the Department of Health and Human Services (HHS) and its related agencies, including for the Office of the Assistant Secretary for Preparedness and Response (ASPR), Biomedical Advanced Research and Development Authority (BARDA), Centers for Disease Control and Prevention (CDC), National Institutes of Health (NIH) and other agencies must be robust and fully funded.

Adopt Incentives and Support Collaborative Efforts that Yield Novel Antibiotics

To create a sustainable, national and global antibiotic R&D enterprise, it is necessary to identify and invest in the right combination of financial incentives ("push" and "pull" mechanisms) that will entice companies to reenter this product R&D area and to help companies, big and small, with innovative technologies to succeed. These incentives are intended to change the "return on investment" or net present value calculation of antibiotics to make them more competitive with other medical products. The Independent Strategic Investment Firm proposed by the HHS Secretary as part of ASPR's Public Health Emergency Medical Countermeasures Enterprise (PHEMCE) review is a good first step in this direction. ***IDSA calls for at least $200 million to support ASPR's proposed strategic investment firm to leverage antibiotic venture capital investments. In addition, we support an allocation of at least $1.7 billion of multi-year funding for BARDA to facilitate advanced development of therapeutics, diagnostics, vaccines, and other technologies, including new antibiotics and diagnostics to treat and detect infections caused by ESKAPE and other serious and life-threatening pathogens.***

Strengthen Coordination of Federal Agencies' Antibiotic Resistance Efforts

Federal agencies with programs related to antibiotic resistance, antimicrobial stewardship, and product R&D include: CDC, NIH, the Food and Drug Administration (FDA), ASPR, BARDA,

the Centers for Medicare and Medicaid Services (CMS), Agency for Healthcare Research and Quality (AHRQ), Health Resources Services Administration (HRSA), and the US Departments of Agriculture (USDA), Defense (DoD), Veterans Affairs, Homeland Security, State (including US Agency for International Development), and Education. Although an Interagency Task Force on Antimicrobial Resistance exists (authorized under Section 319E of the Public Health Service Act) there is inadequate coordination of activities among these agencies. Further, woefully insufficient funding has been provided to support the Task Force's work.

Although many dedicated federal officials sit on the Task Force, no centralized office exists to facilitate the coordination of the Task Force's activities, prioritize the federal response, establish benchmarks by which to measure progress, or provide a platform for ongoing discussion and action across agencies as well as with non-government experts. IDSA has long-championed the creation of a lead office and director within HHS reporting to the ASPR or the Assistant Secretary for Health. The director would lead the existing Task Force, bring new energy and a broad vision, and help to facilitate better coordination of the federal response. We also strongly support the formation of an advisory board of non-government experts that would work with the director and Task Force to establish priorities and ensure progress toward achieving its goals. We are pleased that the Task Force recently released, after a nearly 3 year delay, an updated draft Action Plan that attaches action items to federal coordinators and collaborators. Congressional appropriators should sufficiently fund the Task Force and Action Plan. ***Specifically, IDSA recommends $30 million in funding be provided to HHS in FY2012 to support the Task Force's efforts to implementf the revised Action Plan, and that additional funding be provided in future years once a lead office/director has been established.***

Strengthen Resistance Surveillance, Data Collection, and Control and Prevention Efforts

CDC currently employs several important surveillance systems and other strategies to address antibiotic resistance. Only by understanding the scope and severity of the problem can the US develop and target interventions that will save lives. To respond to current resistance trends and plan for emerging trends, it is necessary that we do a better job in surveying the frequency of resistance to antibiotics among medically important pathogens across geographical areas. To accomplish this, IDSA supports the creation of an integrated network of sentinel sites with diverse geographic representation. Data is necessary for a variety of infections and pathogens. The US also needs to strengthen data collection on the type and quantity of antibiotics used throughout the spectrum of patient care as well as in agricultural settings to define the overuse and misuse of antibiotics. In addition, specimen collection is needed for the evaluation of emerging resistance mechanisms in pathogens of clinical importance. IDSA also supports the adoption of effective antimicrobial stewardship programs in all health care and agricultural settings where antibiotics are prescribed/provided so that these precious drugs are used wisely and their effectiveness is protected. To this end, CDC needs to more aggressively promote the uptake of stewardship programs as well as better infection control practices and immunization policies. CDC's Get Smart programs already play an important role in educating providers and patients about appropriate antibiotic use and their outreach needs to be further extended.

The expansion of CDC's antimicrobial resistance surveillance, data collection, and prevention and control activities is crucial to protect Americans from serious and life-threatening antibiotic

resistant infections. ***To support the activities highlighted above, CDC's antibiotic resistance program funding should be significantly and immediately increased to at least $50 million. IDSA also supports an overall CDC funding level of $7.7 billion.***

Significantly Expand Investments in Antimicrobial-Focused Research

There is a compelling need for more, better funded, and better coordinated federal antimicrobial resistance-related research. ***For this reason, we are calling for an additional $500 million to expand NIH's National Institute of Allergy and Infectious Diseases' (NIAID) support for antibiotic resistance and antibiotic discovery research.*** NIAID's current budget level limits the institute's ability to sufficiently fund critically needed antibiotic resistance-related research, although NIAID has tried to expand its portfolio in recent years. Of importance, in recognition of the growing crisis, NIAID recently announced the establishment of a new clinical trials network focused on antibiotic-resistant bacterial infections. The institute noted, however, that limited funds will be available to support the network, which will be modeled on NIAID's successful HIV/AIDS clinical trials infrastructure. We applaud NIAID's announcement; but this critical work cannot be accomplished without significant additional funding. With such funding, the new network could conduct research on natural histories of disease, surrogate endpoints, pivotal drug trials, post-licensure comparative studies, validation of predictive biomarkers and molecular diagnostics, antimicrobial stewardship studies, and perhaps assessment of the clinical equivalency of generic drugs. All of these research efforts are essential to address both the antibiotic resistance and antibiotic R&D pipeline problems, and few of these studies will be undertaken by industry.

IDSA also has long sought the creation of an Antimicrobial Resistance Strategic Research Plan to define high-priority research needs, and address scientific challenges. As no strategic research plan exists, key research areas remain unaddressed. For example, basic science research should be expanded to further study antibiotic resistance mechanisms and epidemiology, identify new lead compounds, and develop vaccines and immunotherapies to prevent and treat infections in humans and animals. Studies that help to translate promising compounds from pre-clinical research into clinical trials should be expanded. We also need to better define optimal components and goals of antimicrobial stewardship programs in different health care settings, to define clinically relevant patient outcomes, and to develop national metrics to monitor program success. Clinical and health outcomes research is needed to study infections and interventions to improve outcomes and reduce antibiotic exposure. New funding is needed to expand NIAID support in each of these critical areas of research.

Conclusion

IDSA understands the need to get the nation's fiscal house in order. But as infectious diseases experts, we know that today's investment in infectious disease research, public health and prevention, and new treatments will pay significant dividends in the future by preventing needless deaths, dramatically reducing health care costs and improving the quality of life for millions of Americans. In addition, U.S. leadership in antibiotic resistance research and product R&D will translate into worldwide health benefits. We urge the Subcommittee to continue to demonstrate leadership and foresight in this area by appropriating the much-needed resources outlined above in recognition of the lives and dollars that ultimately will be saved.

Written Statement of

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House Appropriations Subcommittee
On Labor, Health and Human Services, and Education
Washington, DC
April 15, 2011

FY 2012 Appropriations Request Summary

	FY10 Actual	FY11 Budget	FY12 Budget	AANA FY 12 Request
HHS / HRSA / BHPr Title VIII Advanced Education Nursing, Nurse Anesthetist Education Reserve	awards amounted to approx. $3.5MM	Grant allocations not specified	Grant allocations not specified	$4 MM for nurse anesthesia education
Total for Advanced Education Nursing, from Title VIII	$64.44 MM for Advanced Education Nursing	$64.44 MM for Advanced Education Nursing	$104.438 MM Advanced Education Nursing	$104.438 MM for Advanced Education Nursing
Title VIII HRSA BHPr Nursing Education Programs	$243,872,000	$243,872,000	$313.075 MM	$313.075 MM
CDC/ Division of Healthcare Quality and Promotion			Maintain level funding	Maintain level funding

The American Association of Nurse Anesthetists (AANA) is the professional association for the 44,000 Certified Registered Nurse Anesthetists (CRNAs) and student nurse anesthetists practicing today, representing over 90 percent of the nurse anesthetists in the United States. Today, CRNAs deliver approximately 32 million anesthetics to patients each year in the U.S. CRNA services include administering the anesthetic, monitoring the patient's vital signs, staying with the patient throughout the surgery, and providing acute and chronic pain management services. CRNAs provide anesthesia for a wide variety of surgical cases and in some states are the sole anesthesia providers in 100 percent of rural hospitals, affording these medical facilities obstetrical, surgical, and trauma stabilization, and pain management capabilities. CRNAs work in every setting in which anesthesia is delivered, including hospital surgical suites and obstetrical

delivery rooms, ambulatory surgical centers (ASCs), pain management units and the offices of dentists, podiatrists and plastic surgeons. Nurse anesthetists are experienced and highly trained anesthesia professionals whose record of patient safety in the field of anesthesia was bolstered by the Institute of Medicine report in 2000, which found that anesthesia is 50 times safer than in the 1980s. (Kohn L, Corrigan J, Donaldson M, ed. *To Err is Human.* Institute of Medicine, National Academy Press, Washington DC, 2000.) Nurse anesthetists continue to set for themselves the most rigorous continuing education and re-certification requirements in the field of anesthesia. Relative anesthesia patient safety outcomes are comparable among nurse anesthetists and anesthesiologists, with a recent *Health Affairs* article, "No Harm Found When Nurse Anesthetists Work without Supervision by Physicians" finding that adverse outcomes were no more prevalent in states that opted out of the Medicare physician supervision requirement of nurse anesthetists than those states that didn't opt-out (Dulisse B, Cromwell J. No Harm Found When Nurse Anesthetists Work Without Supervision By Physicians. *Health Aff.* 2010;29(8):1469-1475).

In addition, a study published in *Nursing Research* indicates that obstetrical anesthesia, whether provided by CRNAs or anesthesiologists, is extremely safe, and there is no difference in safety between hospitals that use only CRNAs compared with those that use only anesthesiologists. (Simonson, Daniel C et al. Anesthesia Staffing and Anesthetic Complications During Cesarean Delivery: A Retrospective Analysis. *Nursing Research*, Vol. 56, No. 1, pp. 9-17. January/February 2007). In addition, a recent AANA workforce study showed that CRNAs and anesthesiologists are substitutes in the production of surgeries. Through continual improvements in research, education, and practice, nurse anesthetists are vigilant in our efforts to ensure patient safety.

CRNAs provide the lion's share of anesthesia care required by our U.S. Armed Forces through active duty and the reserves. For decades, CRNAs have staffed ships, remote U.S. military bases, and forward surgical teams without physician anesthesiologist support. In addition, CRNAs predominate in rural and medically underserved areas, and where more Medicare patients live.

Importance of Title VIII Nurse Anesthesia Education Funding

The nurse anesthesia profession's chief request of the Subcommittee is for $4 million to be reserved for nurse anesthesia education and $104.438 million for advanced education nursing from the Title VIII program. We feel that this funding request is well justified, as we know that more baby boomers retiring will not only reduce our nurse workforce from retirements but will increase the demand from an aging population requiring care. The Title VIII program is an effective means to help address the nurse anesthesia workforce demand.

Increasing funding for advanced education nursing from $64.44 million in FY 2010 to $104.438 million is necessary to meet the continuing demand for nursing faculty and other advanced education nursing services throughout the U.S. The program provides for competitive grants that help enhance advanced nursing education and practice and traineeships for individuals in advanced nursing education programs. This funding is critical to meet the nursing workforce needs of Americans who require healthcare, particularly as we see more patients enter the system with health reform. More APRNs will be needed to fill the gap to ensure access to care. In addition, this funding provides a two-fold benefit for the nurse workforce. It not only seeks to

increase the number of providers in rural and underserved America but also prepares providers at the master's and doctoral levels, increasing the number of clinicians who are eligible to serve as faculty.

There continues to be high demand for CRNA workforce in clinical and educational settings. The supply of clinical providers has increased in recent years, stimulated by increases in the number of CRNAs trained. Between 2000-2009, the number of nurse anesthesia educational program graduates doubled, with the Council on Certification of Nurse Anesthetists (CCNA) reporting 1,075 graduates in 2000 and 2,375 graduates in 2010. This growth is leveling off somewhat, but is expected to continue. However, even though the number of graduates has doubled in eight years, the demand for nurse anesthetists continues to rise as the population ages, the number of clinical sites requiring anesthesia services grows, and CRNA retirements increase.

The problem is not that our 111 accredited programs of nurse anesthesia are failing to attract qualified applicants. It is that they have to turn them away by the hundreds. The capacity of nurse anesthesia educational programs to educate qualified applicants is limited by the number of faculty, the number and characteristics of clinical practice educational sites, and other factors. A qualified applicant to a CRNA program is a bachelor's educated registered nurse who has spent at least one year serving in an acute care healthcare practice environment.

Recognizing the important role nurse anesthetists play in providing quality healthcare, the AANA has been working with the 111 accredited nurse anesthesia educational programs to increase the number of qualified graduates. In addition, the AANA has worked with nursing and allied health deans to develop new CRNA programs. To truly meet the nurse anesthesia workforce challenge, the capacity and number of CRNA schools must continue to grow. With the help of competitively awarded grants supported by Title VIII funding, the nurse anesthesia profession is making significant progress, expanding both the number of clinical practice sites and the number of graduates.

The AANA is pleased to report that this progress is extremely cost-effective from the standpoint of federal funding. Anesthesia can be provided by nurse anesthetists, physician anesthesiologists, or by CRNAs and anesthesiologists working together. As mentioned earlier, the *Health Affairs* study by Dulisse and Cromwell indicates the safety of CRNA care. Another study published recently in *Nursing Economic$* indicates that costs of educating and training a CRNA from undergraduate education through graduate education is roughly 15% of the cost of educating and training an anesthesiologist (Hogan, PF, Seifert RF, Moore CS, Simonson BE, Cost Effectiveness Analysis of Anesthesia Providers, *Nurs Econ.* 2010;28(3): 150-169.) This study also found that among anesthesia delivery models, CRNAs acting independently provide anesthesia services at the lowest economic cost; costs for this model are 25% less than the second lowest cost model in which an anesthesiologist supervises six CRNAs. Nurse anesthesia education represents a significant educational cost-benefit for supporting CRNA educational programs with federal dollars vs. supporting other, more costly, models of anesthesia education.

To further demonstrate the effectiveness of the Title VIII investment in nurse anesthesia education, the AANA surveyed its CRNA program directors to gauge the impact of the Title VIII funding. Of the eleven schools that had reported receiving competitive Title VIII Nurse Education and Practice Grants funding from 1998 to 2003, the programs indicated an average increase of at least 15 CRNAs graduated per year. They also reported on average more than

doubling their number of graduates. Moreover, they reported producing additional CRNAs that went to serve in rural or medically underserved areas.

We believe the Subcommittee should allocate $4 million for nurse anesthesia education for several reasons. First, as this testimony has documented, the funding is cost-effective and needed. Second, this particular funding meets a distinct need not met elsewhere; nurse anesthesia for rural and medically underserved America is not affected by increases in the budget for the National Health Service Corps and community health centers, since those initiatives are for delivering primary and not surgical healthcare. Third, this funding meets an overall objective to increase access to quality healthcare in medically underserved America.

Title VIII Funding for Strengthening the Nursing Workforce

The AANA joins The Nursing Community and the Americans for Nursing Shortage Relief (ANSR) Alliance in support of the Subcommittee providing a total of $313.075 million in FY 2012 for nursing shortage relief through Title VIII. AANA asks that of the $313.075 million, $104.438 million go to Advanced Education Nursing and $4 million go to nurse anesthesia education to help increase clinicians in underserved communities and those eligible to serve as faculty. The AANA appreciates the support for nurse education funding in FY 2010 and past fiscal years from this Subcommittee and from the Congress.

In the interest of patients past and present, particularly those in rural and medically underserved parts of this country, we ask Congress to invest in CRNA and nursing educational funding programs and to provide these programs the sustained increases required to help ensure Americans get the healthcare that they need and deserve. Quality anesthesia care provided by CRNAs saves lives, promotes quality of life, and makes fiscal sense. This federal support for Title VIII and advanced education nurses will improve patient access to quality services and strengthen the nation's healthcare delivery system.

Safe Injection Practices

As a leader in patient safety, the AANA has been playing a vigorous role in the development and projects of the Safe Injection Practices Coalition, intended to reduce and eventually eliminate the incidence of healthcare facility acquired infections. Provider education and awareness, detection, tracking and response are all extremely important to preventing healthcare-associated infections. In the interest of promoting safe injection practice and reducing the incidence of healthcare facility acquired infections, we recommend the Committee maintain its level of funding for CDC's Division of Healthcare Quality and Promotion so they can address outbreaks and promote innovative ways to adhere to injection safety and infection control guidelines. We also hope the committee will support the CDC's efforts around provider education and patient awareness activities, as this issue transcends provider type and it's important to educate all types of providers and patients alike. In light of the recent healthcare-associated transmission of blood-borne pathogens in California, North Carolina, Florida, Colorado, and Nevada, the CDC needs resources to use the knowledge they have gained on detection and be able to develop new strategies to prevent health-care associated transmission of blood borne pathogens.

# # #

Testimony of
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on
FY 2012 Appropriations for the National Institutes of Health
submitted to the
House Committee on Appropriations
Subcommittee on Labor, Health & Human Services, Education and Related Agencies
Representative Dennis Rehberg, Chair
Representative Rosa DeLauro, Ranking Member

April 15, 2011

The Federation of American Societies for Experimental Biology (FASEB) urges Congress to make investment in the National Institutes of Health (NIH) an urgent national priority and respectfully requests an appropriation of $35 billion for the agency in fiscal year 2012. This figure represents an increase that responds to the effects of inflation on the current program level and is needed to continue ongoing initiatives and prevent severe damage to the Nation's capacity for innovation in its fight against disease.

As a federation of 23 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.

NIH is the driving force behind our nation's leadership in biomedical science and the dramatic improvements in our health and quality of life. Because of NIH and the research it supports, we stand on the brink of an era of enormous potential progress against the ravages of disease. NIH funds the research of more than 325,000 scientists at over 3,000 universities, medical schools, and other research institutions across the United States. Eighty percent of NIH funding is distributed through competitive grants to researchers in nearly every Congressional district and the U.S. territories. More than 130 Nobel Prize winners have received support from the agency. NIH considers many different perspectives in establishing scientific priorities and identifies and, within the limits of its budget, funds the most promising and highest quality research to address them. NIH is also training the next generation of researchers to ensure that the U.S. continues to be a global leader in advancing medical science.

Improving Health, Saving Lives

Research funded by NIH has produced an outstanding legacy. NIH-funded discovery has meant that more than one million lives per year are saved due to therapies to prevent heart attacks and

stroke. That alone has increased American life expectancy by 4 years. Biomedical research discovery has also meant that since 2002 deaths from cancer have steadily declined; and in the past 30 years, survival rates for childhood cancers have increased from less than 50 percent to over 80 percent. More recent advances include:

- *Improving Treatments for Acute Myeloid Leukemia (AML):* Investigators have discovered mutations in a gene that affects the treatment prognosis for some patients with AML, an aggressive blood cancer that kills 9,000 Americans annually. The findings may help guide future treatment strategies for individuals with AML, as well as lead to more effective therapies for patients who carry the mutations.

- *Increasing Pediatric Cancer Survival Rates:* A new form of immunotherapy has significantly improved survival rates of children with neuroblastoma, a deadly nervous system cancer responsible for 12 percent of all cancer deaths in children under age 15. The new therapy has dramatically increased the percentage of children who were alive and free of disease progression after two years.

- *Reversing Aspects of Aging:* Researchers have reversed age-related degeneration in a mouse model of aging. While the findings don't prove that natural aging could be halted or reversed, they may lead to new strategies to combat certain age-related conditions.

- *Rapidly Detecting Tuberculosis (TB):* Scientists have developed an automated test that can rapidly and accurately detect TB and drug-resistant TB in patients. The finding could pave the way for earlier diagnosis and more targeted treatment of this disease. TB kills about 1.8 million people each year, and drug-resistant TB is a growing threat. The new test makes it possible to detect TB and drug resistance in a single clinic visit and perhaps begin treatment immediately.

Predictable and Sustainable Funding Will Drive Innovation and Progress

Our leadership in biomedical research has made us the envy of the rest of the world. Our dominant position in the discovery of new drugs and therapies is the result of research conducted by scientists and engineers in academia and in the biotech firms that they have started.[1] A study published in the February 9th issue of the *New England Journal of Medicine* found that 153 new drugs approved by the U.S. Food and Drug Administration during the past 40 years were discovered at least in part by public sector research institutions (universities, research hospitals, nonprofit research institutes, and federal laboratories), highlighting the increasingly important role of the public sector in the development of pharmaceuticals and other medical interventions.[2]

[1] R. Kneller, *Nature Reviews: Drug Discovery* 9 (November) 2010

[2] Ashley J. Stevens, D.Phil., Jonathan J. Jensen, M.B.A., Katrine Wyller, M.B.E., Patrick C. Kilgore, B.S., Sabarni Chatterjee, M.B.A., Ph.D., and Mark L. Rohrbaugh, Ph.D., J.D. The Role of Public-Sector Research in the Discovery of Drugs and Vaccines, *New England Journal of Medicine*, February 9, 2011.

At present, the NIH budget is insufficient to fund all of the promising research that needs to be done. Less than one in five research proposals can be funded. Over the past six years, the number of research project grants funded by NIH has declined in almost every year, and the agency is now funding 2,000 fewer grants that it did in 2004. Due to the extreme competition for support, NIH grant applicants have pared their funding requests to the bare minimum needed to fulfill the goal of their research.

If we fail to continue to capitalize on our investment, others will. We have built laboratories, trained young researchers, and initiated exciting new projects. Potentially revolutionary new avenues of research hold promise for earlier screening and better therapies, but these advances will not become a reality unless the NIH budget is sustained and enhanced to meet inflation's demands. Failure to continue our commitment to biomedical research will terminate important scientific investigations, stunt graduate training, and discourage young scientists who are the key to our future.

The NIH budget is currently $34 billion (including supplemental appropriations). Exciting new initiatives at NIH are poised to accelerate our progress in the search for cures, and it would be tragic if we could not capitalize on the many opportunities before us. A modest increase over the current program level is needed to continue ongoing initiatives and prevent severe damage to our capacity for innovation. Maintaining our current level of effort requires an increase equal to the biomedical research and development price index (BRDPI), which the Bureau of Economic Analysis in the U.S. Department of Commerce estimates will be three percent in FY 2012.

A small fraction of our federal budget, research funding generates an enormous return in new technologies and improved quality of life. Boom and bust cycles are wasteful and inefficient strategies for funding science. The nations medical research agency needs sustainable and predictable budget growth to maximize the return on this investment in the health and longevity of all Americans. To that end, **FASEB recommends an appropriation of $35 billion for NIH in FY 2012.** Thank you for the opportunity to offer FASEB's support for NIH.

THE **AIDS** INSTITUTE

April 15, 2011

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

Dear Chairman Rehberg and Members of the Subcommittee:

The AIDS Institute, a national public policy research, advocacy, and education organization, is pleased to comment in support of critical HIV/AIDS and Hepatitis programs as part of the FY2012 Labor, Health and Human Services, Education and Related Agencies appropriation measure. We thank you for your support of 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

HIV/AIDS remains one of the world's worst health pandemics in history. According to the CDC, over 617,000 people have died of AIDS in the U.S and estimates there are 56,300 new infections each year. That translates into a new infection every 9 ½ minutes. At the end of 2007, an estimated 1.1 million people in the U.S. were living with HIV/AIDS.

Persons of minority races and ethnicities are disproportionately affected by HIV/AIDS. African Americans, who make up 13% of the US population, account for half of the HIV/AIDS cases. HIV/AIDS disproportionately affects the poor and about 70 percent of those infected rely on publicly funded health care.

The U.S. government has played a leading role in fighting HIV/AIDS, both here and abroad. The vast majority of the discretionary programs supporting HIV/AIDS efforts domestically are funded through your Subcommittee. The AIDS Institute, working in coalition with other AIDS organizations, has developed funding request numbers for each of these domestic AIDS programs. We ask that you do your best to adequately fund them at the requested level.

We are keenly aware of budget constraints and competing interests for limited dollars but programs that prevent and treat HIV are inherently federal, as they help protect the public health against a highly infectious virus, which if left untreated, will most likely lead to death and increased infections. *Federal funding is particularly critical at this time since state and local budgets are being severely cut during the economic downturn.*

National HIV/AIDS Strategy

President Obama has released a comprehensive National HIV/AIDS Strategy (NHAS) which seeks to reduce new HIV infections, increase access to care and improving health outcomes for people living with HIV, and reducing HIV-related health disparities. The Strategy sets ambitious goals to be met by 2015 and seeks a more coordinated national response with a focus on those communities where HIV is centered and on programs that work. In order to attain the goals, additional investment in some key areas will be needed and health reform must be implemented.

The Budget proposed by the President requests that up to one percent of HHS discretionary funds appropriated for domestic HIV/AIDS activities, or approximately $60 million, be provided to the Office of the Assistant Secretary for Health to foster collaborations across HHS agencies and finance high priority initiatives in support of the NHAS. Such initiatives would focus on improving linkages between prevention and care, coordinating Federal resources within targeted high-risk populations, enhancing provider capacity to care for persons living with HIV/AIDS, and monitoring key Strategy targets. The AIDS Institute supports this provision and encourages you to include it in the FY12 appropriation measure.

Centers for Disease Control and Prevention-HIV Prevention and Surveillance

FY2010:	$799.3 million
FY2012 Community Request:	$1,314.6 million

The U.S. allocates only about 4 percent of its domestic HIV/AIDS spending on prevention. Investing in prevention today will save money tomorrow. Preventing one infection will save approximately $355,000 in future lifetime medical costs. Preventing all the new 56,000 cases in just one year would translate into an astounding $20 billion in lifetime medical costs.

The CDC is focused on carrying out several goals of the NHAS by 2015. Specifically, they are seeking to 1) lower the annual number of new infections by 25 percent; 2) reduce the HIV transmission rate by 30 percent; and 3) increase from 79 to 90 the percentage of people living with HIV who know their serostatus. New infections are particularly occurring in certain populations, including African-American men and women, and men who have sex with men. In order to address the specific needs of these populations and the increased number of people living with HIV, CDC is going to need additional funding.

While it is estimated that an increase of over $500 million would be needed to achieve the goals of the NHAS, The AIDS Institute supports an increase of at least the $58.4 million over FY10 that the President has proposed. Within this amount, $30.4 million would be from the Prevention and Public Health Fund. We are also supportive of a transfer of $40 million from the Chronic Disease Prevention and Public Health Promotion for HIV school health programs to achieve closer coordination of CDC's HIV prevention programs.

With this funding the CDC would improve core surveillance and use of community viral load, enhance prevention among most affected communities, integrate care and prevention, expand HIV testing and linkage to care services, build capacity, develop evidence-based social marketing campaigns, and improve the quality and monitoring of all programs.

The AIDS Institute is very concerned about the high level of cuts Congress approved for the CDC in FY11. While it is unknown where the $730 million in cuts will be taken, we hope they will not be in the area of HIV prevention. We cannot go backwards in our prevention efforts at such a critical time when there are so many positive promising developments.

Ryan White HIV/AIDS Programs

FY2011:	$2,334.5 million
FY2012 Community Request:	$2,684 million

The centerpiece of the government's response to caring and treating low-income people with HIV/AIDS is the Ryan White HIV/AIDS Program. Ryan White currently serves over half a million low-income, uninsured, and underinsured people. In FY11, all parts of the Program, with the exception of one, experienced an across the board funding cut. This is occurring at a time of increased need and demands on the program. Consider the following:

1) Caseload levels are increasing. People are living longer due to lifesaving medications, there are over 56,000 new infections each year, and increased testing programs will identify thousands of new people infected with HIV each year. With rising unemployment, people are losing their employer-sponsored health coverage.

2) State and local budgets are experiencing cutbacks due to the economic downturn. A survey by the National Alliance of State and Territorial AIDS Directors found that state HIV/AIDS funding reductions totaling more than $170 million occurred in 29 states during FY09. The situation for this year and next will be even worse.

3) States are cutting, and the federal government is proposing, massive cuts to Medicaid. As the payer of last resort, cuts to entitlement programs, such as Medicaid, would place further pressure on the Ryan White Program.

4) There are significant numbers of people in the U.S. who are not receiving life-saving AIDS medications. An IOM report concluded that 233,069 people in the U.S. who know their HIV status do not have continuous access to Highly Active Antiretroviral Therapy.

Specifically, The AIDS Institute requests the following funding levels for each part of the Program:

Part A provides medical care and vital support services for persons living with HIV/AIDS in the metropolitan areas most affected by HIV/AIDS. We request an increase of $75.2 million, for a total of $752 million.

Part B base provides essential services including diagnostic, viral load testing and viral resistance monitoring, and HIV care to all 50 states, DC, Puerto Rico, and the territories. We are requesting a $77 million increase, for a total of $495 million.

The **AIDS Drug Assistance Program (ADAP)** provides life-saving HIV drug treatment to over 200,000 people, or about one in four HIV positive people in care in the U.S. The majority of whom are people of color (65%) and very poor (75% are at or below 200% of the federal poverty level). ADAPs are experiencing unprecedented growth due, in part, to people losing their health

insurance and ADAPs are in crisis. Over the course of one year, the federal government documented an increase of over 30,000 new people to the program. Because of a lack of funding, there are currently 8,000 people in eleven states on waiting lists, thousands more have been removed from the program due to lowered eligibility requirements, and drug formularies have been reduced. The AIDS Institute is very appreciative of the $48 million increase to ADAP in FY11, but it is far from what is currently required and meet the growing number of new people needing ADAP medications in the coming year.

According to NASTAD's recent annual ADAP monitoring report, state funding for ADAPs increased 61% in FY09 to a total of $346 million, and drug company rebates grew 5% to $522 million. Even with the slight increases, the federal share of the overall ADAP budget has decreased.

The true need for ADAP is an increase of $410 million in order to address the current funding crisis. The AIDS Institute requests that you provide an increase that is as close as possible to that amount. We note the President has requested an increase of $57 million, but that would be insufficient to meet the growing demand.

Part C provides early medical intervention and other supportive services to over 248,000 people at over 380 directly funded clinics. We are requesting a $66.2 million increase, for a total of $272 million.

Part D provides care to over 84,000 women, children, youth, and families living with and affected by HIV/AIDS. This family-centered care promotes better health, prevents mother-to-child transmission, and brings hard-to-reach youth into care. We are requesting a $2.5 million increase, for a total of $ 79.9 million.

Part F includes the AIDS Education and Training Centers (AETCs) program and the Dental Reimbursement program. We are requesting a $15.3 million increase for the AETC program, for a total of $50 million, and a $5.5 million increase for the Dental Reimbursement program, for a total of $19 million.

National Institutes of Health-AIDS Research

FY 2011:	$3.06 billion
FY 2012 Community Request:	$3.5 billion

The NIH conducts research to better understand HIV and its complicated mutations, discover new drug treatments, develop a vaccine and other prevention programs such as microbicides, and ultimately develop a cure. The critically important work performed by the NIH not only benefits those in the U.S., but the entire world.

This research has already helped in the development of many highly effective new drug treatments, prolonging the lives of millions of people. As neither a cure nor a vaccine exists, and patients continue to build resistance to existing medications, additional research must continue. NIH also conducts the necessary behavioral research to learn how HIV can be prevented best in various affected communities. We ask the Committee to fund critical AIDS research at the community requested level of $3.5 billion.

Comprehensive Sexuality Education
Since the vast majority of HIV infection occurs through sex, age appropriate education on how HIV is transmitted and how one can prevent transmission is critical. It is for this reason The AIDS Institute is supportive of funding the Teen Pregnancy Prevention Initiative for a total of $135 million. Additionally, we oppose funding of abstinence only education programs, which have proven not to be effective.

Minority AIDS Initiative
The AIDS Institute supports increased funding for the Minority AIDS Initiative (MAI), which is funded by numerous federal agencies. MAI funds services nationwide that address the disproportionate impact that HIV has on communities of color. For FY12, we are requesting a total of $610 million.

Policy Riders
The AIDS Institute is opposed to using the appropriations process as a vehicle to repeal or prevent the implementation of current law or ban funding for certain activities or organizations. This includes implementation of the Affordable Care Act and its component programs, such as the Prevention and Public Health Fund. We also urge you not to interfere with the implementation of programs, such as syringe exchange programs, which are scientifically proven to be effective in the prevention of HIV and Hepatitis.

Viral Hepatitis

The Institute of Medicine (IOM) report ***Hepatitis and Liver Cancer: A National Strategy for Prevention and Control of Hepatitis B and C*** outlines recommendations on how the incidence of Hepatitis B & C infections can be decreased. They include increased public awareness campaigns, heightened testing and vaccination programs, continued research, along with improved surveillance and other prevention programs. The Administration will soon announce a national strategy to eliminate Viral Hepatitis.

In FY10, Congress funded CDC's Viral Hepatitis Division at only $19.8 million. Given the huge impact that Hepatitis B & C have on the health of so many people, the large treatment costs, and to begin to implement the IOM recommendations and the national strategy, The AIDS Institute urges the federal government to make a greater commitment to Hepatitis prevention. For FY12, we request a total of $40 million.

The AIDS Institute asks that you give great weight to our testimony as you develop the FY12 appropriation bill. Should you have any questions or comments, feel free to contact Carl Schmid, Deputy Executive Director, The AIDS Institute (202) 462-3042 or cschmid@theaidsinstitute.org. Thank you very much.

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Association of
American Cancer Institutes

Statement by the Association of American Cancer Institutes on
FY 2012 Appropriations for the Department of Health and Human Services
Subcommittee on Labor, Health and Human Services, Education and Related Agencies
Committee on Appropriations
United States House of Representatives
April 15, 2011

Testimony submitted by:
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The Association of American Cancer Institutes (AACI), representing 94 of the nation's premier academic and free-standing cancer centers, appreciates the opportunity to submit this statement for consideration by the United States House of Representatives' Subcommittee on Labor, Health and Human Services, Education and Related Agencies, Committee on Appropriations.

AACI thanks the administration, Congress and the Subcommittee on their long-standing commitment to ensuring quality care for cancer patients, as well as for providing researchers with the tools that they need to develop better cancer treatments and, ultimately, to cure this disease.

President Obama's FY 2012 budget calls for $31.829 billion for NIH. This is an increase of $1.045 billion (3.4 percent) over the FY 2010 comparable level of $30.784 billion. The President's proposed budget for the National Cancer Institute would be increased by $95 million, to $5.2 billion.

Sustaining progress against cancer requires a federal commitment to funding research through the NIH and NCI at a level that at least keeps pace with medical inflation. With that in mind, AACI is joining with its colleagues in the biomedical research community in supporting the proposed increases for NIH and NCI and in calling on Congress to further strengthen the impact of the President's request by increasing funding to $35 billion for NIH and to $5.9 billion for NCI. The requested increases account for the loss in funds due to the discontinuation of the American Recovery and Reinvestment Act of 2009, and the ongoing shortfall in NIH and NCI funding in relation to the annual change in the Biomedical Research and Development Price Index (BRDPI), which indicates how much the NIH budget must change to maintain purchasing power.

Taking a closer look at the President's proposed FY2012 budget, as with so many complicated and vitally important matters, the devil is in the details. While the President's budget includes a proposed increase of $95.31 million over FY2010 for NCI, the line item funding for Cooperative Clinical Research remains the same as FY2010--$254.487 million. Other NCI line items show funding decreases, including

Comprehensive/Specialized Cancer Centers ($46.001 million decrease) and Research & Development Contracts ($39.409 million decrease).

AACI and its members are acutely aware of the difficult fiscal environment that the country is facing. The vast majority of our cancer centers exist within universities that are undergoing drastic budget reductions and as a consequence, directors at our member cancer centers are already facing extreme budgetary challenges. Furthermore, many of our senior and most promising young investigators are now without NCI funding and are requiring significant bridge funding from private sources. In recent years, however, it has become more challenging to raise philanthropic and other external funds. As a result, we continue to be highly dependent on federal cancer center grants.

Recent developments at one member center, the Nevada Cancer Institute (NVCI), illustrate that need. Serving 15,000 patients since it opened in 2005, NVCI has recently lain off half of its 300 employees. In a local news report, NVCI officials cited a number of reasons for the layoffs, including a miserable economy that has hurt fundraising, a worsening reimbursement environment that provides less money from government and private insurance entities for services rendered, and fewer federal grant dollars in the recession. ("Debt puts Nevada Cancer Institute on heels", *Las Vegas Review-Journal*, April 8 2011.)

Cancer centers are already challenged to provide infrastructure resources necessary to support funded researchers, and cuts in federal cancer center grants will limit our ability to provide well functioning shared resources to investigators who depend on them to complete their research. For most matrix cancer centers, the majority of NCI grant funds are used to sustain the shared resources so essential to basic, translational, clinical and population cancer research, or to provide matching dollars which allow departments to recruit new cancer researchers to a university and support them until they receive their first grants.

As highlighted by NCI Director Harold Varmus in a January "town hall" meeting with NCI staff, independent investigator research is a particularly valuable resource, particularly in the area of genomics and molecular epidemiology. Such research is highly dependent on state-of-the-art shared resources like tissue processing and banking, DNA sequencing, microRNA platforms, proteomics, biostatistics and biomedical informatics. This infrastructure is expensive, and it is not clear where cancer centers would turn for alternative funding if NCI grant contributions to these efforts were reduced.

An investigator and medicinal chemist at a large AACI member center spent seven years developing two new targeted drugs that are now in clinical trial testing. One agent shows promise in cancers of the blood; the other against breast, colon, lung and prostate tumors. Research on these agents required advanced technologies provided by the center's shared resources, including analytical cell-sorting, microarray assays, and toxicopathological evaluations of mouse models, which are an essential part of drug discovery. If budget cuts had forced the closure of one or more of these shared resources, these new targeted therapies might never have made it to the patients who are now benefiting from them. The researcher has eight to ten more compounds in the pipeline, the fate of which hinges largely on the 2012 budget. Unfortunately, hundreds of other promising cancer researchers across the U.S. share this troubling uncertainty.

Cancer Research: Benefiting all Americans

Cancer's financial and personal impact on America is substantial and growing-- one in two men and one in three women will face cancer in their lifetimes, and cancer cost our nation more than $228 billion in 2008 (Centers for Disease Control and Preventions, *Addressing The Cancer Burden: At A Glance 2010*).

The U.S. Centers for Disease Control & Prevention's latest report on cancer survivorship, "Cancer Survivors-United States, 2007", shows that the number of cancer survivors in the United States increased from 3 million in 1971 to 9.8 million in 2001 and 11.7 million in 2007—an increase from 1.5% to 4% of the U.S. population. Cancer survivors largely consist of people who are 65 years of age or older and women. More than a million people were alive in 2007 after being diagnosed with cancer 25 years or more earlier.

Of the 11.7 million people living with cancer in 2007—

- 7 million were 65 years of age or older.
- 6.3 million were women.
- 4.7 million were diagnosed 10 years earlier or more

Investing in cancer research is a prudent step - both for the health of our nation and for our nation's economic well-being.

Cancer research, conducted in academic laboratories across the country, saves money by reducing healthcare costs associated with the disease, enhances the United States' global competitiveness, and has a positive economic impact on localities that house a major research center. While these aspects of cancer research are important, what cannot be overstated is the impact cancer research has had on individuals' lives—lives that have been lengthened and even saved by virtue of discoveries made in cancer research laboratories at cancer centers across the United States.

Biomedical research has provided Americans with better cancer treatments, as well as enhanced cancer screening and prevention efforts. Some of the most exciting breakthroughs in current cancer research are those in the field of personalized medicine. In personalized medicine for cancer, not only is the disease itself considered when determining treatments, but so is the individual's unique genetic code. This combination allows physicians to better identify those at risk for cancer, detect the disease, and treat the cancer in a targeted fashion that minimizes side effects and refines treatment in a way to provide the maximum benefit to the patient.

In the laboratory setting, multi-disciplinary teams of scientists are working together to understand the significance of the human genome in cancer. For instance, the Cancer Genetic Markers of Susceptibility initiative is comparing the DNA of men and women with breast or prostate cancer with that of men and women without the diseases to better understand the diseases. The Cancer Genome Atlas is in development as a comprehensive catalog of genetic changes that occur in cancer.

These projects—along with the work being performed by dedicated physicians and researchers at cancer centers across the United States every day—have the potential to radically change the way cancer, as a collection of diseases, affects the people who live with it every day. Every discovery contributes to a future without cancer as we know it today.

Illustrating the successes realized by cancer research, NCI's most recent Annual Report to the Nation on the status of cancer reported that rates of death in the United States from all cancers for men and women continued to decline between 2003 and 2007, the most recent reporting period available, according to the latest Annual Report to the Nation on the Status of Cancer. The report also finds that the overall rate of new cancer diagnoses for men and women combined decreased an average of slightly less than 1 percent per year for the same period.

Despite those improvements, "cancer disparities" abound, with different groups of cancer sufferers and cancer types showing little improvement or higher rates of incidence. For example, childhood cancer incidence rates (rates of new diagnoses) continued to increase while death rates in this age group decreased. Childhood cancer is classified as cancers occurring in those 19 years of age or younger. And there are several other forms of cancer (e.g. pancreatic, lung) and patient populations (racial and ethnic minorities, the poor, those with psychosocial issues) with high rates of cancer mortality and morbidity. Furthermore, with the increased incidence and survival comes increase in morbidity because 2/3rds of this patient population who survive experience late effects that are classified as serious to life-threatening.

The Nation's Cancer Centers

The nexus of cancer research in the United States is the nation's network of cancer centers represented by AACI. These cancer centers conduct the highest-quality cancer research anywhere in the world and provide exceptional patient care. The nation's research institutions, which house AACI's member cancer centers, receive an estimated $3.31 billion from NCI to conduct cancer research; this represents 67 percent of NCI's total budget (U.S. Department of Health and Human Services, National Institutes of Health, *National Cancer Institute 2009 Fact Book*). In fact, approximately 84 percent of NCI's budget supports research at nearly 650 universities, hospitals, cancer centers, and other institutions in all 50 states. Because these centers are networked nationally, opportunities for collaborations are many—assuring wise and non-duplicative investment of scarce federal dollars.

In addition to conducting basic, clinical, and population research, the cancer centers are largely responsible for training the cancer workforce that will practice in the United States in the years to come. Much of this training depends on federal dollars, via training grants and other funding from NCI. Sustained federal support will significantly enhance the centers' ability to continue to train the next generation of cancer specialists—both researchers and providers of cancer care.

By providing access to a wide array of expertise and programs specializing in prevention, diagnosis, and treatment of cancer, cancer centers play an important role in reducing the burden of cancer in their communities. The majority of the clinical trials of new interventions for cancer are carried out at the nation's network of cancer centers.

Conclusion

These are exciting times in science and, particularly, in cancer research. The AACI cancer center network is unrivaled in its pursuit of excellence, and places the highest priority on affording all Americans access to superior cancer care, including novel treatments and clinical trials. It is through the power of collaborative innovation that we will accelerate progress toward a future without cancer, and research funding through the NIH and NCI is essential to achieving our goals.

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 2012 Funding for the
National Institutes of Health, Department of Health and Human Service
April 15, 2011

Submitted by:
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The Association of Independent Research Institutes (AIRI) respectfully submits this written testimony for the record to the House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies. AIRI appreciates the commitment that the Members of this Subcommittee have made to biomedical research through your strong support for the National Institutes of Health (NIH), and **recommends that you maintain this support for NIH in FY 2012 by providing $31.829 billion for NIH in FY 2012**, which represents a 2.4 percent increase above the FY 2010 level.

AIRI is a national organization of more than 80 independent, non-profit research institutes that perform basic and clinical research in the biological and behavioral sciences. AIRI institutes vary in size, with budgets ranging from a few million to hundreds of millions of dollars. In addition, each AIRI member institution is governed by its own independent Board of Directors, which allows our members to focus on discovery-based research while remaining structurally nimble and capable of adjusting their research programs to emerging areas of inquiry. Researchers at independent research institutes consistently exceed the success rates of the overall NIH grantee pool, and receive about 10 percent of NIH's peer-reviewed, competitively-awarded extramural grants.

In recent years, Congress has taken important steps to jump start the nation's economy through investments in science. Simultaneously, the NIH community is advancing and accelerating the biomedical research agenda in this country by focusing on scientific opportunities to address public health challenges. However, flat NIH budgets since 2003 have affected the agency's ability to pursue new, cutting-edge opportunities. This funding uncertainty is disruptive to

training, careers, long-range projects, and ultimately, to research progress. The research engine needs a predictable, sustained investment in science to maximize the nation's return.

Not only is NIH research essential to advancing health, it also plays a key economic role in communities nationwide. More than 83 percent of NIH funding is spent in communities across the nation, creating jobs at more than 3,000 independent research institutions, universities, teaching hospitals, and other institutions in every state. NIH research also supports long-term competitiveness for American workers. NIH funding forms one of the key foundations for sustained U.S. global competitiveness in industries like biotechnology, medical device and pharmaceutical development, and more.

Highlighted below are examples of how independent research institutes uniquely contribute to the NIH mission and activities.

Translating Research into Treatments and Therapeutics – To further its primary goal of improving health, NIH is engaged in a significant reorganization process focused on advancing translational science. AIRI looks forward to collaborating with NIH in this area as independent research institutes are particularly adept at translating basic discoveries into therapeutics, often partnering with industry. As a network of efficient, nimble independent research institutes that have been conducting translational research for years, AIRI is well-positioned to be a strong partner in bringing research from the bench to the bedside.

Currently, over 15 AIRI member institutions are affiliated and collaborate with the Clinical and Translational Science Awards (CTSA) program. Many AIRI institutes also support research on human embryonic stem cells (hESC) with the hope of discovering new and innovative disease interventions. However, uncertainty surrounding NIH funding and hESC research will hinder the agency's efforts to advance the introduction of new, life-saving cures and treatments into the marketplace.

Fostering the Next Generation Scientific Workforce – The biomedical research community is dependent 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 and ensuring that a pipeline of promising scientists are prepared to make significant and potentially transformative discoveries in a variety of areas.

AIRI supports policies that promote the United States' ability 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 the public health of the nation. The cultivation and preservation of this workforce is dependent upon several factors:

- The ability to recruit scientists and students globally is essential to maintaining a strong workforce.
- Training programs both in basic and clinical biomedical research, initiatives focusing on career development, and recruiting a diverse scientific workforce are important to innovation in biomedical research for the benefit of public health.
- The continued national emphasis on promoting education in the fields of science,

technology, engineering, and mathematics (STEM) is key to bolstering the pipeline.

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. Moreover, efforts to expand the knowledge base in medical and associated sciences bolster the nation's economic well-being and ensure a continued high return on the public investment in research.

AIRI member institutions are private, stand-alone research centers that set their sights on the vast frontiers of medical science, specifically focused on pursuing knowledge about the biology and behavior of living systems and the application of that knowledge to improve human life 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 advanced technology platforms or "cores," AIRI researchers use genomics, imaging, and other broad-based technologies to advance therapeutics development and drug discovery.

Providing Efficiency and Flexibility – AIRI member institutes' small size and flexibility provide an environment that is 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 all research institutions and elsewhere. These collaborative activities help minimize bureaucracy and increase efficiency, allowing for fruitful partnerships with entities in a variety of disciplines and industries. Also, unlike institutes of higher education, independent research institutes are able to focus solely on scientific inquiry and discoveries, 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 economic engines, and exemplify the positive impact of investing in research and science.

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 $31.829 billion for NIH in the FY 2012 appropriations bill**. AIRI looks forward to working with Congress to support research that improves the health and quality of life for all Americans.

TESTIMONY OF

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SUBMITTED TO THE HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES

REGARDING FY12 APPROPRIATIONS FOR THE DEPARTMENT OF HEALTH AND HUMAN SERVICES

APRIL 15, 2011

Mr. Chairman, thank you for the opportunity to submit testimony regarding the FY2012 budget for the National Heart, Lung and Blood Institute, the National Institute of Arthritis, Musculoskeletal and Skin Diseases, and the Centers for Disease Control and Prevention. The National Marfan Foundation is grateful for the subcommittee's strong support of the NIH and CDC, particularly as it relates to life-threatening genetic disorders such as Marfan syndrome. Thanks in part to your leadership we are at a time of unprecedented hope for our patients.

It is estimated that 200,000 people in the United States are affected by Marfan syndrome or a related condition. Marfan syndrome is a genetic disorder of the connective tissue that can affect many areas of the body, including the heart, eyes, skeleton, lungs and blood vessels. It is progressive condition and can cause deterioration in each of these body systems. The most serious and life-threatening aspect of the syndrome is a weakening of the aorta. The aorta is the largest artery carrying oxygenated blood from the heart. Over time, many Marfan syndrome patients experience a dramatic weakening of the aorta which can cause the vessel to dissect and tear.

Early surgical intervention can prevent a dissection and strengthen the aorta and the aortic valves. If preventive surgery is performed before a dissection occurs, the success rate of the procedure is over 95%. If surgery is initiated after a dissection has occurred, the success rate drops below 50%. Aortic dissection is a leading killer in the United States, and 20% of the people it affects have a genetic predisposition, like Marfan syndrome, to developing the complication.

Fortunately, new research offers hope that a commonly prescribed blood pressure medication might be effective in preventing this frequent and devastating event.

FY12 APPROPRIATIONS RECOMMENDATIONS

NATIONAL INSTITUTES OF HEALTH

Mr. Chairman, hope for a better quality of life for patients with Marfan syndrome and related connective tissue disorders lies in NIH-sponsored biomedical research. With that in mind, NMF joins with other voluntary patient and medical organizations in recommending an appropriation of $35 billion for the National Institutes of Health in FY12. , This level of funding will ensure continued expansion of research on rare diseases like Marfan syndrome and build upon the significant investment provided to the NIH in the American Recovery and Reinvestment Act.

NATIONAL HEART, LUNG AND BLOOD INSTITUTE

A) Pediatric Heart Network Clinical Trial

NMF applauds the National Heart, Lung and Blood Institute for its leadership in advancing a landmark clinical trial on Marfan syndrome. Under the direction of Dr. Lynn Mahoney and Dr. Gail Pearson, the institute's Pediatric Heart Network (PHN) has spearheaded a multicenter study focused on the potential benefits of a commonly prescribed blood pressure medication (losartan) on aortic growth in Marfan syndrome patients.

Dr. Hal Dietz, the Victor A. McKusick Professor of Genetics in the McKusick-Nathans Institute of Genetic Medicine at the Johns Hopkins University School of Medicine, and the director of the William S. Smilow Center for Marfan Syndrome Research, is the driving force behind this groundbreaking research. Dr. Dietz uncovered the role that the growth factor *TGF-beta* plays in aortic enlargement, and demonstrated the benefits of losartan in halting aortic growth in mice. He is the reason we have reached this time of such promise and NMF is proud to have supported Dr. Dietz's cutting-edge research for many years.

After four years of recruitment and patient screening, the PHN trial reached its enrollment target of 604 subjects on February 2, 2011. Marfan syndrome patients (age 6 months to 25 years) are

enrolled in the study. Patients are randomized onto either losartan or atenolol (a beta blocker that is the current standard of care for Marfan patients with an enlarged aortic root). We anxiously await the results of this first-ever clinical trial for our patient population. It is our hope that losartan will emerge as the new standard-of-care and greatly reduce the need for surgery in at-risk patients.

Mr. Chairman, NMF is proud to actively support the losartan clinical trial in partnership with the Pediatric Heart Network. Throughout the life of the trial we have provided support for patient travel costs, coverage of select echocardiogram examinations, and funding for ancillary studies. These ancillary studies will explore the impact that losartan has on other manifestations of Marfan syndrome.

B) Evaluation of Surgical Options for Marfan Syndrome Patients

Mr. Chairman, we are grateful for the subcommittee's previous recommendations encouraging NHLBI to support research on surgical options for Marfan syndrome patients.

For the past several years, the NMF has supported an innovative study looking at outcomes in Marfan syndrome patients who undergo valve-sparing surgery compared with valve replacement. Initial findings were published last year in the *Journal of Thoracic and Cardiovascular Surgery*. Some short term questions have been answered, most importantly that valve-sparing can be done safely on Marfan patients by an experienced surgeon. The consensus among the investigators however is that long-term durability questions will not be answered until patients are followed for at least 10 years.

Confirming the utility and durability of valve sparing procedures will save our patients a host of potential complications associated with valve replacement surgery. We hope to partner with the NIH on this important work moving forward.

C) NHLBI "Working Group on Research in Marfan Syndrome and Related Conditions"

In 2007, NHLBI convened a "*Working Group on Research in Marfan Syndrome and Related Conditions.*" Chaired by Dr. Dietz, this panel was comprised of experts in all aspects of basic and clinical science related to the disorder. The panel was charged with identifying key recommendations for advancing the field of research in the coming decade. The recommendations of the Working Group are as follows ---

"Scientific opportunities to advance this field are conferred by technological advances in gene discovery, the ability to dissect cellular processes at the molecular level and imaging, and the establishment of multi-disciplinary teams. The barriers to progress are addressed through the following recommendations, which are also consistent with Goals and Challenges in the NHLBI Strategic Plan.

- Existing registries should be expanded or new registries developed to define the presentation, natural history, and clinical history of aneurysm syndromes.

- Biological and aortic tissue sample collection should be incorporated into every clinical research program on Marfan syndrome and related disorders and funds should be provided to ensure that this occurs. Such resources, once established, should be widely shared among investigators.

- An Aortic Aneurysm Clinical Trials Network (ACTnet) should be developed to test both surgical and medical therapies in patients with thoracic aortic aneurysms. Partnership in this effort should be sought with industry, academic organizations, foundations, and other governmental entities.

- The identification of novel therapeutic targets and biomarkers should be facilitated by the development of genetically-defined animal models and the expanded use of genomic, proteomic and functional analyses. There is a specific need to understand cellular pathways that are altered leading to aneurysms and dissections, and to develop robust in vivo reporter assays to monitor TGFb and other cellular signaling cascades.

- The developmental underpinnings of apparently acquired phenotypes should be explored. This effort will be facilitated by the dedicated analysis of both prenatal and early postnatal tissues in genetically-defined animal models and through the expanded availability to researchers of surgical specimens from affected children and young adults.

We look forward to working closely with NHLBI to pursue these important research goals and ask the Subcommittee to support the recommendations of the Working Group.

NATIONAL INSTITUTE OF ARTHRITIS AND MUSCKULOSKELETAL AND SKIN DISEASES

NMF is proud of its longstanding partnership with the National Institute of Arthritis and Musculoskeletal and Skin Diseases, which is celebrating its 25th anniversary this year. Dr. Steven Katz has been a strong proponent of basic research on Marfan syndrome during his tenure as NIAMS director and has generously supported several "Conferences on Heritable Disorders of Connective Tissue." Moreover, the Institute has provided invaluable support for Dr. Dietz's mouse model studies. The discoveries of fibrillin-1, TGF-beta, and their role in muscle regeneration and connective tissue function were made possible in part through collaboration with NIAMS.

As the losartan trial continues to move forward, we hope to expand our partnership with NIAMS to support related studies that fall under the mission and jurisdiction of the Institute. One of the areas of great interest to researchers and patients is the role that losartan may play in strengthening muscle tissue in Marfan patients. We would welcome an opportunity to partner with NIAMS on this and other research.

CENTERS FOR DISEASE CONTROL AND PREVENTION

Mr. Chairman, one of the most important things we can do to prevent untimely deaths from aortic aneurysms is to increase awareness of Marfan syndrome and related connective tissue disorders.

Last year, the American College of Cardiology and the American Heart Association issued landmark practice guidelines for the treatment of thoracic aortic aneurysms and dissections. The NMF is promoting awareness of the new guidelines in collaboration with other organizations through a new Coalition known as TAD; the Thoracic Aortic Disease Coalition. We hope to partner with the CDC in FY12 to increase awareness of the guidelines so all patients will be adequately diagnosed and treated.

For FY12, NMF joins with the CDC Coalition in recommending an appropriation of $7.7 billion for CDC's core-programs.

ABOUT THE NATIONAL MARFAN FOUNDATION

The NMF is a non-profit voluntary health organization founded in 1981. NMF is dedicated to saving lives and improving the quality of life for individuals and families affected by the Marfan syndrome and related disorders. The Foundation has three major goals: (i) to provide accurate and timely information about the Marfan syndrome to affected individuals, family members, physicians and other health professionals; (ii) to provide a means for those with Marfan syndrome and their relatives to share in experiences, to support one another and to improve their medical care and (iii) to support and foster research.

STATEMENT OF

MR. GARY SINDERBRAND

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SUBMITTED TO THE HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES

REGARDING FY12 APPROPRIATIONS FOR THE DEPARTMENT OF HEALTH AND HUMAN SERVICES

APRIL 15, 2011

Mr. Chairman and members of the Subcommittee, thank you for the opportunity to submit testimony on behalf of the 1.4 million Americans living with Crohn's disease and ulcerative colitis. My name is Gary Sinderbrand and I have the privilege of serving as the Chairman of the National Board of Trustees for the Crohn's and Colitis Foundation of America. CCFA is the nation's oldest and largest voluntary organization dedicated to finding a cure for Crohn's disease and ulcerative colitis -- collectively known as inflammatory bowel diseases.

Let me express at the outset how appreciative we are for the leadership this Subcommittee has provided in advancing funding for the National Institutes of Health.

Mr. Chairman, Crohn's disease and ulcerative colitis are devastating inflammatory disorders of the digestive tract that cause severe abdominal pain, fever and intestinal bleeding. Complications include arthritis, osteoporosis, anemia, liver disease and colorectal cancer. We do not know their cause, and there is no medical cure. They represent the major cause of morbidity from digestive diseases and forever alter the lives of the people they afflict – particularly children. I know, because I am the father of a child living with Crohn's disease.

Seven years ago, during my daughter, Alexandra's sophomore year in college, she was taken to the ER for what was initially thought to be acute appendicitis. After a series of tests, my wife and I received a call from the attending GI who stated coldly: Your daughter has Crohn's disease, there is no cure and she will be on medication the rest of her life. The news froze us in our tracks. How could our vibrant, beautiful little girl be stricken with a disease that was incurable and has ruined the lives of countless thousands of people?

Over the next several months, Alexandra fluctuated between good days and bad. Bad days would bring on debilitating flares which would rack her body with pain and fever as her system sought equilibrium. Our hearts were filled with sorrow as we realized how we were so incapable of protecting our child.

Her doctor was trying increasingly aggressive therapies to bring the flares under control. Asacol, Steroids, Mercaptipurine, Methotrexate and finally Remicade. Each treatment came with its own set of side effects and risks. Every time A would call from school, my heart would jump before I picked up the call in fear of hearing that my child was in pain as the flares had returned. Ironically, the worst call came from one of her friends to report that A was back in the ER and being evaluated by a GI surgeon to determine if an emergency procedure was needed to clear an intestinal blockage that was caused by the disease. Several hours later, a brilliant surgeon at the University of Chicago, removed over a foot of diseased tissue from her intestine. The surgery saved her life, but did not cure her. We continue to live every day knowing that the disease could flare at any time with devastating consequences.

Mr. Chairman, I will focus the remainder of my testimony on our appropriations recommendations for fiscal year 2012.

RECOMMENDATIONS FOR FISCAL YEAR 2012

1) CENTERS FOR DISEASE CONTROL AND PREVENTION

INFLAMMATORY BOWEL DISEASE EPIDEMIOLOGY PROGRAM

As I mentioned earlier, CCFA estimates that 1.4 million people in the United States suffer from IBD, but there could be many more. We do not know the exact number due to the complexity of these diseases and the difficulty in identifying them. The Centers for Disease Control and Prevention's Inflammatory Bowel Disease Program is helping answer this and many other important questions related to these challenging conditions. This program is the only one of its kind and its accomplishments have been applauded by the CDC.

CCFA has been a proud partner with CDC in conducting the research funded under the epidemiology program. For the first two years of the project the Foundation worked collaboratively with Kaiser Permanente in California to better understand the incidence and prevalence of IBD, the natural history of the disease, and why patients respond differently to the same therapy. This research has resulted in 11 publications to date and another 11 papers to be submitted to high-quality peer-reviewed journals. Topics include but are not limited to the following:

- Incidence and Prevalence of IBD
- Patterns of Care and Outcomes in IBD
- Qualitative study of provider opinions
- Utilization of biologics (Infliximab)
- Disparities in Mortality

- Myelosuppression during Thiopurine Therapy for Inflammatory Bowel Disease: Implications for Monitoring Recommendations
- Severity and Flare Algorithms
- Disparities in Surveillance for Colorectal Cancer
- Pediatric Epidemiology

In 2007, our focus shifted to the establishment of the "Ocean State Crohn's & Colitis Area Registry" or OSCCAR. Under the leadership of Dr. Bruce Sands, this study is being conducted jointly by investigators at the Massachusetts General Hospital and Rhode Island Hospital/Brown University. The state of Rhode Island is an excellent location to conduct a population-based IBD study because; 1) it is a small state geographically; 2) it has a diverse ethnic and socioeconomic population that does not tend to migrate out of state: and 3) a small number of gastroenterologists treat essentially all IBD patients within the state. Since 2007, Dr. Sands has been able to recruit virtually all GI physicians in Rhode Island to refer patients into the study. To date, almost 310 patients have been recruited, 89 of whom are pediatric patients. All of this progress will be lost if the program is eliminated in 2012.

The goals of the OSCCAR study moving forward are to: 1) describe the age and sex adjusted incidence rate of Crohn's disease and ulcerative colitis; 2) describe variations in presenting symptoms among children, men and women with newly diagnosed disease; 3) identify factors that predict resistance to steroids, including clinical characteristics and blood test markers that could be useful to treating physicians; 4) identify predictors of the need for surgery; and 5) describe factors that predict either impaired quality of life or a benign course of disease. Mr. Chairman, to ensure that this important epidemiological work moves forward in FY12, CCFA recommends an appropriation of $686,000 (FY10 level).

PEDIATRIC INFLAMMATORY BOWEL DISEASE PATIENT REGISTRY

Mr. Chairman, the unique challenges faced by children and adolescents battling IBD are of particular concern to CCFA. In recent years we have seen an increased prevalence of IBD among children, particularly those diagnosed at a very early age. To combat this alarming trend CCFA, in partnership with the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition, has instituted an aggressive pediatric research campaign focused on the following areas:

- Growth/Bone Development - How does inflammation cause growth failure and bone disease in children with IBD?
- Genetics – How can we identify early onset Crohn's disease and ulcerative colitis?
- Quality Improvement - Given the wide variation in care provided to children with IBD, how can we standardize treatment and improve patients' growth and well-being?
- Immune Response - What alterations in the childhood immune system put young people at risk for IBD, how does the immune system change with treatment for IBD?
- Psychosocial Functioning – How does diagnosis and treatment for IBD impact depression and anxiety among young people? What approaches work best to improve mood, coping, family function, and quality of life.

The establishment of a national registry of pediatric IBD patients is central to our ability to answer these important research questions. Empowering investigators with HIPPA compliant information on young patients from across the nation will jump-start our effort to expand epidemiologic, basic and clinical research on our pediatric population. We encourage the Subcommittee to support our efforts to establish a Pediatric IBD Patient Registry with the CDC in FY12.

2) NATIONAL INSTITUTES OF HEALTH

Throughout its 40 year history, CCFA has forged remarkably successful research partnerships with the NIH, particularly the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), which sponsors the majority of IBD research, and the National Institute of Allergy and Infectious Diseases (NIAID). CCFA provides crucial "seed-funding" to researchers, helping investigators gather preliminary findings, which in turn enables them to pursue advanced IBD research projects through the NIH. This approach led to the identification of the first gene associated with Crohn's -- a landmark breakthrough in understanding this disease.

Mr. Chairman, NIDDK-sponsored research on IBD has been a remarkable success story. In 2008, a consortium of researchers from the United States, Canada, and Europe identified 21 new genes for Crohn's disease. This discovery, funded in part by the NIDDK, brings the total number of known genes associated with Crohn's disease to more than 30 and provides new avenues for the development of promising treatments. We are grateful for the leadership of Dr. Stephen James, Director of NIDDK's Division of Digestive Diseases and Nutrition, for aggressively pursuing this and other promising areas of research.

CCFA's scientific leaders, with significant involvement from NIDDK, have developed an ambitious research agenda entitled "*Challenges in Inflammatory Bowel Diseases.*" In addition, CCFA-affiliated investigators played a leading role in developing the recommendations on IBD in the new NIH National Commission on Digestive Diseases strategic plan. We look forward to working with the NIDDK to advance the cutting-edge science called for in these two roadmaps.

For FY12, CCFA joins with other voluntary patient and medical organizations in recommending an appropriation of $35 billion for the NIH. Once again Mr. Chairman, thank you very much for the opportunity to submit our views for your consideration.

TESTIMONY OF

Mr. Rino Aldrighetti

President
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ON BEHALF OF THE

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REGARDING
FISCAL YEAR 2012 APPROPRIATIONS FOR CDC, NIH AND HRSA

SUBMITTED TO THE
SENATE LABOR-HHS-EDUCATION APPROPRIATIONS SUBCOMMITTEE

APRIL 15, 2011

Mr. Chairman, thank you for the opportunity to submit testimony on behalf of the Pulmonary Hypertension Association (PHA).

I would like to extend my sincere thanks to the Subcommittee for your past support of pulmonary hypertension (PH) programs at the National Institutes of Health, Centers for Disease Control and Prevention, and Health Resources and Services Administration. These initiatives have opened many new avenues of promising research, helped educate hundreds of physicians in how to properly diagnose PH, and raised awareness about the importance of organ donation and transplantation within the PH community.

I am honored today to represent the hundreds of thousands of Americans who are fighting a courageous battle against a devastating disease. Pulmonary hypertension is a serious and often fatal condition where the blood pressure in the lungs rises to dangerously high levels. In PH patients, the walls of the arteries that take blood from the right side of the heart to the lungs thicken and constrict. As a result, the right side of the heart has to pump harder to move blood into the lungs, causing it to enlarge and ultimately fail.

PH can occur without a known cause or be secondary to other conditions such as: collagen vascular diseases (i.e., scleroderma and lupus), blood clots, HIV, sickle cell, or liver disease. PH impacts patients of all races, genders, and ages. Preliminary data from the REVEAL Registry suggests that the ratio of women to men who develop PH is 4:1. Patients develop symptoms that include shortness of breath, fatigue, chest pain, dizziness, and fainting.

Unfortunately, these symptoms are frequently misdiagnosed, leaving patients with the false impression that they have a minor pulmonary or cardiovascular condition. By the time many patients receive an accurate diagnosis, the disease has progressed to a late stage, making it impossible to receive a necessary heart or lung transplant. PH is chronic and incurable with a poor survival rate. Fortunately, new treatments are providing a significantly improved quality of life for patients with some managing the disorder for 20 years or longer.

In 1990, when three PH patients found each other with the help of the National Organization for Rare Diseases, and founded the Pulmonary Hypertension Association, there were less than 200 diagnosed cases of this disease. It was virtually unknown among the general population and not well known in the medical community. They soon realized that this was unacceptable, and formally established PHA, which is headquartered in Silver Spring, Maryland. I am pleased to report that we are making good progress in our fight against this deadly disease. Nine medications for the treatment of PH have been approved by the FDA in the past 16 years.

Today, PHA includes:
- More than 20,000 members and supporters.
- A network of 230+ patient support groups and an active patient-to-patient telephone helpline.
- Three research programs that, through partnerships with the National Heart, Lung and Blood Institute, American Heart Association and the American Thoracic Society, have leveraged our donors' funds to commit more than $10 million toward PH research as of 2011.
- Numerous electronic and print publications, including the first medical journal devoted to pulmonary hypertension – published quarterly and distributed to all cardiologists, pulmonologists, and rheumatologists in the U.S.
- A state-of-the-art website(www.phassociation.org) dedicated to providing educational and support resources to patients, caregivers, and the public.
- A medical education website (www.phaonlineuniv.org), supported in part by the CDC, providing accredited medical education and resources to the medical community

THE PULMONARY HYPERTENSION COMMUNITY

Mr. Chairman, I am privileged to serve as the President of the Pulmonary Hypertension Association and to interact daily with the patients and family members who are seeking to live their lives to the fullest in the face of this deadly, incurable disease.

Carl Hicks is a former Army Ranger and a retired Colonel who led the first battalion into Iraq during the first Iraq war. Every member of his family was touched by pulmonary hypertension after the diagnosis of his daughter Meghan in 1994. I share their story here, in Carl's own words:

We're sorry Colonel Hicks, your daughter Meaghan has contracted primary pulmonary hypertension. She likely has less than a year to live and there is nothing we can do for her.

"Those words were spoken in the spring of 1994 at Walter Reed Army Medical Center. They marked the start down the trail of tears for a young military family that, only hours before, had been in Germany. My family's journey down this trail hasn't ended yet, even though Meaghan's fight came to an end with her death on January 30th, 2009. She was 27.

Pulmonary hypertension (PH) struck our family, as it so often does, without warning. One day, we had a beautiful, healthy, energetic twelve-year old gymnast, the next, a child with a death sentence being robbed of every breath by this heinous disease. The toll of this fight was far-reaching. Over the years, every decision of any consequence in the family was considered first with regards to its impact on Meaghan and her *struggle for breath.*

The investment made by our country in my career was lost, as I left the service to stay nearer my family. The costs for Meaghan's medical care, spread over the nearly fourteen years of our fight, ran well into the seven figures. Meghan even underwent a heart and dual-lung transplant. These challenges, though, were *nothing* compared to the psychological toll of losing Meaghan who had fought so hard for something we all take for granted, a breath of air."

Over the past decade, treatment options, and the survival rate, for pulmonary hypertension patients have improved significantly. As Meaghan's story illustrates, however, courageous patients of every age lose their battle with PH each day. There is still a long way to go on the road to a cure and biomedical research holds the promise of a better tomorrow.

Thanks to congressional action, and to advances in medical research largely supported by the NHLBI and other government agencies, PH patients have an increased chance of managing and living with their pulmonary hypertension. Preliminary REVEAL data suggests that with the discovery and application of effective therapies over the past three decades, median survival has increased from 2.8 years to more than 5 years. However, additional support is needed for research and related activities to continue to develop treatments that will extend the life expectancy and improve quality of life for PH patients.

FY 2012 APPROPRIATIONS RECOMMENDATIONS

A) NATIONAL HEART, LUNG AND BLOOD INSTITUTE

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. Recognizing that we have made tremendous progress, we are also mindful that we are a long way from where we want to be in 1) the management of PH as a treatable chronic disease, and 2) a cure.

We are grateful to the National Heart, Lung and Blood Institute for their leadership in advancing research on PH. Our Association is proud to jointly sponsor investigator training grants (K awards) with NHLBI aimed at supporting the next generation of pulmonary hypertension researchers.

Moreover, we were very pleased that NHLBI recently convened some of the community's leading scientists for a Working on Group on Lung Vascular Research. The panel produced recommendations that should guide pulmonary vascular disease research and treatment, including PH research, in coming years. Their recommendations, published in the American Journal of Respiratory and Critical Care Medicine in October, 2010 are as follows:

- Advance basic scientific research in lung vascular biology utilizing emerging technologies.

- Advance and coordinate basic and clinical knowledge of the pulmonary circulation-right heart axis through novel research efforts utilizing multidisciplinary teams.
- Define interactions between lung vascular components and circulating elements and systemic circulations by fostering novel collaborations.
- Encourage systems analysis to understand and define interactions between lung vascular genetics, epigenetics, metabolic pathways, andmolecular signaling.
- Develop strategies using appropriate animal models to improve the understanding of the lung vasculature in health and in conditions that reflect human disease.
- Enhance translational research in lung vascular disease by comparing cellular and tissue abnormalities identified in animal models to those in human specimens.
- Improve lung vascular disease molecular and clinical phenotype coupling.
- Develop in vivo imaging techniques which assess structural changes in lung vasculature, metabolic shifts, functional cell responses and right ventricular function.
- Develop research consortia that advance basic, translational, and clinical studies, allow for multi-center epidemiological study feasibility, and support junior investigators' training in lung vascular biology and disease.

We encourage the Subcommittee to support the full implementation of these recommendations by the National Institutes of Health.

Mr. Chairman, expanding clinical research remains a top priority for patients, caregivers, and PH investigators. We are particularly interested in establishing a pulmonary hypertension research network. Such a network would link leading researchers around the United States, providing them with access to a wider pool of shared patient data. In addition, the network would provide researchers with the opportunities to collaborate on studies and to strengthen the interconnections between basic and clinical science in the field of pulmonary hypertension research. Such a network is in the tradition of the NHLBI, which, to its credit and to the benefit of the American public, has supported numerous similar networks including the Acute Respiratory Distress Syndrome Network and the Idiopathic Pulmonary Fibrosis Clinical Research Network. We encourage the NHLBI to move forward with the establishment of a PH network in FY12.

For FY2012, PHA joins with other voluntary patient and medical organizations in recommending an appropriation of $35 billion for the National Institutes of Health. This level of funding will ensure continued expansion of research on rare diseases like pulmonary hypertension..

B/ CENTERS FOR DISEASE CONTROL AND PREVENTION

Mr. Chairman, 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. 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.

In FY12, we encourage the subcommittee to establish a specific program at CDC to provide ongoing support for PH education and awareness activities. This would make a tremendous difference in the fight against this devastating disease.

C) "GIFT OF LIFE" DONATION INITIATIVE AT HRSA

PHA applauds the success of the Health Resources and Services Administration's "Gift of Life" Donation Initiative. This important program is working to increase organ donation rates across the country. Unfortunately, the only "treatment" option available to many late-stage PH patients is a lung, or heart and lung, transplantation. This grim reality is why PHA established "Bonnie's Gift Project."

"Bonnie's Gift" was started in memory of Bonnie Dukart, one of PHA's most active and respected leaders. Bonnie battled with PH for almost 20 years until her death in 2001 following a double lung transplant. Prior to her death, Bonnie expressed an interest in the development of a program within PHA related to transplant information and awareness.

PHA has had a very successful partnership with HRSA's "Gift of Life" Donation Program in recent years. Collectively, we have worked to increase organ donation rates and raise awareness about the need for PH patients to "early list" on transplantation waiting lists. For FY 2012, PHA recommends an appropriation of $26 million for this important program.

D) SOCIAL SECURITY DISABILITY

Finally Mr. Chairman, PHA would like to thank the subcommittee for its commitment to address the longstanding backlog of disability claims at the Social Security Administration. We greatly appreciate this investment as a growing number of our patients are applying for disability coverage. On a related note, the SSA recently convened an Institute of Medicine panel to recommend revisions to the disability criteria for cardiovascular diseases. The IOM worked closely with our medical experts to update the disability criteria for our patient population and we were pleased to receive their recommendations earlier this year. We encourage Congress to support this process moving forward.

Once again, thank you for the opportunity to present our views. If you have any questions, or require additional information, please do not hesitate to contact me.

Nemours

Written Testimony of Debbie Chang
Vice President, Policy and Prevention, Nemours; 302-444-9127; dgratale@nemours.org
House Appropriations Subcommittee on Labor, Health & Human Services, Education and Related Agencies
Testimony Addresses the Centers for Disease Control & Prevention & the Health Resources and Services Administration

April 15th, 2011

Nemours thanks Chairman Rehberg, Ranking Member DeLauro and members of the Subcommittee for the opportunity to submit written testimony on the FY 2012 Labor, Health & Human Services, Education and Related Agencies Appropriations bill. Nemours, one of the nation's leading child health systems, is dedicated to improving children's health and well-being by offering a spectrum of clinical treatment, research, advocacy, educational health, and prevention services extending to families in the communities it serves.

About Nemours

Nemours has developed a model of care that integrates clinical preventive and treatment services for children with population-based prevention initiatives. No other health system in the nation has made the same level of investment in community-based prevention programs, policies and practices to reach all children in the community, not just those who cross our doors. Nemours Health and Prevention Services (NHPS) has developed a comprehensive, multi-sector obesity prevention initiative to reach all children in Delaware. To achieve the greatest impact, NHPS considers the many places where children and families spend their time: schools, child care, health care settings, community centers and neighborhoods. The goal is to reinforce consistent messages through policy and practice changes in each setting to help children make healthy food and lifestyle choices and to stay physically active.

In school settings, NHPS works with district-level teams of administrators, teachers, counselors, school nurses, parents and students to encourage wellness policies and provide training and educational tools that support policy and environmental changes to encourage healthier eating and more physical activity on school campuses. In the child care setting, Nemours worked with government leaders to help Delaware become a frontrunner for policies that support healthy eating and physical activity. NHPS provides training and educational tools to help child care providers promote healthy behaviors for young children.

In the primary care setting, Nemours convened pediatric primary care providers from across the state to participate in a learning collaborative focused on improving office-based weight management and health promotion skills. Practitioners learned about new interventions and receive tools for use in the office setting, as well as take-home materials for families. In the community, NHPS works with youth-serving organizations to promote healthy eating and

physical activity and to develop champions who will model the behavior and help spread the message. We also work to create an environment that promotes healthy lifestyles.

Community-based Prevention

As an integrated health system that is very engaged with the community, Nemours sees first-hand the impact of chronic disease on our nation's children. We treat obese young children at our clinics, and we know that unhealthy habits that contribute to obesity are starting at a very young age. In fact, nationally, over 24 percent of children ages 2-5 are already overweight or obese. Much of what influences their health is outside the realm of the health care system, which is why we have made and will continue to make significant investments in community-based prevention. We believe that investing in clinical and community-based prevention is an important way to ensure that children grow up to be healthy adults. We are supportive of the Prevention and Public Health Fund and urge the Committee to utilize the resources provided from this Fund to support the integration of clinical and community-based prevention and to evaluate the outcomes associated with those investments. In particular, we are supportive of Community Transformation Grants.

Community Transformation Grants draw upon the best of what we know works: strong coalitions, multi-sector, public-private partnerships, evidence-based approaches, and evaluation. In Delaware, Nemours has successfully used this combination of approaches to stem the rising curve childhood obesity between 2006 and 2008. These grants allow us to build upon this foundation and spread what works to other communities. The purpose of the grants is to support the implementation, evaluation, and dissemination of evidence-based community preventive health activities in order to reduce chronic disease rates, prevent the development of secondary conditions, address health disparities, and develop a stronger evidence-base of effective prevention programming. In short, these grants would help us in our efforts to help children grow up healthy. If we are serious about the commitment to improving health, then we need to transform the places where children live, learn and play, which is exactly what these grants are designed to accomplish. **We urge the Committee to provide $221.06 million for Community Transformation Grants in FY 2012, which is the level requested by the President.**

Children's Hospital Graduate Medical Education

Another important priority for Nemours is the health care workforce, particularly the pediatric workforce. Children's hospitals care for large numbers of children with complex health conditions. In order to achieve high quality clinical care and outcomes these specialty hospitals need to have well-trained residents and physicians. The Children's Hospital Graduate Medical Education program (CHGME) provides support for graduate medical education to freestanding children's hospitals that train resident physicians. The CHGME program was created to correct an unintended inequity in the GME financing system, which is tied to the number of Medicare beneficiaries being treated at a hospital. Freestanding children's hospitals generally do not provide care to Medicare-eligible patients, and were therefore largely left out of the GME financing system. The CHGME program has addressed this issue.

CHGME supports 55 freestanding children's hospitals that train approximately 40 percent of all pediatricians, 43 percent of all pediatric specialists, and many pediatric researchers and physicians who require pediatric training. In 2009, CHGME supported the training of 5,439 pediatric resident physicians. This is a very important contribution to training our pediatric workforce, which continues to experience shortages, particularly in pediatric specialty care. A 2009 survey by the National Association of Children's Hospitals and Related Institutions (NACHRI) found that national shortages contribute to vacancies in children's hospitals that commonly last 12 months or longer for a number of pediatric specialties. These vacancies often result in longer wait times for children to see pediatric specialists.

At the Alfred I. duPont Hospital for Children, over 300 residents are trained each year. Under the supervision of physicians, these residents provide care for inpatients and also provide primary and specialty care in outpatient settings, including clinics. In 2010, CHGME covered approximately 54% of the cost of the Nemours residency program.

Unfortunately, the President's budget proposes to eliminate funding for this critical program. We urge Congress to reject this short-sighted cut and to continue to provide support for training the next generation of pediatricians, pediatric specialists and pediatric researchers. **Nemours urges the Subcommittee to provide $317.5 million for CHGME in FY 2012, the same amount that was provided in FY 2010.**

Conclusion

Nemours appreciates the opportunity to submit written testimony. As an integrated child health system, we have prioritized investments in clinical and community-based prevention and our workforce because we believe that in the long-run these investments will bend the health curve and the cost curve. We recognize that the nation's fiscal situation requires a close examination of the programs and priorities that the federal government funds. As you make these critical funding decisions, we hope that prevention and the health care workforce will remain priorities of the Subcommittee in FY 2012.

Testimony for the Record
Hearing on Department of Labor Job Training Programs on April 7, 2011
House Subcommittee on Labor, Health and Human Services, Education and Related Agencies
Committee on Appropriations

Thank you for the opportunity to submit written testimony for the April 7th hearing. CLASP is a nonprofit organization that develops and advocates for policies at the federal, state and local levels that improve the lives of low-income people.

Our testimony for the record will focus on three points:

1. The importance of maintaining investments in workforce programs that benefit low-income individuals and those with low education and skill levels
2. The growing body of evidence showing that workforce investments pay off for individuals and society
3. CLASP's recommendations for increasing the effectiveness of the Workforce Investment Act

1. The importance of maintaining investments in workforce programs

As Congress addresses FY 2012 appropriations, we urge Members of the Subcommittee to maintain critical investments in workforce programs. At a time of high unemployment, Workforce Investment Act (WIA) Adult, Dislocated Worker and Youth programs are helping those out of work and the underemployed prepare for jobs and build skills. These programs also help employers meet their needs for skilled workers as the nation recovers from the worst recession since the end of World War II.

The cuts in the final Continuing Resolution for FY 2011 are likely to have an adverse impact on the workforce system, reducing the availability of services at a time of heightened demand. Local areas in Illinois and other states now report waiting lists for initial intake and training services. The more severe cuts in H.R. 1 would have undermined the nation's workforce system. H.R. 1 would have eliminated new funding for the WIA Adult, Dislocated Worker and Youth programs in the Program Year starting on July 1. More specifically, H.R. 1 would have:

- **Eliminated the funding that supports the local youth workforce delivery system across the country.** Local youth programs are critical to helping low-income and disconnected youth enter the labor market, and, in a weak economy, young people are likely to need even more assistance in finding jobs and preparing for postsecondary

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education. According to the Center on Budget and Policy Priorities, WIA would have served 254,000 fewer youth in Program Year 2011 given the scale of the cuts in H.R. 1.

- **Eliminated the funding that supports one-stop career centers and employment and training services for adults and dislocated workers.** The services provided through one-stop career centers help jobless and low-income adults find jobs and prepare for better jobs. Additional services, such as on-the-job training and customized training, can help spur hiring and business growth in local communities. Drastic cuts to services would have led to closure of one-stop career centers and a sharp reduction in the number of unemployed adults and low-income adults receiving services. According to the Center on Budget and Policy Priorities, WIA would have served 6.9 million fewer adults and 1.2 million fewer dislocated workers in Program Year 2011 given the scale of the cuts in H.R. 1.

The funding reductions contained in H.R. 1 overlook the critical role that employment and training programs played during the Great Recession. One-stop career centers and workforce programs became the front line of the response to rising unemployment and economic hardship. More than 8 million individuals received services provided by WIA during 2009 and more than 4.3 million found jobs in one of the most difficult labor markets in decades. In 2008-2009, more than two-thirds of adults and three-quarters of dislocated workers who completed training programs found jobs, according to the U.S. Department of Labor.

As the nation's economy recovers from the Great Recession, it is important to maintain investments in education and workforce programs as the foundation of future economic growth. Education and skill disparities within the U.S. workforce threaten our economic competitiveness. Because of globalization and automation many of the manufacturing and other jobs involving routine tasks are being replaced by those requiring higher order skills.[i] The Georgetown University Center on Education and the Workforce estimates that in the next decade two-thirds of the 47 million projected job openings will require some level of postsecondary education or training, including industry certification. Some 34 percent will require at least a Bachelor's degree, while 30 percent will require some college or a two-year Associate's degree. Only 36 percent of those 47million jobs will require workers with only a high school diploma or less.[ii] The workforce system can address the nation's skill challenges by helping unemployed workers, low-income individuals and those with low education and skill levels build skills and obtain postsecondary credentials that are valued by employers.

2. Growing evidence that workforce development is a good investment, especially for disadvantaged individuals

Since the implementation of WIA in 2000, there have been no experimental evaluations to estimate the impact of workforce services. The Government Accountability Office has noted that the U.S. Department of Labor did not prioritize an impact evaluation in the years following WIA implementation.[iii] However, a rigorous evaluation of WIA services using an experimental design is now under way.[iv]

Recent evaluations demonstrate the benefits of workforce programs in increasing participants' employment and earnings and enabling them to contribute to their local economies.

- A recent experimental study of sector-focused training programs found that participants in these programs earned significantly more than the control group members with most of the earnings gains taking place in the second year. Program participants were more likely to work and work more consistently than control group members; and employed program participants worked more hours, earned higher hourly wages and were significantly more likely to work in jobs that offered benefits. Sector-focused programs usually target rapidly growing jobs that require limited postsecondary education but pay wages at or near the median wage in the economy and that involve intermediary organizations that bring together training providers, employers and workers.[v]

- A 2005 study found that WIA programs lead to positive employment and earnings gains for adults and dislocated workers. In addition, participants in WIA programs were less likely than non-participants to receive public assistance. The authors concluded that WIA services, including training, are effective interventions for adults and dislocated workers (increasing employment by about 10 percentage points and average quarterly earnings by about $800 (in 2000 dollars), when measured in terms of net impacts on employment, earnings, and receipt of TANF for participants.[vi]

- A 2008 DOL evaluation of the Youth Opportunity Grant found positive results, noting increased educational attainment, Pell Grant receipt, labor market participation, and employment rates and earnings for more than 90,000 program participants. The study found that the program increased overall labor force participation rates, specifically for teens ages 16 to 19, women, native-born residents, blacks, and in-school youth; increased the employment rate among blacks, teens, out-of-school youth, and native-born youths; and positively impacted the hourly wages of women and teens.[vii]

- A 2008 DOL report found positive outcomes for WIA Adult program participants, stating "[T]he results… imply large and immediate impacts on earnings and employment for individuals who participate in the WIA Adult program…Those who obtained training services have lower initial returns, but they catch up to others within ten quarters, ultimately registering larger total gains".[viii]

Most evaluations of employment and training programs have focused on a limited range of impact measures, especially employment and earnings gains. Workforce programs also are likely to generate a broader set of benefits to individuals and society. Transitional Jobs programs, which combine time-limited subsidized employment with a comprehensive set of services including case management, have been found to significantly reduce recidivism. In addition, a growing body of research suggests that investments in the adult workforce are likely to pay off for the next generation: when parents obtain additional education and training, their children are likely to achieve improved educational outcomes.[ix]

3. **CLASP's recommendations for increasing the effectiveness of WIA services**

We believe that the best way to improve the effectiveness of WIA services is to move forward with WIA reauthorization, which has languished since 2003. As Congress takes up reauthorization, we call on Congress to:

- **Clarify that the focus of the Adult program should be on the provision of high quality education, training and supports which provide individuals with the necessary skills and experience to access jobs that pay family-supporting wages and have advancement potential.** This redirection is needed to better serve employers and improve the employment prospects and increase earnings for low-income, less educated individuals.

- **Increase the focus and capacity of the workforce system to serve individuals who are low-income, have limited skills and have other barriers to economic success.** This is needed because there has been a steady decline in the share of low-income individuals who exited from the WIA Adult program after receiving intensive or training services. In 2009 low-income individuals represented less than half of those exiting WIA intensive and training services.

- **Revamp the current performance measurement system.** This is needed because the current accountability system for workforce investment programs is not supportive of transforming the system into an effective on-ramp to postsecondary and career success for low-income, low-skilled youth and adults. It has disincentives to serving those who have multiple needs, low education and skill levels and barriers to labor market success.

- **Strengthen connections between workforce investment programs, related education and training programs and economic development.** Better alignment of programs at the federal level will enable states and communities to build career pathways that lead to postsecondary credentials and family-sustaining jobs in key sectors.

- **Use WIA reauthorization to build a stronger, more effective youth delivery system across the nation.** This will require increased investments, strengthening the capacity of Workforce Investment Boards and Youth Councils to play a strategic role in bringing together youth serving systems and resources to structure more comprehensive interventions to support youth's attainment of labor market and postsecondary success.

- **Increase the focus of youth services on youth in high-risk categories such as dropouts, homeless youth, young offenders, disabled youth and those in the foster care system.** In-school youth represent the majority of those served in the WIA youth title. High school dropouts and those with multiple barriers to employment are underserved. Mandating increased service levels for harder to serve youth will not only assure more focused attention on the needs of these groups but changes in program design and interventions to adequately address the barriers to their labor market success.

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- **Continue authorization for targeted funding to economically distressed communities via Youth Opportunity or similar grants to focus on building comprehensive and integrated youth delivery systems in communities of high youth distress.** There is a critical need to rebuild the capacity and infrastructure of the youth delivery systems in communities where 50 to 60 percent of youth are dropping out-of-school and where youth unemployment is at perilous levels. These grants should focus on the cross-system and cross-sector collaboration to build efforts at scale to put high risk out of school youth pathways to postsecondary credentials connected to growing sectors of the regional economy.

Reauthorization of WIA is needed to make the workforce system more effective and more inclusive. We urge Congress to move forward with reauthorization and to maintain investments in workforce programs that benefit individuals, employers and society. Failure to invest in the nation's workforce will undermine the economic recovery and put us at a disadvantage in the global economy.

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I am pleased to present the FY 2012 budget request for NTID, one of eight colleges of RIT, in Rochester, NY. Created by Congress in 1965, we provide university technical and professional education for students who are deaf and hard-of-hearing, leading to successful careers in high-demand fields for a sub-population of individuals historically facing high rates of unemployment and under-employment. We also provide baccalaureate and graduate level education for hearing students in professions serving deaf and hard-of-hearing individuals. NTID students live, study and socialize with more than 15,000 hearing students on the RIT campus.

BUDGET REQUEST:

For FY 2011, Operations funding was increased to $65,437,000 by shifting some Construction funds into Operations (though NTID still received a decrease in total appropriation from FY 2010). This investment by Congress in NTID was *crucial* in order to offset record student enrollment and use of access services, prevent enrollment caps, and avoid the elimination of outreach programs, equipment purchases, and matching endowments. As shown below, NTID's original FY 2012 Budget Request was $64,677,000 in Operations and $2,000,000 in Construction, for a total of $66,677,000.

FY 2012 Budget Request Status

	Operations	Construction	Total
NTID FY 2011 Appropriation	$65,437,000	$240,000	**$65,677,000**
NTID FY 2012 Original Request	$64,677,000	$2,000,000	**$66,677,000**
NTID FY 2012 Updated Request	$65,437,000	$1,240,000	**$66,677,000**

NTID would like to update that request and continue at the FY 2011 Operations level to support our increased enrollment, increased provision of services, and upcoming strategic initiatives (see below). **In order to maintain Operations funding, we would like to modify our original request by shifting $760,000 of our Construction request to Operations. If that is done, then our Operations base for FY 2012 would match the FY 2011 level, thereby allowing us to better meet our Operations needs in FY 2012.** In the meantime, we will continue to seek non-federal funding to support immediate construction/renovation needs while continuing to communicate about critical long-term construction needs.

ENROLLMENT:

In FY 2011 (Fall 2010), we attracted the largest enrollment in our 43-year history – 1,521 students. Truly a national program, NTID has enrolled students from all 50 states. Over the last five years our enrollment has increased 22% (271 students). For FY 2012, NTID anticipates maintaining this record high enrollment level.

NTID Enrollments: Five-Year History

Fiscal Year	Deaf/Hard-of-Hearing Students				Hearing Students			Grand Total
	Undergrad	Grad RIT	MSSE	Sub-Total	Interpreting Program	MSSE	Sub-Total	
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

STUDENT ACCOMPLISHMENTS:

For our graduates, over the past five years, an average of 93% have been placed in jobs commensurate with their education level (using the Bureau of Labor Statistics

methodology). Of our FY 2009 graduates (the most recent class for which numbers are available), 59% were employed in business and industry, 21% in education/non-profits, and 20% in government.

Graduation from NTID has a demonstrably positive effect on students' earnings over a lifetime, and results in a noteworthy reduction in dependence on Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI) and public assistance programs. In FY 2007, NTID, the Social Security Administration, and Cornell University examined approximately 13,000 deaf and hard-of-hearing individuals who applied and attended NTID over our entire history. The studies show that NTID graduates over their lifetimes are employed at a much higher rates, earn substantially more (therefore paying significantly more in taxes), and participate at a much lower rate in SSI, SSDI, and public assistance programs than those who withdraw or who apply but do not attend NTID. Considering the reduced dependency on these federal income support programs, the federal investment in NTID returns significant societal dividends and makes a positive difference in earnings, and in lives.

STRATEGIC INITIATIVES BEGINNING FY2011:

In 2010, NTID completed ***Strategic Decisions 2020***, a strategic plan based on our founding mission statement. This statement sets forth our institutional responsibility to work with students to develop their academic, career and life-long learning skills as future contributors in a rapidly changing world.

Strategic Decisions 2020 establishes key initiatives responding to future challenges and shaping future opportunities. These initiatives include:

- Pursuing enrollment targets and admissions and programming strategies that will result in increasing numbers of our graduates achieving baccalaureate degrees and higher, while maintaining focus and commitment to quality associate-level degree programs leading directly to the workplace;
- Improving services to under-prepared students through working with regional partners to implement intensive summer academic preparation programs in selected high-growth, ethnically diverse areas of the country;
- Expanding NTID's role as a National Resource Center of Excellence regarding the education of deaf and hard-of-hearing students in senior high school (grades 10, 11 and 12) and at the postsecondary level.
- Enhancing efforts to become a recognized national leader in exploring, adapting, testing, and implementing new technologies to enhance access to, and support of, learning by deaf and hard-of-hearing individuals.

NTID ACADEMIC PROGRAMS:

NTID offers high quality, career-focused associate degree programs preparing students for specific well-paying technical careers. NTID also is expanding the number of its transfer associate degree programs, currently numbering seven, to better serve the higher achieving segment of our student population seeking bachelor's and master's degrees in an increasingly demanding marketplace. In support of those deaf and hard-of-hearing students enrolled in the other RIT colleges, NTID provides a range of access services (including interpreting, real-time speech-to-text captioning, and note-taking) as well as tutoring services. One of NTID's greatest strengths is our outstanding track record of assisting high-potential students to gain admission to, and graduate from, the

other colleges of RIT at rates comparable to their hearing peers. A cooperative education (co-op) component is an integral part of academic programming at NTID and prepares students for success in the job market. A co-op gives students the opportunity to experience a real-life job situation and focus their career choice. Over 250 students each year participate in 10-week co-op experiences that augment their academic studies, refine their social skills, and prepare them for the competitive working world.

SUMMARY:

It is extremely important that our Operations funding be maintained at the FY 2011 level as we continue our mission to prepare deaf and hard-of-hearing people to enter the workplace and society. **To continue at this year's Operations level, we ask that $760,000 of the funds we originally requested for Construction be moved into Operations.** Our alumni have demonstrated that they can achieve independence, contribute to society, and find sustainable employment as a result of NTID. We are hopeful that the members of the Committee will agree that NTID, with its long history of successful stewardship of federal funds and outstanding educational record of service with people who are deaf and hard-of-hearing, remains deserving of your support and confidence. 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.

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National Primate Research Centers
Written Statement for the Record
April 15, 2011

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 2012 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 **recommend that you provide $32 billion for NIH in FY 2012**, which represents a 2.4 percent increase above the FY 2010 level. Within this proposed increase the NPRCs also respectfully request that the Subcommittee provide strong support for the NPRC P51 (base grant) program, which is essential for the operational costs of the eight NPRCs. This support would help to ensure that the NPRCs and other animal research resource programs continue to serve effectively in their role as a vital national resource.

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 better health. The NPRCs collaborate as a transformative and innovative network to support the best science and act as a resource to the biomedical research community as efficiently as possible. There is an exceptional return on investment in the NPRC program; ten dollars is leveraged for every one dollar of research support for the NPRCs. It is important to sustain funding for the NPRC program and the NIH as a whole to continue to grow and develop an innovative plan for the future of NIH.

NPRCs' Contributions to NIH Priorities

The NPRCs activities are closely aligned with NIH's 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.

NATIONAL PRIMATE RESEARCH CENTERS

The NPRCs currently are engaged with NIH staff in a comprehensive strategic planning process to further enhance the capabilities of the NPRCs to serve as a resource across all NIH institutes and centers. The NPRC consortium strategic plan has as its center and driving force the scientific priorities that drive translational work into better interventions and diagnostics for improved human health. Outlined below are a few of the overarching goals of the plan, including specifics of how the NPRCs are striving to achieve these through programs and activities across the centers.

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 NIH Clinical and Translational Science Awards (CTSA) program through their host institution. Specifically, the nonhuman primate models at the NPRCs often provide the critical link between research with small laboratory animals and studies involving humans. As the closest genetic model to humans, nonhuman primates serve in the development process of new drugs, treatments, and vaccines to ensure safe and effective use for the public.

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.

Foster Public Understanding of Science – The NPRCs sponsor active outreach programs to promote an understanding of biomedical research for students of all ages. They are strongly supportive of getting students interested in the biomedical research workforce pipeline at an early age. For example, the Yerkes NPRC supports a program that connects with local high schools and colleges in Atlanta, Georgia, and invites students to participate in research projects taking place at their field station location. The Oregon NPRC recently hosted 23 "Road Scholars"—formerly Elderhostel—for three days of intensive exploration of ongoing projects at the adult layperson level. The NPRCs have many other highly subscribed summer and yearlong programs for educators, students, and trainees that tap into the expertise at the NPRCs.

Offer Technologies to Advance Translational Research and Expand Informatics Approaches to Support Research – The NPRCs have been leading the development of a new Biomedical Informatics Research Network (BIRN) for linking brain imaging, behavior, and molecular informatics in nonhuman primate preclinical models of neurodegenerative diseases. Using the cyberinfrastructure of BIRN for data-sharing, this project will link research and information to other primate centers, as well as other geographically-distributed research groups.

NATIONAL PRIMATE RESEARCH CENTERS

Translational Science at the NPRCs

Animal models are an essential tool for translating basic biomedical research to treatments and cures for patients, and the NPRCs are a national resource instrumental to this effort. The network of eight NPRCs collaborates across many disciplines and institutions, with the goal of advancing biomedical knowledge to understand disease and improve human and animal health. Below are specific examples of translational research conducted at each of the eight NPRCs.

In work conducted at the **California National Primate Research Center**, Immunoglobulin G (IgG) antibodies purified from mothers of children with autism and mothers of typically developing children were injected into pregnant rhesus monkeys. The offspring were then evaluated both neurologically and behaviorally. Offspring of mothers who received IgG from mothers of children with autism demonstrated significantly higher levels of repetitive behaviors than the offspring who received control antibodies. There are currently no diagnostic tests for autism. This research identifies one potential autoimmune cause of autism. Moreover, detection of the maternal autoantibodies may become an early diagnostic test for increased risk of having a child with autism. This research, which relied on treating pregnant rhesus monkeys, could not have been conducted without the facilities provided by the national primate center.

Rhesus monkeys are widely-used as animal models across many fields of biomedical research because of their genetic, physiological, behavioral, and anatomical similarities to humans. Scientists at the **New England National Primate Research Center** are taking advantage of the genetic similarity between rhesus monkeys and humans to create the first monkey model of alcoholism genetics. Recent studies in human alcoholics who are treated with naltrexone, a leading medication for alcohol dependence, have shown that the medication works better in people who have a specific genetic variant in the OPRM1 gene. Scientists at the New England NPRC identified a similar genetic change in the rhesus monkey OPRM1 gene, and have shown that monkeys with the genetic change not only drink more alcohol but also have a comparable genetically-determined response to naltrexone to that seen in some human alcoholics. This animal model gives scientists a new way to create personalized medications for the treatment of alcoholism.

A new technique developed by a research team at the **Oregon National Primate Research Center** offers a way for women with mitochondrial diseases to have their own children without passing on defective genetic material. According to the scientists, defective genes in mitochondria can be passed to children at a frequency of 1 in 4,000 births and can lead to a variety of diseases. Symptoms of these potentially fatal illnesses include dementia, movement disorders, blindness, hearing loss, and problems of the heart, muscle, and kidney. Following this successful study in a nonhuman primate model, scientists believe that the technique could be applied quickly to humans to prevent devastating diseases.

In 2005, researchers were looking for an animal model in which to test a prototype device which might ameliorate degenerative disc disease, a major cause of disability in working-age adults. The baboon was chosen as an appropriate animal model for safety testing of the new device because of its upright posture and the high magnitude of forces placed on the vertebral column during the baboon's natural movement. After a small pilot study, two subsequent pre-clinical

studies were performed at the **Southwest National Primate Research Center**. This was an international effort in which specialists from Denmark, Canada, and the United Kingdom visited the Primate Center on numerous occasions to participate in the studies. The data from these studies along with data from human clinical trials are now being assembled for submission to the U.S. Food and Drug Administration for approval to use the artificial disc in the U.S. as an alternative for the treatment of degenerative lumbar spinal disease.

Testing the safety and efficacy of potential compounds in nonhuman primates is virtually essential to advancing microbicide candidates to clinical trials to prevent HIV transmission. There are far too many microbicide candidates in development for all of them to be tested in human trials. Over the years, the **Tulane National Primate Research Center** has facilitated microbicide studies in nonhuman primates that have led to human clinical trials, and have been the only successful predictor of success or failure of compounds in these trials. Furthermore, candidates that were not sufficiently tested in nonhuman primates prior to human trials were shown to fail, and later studies, once performed in macaques, confirmed they would have been predictive of failure. Studies completed at the Tulane NPRC have resulted in Merck releasing one of these compounds to the International Partnership for Microbicides (IPM) for microbicide development and human clinical testing. Based on the positive results in macaque studies, the IPM also has been granted license to pursue topical development of Pfizer's Maraviroc as a microbicide. Nonhuman primate testing has resulted in a wealth of information that has prevented expensive clinical trials in humans that would have otherwise been fruitless.

Recovery of function after stroke, traumatic brain injury or spinal cord injury is a significant medical challenge for millions of patients in the U.S. A promising new treatment for many of these disabled survivors is an implantable recurrent brain-computer interface (R-BCI). The **Washington National Primate Research Center** developed R-BCI, a "neurochip" that records neural activity from the brain and transforms that activity into stimuli delivered to the brain, spinal cord, or muscles during free behavior. R-BCI technology has the clinical potential to aid patients paralyzed by ALS or spinal cord injury to regain some motor control directly from cortical cells and may also be used to strengthen weak connections impaired by stroke.

Researchers and physicians are getter closer to a novel diagnostic test for polycystic ovary syndrome (PCOS), which has staggering adverse physiological, psychological, and financial consequences for women's reproductive health. Scientists at the **Wisconsin National Primate Research Center** are studying the profile of metabolites in both monkey and patient samples of blood, urine, sweat, and breath molecules to identify signals in the body's internal chemistry that are consistent with the syndrome. From the vast pool of metabolites in their samples, they have found a handful that rise to the surface as indicators of PCOS. These telltale molecules could become the basis for the first-ever diagnostic test for the syndrome.

A recent study based on work conducted at the **Yerkes National Primate Research Center** with nonhuman primates illustrates the promise of the Visual Paired Comparison (VPC) task for the detection of mild memory impairment associated with Alzheimer's disease (AD). To investigate this possibility, the Yerkes NPRC recently extended their collaborations to include the Department of Computer Sciences at Emory University. The results show that eye movement

characteristics including fixation duration, saccade length and direction, and re-fixation patterns can be used to automatically distinguish impaired and normal subjects. Accordingly, this generalized approach has proven useful for improving early detection of AD, and may be applied, in combination with other behavioral tasks, to examine cognitive impairments associated with other neurodegenerative diseases. Researchers at the Yerkes NPRC have developed two patents based on this work.

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." In prior years, funding was set aside that fulfilled the infrastructure needs of the NPRCs and other animal research facilities. The NPRCs ask the Subcommittee to provide strong support for construction and renovation of animal facilities through C06 and G20 programs. Without proper infrastructure, the ability for animal facilities, including the NPRCs, to continue to meet the high demand of the biomedical research community will be unattainable.

The NPRCs urge you to provide $32 billion for NIH in the FY 2012 appropriations bill. 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.

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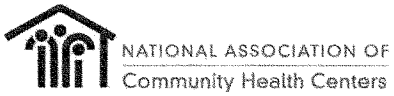

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Introduction

Chairman Rehberg, Ranking Member DeLauro, and Distinguished Members of the Subcommittee:

My name is Dan Hawkins, and I am the Senior Vice President for Public Policy and Research at the National Association of Community Health Centers. On behalf of the 23 million patients served nationwide by health centers; 150,000 full-time health center staff; and countless volunteer board members; I want to thank the Subcommittee for your support of our mission to deliver affordable and accessible care to all Americans. I am pleased to have an opportunity to submit testimony for your consideration as you prepare the FY2012 Labor-Health and Human Services-Education and Related Agencies Appropriations bill.

About Community Health Centers

Health centers offer cost-effective, high-quality, and patient-directed primary and preventive care in 8,000 rural and urban underserved communities across the United States. By statute, health centers must be located in a medically underserved area (MUA) or serve a medically underserved population (MUP) and provide comprehensive primary care services to all community residents regardless of insurance status – offering care on a sliding fee scale. Because of this, health centers serve as the "health care home" for America's most vulnerable

populations, including one-third of individuals living below poverty, one in seven Medicaid beneficiaries, and one in seven of America's uninsured. And nearly half of health center organizations are located in our nation's rural areas. Federal grant dollars appropriated by this Subcommittee and made available through the Health Centers program make up, on average, approximately 20 percent of health centers' operating revenues. These funds are what allow health centers to locate in MUAs and cover the costs of providing primary care to those who cannot afford it, while also effectively delivering coordinated care to all patients.

Presidents of both parties and Members on both sides of the aisle – including many Members of this Subcommittee – have long-recognized the value of health centers. As a result and with bipartisan support, health centers have been on an expansion path for over a decade. Within the past two years, as a result of investments made by Congress, 127 new health centers opened and 3.7 million new patients received access to care at virtually every health center in the country. I'd like to elaborate on why the Health Centers program is such a worthwhile investment for our nation that produces documented savings to the health system – a primary reason this program has been able to count on the Subcommittee's support for several decades.

Health centers save the country money by keeping patients out of costlier health care settings (like emergency departments and hospitals), coordinating care amongst providers of many health disciplines, and effectively managing chronic conditions. Medicaid beneficiaries who rely on health centers for routine care are 19% less likely to use the emergency department (ED) and 11% less likely to be hospitalized for ambulatory care-sensitive (ACS) conditions when compared to beneficiaries who see other providers.[i] Additionally, counties with at least one health center have 25% fewer ED visits for ACS conditions than counties without a health center presence.[ii] By providing timely and appropriate care, health centers save over $1,200 per

person per year, lowering costs across the health care system – from ambulatory care settings to hospital stays.[iii] All told, health centers currently generate $24 billion in savings each year. This is all possible through an investment of just $1.67 per patient per day.[iv]

Health centers meet or exceed national practice standards for chronic condition treatment and ensure that their patients receive more recommended screening and health promotion services than patients of other providers – despite serving underserved and traditionally at-risk populations.[v] The Institute of Medicine (IOM) and the U.S. Government Accountability Office (GAO) have recognized health centers as models for screening, diagnosing, and managing a wide array of relatively common and costly chronic conditions such as diabetes, cardiovascular disease, asthma, depression, cancer, and HIV.[vi] Specifically related to diabetes, a leading cause of death and disability, health centers significantly reduce the expected lifetime incidence of diabetes complications, including blindness, kidney failure, and certain forms of heart disease.[vii] America's health centers also play an important role in improving access to prenatal care and improving birth outcomes. Health centers have demonstrated their ability to reduce the disparity of low birth weight by at least 50 percent compared to national average.[viii]

A key feature of the health center model is that each non-profit entity is locally-owned and directed by a patient majority board that ensures the health center is accountable and responsive to the needs of the community it serves. Research has demonstrated that this type of consumer participation on governing boards ensures higher quality care, lower costs of services, and better results.[ix] In addition to tailoring their services to make health care delivery individualized to unique local circumstances, health centers also have a substantial and positive economic impact on their communities. In 2009 alone, health centers generated $20 billion in total economic benefit and created 189,158 jobs.[x]

Impact of H.R. 1473 on the Health Centers Program

Given yesterday's passage of the FY2011 Continuing Resolution, H.R. 1473, I thought it important to share our analysis of how H.R. 1473 impacts current and future health center operations and services.

As you are aware, summary documents from the full Appropriations Committee indicate that H.R. 1473 would reduce discretionary funding for health centers by $600 million relative to the FY2010-enacted level of $2.19 billion. Together with the $1.0 billion in FY2011 funding available for health centers through the Affordable Care Act (ACA), health centers would have a net increase of approximately $400 million in funding for FY2011. We understand that the final determination of the Health Centers program's funding rests with the Department of Health and Human Services (HHS) and Health Resources and Services Administration (HRSA) but are appreciative that the Committee recommends sufficient funding to continue existing health center efforts, including the new centers and patients added in the past two years.

While we are heartened there should be no interruption of existing health center activities, we are concerned that a significant portion of the $400 million increase is needed to continue ongoing operations – leaving very limited funding to support expansion efforts that would otherwise have been possible if ACA resources were not being redirected to continue existing operations.

Currently, 60 million Americans lack access to a routine source of care.[xi] Prior to H.R. 1473, health centers were on track to double their capacity and serve 40 million patients over the next five years, reaching a sizeable portion of the medically underserved individuals who would otherwise be forced to seek care in EDs, or delay care until hospitalization is the only option.

HRSA previously announced several FY2011 funding opportunities, including grants for new health centers and support for expanded capacity at virtually every existing health center nationwide. These opportunities produced: (1) over 800 applications submitted for 350 New Access Point (new health center) awards, demonstrating the great need across the country for new centers to serve patients who most need access to primary care; and (2) nearly 1,100 health center grantee applications submitted to expand health center services, adding new medical, oral, behavioral, pharmacy, and vision capacity.

The proposed reduction to the Health Center program's discretionary funding leaves HRSA far short of the funding needed to make their previously-announced awards at this time. We look forward to working with the Subcommittee as you prepare the FY2012 bill so that these very worthwhile applications can be funded.

Conclusion

As the Congress works to tackle our nation's deficit, I understand Members of this Subcommittee are faced with incredibly difficult decisions about funding levels for the programs within the FY2012 Labor-Health and Human Services-Education and Related Agencies Appropriations bill. Health centers have proven time and time again, however, that the federal investment in the Health Centers program is prudent – translating to improved health outcomes for our most vulnerable Americans and reduced health care expenditures for this nation. I'd ask for this Subcommittee's support in continuing the bipartisan expansion of health centers in FY2012 to ensure that our shared goal of improved access to high-quality and cost-effective care is realized.

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Fiscal Year 2012 Appropriations
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TESTIMONY OF THE PHYSICIAN ASSISTANT EDUCATION ASSOCIATION

SUBMITTED TO THE
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,
EDUCATION, AND RELATED AGENCIES
COMMITTEE ON APPROPRIATIONS
UNITED STATES HOUSE OF REPRESENTATIVES
REGARDING FISCAL YEAR 2012 APPROPRIATIONS

April 13, 2011

On behalf of its membership, the 156 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) 2012 appropriations for PA education programs that are authorized through Title VII of the Public Health Service Act.

PAEA is a member of the Health Professions and Nursing Education Coalition (HPNEC) and we support the HPNEC recommendation for funding of at least $762.5 million in FY 2012 for the health professions education programs authorized under Title VII and VIII of the Public Health Service Act and administered through the Health Resources and Services Administration (HRSA). HPNEC is an informal alliance of more than 60 national organizations representing schools, programs, health professionals, and students and dedicated to ensuring that the health care workforce is trained to meet the needs of the country's growing, aging, and diverse population.

Need for Increased Federal Funding
Faculty development is one of the profession's critical needs. In order to attract the best qualified to teaching, PA education programs must have the resources to train faculty in academic skills, such as curriculum development, teaching methods, and laboratory instruction. The challenges of teaching are broad and varied and include understanding different pedagogical theories, writing instructional objectives, and learning and applying educational technology. Most educators come from clinical practice and these skills are essential to transitioning to teaching. Educators are a critical element of meeting the nation's demand for an increased supply of primary care clinicians.

Generalist training, workforce diversity, and practice in underserved areas are key priorities identified by HRSA. It is increasingly important that the health workforce better represents America's changing demographics, as well as addresses the issues of disparities in health care. PA programs have been successful in attracting students from underrepresented minority groups and disadvantaged backgrounds. Studies have found that health professionals from underserved areas are three to five times more likely to return to underserved areas to provide care.

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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 156 accredited PA education programs in the United States – a growth of 22% in less than five years; together these programs graduate nearly 6,000 PA students each year. PAs are educated as generalists in medicine; their flexibility allows them to practice in more than 60 medical and surgical specialties. More than one-third of PA program graduates practice in primary care.

The average PA education program is 27 months in length. Typically, one year is devoted to classroom study and approximately 15 months is devoted to clinical rotations. The typical curriculum includes 400 hours of basic sciences and nearly 600 hours of clinical medicine.

As of today, approximately 20 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. In March 2006, there were a total of 7,608 applicants to PA education programs; as of March 2011, there were 16,112 applicants to PA education programs. This represents a 112% 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, which has grown by more than 10 percent each year since the year 2000. The Bureau of Labor Statistics projects a 39% increase in the number of PA jobs between 2008 and 2018. With its relatively short initial training time and the flexibility of generalist-trained PAs, the PA profession is well-positioned to help fill projected shortages in the numbers of health care professionals.

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.

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Title VII funding fills a critical need for curriculum development and faculty development. Funding enhances clinical training and education, assists PA programs with recruiting applicants from minority and disadvantaged backgrounds, and funds innovative programs that focus on educating a culturally competent workforce. Title VII funding increases the likelihood that PA students will practice in medically underserved communities with health professional shortages. The absence of this funding would result in the loss of care to patients in underserved areas.

Title VII support for PA programs has been strengthened with the enactment of the Patient Protection and Affordable Health Care Act (P.L. 111-148), which provides a 15 percent carve out in the appropriations process for PA programs. This funding will enhance capabilities to train a growing PA workforce and is likely to increase the 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 2012 Funding

The Physician Assistant Education Association requests the Appropriations Committee to support funding for Title VII and VIII health professions programs at a minimum of $762.5

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million for FY 2012. This level of funding is crucial to support the nation's demand for primary care practitioners, particularly those who will practice in medically underserved areas and serve vulnerable populations. Additionally we encourage support for the new programs and responsibilities contained in the Patient Protection and Affordable Care Act (P.L. 111-148), including a minimum of $10 million to support PA education programs. We thank the members of the subcommittee for their 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 2012 funding recommendation.

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FY 2012

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Sid L. Scruggs III International
President
Lions Clubs International

Lions Clubs International -- Labor, HHS, Education Priorities FY 2012

Statement of Sid L. Scruggs III
President, Lions Clubs International Foundation
Before the U.S. House Subcommittee on Labor, HHS, Education, and Related Agencies
April, 2011

I would like to begin by thanking Chairman Denny Rehberg, Ranking Member Rosa DeLauro and members of this distinguished Committee for the opportunity to provide this testimony on spending priorities before the Labor, HHS, Education, and Related Agencies Subcommittee. I would also like to commend you, Mr. Chairman, and your colleagues, for examining the way service organizations can collaborate with the Federal government in meeting pressing community needs for improved health and education services.

Lions Clubs International represents the largest and most effective NGO service organization presence in the world. Awarded and recognized as the #1 NGO organization for partnership globally by The Financial Times 2007, Lions Clubs International also holds a four star (highest) rating from the CharityNavigator.com (an independent review organization).

Lions and its official charity arm, Lions Clubs International Foundation (LCIF), have been world leaders in serving the vision, hearing, youth development, and disability needs of millions of people in America and around the world, and we work closely with other NGOs such as Special Olympics International to accomplish our common service goals. Since LCIF was founded in 1968, it has awarded more than 9,000 grants, totaling more than US $700 million for service projects ranging from affordable hearing aids to diabetes-prevention. All Administrative costs are paid for through interest earned on investments, allowing LCIF to maximize out impact on the community and demonstrating the motto "We Serve."

Soon after its founding in Chicago in 1917, Lions Clubs became a service-oriented "export" to the World. Our current 1.35 million-member global membership, representing over 206 countries, serves communities through the following ways: protect and preserve sight; provide disaster relief; combat disability; promote health; and serve youth. The 12,000 individual Lions Clubs representing over 375,000 individual citizens in North America are constantly expanding to add new programs its volunteers are working to bring health services to as many communities as possible.

Today, we face many complex challenges in the health and education sector, from preventable diseases that cause blindness in children to bullying, violence, and drug use among school-aged children. I will offer a brief summary of my remarks through an overview of where Lions Clubs International is involved in programs under the general jurisdiction of the Labor-HHS-Education Subcommittee, and where we recommend areas where Federal partnerships should be maintained and strengthened.

I. Health and Human Services

Domestic Sight Services

Thought our network of foundations and programs across America, Lions remains the single largest provider of charitable vision care, eyeglasses and hearing care services to needy and indigent people. Some of our major sight initiatives include:

- The Sight for Kids Program in collaboration with Johnson and Johnson. The program has provided 6 million vision screenings and eye-health education programs for children.

- Core 4 Preschool Vision Screening program enables Lions to conduct screenings for children in preschools. The program strives to deliver early detection and treatment for the most common vision disorders that can lead to amblyopia or "lazy eye." LCIF has also provided grants and services to those affected by eye conditions that cannot be improved medically.

- Lions Clubs sponsored "United We Serve Health Week" Signature Events around the country. These Health Week efforts, in conjunction with the White House, were effective in bringing awareness to vision health issues.

National Eye Institute – Vision Health Recommendations

Lions Clubs 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.

In 1925, Helen Keller challenged Lions to become "Knights of the Blind." That challenge led Lions to achieve historic achievements in the creation of the "White Cane" mobility tool in the 1940s, the world's first eye bank in the 1950s and guide dog schools in the 1960s. Lions also played an important role in the creation of a free-standing eye institute separate from the then-National Institute for Neurological Diseases and Blindness. The National Eye Institute Act was signed into law by President Johnson in 1968 as the nation's lead Institute within the NIH to prevent blindness and save and restore vision of all Americans. NEI-funded research is resulting in treatments and therapies that save vision and restore sight, resulting in reduced healthcare costs and higher productivity.

Lions Clubs International is concerned that proposals to reduce NIH funding to FY2008 levels would result in NEI funding for FY 2011 at $667 million, or a $30 million loss. This would result in 43 fewer investigator-initiated research grants to save or restore vision. According to the National Association Eye and Vision Research, this funding reflects little more than one percent of the $68 billion annual cost of eye disease and vision impairment in the United States.

Lions Clubs supports FY 2012 NIH funding at $35 billion. This funding level would ensure that NIH can maintain the number of multi-year investigator-initiated research grants, and enables NEI to build upon its record of basic clinical/translational research. We also support an increase in NEI funding above the 1.8 percent proposed by the President.

Vision 2020 USA Partnership

VISION 2020 USA members, including Lions Clubs International, share a commitment to blindness prevention, preserving sight, and ensuring that all individuals receive the vision and eye health care they need and deserve. We are particularly interested in ensuring that Congress provides for Fiscal Year (FY) 2012 to support the following programs and initiatives:

- Sustainment of at least $3.23 million for vision and eye health initiatives at the Centers for Disease Control and Prevention (CDC)
- Support of the Maternal and Child Health Bureau's (MCHB) National Center for Children's Vision and Eye Health

Vision-related conditions affect people across the lifespan from childhood through elder years. Fortunately, in children, many serious ocular conditions – such as amblyopia, nearsightedness, farsightedness, and astigmatism – are treatable, if diagnosed at an early stage. Yet, too many children do not receive vision screenings or follow-up comprehensive eye examinations and treatment. More than 80 million Americans are at risk for a potentially blinding eye disease such as diabetic retinopathy, glaucoma, cataract, and age-related macular degeneration. With the aging of the baby-boom generation, this problem will only worsen over time. In fact, if nothing is done, the number of blind Americans is expected to double by 2030. This is especially troubling because almost half of all blindness can be prevented through early intervention and treatment.

With FY 2012 appropriations that maintain current funding for vision and eye health efforts of the CDC and increased resources for the NIH and NEI, these federal vision and eye health partners will have the resources they need to sustain and expand their respective efforts and programs to advance the prevention, diagnosis, and treatment of vision problems and eye disease.

Lions Affordable Hearing Aid Project (AHAP)

Lions Clubs International is committed to fighting hearing loss as well as blindness. By listening to community health organizations across the country, Lions Clubs International and their volunteer members became aware of the lack of quality and affordable hearing care, especially for people with incomes below or at 200% of the poverty level. Many people have been unable to access other personal and family resources to purchase hearing aids, and have been denied state and federal assistance.

Lions Clubs 14 centers have been working to expand output in this area as demand continues to rise with a network of mobile health units and community based programs that screen more than two million people each year and provide hearing aids to 14,000 low income patients.

The statistics are unacceptable: 31 million persons in the United States experience some form of hearing loss, yet only 7.3 million opt to use hearing aids. According to audiology researchers, the market penetration for hearing aids is about 23.6%. For every four patients that enter a practice needing hearing aids, only one will purchase them. The median price tag is $1900 (2005) for a digital hearing aid and prices go as high as $4000. State Foundations, public health departments, and aging departments are in need of assistance in this area.

With the recent 25-30% increase in people seeking assistance for hearing aids, there is an immediate public imperative to address the problem. Federal dollars are stretched, but Federal support in this area would have significant public health dividends in difficult economic times.

II. "Lions Quest"/Education/Health Programs

Lions Clubs International's youth development initiatives, known collectively as "Lions Quest," have been a prominent part of school-based K-12 programs since 1984. Fulfilling its mission to teach responsible decision-making, effective communications and drug prevention, Lions Quest has been involved in training more than 350,000 educators and other adults to provide services for over 11 million youth in programs covering 43 states. LCIF currently invests more than $2 million annually in supporting life skills training and service learning, and that funding is matched by local Lions, schools and other partners.

Lions Quest curricula incorporate parent and community involvement in the development of health and responsible young people in the areas of: life skills development (social and emotional learning), character education, drug prevention, service learning, and bullying prevention. There is even a physical fitness component to this program that can assist Federal goals of reducing obesity in school-aged children.

These Lions Quest programs provide strong evidence of decreased drug use, improved responsibility for students own behavior, as well as stronger decision-making skills and test scores in math and reading. In August 2002, Lions Quest received the highest "Select" ranking from the University of Illinois at Chicago-based Collaborative for Academic, Social and Emotional Learning (CASEL) for meeting standards in life skills education, evidence of effectiveness and exemplary professional development.

Lions Quest has extensive experience with Federal programs. Lions Quest Skills for Adolescence received a "Promising Program" rating from the U.S. Department of Education Safe and Drug Free Schools and a "Model" rating from the U.S. Department of Health and Human Services Substance Abuse and Mental Health Services Administration (SAMHSA).

Lions Quest also has extensive experience of partnering with state service commissions to reach more schools and engage more young people in service learning. Successful partnerships have been active in Michigan, New York, Oklahoma, Tennessee and West Virginia with progress being made in Texas and Ohio.

Service Learning Initiatives

Lions Quest has also pursued Learn and Serve Grant funding to support implementation of Lions Quest programming in several states. We strongly support Congressional efforts to fund Service Learning Initiatives through the Corporation for National and Community Service and AmeriCorps. We support the expansion of programs and initiatives to provide service learning school-based programs for students as well as Innovative and Community-Based Service-Learning Programs and Research.

Communities across America use national service participants and community volunteers to meet the increased demand for youth education and training services. CNCS is working closely with Lions Clubs International and its Lions Quest youth education program in several Tennessee, Ohio, Maryland, Georgia, and New York with targeted and school-wide programs in service-learning, life skills training, social and emotional learning, increased attendance and improved classroom behavior.

Nationally, federal support for community organizations through the Corporation for National and Community Service leverages $799 million in matching funds from companies, foundations and other sources such as Lions Clubs.

Social and Emotional Learning Programs

In addition, Lions Clubs recommends Congressional support for social and emotional learning (SEL) programs that stimulate growth among schools nationwide through distribution of materials and teacher training, and to create opportunities for youth to participate in activities that increase their social and emotional skills. Not only do SEL curricula contribute to the social and emotional development of youth, but they also provide invaluable support to students' school success, health, well-being, peer and family relationships, and citizenship. While still conducting scientific research and reviewing the best available science evidence, over time Lions Clubs and its SEL partners have increasingly worked to provide SEL practitioners, trainers and school administrators with the guidelines, tools, informational resources, policies, training, and support they need to improve and expand SEL programming.

Overall, SEL training programs and curricula have outstanding benefits for school-aged children:

- SEL *prevents* a variety of problems such as alcohol and drug use, violence, truancy, and bullying. SEL programs for urban youth emphasize the importance of cooperation and teamwork.
- Positive outcomes increase in students who are involved in social and emotional learning programming by an average of *11 percentile points* over other students.
- With greater social and emotional desire to learn and commit to schoolwork, participants benefit from improved attendance, graduation rates, grades, and test scores. Students become caring, concerned members of their communities.

Conclusion

Lions Clubs remains committed to domestic activities such as major sight initiatives and positive youth development and youth service programs. Today we face great health and educational challenges, and Lions Clubs International understands the importance not only of community service but of instilling those among members of our next generation. The success of non-profit entities such as Lions Clubs show what the service sector can do for economic and social development of communities that are especially hard hit by the recession, and we are committed to forming more effective alliances and partnerships to increase our domestic impact. We look forward to working with you and your colleagues on taking up these important challenges.

About Sid L. Scruggs III

Sid L. Scruggs III was elected President of Lions Clubs International at the 93rd International Convention in Sydney, Australia. A member of the Vass Lions Club of Vass, North Carolina, President Scruggs has held many offices within Lions Clubs International, including club president, multiple district extension chairperson and district governor.

President Scruggs has been a presenter at the USA/Canada and Europa Leadership forums and an instructor for the Lions Clubs International Leadership Institute and the District Governors-elect School. He is actively involved with dog guides for the blind and serves as Chairperson for the Governor Morehead School of the Blind Board of Directors, a member of the Board of Directors of the Raleigh Lions Clinic for the Blind, Inc., a life Member of the North Carolina Lions Foundation, a life member of American Airlines Grey Eagles Association, and a life member of the United States Naval Academy Alumni Association. North Carolina Governor Mike Easley presented him with the Order of the Lone Leaf Pine for his work with the blind and his humanitarian service.

In recognition of his service, Scruggs has received four Lion of the Year awards, the 100% Club President Award, eight New Club Extension Awards, the Governor of Excellence Award, the Key of Nations Award, an International President's Leadership Award, eight International President's Awards and the Ambassador of Goodwill Award, the highest honor presented by the International Association of Lions Clubs.

Career

After graduation from the United States Naval Academy in 1960, he was assigned to teach sailing and seamanship before entering the Naval Aviation program at Pensacola, Florida. He eventually served two tours in Vietnam onboard several aircraft carriers. His duties included avionics division officer, weapons training officer, and service on a carrier nuclear safety board. While serving as a flight instructor in the Advanced Jet Training Command, he left the Navy to take a pilot's job with American Airlines where he flew several types of airliners and became a Flight Standards Superintendent.

For additional information about Lions Clubs International and our priorities, please contact:

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National League
for **Nursing**

Testimony Regarding Fiscal Year 2012 Appropriations for Title VIII Nursing Workforce Development Programs
April 15, 2011

Submitted by: National League for Nursing
To: Subcommittee on Labor, Health & Human Services, Education, and Related Agencies, Committee on Appropriations, U.S. House of Representatives
Agency Addressed: Health Resources and Services Administration

The National League for Nursing (NLN) is the premiere organization dedicated to promoting excellence in nursing education to build a strong and diverse nursing workforce to advance the nation's health. With leaders in nursing education and nurse faculty across all types of nursing programs in the United States – doctorate, master's, baccalaureate, associate degree, diploma, and licensed practical – the NLN has more than 1,200 nursing school and health care agency members, 34,000 individual members, and 24 regional constituent leagues.

The NLN *urges the subcommittee to fund the following Health Resources and Services Administration (HRSA) nursing programs:*

- *The Nursing Workforce Development Programs, as authorized under Title VIII of the Public Health Service Act, at $313.075 million in FY 2012; and*
- *The Nurse Managed Health Clinics, as authorized under Title III of the Public Health Service Act, at $20 million in FY 2012.*

NURSING EDUCATION IS A JOBS PROGRAM

According to the U.S. Bureau of Labor Statistics (BLS), the registered nurse (RN) workforce will grow by 22 percent from 2008 to 2018, resulting in 581,500 new jobs. This growth will be much faster than the average for all occupations. The April 1, 2011 BLS *Employment Situation Summary – March 2011* likewise reinforces the strength of the nursing workforce to the nation's job growth. While the nation's overall unemployment rate was little changed at 8.8 percent for March 2011, the employment in health care increased in March with the addition of 37,000 jobs (i.e., a 36.6 percent rise from February 2011) at ambulatory health care services, hospitals, and nursing and residential care facilities.

Nursing is the predominant occupation in the health care industry, with more than 3.78 million active, licensed RNs in the United States in 2009. BLS notes that health care is a critically important industrial complex in the nation. Growing steadily even during the depths of the recession, health care is virtually the only sector that added jobs to the economy on a net basis since 2001. Over the last 12 months, health care added 283,000 jobs, or an average of 24,000 jobs per month.

The Nursing Workforce Development Programs provide training for entry-level and advanced degree nurses to improve the access to, and quality of, health care in underserved areas. These Title VIII nursing education programs are fundamental to the infrastructure delivering quality, cost-effective health care. The NLN applauds the subcommittee's bipartisan efforts to recognize that a strong nursing workforce is essential to a health policy that provides high-value care for every dollar invested in capacity building for a 21st century nurse workforce.

Yet, the current $243.872 million in FY 2010 for the Title VIII programs falls short of the health care inequities facing our nation. Absent consistent support, recent boosts to Title VIII will not fulfill the expectation of paying down on asset investments to generate quality health outcomes; nor will episodic increases in funding fill the gap generated by a 13-year nurse shortage felt throughout the entire U.S. health system.

THE NURSE PIPELINE AND EDUCATION CAPACITY

Albeit the recession resulted in some stability in the short-term for the nurse workforce, policy makers must not lose sight of the long-term growing demand for nurses in their own districts and states. For the complete perspective, the NLN's findings from the *Annual Survey of Schools of Nursing – Academic Year 2009-2010* cast a wide net on all types of nursing programs, from doctoral through diploma, to determine rates of application, enrollment, and graduation. The survey creates a true picture of nursing education. Key findings include:

- **Expansion of nursing education programs impeded by shortage of faculty and clinical placements.** The overall systemic capacity of prelicensure nursing education continues to fall well short of demand. Fully 42 percent of all qualified applications to basic RN programs were met with rejection in 2010. Associate degree in nursing (ADN) programs rejected 46 percent of qualified applications, compared with 37 percent of baccalaureate of science in nursing (BSN) programs. Notably, the nation's practical nursing (PN) programs turned away 40 percent of qualified applications.

- **Yield rates continued to grow.** Yield rates – a classic indicator of the competitiveness of college admissions – remain extraordinarily high among both pre- and postlicensure nursing programs. A stunning 94 percent of all applicants accepted into ADN programs, and 93 percent of those accepted in PN programs, went on to enroll in 2010. Yield rates among the other program types were nearly as high, averaging 89 percent for RN-to-BSN programs; 86 percent for RN diploma programs, master's in nursing (MSN) programs, and doctoral programs; and 84 percent for BSN programs.

NURSE SHORTAGE AFFECTED BY FACULTY SHORTAGE

A strong correlation exists between the shortage of nurse faculty and the inability of nursing programs to keep pace with the demand for new RNs. Increasing the productivity of education programs is a high priority in most states, but faculty recruitment is a glaring problem that likely will grow more severe. Without faculty to educate our future nurses, the shortage cannot be resolved.

The NLN's findings from the *2009 Faculty Census* show that:

- **Shortages of faculty and clinical placements impeded expansion.** A shortage of faculty continues to be cited most frequently as the main obstacle to expansion by RN-to-BSN and doctoral programs – indicated by 47 and 53 percent, respectively. By contrast, prelicensure programs are more likely to point to a lack of available clinical placement settings as the primary obstacle to expanding admissions.

- **Inequities in faculty salaries added to shortage difficulties.** Despite a national shortage of nurse educators, in 2009 the salaries of nurse educators remained notably below those earned by similarly ranked faculty across higher education. At the professor rank nurse educators suffer the largest deficit with salaries averaging 45 percent lower than those of their non-nurse colleagues. Associate and assistant nursing professors were also at a disadvantage, earning 19 and 15 percent less than similarly ranked faculty in other fields, respectively.

TITLE VIII FEDERAL FUNDING REALITY

Today's undersized supply of appropriately prepared nurses and nurse faculty does not bode well for our nation. The Title VIII Nursing Workforce Development Programs are a comprehensive system of capacity-building strategies that provide students and schools of nursing with grants to strengthen education programs, including faculty recruitment and retention efforts, facility and equipment acquisition, clinical lab enhancements, and loans, scholarships, and services that enable students to overcome obstacles to completing their nursing education programs. HRSA's Title VIII data below provide perspective on a few of the current federal investments.

Nurse Education, Practice, Quality, and Retention Grants (NEPQR) – NEPQR funds projects addressing the critical nursing shortage via initiatives designed to expand the nursing pipeline, promote career mobility, provide continuing education, and support retention. In FY 2010, NEPQR funded 108 infrastructure grants, including the launching of 22 nurse managed health centers, four nurse internships, and five new accelerated baccalaureate programs. Also in FY 2010, the program expanded with the Nursing Assistant (NA) and Home Health Aide (HHA) program awarding grants to 10 colleges or community-based training programs.

Comprehensive Geriatric Education Program (CGEP) – CGEP funds training, curriculum development, faculty development, and continuing education for nursing personnel who care for older citizens. In academic year 2009-2010, 27 CGEP grantees provided education and training to 3,030 RNs/RN students; 260 advanced practice registered nurses (APRNs); 221 faculty; 110 HHSs; 483 LPNs/LPN students; 730 NAs; 810 allied health professionals; and 929 laypersons, guardians, activity directors.

Advanced Nursing Education (ANE) Program – ANE supports infrastructure grants to schools of nursing for advanced practice programs preparing nurse-midwives, nurse anesthetists, clinical nurse specialists, nurse administrators, nurse educators, public health nurses, or other advanced level nurses. In addition, the Advanced Nursing Education Expansion (ANEE) program provides grants to schools of nursing to accelerate the production of primary care advanced practice nurses. In FY 2009, 151 schools of nursing received grants through the ANE Program and enrolled 7,518 advanced nursing education students. In FY 2010, 26 schools of nursing received grants under ANEE to support the production of over 600 primary care APRNs.

NURSE MANAGED HEALTH CLINICS (NMHC)

Most leading authorities recognize that there will be a shortage of primary care providers over the next decade. With the recent growth of NMHCs, APRNs have demonstrated their flexibility as they practice independently or collaborate with physicians in both primary care and specialty areas. This shift suggests that professionals' practice can be directed to changing workforce and population needs as the increased use of APRNs holds the potential for improving access, reducing costs for high-value care, and changing patterns of care.

NMHCs deliver comprehensive primary health care services, disease prevention, and health promotion in medically underserved areas for vulnerable populations. Approximately 58 percent of NMHC patients either are uninsured, Medicaid recipients, or self-pay. The complexity of care for these patients presents significant financial barriers, heavily affecting the sustainability of these clinics.

In FY 2010, HRSA awarded $15,268,000 for 10 three-year infrastructure grants to community-based NMHCs. While providing access points in areas where primary care providers are in short supply, the expansion of the NMHCs also increased the number of structured clinical teaching sites available to train nurses and other primary care providers. These clinics funded by HRSA in FY 2010 expect to train 900 primary care nurse practitioners during their three-year grants. Appropriating $20 million in FY 2012 to NMHCs would increase access to primary care for thousands of uninsured people in rural and underserved urban communities. The funding of additional NMHCs likewise will enable schools of nursing to increase innovative clinical teaching site opportunities for nursing students, which will directly expand the capacity of nursing school enrollments.

The NLN can state with authority that the deepening health inequities, inflated costs, and poor quality of health care outcomes in this country will not be reversed until the concurrent shortages of nurses and qualified nurse educators are addressed. Your support will help ensure that nurses exist in the future who are prepared and qualified to take care of you, your family, and all those who will need our care. Without national efforts of some magnitude to match the health care reality facing our nation today, a calamity in nurse education and in health care generally may not be avoided.

The NLN urges the subcommittee to strengthen the Title VIII Nursing Workforce Development Programs by funding them at a level of $313.075 million in FY 2012. We also recommend that the Nurse Managed Health Clinics, as authorized under Title III of the Public Health Service Act, be funded at $20 million in FY 2012.

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TESTIMONY SUBMITTED BY THE

National Association of State Head Injury Administrators

TO THE

HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR-HHS-EDUCATION-RELATED AGENCIES

APRIL 18, 2011

Dear Chairman Denny Rehberg and Ranking Member Rosa DeLauro:

Thank you for this opportunity to submit testimony regarding the fiscal year 2012 budget as it pertains to funding for programs authorized by the Traumatic Brain Injury (TBI) Act of 1996, as amended in 2008. The TBI Act authorizes funding to the US Department of Health and Human Services (HHS) to carry out the intent of the Act through the (1) Centers for Disease Control and Prevention (CDC) for purposes of brain injury surveillance, prevention and education; and the (2) Health Resources and Services Administration (HRSA) for grants to State governmental agencies and to Protection and Advocacy Systems to improve and increase access to rehabilitation services and community services and supports for individuals with TBI and their families.

NASHIA is a non-profit organization representing State governmental officials who administer an array of short-term and long-term rehabilitation and community services and supports for individuals with TBI and their families. These services are generally financed through an array of federal, State and dedicated funds (State trust funds) with the HRSA Federal TBI grants used to support and improve the necessary infrastructure to support these service systems. While NASHIA is well aware that federal funds are becoming increasingly difficult to obtain, NASHIA is recommending increased funding for the federal TBI Act programs because:

- The number of Americans who sustain a TBI is increasing, especially among the elderly and young children, and among our men and women in uniform as a result of the wars in Iraq and Afghanistan, while at the same time,

- States are experiencing significant budget cuts impacting rehabilitation and community services and supports for individuals with TBI, yet

- The number of States receiving grants has been *reduced* from 49 to 21 due to recent changes in HRSA policy and the level of appropriations to support State grant activities.

These factors, as well as the overall economy, are creating a strain on State TBI systems. As the TBI Act program is the *only* federal funding to help States to better serve individuals with TBI, NASHIA recommends:

- $10 million for the CDC programs to support TBI registries and surveillance; to develop Brain Injury Acute Care Guidelines, and to expand prevention and public education regarding injury prevention, including sports-related concussions (mild TBI)
- $ 8 million for the HRSA Federal TBI State Grant Program to increase the number of grants to States
- $ 4 million for the HRSA Federal TBI Protection & Advocacy (P&A) Systems Grant Program to increase the amount of grant awards

HRSA FEDERAL TBI STATE GRANT PROGRAM

Since 1997, HRSA has awarded grants to 48 States, District of Columbia and one Territory to develop and improve services and systems to address the short-term and long-term needs. These grants have been time limited and are relatively small. Two years ago, HRSA increased the amount of the award from approximately $100,000 to $250,000 to make it more feasible for States to carry out their grant goals and the legislative intent. While this increased amount is more attractive to States, this change reduced the number of grantees from 49 to 21 -- less than half of the States and Territories. As a result, States that do not have federal funding are finding it increasingly more difficult to sustain their previous efforts, let alone expand and improve, due to other budget constraints in their States.

Over the course of the grant program, States, depending on individual State needs, have developed State plans for improving service delivery; information & referral systems; service coordination systems; outreach and screening among unidentified populations such as children, victims of domestic violence, and veterans; and training programs for direct care workers and other staff. States have also conducted public awareness and educational activities that have helped States to leverage and coordinate funding in order to maximize resources to the benefit of individuals with TBI.

In keeping with the HRSA Federal TBI State Grant Program most States have identified a lead State agency responsible for providing and coordinating services and an advisory board to plan and coordinate public policies to better serve individuals who frequently needs assistance from multiple agencies and funding streams in order to address the complexity of their needs.

STATE COLLABORATIVE EFFORTS TO ADDRESS THE NEEDS OF VETERANS

The HRSA grant funding has been used to address the needs of returning service members and veterans with TBI and their families. Since service members and veterans first began to return from Iraq and Afghanistan, States have been contacted by families

and returning servicemembers, especially those who served in the National Guard and Reserves, to obtain community resources in order to return to work, home and community.

NASHIA and some individual States have reached out to US Department of Veterans Affairs (VA), particularly staff from individual Polytrauma Centers, to promote collaboration in order to better understand VA benefits for veterans that may be seeking State services, and for VA to understand what is available in the communities. In addition, some States have added representatives from VA, National Guard and Reserves, State Veterans Affairs, and/or veterans organizations to serve on their State advisory board in order to improve communications and policies across these programs.

THE INCIDENCE AND PREVALENCE OF TBI IS ON THE RISE

CDC released new data last year showing that the incidence and prevalence of TBI in the United States is on the rise. CDC reported that each year, an estimated 1.7 million people sustain a TBI. Of that amount: 52,000 die; 275,000 are hospitalized; and 1.365 million (nearly 80%) are treated and released from an emergency department. TBI is a contributing factor to a third (30.5%) of all injury-related deaths in the United States. About 75% of TBIs that occur each year are concussions or other forms of mild TBI. The number of people with TBI who are not seen in an emergency department or who receive no care is unknown." (www.cdc.gov/TraumaticBrainInjury/statistics.hml)

The data collected by CDC relies heavily on State data, gathered through State registries and hospital discharge data. These numbers do not include the veterans who sustained TBIs in Iraq or Afghanistan and now use private or State funded resources for care, or undiagnosed TBIs.

ABOUT STATE RESOURCES AND SERVICES

Since the 1980s, States have developed services and supports largely in response to families who often seek help in crisis situations, such as loss of job due to TBI; or out of control behaviors or substance abuse that may result in family violence or dangerous situations to self and others; and the need for overall help in providing care to their family members who have extensive medical, behavioral and cognitive problems. A critical service that States provide is service coordination to help coordinate and maximize resources and supports for individuals with TBI and their families.

Over the past 25 years, States have developed service delivery systems that generally offer information and referral, service coordination, rehabilitation, in-home support, personal care, counseling, transportation, housing, vocational and other support services for persons with TBI and their families. These services are funded by State appropriations, designated funding (trust funds), Medicaid and Rehabilitation Act programs and are administered by programs located in the State public health, Vocational Rehabilitation, mental health, Medicaid, developmental disabilities, education or social services agencies.

Approximately half of all States have a dedicated funding mechanism, mainly through traffic related fines, and about half of all States also administer a Medicaid Home and

Community-Based Services (HCBS) Waiver for individuals with brain injury who are Medicaid eligible. Individuals with TBI are also served in other State waiver programs designed for physical disabilities, developmental disabilities, elderly and other populations. Some States have the advantage of both waiver and trust fund programs, in addition to other State and federal resources.

As private insurance generally does not provide for extended rehabilitation and long-term care, supports and services, most long-term services and supports for persons with TBI are administered by the States. These programs are funded mainly through the shared federal/State Medicaid Home and Community-based Services Waivers (HCBS) program and Medicaid State Plan services, such as personal assistance, nursing homes and in-home care.

Medicaid HCBS Waivers for Individuals with TBI have grown significantly in recent years, doubling from 5,400 individuals served in 2002 to 11,214 in 2006, at a cost of $155 million in 2002 to $327 million in 2006 (Kaiser Commission on Medicaid and the Uninsured (2007, December); Medicaid Home and Community-Based Service Programs: Data Update, The Henry J. Kaiser Family Foundation, Washington DC).

Without appropriate services and supports, individuals with TBI may become homeless, or inappropriately placed in institutional settings or end up in State or local Correctional facilities due to their cognitive and behavioral disabilities. A recent report issued by the Centers for Disease Control and Prevention (CDC) cited other jail and prison studies indicating that 25-87% of inmates report having experienced a TBI as compared to 8.5% in a general population reporting a history of TBI.

ABOUT NASHIA

The mission of NASHIA is to assist State government in promoting partnerships and building systems to meet the needs of individuals with brain injury and their families. Since 1990, NASHIA has held an annual State-of-the-States conference, and has served as a resource to State TBI program managers. NASHIA also maintains a website (www.nashia.org) containing State program contacts and other resources. NASHIA members include State officials administering public TBI programs and services, and associate members who are professionals, provider agencies, state affiliates of the Brain Injury Association of America (BIAA), family members and individuals with brain injury.

Should you wish additional information on State services and resources, or other information, please do not hesitate to contact Rebeccah Wolfkiel, Governmental Consultant at 202-480-8901 (office) or 202-603-9686 (cell) or rwolfkiel@ridgepolicygroup.com. You may also contact Susan L. Vaughn, Director of Public Policy, at 573-636-6946 or publicpolicy@nashia.org or William A.B. Ditto, Chair of the Public Policy Committee, at williamabditto@aol.com.

Thank you.

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Karen A. Daley, PhD, MPH, RN, FAAN
President

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Chief Executive Officer

May 4, 2011

The Honorable Dennis Rehberg
Chairman
House Appropriations Subcommittee
on Labor, HHS and Education
2358 Rayburn House Office Building
Washington, DC 20515

The Honorable Rosa DeLauro
Ranking Member
House Appropriations Subcommittee
on Labor, HHS and Education
2358 Rayburn House Office Building
Washington, DC 20515

Dear Chairman Rehberg and Ranking Member DeLauro:

On behalf of the American Nurses Association (ANA), the only full-service professional organization representing the interests of the nation's 3.1 million registered nurses, I am writing to urge you to make funding for the Title VIII Nursing Workforce Development programs a priority in the FY 2012 Labor, Health and Human Services, and Education Appropriations bill.

A sufficient supply of nurses is critical in providing our nation's population with quality health care. Registered Nurses (RNs) and Advanced Practice Registered Nurses (APRNs) play an integral role in the delivery of primary care and help to bring the focus of our health care system back where it belongs—on the patient and the community. The current U.S. nursing shortage is already having a detrimental impact on our health care system, and it is expected to grow to a 260,000 nurse shortfall by 2025. 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.

As noted above, the nursing shortage is having a detrimental impact on the entire health care system. Numerous studies have shown that nursing shortages contribute to medical errors, poor patient outcomes, and increased mortality rates. A study published in the March 17, 2011 issue of the *New England Journal of Medicine* shows that inadequate staffing is tied to higher patient mortality rate. 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.

The Nursing Workforce Development programs, authorized under Title VIII of the Public Health Service Act (42 U.S.C. 296 et seq.) support the supply and distribution of qualified nurses to meet our nation's healthcare needs. Over the last 46 years, Title VIII programs have addressed each aspect of the nursing shortages – education, practice, retention, and recruitment.

- Title VIII provides **the largest source of federal funding for nursing education**, offering financial support for nursing education programs, individual students, and nurses.
- These programs bolster nursing education at all levels, from entry-level preparation through graduate study.

- Title VIII programs favor institutions that educate nurses for practice in **rural and medically underserved communities.**
- In FY 2008, these programs provided loans, scholarships, traineeships, and programmatic support to **77,395 nursing students and nurses.**

Title VIII Nursing Workforce Development programs hold the promise of recruiting new nurses into the profession, promoting career advancement within nursing and improving patient care delivery. However, this promise cannot be met without continued, robust investment. ANA strongly urges this Subcommittee to make funding for the Title VIII Nursing Workforce Development programs a priority in the FY 2012 Labor, Health and Human Services, and Education Appropriations bill.

Sincerely,

Rose L. Gonzalez

Rose Gonzalez, MPS, RN
Director of Government Affairs

The US Member of the International Council of Nurses • An Equal Opportunity Employer

Testimony

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

Mark Rey, former Undersecretary of the U.S. Department of Agriculture

Danica Luedtke, Former Job Corps Student
Kicking Horse Job Corps, Ronan, MT

May 13, 2011

Mark Rey, former Undersecretary of the U.S. Department of Agriculture

Mr. Chairman, members of the Subcommittee, thank you for this opportunity to talk about a very important program – Job Corps. My name is Mark Rey, former Undersecretary for the U.S. Department of Agriculture (USDA) during George W. Bush's administration, and current volunteer Board member of the National Job Corps Association (NJCA) – a nationwide network of businesses, non-profits, community colleges, employers and community partners dedicated to promoting and expanding Job Corps.

During my tenure as Undersecretary of Agriculture, I was the USDA official responsible for working with the U.S. Department of Labor (DOL) on the administration of Job Corps. The USDA Forest Service administers 28 Job Corps training facilities in 18 different states, more than any other Job Corps operator in the system.

I became very familiar with the program, and in fact toured many Job Corps centers located across the country. I am familiar with the operations of the Anaconda and Trapper Creek Civilian Conservation Job Corps Centers located in Montana. Through this unique opportunity within USDA, I learned how Job Corps' unique and comprehensive residential, academic and career preparation services led to the program's success and effectiveness.

Specifically, I was able to see firsthand a key component that facilitates the program's effectiveness, namely its market-driven approach to meeting the needs of America's employers. On a regular basis, Job Corps centers work closely with local businesses to customize career trades so students are fully prepared to enter employment upon graduation. Moreover, centers

work with employers to coordinate internship opportunities so students have real-world experiences before they embark on – in many cases – their first career. The result, local businesses have a steady pipeline of ready-to-work and qualified entry-level employees. Job Corps prepares young adults for careers in over 100 skilled trades that business and labor demand, including health care, information technology, security, business technology and hospitality. That's good for business, good for families, and good for the economy.

Job Corps' unique residential nature also allows the program to provide young adults' not only high school diplomas and industry-recognized credentials, but also the quality social and employability skills training that employers regularly cite as the most important entry-level workforce qualification. Job Corps is a pro-business, anti-poverty, anti-crime program with a proven record of success. In just nine to ten short months, the vast majority of Job Corps graduates earn a high school diploma, embark on a career leading to independent lives, and improve their literacy and numeracy levels by more than two grade levels.

Perhaps most important, I came away impressed with the students. They were not, as I first suspected they would be, troubled, unmotivated or academically challenged. To the contrary, the students were intelligent young people from disadvantaged backgrounds or broken homes that were highly motivated to secure a marketable trade, find gainful employment, continue their education, and better themselves. Job Corps has been a particular success in Montana with three operating centers that have produced over 4,800 working alumni scattered throughout the state.

I know that the Subcommittee has difficult financial and political decisions to make over the next several months; however, the Job Corps community is sincerely grateful for your good faith in the program. Every Job Corps graduate that is placed in a job is one less burden on the social safety net. Each year the 124 Job Corps centers located across the nation provide career technical training and job placement services to over 60,000 out-of-school, out-of-work youth who might otherwise cost American taxpayers millions of dollars. Job Corps helps American taxpayers recover these costs by providing a path for these dropouts to complete their high school education and earn the skills to start a career.

Finally, studies have shown that each dollar invested in Job Corps stimulates an additional $1.91 in economic activity and for every million dollars spent, 24 jobs are directly and indirectly created. That means that the federal investment in Job Corps results in: (1) more than $3 billion in annual economic activity and (2) the creation of nearly 42,000 local jobs. Job Corps' return on investment goes beyond providing America's youth with everything they need to start a career or move on to higher education. Job Corps also represents millions of dollars that help rebuild our struggling economy.

On behalf of the NJCA, I urge you to include a strong investment for Job Corps in the fiscal year 2012 Labor, Health and Human Services and Education Appropriations bill. Specifically, I encourage you to include $1.787 billion for Job Corps in the FY 2012 bill. Of the total amount requested, $1.677 billion is for Job Corps' operations account. Funds would allow Job Corps to:

- educate and train more than 60,000 out-of-school, out-of-work youth who might otherwise cost the U.S. millions of dollars each year in public assistance.

- operate, at full capacity, the 124 existing Job Corps centers.
- operate, at full capacity, the five new Job Corps centers *mandated* by Congress: Pinellas (FL), Milwaukee (WI), Ottumwa (IA), Manchester (NH) and Wind River (WY).
- support or create approximately 42,000 jobs in local communities, over 90 percent of which are private sector jobs.
- stimulate approximately $2 of local activity for every $1 spent by Job Corps.

In conclusion, I strongly believe that American taxpayers want to support and expand programs that create new contributors to the system, and limit programs that drain and draw from the system. Job Corps does just that – creates financially independent members of society in hundreds of local communities. Job Corps is not a program that can be put on a back burner and resuscitated at the last minute without consequences. When America's disengaged youth don't have Job Corps as an opportunity, they are much more likely to be on the street and unemployable which causes other costly public assistance alternatives. Job Corps is an important part of our nation's rich history. Just imagine, nearly 3 million of America's youth have embarked on a career path, pursued further education or enlisted in the military because of Job Corps. If one success story touches a person, 3 million is proof positive that Job Corps works.

Danica Luedtke, Former Job Corps Student
Kicking Horse Job Corps, Ronan, MT

My name is Danica Luedtke. I would like to start by thanking you for your time and this opportunity to tell you my Job Corps success story. I was a non-resident student at Kicking Horse Job Corps in Ronan, MT, from 2004 to 2005. This experience changed my life.

I am a tribal member from the Flathead Indian Reservation in Montana, which has a very diverse population. I am the oldest of three children as well as a first generation college student/graduate. My parents always encouraged my siblings and myself to pursue higher education, but being at an income disadvantage found it to be unattainable without a lot of assistance.

I always knew that I wanted to continue my education but was scared at pursuing this dream with little knowledge and help. Without the funds for my higher education dream I was lost, unable to pursue my goals. This is when I was informed of the opportunities that Kicking Horse could offer. I was reluctant at first because I was unfamiliar with the mission and purpose of Job Corps. It wasn't until talking with the encouraging and supportive center staff that I realized they are people who really care and will help me to succeed.

In September of 2004, I enrolled in Kicking Horse Job Corps to embark on an education adventure that would change my life. Through Kicking Horse, I was able to attend the Dental Assisting program at Salish Kootenai College. Through my training I obtained the skills needed to become a dental assistant but also the soft skills needed to enter the working world. Job Corps helped me to become accountable, confident, respectful, helpful, resourceful, and professional. I graduated from Kicking Horse Job Corps and Salish Kootenai College with a Certificate of Completion and an Associate of Applied Science degree.

Upon graduating, I successfully completed the certification exam (Dental Assisting National Board) to become a Certified Dental Assistant. Over the next two years, I worked in 3 different private practice offices in western Montana. Each practice was a unique learning experience and an opportunity for me to expand my professional dental assisting career.

I was then able to pursue my undergraduate studies at Montana State University-Billings where I graduated with a Bachelor in Applied Science with emphasis in Healthcare Administration. Through my entire journey Kicking Horse staff was behind me with letters of recommendation, references, constant encouragement and support.

Over the years I have always felt an obligation to Kicking Horse as they have played a great role in helping me achieve my goals. In September of 2007 I began as an instructor in Kicking Horses Job Corps dental assisting program at Salish Kootenai College. This was my chance to give back to the program that helped me. Over, the past 4 years I have strived to be a helpful and engaging instructor and give all the students the same great opportunity and skills training that Kicking Horse has provided me.

As an instructor I have seen students come from diverse walks of life. The one thing I know is, Kicking Horse offers a safe, stable, encouraging environment for students to achieve their personal and vocational goals. Without Kicking Horse and other Job Corps centers around the country many of these students, like me, would never have the opportunity to seek a better adult life.

I am so proud of each and every student that I have the opportunity to work with because when they leave they hold their heads high. Through Job Corps they are given the opportunity to steer their lives in a more promising direction. For the students who attend Job Corps this may be their only second chance and opportunity to grab life by the reins. There is no sense in having hopes and dreams if there are no means of achieving them.

Submitted by: The National Postdoctoral Association
Testimony for: Subcommittee on Labor, Health and Human Services, Education and Related Agencies, Committee on Appropriations, The U.S. House of Representatives
In regard to: The National Institutes of Health

May 20, 2011

Chairman Rehberg, Vice Chair Alexander, and Members of the Subcommittee:

Thank you for this opportunity to testify in regard to the Fiscal Year 2012 funding for the National Institutes of Health (NIH). We are writing today in regard to support for postdoctoral scholars, **specifically in support of the 4-percent increase in the NIH Ruth L. Kirschstein National Research Service Awards (NRSA) training stipends**, as requested in the President's Budget.

Background: Postdocs are the Backbone of U.S. Science and Technology

According to estimates by The National Science Foundation (NSF) Division of Science Resource Statistics, there are approximately 89,000 postdoctoral scholars in the United States[1]. The NIH and the NSF define a "postdoc" as: ***An individual who has received a doctoral degree (or equivalent) and is engaged in a temporary and defined period of mentored advanced training to enhance the professional skills and research independence needed to pursue his or her chosen career path.*** The number of postdocs has been steadily increasing. The incidence of individuals taking postdoc positions during their careers has risen, from about 25 percent of those with a pre-1972 doctorate to 46 percent of those receiving their doctorate in 2002–05[2]. Moreover, the number of science and engineering doctorates awarded each year is steadily rising with doctorates awarded in the medical/life sciences almost tripling between 2003 and 2007[3].

Postdocs are critical to the research enterprise in the United States and are responsible for the bulk of the cutting edge research performed in this country. Consider the following:

- According to the National Academies, postdoctoral researchers "have become indispensable to the science and engineering enterprise, performing a substantial portion of the nation's research in every setting."[4]
- Postdoctoral training has become a prerequisite for many long-term research projects.[5] In fact, the postdoc position has become the *de facto* next career step following the receipt of a doctoral degree in many disciplines.
- The retention of women and under-represented groups in biomedical research depends upon their successful and appropriate completion of the postdoctoral experience.
- Postdoctoral scholars carry the potential to solve many of the world's most pressing problems; they are the principal investigators of tomorrow.

Unfortunately, postdocs are routinely exploited. They are paid a low wage relative to their years of training and are often ineligible for workman's compensation, disability insurance, paid maternity or paternity leave, employer-sponsored medical benefits, and retirement accounts.

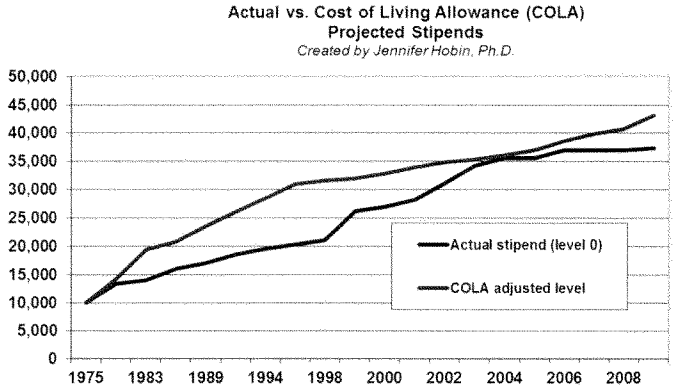
The National Postdoctoral Association (NPA) advocates for policies that support and enhance postdoctoral training. NPA members advocate for policy change on the national level and also within the research institutions that host postdoctoral scholars. To date, more than 150 institutions have adopted portions of the NPA's recommended practices, but low compensation remains one of the serious issues faced by the postdoctoral community.

Problem: NRSA Stipends are Low and Don't Meet Cost-of-Living Standards; For Better or Worse, Postdoc Compensation is Based on NRSA Stipends

The NIH leadership has been aware that the NRSA training stipends are too low since 2001, after the publication of the results of the National Academy of Sciences (NAS) study, *Addressing the Nation's Changing Needs for Biomedical and Behavioral Scientists.* In response, the NIH pledged (1) to increase entry-level stipends to $45,000 by raising the stipends at least 10 percent each year and (2) to provide automatic cost-of-living increases each year thereafter to keep pace with inflation. Most recently, the 2011 NAS study, *Research Training in the Biomedical, Behavioral, and Clinical Research Sciences,* called for, among other recommendations, increased funding to support more NRSA positions and to fulfill the NIH's 2001 commitment to increase pre-doctoral and postdoctoral stipends.

Without sufficient appropriations from Congress, the NIH has not been able to fulfill its pledge. In 2007, the stipends were frozen at 2006 levels and since then have not been significantly increased. The stipends were increased by one percent each year in 2009 and 2010 and by two percent in 2011. The 2011 entry-level training stipend remains low, at $38,496, the equivalent of a GS-8 position in the federal government (NIH Statement NOT-OD-10-047), despite the postdocs' advanced degrees and specialized technical skills. Furthermore, this stipend remains far short of the promised $45,000. Certainly, it is not reflective of any cost-of-living increases (please see Figure 1).

Figure 1.



It is not only the NRSA fellows who remain undercompensated; the impact of the low stipends extends beyond the NRSA-supported postdocs. **The NPA's research has shown that the NIH training stipends are used as a benchmark by research institutions across the country for establishing compensation for postdoctoral scholars.** Thus, an unintended consequence is that institutions undercompensate all of their postdocs, who must then struggle to make ends meet, which in turn affects their productivity and undermines their efforts to solve the world's most critical problems. Additionally, many are leaving their research careers behind because of the low compensation. In order to keep the "best and the brightest" scientists in the U.S. research enterprise, the NPA believes that it is crucial that Congress appropriate funding for

the 4-percent increase in training stipends, as a moderate yet substantial step towards reaching the recommended entry-level stipend of $45,000.

Solution: Keep the NIH's Original Promise to Raise the Minimum Stipends

We ask the Subcommittee to appropriate $794 million for the 4-percent stipend increase, as requested in the President's proposed budget (http://www.nih.gov/about/director/budgetrequest/NIH_BIB_020911.pdf)**:**

> *As part of the President's initiative in FY 2012 to emphasize support for science, technology, engineering, and mathematics (STEM) education programs, the budget proposes a four percent stipend increase for predoctoral and postdoctoral research trainees supported by NIH's Ruth L. Kirschstein National Research Service Awards program. A total of $794 million is requested in FY 2012 for this training program. The proposed increase in stipends will allow NIH to continue to attract high quality research trainees that will be available to address the Nation's future biomedical, behavioral, and clinical research needs.*

The NPA believes it is fair, just, and necessary to increase the compensation provided to these new scientists, who make significant contributions to the bulk of the research discovering cures for disease and developing new technologies to improve the quality of life for millions of people in the United States. Please do not hesitate to contact us for more information. **Thank you for your consideration.**

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[1] National Science Foundation Division of Science Resource Statistics. (January 2010). Science and engineering indicators 2010. Arlington, VA: National Science Board.
[2] Ibid.
[3] Ibid.
[4] COSEPUP. (June 2001). Enhancing the postdoctoral experience for scientists and engineers. Washington, D.C.: National Academy Press. p. 10.
[5] COSEPUP. (June 2001). Enhancing the postdoctoral experience for scientists and engineers. Washington, D.C.: National Academy Press. p. 11.

American Dental Education Association
Testimony for the Subcommittee on Labor, Health and Human Services, Education and Related Agencies
Regarding the Department of Health and Human Services:

The American Dental Education Association (ADEA)[1] respectfully submits this statement for the record and for your consideration as you begin to prioritize fiscal year 2012 appropriation requests. ADEA urges you to preserve the funding and fundamental structure of federal programs that provide prevention of dental disease, access to oral health care for underserved populations, and access to careers in dentistry and oral health services.

As you know, ADEA's membership is comprised of all 61 dental schools in the United States. These academic dental institutions make substantial contributions to the oral health and well-being of the nation. Services are provided through campus and offsite dental clinics where students and faculty provide patient care as dental homes to the uninsured and underserved populations. However, in order to continue to provide these services, there must be adequate funding. Therefore, it is critical that funding for oral health care, delivery of services, and research be preserved in order to ensure the level of care that is necessary for all segments of the population.

ADEA's requests build upon funding from the American Economic Recovery and Reinvestment Act (ARRA), the Labor, Health and Human Services and Education fiscal year 2010 Appropriations, and the Continuing Resolution for FY 2011. We are asking the committee to maintain adequate funding for the ***dental programs in Title VII of the Public Health Service Act; the National Institutes of Health and the National Institute of Dental and Craniofacial Research; the Dental Health Improvement Act; Part F of the Ryan White HIV/AIDS Treatment and Modernization Act: the Dental Reimbursement Program and the Community-Based Dental Partnerships Program; and State-Based Oral Health Programs at the Centers for Disease Control and Prevention***. These programs enhance and sustain state oral health departments, fund public health programs proven to prevent oral disease, fund research to eradicate dental disease, and fund programs to develop an adequate workforce of dentists with advanced training to serve all segments of the population including children, the elderly, and those suffering from chronic and life-threatening diseases.

$30 million for Primary Oral Healthcare Workforce Improvements (HHS)

The dental programs in Title VII, Section 748 of the Public Health Service Act that provide training in general, pediatric, and public health dentistry and dental hygiene are critical. Support

[1] The American Dental Education Association represents all 61 U.S. dental schools, 700 dental residency training programs, nearly 600 allied dental programs, as well as more than 12,000 faculty who educate and train the nearly 50,000 students and residents attending these institutions. It is at these academic dental institutions that future practitioners and researchers gain their knowledge, where the majority of dental research is conducted, and where significant dental care is provided.

for these programs will help to ensure there will be an adequate oral health care workforce to care for the American public. The funding supports predoctoral oral health education and postdoctoral pediatric, general, and public health dentistry training. The investment that Title VII makes not only helps to educate dentists and dental hygienists, but also expands access to care for underserved communities.

Additionally, Section 748 addresses the shortage of professors in dental schools with the dental faculty loan repayment program and faculty development courses for those who teach pediatric, general, or public health dentistry or dental hygiene. There are currently almost 400 open faculty positions in dental schools. These two programs provide schools with assistance in recruiting and retaining faculty.

$35 billion for the National Institutes of Health, including $468 million for the National Institute of Dental and Craniofacial Research (NIDCR)

Discoveries stemming from dental research have reduced the burden of oral diseases, led to better oral health for millions of Americans, and uncovered important associations between oral and systemic health. Dental researchers are poised to make breakthroughs that can result in dramatic progress in medicine and health, such as repairing natural form and function to faces destroyed by disease, accident, or war injuries; diagnosing systemic disease from saliva instead of blood samples; and deciphering the complex interactions and causes of oral health disparities involving social, economic, cultural, environmental, racial, ethnic, and biological factors. Dental research is the underpinning of the profession of dentistry. With grants from NIDCR, dental researchers in academic dental institutions have built a base of scientific and clinical knowledge that has been used to enhance the quality of the nation's oral health and overall health.

Also, dental scientists are putting science to work for the benefit of the health care system through translational research, comparative effectiveness research, health information technology, health research economics, and further research on health disparities. NIDCR continues to make disparities a priority with continued funding for the Centers for Research to Reduce Disparities in Oral Health at Boston University, the University of California, San Francisco, and the University of Colorado at Denver, the University of Florida, and the University of Washington.

$20 million for the Dental Health Improvement Act (DHIA)

Section 340G of the Public Health Service Act created the Grants to States to Support Oral Health Workforce Activities as authorized by the Dental Health Improvement Act. This program supports the development of innovative dental workforce programs specific to the state's dental workforce needs and increases access to dental care for underserved populations.

In 2010, Congress provided at total of $17.5 million to assist states in developing flexible dental workforce programs tailored to meet states' individual workforce needs. Grants are being used to support a variety of initiatives including, but not limited to: loan repayment programs to recruit culturally and linguistically competent dentists to work in underserved communities; rotating residents and students in rural areas; recruiting dental school faculty; training pediatricians and family medicine physicians to provide oral health services (screening exams, risk assessments, fluoride varnish application, parental counseling, and referral of high-risk patients to dentists); and supporting tele-dentistry. We expect FY 2011 appropriations to continue to fund the FY 2010 awarded grants, many of which are three-year projects.

$19 million for Part F of the Ryan White HIV/AIDS Treatment and Modernization Act: Dental Reimbursement Program (DRP) and the Community-Based Dental Partnerships Program

Patients with compromised immune systems are more prone to oral infections like periodontal disease and tooth decay. By providing reimbursement to dental schools and schools of dental hygiene, the Dental Reimbursement Program (DRP) provides access to quality dental care for people living with HIV/AIDS while simultaneously providing educational and training opportunities to dental residents, dental students, and dental hygiene students who deliver the care. DRP is a cost-effective federal/institutional partnership that provides partial reimbursement to academic dental institutions for costs incurred in providing dental care to people living with HIV/AIDS. Congress, recognizing that dental care is a "core medical service" needed by HIV patients provided $13.6 million to fund Part F in 2010.

$107 million for Diversity and Student Aid

- $24 million for Centers of Excellence (COE)
- $60 million for Scholarships for Disadvantaged Students (SDS)
- $22 million for Health Careers Opportunity Program (HCOP)
- $1.2 million for Faculty Loan Repayment Program (FLRP)

Title VII Diversity and Student Aid programs play a critical role in helping to diversify the health profession's student body and thereby the health care workforce. For the last several years, these programs have not enjoyed adequate funding to sustain the progress that is necessary to meet the challenges of an increasingly diverse U.S. population.

$25 million for Oral Health Programs at the Centers for Disease Control and Prevention (CDC)

The CDC Oral Health Program expands the coverage of effective prevention programs. The program increases the basic capacity of state oral health programs to accurately assess the needs of the state, organize and evaluate prevention programs, develop coalitions, address oral health in state health plans, and effectively allocate resources to the programs. This strong public health response is needed to meet the challenges of oral disease affecting children, and vulnerable populations.

As the oral health programs at the CDC are so important, we have serious concerns about the proposal to downgrade the status of the Division of Oral Health (DOH) at the CDC to a branch. We request that you do everything you can to prevent this move.

Thank you for your consideration of this request. ADEA looks forward to working with you to ensure the continuation of congressional support for these critical programs. Please feel free to use us a resource on any issue affecting the oral health care of the nation.

If you should have any questions regarding the aforementioned, please contact Deborah Darcy, ADEA Director of Congressional Affairs at (202) 289-7201 x 163.

Testimony
To the
Labor-HHS-Education Subcommittee
Committee on Appropriations
U.S. House of Representatives

In Support of
FY 2012 Funding
For NIMH and SAMHSA

By
Helen S.
Individual Suffering
From
Borderline Personality Disorder

And

Beth and Rob Elliott in New York,
Diane and Jim Hall in Texas,
And
Other Concerned Parents
Of
Individuals Suffering
From
Borderline Personality Disorder

April 15, 2011

Introduction

On April 1, 2009, the U.S. House of Representatives unanimously passed House Resolution 1005 supporting the month of May as Borderline Personality Disorder Awareness Month. The resolution stated that "despite its prevalence, enormous public health costs, and the devastating toll it takes on individuals, families, and communities [borderline personality disorder] only recently has begun to command the attention it requires."

Borderline personality disorder (BPD) is the most maligned, misunderstood and misdiagnosed of all the major mental disorders. It is serious and often life-threatening, characterized by severe emotional pain and extreme emotional and behavioral dysregulation and expressed by impulsivity (such as reckless driving, risky sex, wild spending), extraordinary negative emotion (such as anger, shame,), chaotic relationships, deep-seated fear of abandonment, and difficulties maintaining a stable and accepting sense of self. Suicidality, self-harm (such as cutting), and substance abuse are highly prevalent.

Although not as well known as bi-polar disorder or schizophrenia, borderline personality disorder is estimated to be far more prevalent than either, afflicting up to 18 million people. The human suffering and economic costs are high. Here are some statistics presented at a Congressional Briefing sponsored by the National Education Alliance for Borderline Personality Disorder (NEA-BPD) and the National Alliance for Mental Illness (NAMI) on May 19, 2010:

- 10% of adults with this disorder take their own lives;
- 33% of youth who commit suicide have features of this disorder;
- 20% of psychiatric hospital patients and more than 10% of outpatients suffer from BPD;
- 17% of prison inmates suffer from its symptoms;
- 50% of individuals with the disorder are severely impaired in their ability to support themselves economically.

In addition, there is the collateral damage suffered by the families of these individuals in terms not only of emotional pain, but also decreased productivity, the cost of health care, and disruption of normal family life; and communities bear the burden of increasingly greater demands on schools, mental and health care facilities, the criminal justice system, and public assistance. .

Borderline personality disorder was regarded as untreatable for many years, but today treatments have been developed that are effective for many individuals. At the same time, diagnosis remains difficult, appropriate treatments are not widely available, and stigma and ignorance remain major obstacles to their implementation. There is still much work to be done to address the human suffering, lost potential, and major mental health and public policy issues of this disorder.

Testimony of Helen S.

To the House Labor-HHS-Education Subcommittee
Committee of Appropriations
May 20, 2011

Chairman Rehberg and Members of the Subcommittee, I am grateful for the opportunity to provide written testimony to the Subcommittee. My name is Helen and I suffer from borderline personality disorder.

People ask me what it's like to have borderline personality disorder. Words and language fail. But there's a photograph from the Viet Nam war... it's a little girl running down a dirt road straight into the camera. She is naked, her clothes burned away by napalm. Her little face is contorted with agony and terror. She is screaming. Several people off to the side of the road are not even interested. She's utterly alone. I call her the "Burning Girl." This is what a borderline feels like inside.

My medical history is roughly the length of Beowulf, but here are some numbers: 3 hospitalizations; 30 consecutive years of individual therapy; $1.3 million in treatment costs (all cash, no reimbursements); and $2 million in lost salary and benefits;
52 medications over 29 consecutive years – currently 8 medications; 4 diagnoses – bipolar, anorexia/bulimia, post-traumatic stress disorder, and borderline.

The diagnosis of borderline came last. I want you to know it is a mongrel diagnosis because of the shame, stigma, and contempt. Nowhere is it more pernicious than with mental health professionals. Worst is the invalidation, as if overnight I'd turned into a mad dog. Self-injury, suicide and extreme dissociation can be lurid, repellant and seemingly intractable, but I'm not a mad dog. No person wants to use these methods. As Proust said, "To kindness and knowledge we make promises. But pain we obey." So cutting has its own perverse logic and beneficence. It's a form of communication, a language written on the body. It says "This is how much pain I feel."

Here's how government funding has significantly helped me recover. First, through NIMH support of the National Education Alliance for Borderline Personality Disorder – a grassroots movement of professionals – with the essential inclusion of borderlines and their families - who are disproving the conventional ignorance of the illness. Second, funding of Dialectical Behavior Therapy (DBT) through NIMH. In conjunction with individual therapy, DBT provides pragmatic methods, dozens of skills to regulate emotions, negotiate relationships, and execute strategies for life and work. Third, NIMH leadership in validating BPD as a national concern.

Let's be frank – I can make this testimony because I'm white, overeducated, and English is my first language. But I represent so many people who can't: my friend Linda, a middle-aged blind woman with a dysfunctional seeing-eye dog, who didn't miss a day of DBT group in eight months; and Sherri, a young African-American who worked in a subway toll booth; she had two small children, two top teeth missing, and too many abusive boyfriends. One day she just disappeared. I wish you could see the striving, the will to connect and contribute, and the lost potential. I know firsthand how many could be saved with more research and education.

You, all of you, have the greatest power to lead the battle against borderline personality disorder, to reverse the inhumane negligence of human beings capable of recovery. Please don't throw us away. There is so much work to be done. Think of 18 million Americans – burning. Please include us in the world in which mental illnesses are prevented and cured. We belong there. We borderlines have the capacity and will to reside in that world. Thank you.

Testimony of Concerned Parents of Individuals Suffering from Borderline Personality Disorder
To the House Labor-HHS-Education Subcommittee
Committee of Appropriations
May 20, 2011

Chairman Rehberg and Members of the Subcommittee, thank you on behalf of ourselves and our loved ones, for giving us this opportunity to present this testimony.

Every parent watches their child grow up with great hopes and dreams of a happy and healthy future. The cruel irony of this disorder is that it most often becomes evident in our children just as they are on the cusp of adulthood. As parents, we are mystified when they become increasingly angry, volatile and self-destructive. We consult a series of experts and doctors about their behavior, often for years, without finding answers or relief. College savings go for treatment and medications; our hopes and dreams change into the daily reality of coping with repeated mental, physical, social, and familial crises. Our children are no longer progressing towards a functional and gratifying adulthood. Our management of a now disrupted family life itself gives way to greater and greater micro-focus and support for the less and less functional adult child, while they themselves may turn to cutting or substance abuse to relieve excruciating emotional pain. This pain, along with anger and impulsivity may lead some to commit criminal acts or engage in violent or risky behavior. An alarming number turn to suicide as their only way out.

If we are lucky, our search may lead us to the proper diagnosis, access to effective therapy, and gradual improvements. Although there are no medications specific for the disorder, there are some prescriptions that can help to manage symptoms. The good news is that with proper treatment, sufferers can experience remission of symptoms and be able to resume their navigation toward a functional adult life. However, remission is not the same as recovery and the path from remission to recovery remains largely uncharted.

Several organizations have been at the forefront of creating a brighter future for our loved ones. One of those is **The National Education Alliance for Borderline Personality Disorder** (NEA-BPD). Formed in 2001, NEA-BPD is a non-profit organization staffed by volunteer consumers, family members, and professionals. NEA-BPD seeks to advance the borderline personality disorder agenda by raising public awareness of borderline, providing education, and promoting research about borderline personality disorder through a variety of programs. For example, with partial funding from a grant from the **National Institute of Mental Health** (NIMH), NEA-BPD has hosted over 30 conferences worldwide, featuring internationally recognized borderline researchers and scientists and attended by professionals, family members, and consumers alike.

Realizing that it was of upmost importance to increase awareness and educate people across the Nation about this devastating and highly stigmatized mental disorder afflicting nearly 18 million Americans, NEA-BPD has turned to Congress for its help and support. **Two Congressional Luncheon Briefings** on Borderline Personality Disorder were held in May 2007 and 2010. The first Briefing was Co-Hosted by Representative Nita Lowey (D-NY) and former Representative Tom Davis (R-VA). The second Briefing was Co-Hosted by Representatives Frank Wolf (R-VA) and Chris Van Hollen (D-MD). The Director of **National Alliance on Mental Illness** (NAMI), the Director of NIMH, and the President-elect of the **American Psychiatric Association** gave presentations at this Briefing.

The Committee on Appropriations of the U.S. House of Representatives (House Report 111-220) requested a report from **the National Institute of Mental Health** regarding its plans to enhance its programs for borderline personality disorder. NIMH submitted a report to Congress in May 2010 entitled "Congressional Appropriations Committee Report on Borderline Personality Disorder" to the Committees on Appropriations of the U.S. House of Representatives and the Senate. NIMH's report stated that the collective efforts from maximizing NIMH-sponsored research will, in turn, lead to improved diagnosis, prevention and interventions for borderline personality disorder.

The Committee on Appropriations also requested a report from the **Substance Abuse and Mental Health Services Administration** (SAMHSA) about its plans to expand its programs and services regarding borderline personality disorder. SAMHSA submitted a report to Congress in July 2010 entitled "Report to Congress on Borderline Personality Disorder" to the Committees on Appropriations of the U.S. House of Representatives and the Senate. SAMHSA's report stated that they are committed to providing a full range of prevention, promotion and treatment services to individuals with borderline, their families, and the communities in which they live.

As evidenced in these reports, NIMH and SAMHSA place a high priority on addressing Borderline Personality Disorder and the needs of individuals afflicted with it. **As parents who are speaking for so many families that grapple with BPD, we urge you to provide full funding for the FY 2012 budget requests of both NIMH and SAMHSA, in order that their work might continue undiminished in the fight to reduce the human and economic toll of this disorder.** Thank you.

Fax: 202-225-3509
Ms. Kristin Smith

Dear Ms. Smith,

Our foundation would like to receive an application to appear before the Committee.

The Mollie Biggane Melanoma Foundation is a public non-profit 501c foundation. We were established in 2000, following the death of our twenty year old daughter from melanoma. It is our mission to increase awareness for melanoma prevention, provide information and services on skin cancer detection, and support melanoma patients through education of the latest treatments. Mollie's Fund has created and produced an 14 minute educational DVD, "The Dark Side of the Sun" the corresponding CD Teacher's Plan was written by health teachers of the NY State APHERD organization. This resource is aligned with the revised National Health Educational Guidelines. We have been able to distribute these educational materials throughout the United States. Our wallet sized brochure "Have You Checked Your Skin Lately?" has been translated into Spanish. Distribution to the public has been through sporting events, health fairs, and medical offices. Recently, we completed a free app which educates millions about the importance of being skin cancer safe. Our foundation has provided many public service announcements through the years that have been shown on TV, radio, national newspapers and train stations.

If we were selected to appear, we would like to discuss the necessity of skin cancer and melanoma educational programs. Statistics tell us that one out of five of us will develop some form of skin cancer in our lifetime. In this country, one person dies each hour from melanoma. And, melanoma is the leading cause of cancer death in women ages 25-30; second to breast cancer in women aged 30-34 (seer.cancer.gov). However, melanoma, if caught early can be cured. Because of increased statistics, either my husband, Jack or I would want to discuss the necessity of further education and prevention initiatives.

Maggie Biggane
www.molliesfund.org
168 Euston Road, Garden City, NY 11530

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