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DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES APPROPRIATIONS FOR 2009

HEARINGS

BEFORE A

SUBCOMMITTEE OF THE

COMMITTEE ON APPROPRIATIONS

HOUSE OF REPRESENTATIVES

ONE HUNDRED TENTH CONGRESS

SECOND SESSION

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

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NOTE: Under Committee Rules, Mr. Obey, as Chairman of the Full Committee, and Mr. Lewis, as Ranking Minority Member of the Full Committee, are authorized to sit as Members of all Subcommittees.

CHERYL SMITH, SUE QUANTIUS, NICOLE KUNKO,
TERI BERGMAN, CHARMAINE MERCER, and ANDRIA OLIVER,
Subcommittee Staff

PART 7

STATEMENTS OF INTERESTED INDIVIDUALS AND ORGANIZATIONS

Printed for the use of the Committee on Appropriations

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DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES APPROPRIATIONS FOR 2009

TESTIMONY OF INTERESTED INDIVIDUALS AND ORGANIZATIONS

THURSDAY, MARCH 13, 2008.

FISCAL YEAR 2009 FUNDING FOR THE INDEPENDENT LIVING PROGRAM OF THE REHABILITATION ACT OF 1973, AS AMENDED (TITLE VII, PART C)

WITNESS

KELLY BUCKLAND, EXECUTIVE DIRECTOR, IDAHO STATE INDEPENDENT LIVING COUNCIL, BOISE, IDAHO, NATIONAL COUNCIL ON INDEPENDENT LIVING, DEPARTMENT OF HEALTH AND HUMAN SERVICES

Mr. OBEY. Well, good morning, everyone. Let me go over a few things before we get started. First of all, please do not be surprised by the fact that we do not have more members of the Subcommittee here. As you can see, there is a Congressional ceremony going on in the Rotunda honoring U.S. military, and a number of members are over there. We had a choice of delaying this session or keeping it on schedule, and out of courtesy to the witnesses who have come from out of town, we thought it best to proceed with the original schedule.

Secondly, please do not take any lack of comment from members of the Subcommittee as being a lack of interest. We are simply trying to keep the schedule on time, also taking into account that in this puzzle factory votes occur from time to time on the House floor that blow away any chance of having an orderly hearing. So we like to try to get a little bit ahead of the clock so that, if that occurs, we do not wind up discombobulating everybody at the end of the process.

So we will try to restrain ourselves on this side of the table as much as possible and let you do the talking today, and we will, I hope, be thinking while you are talking.

Mr. Walsh, do you have any comments before we proceed?

Mr. WALSH. Mr. Chairman, I absolutely agree with everything you said. [Laughter.]

Mr. OBEY. How about Mr. Simpson?

Mr. SIMPSON. I do not have anything. I agree with everything also.

Mr. OBEY. Okay, then, our first witness, National Council on Independent Living, Kelly Buckland.

Mr. BUCKLAND. Good morning, Mr. Chairman, members of the Committee, Representative Simpson. It is good to see you. My name is Kelly Buckland. I am honored to appear before you today to ask you to consider reaffirming your commitment to Americans with disabilities by increasing funding for Centers for Independent Living by $100,000,000. As the President of the National Council on Independent Living (NCIL) and as a person with a disability, I am dedicated to increasing the availability of the extremely cost-effective services that centers provide.

NCIL is the oldest cross-disability, national grassroots organization run by and for people with disabilities. NCIL envisions a world in which people with disabilities are valued equally and participate fully.

Centers for Independent Living are non-residential, community-based, non-profit organizations in all but five Congressional districts that are designed and operated by individuals with disabilities. They provide four core services: Advocacy, information referral, peer support, and independent living skills training. CILs are unique in that they operate in according to a strict philosophy of consumer control in which people with disabilities of any age directly govern and staff the Center. Each of the 336 federally funded Centers are unique because they reflect the interest of their individual communities.

During fiscal years 2004 through 2006, Centers for Independent Living provided independent living services to over 3 million individuals with disabilities and moved 8,381 people out of nursing homes and other institutions. Beyond the direct services that they provide, Centers seek ways to broadly change traditional service delivery in their communities and throughout the Nation, including reform of the long-term care system.

For over 30 years, Centers for Independent Living have sought community-based programs to assist people with disabilities. When services are delivered in an individual's home, rather than a costly nursing facility or other institution, the result is tremendous cost savings to Medicaid and Medicare, while enabling people with disabilities to become independent, financially self-sufficient, and less reliant upon long-term government supports.

Indeed, Mr. Chairman, research conducted in your home State of Wisconsin found that community-based services are at least 21 percent less expensive than nursing home placements. The success in Wisconsin reflects the system's change activities that Centers for Independent Living are struggling to perform on their meager budgets. Such initiatives, if replicated nationwide through increased funding of the Independent Living program, will assist people to regain the right to live, work, and participate independently in society.

NCIL estimates that to meet the current demand and overcome three years of funding cuts, appropriations for Independent Living will need to be increased by $100,000,000. Increased funding should be reinvested from the $160,000,000 that Centers have

saved the Federal Government over the last three years by moving people with disabilities out of costly nursing homes and other institutions.

Supporting Centers in their mission to reintegrate people with disabilities into their communities is both morally sound and financially expedient. Vesting in Centers for Independent Living makes sense. In 2008, Centers are able to attract an additional $267,000,000 through grants, contracts, State funds, and a variety of other creative funding sources. In other words, we make the taxpayers' money work for you and work for our consumers.

Current funding levels barely sustain the day-to-day operations. Without increased funds, our vision to achieve full integration of people with disabilities into society will be undercut and taxpayers will continue to pay for costly nursing homes and bear the economic impact of continued dependence.

Centers for Independent Living are an excellent service and a bargain for America. They help keep people active, engaged in their communities, and they save the taxpayer money. Funding Centers for Independent Living makes sense, common sense, and dollars and cents.

Mr. Chairman, thank you again for this opportunity, and members of the Subcommittee, thank you. We will follow up with each of you and invite you to visit a Center for Independent Living so that you can see firsthand their contributions to your Congressional district.

[The information follows:]

Kelly Buckland, Executive Director
Idaho State Independent Living Council
Boise, Idaho

March 13, 2008

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

on behalf of the
National Council on Independent Living
About Fiscal Year 2009 funding for the Independent Living Program of the Rehabilitation Act of 1973, as Amended
(Title VII, Part C)

Good morning, Mr. Chairman and Members of the Subcommittee.

My name is Kelly Buckland and I would like to start by thanking you for your commitment to enabling people with disabilities to participate fully in their communities by investing in the Independent Living Program.

Today, I am honored to appear again before your Subcommittee to ask that you consider reaffirming your commitment to more than 54 million Americans with disabilities by increasing funding for Centers for Independent Living (CILs) by $100 million, for a total of $173.3 million in FY 2009. I am not making this request as one who would benefit from such an appropriation. Rather, I am asking as the President of the National Council on Independent Living (NCIL), as the Executive Director of the Idaho State Independent Living Council, and as a person with a disability who remains dedicated to increasing the availability of the invaluable and extremely cost-effective services Centers provide.

NCIL is the oldest cross-disability, national grassroots organization run by and for people with disabilities. NCIL's membership includes people with disabilities, Centers for Independent Living, Statewide Independent living Councils, and other disability rights organizations. As a membership organization, NCIL advances independent living and the rights of people with disabilities through consumer-driven advocacy. NCIL envisions a world in which people with disabilities are valued equally and participate fully.

Centers for Independent Living are non-residential, community-based, non-profit organizations in all but five Congressional Districts that are designed and operated by individuals with disabilities and provide four core services: advocacy, information and referral, peer support, and independent living skills training. CILs are unique in that they operate according to a strict philosophy of consumer control, in which people with any type of disability, including people with mental, physical, sensory, cognitive, and developmental disabilities, of any age, directly govern and staff the Center. Each of the 336 federally funded Centers are unique because they are run by people with disabilities and reflect the best interest of each community individually.

Centers for Independent Living address discrimination and barriers that exist in society through direct advocacy. These barriers are sometimes architectural, but more often reflect attitudes and prejudices that have been reinforced for generations. They have deterred people with disabilities from working, leaving many in poverty and unjustly detained in institutions. As my own life experience has proven, with increased opportunities, individuals with disabilities can claim their civil rights and participate in their communities in ways their non-disabled counterparts often take for granted.

Because of the Independent Living Movement's influence on my life, I have been actively involved in disability issues since 1979. Over the past two and a half decades, I have worked closely with the Idaho State Legislature on issues affecting people with disabilities, including passage of the Personal Assistance Services Act and the Fathers and Mothers Independently Living with their Youth (FAMILY) Committee, which changed all of the Child Custody Laws in Idaho to protect the rights of parents with disabilities. And it is my honor to appear before you today on behalf of the nation's Centers for Independent Living.

CILs often identify and implement needed services in their communities that remain unfunded. NCIL estimates that to meet the current demand and overcome three years of funding cuts, appropriations for the IL Program will need to increase by $100 million. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream of society. $100 million of the $160 million Centers have saved the Federal government over the past three years should be reinvested immediately. Considering the amount of money that could be saved simply by supporting Centers in their mission to reintegrate people with disabilities unjustly detained in nursing homes and other institutions, this solution is both morally sound and financially expedient.

According to data collected by the Rehabilitation Services Administration, during Fiscal Years 2004 – 2006, Centers for Independent Living:

- ✓ Attracted over $520 million through private, state, local, and other sources annually;
- ✓ Moved 8,381 people out of nursing homes and institutions, saving states and the Federal government well over $160 million, not to mention improving people's quality of life, and;
- ✓ Provided the core services of advocacy, information and referral, peer support, and independent living skills training to over 3 million individuals with disabilities. [1]

In that same period, Centers provided other services to over 659,000 individuals with disabilities in their respective communities that included:

- ✓ Services to over 56,000 youth with disabilities;
- ✓ Assistance to over 169,000 people in securing accessible, affordable, and integrated housing;
- ✓ Transportation services to over 106,000 people with disabilities;
- ✓ Personal assistance services to over 163,000 people with disabilities;
- ✓ Vocational and employment services to 105,000 people with disabilities, and;
- ✓ Assistance with Assistive Technology for 114,000 people with disabilities.

Beyond the direct services they provide, CILs seek ways to broadly change traditional service delivery in their communities and throughout the nation, including reform of the long-term care system. For over 30 years, Centers for Independent Living have sought community-based programs to assist people with all types of disabilities, across the lifespan, to remain in or return

[1] Rehabilitation Services Administration response to NCIL Freedom of Information Act request 08-00115-F. November 19, 2007

to their family and friends, in their homes and communities. When such services are delivered in an individual's home, rather than a costly nursing facility or other institution, the invariable result is tremendous cost savings to Medicaid, Medicare and states, while enabling people with disabilities to become more independent, financially self-sufficient, and less reliant on long term government supports.

Cost-effectiveness of Community-based Services

Indeed, Mr. Chairman, research conducted by your home state found that community-based services are at least 21% less expensive than nursing home placements. According to the Wisconsin Department of Health and Family Services:

> The total cost in Medicaid Assistance (MA) "...in Fiscal Year 2007 of serving the individuals under the Community Relocation Initiative during the period they lived in their new community settings was $30.7 million. If instead these individuals had remained in their institutional settings during this time period, their MA cost of services would have been $39.3 million... the Community Relocation Initiative produced total savings of $8.6 million in FY07."
>
> Moreover, the report found that "the average daily community cost of individuals served under the nursing home diversion program in FY07 was $59.61, of which $50.33 was waiver costs and $9.28 was card costs. The projected daily MA cost of serving these individuals if they had entered a nursing home is $130.87, assuming that their institutional costs would have been similar to those of the individuals served under the Community Relocation Initiative. The estimated cost of the individuals relocated under the nursing home diversion program in SFY07 is $723,400 all funds. The projected cost of serving these individuals in nursing homes, if they had needed to enter a nursing home, during the same time period was more than double this amount, at $1.6 million all funds." [2]

The Wisconsin Community Relocation Initiative's success reflects the systems change activities CILs are struggling to perform on their meager budgets, which have been cut for the past three years despite increased demand for services. Such initiatives if replicated nationwide through increased funding of the Independent Living Program will assist people with all types of disabilities across the lifespan to gain the right to live, work, and participate independently in society.

In 1999, Independent Living Research Utilization (ILRU) conducted a study to determine what work Centers accomplish. The study found that each Center needs an annual base funding of $250,000 to fully carry out the responsibilities assigned them.[3] That figure would be significantly higher today, given increased mandated responsibilities and inflation. Yet, current funding (under Part C of Title VII of the Rehabilitation Act) provides only $73.3 million to support 336 Centers throughout the country. The average grantee receives approximately $218,000, which

[2] Wisconsin Department of Health and Family Services. 2007. Community Relocation Initiative an Opportunity for People in Nursing Homes.
[3] Independent Living Research Utilization, 1999.

often includes funding for one or more satellites. After three consecutive years of funding cuts, Independent Living is now funded below the FY 2003 base level.

Clearly, investing in Centers for Independent Living makes sense. In 2000, with the $48 million Centers received in federal funding, they were able to attract an additional $267 million through grants, contracts, state funds, and a variety of other creative funding sources. The percentage of Title VII funds as part of the gross revenue had dropped 2% and fee-for service had increased by 2%, showing CILs have diversified their funding. In other words, we make the taxpayers money work for you and for our consumers.

Transition Services in Rehabilitation Act Reauthorization

Based on growing consumer demand and population trends, NCIL strongly supports the current Senate draft bill to reauthorize the Rehabilitation Act of 1973, as amended. This reauthorization, a decade in the making, creates a fifth core service: transition. This includes youth transition from school to higher education and work, and development and support of moving people out of costly Medicaid nursing home facilities into their communities. We are working with your colleagues on the relevant authorizing committees in both chambers of Congress to enact this additional service. Funding these sorely needed transition services will be critical to promoting effective employment outcomes, successful nursing home transition, and increased community participation for transitioning students.

Current funding levels barely sustain day-to-day operations. Centers struggle to meet the demands of the community and provide leadership and common sense solutions. Without increased funds our vision to achieve full integration of people with disabilities in society will be undercut and taxpayers will continue to pay for costly Medicaid nursing homes and bare the economic impact of negative employment outcomes and continued dependence on programs that disincentivize work and community involvement.

Centers for Independent Living are an excellent service and a bargain for America. They keep people active and engaged in their communities, and they save taxpayer money. Funding Centers for Independent Living makes sense: common sense and dollars and cents.

Thank you again for this opportunity, Mr. Chairman and Subcommittee members. We will follow up with each of you to invite you to visit your local Center for Independent Living so you can see first hand their contributions to your Congressional Districts. We look forward to working with you to ensure that Americans with disabilities have the opportunity become active members of society. Please do not hesitate to contact Deb Cotter of the NCIL Policy staff if we can provide you with additional information. Deb can be reached at (202) 207-0334, ext 1008 or deb@ncil.org.

Mr. OBEY. Thank you very much.

And let me apologize, because I forgot to do one other thing in setting the context for the testimony today. I want everyone to understand that I think virtually every member of this Subcommittee, on both sides of the aisle, will be very sympathetic to most of the causes that we hear addressed today. We have one specific problem: the appropriation bills that were signed last year by the President were some $22,000,000,000 below the level that this Committee eventually produced because the White House refused to budge on its overall funding levels for appropriation bills.

This year, just to stay at the level of funding that was provided by those bills last year, we will have to add back roughly $26,000,000,000 that the President's budget cuts from a variety of domestic programs. That makes it very difficult to be responsive sufficiently to the many good causes we will hear about today, and I just want people to be aware of what the root of the problem is as we address these issues.

But thank you. It is good to see you again. I appreciate your coming.

Mr. BUCKLAND. It is good to see you again, Mr. Chairman. Thank you.

Mr. OBEY. If any member of the Committee has any comments or any questions at any time, please, just volunteer.

Mr. SIMPSON. Well, Mr. Chairman, I just want to thank Kelly for coming out. I have known Kelly since, what, legislative days, years ago, it seems like.

But thank you for taking the time to come out and testify. We appreciate it very much.

Mr. BUCKLAND. Thank you, Representative Simpson. It is good to see you again.

THURSDAY, MARCH 13, 2008.

FISCAL YEAR 2009 FUNDING FOR OCCUPATIONAL SAFETY AND HEALTH ADMINISTRATION, EMPLOYMENT AND TRAINING ADMINISTRATION, AND OFFICE OF LABOR MANAGEMENT STANDARDS

WITNESS

ARLENE HOLT BAKER, EXECUTIVE VICE PRESIDENT, AMERICAN FEDERATION OF LABOR-CONGRESS OF INDUSTRIAL ORGANIZATIONS (AFL–CIO)

Mr. OBEY. And now American Federation of Labor and Congress of Industrial Organizations, or, as people know it, AFL–CIO, Arlene Holt Baker.

Ms. BAKER. Good morning, Mr. Chairman and members of the Committee. I would like to thank you for this opportunity to testify this morning. My name is Arlene Holt Baker. I am the Executive Vice President of the AFL–CIO. The AFL–CIO is a federation that represents 56 affiliates and 10.5 million working families in all sectors in the United States economy.

On behalf of the AFL–CIO, I thank you for the difficult work you do. The scarce resources over which this Subcommittee has jurisdiction cannot meet all the needs our Country faces. For the sake

of time, I am limiting my testimony to some of the most pressing priorities of the AFL–CIO; however, we will continue to engage the Appropriations Committee throughout the remainder of this Congress on a full range of funding issues.

President Bush's eighth and final budget to Congress overwhelmingly ignores the needs and priorities of working families. The Bush fiscal year 2009 budget preserves expensive tax cuts for the wealthy and dramatically boosts military spending, while cutting crucial programs for the most vulnerable Americans: Children, the elderly, the poor, and the sick. The President continues to propose major cuts in domestic appropriations and entitlements over the next five years, starting with $23,000,000,000 in fiscal year 2009, totaling a massive $474,000,000,000 in cuts over five years.

Even though unemployment is on the rise and our economy is in serious distress, the President's budget contains over $1,000,000,000 for cuts for job training and employment security programs. Under this proposal, job training programs for dislocated workers, young people, Native Americans, migrant and seasonal farm workers will all suffer major cuts, along with a program that enables low-income senior citizens to work with community-based organizations in neighborhoods across the Country.

Although the President has proposed some reforms and a modest increase in funding the Trade Adjustment Assistance program, his reforms and his budget request fall far short of the essential improvements in the TAA bill already approved by a bipartisan majority in the House of Representatives, a bill he has irresponsibly vowed to veto.

This Bush Administration budget continues to underfund many basic, important programs that have been enacted over decades to protect America's workers from abusive employer practices. Yet, at the same time, the Bush Administration continues to seek even further increases in funding for offices of the Labor Department that have been politicized and that have institutionalized the harassment of union activists who are engaged in their fundamental and legal right to belong to a union and participate in the lawful exercise of that right.

In particular, the Department should be halted from moving forward with the implementation of the intrusive 9-page disclosure form, the LM–30, which would provide an extreme and unfair burden on rank and file union members who perform representational tasks such as resolving shop floor disputes or conducting safety inspections.

With this budget, the President has also turned his back on the brave men and women who responded to the devastating September the 11th attacks at the World Trade Center. These workers desperately need medical care, but the President's budget will slash funding for the World Trade Center Medical Screening and treatment program by 77 percent, from $108,000,000 to just $25,000,000.

And the President's budget puts other workers at greater risk. Funding for the research agency, the National Institute for Occupational Safety and Health, will be cut 10 percent. At the Department of Labor, a small increase in funding has been requested for the Federal enforcement program for the Occupational Safety and

Health Administration, but the worker safety and health training program will be eliminated under the budget. And the budget proposes to reduce funding for coal mine safety enforcement and for the development of new mine safety standards at a time when coal mine catastrophes continue, and when the Mine Safety and Health Administration is already failing to meet the legal deadlines for issuing new protective standards.

Although 47 million Americans lack health insurance and millions more need coverage and struggle every day with rising costs——

I see, Mr. Chairman, that the light is on. I will stop at this point and you can read the rest of it in the written testimony. We thank you for this opportunity to testify before the Committee.

[The information follows:]

Testimony of Arlene Holt Baker
Executive Vice President, American Federation of Labor - Congress of Industrial Organizations (AFL-CIO)
Washington, DC

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

Thursday, March 13, 2008
10:00 a.m.

Testimony on the funding priorities of America's working families that fall within the jurisdiction of the Appropriations Committee Subcommittee on Labor, Health and Human Services, Education and Related Agencies. It includes the AFL-CIO's views on the President's fiscal year 2009 budget submission and recommendations on funding for the Workforce Investment Act, Unemployment Insurance, Employment Services, Trade Adjustment Assistance, worker safety and health programs including OSHA, NIOSH, MSHA and the World Trade Center Health Program, and the Office of Labor Management Standards.

Mr. Chairman and members of the Committee, I would like to thank you for the invitation to testify before your panel. My name is Arlene Holt Baker and I am Executive Vice President of the American Federation of Labor - Congress of Industrial Organizations (AFL-CIO). The AFL-CIO has 56 affiliated unions and represents 10.5 million working people in all sectors of the United States economy.

While every Appropriations subcommittee has jurisdiction over federal spending that is important to our affiliates and members, the Subcommittee on Labor, Health and Human Services, Education and Related Agencies has jurisdiction over many federal programs that are vitally important to America's working families. This subcommittee is also responsible for funding many of the most important programs that comprise the social and economic safety net that a progressive and compassionate society provides to its most vulnerable citizens.

On behalf of the AFL-CIO, I thank you for the difficult work you do. The scarce resources over which this subcommittee has jurisdiction cannot meet all the needs our country faces after the seven years of abuse and neglect that is the legacy of the Bush-Cheney administration. For the sake of time, I am limiting my testimony to some of the most pressing priorities the AFL-CIO has identified. However, we will continue to engage the Appropriations Committee throughout the remainder of this Congress on a full range of funding issues.

President Bush's eighth and final budget to Congress overwhelmingly ignores the needs and priorities of working Americans. The Bush FY 2009 budget preserves expensive tax cuts for the wealthy and dramatically boosts military spending, while cutting crucial programs for the most vulnerable Americans—children, the elderly, the poor and the sick.[1] The President continues to propose major cuts in domestic appropriations and entitlements over the next five years, starting with $23 billion in FY 2009, totaling a massive $474 billion in cuts over five years.[2]

Even though unemployment is on the rise and our economy is in serious distress, the President's budget contains over $1 billion in cuts for job training and employment security programs. Under this proposal, job training programs for dislocated workers, young people, Native Americans, and migrant and seasonal farm workers will all suffer major cuts, along with a program that enables low-income senior citizens to work with community-based organizations in neighborhoods across the country.

Although the President has proposed some reforms and a modest increase in funding for the Trade Adjustment Assistance (TAA) program, his reforms and his budget request fall far short of the essential improvements in the TAA bill already approved by a bipartisan majority in the House of Representatives – a bill he has irresponsibly vowed to veto.

This Bush Administration budget continues to underfund many basic, important programs that have been enacted over decades to protect America's workers from abusive employer practices. Yet at the same time, the Bush Administration continues to seek even further increases in funding for offices of the Labor Department that have been politicized and that have institutionalized the harassment of union activists who are engaged in their fundamental and legal right to belong to a union and participate in the lawful exercise of that right. In particular, the Department should be

halted from moving forward with the implementation of the intrusive nine-page disclosure form, the LM-30, which would provide an extreme and unfair burden on rank and file union members who perform representational tasks such as resolving shop floor disputes or conducting safety inspections.

With his budget, the President has also turned his back on the brave men and women who responded to the devastating September 11 attacks at the World Trade Center. Thousands of these workers are now sick, many are disabled and some have died. These workers desperately need medical care, but the President's budget will slash funding for the World Trade Center Medical Screening and treatment program by 77 percent -- from $108 million to just $25 million. This is a cruel and dishonest rejection of the brave men and women who toiled for months on the rescue and recovery efforts at the World Trade Center site.

And the President's budget puts other workers at greater risk. Funding for the research agency, the National Institute for Occupational Safety and Health (NIOSH), will be cut 10 percent. At the Department of Labor, a small increase in funding has been requested for the federal enforcement program for the Occupational Safety and Health Administration, but the worker safety and health training program will be eliminated under the Bush budget. And the budget proposes to reduce funding for coal mine safety enforcement and for the development of new mine safety standards at a time when coal mine catastrophes continue and when the Mine Safety and Health Administration (MSHA) is already failing to meet legal deadlines for issuing new protective standards.

Although 47 million[3] Americans lack health insurance and millions more with coverage struggle to meet rising costs, the Bush tax proposal will actually make those who have coverage pay more, while providing no real help for the uninsured. Unconscionably, the proposed budget will also cut more than $196 billion[4] over five years from Medicare and Medicaid, shift more costs to the states and limit eligibility for children who now receive coverage under the State Children's Health Insurance Program (SCHIP).

In short, the Bush budget is dangerously unmindful of our shaky economy and the perilous hold by many working families in our nation's middle class. It shortchanges the vital needs of America's workers, while giving priority to special interests and an anti-worker political agenda.

In my full written testimony that follows, I have singled out a few of the many priority areas in which the committee should do everything in its power to address important disparities.

PROGRAMS FOR JOB TRAINING AND JOBLESS WORKERS

Workforce Investment Act Programs

The President's FY 2009 budget proposes to eliminate Workforce Investment Act adult, youth and dislocated worker programs and consolidate funding into state block grants to be used for unproven Career Advancement Accounts that will provide less help to unemployed workers. Additionally, the budget will cut the total commitment to all training and assistance programs immediately.

Our nation's workforce training programs are often the last resort for low-income and disadvantaged workers who have been neglected by their employers and the underfunded student financial aid system. These are the workers who will be hurt most by these cuts. The President's continued cutting of job training funding and assistance for unemployed workers compounds the labor market problems working families have experienced since 2001 and worsens their economic anxiety.

Unemployment Insurance and Employment Service Programs
The FY 2009 budget proposes to cut Employment Security programs that support state Unemployment Insurance and Job Service activities, national activities and one-stop/labor market information programs by $685 million in real dollars compared to FY 2008. The FY 2009 budget represents a $1.5 billion cut from FY 2001 for these programs. Such cuts will significantly impair the ability of our nation's workforce system to provide career information to jobless workers and reduce the capacity to link employers and jobseekers in an effective manner.

President Bush's plan to eliminate the Employment Service will undermine the principle of an unbiased, nonpartisan agency to administer job referrals and assist in the payment of UI and Trade Adjustment Assistance benefits. The president's plan will lead to the privatization and contracting out of vitally important employment security functions, thereby compromising control over and accountability for federal resources.

The elimination of the Employment Service will hurt millions of unemployment insurance claimants and other jobless workers as well as employers seeking job applicants. It will have a particularly devastating effect on trade-impacted workers and veterans, as well as low skilled, minority and long-term unemployed workers who rely on the Employment Service for help.

The AFL-CIO urges the Committee to support our nation's public labor exchange system not only by turning back the administration's attempt to eliminate it, but also by providing resources to begin rebuilding that system, which has suffered from many years of disinvestment.

Trade Adjustment Assistance (TAA) Programs
Unfair and inequitable trade policies are shrinking the middle class and fostering the flight of good jobs overseas. Between 2001 and 2006, an average of 159,000 workers per year were certified as eligible for Trade Adjustment Assistance (TAA), a program designed to provide income support and training to workers who lose their jobs due to trade with certain countries.[5]

Renewed in 2002 and combined with the NAFTA Transitional Adjustment Assistance Program, the new TAA program increased the number of workers potentially eligible for training and income support when they lose jobs because of international trade. It also extended some health care coverage to eligible participants. Lack of resources and funding, however, has resulted in significant problems in the adequacy and responsiveness of the program. The President's FY 2009 budget proposal will only worsen those problems. Assuming the President's trade policies continue to eliminate jobs for American workers, nearly 40,000 affected workers will not receive assistance because of the limited resources the administration proposes to make available in the FY 2009 budget.

Worker Safety and Health Programs

President Bush's FY 2009 budget request for worker safety and health programs is a very mixed picture. Funding for some programs, including federal Occupational Safety and Health Administration (OSHA) enforcement, is increased. But other programs, including the National Institute for Occupational Safety and Health (NIOSH), suffer major cuts. Those programs designed to expand and improve knowledge about hazards and protections, including research, standard setting and training, are being cut or neglected. With this latest budget, the nation will fall further behind in efforts to address many serious safety and health problems workers face on the job.

The President has proposed a reduction in funding for the Mine Safety and Health Administration (MSHA) over FY 2008 levels. The coal enforcement program will be cut by nearly $10 million and the standards development office by $350,000, at a time when coal mine catastrophes continue and when MSHA is failing to meet legal deadlines for issuing new protective standards.

For FY 2009, President Bush has proposed a $28 million cut in the NIOSH budget, reducing the nation's commitment to researching and preventing workplace injuries, diseases and deaths. With this combined budget request of $1.08 billion for the federal job safety agencies, in FY 2009, the Bush Administration proposes to spend only $7.39 per American worker to protect them from job injuries, illnesses and death.[6]

The Bush Administration proposes to totally eliminate funding for OSHA's worker safety and health training and education programs, as it also proposed in FY 2008. Indeed, every year since taking office, the Administration has sought to slash or eliminate funding for worker training. But each year the Congress has rejected these proposed cuts and maintained funding for worker safety training programs. At the same time, the Administration has proposed significant increases in funding for compliance assistance programs for employers, requesting a total of $131.1 million, which represents 26 percent of the overall OSHA budget.

For FY 2009, the Bush Administration has also proposed to slash funding for the World Trade Center (WTC) Screening and Treatment Program for 9/11 responders who are now sick as a result of exposures at Ground Zero. Only $25 million is requested for this program in FY 2009, compared to $108 million appropriated by Congress in FY 2008. This does not include emergency funding appropriated in earlier years for this program carried over to FY 2008. NIOSH, which administers this program, has estimated the annual cost of the program at $218 million. The President's FY 2009 budget proposal will leave thousands of sick workers without access to necessary medical treatment for their 9/11 conditions.

The AFL-CIO urges the Committee to increase the investment in worker safety and health programs. In particular, we ask that funding for worker safety and health training programs be maintained, that funding for OSHA and MSHA standard setting be increased so protections for major workplace hazards can be issued in a timely manner, and that funding for federal and state enforcement be enhanced. In addition, we urge the committee to increase funding for NIOSH, and include adequate funding for the World Trade Center Health Program, so those who are sick and at risk of disease can receive the medical treatment and health monitoring they need.

Labor Department Programs to Audit, Investigate and Prosecute Unions
Finally, we would like to address the efforts of the Department of Labor, under this administration, to harass, intimidate, and persecute unions and union activists who seek to engage in the lawful pursuit of representative duties. Despite its cuts in programs protecting workers, the Bush administration continues to seek funding increases in its FY 2009 budget for programs that audit, investigate and prosecute unions. New and proposed DOL reporting requirements dramatically increase the time, effort and expense to labor unions, their officers and employees of complying with disclosure requirements.

The FY 2009 budget proposed a $13.3 million increase in funding from FY 2008 for the Office of Labor Management Standards (OLMS). This represents a 29.6 percent increase from FY 2008 (a 26.7 percent increase in real dollars) and an increase of 91.0 percent from FY 2001.

Additionally, the Department continues to move forward with the implementation of a burdensome and intrusive nine-page disclosure form. For almost 50 years, Department of Labor has required a simple two-page report known as the "LM-30." This new rule dramatically increases the number of people who are covered by the an LM-30, now reaching rank and file union members who perform representational tasks such as resolving shop floor disputes, or conducting safety inspections during their workday without a loss of pay. This affects at least 100,000 union members not previously subject to the rule. If these members spend more than 250 hours per year on these activities, they must report all other personal financial information required by the new LM-30.

These newly covered workers now are required to disclose arms-length personal financial transactions that create no conflicts of interest. These now reportable transactions include: savings accounts or personal loans with union-sponsored credit unions and personal loans (such as home mortgages and student loans) to the union member or any members of the immediate family from banks that do any business with the worker's union or a union-sponsored benefit plan or do substantial business (10 percent or more) with a union-represented employer. This private and personal information will be posted on DOL's website for public inspection.

The AFL-CIO believes that it is fair and appropriate for Congress to put a halt to this onerous regulation and force DOL to return to the reporting requirements in place for 50 years.

Again, on behalf of the AFL-CIO, I wish to thank the committee for all of the work it does. I am greatly honored to have been allowed to testify before you.

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[1] Robert Greenstein, James Horney and Richard Kogen, The Dubious Priorities of the President's Budget, Center on Budget and Policy Priorities, February 7, 2008.
[2] Ibid.
[3] U.S. Census Bureau, Income Poverty and Health Insurance Coverage in the United States: 2006.
[4] Including proposed savings from regulatory changes, the cuts exceed $201 billion over five years.
[5] U.S. Department of Labor, Trade Adjustment Assistance (TAA) Estimated Number of Workers Covered by Certifications, 1975-2007, http://www.doleta.gov/tradeact/taa_certs.cfm. Persons who lose their jobs due to trade with China are not eligible for Trade Adjustment Assistance benefits and services.
[6] According to BLS, in December 2007 there were 146,211,000 workers employed in the United States. http://www.bls.gov/news.release/pdf/empsit.pdf

Subcommittee on Labor, HHS, Education and Related Agencies

Witness Disclosure Requirement – "Truth in Testimony"
Required by House Rule XI, Clause 2(g)(4)

Your Name: Arlene Holt Baker		
1. Are you testifying on behalf of a Federal, State, or Local Governmental entity?	Yes	No **X**
2. Are you testifying on behalf of an entity other than a Government entity?	Yes **X**	No
3. If your answer to question number 2 is yes, please list any federal grants or contracts (including subgrants or subcontracts) which you have received since October 1, 2005: None		
4. Other than yourself, please list what entity or entities you are representing: American Federation of Labor - Congress of Industrial Organizations (AFL-CIO)		
5. If your answer to question number 2 is yes, please list any offices or elected positions held or briefly describe your representational capacity with the entities disclosed in question number 4: Executive Vice President		
6. If your answer to question number 2 is yes, do any of the entities disclosed in question number 4 have parent organizations, subsidiaries, or partnerships to the entities for whom you are not representing?	Yes	No X
7. If the answer to question number 2 is yes, please list any federal grants or contracts (including subgrants or subcontracts) which were received by the entities listed under question number 4 since October 1, 2005, including the source and amount of each grant or contract: N/A		

Signature: Frances Arlene Holt Baker Date: 3/11/08

Please attach this sheet, along with you curriculum vitae (résumé), to your written testimony.

ARLENE HOLT BAKER
AFL-CIO Executive Vice President

Arlene Holt Baker's experience as a union and grassroots organizer spans more than 30 years. On Sept. 21, 2007, she was approved unanimously as executive vice president by the AFL-CIO Executive Council, becoming the first African American to be elected to one of the federation's three highest offices and the highest-ranking African American woman in the union movement. In this position, Holt Baker builds on her legacy of inspiring activism and reaching out to diverse communities to support the needs and aspirations of working people.

One of seven children of a domestic worker and a laborer in Fort Worth, Texas, Holt Baker got her first job in high school through President Lyndon Johnson's poverty initiative. Working after school at the $1.40-an-hour minimum wage, she earned higher hourly pay than her mother did working full time.

Holt Baker began her work in the labor movement with AFSCME. She moved through the ranks of AFSCME and, as an organizer and international union representative, was successful in helping to organize public-sector workers in California and helping them win contracts that provided better wages and pay equity for women.

As AFSCME's international union area director in California from the late 1980s to 1995, Holt Baker worked with AFSCME councils, locals, labor councils and allies advocating for working families. Also in California, she also helped run AFSCME's political activities, working with AFSCME council and local leaders to mobilize union voters in numerous national, statewide, county and municipal elections. Holt Baker was an active member of the Los Angeles County Federation of Labor.

During that time, she was appointed by then-California Speaker of Assembly Willie L. Brown Jr. to serve on the Comparable Worth Task Force Committee and also sat on the board of directors of the Southern California Industrial Relations Research Association. Holt Baker has received numerous civic awards for her work as a labor and community advocate.

She was an active member of the California Democratic Party, serving as a state delegate to the Democratic National Convention for the elections held between 1980 and 1996 and as first vice chair of the state Democratic Party from 1993 to 1996.

In 1995, Holt Baker came to the AFL-CIO as executive assistant to Executive Vice President Linda Chavez-Thompson. Her work included the successful campaign to defeat the anti-worker Prop. 226 in California, which was designed to weaken the voices of union members in the political process. She also was instrumental in organizing a massive labor-movement-wide show of support for the more than 20,000 migrant workers who pick and process strawberries in California, as the workers struggled to join a union through the Farm Workers.

Arlene Holt Baker
AFL-CIO Executive Vice President

As the first director of the AFL-CIO Voice@Work campaign in 1999, Holt Baker launched a dynamic movement to engage elected officials, clergy members, community leaders and others in support of workers' freedom to form unions. In 2000, she ran the federation's member education and get-out-the-vote effort in the key swing state of Pennsylvania and later coordinated the AFL-CIO's Count Every Vote activity in the Florida recount.

Beginning in 2004, Holt Baker served as president of the nonpartisan voter education and mobilization effort Voices for Working Families, which registered and mobilized thousands of women and people of color to vote in under-registered communities.

She returned to the federation in 2006 to lead the AFL-CIO's Gulf Coast Recovery effort. That work has included partnering with the AFL-CIO Housing Investment Trust's Gulf Coast Revitalization Program and the Building Trades Gulf Coast Pilot Project to bring affordable housing and good jobs to people in the region. This also includes working closely with national and local advocates in fighting for the just rebuilding of the Gulf region.

# # #

September 2007

Mr. OBEY. Thank you very much. Appreciate your coming.

Ms. Jackson Lee.

Ms. JACKSON LEE. Good morning. Good to see you.

Ms. BAKER. Good morning.

Ms. JACKSON LEE. Let me just ask you about the LM–30 disclosure form. Can you explain what it would take or what at least the AFL–CIO believes it would take to get rid of this form? Because I agree with you.

Ms. BAKER. Well, our concern is that, as you know, the form before was basically a two-page form. This has increased to a nine-page form, and our rank and file members, who are basically shop stewards now, if they are participating in handling grievances on a shop floor and it goes over more than 250 hours a year, they now have to file a form and they also have to include personal financial information to show that there is no conflict of interest with banks that possibly their unions are doing business with.

This certainly is not something a shop steward would do, and it would have such a chilling impact on shop stewards, and it would prevent them from doing their job. So we really think it should be rolled back to what was previously in place. This really is not necessary; it is burdensome.

Mr. OBEY. Thank you very much.

THURSDAY, MARCH 13, 2008.

IMPACT AID TRANSITION PROGRAM

WITNESS

JONATHAN HAKE, CMSGT (RET.), DIRECTOR, MILITARY AND GOVERNMENT RELATIONS, AIR FORCE SERGEANTS ASSOCIATION

Mr. OBEY. Next, Air Force Sergeants Association.

Is it Jonathan Hake?

Sergeant HAKE. Hake, yes, sir.

Mr. OBEY. Thanks for coming.

Sergeant HAKE. Good morning, Mr. Chairman and distinguished Committee members. On behalf of the 125,000 members of the Air Force Sergeants Association, I thank you for this opportunity.

There are countless programs and their associated requirements before you, as you mentioned earlier, limited resources. We also realize that you are trusted to budget wisely, and the decisions you make are based on many factors, but I will confine my remarks to just two areas this morning. These are Impact Aid and tuition assistance.

The first is Impact Aid. The program is essential to the quality of life of airmen that have school aged children from kindergarten to twelfth grade. Like many Americans, these service members want the best for their children. They want them to succeed. And a key element to that is a quality education.

Public schools surrounding military installations and serving large service member populations often struggle because of local tax revenue shortfalls. Some school districts have noted that and increased taxes in their local areas. We think that is unfair to those residing around the installations and to those constituents. Some have even suggested we pay enrollment fees for public

schools, or some service members believe sending their children to a private school is the only option. Both of those options are expensive and enlisted members are at the low end of this pay scale.

I see my time is up.

Mr. OBEY. No, no, no, ignore that. She was just setting it and I think hit the wrong button, so ignore that.

Sergeant HAKE. I am sorry.

Both options are costly, and enlisted members, as you know, are at the low end of the pay scale, so these are not good options.

Housing privatization is also something that Congress has done tremendous strides to get improvements of the quality of the housing for those that serve, but those may not always be considered Federal property. And if they are not Federal property, the difference in compensation and Impact Aid goes from $2,000 a child to $400 a child, which is a significant difference and would be devastating.

As remarkable as it may seem, as you mentioned earlier, the current Administration has projected a budget $1,000,000 below what Congress appropriated last year. We find this very disappointing. We would ask the Committee to again this year take action in funding Impact Aid in 2009 at the level which you did in 2008.

The second area I would like to highlight quickly is Transition Assistance Programs. The National Defense Authorization Act of 1991 and associated public law established this program to help military members transition after their tour of duty. Transition Assistance Program employment workshops, VA Benefits Briefings, and the Disabled Transition Assistance Program provide valuable job placement assistance, training opportunities, and it really just helps those members of our society be better prepared for the challenges ahead.

In the fiscal year 2009 budget request for the Department of Labor, the Administrator highlighted helping veterans transition as a priority, and yet only requested $5,000,000 more. We think, with the sustained high operations tempo, retaining soldiers, sailors, airmen, and Marines, will become a challenge, as it has been in the past, and the demand for these programs will grow. We urge this Committee to fully fund the requested increase and would welcome additional resources to meet the need.

I will close by thanking you again, Mr. Chairman, for this opportunity to share our perspective. We appreciate the difficult choices this Committee must make and hope the information we have provided is helpful. Thank you. This concludes my statement.

[The information follows:]

STATEMENT BY
CMSGT (RET.) JONATHAN E. HAKE
DIRECTOR, MILITARY AND GOVERNMENT RELATIONS
AIR FORCE SERGEANTS ASSOCIATION

FOR

THE HOUSE COMMITTEE ON APPROPRIATIONS

SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION & RELATED AGENCY APPROPRIATIONS

Impact Aid

Transition Assistance Program

March 13, 2008 at 10:00 AM
Rayburn House Office Building, Room 2358-C

AIR FORCE SERGEANTS ASSOCIATION
5211 Auth Road, Suitland, Maryland 20746
(800) 638-0594 or (301) 899-3500
E-mail: staff@afsahq.org Home Page: www.afsahq.org

**** A participating organization in The Military Coalition ****

Mr. Chairman and distinguished committee members, on behalf of the 125,000 members of the Air Force Sergeants Association, I thank you for the opportunity to present our views on two vitally important issues within the context of the FY 2009 budget for the Departments of Education, Labor, and Health and Human Services.

Air Force Sergeants Association represents Active Duty, Guard, Reserve, retired, and veteran enlisted Airmen and their families. We are grateful for this committee's efforts and I can't overstate the importance your work is to those serving this nation.

Impact Aid

Military leaders often use the phrase, "we recruit the member, but retain the family" when talking about quality of life and retention. Impact Aid is a program at the very core of this premise, because it directly affects the quality of educational programs provided to the children of military service members.

These children lead unique lives, fraught with challenges associated with frequent changes in schools, repeatedly being uprooted and having to readjust to new communities and friends. Worrying about what resources might or might not be available to school administrators should not be yet another concern heaped upon them and their parents.

The Impact Aid program provides federal funding to public school districts with significant enrollment of students with a parent who is a member of the Armed Forces, living on and/or assigned to a military installation (federally-owned land).

The budget proposed by the administration calls for a freeze in funding for this important program. We find this to be very disappointing. The implicit statement in this action is military children are a lower priority than others in our nation. We ask this committee to take the steps necessary to show our military men and women that the education of their children is as important as the next child.

AFSA is grateful Congress increased Impact Aid funding by $100 million in FY 2008 and urge similar action in FY 2009.

Transition Assistance Programs

America's sons and daughters repeatedly answer this nation's call to duty as part of an all-volunteer military force. At the end of their tours of duty, whether that is a few years or after decades of service, all transition to civilian life.

Section 502 of the National Defense Authorization Act of FY 1991 , P.L. 101-510, codified in sections 1141-1143 and 1144-1150 of title 10, United States Code, authorized comprehensive transition assistance benefits and services for separating service members and their spouses.

From that legislation grew a valuable partnership between the Department of Labor and the Departments of Defense, Veterans Affairs and Homeland Security to provide Transition Assistance Program (TAP) employment workshops, VA Benefits Briefings and the Disabled Transition Assistance Program (DTAP). These programs and briefings provide service members valuable job placement assistance, training opportunities, and education on veteran benefits so they make informed choices about post-service opportunities.

We urge this committee to continue fully funding transition assistance programs.

In addition, we ask you to support the administration's initiative to pass legislation and fund a program that would create hiring preferences across federal government for military spouses. Under current law, veterans of America's Armed Forces are entitled to preferences over others in competitive hiring positions in Federal government. We believe the sacrifice of family members warrant this consideration as well.

Please allow me to close by reminding you of something I'm certain you know and appreciate--every day Americans step forward to guarantee freedom and liberty, so too must the nation be fully committed to caring for them and their family members. This committee can take the requisite steps to ensure that goal becomes reality.

Again, Mr. Chairman, we thank you for this opportunity to share our perspective. We appreciate the many difficult decisions this committee must make and hope the information we provided proves helpful.

On behalf of all Air Force Sergeants Association members, we appreciate your efforts and, as always, remain ready to support you in matters of mutual concern.

CURRICULUM VITAE

CMSgt (Ret.) Jonathan E. Hake is the Director, Military and Government Relations, Air Force Sergeants Association, a 125,000 member, not-for-profit 501 c 19 veterans organization that lobbies for improved quality-of-life benefits for enlisted personnel and their families. Chief Hake is directly responsible to the Chief Executive Officer and members associated with over 150 chapters around the world.

Chief Hake served nearly 30 years in the United States Air Force at 14 stateside and overseas locations. His final duty assignment was Command Chief Master Sergeant, Air Force Materiel Command, providing advice to Commanders, Senior Executive Service civilians, and senior enlisted leaders on the training, readiness and welfare of over 13,000 Airmen assigned to 10 major Air Force installations. He joined the Air Force Sergeants Association staff in March 2008.

DISCLOSURE OF FEDERAL GRANTS OR CONTRACTS

The Air Force Sergeants Association (AFSA) does not currently receive, nor has the association ever received, any federal money for grants or contracts. All of the association's activities and services are accomplished completely free of any federal funding.

Mr. OBEY. Thanks for your time.

THURSDAY, MARCH 13, 2008.

ELEMENTARY AND SECONDARY SCHOOL COUNSELING PROGRAM GRANT (ESSCP)

WITNESSES

CAROLINE WILLIAMS, CURRICULUM SPECIALIST, MILWAUKEE PUBLIC SCHOOL DISTRICT, MILWAUKEE, WISCONSIN, AMERICAN SCHOOL COUNSELOR ASSOCIATION (ASCA)

JANET L. MAYS, SCHOOL COUNSELOR, OLIVER WENDELL HOLMES K–8 SCHOOL, MILWAUKEE PUBLIC SCHOOL DISTRICT, MILWAUKEE, WISCONSIN

Mr. OBEY. Next we have American School Counselor Association, Caroline Williams. Good morning.

Ms. WILLIAMS. Thank you for giving us the opportunity to speak with you today. My name is Caroline Williams, and I am pleased to represent the American School Counseling Association and the 100,000 school counselors across the Country. I am the School Counseling Curriculum Specialist for Milwaukee public schools and my district received an Elementary and Secondary School Counseling Program grant in 2006. With this funding, we hired additional school counselors who are currently implementing research-based programs under a Comprehensive School Counseling Model.

Some demographic risk indicators I would like to share. Milwaukee public schools is the largest school district in Wisconsin. It serves 87,360 students in 207 schools. Milwaukee public schools has a high student mobility rate and most recently has been sanctioned as a district in need of improvement. Most students in our district are economically disadvantaged; 71 percent qualify for free and/or reduced lunch. The homeless population in Milwaukee has increased since we received our grant. The total number of families recorded as homeless is currently 1,710 and is projected to rise to 2,900 by the end of the school year. Milwaukee's high crime and incarceration rate add to the backdrop of significant behavioral risk factors.

Unfortunately, these problems do not affect all students equally. English language learners represent approximately 21.8 percent of our population. African-American students represent 57.4 percent of our student enrollment, but they also represent 71 percent of the homeless population. The suspension rate overall is 24 percent. These shocking demographic and behavioral risk factors truly represent a district that needs the type of discretionary funds provided under the Elementary and Secondary School Counseling Program.

All elementary schools under the Elementary and Secondary School Counseling Program grant have insufficient school counseling staff. The number of schools without school counselors has grown consistently and significantly over the past five years. The current counselor to student ratio district-wide is one counselor to 987 students, compared with the one counselor to 250 student ratio which is recommended by the American School Counselor Association and other organizations.

Less than 5 percent of elementary schools have counselors. The elementary school counselor to student ratio is one counselor to 1,154 students. As a result of the Elementary and Secondary School Counseling Program funding, the elementary school counselors have been able to significantly increase the number of students served. We also have developed two critical documents, a district Comprehensive School Counseling Manual and a Parent/Student Conferencing Manual, that will be utilized by grant counselors. This is only our second year of the grant funding, and we have seen some marvelous new services provided to families that were left out in the past.

On behalf of the students and families of Milwaukee public schools, I am very thankful for this funding and most definitely see the desperate need for its continuance.

At this time, I would like to introduce Ms. Janet Mays, who is one of the counselors working with the grant.

Ms. MAYS. Good morning. I am noticing the time.

My name is Janet L. Mays, and for the past 10 years I have been the school counselor at Oliver Wendell Holmes School. Our school is a Title I school of 404 students; 23 percent are special education students, 98 percent receive free or reduced lunch. We are located in a high poverty neighborhood in an area where violence often occurs.

We are extremely fortunate to have 1.5 school counselors now serving in our school as part of the Elementary and Secondary School Counseling Program. This reduces our student to counselor ratio to 263 to 1, having a tremendous positive impact on the lives of the students and their families in a variety of ways.

As we strive to create an environment conducive to learning, our students and their families face many adverse challenges. For example, in less than one year, we had a second grader struck by a day care van and killed in front of the school as other children looked on, an eighth grader hit by stray bullets in her chest and face, and a sixth grader who saw his uncle shot and killed during a drive-by. Less than three weeks ago, five students were walking home from our Afterschool CLC Learning Program and they were caught in the crossfire between two cars on the corner of the playground.

In each of these cases, students and their families were extremely traumatized and received immediate counseling support to work through the grief, the school social worker helped in assessing available community and family resources, and the school psychologist provided the staff with support needed to restore a sense of calm and security with students in their classrooms. The support staff worked in a seamless integration of service delivery to provide the most efficient, effective service delivery possible. While we could never have anticipated this number of incidents occurring with such frequency, our ability to meet this need would have not been possible without the assistance of the ESSCP funding.

But our school is not just about crises. Like all school counseling programs, our fundamental goal is to help students overcome barriers to learning so they can achieve success in school and beyond. A family in our school was left homeless when they discovered that the person they were living with was selling drugs out of the home.

One of the children in this family managed to stay on the honor roll while living out of a car with her mother and four siblings. The team consisting of a school counselor, school social worker, and school psychologist made sure that the family had safe housing, food and clothing, as well as the mental health and counseling services they needed while working with the teachers to identify and integrate successful classroom strategies for these students.

With decreasing amounts of money allocated for schools and increasing operational costs, many staff positions are being completely eliminated. But for at-risk children and families, building trusting, positive relationships are crucial to success and can only take place with stable staff.

A few years ago, one of my students noticed that many of his favorite staff members did not return to school in the fall year after year. He came to me with tears in his eyes and asked, Ms. Mays, are you going to be back in the fall? I calmly reassured him that, God willing, I would return. The student is now a junior at a top high school, currently on the honor roll and working as a counselor at a summer camp. He is doing all of this while providing support for his aging grandmother, his primary caregiver. For many children and families, the school is a sanctuary and the staff is an alternative family, helping with even the most basic of needs.

Funding from this grant has enabled us to implement proactive programming such as peaceful conflict resolution, problem-solving, manner skills for students. Partnerships have made it possible for us to have on-site full-time nursing services and annual dental services for students—

Oh, I am sorry. I see that the time has been cut short. I thank you for taking the time and we appreciate everything that you do for our students.

[The information follows:]

Testimony of
Caroline Williams
Curriculum Specialist
Milwaukee Public School District
Milwaukee, Wisconsin

And
Janet L. Mays
School Counselor
Oliver Wendell Holmes K-8 School
Milwaukee Public School District
Milwaukee, Wisconsin

Thursday, March 13, 2008
10:00 A.M.

Representing the American School Counselor Association (ASCA)

The following testimony will be summary of data and anecdotal information to encourage the Subcommittee to restore funding for the Elementary and Secondary School Counseling Program Grant (ESSCP).

Testimony of Caroline Williams

Curriculum Specialist, Milwaukee Public School District
Milwaukee, Wisconsin

On the Elementary and Secondary School Counseling Program Grant Program

Submitted to the
House Committee on Appropriations
Subcommittee on Labor, Health and Human Services, Education and Related Agencies
March 13, 2008

Good morning, thank you for giving us the opportunity to speak with you today. My name is Caroline Williams, and I am pleased to represent the American School Counselor Association and the 100,000 school counselors across the country. I am the School Counseling Curriculum Specialist for the Milwaukee Public School District in Milwaukee, Wisconsin. My district received an Elementary and Secondary School Counseling Program (ESSCP) grant in 2006. With this funding, we hired additional school counselors who are currently implementing researched-based programs under a Comprehensive School Counseling Model.

Demographic Risk indicators:

Milwaukee Public schools is the largest school district in Wisconsin. It serves 87,360 students in 207 schools. Milwaukee Public schools has a high student mobility rate, and most recently has been sanctioned as a district in need of improvement. Most students in our district are economically disadvantaged; 71% qualify for free and /or reduced lunch. The homeless population in Milwaukee has increased since we received our grant. The total number of families recorded as homeless is currently 1,710 and is projected to rise to 2,900 by the end of the school year. Milwaukee's high crime and incarceration rate add to the backdrop of significant behavioral risks factors.

Unfortunately, these problems do not affect all students equally. English language learners represent approximately 21.8% of our population; African American students represent 57.4% of the student enrollment but 71% of the homeless population. The suspension rate overall is 24%. These shocking demographic and behavioral risk factors truly represent a district that needs the type of discretionary funds provided under the ESSCP grant.

All elementary schools under the ESSCP grant had insufficient counselor staffing. The number of schools without school counselors has grown consistently and significantly over the past five years. The current counselor to student ratio district wide is 1 counselor to 987 students compared with the one counselor to 250 students ratio recommended by the American School Counselor Association and other organizations. Less than five percent of elementary schools have school counselors. The elementary counselor to student ratio is *1 counselor to 1,154 students.* As a result of the ESSCP funding, the elementary school counselors have been able to significantly increase the number of students served. We also have developed two critical documents; a district Comprehensive School Counseling Manual and a Parent/ Student

Conferencing Manual that will be utilized by grant school counselors. This is the second year of our grant funding and we've seen marvelous new practices established and increased services to students and families that were left out in the past.

On behalf of the students and families of Milwaukee Public School I am very thankful for this funding and most definitely see the desperate need for its continuance.

I would like to introduce Ms. Janet Mays who is one of the counselors working with this grant.

Testimony of Janet L. Mays

School Counselor, Oliver Wendell Holmes K-8 School
Milwaukee Public School District
Milwaukee, Wisconsin

On the Elementary and Secondary School Counseling Program Grant Program

Submitted to the
House Committee on Appropriations
Subcommittee on Labor, Health and Human Services, Education and Related Agencies
March 13, 2008

Good Morning. My name is Janet L. Mays and for the past ten years I have been the school counselor at Oliver Wendell Holmes K-8 School in Milwaukee. Our school is a Title I school of 404 students, 23% are special education students, 98% receive free or reduced lunch. We are located in a high poverty neighborhood, in an area where violence often occurs.

We are extremely fortunate to have 1.5 school counselors now serving our school as part of the Elementary and Secondary School Counseling Program grant (ESSCP). This reduces our student to counselor ratio to 263.3 to 1, having a tremendous positive impact on lives of the students and their families in a variety of ways.

As we strive to create an environment conducive to learning, our students and their families face many adverse challenges. For example, in less than one year, we had a second grader struck by a day care van and killed in front of the school as other children looked on, an eighth grader hit by stray bullets in her chest and face and a sixth grader who saw his uncle shot and killed during a drive-by shooting. Less than three weeks ago, five students were walking home from our after school Community Learning Center Program and were caught in the crossfire between two cars at the corner of the playground.

In each of these cases, students and their families were extremely traumatized and received immediate counseling support to work through the grief, the school social worker helped accessing available community family resources and the school psychologist provided staff the help needed to restore a sense of calm and security with students in their classrooms. Our support staff worked in a seamless integration of service delivery to provide the most efficient, effective delivery possible. While we could have never anticipated this number of incidents occurring with such frequency, our ability to meet this need would not have been possible without the ESSCP funding.

But our school is not just about crises. Like all school counseling programs, our fundamental goal is to help students overcome barriers to learning so they can achieve success in school and

beyond. A family in our school was left homeless when they discovered that the person they were living with was selling drugs out of the home. One of the children in this family, managed to stay on the honor roll while living out of a car with her mother and four siblings. The team consisting of a school counselor, school social worker and school psychologist made sure that the family had safe housing, food and clothing as well as the mental health and consulting services they needed while working with the teachers to identify and integrate successful classroom strategies for these students.

With decreasing amounts of money allocated for schools and increasing operational costs, many staff positions are being completely eliminated. For at-risk children and families, building trusting, positive relationships are crucial to success and can only take place with stable staff.

A few years ago, one of my students noticed that many of his favorite staff members did not return to school in the fall year after year. He came to me with tears in his eyes and asked, "Ms. Mays, are **you** going to be back in the fall?" I calmly reassured him that God willing, I would return. The student is now a junior at a top high school, currently on the honor roll and working as a counselor at a summer camp. He's doing all this while providing support for his aging great grandmother, his primary caregiver. For so many children and families, the school is a sanctuary and staff function as an alternative family, helping with even the most basic needs.

Funding from the grant has enabled us to implement proactive programs such as peaceful conflict resolution, problem-solving and manners skills for students. Partnerships have made it possible for us to have on-site full-time nursing services and annual dental services for students, part-time nursing services and healthy food selection and preparation for families. We now have overnight family camp at least twice a year to build positive family connections and monthly family nights and book clubs at our school where families learn strategies to support their children academically. For the first time, over 95% of our eighth graders indicated their intent to go to college and some have received scholarships and have participated in pre-college university programs in Milwaukee, Platteville and Stevens Point. Our middle school students have business leaders from the Rotary Club as mentors to help them make school to work connections in preparation for the real world.

At a time when violence and tragedy are frequent occurrences in students' lives, yet they are being told to excel academically and exceed numerous standards, I find it hard, if not impossible for exceptional academic achievement to occur with the most at risk students without the help and support of not only classroom teachers but a cohesive comprehensive support staff, which can greatly increase children's chances for success and a happy healthy, productive future. This will begin to break the cycle of poverty and create a foundation for a vibrant, constructive and caring community.

With the continued support of ESSCP grant I and many other staff members will be able to respond affirmatively to the question, "Will **you** be here in the fall?"

Thank you again for your time, for your support and for everything you do for students.

Mr. OBEY. Thank you for coming and thank you for what you do.

THURSDAY, MARCH 13, 2008.

DEPARTMENT OF EDUCATION 21ST CENTURY COMMUNITY LEARNING CENTERS PROGRAM

WITNESS

PRISCILLA M. LITTLE, ASSOCIATE DIRECTOR, HARVARD FAMILY RESEARCH PROJECT

Mr. OBEY. Next, Afterschool Alliance, Priscilla Little.

Ms. ARGERSINGER. Good morning. I am Erica Argersinger, the Policy Director for the Afterschool Alliance.

Millions of children benefit from the 21st Century Community Learning Centers, and I thank members of the Committee and the Chairman for your support in making quality afterschool programs available to our children. I am proud to introduce Priscilla Little, Associate Director of the Harvard Family Research Project, who will discuss the latest research on quality afterschool programs.

Ms. LITTLE. Thank you and thank you for the opportunity to provide testimony today on Afterschool and the 21st Century Community Learning Centers Program. I have spent the past 10 years of my work at Harvard University devoted to building the knowledge base for Afterschool, compiling literally hundreds of research and evaluation studies into a national database and helping people understand what they are telling us about effective programming and how best to use research for policy practice.

And I want to just tell you a very simple message. Afterschool programs are a critical component of children's education and development, and, in part thanks to the 21st Century Grants Program, we have a good solid evidence base to support this claim. The 21st Century Program spawned new money, new programs, and new research and evaluation studies. In addition to the studies conducted of 21st Century Programs directly, many other evaluations that I have tracked, read, and written about include programs which receive 21st Century funding as one of many blended funding sources they have leveraged to support their work.

Even though the 21st Century Program began in the 20th century, it was aptly named as a program that could support the development of the skills necessary for young people to support America's effort to stay competitive in a 21st century global economy. Since its inception 10 years ago, we have learned a lot about the enormous potential for afterschool programs to support a range of positive learning and developmental outcomes, and let me just give you one example from the CS-funded Study of Promising Afterschool Programs.

This study included 3,000 students participating in Afterschool nationwide, including some funded by 21st Century, and found that regular attendance in these afterschool programs over a two-year period was significantly associated with gains in standardized math test scores and better work habits. In addition to academic achievement outcomes, there are a host of positive behavioral, prevention, and health outcomes associated with participation, and I refer you to my written testimony for that information.

Do all afterschool programs deliver on these outcomes? Of course not. First, different programs target different sets of skills, and it is not appropriate to think one program can do it all. Second, we have learned a lot from the research about specific factors that make a big difference in whether or not programs can get these outcomes, and these map on to some key aspects of 21st Century.

First, the research we have conducted at Harvard underscores a consistent pattern of winners and losers when it comes to access to afterschool opportunities, with middle and upper income children and youth getting access to and taking more advantage of enrichment outside of school. Twenty-first Century investments help level the playing field by targeting low income, poorly performing schools to ensure that all children and youth have access to programs, not just those who can afford them.

Finally, we all know that learning does not stop when the school bell rings. Supporting learning throughout the day, throughout the year, and throughout a child's life requires partnerships, and this is an area where 21st Century Programs are particularly strong. The typical 21st Century Program has six community partners who contribute to the project by providing services and resources not directly funded by the program itself. These partners serve to improve quality, help engage children and youth throughout the community, and help 21st Century Programs leverage additional resources for sustainability.

In closing, I want to reiterate that we know a lot about what works for children and youth during the afterschool hours and underscore the importance of 21st Century Grants Program as a core educational and developmental support for our Nation's children. I encourage you to use the research to make informed decisions about resource allocations and set reasonable expectations for participation in 21st Century Programs. Thank you very much.

[The information follows:]

Harvard Family Research Project
Harvard Graduate School of Education

Since 1983, we have helped stakeholders develop and evaluate strategies to promote the well being of children, youth, families, and their communities.

United States House of Representatives

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

Hearing Date
March 13, 2008

Hearing Time
10:00 AM

Testimony by:
Priscilla M. Little, Associate Director
Harvard Family Research Project

On Behalf of
Harvard Family Research Project.

Testimony on the Department of Education 21st Century Community Learning Centers Program

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Research citations and additional information on research studies available at:
http://www.gse.harvard.edu/hfrp/projects/afterschool/resources/issuebrief10/index.html

Chairman Obey and Members of the Subcommittee:
Thank you for the opportunity to provide testimony at this important hearing on education funding. My name is Priscilla Little and I am the associate director of the Harvard Family Research Project at the Harvard University Graduate School of Education. I have spent the past ten years of my work devoted to building the knowledge base for after school, compiling literally hundreds of research and evaluation studies into a national database and helping people understand what these studies are telling us about effective programming and how best to use research for policy and practice. I also sit on numerous evaluation advisory boards, including the technical working group for the 21st CCLC implementation study and the evaluation task force for the 21st CCLC Profile and Performance Information Collection System (PPICs), the monitoring and evaluation tool used by all 21st CCLC programs.

I want to start with a very simple message: **After school programs are a critical component of children's education and development and, in part thanks to the 21st CCLC grants program, we have a good solid evidence base to support this claim.** The 21st CCLC grants program spawned new money, new programs, and new research and evaluation studies. In addition to the studies conducted of 21st CCLC programs directly, many other evaluations that I have tracked, read, and written about, like the TASC programs in New York and LAs BEST in Los Angeles include programs which receive 21st CCLC funding as one of many blended funding sources they have leveraged to support their work. And it is this larger evidence base on which I base my testimony to you today. The studies that I have chosen all employed rigorous research designs that involved either a comparison or control group, thus increasing the generalizability of the findings.

Even though the 21st CCLC program began in the 20th century, it was aptly named as a program that could support the development of the skills necessary for young people to support America's effort to stay competitive in a 21st century global economy. Since its inception 10 years ago we have learned a lot about the enormous potential after school programs have to support a range of positive learning and developmental outcomes, outcomes that can help young people succeed in school and in their community and prepare them for post secondary success, including attending college, getting competitive wage jobs, and being engaged community and family members.

Participation in well implemented after school programs can support academic achievement and school success. It can result in: less disciplinary action; lower dropout rates; better academic performance in school, including better grades and test scores; greater on-time promotion; improved homework completion; and improved work habits. For example:
A statewide evaluation of Louisiana's 21st CCLC programs revealed that participants showed significant improvements over nonparticipants on the Iowa Test of Basic Skills, particularly for those students who attended the programs regularly. [1]
A two-year longitudinal Study of Promising After-School Programs examined the effects of participation in quality after school programs among almost 3,000 youth in 35 elementary and middle school after school programs located in 14 cities and 8 states. New findings from that study indicate that elementary and middle school students who participated in high-quality after school programs, alone or in combination with other activities, across two years demonstrated significant gains in standardized math test scores, when compared to their peers who were regularly unsupervised after school. Further, regular participation in after school programs was associated with improvements in work habits and task persistence.[2]

Research citations and additional information on research studies available at:
http://www.gse.harvard.edu/hfrp/projects/afterschool/resources/issuebrief10/index.html

A recent meta-analysis combined the results of 56 quasi-experimental and experimental studies of after school programs for at-risk youth and found that programs demonstrated positive effects on both reading and math achievement.[3]
Evaluations of the school-based TASC programs in New York, which emphasize academic enrichment, homework assistance, the arts, and recreation, have demonstrated that participants outperform similar nonparticipants on math test scores and high school Regents Examination scores, as well as high school credits earned and school attendance rates.[4] In addition to focused academic content, the TASC evaluation revealed that including a broad variety of enrichment activities, in addition to activities devoted to developing skill building and mastery, was one of the primary common features of high-performing programs.[5]

Many research studies that I have reviewed go on to say that the most successful programs are ones that foster engagement in learning as a precursor to getting good academic results. For example:
A review of academic achievement programs conducted by Child Trends, as well as first year findings from an evaluation of 550 out-of-school time programs sponsored by New York City's Department of Youth and Community Development (DYCD), conclude that developing a highly focused academic component aligned with academic goals may be important for producing good outcomes. However, an all-encompassing and exclusive focus on academics may be detrimental. In other words, the more multifaceted after school programs are likely to reap the biggest academic gains.[6]
A meta-analysis of 93 studies of summer school programs found that they led to increases in participants' knowledge and skills. In particular, programs aimed at remediation of learning deficiencies and programs focused on learning acceleration both produced positive impacts on youth's knowledge and skills.[7]

It is important to note that the common thread among all these studies is not just that the programs intentionally tried to improve academic performance and therefore offered academic support, but that they combined it with other enrichment activities to achieve positive academic outcomes, and this is what many 21st CCLC programs strive to do. Extra time for academics by itself may be necessary but may not be sufficient to improve academic outcomes. Balancing academic support with a variety of engaging, fun, and structured extracurricular or cocurricular activities that promote youth development in a variety of real-world contexts appears to support and improve academic performance.

But to succeed in a competitive global economy young people need to be equipped with a set of skills that goes beyond the 3 R's...they need to become effective communicators, know how to develop and sustain relationships, solve problems, and have a strong sense of self. Turning to the research there is solid evidence that 21st CCLC and other after school programs can support a range of behavioral outcomes including: social and communication skills; relationships with others; self-confidence; development of initiative; and feelings and attitudes toward self and school. For example, a recent meta-analysis of over 70 after school programs that attempted to promote personal and social skills found that across studies, after school programs could improve youth self-esteem and self-confidence, particularly in programs with a strong intentional focus on improving social and personal skills.[8] This is a particularly important finding: It speaks to the need for strong program design with an intentional focus on the desired outcomes, regardless of what those outcomes might be.

Research citations and additional information on research studies available at:
http://www.gse.harvard.edu/hfrp/projects/afterschool/resources/issuebrief10/index.html

Participation in after school programs gets children and youth off the streets and under supervision and potentially prevents some risky behaviors. The hours from 3 to 6 p.m. present several potential hazards to a young person's development. These are the hours associated with the peak time for juvenile crime and juvenile victimization and the hours when teens ages 16–17 are most likely to be in or cause a car crash. Furthermore, based on a survey of 2,000 high school students that looked at the relationship between after school supervision and sexual activity, the American Academy of Pediatrics found that 56% of youth surveyed reported being home for 4 or more hours unsupervised after school. Youth who were unsupervised for 30 or more hours per week were more likely to be sexually active than those who were left alone for 5 hours a week or less. In addition, those left unsupervised for more than 5 hours per week had more sexually transmitted diseases, particularly among boys.

Beyond a safe haven, research and evaluation studies have also demonstrated the positive impact of participation in after school programs on a range of prevention outcomes including: avoidance of drug and alcohol use, avoidance of sexual behaviors, and reduction in juvenile violence. For example:
The Children's Aid Society Carrera Adolescent Pregnancy Prevention Program showed positive impacts on reducing pregnancies, teen sex, and boys' marijuana usage.[9]
A longitudinal study of the effect of participation in LA's BEST programs on juvenile crime tracked students from 1994 through 2003. It compared LA's BEST participants to two matched groups of students who either attended LA's BEST schools but not LA's BEST programs, or attended schools that did not have an LA's BEST program. Results indicate that participation in LA's BEST was significantly related to lower incidences of juvenile crime. Researchers estimate that this translates into an average savings to society of $2.50 for every dollar invested in the program.[10] While participation rates were a key factor in crime reduction (see discussion of participation below), this is powerful evidence of the potential long-term effects of and benefits to society from after school programs.

Finally, after school programs are viewed as one of many places that can tackle the growing problem of obesity among our nation's children and youth. Startling new statistics reveal that, by 2010, almost 50% of America's children will be obese; furthermore, almost two thirds of American children get little or no physical activity. Can after school programs promise to reduce body mass index (the common measure for obesity)? Probably not, although some evaluations have demonstrated improvements on this measure. Similar to impact on academic achievement test scores, it takes more than a few hours a week of after school participation to move the needle on significant markers of change. But after school programs can contribute to healthy lifestyles and increased knowledge about nutrition and exercise. For example, the Yale Study of Children's After School Time, a longitudinal study of over 650 youth at 25 after school programs in Connecticut, found that youth who participated in after school programs were more likely than nonparticipants to experience reductions in obesity, after accounting for a variety of differences between participants and nonparticipants. This was true even after controlling for youth's initial BMI status at the beginning of the study, as well as demographic factors like poverty, race, and ethnicity.[11]

Now, do all after school programs deliver on all these outcomes? Of course not. First, different programs target different sets of skills and it isn't appropriate to think one program can do it all.

Research citations and additional information on research studies available at:
http://www.gse.harvard.edu/hfrp/projects/afterschool/resources/issuebriefl0/index.html

Second, we have learned a lot from the research about specific factors that make a big difference in whether or not a program can get these outcomes, and these map onto some key aspects of the 21st CCLC programs.

First, the research I have conducted underscores **a consistent pattern of winners and losers when it comes to access to after school opportunities,** with middle and upper income children and youth getting access to and taking more advantage of enrichment outside of school. [12] Specifically, children and youth whose families have higher incomes and more education: are more likely to participate in after school activities; do so with greater frequency during the week; participate in a greater number of different activities within a week or a month; and are more likely to participate in enrichment programs, while their disadvantaged peers are more likely to participate in tutoring programs, thus not reaping the benefits associated with enrichment experiences.

These findings are particularly troublesome given the many studies and research syntheses—such as those from Child Trends, American Youth Policy Forum, and Harvard Family Research Project—which conclude that youth experience greater gains across a wide variety of outcomes if they participate with greater frequency (more days per week) in a more sustained manner (over a number of years).[13] **21st CCLC investments help level the playing field by targeting low income and poorly performing schools to ensure that all children and youth have access to programs, not just those who can afford them.**

Second, as I said above, **sustained and frequent participation in programs is important in getting good outcomes.** The latest 21st CCLC PPICS data indicates that more mature programs are more likely to be able to deliver on quality (Learning Points Associates, 2007), which gets students participating more frequently, with higher levels of engagement, which then helps them reap maximum benefit from the participation. Other research studies confirm this.

Following up on students with long-term involvement (at least four years) in the LA's BEST program revealed that greater participation was significantly related to positive achievement on standardized tests of mathematics, reading, and language arts, when the influence of gender, ethnicity, income, and language status was controlled for.[14]
Teach Baltimore is a summer academic program that proactively addresses the problem of summer learning loss by helping students develop and practice literacy skills over the summer vacation in a safe and fun environment. A randomized three-year field trial explored the effects of a multiyear summer school program in preventing summer learning losses and promoting longitudinal achievement growth. The total treatment group included 438 students from high-poverty schools. Results from the study indicate that students who participated at high levels for at least two of the three summers demonstrated statistically significant effects on learning across all three literacy domains that were tested.[15] **These findings underscore the importance of programs being able to count on sustainable, multi-year funding that enables them the maturity to get good results.**

Third, many new research studies indicate that **program quality is inextricably tied to student outcomes, with low quality programming actually doing harm in terms of supporting students' development**[16] Emerging research on after school program quality and its relationship to outcomes indicates that quality after school programs must do more than just ensure effective management practices and provide adequate physical and psychological safety. Quality after school

Research citations and additional information on research studies available at:
http://www.gse.harvard.edu/hfrp/projects/afterschool/resources/issuebrief10/index.html

programs also share the following features: appropriate supervision and structure, well-prepared staff; intentional programming with opportunities for autonomy and choice, and strong partnerships among the various settings in which program participants spend their day—schools, after school programs, and families.

Unlike research on outcomes, research on after school program *quality* is largely descriptive, with only a handful of rigorously designed studies. Evidence regarding the characteristics of program quality is largely dependent on correlational studies and expert opinion. However, a small but powerful set of studies provides an emerging picture of some of the key elements of after school program quality and how they affect a range of developmental outcomes. For example in their meta-analysis of 73 after school programs' impacts, Durlak and Weisberg found that positive impacts on academic, prevention, and developmental outcomes were concentrated in the programs that utilized strategies characterized as *sequenced* (using a sequenced set of activities designed to achieve skill development objectives), *active* (using active forms of learning to help youth develop skills), *focused* (program components devoted to developing personal or social skills), and *explicit* (targeting of specific personal or social skills). Moreover, the researchers found that, as a group, programs missing *any* of these four characteristics did not achieve positive results. These findings point to the importance of targeting specific goals, and designing activities around those goals intentionally.[17]

21st CCLC programs are particularly well-poised to deliver quality programming. 21st CCLC is an extremely competitive program which means that only the best, well-implemented programs receive funding. Also related to quality, there is a 3 percent set-aside for states to use for training, technical assistance, and evaluation and State Education Agencies use this to provide ongoing training and technical assistance on resources and tools to promote quality implementation and staff development.

Finally, we all know that learning doesn't stop when the school bell rings. **Supporting learning throughout the day, throughout the year, and throughout a child's life requires partnerships.** Programs are more likely to exhibit high quality when they effectively develop, utilize, and leverage partnerships with a variety of stakeholders like families, schools, and communities. For example, in the Massachusetts Afterschool Research Study, researchers found that programs with stronger relationships with school teachers and principals were more successful at improving youth's homework completion, homework effort, positive behavior, and initiative. This may be because positive relationships with schools can foster high-quality, engaging, and challenging activities and can also promote staff engagement.[18] **Developing partnerships is an area where 21st CCLC programs are strong.** The typical 21st CCLC program has six community partners who contribute to the project by providing services and resources not directly funded by the program itself. These partners serve to improve program quality, help engage children and youth throughout the community, and help 21st CCLC programs leverage additional resources for sustainability

In closing, I want to reiterate that we know a lot about what works for children and youth during the after school hours and underscore the importance of the 21st CCLC grants program as a core educational and developmental support for our nation's children. I encourage you to use the research I have presented to make informed decisions about resource allocations, and set reasonable expectations for participation in 21st CCLC programs.

Research citations and additional information on research studies available at:
http://www.gse.harvard.edu/hfrp/projects/afterschool/resources/issuebrief10/index.html

Mr. OBEY. Thank you.

I would simply point out that last year this Committee added $100,000,000 to the President's Afterschool budget. This year he is recommending a cut of $281,000,000 and he is trying to turn it into a voucher program. Net result would be about one million kids presently on the program could be eliminated.

Thank you for your testimony.

Ms. LITTLE. Thank you for that.

THURSDAY, MARCH 13, 2008.

STUDENT FINANCIAL ASSISTANCE

WITNESS

EDITH L. BARTLEY, DIRECTOR OF GOVERNMENT AFFAIRS, UNITED NEGRO COLLEGE FUND

Mr. OBEY. Next, United Negro College Fund, Edith Bartley.

Ms. BARTLEY. Good morning, Chairman Obey and distinguished members of the Subcommittee. I am Edith Bartley, Director of Government Affairs for the United Negro College Fund. It is an honor and a privilege to appear before you today as you consider funding priorities relevant to the fiscal year 2009 Labor-HHS Education Appropriations.

On behalf of UNCF and our 39 member institutions, I would like to thank you for your steadfast support of the Nation's historically black colleges and universities. UNCF's primary goal is to increase opportunities for access to higher education. During our 64-year existence, UNCF has raised more than $2,300,000,000 to support our member institutions. Today, UNCF supports more than 64,000 students at over 900 colleges and universities across the Nation.

The Title III–B part of the Higher Education Act, entitled Strengthening Black Colleges and Universities, continues to be the primary source of institutional assistance for America's HBCUs. UNCF hopes this Subcommittee will continue to support increases to the current authorization levels.

During the last session of Congress, your Subcommittee supported $170,000,000 in additional Title III–B funding for HBCUs under the College Cost Reduction Act. These funds, $85,000,000 per year for two years, were a significant lift for Congress and, at the same time, a wise investment. The majority of HBCU programs were level-funded during the 2008 House and Senate appropriations cycle, and the cut across the board left many programs funded at 2007 levels.

The President's fiscal year 2009 budget proposes that $85,000,000 of these funds be counted towards his $238,000,000 level-funded proposal. UNCF urges the Committee to reject proposed cuts to HBCUs and push for the maximum funding possible.

The President also proposes only a modest increase in Pell Grant funding. Remember, UNCF schools are small. HBCU endowments pale in comparison to majority institutions, and most students attending HBCUs are first generation college students who need the maximum level of scholarships and grants available in order to minimize incurring disproportionate levels of student loan debt.

UNCF requests that the members of the Committee push for increased appropriations to support increased Pell Grant levels. The average tuition at a UNCF member school is $20,657, which is, on average, half of the amount of tuition at a majority institution. However, roughly 70 percent of students at UNCF schools come from families with incomes below $30,000; and students at UNCF schools graduate with roughly $17,000 in undergraduate student loan debt.

In addition to student and institutional aid, UNCF urges the Committee to support funding for the Digital and Wireless Technology Act. This bill, now attached to the House HEA bill, will help close the information and technology gap that exists between minority-serving institutions and majority schools.

Finally, please remember HBCUs produce well-rounded, globally competitive graduates. In 2003, Xavier University, a UNCF school, produced as many successful African-American medical school applicants as the University of Maryland, Harvard, and Johns Hopkins African-American applicants. HBCUs and their graduates hold great significance within American history, the future of our Nation, and the African-American in particular.

While many accounts funded within your Subcommittee are of great importance to UNCF, we have submitted a chart as part of our written testimony outlining our proposed funding levels for relevant programs, and we thank you for this opportunity and your continued support.

[The information follows:]

Written Testimony

Submitted to the

House Appropriations Committee

Subcommittee on Labor-HHS-Education

By

Edith L. Bartley

Director of Government Affairs

United Negro College Fund

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Chairman Obey and distinguished Members of the subcommittee, I am Edith L. Bartley, Director of Government Affairs of the United Negro College Fund (UNCF). Thank you for inviting UNCF to appear before you today as you consider funding priorities relevant to the FY 09 Labor-HHS-Education Appropriations bill.

BACKGROUND

On behalf of UNCF and our 39 member institutions, I would like to thank the subcommittee for your steadfast support of nation's Historically Black Colleges and Universities (HBCUs). As you know, HBCUs are a vital component within national efforts to enhance the nation's capacity and maintain its leadership position in the global marketplace. More than 50 percent of the nation's African American public school teachers and 70 percent of all African American dentists and physicians earned degrees at HBCUs. In 2003, Xavier University (a UNCF school) produced as many successful African American medical school applicants (84) as the University of Maryland, Harvard, and Johns Hopkins Universities' African American applicants combined (84). HBCUs and their graduates hold great significance within American history, the future of our nation and the African American community in particular.

UNCF represents the nation's 39 private HBCUs. Our schools are relatively small and while our institutions were created from modest beginnings, we have and continue to produce well rounded globally competitive graduates who are community service oriented. The United Negro College Fund, the nation's oldest and most successful minority higher education assistance organization fulfills its primary goal by increasing opportunities for access to higher education. During our 64 year existence, UNCF has raised more than $2.3 billion to support our HBCU member institutions and administered nearly 300 programs including scholarships, mentoring programs, summer enrichment, study abroad, curriculum, faculty and leadership development. Today, UNCF supports more than 65,000 students at over 900 colleges and universities across the country.

The Title III, Part B, Strengthening Historically Black Colleges and Universities program has been, and continues to be the primary source of institutional assistance for America's HBCUs. Title III, Part B funding supports strategic planning initiatives, academic program enhancements, administrative and fiscal management, student services, physical plant improvements and general institutional development. While UNCF has developed and shared specific recommendations with the House and Senate Committees related to the reauthorization of the Higher Education Act of 1965 and the Title III, Part B program in particular, UNCF seeks increased FY '09 resources from this Committee as well in coordination with reauthorization efforts. Specifically, we hope this committee will continue to support increases to the current Title III B authorization levels.

While budget constraints are a challenge across federal agencies, this subcommittee has demonstrated a consistent recognition of the importance of HBCUs and the Title III funding that our schools rely upon to help bridge the gap in available resources that most non-HBCUs readily enjoy. During the last session of Congress, your subcommittee

along with other Members of Congress supported $170 million in additional mandatory Title III B funding for HBCUs. UNCF recognizes that during the current budget constraints, this was a significant lift for Congress and at the same time a wise investment in our nation's future. The majority of HBCU programs at each federal agency were level funded within the FY '08 House and Senate appropriations legislation and across the board cuts left many of these programs funded below FY 07 levels. The funds under the College Cost Reduction Act provided much need resources to support programs under Title III B.

While these funds were intended to be in addition to any regularly appropriated funds, the President's FY 09 budget proposes that $85 million of these funds be counted towards the Administration's $238 million proposed level funding for HBCUs. In essence, the Administration is mixing mandatory and discretionary pools of funding and proposes significant cuts across the Minority Serving Institution's Community. UNCF urges the Committee to reject the President's proposed cuts to HBCU funding and to push for the maximum level of funding possible for our schools.

Likewise, the President has proposed only a modest increase in Pell Grant funding. The majority of students attending HBCUs are first generation college students who need the maximum level of scholarships and grants available in order to minimize incurring disproportionate levels of student loan debt. Sadly, during the last ten years alone, loan aid funding has more than doubled making loans the most readily available form of financial assistance. UNCF requests that the members of this Committee push for increased appropriations to support increased Pell Grant levels. The average tuition at a UNCF member school is $20,657 which is on average half of the amount of tuition at a majority institution. However, roughly 70% of students at UNCF schools come from families with incomes below $30,000. After Pell Grant awards and other support, the average UNCF scholarship amount is $4,375. Students at UNCF schools are left with a $5,000-$6,000 unmet need and our students graduate with an average of $17,000 in loan debt. In addition to Pell Gants, funds for Work study and TRIO are critical to ensuring access to higher education and achievement.

In addition to student and institutional aid, UNCF urges the Committee to provide funding to support the Digital and Wireless Technology Act, H.R. 694, once enacted into law. This bill, now attached to the House HEA bill will help close the information technology gap that exists between MSI and majority schools by authorizing $250 million in grants to support technology equipment and infrastructure on the campuses of MSIs.

Finally, while many accounts funded through the Labor-HHS-Education appropriations are of great importance to UNCF, I have submitted a chart as part of the UNCF written testimony outlining our proposed funding levels for relevant programs.

Thank you, Mr. Chairman for this opportunity to testify before the Committee.

UNITED NEGRO COLLEGE FUND
FY09 LABOR-HHS-EDUCATION BUDGET RECOMMENDATIONS

DEPARTMENT/ AGENCY PROGRAMS	FY 2007 APPROPRIATIONS	FINAL FY08 APPROPRIATIONS	FY09 UNCF REQUEST	FY09 PRESIDENT'S REQUEST	FY09 UNCF REQUEST
DEPARTMENT OF EDUCATION STUDENT FINANCIAL ASSISTANCE					
Pell Grant (Maximum Award)	$13,222 ($4,310[2])	$14,215 million ($4,731[3])	$17,349 million[4] ($5,100)	$16,851 ($4,800[5])	$17,349 million ($5,100)
TRIO	$828 million	$828 million	$1 billion	$828 million	$1 billion
Supplemental Educational Opportunity Grants	$771 million	$757.5 million	$1 billion	$0	$1 billion
Leveraging Educational Assistance Partnership Program (LEAP)	$64.5 million	$63.85 million	$100 million	$0	$100 million
Federal Work Study	$980 million	$980 million	$1.25 billion	$980 million	$1.25 billion
Federal Perkins Loans	$65.5 million	$64.3 million	$100 million	$0	$100 million
Federal Family Education Loans (credit activity), Legislative Proposal on Mandatory Outlays	$2,700.7 million	$4,698.5 million	N/A	$1,817.5 million	N/A
Academic Competitiveness Grants/SMART Grants	$850 million	$395 million[6]	$1.2 billion	$960 million	$1.2 billion
GEAR UP	$303.1 million	$303.4 million	$350 million	$303.4 million	$350 million
Thurgood Marshall Legal Education Opportunity Program	$2.946 million	$2.895 million	$5 million	$0	$5 million

[1] FY09 recommendations reflect funding requested through FY08 appropriations, pending input from coalition

[2] H.J. Res 20 added $615 million to increase maximum award to $4,310

[3] This reflects maximum Pell Grant funding within FY08 Omnibus appropriations ($4,241), when combined with mandatory funds provided in the College Cost Reduction Act

[4] Based on calculating $400 million per $100 increase

[5] $4,300 discretionary; $490 mandatory add-on (College Cost Reduction Act)

[6] The amended bill also rescinds $525,000,000 from unobligated balances under the mandatory Academic Competitiveness and SMART grants program. These balances are not needed to pay Academic Competitiveness and SMART grant awards in the 2008-2009 award year and will offset additional costs in the Pell Grant program.

DEPARTMENT/ AGENCY PROGRAMS	FY 2007 APPROPRIATIONS	FINAL FY08 APPROPRIATIONS	FY08 UNCF REQUEST	FY09 PRESIDENT'S REQUEST	FY09 UNCF REQUEST
DEPARTMENT OF EDUCATION AID FOR INSTITUTIONAL DEVELOPMENT/PROGRAM DEVELOPMENT					
Title III, Part A	$79.5 million	$78.1 million	$126.3 million	$78.1 million	$126.3 million
Title III, Part B, Section 323	$238.095 million	$323.095 million	$260 million[7]	$238.095 million[8]	$345.0 million
Discretionary Funding	*$238.095 million*	*$238.095 million*	*$260 million*	*$153.095 million*	*$260 million*
Mandatory Funding (see: College Cost Reduction Act)	*$0*	*$85.0 million*	*$0*	*$85.0 million*	*$85.0 million*
Title III, Part B, Section 326	$57.915 million	$56.903 million	$75 million	$56.903 million	$75 million
Title III, Part C, Endowment Grant	$0	$0	$25 million	$0	$25 million
HBCU Capital Financing	$209,000	$185,000	$308,000	$354,000	$308,000
Minority Science and Engineering Improvement Program (MSEIP)	$8.73 million	$8.58 million	$20 million	$8.58 million	$20 million
Title VI, Institute for International Public Policy (IIPP)	$1.6 million	$1.67 million	$3 million	$1.67 million	$3 million
Title VI, International Education (domestic/overseas programs)	$104.2 million	$107.3 million	$132.2 million	$107.3 million	$132.2 million
DEPARTMENT OF EDUCATION OTHER PROGRAMS					
Title II, Teacher Quality Enhancement Grants	$59.895 million	$33.7 million	$190 million	$0	$190 million
Howard University	$233.9 million	$233.2 million	$237.4 million	$233.2 million	$237.4 million

[7] This request was made prior to passage of the College Cost Reduction Act, and thus does not reflect additional mandatory funding for Section 323 secured therein

[8] $85 million cut represents an offset of additional mandatory funding secured for Section 323 in the College Cost Reduction Act [Note: Funding levels for Section 323 and Section 326 may increase, per final enactment of the Cooper Amendment to HEA]

DEPARTMENT/ AGENCY PROGRAMS	FY 2007 APPROPRIATIONS	FINAL FY08 APPROPRIATIONS	FY08 UNCF REQUEST	FY09 PRESIDENT'S REQUEST	FY09 UNCF REQUEST
DEPARTMENT OF HEALTH & HUMAN SERVICES					
Health Professionals for Diversity/HRSA	$63.8 million	$69.7 million	$117.6 million	$0	$117.6 million
• *Minority Centers of Excellence*	*$11.9 million*	*$12.8 million*	*$33.6 million*	*$0*	*$33.6 million*
• *Health Careers Opportunity Program*	*$3.96 million*	*$9.8 million*	*$35.6 million*	*$0*	*$35.6 million*
• *Scholarships for Disadvantaged Students*	*$46.657 million*	*$45.8 million*	*$47.128 million*	*$0*	*$47.128 million*
• *Faculty Loan Repayment*	*$1.29 million*	*$1.27 million*	*$1.3 million*	*$0*	*$1.3 million*
NIH National Center on Minority Health Disparities	$199.1 million	$199.569 million	$210.746 million	$199.569 million	$210.746 million
NIH Research Centers at Minority Institutions	$52.672 million	$0	$55 million	$53.58 million	$55 million
PHS Office of Minority Health	$53.455 million	$48.7 million	$65 million	TBD	$65 million
NIH Minority Access to Research Centers (MARC)	$30.6 million	TBD	$35 million	TBD	$35 million
NIH Minority Biomedical Research Support (MBRS)	$113.8 million	$0	$120 million	$110.4 million	$120 million
National Youth Sports Program	$0[9]	$0	$18 million	$0	$18 million

[9] According to a March 6, 2007 letter submitted to the House Labor-HHS-Education Appropriations subcommittee by Representatives Ron Kind, Yvette Clarke, Zach Wamp and Jim Ramstad, NYSP has not received any new federal funding since FY2005, with the program being supported in FY2006 with $3 million in carryover funds.

Mr. OBEY. Thank you. Again, let me point out that last year the College Cost Act enacted increases of $255,000,000 more for HBCUs. The President proposes to rescind $85,000,000 this year.

Ms. BARTLEY. Yes.

Mr. OBEY. Thank you much.

Ms. BARTLEY. Thank you.

THURSDAY, MARCH 13, 2008.

FUNDING FOR MENTORING

WITNESS

MARGO S. PEDROSO, SENIOR VICE PRESIDENT, PUBLIC POLICY, MENTOR/NATIONAL MENTORING PARTNERSHIP

Mr. OBEY. Next, MENTOR/National Mentoring Partnership, Margo Pedroso.

Ms. PEDROSO. Mr. Chairman, Ranking Member Walsh, I appreciate the opportunity to testify in support of the $100,000,000 in Federal funding for youth mentoring. That is $50,000,000 each for the Department of Education's Mentoring Programs Grants and the Department of Health and Human Services Mentoring for Children of Prisoners Program. I am here today on behalf of MENTOR/National Mentoring Partnership. We are an advocate and a resource for youth mentoring programs around the Country and we work with a national network of mentoring partnerships about 4100 mentoring programs around the Country.

Youth mentoring is a simple, yet powerful concept: An adult provides guidance, support, and encouragement to help a young person achieve success in life. Numerous students document that high-quality mentoring results in better attendance at school, it lowers dropout rates, and it decreases involvement with drugs and violent behaviors. We believe that mentoring is an effective strategy that addresses both the academic and non-academic needs of struggling young people. Further details on the outcomes for youth involved in mentoring relationships are in my written testimony.

To get the kind of results I have just touched on, research shows that mentoring programs must operate high-quality programs following best practices; they must have well-trained staff; they must recruit and thoroughly screen and train their volunteers; and they must provide ongoing monitoring and support for mentoring relationships. When programs follow these proven practices, mentoring relationships last longer and are closer, and have strong positive impacts on young people.

These effective practices come at a cost. We find that it is about $1,000 to $1,500 per child per year to run an effective mentoring relationship. The mentoring field must have continued access to Federal funds if we are going to be able to serve more children and serve them well. And we do need to serve more children. Just 17 percent of the 17.6 million young people that could benefit from having a mentor are currently in mentoring relationships. Clearly, the demand for mentoring far exceeds what mentoring programs are currently able to provide.

Since fiscal year 2004, Congress has wisely devoted approximately $100,000,000 each year to Federal funding, split between

the two programs I mentioned previously: The Department of Education's Mentoring Programs Grants and Health and Human Services Mentoring Children of Prisoners Programs. Both of these are competitive grant programs that provide funding to local organizations to either start mentoring programs or expand the ones they already have.

The President's budget request for fiscal year 2009 proposes $50,000,000 for the Mentoring Children of Prisoners Program, a slight increase from the fiscal year 2008 funding level of $48,600,000. We support this request and encourage Congress to provide that $50,000,000.

Unfortunately, the President's proposed budget for fiscal year 2009 would eliminate all funding for the Department of Education Mentoring Programs Grants. This program was funded at $48,500,000 in 2008 and we request that Congress restore the traditional level of $50,000,000 to this program.

The proposed elimination of ED's Mentoring Programs grants would have an extremely detrimental impact on mentoring: 164 grantees from the fiscal year 2007 cohort would lose the final year of funding for their three-year grants, likely resulting from closure or downsizing of these programs and ending hundreds, if not thousands, of mentoring relationships.

Besides the immediate impact, the elimination of this program would mean the end of the only authorized Federal program exclusively focused on providing mentors for young people at risk of failing academically. In the seven years the program has been in existence, 641 grants have been awarded to local organizations in every State, including urban, rural, and suburban settings. These grants have totaled nearly $300,000,000, and we estimate that around 200,000 young people have benefitted from mentoring relationships during this funding.

Eliminating this grant program will significantly impact the ability of mentoring programs to continue to serve children and will ultimately mean fewer children in mentoring relationships. We cannot afford to backslide and increase the mentoring gap.

In conclusion, I respectfully request that Congress provide $50,000,000 each for Education's Mentoring Programs and HHS's Mentoring Children of Prisoners Program. On behalf of the thousands of mentoring programs and millions of young people in mentoring relationships today, I commend you for your past support of this funding and strongly encourage you to continue this wise investment in the future of our young people. Thank you.

[The information follows:]

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Testimony before the House Committee on Appropriations
Subcommittee on Labor, Health and Human Services,
Education, and Related Agencies

Public Witness Testimony
March 13, 2008
10:00 a.m.

With Regard to Funding for Mentoring:

- **$50 million for the U.S. Department of Education's Mentoring Programs grants**
- **$50 million for the U.S. Department of Health and Human Services' Mentoring Children of Prisoners program**

Chairman Obey and Ranking Member Walsh, I thank you for the opportunity to testify today in support of $100 million in federal funding for youth mentoring. This request comprises $50 million for the U.S. Department of Health and Human Services' Mentoring Children of Prisoners program, identical to the President's budget request, and $50 million for the U.S. Department of Education's Mentoring Programs grants, which is a slight increase over last year's funding. Unfortunately, the President's proposed budget would eliminate the Mentoring Programs grants at the U.S. Department of Education.

I provide testimony today on behalf MENTOR/National Mentoring Partnership, representing our founding chairman Geoffrey T. Boisi and founding board member Bill Russell. MENTOR is the nation's leading advocate and resource for mentoring, delivering the research, policy recommendations, advocacy, and practical performance tools that facilitate expansion of mentoring initiatives. We believe that, with the help and guidance of an adult mentor, each child can unlock his or her potential.

For nearly two decades, MENTOR has worked to expand the world of quality mentoring. In cooperation with a national network of *Mentoring Partnerships* and with more than 4,100 mentoring programs nationwide, MENTOR helps to connect young people who want and need caring adults in their lives with the power of mentoring.

We seek to leverage resources and provide the tools that local mentoring programs need to operate high-quality mentoring, build greater awareness of the need for mentors, and raise the profile of mentoring among corporate leaders, foundation executives, policymakers, and researchers. As such, the ultimate beneficiaries of our work are the three million young people who are currently benefiting from the guidance of caring adult mentors. And through the combined efforts of the mentoring field, we seek to close the mentoring gap so that the nearly 15 million children who currently need mentors can gain access to them.

It is on behalf of those 4,100 mentoring programs and the nearly 15 million children nationwide who need mentors that I testify today.

Benefits of Mentoring

Youth mentoring is a simple, yet powerful concept: an adult provides guidance, support and encouragement to help a young person achieve success in life. Mentors serve as role models, advocates, friends, and advisors. Mentoring programs of all shapes and sizes across this country exist for one reason: to build strong, effective relationships between caring adults and young people who might not otherwise have positive adult role models in their lives.

Even with that common purpose, youth mentoring is not a one-size-fits-all proposition; each child's needs are unique and require unique approaches. Mentoring today offers many options – the traditional one-to-one format, team and group mentoring, peer mentoring, and even online mentoring. And mentoring programs are run by nonprofit community-based organizations, schools, faith-based organizations, local government agencies, workplaces, and more.

Mentoring has become a widespread intervention for young people because research demonstrates that youth who participate in mentoring relationships experience a multitude of

positive benefits. It is a flexible approach that can be tailored to meet the needs of young people facing a variety of challenges and circumstances.

Numerous studies document that mentors help young people augment social skills and emotional well-being, improve cognitive skills, and plan for the future. High-quality mentoring also results in better attendance at school, lowers dropout rates, and decreases involvement with drugs and violent behavior. In particular, I would like to call your attention to a few studies on mentoring:

- Educational Achievement: In a review of ten mentoring program evaluations, ChildTrends found that youth participating in mentoring relationships experience positive academic returns through better school attendance, a greater chance of going on to higher education, and more positive attitudes towards school and teachers (Jekielek, Moore, Hair, and Scarupa, "Mentoring: A Promising Strategy for Youth Development," *ChildTrends Research Brief*, February 2002).

- Health and Safety: In a survey of adolescents, Sharon Beier and colleagues found that those with mentors were significantly less likely to participate in high-risk behaviors, including smoking, drug use, carrying a weapon, and unsafe sex (Beier, Rosenfeld, Spitalny, Zansky, and Bontemmpo, "The potential role of an adult mentor in influencing high-risk behaviors in adolescents," *Archives of Pediatric Medicine 154* (2000)).

- Social and Emotional Development: A study conducted by Dr. Jean Rhodes and colleagues found that mentoring relationships led to increases in the levels of intimacy, communication, and trust that adolescents felt toward their parents. These improvements led to positive changes in many areas, such as the adolescents' sense of self-worth and scholastic achievement (Rhodes, Grossman, and Resch, "Agents of change: Pathways through which mentoring relationships influence adolescents' academic adjustment," *Child Development 91* (2000)).

I would also like to address a particular challenge facing our nation today: the high rate at which young people drop out of high school. Nearly one-third of all high school students drop out before receiving their diploma, a rate which approaches 50% for minority students. Research on the dropout rate shows that young people can fail to graduate for a wide variety of reasons, including: lack of connection to the school environment, lack of motivation or inspiration, chronic absenteeism, lack of parental involvement, personal reasons such as teen pregnancy, and failing in school.[1,2] Clearly our young people are facing a host of issues that are contributing to a lack of academic success, as well as the potential to drop out of school.

We know that young people who drop out will face a future of unemployment, government assistance, and even criminal involvement. We need to do better by these young people before they reach the point of dropping out of high school. Fortunately, youth mentoring can play in important role in addressing the issues young people face within the learning environment. Research demonstrates that many of the impacts of mentoring can directly address the

[1] Bridgeland, John M. et al. (2006). The Silent Epidemic: Perspectives of High School Dropouts. Civic Enterprises in Association with Peter D. Hart Research Associates for the Bill & Melinda Gates Foundation.
[2] Harmacek, Marilyn, ed. (2002). Youth Out of School: Linking Absences to Delinquency. 2nd ed. Colorado: The Colorado Foundation for Families and Children.

underlying causes of our nation's dropout crisis. Mentoring is an important tool to help address dropout risk factors, and help ensure that young people are supported in their effort to graduate from high school and make a successful transition to adulthood. Specific impacts of mentoring include:

- Mentored youth feel greater competence in completing their schoolwork[3], which is linked to higher levels of classroom engagement and higher grades.[4]
- School-based mentored youth experience enhanced connectedness to schools, peers and society[5], and have more positive attitudes toward school and teachers.[6]
- Evaluations of mentoring programs indicate that both one-to-one mentoring and group mentoring result in better school attendance for mentored youth.[7]
- Mentored youth experience improvements in parental relationships and their own sense of self-worth.[8]
- Mentored youth are significantly less likely to participate in high-risk behaviors, including substance abuse, carrying a weapon, unsafe sex, and violent behaviors.[9]

Because of these impacts, we believe that mentoring is an effective strategy that addresses both the academic and nonacademic needs of struggling young people. It can help ensure that students come to school and are ready and able to learn.

High-Quality Mentoring Generates the Strongest Impact

Like any youth-development strategy, mentoring works best when measures are taken to ensure quality and effectiveness. Money, personnel and resources are required to initiate and support quality mentoring relationships. The average per-child expenditure for a mentoring match that adheres to MENTOR's *Elements of Effective Practice*™ is between $1,000 and $1,500 per year, depending on the program model.

Successful mentoring programs must have well-trained staff familiar with the needs of the community. One-third of mentoring programs indicate that hiring and retaining quality staff can be a challenge due to low salaries. Vigorous recruitment campaigns must be conducted to attract volunteers, as over 80% of programs have young people on their waiting lists for mentors.

Program staff must interview each potential volunteer, check references, and perform criminal background checks. Just a thorough background check can cost as much as $50 - $75 per volunteer. Once the screening process is complete, each mentor must receive quality training prior to being matched with a mentee. The work of the mentoring program does not end with the

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[3] Linnehan, F. (2005) "The relation of a work-based mentoring program to the academic performance and behavior of African-American students," *Journal of Vocational Behavior*, 59(3).

[4] Utman, C. H. (1997). "Performance effects of motivational state: A meta-analysis," *Personality and Social Psychology Review*, 1, 170-182.

[5] Karcher, M.J. (2005). "The effects of school-based mentoring and high school mentors' attendance on their younger mentees' self-esteem, social skills and connectedness." Psychology in the Schools.

[6] Jekielek, Susan M. et al. (2002). Mentoring: A Promising Strategy for Youth Development. ChildTrends Research Brief, Washington, DC.

[7] Sipe, Cynthia L. (1999). *Mentoring Adolescents: What have we learned? Contemporary Issues in Mentoring*, Grossman, Jean Baldwin (ed.), Public/Private Ventures.

[8] Jekielek, Susan M. et al. (2002). Mentoring Programs and Youth Development: A Synthesis. ChildTrends, Washington, DC.

[9] Beier, Rosenfeld, Spitalny, Zansky, and Bontemmpo. (2000). "The potential role of an adult mentor in influencing high-risk behaviors in adolescents." *Archives of Pediatric Medicine*, 15.

first meeting of the mentor and young person – both mentors and young people require ongoing support, monitoring, and guidance.

All of these elements are critical because research clearly links program quality with positive outcomes. According to Dr. Jean Rhodes, professor of psychology at University of Massachusetts-Boston and leading researcher in the field of mentoring, screening, training and ongoing support are essential to the longevity of mentoring relationships, and to the ultimate success of mentoring relationships.

Rhodes also found that the longer a mentoring relationship lasts, the greater the positive, long-lasting effect it has on a young person. Other researchers in the field have substantiated her findings as well.[10] In essence, when properly prepared and supported, a mentor is more likely to connect with the young person and to stick with the relationship when times get hard.

Need for Federal Dollars

The mentoring field absolutely needs continued access to federal funds if we are to serve more children and serve them well. America has a wide mentoring gap. There are approximately 17.6 million young people who need or want mentors – yet just 3 million of them are in formal mentoring relationships nationwide. This means we have a mentoring gap consisting of nearly 15 million young people.

The demand for mentoring far exceeds the current capacity of local mentoring programs and the number of adults who volunteer as mentors, leaving thousands of children on waiting lists for mentors. And, as mentioned previously, it takes financial resources to be able to adhere to mentoring best practices and provide quality mentoring experiences to young people.

Since FY2004, Congress has wisely devoted approximately $100 million annually for youth mentoring, split evenly between two critical grant programs:

- Department of Education's Mentoring Programs grants. This program provides grants to local mentoring organizations to establish or expand their mentoring program. It can support recruiting, screening, and training of mentors, as well as hiring and professional development of mentoring coordinators and support staff. Community-based organizations, faith-based organizations, and schools are eligible to apply for funding.
- Department of Health and Human Services' Mentoring Children of Prisoners program. This program provides funding to organizations that match mentors with young people whose parents are incarcerated, and is also open to community- and faith-based organizations.

Both of these grant programs provide much-needed federal dollars to help mentoring programs get established or to expand to serve more children. Both are competitive grant programs, with all funding being awarded to local organizations. The RFPs for both programs require applicants to detail how they will be able to carry out key mentoring best practices. Since 2004, coinciding

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[10] Dubois, D.L. (2000) "Effectiveness of Mentoring Programs for Youth: A Meta-analytic Review," *American Journal of Community Psychology, 30*(2); and
Public/Private Ventures (2000). *Mentoring School-Age Children: Relationship Development in Community-Based and School-Based Programs.*

with this significant increase in federal support, we have seen the number of young people in mentoring relationships grow from 2.5 million to the current level of 3 million. Clearly, this funding is having an impact on the mentoring gap.

The President's budget request for FY2009 proposes $50 million for the HHS Mentoring Children of Prisoners (MCP) program, a slight increase from the FY2008 final funding level of $48.6 million. We support this funding level, and request that Congress continue to support the MCP program at the traditional $50 million level.

Unfortunately, the President's proposed FY2009 budget would eliminate the Department of Education's Mentoring Programs grants. This program was funded at $48.5 million for FY2008, and we request that Congress restore $50 million in funding for this program in FY2009.

The proposed elimination of ED's Mentoring Programs grants will have an extremely detrimental impact on mentoring. First, $50 million in funding is needed for FY2009 simply to support commitments already made to existing grantees. All grants awarded under this program are three-year projects, and require continued appropriations. A total of 164 organizations, who first received funds in FY2007, would lose the final year of funding for their grants. And, we expect nearly 100 new grants to be awarded this year – those organizations would receive just one year of funding, which is not an efficient use of federal dollars. Those organizations that see their funding terminate early would likely have to downsize or even close. This would likely result in the premature end to hundreds—if not thousands—of mentoring relationships. Research shows that when mentoring relationships terminate unexpectedly, it can have a detrimental impact on the child.

Besides the immediate one-year impact, the elimination of this program will mean the end of the only authorized federal program specifically focused on providing mentors for young people at risk of failing academically. In the seven years the program has been in existence, 641 grants have been awarded to local mentoring programs in every state, including rural, suburban and urban settings. These grants have totaled nearly $300 million. This means that approximately 200,000 young people are benefiting from a mentoring relationship that otherwise likely would not have been able to.

Eliminating this grant program will significantly impact the ability of mentoring programs to continue to serve children, and will ultimately mean fewer children in mentoring relationships. Over three-quarters of mentoring programs report that fundraising is a challenge, and over half are concerned about having to close or downsize due to lack of funding. And, as mentioned previously, there are nearly 15 million children that still wait for mentors. We cannot afford to backslide and increase the mentoring gap.

In conclusion, I respectfully request that Congress provide $50 million each for the ED Mentoring Programs grants and the HHS' Mentoring Children of Prisoners program. On behalf of the thousands of mentoring programs and millions of mentored children across the country, I commend you for your past support of this funding, and strongly encourage you to continue this wise investment in our young people. Thank you for your consideration.

Mr. OBEY. Thank you very much.

THURSDAY, MARCH 13, 2008.

BIOTERRORISM

WITNESS

DAVID FLEMING, M.D., DIRECTOR OF PUBLIC HEALTH FOR SEATTLE-KING COUNTY, WASHINGTON, MEMBER, BOARD OF DIRECTORS, TRUST FOR AMERICA'S HEALTH, DEPARTMENT OF HEALTH AND HUMAN SERVICES

Mr. OBEY. Next, Trust for America's Health, David Fleming.

Dr. FLEMING. Mr. Chairman, members of the Committee, good morning. I am David Fleming. I am here as a Board Member of Trust for America's Health, or TFAH. I am also the Director and Health Officer for the Health Department of Seattle-King County in the State of Washington. Thank you for the opportunity to be here today.

I have been lucky in my career to work at the local, State, national, and international level in public health and to see public health practiced from a variety of perspectives. It is clear we are facing a time of unprecedented opportunity for saving lives, saving money, and improving health in our Nation; and that is good news, because Americans deserve a well-financed, modern, public health system. It is only rational that as we worry about rising health care costs and threats like pandemic influenza, that resources for public health should be on the rise. But we live in irrational times.

The President's fiscal year 2009 budget is proposing huge reductions in public health spending across this Country. The CDC's budget would be cut by $433,000,000, continuing an alarming, potentially disastrous trend of disinvestment in the very programs that are saving lives and reducing health care costs. I am asking you not to let this happen.

As a local health officer, let me give you a report directly from the front lines. Federal funding makes a critical difference in my community's and every community's ability to protect Americans from threats. Dollars you provide will be well spent. In fact, I urge you to attach to these resources clear accountabilities and deliverables for improving the health outcomes in our communities.

The bottom line is that TFAH supports increased funding for a number of critical community-based programs, and I am submitting that for the record.

In my remaining time, let me briefly outline two priorities. The first is chronic diseases, which account for 70 percent of deaths in this Country and almost 75 percent of health care spending. Most are preventable; they do not need to happen.

In my community, we have an amazing federally-funded program called Steps. Using community outreach and mobilization, we are attacking asthma, diabetes, and obesity in the poorest parts of my county. In a few short years, the proportion of kids buying soda and junk food in schools has dropped 50 percent and asthma hospitalizations are dropping at 10 percent per year.

Unfortunately, Federal funding for my county's Steps program was eliminated in the 2008 budget. Many other Steps communities

around the Country are now facing the same prospect in the 2009 budget. Please restore funding for Steps and other critical community-based chronic disease prevention programs.

My second priority is preparedness. Recently, TFAH released its annual Ready or Not report on our Nation's preparedness. The good news is we found significant improvement in State preparedness over prior years. The bad news is that there are many areas, like medical surge capacity, where we are woefully unprepared and we have a crisis in the making.

Funding for the Preparedness Cooperative Agreements to States and localities has been drastically cut in recent years and the 2009 budget proposes an additional 18 percent reduction. This greatly diminished Federal support for all-hazards approaches to preparedness puts programs that have been created and are now working in jeopardy, and puts the health and safety of the people in my community at risk. I ask you to restore these capacity-building grants to their fiscal year 2005 level of $919,000,000.

Mr. Chairman, I appreciate this opportunity to testify because every day across this Country dedicated public health practitioners save lives, protect our community and our Nation. We have got the will; we have got the ability; we have got the passion. But we need resources to get this job done and we are looking to you for leadership. Thank you.

[The information follows:]

Written Testimony of David Fleming, MD

Director of Public Health for Seattle-King County, Washington &
Member, Board of Directors
Trust for America's Health

before the

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

Thursday, March 13, 2008, 10:00 AM

For further information, please contact:
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Summary of Written Testimony:

Americans deserve a well-financed, modern, and accountable public health system. Yet, the President's FY 2009 budget would cut the Centers for Disease Control and Prevention's (CDC) budget by approximately seven percent. There is increasing evidence that community level interventions, the kind of programs that CDC funding supports, make a difference in health outcomes and costs. Trust for America's Health (TFAH) supports funding the following programs:

Chronic Diseases
Chronic diseases, most of which are preventable, account for 70 percent of deaths in the U.S. and approximately 75 percent of health care spending. Yet the President's budget would cut funding for chronic diseases by over $28 million. TFAH supports:

- $65 million for CDC's Division of Nutrition, Physical Activity and Obesity
- $30 million for CDC's Steps to a Healthier U.S.
- $33.6 million for CDC's School Health Program, in the Division of Adolescent School Health

Emergency Preparedness and Public Health Workforce
Despite progress made in recent years, there are many areas, such as creating medical surge capacity, where we remain woefully under-prepared. We are deeply concerned that the greatly diminished federal support for an all-hazards approach to preparedness will put the progress we have made at risk. TFAH supports:

- $919 million for CDC's Public Health Emergency Preparedness Cooperative Agreements
- $474 million for the Assistant Secretary for Preparedness and Response's (ASPR) Hospital Preparedness Program
- $500 million for ASPR's Biomedical Advanced Research and Development Authority
- $15 million for the Medical Reserve Corps, within the Office of the Surgeon General
- $5 million for 65 CDC/CSTE first-year applied epidemiology fellows.

Pandemic Influenza
H5N1 has infected millions of birds and resulted in over 200 deaths in humans, with a human case fatality rate of approximately 61%. TFAH supports:

- $313 million for pandemic preparedness activities at the CDC, National Institutes of Health, Food and Drug Administration and the Office of the Secretary
- $350 million for state and local pandemic flu preparedness
- $507 million for building vaccine production capacity, maintaining a supply of eggs, and enabling HHS to purchase medical countermeasures for its critical employees
- $870 million, requested in FY 2008, for the acquisition of egg-based vaccine and antivirals

Environmental Health
Disease detection and surveillance activities are vital to stemming an infectious disease outbreak, tracking rises in chronic diseases, or responding to a bioterror event. TFAH supports:

- $53.7 million for CDC's Environmental Health Laboratory
- $50 million for CDC's National Environmental Public Health Tracking Network.

My name is David Fleming, and I appear today as a Trust for America's Health (TFAH) Board Member. I also am the Director of Public Health for Seattle-King County, Washington. I am grateful for the opportunity to speak to the Subcommittee about public health appropriations.

Americans deserve a well-financed, modern, and accountable public health system. As we worry about rising health care costs and continued threats from terrorism or natural threats such as pandemic influenza, resources for public health should be on the rise, not decreasing as proposed in the President's FY 2009 budget. Indeed, the Centers for Disease Control and Prevention's (CDC) budget would be cut by $433 million, or seven percent. Almost every program that provides support for prevention and public health at the state and local level would be cut, continuing an alarming trend of disinvestment in the very programs that save lives and reduce long-term health care costs.

As a local health officer, I can attest to the difference federal funding makes in our community's, and every local community's, capacity to give Americans the protection they need and deserve. And, as I urge you to provide additional funding for public health activities, I hope you will also hold us accountable for improving the health outcomes in our communities. Mr. Chairman, in your home state of Wisconsin, annual county health rankings are published and have become the basis for program and policy development. This should become the standard for all federal public health programs.

Case for support

There is increasing evidence that community level interventions, the kind of programs that CDC funding supports, make a difference in health outcomes and health care costs. TFAH is leading a consensus building initiative entitled, the *Healthier America Project*. The *Project* will make the economic case for increased investments in public health. One of the central elements of the *Project* is to define the financing needs for public health for the next decade. TFAH and the New York Academy of Medicine have convened an expert panel to ascertain the current spending levels by the public health sector. The panel will soon be making a recommendation regarding how much additional funding the U.S. should invest in public health. TFAH is also working with the Urban Institute and Prevention Institute to develop an economic model that demonstrates the return on investment of certain community-level public health interventions, like physical activity, improved nutrition, or smoking cessation programs, and the corresponding savings by funding source. We hope the results of this model, to be released later this spring, will influence your investment choices as you consider the FY 2009 budget.

To help ensure the implementation of effective community-based interventions, Trust for America's Health supports increased funding for a number of programs.

Chronic Diseases
Chronic diseases, most of which are preventable, account for 70 percent of deaths in the U.S. and approximately 75 percent of health care spending. Yet the President's budget would cut funding for chronic disease prevention and health promotion by over $28 million, bringing cuts to over $100 million in inflation-adjusted dollars since FY 2003.

In the U.S., 2/3 of adults are obese or overweight, and the rate of childhood obesity has tripled over the last 20 years. CDC's Division of Nutrition, Physical Activity and Obesity (DNPAO), which provides funding that allows state health departments to develop a nutrition and physical activity infrastructure, has been virtually flat funded over the past three years, with only small increases that have not kept pace with inflation. Similarly, funding levels for the Division of Adolescent School Health (DASH) have actually decreased over the last five years. DASH's School Health Program assists states in improving the health of children through a school level program that engages families and communities and develops healthy school environments. To begin to mitigate the obesity epidemic, we need chronic disease prevention and promotion programs in all 50 states. That will require $65 million for the DNPAO and at least an additional $20 million for DASH's School Health program to fund all states that have been approved.

Another important anti-obesity program is Steps to a Healthier U.S. Steps grants support communities, cities and tribal entities to implement health promotion programs and community initiatives. TFAH supports at least $30 million for the Steps Program.

We have been fortunate to receive Steps funding to support our local efforts to prevent and control chronic diseases in King County. Steps to Health King County is a coalition that has brought together public health, schools, community-based organizations, health care organizations and parks to implement innovative programs and support cutting-edge policies to promote community health. For example, Steps has provided funding to three school districts to hire school health coordinators. The coordinators have been instrumental in implementing the DASH School Health Program. They staffed a successful effort in Seattle to remove junk food from school vending machines and increase the quality of physical education. Steps members provided critical advocacy support for making the changes in school policies needed implement these efforts. They provided testimony and support for our Board of Health's recent success in developing an ordinance that will make nutrition information available for customers of chain restaurants. Steps partners, with Steps funds, have implemented physical activity programs for children and youth. They have trained medical providers in preventing and managing obesity. Yet funding for Steps has decreased dramatically over recent years, from $43 million in FY 2007 to $15 million in the President's proposed budget for FY 2009. We support restoration of Steps funding because action at the local level is essential if we are to begin to mitigate the obesity epidemic.

Preparing for Public Health Emergencies
In December of last year, TFAH released its annual "*Ready or Not*" report on our nation's preparedness. The good news is that TFAH found significant improvement in state preparedness over prior years. Unfortunately, there are many areas, such as creating medical surge capacity, where we remain woefully under-prepared. That is why we are deeply concerned that the greatly diminished federal support for an all-hazards approach to preparedness will put the progress we have made at risk.

Funding for the Public Health Emergency Preparedness (PHEP) Cooperative Agreements to states and localities -- where public health actually happens -- has been drastically cut in recent years. With these funds, local health departments have enhanced their disease surveillance systems and trained their staff in emergency response. Over ninety percent of local health departments have developed mass vaccination and prophylaxis planning, conducted all-hazards preparedness training, and implemented new or improved communication systems. All states have established the infrastructure necessary to evaluate urgent disease reports and to activate emergency response operations 24 hours a day. A recent report by the National Association of County and City Health Officials clearly detailed the impact of recent cuts, with staff time, planning, and acquisitions of equipment and supplies cut by upwards of 25 percent.

Unfortunately, the President's budget proposes another cut, totaling eighteen percent, as well as cuts of $62 million, or over 14 percent, to hospital preparedness funding due to a proposed realignment of grant funding cycles. The primary focus of the Hospital Preparedness Program (HPP) is to improve the capacity of the Nation's hospitals and other supporting healthcare entities to respond to bioterrorist attacks, infectious disease epidemics, and other large-scale emergencies by enabling hospitals, EMS and health centers to plan a coordinated response. TFAH recommends restoring funding for the PHEP cooperative agreements to FY 2005 levels ($919 million) and providing $474 million for the HPP.

The President's budget proposes $250 million for the Biomedical Advanced Research and Development Authority (BARDA). BARDA was established in 2006 to help jumpstart a new cycle of innovation in vaccines, diagnostics and therapeutics to combat health threats. 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. TFAH requests $500 million for BARDA, with two years of fiscal availability.

Public Health Workforce

In order to prepare for any public health emergency, it is necessary to have a well-trained workforce. The Office of the Civilian Medical Reserve Corps, located in the Office of the Surgeon General, supports local public health and helps provide for an adequate supply of volunteers in the case of a Federal, State, local, territorial or tribal public health emergency. MRC units are community-based and serve as a way to locally organize and utilize volunteers desiring to prepare for and respond to emergencies and promote healthy living throughout the year. TFAH supports fully funding the President's request of $15 million for the Office of the Civilian Volunteer Medical Reserve Corps to enable the MRC to award more capacity building grants, which local units use for a variety of purposes, such as purchasing equipment, training, purchasing uniforms and providing salaries for coordinators. Funding will also help the MRC to develop federal deployment capacity for use during public health emergencies.

Public health epidemiologists are another important part of our nation's public health workforce. Public health epidemiologists investigate and monitor public health threats. They identify risk factors for diseases, such as obesity, diabetes and HIV/AIDS, identify potential relationships

between exposures and disease, provide the foundations for public health interventions, and help combat disease outbreaks, such as West Nile Virus and seasonal influenza. A 2006 national assessment of epidemiologic capacity shows the number and level of training of epidemiologists is perceived as seriously deficient in most states. CDC's training fellowship program for epidemiologists can help expand state capacity and provide future leadership in the field. TFAH recommends providing $5 million for CDC's Office of Workforce and Career Development to support 65 CDC/Council of State and Territorial Epidemiology (CSTE) first year applied epidemiology fellows.

Bolstering the Nation's Ability to Detect and Control Infectious Diseases such as Pandemic Influenza

Since 2003, scientists have become increasingly concerned that the H5N1 strain of avian influenza could become more contagious among humans and mutate into a strain against which humans have little or no immunity. H5N1 has infected millions of birds and resulted in 235 deaths in humans, with a human case fatality rate of over 61%.

In November 2005, President Bush requested $7.1 billion over three years for emergency funding for pandemic influenza preparedness. In FY 2006, Congress appropriated $5.6 billion to the Department of Health and Human Services (HHS) for emergency and agency funding for pandemic preparedness. The funding has been used for stockpiling enough antiviral drugs for the treatment of more than 50 million Americans, licensing a pre-pandemic influenza vaccine, developing rapid diagnostics and completing the sequencing of the entire genetic blueprints of 2,250 human and avian influenza viruses.

To enhance our pandemic preparedness, TFAH recommends fully funding the President's FY 2009 request for $313 million for ongoing pandemic preparedness activities at the CDC, National Institutes of Health (NIH), Food and Drug Administration (FDA) and the Office of the Secretary. TFAH also supports the President's request of $507 million to be used to build vaccine production capacity, maintain a ready supply of eggs for the production of vaccine, and enable HHS to purchase medical countermeasures for its critical employees and contractors, as well as the Indian Health Service population. The Administration has also requested that Congress fund the $870 million requested by the President in FY 2008 for one-time pandemic preparedness activities, including acquiring vaccine, purchasing antivirals, and accelerating research and development for rapid diagnostic tests. TFAH supports this request.

The one major gap in pandemic preparedness not addressed in the President's budget is funding for states and localities. In April, the Department of Health and Human Services will release the final installment of the $600 million appropriated in FY 2006 for state and local pandemic preparedness activities. This funding has been used to conduct statewide pandemic influenza preparedness summits, assess and address preparedness gaps, develop antiviral distribution plans, review and update State pandemic plans, and conduct exercises at the state and local levels, including mass vaccination using seasonal flu clinics, school closures and medical surge. These are clearly not one-time activities. A recurring funding source is needed for ongoing state and local pandemic preparedness activities. To further exacerbate the current situation, as referenced earlier, over the past few years, states and localities have experienced major cuts to CDC's Public Health Emergency Preparedness Cooperative Agreements. We are concerned that

these cuts, in addition to the elimination of the state and local pandemic preparedness funds, will limit states' ability to continue to conduct exercises. As a result, we urge you to provide $350 million in recurring, *annual* funding for state and local pandemic preparedness activities.

Environmental Health

One final area of interest for TFAH is the connection between our environment and our health. For more than 30 years, the Environmental Health Laboratory of the National Center for Environmental Health has been performing biomonitoring measurements. Biomonitoring is the direct measurement of people's exposure to toxic substances in the environment. By analyzing blood, urine, and tissues, scientists can measure actual levels of almost 300 chemicals in people's bodies, and determine which population groups are at high risk for exposure and adverse health effects, assess public health interventions, and monitor exposure trends over time. Additional funds are needed to upgrade facilities and equipment and to bolster the workforce. Of the suggested $20 million increase, ten million would be used to enhance state public health laboratory biomonitoring capabilities, including upgrading facilities and equipment and bolstering workforce capacity. The remaining $10 million would be used to provide technical assistance and training to states.

The Pew Commission on Environmental Health in 2000 recommended the development of a Nationwide Health Tracking Network to help track environmental hazards and the diseases they may cause. The Network would coordinate and integrate local, state, and federal health agencies' collection of critical health and environmental data. Since 2002, Congress has provided funding for pilot programs, funding only 16 states and one city in FY 2007, down from 24 grantees. Since FY 2002, tracking has led to 38 public health actions to prevent or control potential adverse health effects from environmental exposures. In FY 2007, seventeen public health actions were completed based on information obtained from tracking. The Tracking Network is scheduled to be launched in 2008. TFAH recommends providing $50 million for CDC's Environmental and Health Outcome Tracking Network to expand it to 22 new states and support the continued development of a sustainable Network.

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

David Fleming, M.D.
Director and Health Officer
Public Health – Seattle & King County

David W. Fleming, MD, is Director and Health Officer for Public Health - Seattle & King County, a large metropolitan health department with over 2400 employees, 28 sites, and a budget of $267 million, serving a resident population of 1.8 million people. Department activities include core prevention programs, environmental health, community oriented primary care, emergency medical services, correctional health services, Public Health preparedness, and community-based public health assessment and practices.

Prior to assuming this role, Dr. Fleming directed the Bill & Melinda Gates Foundation's Global Health Strategies Program. In this capacity, Dr. Fleming was responsible for the creation, development, and oversight of cross-cutting programs targeting diseases and conditions disproportionately affecting the world's poorest people and countries. He oversaw the Foundation's portfolios in vaccine-preventable diseases, nutrition, newborn and child health, leadership, emergency relief, and cross-cutting strategies to improve access to health tools in developing countries.

Dr. Fleming has also served as the Deputy Director of the Centers for Disease Control and Prevention (CDC). While at CDC, Dr. Fleming led efforts to develop the agency's scientific and programmatic capabilities, and served as the principal source of scientific and programmatic expertise in CDC's Office of the Director. He provided oversight of CDC's global health portfolio through its Office of Global Health, and also oversaw the Director's offices of Minority Health, Women's Health, and the Associate Director for Science.

Dr. Fleming has published scientific articles on a wide range of public health issues. He has served on a number of Institute of Medicine and federal advisory committees, the Boards of the Global Alliance for Vaccines and Immunizations and the Global Alliance for Improved Nutrition, as President of the Council of State and Territorial Epidemiologists and as the State Epidemiologist of Oregon.

Dr. Fleming received his medical degree from the State University of New York Upstate Medical Center in Syracuse. He is board certified in internal medicine and preventive medicine and serves on the faculty of the departments of public health at both the University of Washington and Oregon Health Sciences University.

Mr. OBEY. Thank you again. Let me simply cite the record. The President proposed a $221,000,000 cut in this program last year. The omnibus appropriation bill, which we passed, instead added $393,000,000 to the President's request for CDC. This year, as you say, he has again proposed a $475,000,000 cut.

Dr. FLEMING. Thank you, Mr. Chairman.

Mr. OBEY. Thank you very much. Appreciate your time.

THURSDAY, MARCH 13, 2008.

CENTERS FOR DISEASE CONTROL AND PREVENTION'S BUDGET FOR FISCAL YEAR 2009

WITNESS

GEORGES C. BENJAMIN, M.D., FACP, FACEP (EMERITUS), EXECUTIVE DIRECTOR OF THE AMERICAN PUBLIC HEALTH ASSOCIATION, WASHINGTON, D.C., CENTERS FOR DISEASE CONTROL AND PREVENTION COALITION, DEPARTMENT OF HEALTH AND HUMAN SERVICES

Mr. OBEY. Centers for Disease Control and Prevention Coalition, Dr. Georges Benjamin.

Dr. BENJAMIN. Good morning, Mr. Chairman and Ranking Member Walsh. My name is Dr. Georges Benjamin, and I am the Executive Director of the American Public Health Association. But today I am here to speak to you on behalf of the CDC Coalition to express our views on the importance of providing adequate funding for the Centers for Disease Control and Prevention's budget for fiscal year 2009. The CDC Coalition is a group of over 100 groups committed to strengthening our Nation's prevention programs.

We, of course, have appreciated the Subcommittee's support over the years, and we recognize how real tough it is to find money, and even tougher to prioritize spending. But as my good friend, David Fleming, just said, obviously, the CDC's Federal funding provides the foundation for our core public health programs. Over 70 percent of these dollars go directly to communities and we believe that the CDC should be supported as an agency. So we are recommending an adequate level, at least for this year, of $7,400,000,000—which includes funding for the Agency for Toxic Substances and Disease Registry as well—for CDC's core programs; and, of course, that would not include the dollars for Vaccines for Children Program.

The CDC's budget has actually shrunk since 2005, in terms of real dollars, by over almost 4 percent, over almost $500,000,000. The current Administration request for fiscal year 2009 cuts the CDC budget by $475,000,000 below the fiscal year 2008 level; increases cuts to State and local preparedness funding, as you heard, chronic disease programs, infectious disease programs and detection, including things like West Nile Virus; and control elimination of Preventive Health Services Block Grant. We believe this request is inadequate and, quite frankly, many of the cuts appear to be arbitrary in nature.

Since 2005, these cuts in CDC we think worked in a very damaging way to decrease the capacity for the CDC and we just think these cuts are going in the wrong direction.

Just to point out, in California, the REACH Program. I mean, a small cut, but $125,000. Over $90,000,000 in the Preventive Health Services Block Grant. At least when I was in government looking at these kinds of budgets, this basically is a budget that has really no policy coherence whatsoever. And we hope that, as you are making these very, very difficult choices, you will be able to prioritize some funding back to the Centers for Disease Control and Prevention.

With that, I will stop and be happy to take any questions you might have.

[The information follows:]

CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC) COALITION

American Public Health Association 800 I Street, NW, Washington, D.C. 20001 (202) 777-2514

Testimony of Georges C. Benjamin, MD, FACP, FACEP (Emeritus)
Executive Director of the American Public Health Association
Washington, DC
On behalf of the CDC Coalition
Concerning the Centers for Disease Control and Prevention's Budget for Fiscal Year 2009
House Appropriations Subcommittee on Labor, Health and Human Services and Education
March 13, 2008, 10:00 am

The CDC Coalition is a nonpartisan coalition of more than 100 groups committed to strengthening our nation's prevention programs. Our mission is to ensure that health promotion and disease prevention are given top priority in federal funding, to support a funding level for the Centers for Disease Control and Prevention (CDC) that enables it to carry out its prevention mission, and to assure an adequate translation of new research into effective state and local programs. Coalition member groups represent millions of public health workers, researchers, educators, and citizens served by CDC programs.

The CDC Coalition believes that Congress should support CDC as an agency—not just the individual programs that it funds. **In the best judgment of the CDC Coalition—given the challenges and burdens of chronic disease, a potential influenza pandemic, terrorism, disaster preparedness, new and reemerging infectious diseases, increasing drug resistance to critically important antimicrobial drugs and our many unmet public health needs and missed prevention opportunities—we believe the agency will require funding of at least $7.4 billion (including funding for the Agency for Toxic Substances and Disease Registry) for CDC's core programs. This request does not include the mandatory funding provided for the Vaccines for Children Program (VFC).**

Mr. Chairman and members of the Subcommittee, my name is Dr. Georges Benjamin and I serve as the Executive Director of the American Public Health Association. **I am here today to speak to you on behalf of the CDC Coalition** to express our views on the importance of providing adequate funding for the Centers for Disease Control and Prevention's budget for fiscal year 2009. The CDC Coalition is a nonpartisan coalition of more than 100 groups committed to strengthening our nation's prevention programs. Our mission is to ensure that health promotion and disease prevention are given top priority in federal funding, to support a funding level for the Centers for Disease Control and Prevention (CDC) that enables it to carry out its prevention mission, and to assure an adequate translation of new research into effective state and local programs. Coalition member groups represent millions of public health workers, researchers, educators, and citizens served by CDC programs.

The CDC Coalition believes that Congress should support CDC as an agency—not just the individual programs that it funds. In the best judgment of the CDC Coalition—given the challenges and burdens of chronic disease, a potential influenza pandemic, terrorism, disaster preparedness, new and reemerging infectious diseases, increasing drug resistance to critically important antimicrobial drugs and our many unmet public health needs and missed prevention opportunities—**we believe the agency will require funding of at least $7.4 billion (including funding for the Agency for Toxic Substances and Disease Registry) for CDC's core programs.** This request does not include the mandatory funding provided for the Vaccines for Children Program (VFC).

The CDC Coalition appreciates the Subcommittee's work over the years, including your recognition of the need to fund chronic disease prevention, infectious disease prevention and treatment, and environmental health programs at CDC. 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.

CDC's budget has actually shrunk since 2005 in terms of real dollars – by almost 4 percent. If you add inflation, the cuts are even worse – and these are cuts to the core programs of the agency. The current administration request for FY 09 cuts the CDC budget by $475 million below the FY08 level including cuts to state and local preparedness funding, chronic disease programs, infectious disease detection and control and elimination of the Preventive Health and Health Services Block Grant. This request is inadequate and many of the cuts appear to be arbitrary in nature. Since 2005, CDC has sustained a total cut to core budget categories of over half a billion dollars. We are moving in the wrong direction, especially in these challenging times when public health is being asked to do more, not less. It simply does not make any sense to cut the budget for CDC's core public health programs at a time when the threats to public health are so great. Funding public health outbreak by outbreak is not an effective way to ensure either preparedness or accountability. Until we are committed to a strong public health system, every crisis will force trade offs.

The Multiple Roles of the CDC

CDC serves as the lead agency for bioterrorism preparedness and must receive sustained support for its preparedness programs in order for our nation to meet future challenges. In the best judgment of CDC Coalition members, given the challenges of terrorism and disaster preparedness, and our many unmet public health needs and missed prevention opportunities we strongly oppose the President's proposed $135.5 million cut to the state and local capacity grants. While we understand that this cut is part of a realignment of the grant funding cycles, we are concerned that this funding must now be restored in the FY2010 budget. We ask the Subcommittee to restore these cuts to ensure that our states and local communities can be prepared in the event of an act of terrorism or other public health threat this year and in future years. Unfortunately, this is not a threat that is going away.

Public health programs delivered at the state and local level should be flexible to respond to state and local needs. Within an otherwise-categorical funding construct, the Preventive Health and Health Services (PHHS) Block Grant is the only source of flexible dollars for states and localities to address their unique public health needs. The track record of positive public health outcomes from PHHS Block Grant programs is strong, yet so many requests go unfunded. However, the President's budget once again proposes the elimination of the PHHS Block Grant. We greatly appreciate the work of the Subcommittee to at least partially restore the fiscal year 2008 elimination of the Block Grant. Nevertheless, the cut to the Block Grant in fiscal year 2006 reduces the states' ability to tailor federal public health dollars to their specific needs.

Addressing Urgent Realities

Heart disease remains the nation's No. 1 killer. In 2005, more than 652,000 people died from heart disease, accounting for nearly 27% of all U.S. deaths. Of those who died from heart disease, 51% were women. Stroke is the third leading cause of death and is a leading cause of disability. In 2005, stroke killed more than 143,000 people (61% of them women), accounting for about 1 of every 17 deaths. In 1998, the U.S. Congress provided funding for CDC to initiate a national, state-based Heart Disease and Stroke Prevention Program with funding for eight states. Now, 33 states and the District of Columbia are funded, 20 as capacity building and13 as basic implementation. We must expand these efforts to continue the gains we have made in combating heart disease and stroke.

The CDC funds proven programs addressing cancer prevention, early detection, and care. Cancer is the second most common cause of death in the United States. In 2008, more than 1.4 million new cases of cancer will be diagnosed, and about 565,650 Americans— more than 1,500 people a day— are expected to die of the disease. The financial cost of cancer is also significant. According to the National Institutes of Health, in 2007, the overall cost for cancer in the United States was more than $219 billion: $89 billion for direct medical costs, $18.2 billion for lost worker productivity due to illness, and $112 billion for lost worker productivity due to premature death.

Among the ways the 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 jointly set priorities and implement specific cancer prevention and control activities customized to address each state's particular needs. CDC also funds programs to raise awareness about colorectal,

prostate, lung, ovarian and skin cancers, and the National Program of Cancer Registries, a critical registry for tracking cancer trends in all 50 states.

Chronic Obstructive Pulmonary Disease (COPD) – which includes emphysema and chronic bronchitis – is the fourth leading cause of death in the U.S. More than 12 million U.S. adults have been diagnosed with COPD, but an equal number are believed to have the disease but have not yet been diagnosed. In its FY09 Congressional Justification, CDC expressed interest in "developing a roadmap to explore the public health issues related to COPD." We ask the Subcommittee to support the development of the initial assessment and planning of such a roadmap.

Although more than 20 million Americans have diabetes, 6.2 million cases are undiagnosed. From 1980–2002, the number of people with diabetes in the United States more than doubled, from 5.8 million to 13.3 million. Each year, 12,000–24,000 people with diabetes become blind, more than 42,800 develop kidney failure, and about 82,000 have leg, foot, or toe amputations. Preventive care such as routine eye and foot examinations, self-monitoring of blood glucose, and glycemic control could reduce these numbers. Unfortunately funding for diabetes, along with many other core CDC programs, has either been cut or flat funded for the past several years. Without additional funds, most states will not be able to create programs based on these new data. States also will continue to need CDC funding for diabetes control programs that seek to reduce the complications associated with diabetes.

Over the last 25 years, obesity rates have doubled among adults and children, and tripled in teens. Obesity, diet and inactivity are cross-cutting risk factors that contribute significantly to heart disease, cancer, stroke and diabetes. The CDC funds programs to encourage the consumption of fruits and vegetables, to get sufficient exercise, and to develop other habits of healthy nutrition and activity. In order to fully support these activities, we urge the Subcommittee to provide at least $30 million for the Steps to a Healthier US program, including the Pioneering Healthier Communities program, and $65 million for CDC's Division of Nutrition and Physical Activity.

Childhood immunizations provide one of the best returns on investment of any public health program. For each birth cohort vaccinated, society saves $33.4 billion in indirect costs and $9.9 billion in direct health care costs, in addition to saving 33,000 lives and preventing 14 million cases of disease. Despite the incredible success of the program, it faces serious financial challenges. In the past 10 years, the number of recommended childhood vaccines has jumped from 10 to 16. Even more striking, the cost of fully vaccinating an adolescent female has increased from $285 to over $1200 in past eight years alone. Despite these challenges funding for vaccine purchases under Section 317 has remained stagnant. The consequence of this disconnect, is that while 747,000 children and adolescents could potentially receive their full series of vaccinations with 317 funds in 1999, that number has plummeted by over 70% to just 218,000 in 2007.

More than 400,000 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 4,000 young people try their first cigarette. At the same time, daily participation in high school physical education classes dropped from 42% in 1991 to 32% in 2001. Almost 80% 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 about 3 million become infected with a sexually

transmitted disease. School health programs are one of the most efficient means of correcting these problems, shaping our nation's future health, education, and social well-being.

CDC provides national leadership in helping control the HIV epidemic by working with community, state, national, and international partners in surveillance, research, prevention and evaluation activities. The CDC estimates that up to 1,185,000 Americans are living with HIV, one-quarter of who are unaware of their infection. Also, the number of people living with HIV is increasing, as new drug therapies are keeping HIV-infected persons healthy longer and dramatically reducing the death rate. Prevention of HIV transmission is our best defense against the AIDS epidemic that has already killed over 550,000 U.S. citizens and is devastating the populations of nations around the globe, and CDC's HIV prevention efforts must be expanded.

The United States has the highest sexually transmitted diseases (STD) rates in the industrialized world. More than 18 million people contract STDs each year. In one year, our nation spends over $8.4 billion to treat the symptoms and consequences of STDs. Elimination of STDs, especially syphilis, is now within our grasp. These welcome opportunities, if adequately funded now, will save millions in annual health care costs in the future. Untreated STDs contribute to infant mortality, infertility, and cervical cancer. State and local STD control programs depend heavily on CDC funding for their operational support.

CDC conducts several surveys that help track health risks and provide information for priority setting at the state and local levels. The Behavioral Risk Factor Surveillance System, Youth Risk Behavior Survey, Youth Tobacco Survey, and National Health and Nutrition Examination Survey (NHANES) are important national sources of objective health data. NHANES is a unique collaboration between CDC, the National Institutes of Health (NIH), and others to obtain data for biomedical research, public health, tracking of health indicators, and policy development. Mobile exam centers travel throughout the country to collect data on chronic conditions, nutritional status, medical risk factors (e.g., high cholesterol level, obesity, high blood pressure), dental health, vision, illicit drug use, blood lead levels, food safety, and other factors that are not possible to assess by use of interviews alone. Ensuring adequate funding for this survey is essential for determining rates of major diseases and health conditions and developing public health policies and prevention interventions.

We must address the growing disparity in the health of racial and ethnic minorities. CDC's Racial and Ethnic Approaches to Community Health (REACH), is helping states address serious disparities in infant mortality, breast and cervical cancer, cardiovascular disease, diabetes, HIV/AIDS and immunizations. Our members are committed to ending the disparities. We encourage the Subcommittee to reject the president's proposed cuts and to provide adequate funds for CDC's REACH program.

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

Unintentional injuries are the leading cause of death in the United States for people ages 1-44. In December, 2007, the CDC released the results of a study of injury deaths. Following a 25-year decline in injury mortality rates, there was a 5.5% increase in injury mortality from 1999 to 2004. Newly available 2005 data shows an even greater increase - 8.2% - with 173,753 reported injury deaths in the U.S. Add injury-related disability, both short- and long-term, hospitalizations and emergency department visits and the economic burden of medical treatment and lost productivity totals over $406 billion. It becomes clear that we have a growing public health problem. We urge you not only to restore the administration's proposed cuts to CDC's injury prevention and control programs, but to increase funding for injury prevention and control programs.

Of the four million babies born each year in the United States, 3% are born with one or more birth defects. Birth defects are the leading cause of infant mortality, accounting for more than 20% of all infant deaths. Children with birth defects who survive often experience lifelong physical and mental disabilities. An estimated 54 million people in the U.S currently live with a disability, and 17 percent of children under the age of 18 have a developmental disability. Direct and indirect costs associated with disability exceed $300 billion.

Created by the Children's Health Act of 2000 (P.L. 106-310), the National Center on Birth Defects and Developmental Disabilities (NCBDDD) at CDC conducts programs to protect and improve the health of children and adults by preventing birth defects and developmental disabilities; promoting optimal child development and health and wellness among children and adults with disabilities.

We also encourage the Subcommittee to provide adequate funding for CDC's Environmental Public Health Services Branch to revitalize environmental public health services at the national, state and local. The agencies that carry out these services are fragmented and their resources are stretched. These services are essential to protecting and ensuring the health and well being of the American public from threats associated with West Nile virus, terrorism, E. coli and lead in drinking water. We encourage the Committee to provide at least $50 million for CDC's Environmental Health Tracking Network and to provide $11.1 million to CDC's environmental health activities to develop and enhance CDC's capacity to help prepare for and adapt to the potential health effects of climate change. This funding would allow CDC to establish a climate change program within the agency to develop staff expertise, to fund academic and other institutions in their efforts to research the impacts of climate change on public health, to create a Center of Excellence at CDC to serve as a national resource for government leaders and the public on climate change science health, to improve global disease detection capabilities and to conduct outreach and education for our state and local public health workers.

We appreciate the Subcommittee's hard work in advocating for CDC programs in a climate of competing priorities. We encourage you to restore the cuts proposed by the administration and to consider our request for **$7.4 billion** (including funding for the Agency for Toxic Substances and Disease Registry) for CDC's core programs.

Members of the CDC Coalition

Advocates for Youth
AIDS Action
AIDS Alliance for Children, Youth and Families
AIDS Institute
AIDS Foundation Chicago
Alan Guttmacher Institute
Alliance to End Childhood Lead Poisoning
American Academy of Ophthalmology
American Academy of Pediatrics
American Association for Health Education
American Association of Orthopedic Surgeons
American Cancer Society
American College of Obstetricians and Gynecologists
American College of Preventive Medicine
American College of Rheumatology
American Dietetic Association
American Foundation for AIDS Research
American Heart Association
American Indian Higher Education Consortium
American Lung Association
American Medical Women's Association
American Optometric Association
American Podiatric Medical Association
American Psychological Association
American Psychological Society
American Public Health Association
American Red Cross
American School Health Association
American Society for Clinical Pathology
American Society for Gastrointestinal Endoscopy
American Society for Microbiology
American Society for Reproductive Health
American Thoracic Society
American Urological Association
Arthritis Foundation
Assn. for Professionals in Infection Control & Epidemiology
Association of American Medical Colleges
Association of Maternal & Child Health Programs
Association of Minority Health Professions Schools
Association of Public Health Laboratories
Association of Reproductive Health Professionals
Association of Schools of Public Health
Association of State and Territorial Health Officials
Association for Prevention Teaching and Research
Barbara Levine & Associates
Brain Injury Association
Bread for the World Institute
Campaign for Tobacco-Free Kids
CDC Foundation
Center for Science in the Public Interest
Coalition for Health Funding
Coalition for Health Services Research
Commissioned Officers Association of the U.S. Public Health Service
Consortium for Citizens with Disabilities
Consortium of Social Science Associations
Council of Professional Association on Federal Statistics
Council of State and Territorial Epidemiologist
Crohn's and Colitis Foundation of America
Environmental Defense
Every Child By Two
Families USA
Gay and Lesbian Medical Association
Health and Medicine Counsel of Washington
Hepatitis Foundation International
Home Safety Council
Immune Deficiency Foundation
Infectious Diseases Society of America
Latino Council on Alcohol & Tobacco
Legal Action Center
March of Dimes
National Association of State EMS Officials
National Alliance of State and Territorial AIDS Directors
National Association of Children's Hospitals
National Association of County and City Health Officials
National Association of Councils on Developmental Disabilities
National Association of Local Boards of Health
National Association of School Nurses
National Athletic Trainers' Association
National Black Nurses Association
National Coalition for the Homeless
National Coalition of STD Directors
National Council of La Raza
National Episcopal AIDS Coalition
National Family Planning and Reproductive Health Association
National Health Care for the Homeless Council
National Hemophilia Foundation
National Medical Association
National Osteoporosis Foundation
National Partnership for Immunization
National Rural Health Association
National Safe Kids Campaign
National Association for Public Health Statistics & Information Systems & Information Systems
Partnership for Prevention
Planned Parenthood Federation of America
Powers, Pyles, Sutter and Verville
Research!America
Society for Maternal Fetal-Medicine
Society for Public Health Education
Society of General Internal Medicine
Spina Bifida Association of America
Trust for America's Health
U.S. Conference of Mayors
United Cerebral Palsy
YMCA of the USA
YWCA of the USA/Office of Women's Health Initiative

Mr. OBEY. Thank you very much.

THURSDAY, MARCH 13, 2008.

CENTERS FOR DISEASE CONTROL AND PREVENTION'S BUDGET FOR FISCAL YEAR 2009

WITNESS

BRYAN BECKER, M.D., PRESIDENT-ELECT, NATIONAL KIDNEY FOUNDATION (NKF), DEPARTMENT OF HEALTH AND HUMAN SERVICES

Mr. OBEY. Next, National Kidney Foundation, Dr. Bryan Becker.

Dr. BECKER. Good morning, Mr. Chairman, members of the Subcommittee. I am President-Elect of the National Kidney Foundation and today is World Kidney Day. National Kidney Foundation patient advocates are visiting many of their Congressional delegations discussing chronic kidney disease.

Twenty-six million Americans have chronic kidney disease and the prevalence of chronic kidney disease has gone up 30 percent over the last two decades in the United States. My great State of Wisconsin has enough people with chronic kidney disease to fill Lambeau Field, one of our signature landmarks. Unfortunately, most of the people with chronic kidney disease do not know that they have it.

The Medicare End Stage Renal Disease Program, a marvelous program that treats patients with kidney failure with dialysis or transplantation, regardless of age or other disability, is the only disease-specific coverage under the program. But we are not talking about kidney failure; we are talking about chronic kidney disease. We are talking about patients that just have a mild degree of kidney dysfunction. And if we look at Medicare datasets, this number of individuals accounts for 21 percent of Medicare expenditures at present.

Until 2005, there was no national public health program addressing early detection and treatment of chronic kidney disease. Congress provided $2,000,000 to initiate a chronic kidney disease program at the CDC in that year. NKF is requesting a very modest $3,000,000 for that program in fiscal year 2009. The kidney program will identify high-risk individuals, develop community-based systems for improved detection and treatment, and disseminate best practices for early detection and treatment.

We know that early detection and appropriate treatment can limit chronic kidney disease and limit the number of people who develop kidney failure. The CDC has funded the development of the CKD surveillance system feasibility study and pilot programs and an expert panel which met last March has now laid the foundation for a true public health strategy for chronic kidney disease, including cooperative agreement with State-based screening demonstration projects.

The modest request for additional funding will expand that infrastructure and increase the community-based demonstration projects, extending them even into CKD monitoring for progression of CKD.

Individuals with diabetes, high blood pressure, cardiovascular disease, or a family history of chronic kidney disease are all at

great risk; and because CKD is asymptomatic early, we know detection is critical. The Chronic Kidney Disease Program at the CDC will help us improve our early diagnosis and enable health care providers to do what is right for this large set of patients in our Country.

Thank you very much for your past support and consideration for this request.

[The information follows:]

I am Bryan Becker, President-elect of the National Kidney Foundation (NKF) and a nephrologist or kidney doctor at the University of Wisconsin in Madison. NKF is a major voluntary health organization seeking to prevent kidney and urinary tract diseases, to improve the health and well-being of individuals and families affected by these diseases, and increase the availability of all organs for transplantation. Through our 47 affiliates and divisions throughout the nation, we conduct programs in research, professional education, patient and community services, public education and organ donation.

Today is World Kidney Day. In 2006, the International Society of Nephrology and the International Federation of Kidney Foundations declared that the second Thursday in March is to be observed as "World Kidney Day," to increase awareness of the prevalence and impact of chronic kidney disease. NKF is hosting kidney disease awareness activities across the nation to highlight the importance of early detection, and our patient advocates are visiting their congressional delegations in the Nation's Capital.

Twenty-six million Americans have chronic kidney disease (CKD) and the prevalence of CKD is growing, from 10% of the population in 1988 to 13% in 2004. While many individuals have early stage kidney disease and should be monitored, millions are in more advanced stages of kidney disease when treatment is warranted. In Wisconsin, we have enough people with CKD to fill one of our landmark spots, Lambeau Field. Unfortunately, most people are not aware that they have kidney disease.

Nearly 500,000 individuals have End Stage Renal Disease (ESRD), irreversible kidney failure requiring either dialysis or a kidney transplant to survive, and the number of Americans with ESRD is expected to increase rapidly to 661,000 by 2010 and 800,000 by 2020. In 2005, nearly 107,000 individuals progressed to end-stage failure; by comparison, fewer than 77,000 new cases were reported in 1996. In Wisconsin, 5,000 people have end stage kidney failure and while this number may seem small, this rate of ESRD is about 15% higher than the U.S. average. Maybe most important, certain populations are disproportionately affected, including African Americans, who represent approximately one-third of all cases of ESRD.

Medicare covers replacement therapy (dialysis or transplantation) regardless of age or other disability, the only disease-specific coverage under the program. The Medicare ESRD program celebrates its 35th anniversary this year and has saved millions of lives. NKF is very grateful for this support. However, the cost to Medicare attributable to CKD and ESRD is substantial. Less than 7% of the Medicare population carries a diagnosis of CKD, but individuals with CKD account for 21% of Medicare expenditures (Source: U.S. Renal Data System 2007 Annual Report). Furthermore, CKD multiplies the risk of concomitant diseases. For example, CKD patients are up to 100 times more likely to die from cardiovascular disease than live long enough to progress to kidney failure.

Despite the tremendous social and economic impact of CKD, no national public health program focusing on early detection and treatment existed until 2005. In 2005, Congress provided funding for a Chronic Kidney Disease Program at the Centers for Disease Control and Prevention. Congress appropriated $2 million for this program for FY 2008 and NKF is requesting $3 million for CDC's CKD program in FY 2009. Treatments exist to potentially slow progression of kidney disease and prevent its complications, but if individuals are diagnosed too late they will never get the chance to benefit from these promising therapies. 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.

Planning for the CDC CKD program is well underway. CDC has funded the development of a CKD surveillance system and will implement a feasibility study and pilot program for this system. An expert panel met in March 2007 and laid the foundation for a Public Health Strategy for Chronic Kidney Disease. The agency is presently determining which of these recommendations to initiate first. CDC also will examine the economic burden of CKD, including health care costs, life years lost, and the benefit of early interventions. The agency has entered into a cooperative agreement for state based screening of CKD as a demonstration project.

For FY 2009, NKF requests additional funding to continue planning for capacity and infrastructure at CDC for the CKD program. We also propose additional funding be provided to increase the number of state-based community demonstration projects for early detection. In addition to the detection initiative, CKD progression will be monitored as part of these demonstration projects.

The risk factors for chronic kidney disease are clear. Individuals with diabetes, hypertension, cardiovascular disease, and a family history of CKD are all at higher risk. However, CKD is asymptomatic in its early stages and it is not uncommon to receive a diagnosis just prior to the start of dialysis (one study reported 43% of African Americans with kidney failure were not aware of the disease until one week before their kidneys failed). The CDC Chronic Kidney Disease Program will help increase early stage diagnosis and enable health care providers to implement appropriate interventions to slow the progression of CKD.

Thank you for your past support and your consideration of our request.

Comments submitted on behalf of the
National Kidney Foundation
30 East 33rd Street
New York, NY 10016

Mr. OBEY. Thank you. Appreciate your time.

THURSDAY, MARCH 13, 2008.

CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)—NATIONAL INSTITUTE FOR OCCUPATIONAL SAFETY AND HEALTH (NIOSH)

WITNESS

JAMES K. BROWN, M.D., FRIENDS OF NIOSH, DEPARTMENT OF HEALTH AND HUMAN SERVICES

Mr. OBEY. Next, Friends of NIOSH, Dr. James Brown.

Dr. BROWN. Mr. Chairman, thank you for the opportunity to present testimony to the Subcommittee in support of funding for the National Institute of Occupational Safety and Health. My name is Jim Brown. I am Professor of Medicine at UC-San Francisco and a staff physician in lung disease at the San Francisco VA. I am testifying on behalf of the Friends of NIOSH, which is a coalition of business, labor, medical, professional, and educational organizations interested in helping the Nation reduce work-related illnesses and injury.

For fiscal year 2009, Friends of NIOSH request a $50,000,000 increase for NIOSH. This increase would enable NIOSH to keep pace with the changing nature of work-related illnesses and ensure that research and education to prevent work-related disease and injuries remain a high priority.

NIOSH is the primary Federal agency responsible for conducting research and making recommendations for prevention of work-related illnesses and injury. It collects information, collaborates with all stakeholders to identify the highest priority causes of these work-related problems, conducts biomedical research to find solutions, and translates the knowledge gained in solutions into products and services that improve the safety and health of workers in all sectors of the United States economy.

It supports programs in every State. As part of these State activities, NIOSH evaluates workplace hazards and recommends solutions when requested by employers, workers, and government agencies. It builds State worker safety and health capacity through grants and cooperative agreements; it funds occupational safety and health research; and it supports occupational safety and health training programs.

The many causes of occupational injury and illness represent a striking burden on American health and well-being, as reflected by the following observations:

Each day, an average of 9,000 U.S. workers sustain disabling injuries on the job; 16 workers die from injuries suffered at work, and 137 workers die from work-related illness.

In 2005, more than 4.2 million workers sustained work-related injuries and illnesses in the private sector alone.

These are especially distressing statistics because most work-related fatalities, injuries, and illnesses are preventable with effective, professionally directed health and safety programs.

Furthermore, we do not work in a static environment. Between 2000 and 2015, the number of workers 55 years and older will in-

crease by 72 percent, to over 31 million workers. Work-related injury and fatality rates begin increasing at age 45, with rates for workers 65 years and older nearly three times as high as the average for all workers.

We also constantly face new threats to worker health. The heightened awareness of terrorist threats, as well as the increased responsibilities of first responders and other homeland security professionals illustrate the need for strengthened workplace health and safety in the ongoing war on terror.

NIOSH developed more effective methods to test for anthrax contamination in congressional offices. These procedures were quickly adopted by the Coast Guard, FBI, and government building contractors.

In response to ongoing safety concerns regarding the tunnels under the U.S. Capitol, NIOSH was asked to evaluate health hazards in the tunnels for workers who maintain the plumbing that provide steam and water to Congress, Library of Congress, Supreme Court, and other Federal buildings.

NIOSH took a lead role in the safety of 9/11 emergency responders in New York City and Virginia, with NIOSH trained professionals applying their technical expertise to meet immediate protective needs and safeguard the health of cleanup workers. NIOSH now administers awards to provide health screening of World Trade Center responders.

Thank you for the opportunity to report the great need for research and training in occupational health and safety. Thank you.

[The information follows:]

Friends of NIOSH

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

Presented by:
James K. Brown MD

On behalf of:
The Friends of NIOSH

March 13, 2008

Summary:
The following is a written transcript of oral testimony with regard to the FY 2009 Labor, Health and Human Services, and Education Appropriations bill, in support of increased and continued funding for the Center for Disease Control and Prevention's National Institute for Occupational Safety and Health.

Mr. Chairman, members of the subcommittee, thank you for the opportunity to present testimony to the Subcommittee in support of funding for the National Institute for Occupational Safety and Health (NIOSH). My name is Dr. James Brown and I am a pulmonary physician and the San Francisco VA. **I am testifying on behalf of the Friends of NIOSH,** a coalition of business, labor, medical professional and education organizations that are interested in helping the nation reduce losses associated with work-related illnesses and injuries.

Fiscal Year 2009 Request

In fiscal year 2009 Friends of NIOSH requests a $50 million increase for NIOSH over the fiscal year 2008 appropriated level. A $50 million increase would enable NIOSH to keep pace with the changing nature of work and ensure that research and education to prevent work-related disease and injuries remain a high priority.

The National Institute of Occupational Safety and Health (NIOSH) is the primary federal agency responsible for conducting research and making recommendations for the preventions of work-related illness and injury. NIOSH was established by the Occupational Safety and Health Act of 1970 with the mandate to conduct research in occupational safety and health and to provide educational opportunities for occupational safety and health professionals. The NIOSH mission spans the spectrum of activities necessary for the prevention of work-related illness, injury, disability, and death by collecting information and collaborating with all stakeholders to identify highest priority causes, conducting biomedical research (both applied and basic), engineering solutions to hazards, and translating the knowledge gained and solutions created from this interdisciplinary research into products and services that improve the safety and health of

workers in all sectors of the U.S. economy. As part of its mission, NIOSH supports programs in every state to improve the health and safety of workers.

As part of these State Activities, NIOSH:

- Evaluates workplace hazards and recommends solutions when requested by employers, workers, or state or federal agencies;
- Builds State worker safety and health capacity through grants and cooperative agreements;
- Funds occupational safety and health research on a wide variety of topics at universities and other organizations; and
- Supports occupational safety and health training programs.

The many causes of occupational injury and illness represent a striking burden on America's health and well-being. Yet, despite significant improvements in workplace safety and health over the last several decades:

- An average of 9,000 U.S. workers sustain disabling injuries each day on the job, 16 workers die from an injury suffered at work, and 137 workers die from work-related diseases.

- In 2005, more than 4.2 million workers sustained work-related injuries and illnesses in the private sector alone.

- The Liberty Mutual 2005 Workplace Safety Index estimates that employers spent $50.8 billion in 2003 on wage payments and medical care for workers hurt on the job; the indirect costs exceeded $200 billion.

This is an especially tragic situation because most work-related fatalities, injuries and illnesses are preventable with effective, professionally directed, health and safety programs.

Furthermore, we do not live in a static environment. The rapidly changing workplace continues to present new health risks to American workers that need to be addressed through occupational safety and health research. For example, between 2000 and 2015, the number of workers 55 years and older will increase 72 percent to over 31 million. Work related injury and fatality rates begin increasing at age 45, with rates for workers 65 years and older nearly three times as high as the average for all workers.

In addition to factors that increasingly affect the vulnerability of our workers, we constantly face new threats to worker health. The heightened awareness of terrorist threats, and the increased responsibilities of first responders and other homeland security professionals, illustrates the need for strengthened workplace health and safety in the ongoing war on terror.

Thanks to the Subcommittee's support for occupational health and safety research, NIOSH developed more effective methods to test for anthrax contamination in congressional offices. These procedures were quickly adopted by the Coast Guard, the FBI, and government building

contractors. More recently, in response to ongoing safety concerns regarding the tunnels under the U.S. Capitol Complex, NIOSH was asked to evaluate health hazards in the tunnels for workers who maintain the plumbing that provides steam and chilled water to Congress, the Library of Congress, the Supreme Court and other federal buildings.

In addition, occupational health and safety professionals have worked for several years with emergency response teams to minimize losses in the event of a disaster. NIOSH took a lead role in protecting the safety of 9/11 emergency responders in New York City and Virginia, with NIOSH University based Education and Research Center (ERC) trained professionals applying their technical expertise to meet immediate protective needs and conducting ongoing activities to safeguard the health of clean-up workers. Additionally, NIOSH is now administering grants to provide health screening of World Trade Center responders.

Thank you for the opportunity to report the great need for research and training in occupational safety and health.

Mr. OBEY. Thank you very much.

Let me just point out last year the President requested $252,900,000. This Committee added $21,000,000 to his request. This year the President is suggesting a $28,000,000 cut. I have to say I am biased; I think that NIOSH is one of those agencies squeezed the most.

I recall, a number of years ago, when I got Dr. Irving Selikoff to come to my district to do an epidemiological study on behalf of grain workers in one of my major cities because a number of them were having severe respiratory problems, and the CEO of that grain elevator went ballistic and swore to me that there were no problems whatsoever on the floor. Well, I had been in that grain elevator; I, myself, had had a severe reaction to the grain. So I simply suggested to him that he ought to change places with his workers for a week; let them sit in his office while he worked on the shop floor; he might have a different attitude about the problem.

NIOSH is crucial to dealing with problems like that. Thank you very much.

Dr. BROWN. Thank you, Mr. Chairman.

THURSDAY, MARCH 13, 2008.

HEALTH RESOURCES AND SERVICES ADMINISTRATION—CHILDREN'S HOSPITALS GRADUATE MEDICAL EDUCATION

WITNESS

JOSEPH WRIGHT, M.D., MPH, EXECUTIVE DIRECTOR, CHILD HEALTH ADVOCACY INSTITUTE, CHILDREN'S NATIONAL MEDICAL CENTER, WASHINGTON, D.C., THE NATIONAL ASSOCIATION OF CHILDREN'S HOSPITALS, ALEXANDRIA, VIRGINIA, DEPARTMENT OF HEALTH AND HUMAN SERVICES

Mr. OBEY. National Association of Children's Hospitals, Joseph Wright.

Dr. WRIGHT. Chairman Obey and Ranking Member Walsh, thank you for the opportunity to testify today in support of the Children's Hospitals Graduate Medical Education Program. I am Dr. Joseph Wright, Executive Director of the Child Health Advocacy Institute at Children's National Medical Center here in Washington, D.C., and have practiced pediatric emergency medicine for 18 years there. I am here today on behalf of the National Association of Children's Hospitals and the 60 independent children's teaching hospitals that qualify for CHGME funding, including Children's National Medical Center.

Congress established the CHGME program in 1999 to address a disparity in Federal graduate medical education support that existed between adult teaching hospitals and independent children's teaching hospitals. Because independent children's hospitals treat children and not the elderly, they are largely excluded from the predominant payer of graduate medical education: Medicare.

Prior to CHGME, children's teaching hospitals received one-two hundredth the Federal GME support that adult teaching hospitals received. Thanks to this Subcommittee's leadership and the broad bipartisan Congressional support, the CHGME program currently

provides about 80 percent of the GME support that Medicare provides to adult teaching hospitals.

CHGME funding has been absolutely essential to children's hospitals and the future of pediatric medicine. Less than one percent of all independent teaching hospitals train 35 percent of all pediatricians and half of all pediatric subspecialists. CHGME hospitals provide half of all hospital care for seriously ill children in this Country and serve as the Nation's premier pediatric research centers.

CHGME has been remarkably successful in erasing the decline in a number of pediatric residencies that existed prior to its enactment. CHGME has enabled children's hospitals to sustain and expand residency programs at a time of national pediatric workforce shortages.

Since the program was instituted, CHGME recipient hospitals have accounted for more than 67 percent of the growth in the number of pediatric subspecialty trainees and 76 percent of the growth in the number of all pediatric residents.

Since fiscal year 2000, the first year that we received CHGME support at my hospital, Children's National has experienced a 30 percent increase in the number of residents and fellows that we train. We have added specialties and now operate 17 ACGME accredited programs.

Now, as you know, with only one exception, in fiscal year 2005, the President has consistently proposed to cut CHGME funding in his annual budget. This year, the President's budget proposed the elimination of CHGME. Fortunately, this Subcommittee and Congress have consistently sustained the program's funding.

In 2006, Congress reauthorized the CHGME program with nearly unanimous approval, providing $330,000,000 in authorized funding. Last year, Congress appropriated $301,700,000 for the program. In its reauthorization, Congress reinforced the fact that CHGME is a targeted, fiscally-responsible, slow-growth program.

In the last five years, CHGME's funding has grown at an annual rate of just 0.8 percent, from $290,000,000 in fiscal year 2003 to less than $302,000,000 in fiscal year 2008. It operates under extensive data reporting requirements, which were further strengthened in its reauthorization.

We deeply appreciate the support this program has received from so many members of this Subcommittee. We are grateful for the leadership of Chairman Obey and Ranking Member Walsh, and former Chairman Ralph Regula and Bill Young. CHGME is not only important to the Nation's children's hospitals, it is absolutely critical to all children's health and the future of pediatric medicine in this Country.

I ask that you please ensure continuation of the strong successful CHGME program that exists today by appropriating the fully authorized level of $330,000,000 for CHGME in fiscal year 2009. Thank you very much.

[The information follows:]

National Association of
Children's Hospitals

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Alexandria, VA 22314
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Testimony of Joseph L. Wright, MD, MPH
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Children's National Medical Center
Washington, DC

on behalf of

The National Association of Children's Hospitals
Alexandria, Virginia

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

March 13, 2008 – 10:00 a.m.

Summary of Testimony

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

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

The testimony concludes by respectfully asking the subcommittee to appropriate full authorized funding -- $330 million – for CHGME in Fiscal Year 2009.

NATIONAL ASSOCIATION OF CHILDREN'S HOSPITALS

WRITTEN TESTIMONY

Children's National Medical Center, a 283 bed not-for-profit academic medical center in Washington, DC, has provided hope to sick children and their families throughout the metropolitan region for more than 135 years. Children's National's mission is to improve health outcomes for children regionally, nationally and internationally, to be a leader in creating innovative solutions to pediatric healthcare problems, and to excel in care, advocacy, research and education to meet the unique needs of children, adolescents and their families. Children's National is consistently ranked among the best pediatric hospitals in America by *US News & World Report.*

The National Association of Children's Hospitals – N.A.C.H. – is the public policy affiliate of the National Association of Children's Hospitals and Related Institutions (NACHRI). N.A.C.H. is a trade organization of 141 children's hospitals and supports children's hospitals in addressing public policy issues that affect their ability to fulfill their missions to serve children and their families. N.A.C.H. fulfills its mission and vision through federal advocacy, collaboration and communication designed to strengthen the ability of children's hospitals and health systems to influence public policy makers, understand federal and state policy issues, advance access and quality of health care for all children, and sustain financially their missions of clinical care, education, research and advocacy.

CHGME Background

Congress established the Children's Hospitals Graduate Medical Education (CHGME) program in 1999 to address a disparity in federal graduate medical education support that existed between adult teaching hospitals and independent children's teaching hospitals. Because they treat children and not the elderly, independent children's teaching hospitals were effectively left out of the only remaining major source of federal GME support – Medicare.

In 1998, Medicare paid an adult teaching hospital, on average, more than $60,000 per full time equivalent (FTE) resident through direct and indirect medical education payments. Despite fulfilling the same academic mission, Medicare paid independent children's teaching hospitals on average less than $400 per resident (children with end-stage renal disease qualify for Medicare). Medicaid GME payments, which are left to the discretion of states to provide, were, and still are, well below costs.

The disparity in GME support put independent children's hospitals at a significant competitive disadvantage, placed their missions of clinical care, education and research at grave risk, and jeopardized an already precarious pipeline of pediatric specialists.

CHGME: Increasing the Pediatric Workforce, Benefiting All Children

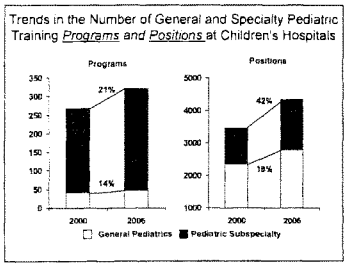
Independent children's teaching hospitals, which represent less than 1 percent of all hospitals, train 35 percent of all pediatricians, half of all pediatric sub-specialists and the great majority of pediatric researchers. In addition, they provide half of all hospital care to seriously ill children and serve as the nation's premier pediatric research centers.

CHGME funding, which currently provides about 80% of the GME support that Medicare provides to adult teaching hospitals, has enabled children's hospitals to reverse the decline in pediatric training seen in the 1990s, expand pediatric training programs and improve the quality and depth of their training. According to data provided by the American Medical Association, between 2000 and 2006, the first years during which hospitals received CHGME funding, children's hospitals accounted for three quarters of the growth in pediatric residents trained nationally. Without this expanded training, there would have been a net decline in the number of pediatric residents.

CHGME has also played a critical role in addressing the nation's serious shortage of pediatric sub-specialists. In 2003, the most recent year for which data is available, one third of health referral regions did not have a pediatric cardiologist; more than half did not have a pediatric nephrologist, and nearly three quarters did not have a pediatric neurologist. Thanks to CHGME, children's hospitals accounted for two-thirds of the growth in new pediatric subspecialty residents trained between 2000 and 2006.

Since 2000, children's hospitals increased both the number of their residency programs and the number of residents trained in response to local, regional and national needs *(See Figure 1)*. They did so despite caps on CHGME funding and caps on the number of full time equivalent residents that may be counted in accordance with Medicare rules.

Figure 1



Note: Includes only American Board of Pediatrics Programs and excludes combined programs such as internal medicine/pediatrics. Data from the Graduate Medical Education Database, copyright 2006, American Medical Association, Chicago, Illinois.

CHGME has enabled children's hospitals to improve the caliber of their training by introducing new training curricula in areas such as quality measurement, health information technology, and serving vulnerable children in underserved urban and rural areas. By strengthening the nation's pediatric workforce, CHGME benefits all children, not just those treated at independent children's teaching hospitals.

Children's hospitals also train the majority of tomorrow's pediatric researchers. Scientific discovery rests upon the strong academic programs of teaching hospitals. By advancing research and teaching in a single setting, teaching hospitals combine the two critical ingredients for successful scientific discovery in medicine: scientific breakthroughs and rapid translation to the bedside. Children's teaching hospitals' scientific discoveries have helped children survive once fatal diseases such as polio and cancer, to grow and thrive with once crippling disabilities such as cerebral palsy and to become economically self-supporting adults managing such chronic conditions as juvenile diabetes and spina bifida.

The Children's National Medical Center Experience

Since Fiscal Year 2000, Children's National has experienced a nearly 30% increase in the number of residents and fellows it trains. The hospital has added specialties and now operates 17 ACGME accredited programs. Because Children's National now has dedicated CHGME funding for its training programs, it can target other resources to better meet the needs of all children in the Washington metropolitan region.

Through its seven regional outpatient centers in Maryland and Virginia, seven primary care health centers in the District of Columbia, mobile health and immunization units, school nurse program in the District's public schools and management of health care for the District's children in foster care, Children's National is committed to improving health care for all children throughout the Washington metropolitan region. As the largest non-governmental provider of pediatric health care in the District of Columbia, Children's National is the pediatric health care safety net for all children in the region. Nearly 50% of the hospital's inpatient population relies on Medicaid or SCHIP for health coverage, as do more than 95% of the children who visit its primary care health centers. CHGME funding allows Children's National to simultaneously fulfill its academic mission and its mission to serve all children in the region, regardless of ability to pay.

FY 2009 Funding Request: $330 Million

In 2006, Congress reauthorized the CHGME program with nearly unanimous approval, providing $330 million annually in authorized funding. Congress appropriated $301.7 million for the program in FY 2008. In the reauthorization, Congress reinforced the fact that CHGME is a targeted, fiscally responsible and slow-growth program. In the last five years, CHGME funding has grown at an annual rate of 0.8 percent, from $290 million in FY 2003 to less than $302 million in FY 2008. It

operates under rigorous data reporting requirements, which were further strengthened in the reauthorization.

With only one exception, in FY 2005, the president has consistently proposed to cut CHGME funding in his annual budget. This year, the president's budget proposed the elimination of CHGME. The nation's independent children's hospitals applaud members of the House Labor-HHS Appropriations Subcommittee for providing strong, consistent CHGME funding. In particular, children's hospitals appreciate the tireless leadership provided by Chairman Obey, Ranking Member Walsh, and former chairmen Ralph Regula and Bill Young.

CHGME is not only important to the nation's children's hospitals, it is absolutely critical to all children's health care and the future of pediatric medicine. Children's hospitals respectfully ask the Subcommittee to ensure continuation of the strong, successful CHGME program that exists today by appropriating the fully authorized level of $330 million in FY 2009.

Joseph L. Wright, MD, MPH is Executive Director of the Child Health Advocacy Institute, a newly established center of excellence at Children's National Medical Center (Children's National) in Washington, DC. In that capacity, Dr. Wright provides strategic leadership for the organization's advocacy mission, public policy positions and community partnership initiatives. Academically, he is a Professor and Vice Chairman in the Department of Pediatrics, as well a Professor of Emergency Medicine and Health Policy at the George Washington University Schools of Medicine and Public Health. He has been attending faculty in the Division of Emergency Medicine at Children's National since 1993, and is founding director of the division's Institute for Prehospital Pediatrics and Emergency Research. He also provides state-level leadership as the EMS Medical Director for Pediatrics within the Maryland Institute for Emergency Medical Services Systems (MIEMSS), and national leadership as senior investigator of the federally-funded Emergency Medical Services for Children National Resource Center.

Dr. Wright's major areas of scholarly interest include emergency medical services for children, injury prevention and the needs of underserved communities. He has received recognition for his advocacy work throughout his career, including the Shining Star award from the Los Angeles-based Starlight Foundation for outstanding community service, and has been inducted into Delta Omega, the nation's public health honor society. He has been appointed to key national advisory bodies, including the inaugural National EMS Advisory Council and several within the Institute of Medicine and the American Academy of Pediatrics where he currently chairs the Academy's subcommittee on Violence Prevention. Dr. Wright has delivered expert testimony before Congress on several occasions, has made numerous national media appearances and lectures widely to both professional and lay audiences.

Grant Disclosure: Children's National Medical Center, Washington, DC

Active Federal CRI Awards as March 3, 2008

Sponsor Name	ID Number	Project Title	Project Period Start Date	Project Period End Date	Awarded Budget Period Total	Prime or Subrecip
Department of Defense	USAMRAA #W81XWH-05-1-0616-P00002	Duchenne Muscular Dystrophy Translational Research Program	01-Oct-2005	30-Sep-2007	819,777	Prime
Department of Education	UC Irvine contract	Rehabilitation Training Center for Neuromuscular Disesases.	01-Dec-2007	30-Nov-2008	117,423	Subrecipient
Department of Health & Human Services	1APHPA006026-03-00	Enhanced Healthy Generations Program	01-Sep-2005	31-Aug-2010	350,000	Prime
Environmental Protection Agency	XA-83157401-3	Smoke-Free Homes Champions: Pediatric Cllinicians Making Children's Homes Smoke Free	01-Dec-2003	31-May-2008	0	Prime
Food & Drug Administration	FDA-FD-002128	Pirfenidone in Children with PNs in NF1. Yr 04 cont.	30-Sep-2006	29-Sep-2007	346,761	Prime
Health Resources and Services Administration/DHHS	1R40MC08963-01-00	The interplay between bedsharing and other known risk factors for SIDS in African American infants	01-Feb-2008	31-Jan-2009	100,000	Prime
	4T73MC03181-04-00	Leadership Education in Neurodevelopmental and Related Disabilities (LEND)	01-Jul-2004	30-Jun-2008	400,000	Prime
	5U03MC00006-07-00	Cheaspeake Atlantic Research Network for EMSC (CARN).	01-Sep-2005	31-Aug-2008	742,630	Prime
Maternal and Child Health Bureau/Health Resources and Services	1H33MC06715-03-00	DC Partnership 2005/Emergency MedicalServices for Children	01-Mar-2006	28-Feb-2007	115,000	Prime
National Cancer Institute/NIH/DHHS	2U01CA081457-06	PBTC Phase I/II Trial of Intra-cerebral IL13-PE38QQR Infusion in Pediatric Patients with Recurrent Malignant Glioma.	01-Apr-2007	31-Mar-2008	90,034	Subrecipient
	5K08NS051477-02	Creation of PDGF-C Autocrine Loop by HIC1 Inactivation	09-Apr-2007	28-Feb-2012	145,800	Prime
	2R01CA042361-17	Gangliosides and the Biology of Human Neuroblastoma	01-Apr-2004	31-Mar-2009	261,674	Prime
	5R01CA061010-11	Glycobiology of Human Medulloblastoma.	09-Jul-1990	28-Feb-2007	636,148	Prime
	U10CA98543-05	Children's Oncology Group- Chairman's Award Radiology	01-Mar-2003	28-Feb-2008	13,212	Subrecipient

Sponsor Name	ID Number	Project Title	Project Period Start Date	Project Period End Date	Awarded Budget Period Total	Prime or Subrecip
	5R03CA106887-02	Characterizing the Obesity of Long-Term Cancer Survivors.	25-Jun-2004	31-May-2007	0	Prime
	1R01CA106532-01A1	Complex Ganglioside Function in Neuroblastoma.	14-Dec-2004	30-Nov-2008	247,903	Prime
	5R01HL079912-03	Pulmonary Hypertension and the Hypoxic Response in SCD.	01-Aug-2005	31-Jul-2009	257,717	Subrecipient
	5R01CA111835-02	Role of Platelet-Derived Growth Factor Receptor in Medulloblastoma Progression	01-May-2006	30-Apr-2011	257,494	Prime
	M01RR020359-05	Opioid and Analgesia in Children and Adolescents with Sickle Cell Disease	01-Dec-2006	30-Nov-2008	0	Prime
National Center for Research Resources/NIH/DHHS	1K23RR024467-01	Analysis of Bone Health in African American Children with Forearm Fractures	28-Sep-2007	31-Jul-2008	150,795	Prime
	5K12RR17613-05	PCRSP	01-Aug-2004	31-Jul-2008	0	Prime
	5U54RR019453-03	Rare Disease CRC-Urea Cycle Disorder- Yr03	30-Sep-2003	31-Jul-2007	1,202,075	Prime
	K12RR017613-05	TDM in HIV-Infected Pediatric Patients	01-Aug-2004	31-Jul-2008	0	Prime
	5K24RR019729-04	Optimizing Pain Treatment in the Preterm Infant	01-Jul-2004	30-Jun-2009	141,423	Prime
	5K23RR020069-03	Analysis of Immunity and Thrombosis in Acute Lung Injury.	23-Sep-2005	30-Jun-2010	124,686	Prime
	5M01RR020359-04	CReFF Award-Berl	01-Feb-2005	30-Nov-2008	0	Prime
	5K12RR17613-05	PCRSP Appointment	01-Aug-2006	31-Jul-2008	0	Prime
	2P20MD00198-06	Establishing Exploratory NCMHD Research Centers of Excellence	01-Oct-2007	31-May-2012	88,320	Subrecipient
	5P20MD00165-05	DC-Baltimore Center to Improve Child Health Disparities.	30-Sep-2002	31-Jul-2008	0	Prime

Sponsor Name	ID Number	Project Title	Project Period Start Date	Project Period End Date	Awarded Budget Period Total	Prime or Subrecip
	1K01MH069593-01A1	Neighborhood Risk Factors for Maternal Depression.	01-Aug-2004	31-Jul-2009	149,594	Prime
	5P20MD00165-05	Analysis of Bone Health in African American Children with Distal Forarm Fractures	01-Jan-2006	31-Jul-2008	0	Prime
National Center on Minority Health and Health	NHLBI-263-MJ205189	Novel Gene and Genetic Pathways Essential for Mamallian Heart	01-Nov-2001	31-Jan-2007	82,359	Prime
	5U10HL083748-02	Howard-CNMC Sickle Cell Disease Clinical Research Center.	17-Apr-2006	31-Mar-2007	45,710	Prime
	2R01HL067229-06	Transfusion Infection Pediatric Prospective Study (TRIPPS)	01-Aug-2007	31-Jul-2008	317,102	Prime
	1K12HL090020-01	Genetics and Genomic Approaches to Lung Diseases and Disorders in Washington, DC	27-Sep-2007	31-Jul-2008	399,600	Prime
National Heart, Lung, and Blood Institute/NIH/DHHS	5R01HL55605-10	Pathogenesis of HIV-Associated HUS in Children. Yr08	01-Dec-2001	30-Nov-2006	0	Prime
	5R01AI048837-06	Dynamics of Peripheral T Cell Repertorie	01-Aug-2003	28-Feb-2007	0	Prime
	5R21CA109011-02	A Novel Animal Model System of AIDS-Kaposi Sarcoma	11-Jun-2004	31-May-2005	0	Prime
	1R01AI057906-01A2	HCMV UL37 Proteins: Trafficking & Functional Diversity	01-Jun-2005	28-Feb-2010	308,815	Prime
	5K08AI052261-06	Apoptotic Signaling in Viral Myocarditis	02-Aug-2006	31-Mar-2009	0	Prime
National Institute of Allergy and Infectious Diseases/NIH/DHHS	1R01AR052027-01A2	Molecular Pathophysiology of FSHD Muscular Dystrophy via Genome-Wide Approaches	15-Mar-2007	28-Feb-2008	356,900	Prime
	5R0AR050478-05	Pathogenesis of Autoimmune Myositis: Role of MHC Class 1	01-Nov-2005	31-Jan-2007	0	Prime
	5HD040562-04	Adolescent Medicine Trials Network for HIV/ADIS . 04yr Cont	16-Apr-2001	28-Feb-2011	495,802	Prime
	5U54HD053177-03	Wellstone Fellowship Supplement	05-Jan-2007	30-Jun-2007	166,000	Prime

Sponsor Name	ID Number	Project Title	Project Period Start Date	Project Period End Date	Awarded Budget Period Total	Prime or Subrecip
National Institute of Arthritis and Musculoskeletal and Skin	1R49CE001002-02	Clinical Decision Rule to Identify Childtren with Intr-abdominal Injuries.	01-Sep-2006	31-Aug-2007	24,807	Subrecipient
	5U10HD049981-04	Cooperative Clinical Research Agreement	01-Feb-2005	30-Nov-2008	0	Prime
National Institute of Child Health and Human Development/NIH/DHHS	1U10HD045993-01	Washington, D.C. Collaborative PPRU	01-Jan-2004	31-Dec-2008	305,578	Prime
	5K12HD001399-08	Comprehensive CSF Proteomics in Leukodystrophies. (CHRC#5)	01-Jul-2004	30-Jun-2007	108,000	Prime
	5K12HD001399-08	Ultrahigh Frequency Cardiography of Cardiomyopathies in(CHRC#6)	01-Jul-2004	30-Jun-2007	107,376	Prime
	N01-HD-4-3393	Pediatric Off-Patent Drugy Study (PODS) Center - Lorazepam for Treatment of STatus Epilepticus	30-Sep-2004	31-Aug-2008	1,664,663	Prime
	1R01HD048051-01	Molecular Signature of Muscle Rehab After Limb Disuse	28-Sep-2004	31-Jul-2009	86,090	Subrecipient
	5U10HD049981-04	Assessment and Prediction of Functional Status	01-May-2005	30-Nov-2007	435,400	Prime
	5K12HD001399-05	Characterization of the Mechanism of Ganglioside-induced Toll-like Receptor Inhibition	01-Jul-2005	30-Jun-2007	0	Prime
	5K12HD001399-05	HIC-1 Inactivation and PDGF Autocrine Signaling.	01-Jul-2005	30-Jun-2007	0	Prime
	5R24HD050846-03	Integrated Molecular Core for Rehabilitation Medicine.	01-Aug-2005	31-Jul-2007	703,551	Prime
	5U54HD053177-03	Wellstone MD Center CNMC	30-Sep-2005	30-Jun-2007	196,804	Prime
	1K24HD049828-01A1	Factors Influencing the Racial Disparity of SIDS	01-Jul-2006	30-Jun-2011	158,498	Prime
	W81XWH-05-1-0616-P00002	Duchenne Muscular Dystrophy Translational Research Program - Core B	01-Oct-2005	30-Sep-2007	226,529	Prime
	W81XWH-05-1-0616-P00002	Duchenne Muscular Dystrophy Translational Research Program - Project 2	01-Oct-2005	30-Sep-2007	230,388	Prime

Sponsor Name	ID Number	Project Title	Project Period Start Date	Project Period End Date	Awarded Budget Period Total	Prime or Subrecip
	5U54HD053177-03	Wellstone MD Center CNMC - Core B	30-Sep-2005	30-Jun-2007	208,933	Prime
	5U54HD053177-03	WELLSTONE MUSCULAR DYSTROPHY CENTER - CNMC - CORE C	30-Sep-2005	30-Jun-2007	195,299	Prime
	5U54HD053177-03	Wellstone MD Center CNMC - Project 1	30-Sep-2005	30-Jun-2007	251,353	Prime
	5U54HD053177-03	Wellstone Muscular Dystrophy Center - CNMC Project 2	30-Sep-2005	30-Jun-2007	184,549	Prime
	5U54HD053177-03	WELLSTONE MUSCULAR DYSTROPHY CENTER - CNMC PROJECT 2 CHEN	30-Sep-2005	30-Jun-2007	261,525	Prime
	5U54HD053177-03	Wellstone Muscular Dystrophy Center - CNMC Project 3 (Partridge)	30-Sep-2005	30-Jun-2007	201,087	Prime
	3U10HD045993-03S1	MSCDA in Pediatric Pharmacology	01-Sep-2006	31-Dec-2008	127,690	Prime
	1 K23 RR022227	Low Glycemic Load Diets in Latino Children at Risk for Type 2 Diab	28-Aug-2006	31-Jul-2009	124,528	Prime
	U54DE142640-04	NE Center for Research to Reduce Oral Health Disparities Yr04	01-Aug-2002	31-Jul-2007	0	Subrecipient
	R44 DK060302-02A1	Organized Lipid Matrix: Fatty Acids and Choline in Cystic Fibrosis	01-Dec-2006	30-Jun-2007	0	Subrecipient
	3R01DK049419-10S2	BFGF Low Affinity Receptors and HIVAN-Minority Supplement	01-Mar-2007	28-Feb-2009	141,100	Prime
	5U01DK61731-06	Treatment of Nonalcoholic Fatty Liver Disease in Children	01-May-2007	30-Apr-2008	44,955	Subrecipient
National Institute of Dental and Craniofacial Research/NIH/DHHS	3R01DK049419-10S1	BFGF Low Affinity Receptors and HIVAN	01-Mar-2007	29-Feb-2008	60,804	Subrecipient
National Institute of Diabetes and Digestive and Kidney	U01DK063549-02	MMF/IgAN Study	01-Sep-2004	31-Aug-2007	0	Subrecipient
	1R43DK069106-01	Genotype analysis for Diagnosis of Urea Cycle Disorders.	15-Jul-2005	31-Aug-2007	100,000	Subrecipient
	2R01DK049419-09A2	BFGF Low Affinity Receptors and HIVAN	01-Apr-2006	28-Feb-2007	296,531	Prime

Sponsor Name	ID Number	Project Title	Project Period Start Date	Project Period End Date	Awarded Budget Period Total	Prime or Subrecip
	2R01DK47870-13	The molecular Bases of Inherited Urea Cycle Disorders and Ureagenesis Regulation	01-Aug-2007	31-Jul-2008	348,155	Prime
	1R01NS056427-01	Characterization of Sox17 as a Regulator of Oligodendrocyte Diff	01-Apr-2007	31-Mar-2008	363,127	Prime
	9R01AR055100-05A2	Functional SNPs Associated with Human Muscle Size and Strength	01-Dec-2006	30-Nov-2007	682,713	Prime
	1K99NS057944-01	A Role for EGF Receptor Signaling in Oligodendrocyte Development and Repair	01-Jun-2007	31-Mar-2008	88,113	Prime
	5U01NS045911-05	Childhood Absence Epilepsy Rx, PK-PD Pharmacogenetics	01-Nov-2006	31-Oct-2007	0	Subrecipient
	5R01NS045702-04	A Common Glial-Neuronal Progenitor in Postnatal Brain	15-Sep-2004	31-May-2008	352,409	Prime
	5R01NS0051852-04	Neocortical Neurogenesis and Mititic Spindle Dynamics.	15-Feb-2005	31-Jan-2010	0	Prime
National Institute of Neurological Disorders and Stroke/NIH/DHHS	2R01NS029525-13A1	Improved Diagnostics of the Muscular Dystrophies.	18-Mar-2005	28-Feb-2008	559,206	Prime
	5K12NS052159-02	Neurological Sciences Academic Development at CNMC	15-Aug-2006	31-Jul-2008	135,486	Prime
	5K12NS052159-02	Neurological Science Academic Development At CNMC			0	Prime
	7R01DA020140-02	Development of the Basal Telencephalic Limbic System	01-Mar-2006	29-Feb-2008	348,673	Prime
	FDA FD-R-002128	Telomere Maintenance Mechanisms in Human Osteosarcoma	11-Jul-2007	10-Jul-2008	98,569	Prime
	1U10HD049981-01	CRISIS protocol	01-Sep-2007	30-Nov-2007	41,995	Prime
	2K12RR17613-05S1	Pediatric Clinical Research Scholar Program - Bench to Bedside Award	01-Aug-2005	31-Jul-2008	0	Prime
	5U10HD030447-14	Improving Minority Child Health in Washington, DC (Smoking Protocol)	01-May-2007	30-Apr-2008	245,127	Prime
	5U10HD030447-14	Improving Minority Child Health in Washington, DC (Diabetes Protocol)	01-May-2007	30-Apr-2008	159,145	Prime

Sponsor Name	ID Number	Project Title	Project Period Start Date	Project Period End Date	Awarded Budget Period Total	Prime or Subrecip
National Institute on Drug Abuse	M01RR020359-04	Robb - CReFF Award	01-Dec-2006	30-Nov-2008	0	Prime
National Institutes of Health	M01RR020359-04	Kuehl - CReFF Award	01-Dec-2006	30-Nov-2008	0	Prime
	1R42HL086294-01A1	Bio-Effects of Ultra-High MRI Gradient Slew Rates	01-Dec-2007	30-Nov-2008	117,398	Subrecipient
	GCRC 5M01RR020359-04	GCRC Administrative Core year 4	01-Dec-2007	30-Nov-2008	452,075	Prime
	GCRC 5M01RR020359-04	GCRC Nutrition Core year 4	01-Dec-2007	30-Nov-2008	88,306	Prime
	GCRC 5M01RR020359-04	GCRC Genetics Core year 4	01-Dec-2007	30-Nov-2008	194,821	Prime
	GCRC 5M01RR020359-04	GCRC NPEC core year 4	01-Dec-2007	30-Nov-2008	142,276	Prime
	GCRC 5M01RR020359-04	GCRC Nursing core year 4	01-Dec-2007	30-Nov-2008	921,824	Prime
	GCRC 5M01RR020359-04	GCRC Bioinfo/RSO core year 4	01-Dec-2007	30-Nov-2008	434,023	Prime
	5K23DK62161-05	Youth Type 1 Diabetes Nonadherence Prevention Program	15-Sep-2002	30-Jun-2008	0	Prime
	5U10HD030447-14	Improving Minority Child Health in Washington, DC	01-May-2007	30-Apr-2008	284,816	Prime
	2R44NS039723	Neonatal Optical Non-Invasive Brain Oxygenation Monitor	01-Aug-2004	30-Sep-2008	0	Subrecipient
					21,435,049	

Mr. OBEY. Thank you. Again, last year, the President proposed a $100,000,000 cut in this program. This Committee restored the funds. For the coming year, the President is proposing to eliminate the entire $300,000,000 program.

Thank you much.

THURSDAY, MARCH 13, 2008.

RURAL HEALTH

WITNESS

PAUL MOORE, PRESIDENT, NATIONAL RURAL HEALTH ASSOCIATION, MOORE, OKLAHOMA, DEPARTMENT OF HEALTH AND HUMAN SERVICES

Mr. OBEY. National Rural Health Association, Paul Moore.

Mr. MOORE. Thank you, Mr. Chairman, Ranking Member Walsh, and distinguished members of the Subcommittee. I thank you for the opportunity to testify on the rural health safety net that is made up of programs in the Labor, Health and Human Services Education and Related Agencies appropriations bill.

My name is Paul Moore, and I serve as the President of the National Rural Health Association. We are a national nonprofit member-driven organization whose mission is to improve the health of rural Americans. I have a long history of working with the programs under your jurisdiction in a number of health care roles: as a community pharmacist, as a hospital administrator, a home health administrator, an EMS administrator.

Mr. Chairman, it will be no surprise to the members of this Subcommittee that rural health care providers and their communities tend to have fewer patients and also have less financial resources than their urban counterparts. It is often difficult to invest in the infrastructure, technologies, and activities that are needed to improve quality, expand delivery of care options, or even to recruit health care professionals.

Yet, studies show that rural hospitals are leaders in the nationwide quality movement. With the right resources, these rural hospitals can provide care with even better quality outcomes than their urban counterparts.

Other rural health providers have similar opportunities. The rural health safety net programs each have their own individual goals and objectives, but, in practice, they work together to provide the technical assistance and the resources needed by the rural health providers and their communities.

These programs, which are outlined in my testimony, include such Federal initiatives as the Rural Health Outreach and Network Grants, the Rural Telehealth Grants, and the Small Hospital Improvement Program. These Federal programs and others highlighted in my written testimony have worked to provide the expertise, assistance, and guidance that we need.

In regards to training, evidence clearly shows that if you provide training to medical students in a rural environment, they are likely to practice there. This is the only way we will be able to overcome the growing workforce crisis in rural America. Already, many rural

communities are in a health profession shortage area or medically underserved area.

The long-term projections show that there are more retirements of rural health professionals than the number being trained to take their places. This calls for a radical rethinking of training, of recruitment, and care coordination, which is already underway. Programs such as the National Health Service Corps, Title VII, Title VIII must be continued and strengthened.

Rural America is not asking for a lot. Our request is exceedingly modest. Excluding the community health centers, the programs making up the rural health safety net costs approximately $300,000,000. This is not enough money to have any significant impact on the overall Federal budget deficit or the fiscal environment; yet, it will have a huge impact on rural America. In the long run, the Federal Government will pay a much higher cost should it walk away from its commitment to monitor and to improve the health care in rural America.

Mr. Chairman, it is clear that the rural health safety net programs that this Subcommittee oversees work. The evidence demonstrates that they improve all facets of the rural delivery system. But we must continue to fund and improve the programs. Without this, the future of 62 million rural Americans is at stake.

I thank you for the opportunity to present to you today. Thank you.

[The information follows:]

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Paul Moore
Rural Community Pharmacist
President, National Rural Health Association
Moore, Oklahoma
House Committee on Appropriations
Subcommittee on Labor, Health and Human Services, Education and Related Agencies
Public Hearing
March 13, 2008
10:00 a.m.

SUMMARY

On behalf of the National Rural Health Association (NRHA) and the 62 million rural Americans we serve, I am honored to present the following testimony to the House Committee on Appropriations, Subcommittee on Labor, Health and Human Services, Education and Related Agencies. My testimony focuses on a group of programs that we have labeled the "rural health safety net." These programs within the Department of Health and Human Services reside primarily within the Federal Office of Rural Health Policy but are also found at the Bureau of Health Professions and the Bureau of Primary Health Care. These programs strengthen and build upon our rural health delivery system.

Rural health providers and their communities tend to have fewer patients and also have less financial resources than their urban counterparts. Due to this, it is often difficult for rural providers and their communities to invest in the resources, technologies and activities that are needed to improve quality, expand delivery of care options or even recruit health professionals. However, by using the simple suggestions that are detailed in my testimony, we can do great things with modest resources. Studies suggest that rural hospitals are leaders in the nationwide quality movement and can provide care that can be better than their urban counterparts. In regards to training, evidence clearly shows that if you provide training to medical students in a rural environment, they are likely to practice there. Simple, efficient programs like these can make a huge difference to the provision of health care in rural America.

The rural health safety net programs work. The evidence demonstrates that they improve all facets of the rural delivery system. But we must continue to fund and improve the programs. Without this, the future health of 62 million rural Americans is in peril.

On behalf of the National Rural Health Association (NRHA), thank you for this opportunity to testify before the House Subcommittee on Labor, HHS, Education and Related Agencies, that help strengthen the rural health safety net. The NRHA is a national, non-profit membership organization whose mission is to improve the health of rural Americans. The NRHA provides leadership on rural health issues through advocacy, communications, education and research.

In addition to serving as the President of the NRHA, I have a long history of involvement in rural health and the programs funded by your subcommittee. My experience in rural health care include my time as a community pharmacist, hospital administrator and home health executive, which allows me the opportunity to understand how each of these providers interact with the wider health system and thus how the subcommittee's programs help or hinder the rural health system. Over the years, I have also helped to review some of the rural health grant programs, so I understand the tremendous need and demand that is found for these programs.

My experience tells me something that will be no surprise to this committee – rural America is unique. The way that rural areas provide health care services to residents differ from urban areas. Small, rural hospitals, in addition to being the only source of emergency care, are often a community's only resource for health care services such as long-term care, home health services and outpatient services. Rural residents tend to have access to a narrower and more costly range of health care services and to be served by fewer health care providers. These issues are compounded by significant problems in recruiting and retaining an adequate and quality trained health care workforce in rural areas. These differences necessitate a budget that understands the unique needs of rural America and provides funding for programs that meet these needs.

The NRHA monitors a group of programs under this subcommittee's jurisdiction that we have labeled the "rural health safety net." These programs cover a variety of different topics from technical assistance and research to providing care to workforce development; the one thing they share is that they work together to strengthen the entire rural health landscape. With few exceptions, these programs do not "keep the doors open" for rural providers. Insurance reimbursement, Medicare, Medicaid, SCHIP, and patients' payments all do that for the care that is provided. Instead, these programs provide a much needed investment in the future.

Due to the smaller sizes and narrow financial margins of most rural providers, they do not have the ability to make the same types of investments into new systems of care as some of our urban counterparts. The future health care delivery system would look very much the same as the one of today without these federally appropriated programs. This is simply not acceptable. Rural communities need to invest in health information technology. They need to be able to lead the nationwide quality movement. They need to form networks to coordinate care and collaborate to use their resources wisely. They need to serve their communities to the best of their ability. The programs that I mention throughout my testimony help us do that. They do not require a lot of money, but this small investment, or the lack thereof, as has so often unfortunately been the case in recent years, goes a long way to strengthening the rural health delivery system.

The specific programs within NRHA's fiscal year 2009 funding requests are outlined below:

PROVIDING SERVICES TO RURAL AMERICANS

While the focus of most of the programs that make up the "rural health safety net" are clearly directed at the future health delivery systems, there are two discretionary programs that have a large impact on the services in rural communities. Without these programs, millions of rural Americans would not have access to high quality health care that they deserve.

Community Health Centers are in need of little introduction to this subcommittee. Over the last decade, we have seen tremendous Congressional support for expanding the Community Health Center program, including many new sites in rural communities. This program has been successful in providing care to underserved and uninsured patients in the areas that new sites have been developed. However, there are many communities that are not served under this program and hence the push for continued expansion, while still maintaining the current facilities. **Request: $2.3 billion**

Patient Navigator line item places trained "patient navigators" in community-based health facilities to help patients navigate an often fragmented and complicated system of care. Such navigators increase early diagnosis, improve quality, and save the health system the treatment costs of preventable complications. The program can be incredibly helpful in bridging rural communities to urban specialty care, which does not always understand the cultural differences. **Request: $8.1 million**

PROVIDING TECHNICAL ASSISTANCE AND RESEARCH TO RURAL PROVIDERS

These programs each have individual goals and objectives outlined below. In practice, however, they work well together to provide the technical assistance and resources needed by rural health providers and their communities. Due to the small size of many rural providers, we do not have the staffs that our urban counterparts may to have this expertise in-house. We rely on these programs to help provide the expertise and guidance we need.

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 policy makers, both in Washington and throughout the Nation, better understand the problems that rural communities face in assuring access to health care for their residents. This research was essential to Congress during the Medicare Modernization Act of 2003 and other bills to make sure that changes to the Medicare system would not negatively impact rural America. **Request: $9.7 million**

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: $53.9 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: $9.2 million**

Rural Hospital Flexibility Grants fund quality improvement and emergency medical service projects for the 1,292 Critical Access Hospitals (CAHs) 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 during fiscal year 2007 provided 1,622 small rural hospitals (50 beds or less) across the country with funding to help improve their business operations, focus on quality improvement and to ensure compliance provisions related to health information privacy. **Request: $39.2 million**

Rural and Community Access to Emergency Devices assists communities in purchasing emergency devices and training potential first responders in their use. These devices have a large price tag putting them out of reach of many rural communities. Yet, the savings in lives are even greater. Defibrillators double a victim's chance of survival after sudden cardiac arrest, which an estimated 163,221 Americans experience every year. The program is essential to placing these live saving devices into our rural communities. **Request: $3.1 million**

Rural Emergency Medical Services (EMS) projects identify methods that help rural EMS address the unique needs of providing care in a rural community, including recruiting, training and certifying personnel; acquiring protective gear; and educating the public. In addition, we request restored funding for the **Rural EMS and Trauma Technical Assistance Center**, which provided significant support to rural EMS programs to improve service. These line items have not been funded the last couple years by Congress. In the meantime, the need for technical assistance to rural EMS providers has only grown. All EMS providers in rural communities are struggling. Most are volunteer services with only basic training. Technical assistance is needed to assure that the future EMS providers have the training they need to save lives. **Request: $0.9 million**

Rural 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: $7.1 million**

TRAINING AND RECRUITING THE FUTURE RURAL HEALTH CARE WORKFORCE

Said simply, rural America faces a growing workforce crisis. Already many rural communities are in Health Professional Shortage Areas or Medically Underserved Areas. The long-term projections show more retirements of rural health professionals than the number being trained to take their places. This calls for a radical rethinking of training, recruitment and care coordination, which is already underway. During this transition, however, programs that are proven and working needed to be continued and strengthened as outlined below.

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. This is done both through a loan repayment program and scholarships. The evidence indicates that a scholarship, when targeted to rural students, has the greatest impact in bringing health professions to rural communities in the long run. But no matter which portion of the program a student takes advantage of, rural communities need this program to be expanded. **Request: $133.9 million**

Title VII Health Professions Training Programs are a collection of programs that focus on different facets of the challenge of training health professionals that will serve rural and underserved communities including minority populations. The NRHA strongly supports these training programs and the related Title VIII Nursing Training Programs. A few programs with a particular rural focus that I would like to highlight are:

- **Area Health Education Centers (AHECs)** are the workforce development, training and education machine for the nation's health care safety-net programs. Nationwide, in 2006, AHECs introduced over 308,000 students to health career opportunities, supported health professional for over 111,000 health professional students at over 19,000 community-based practice settings and over 368,000 health professionals received continuing education. **Request: $36.9 million**
- **Geriatric Programs** train health professionals in geriatrics and provide 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: $32.1 million**
- **Quentin Burdick Rural Interdisciplinary Training** has not been funded by Congress since fiscal year 2005. The program helped rural communities train professionals that understood the entire health care landscape, which is important when you are the only provider in a community. **Request: Restore the program**

CONCLUSION

As you can see, this subcommittee's work has a substantial impact on the long term health of rural America. Each of these programs is unique; they each deal with different challenges of the rural health safety net. Yet, together they strengthen the overall fabric that is rural health. Without any one of them, the future rural health system will be diminished. We need each part to have a vibrant future.

Rural America is not asking for a lot. We understand the budget and fiscal challenges that this Congress faces. Our request is exceedingly modest. For most programs in the rural health safety net, our request is based on full funding as the U.S. Congress passed last year, plus an upward adjustment to account for inflation, before the President's veto led to across the board cuts. This is perhaps not enough to meet all the need of rural communities, but it will allow us to continue our work to improve the rural health safety net.

In return, we implore you to acknowledge that the minimal level of savings that could be realized by cutting these programs would be far outweighed by the harm of dismantling them. In the long run, the federal government will pay a much higher cost should it walk away from its commitment to monitor and improve health care in rural America.

Together, not factoring in Community Health Centers, this request amounts to little more than $334 million, not enough to save the government money but enough to provide serious benefits to rural America. We urge you to recognize their importance and fully fund the rural health safety net in the fiscal year 2009 Labor-HHS Appropriations Bill.

On behalf of the membership of the National Rural Health Association, thank you for this opportunity to testify and provide our recommendations for the fiscal year 2009 Appropriations Bill.

Mr. OBEY. Thank you. And again let me point out, last year, the President proposed a $142,000,000, or 50 percent, cut to rural health programs. This Committee restored that funding and added $5,000,000 more. Again this year, the President is proposing a $112,000,000, or 82 percent, cut in the program.

Thanks much.

Mr. MOORE. Thank you, Mr. Chairman.

THURSDAY, MARCH 13, 2008.

FISCAL YEAR 2009 APPROPRIATIONS FOR THE NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASES

WITNESS

DEE GAILEY RYAN, NEPHCURE FOUNDATION, DEPARTMENT OF HEALTH AND HUMAN SERVICES

Mr. OBEY. Next, on behalf of NephCure, Dee Gailey Ryan.

Ms. RYAN. Chairman Obey and members of the Subcommittee, thank you for the opportunity to appear before you today. I am Dee Ryan, and my husband is Lieutenant Colonel John Kevin Ryan, U.S. Air Force and Iraq war veteran. I am here today to tell you about our six-year-old daughter Jenna. She is suffering from nephrotic syndrome, a medical problem caused by rare diseases of the kidney filter, which causes leakage of protein into the urine and can often cause kidney failure.

Our physician tells us Jenna has one of two filter diseases called Minimal Change Disease or Focal and Segmental Glomerulosclerosis. According to a Harvard University report, there are presently 73,000 people in the United States who have lost their kidneys as a result of FSGS.

Unfortunately, the causes of FSGS and other filter diseases are very poorly understood. In October of 2007, Jenna began to experience general swelling of her body, intermittent abdominal pain, fatigue, and general malaise. Then she developed a cough and her stomach became dramatically distended. We rushed Jenna to the emergency room, where her breathing became more and more labored and her pulse raced. She had symptoms of pulmonary edema, tachycardia, hypertension, and pneumonia. Her lab results showed a large amount of protein in the urine and a low concentration of the blood protein albumin, consistent with a diagnosis of FSGS. Jenna's condition did not begin to stabilize for several frightening days.

We are frightened by her doctor's warnings that NS and its treatment are associated with growth retardation and other medical complications, including heart disease. Jenna has already developed hypercholesterolemia. This is a lot for a little girl in kindergarten to endure.

Jenna's prognosis is currently unknown because nephrotic syndrome can reoccur and NS has been known to commonly reappear even after a kidney transplant. Even with a transplant, FSGS can dramatically shorten one's life span.

Accompanying me at today's hearing is Michael Levine. Michael's son Matthew is desperately ill with FSGS. Without improvements

in treatments brought about by additional research, Matthew's fate is uncertain. It is more than likely that Matthew will require a kidney transplant in the near future. And even then there is no guarantee at all that transplanted kidneys will reverse Matthew's illness.

As parents, we are working against the clock to find answers to these terrible disorders which seriously debilitate our children, tear our families apart, and keep us awake at night.

Mr. Chairman, because the causes of FSGS and nephrotic syndrome are poorly understood, I am asking you to please significantly increase funding for the National Institutes of Health so that treatments can be found for Jenna, Matthew, and other people who suffer from FSGS and NS.

Also, please support the establishment of a collaborative research network which would allow scientists to create a patient registry and biobank for NS/FSGS and that would allow coordinated studies of these deadly diseases for the first time.

Finally, please urge the National Institute of Diabetes and Digestive and Kidney Disease to fund more grants on FSGS/NS research consistent with its recent program announcement entitled Grants for Basic Research in Glomerular Disease.

Mr. Chairman and members of the Subcommittee, on behalf of Jenna, Matthew Levine, and the thousands of people suffering from NS and FSGS, thank you for this opportunity. We appreciate the opportunity to speak before the Subcommittee and for your consideration of our request.

[The information follows:]

AMBASSADORS

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STATEMENT OF THE NEPHCURE FOUNDATION

ON

FISCAL YEAR 2009 APPROPRIATIONS FOR THE

NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASES

TO THE HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES

PRESENTED BY
DEE GAILEY RYAN
STAFFORD, VIRGINIA

MARCH 13, 2008

SUMMARY OF RECOMMENDATIONS FOR FY09:

1) **A 6.5% INCREASE FOR THE NATIONAL INSTITUTES OF HEALTH (NIH) AND THE NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASES (NIDDK).**

2) **THE DEVELOPMENT OF A PATIENT REGISTRY WITHIN THE NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASES (NIDDK) TO FACILITATE COLLABORATIVE RESEARCH EFFORTS.**

3) **SUPPORT CONTINUED EXPANSION OF THE FSGS/NS RESEARCH PORTFOLIO AT NIDDK BY FUNDING MORE RESEARCH PROPOSALS GENERATED BY THE RECENT PROGRAM ANNOUNCEMENT *GRANTS FOR BASIC RESEARCH IN GLOMERULAR DISEASE (R01)* (PA-07-367).**

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One Family's Story

Chairman Obey and members of the Subcommittee thank you for the opportunity to present testimony today, I am Dee Ryan and my husband is Lieutenant Colonel John Kevin Ryan, an Iraq war veteran. I would like to tell you about my 6 year old daughter Jenna's nephrotic syndrome (NS), a medical problem caused by rare diseases of the kidney filter. When affected, these filters leak protein from the blood into the urine and often cause kidney failure requiring dialysis or kidney transplantation. We have been told by our physician that Jenna has one of two filter diseases called Minimal Change Disease (MCD) or Focal and Segmental Glomerulosclerosis (FSGS). According to a Harvard University report there are presently 73,000 people in the United States who have lost their kidneys as a result of FSGS. Unfortunately, the causes of FSGS and other filter diseases are very poorly understood.

In October of 2007 my daughter began to experience general swelling of her body and intermittent abdominal pain, fatigue and general malaise. Jenna began to develop a cough and her stomach became dramatically distended. We rushed Jenna to the emergency room where her breathing became more and more labored and her pulse raced. She had symptoms of pulmonary edema, tachycardia, hypertension, and pneumonia. Her lab results showed a large amount of protein in the urine and a low concentration of the blood protein albumin, consistent with the diagnosis of FSGS. Jenna's condition did not begin to stabilize for several frightening days.

Following her release from the hospital we had to place Jenna on a strict diet which limited her consumption of sodium to no more than 1,000 mg per day. Additionally, Jenna was placed on a steroid regimen for the next three months. We were instructed to monitor her urine protein levels and to watch for swelling and signs of infection, in order to avoid common complications such as overwhelming infection or blood clots. Because of her disease and its treatment, which requires strong suppression of the immune system, Jenna did have a serious bacterial infection several months after she began treatment.

We are frightened by her doctor's warnings that NS and its treatment are associated with growth retardation and other medical complications including heart disease. As a result of NS, Jenna has developed hypercholesterolemia and we worry about the effects the steroids may have on her bones and development. This is a lot for a little girl in kindergarten to endure.

Jenna's prognosis is currently unknown because NS can reoccur. Even more concerning to us is that Jenna may eventually lose her kidneys entirely and need dialysis or a kidney transplant. While kidney transplantation might sound like a cure, in the case of FSGS, the disease commonly reappears after transplantation. And even with a transplant, end stage renal disease caused by FSGS dramatically shortens one's life span.

The NephCure Foundation has been very helpful to my family. They have provided us with educational information about NS, Minimal Change Disease, and FSGS and the organization works to provide grant funding to scientists for research into the cause and cure of NS.

Mr. Chairman, because the causes of Nephrotic Syndrome are poorly understood, and because we have a great deal to learn in order to be able to effectively treat NS, I am asking you to please significantly increase funding for the National Institutes of Health so that treatments can be found for other people like Jenna who suffer from NS. Also, please support the establishment of a collaborative research network that would allow scientists to create a patient registry and biobank for NS/FSGS, and that would allow coordinated studies of these deadly diseases for the first time. Finally, please urge the National Institute of Diabetes and Digestive and Kidney Disease (NIDDK) to continue to focus on FSGS/NS research in general, consistent with the recent program announcement entitled *Grants for Basic Research in Glomerular Disease (R01)* (PA-07-367).

Mr. Chairman, on behalf of the thousands of people suffering from NS and FSGS and the NephCure Foundation, thank you for this chance to speak before the Subcommittee and for your consideration of my request; Thank you.

More Research is Needed

We are no closer to finding the cause or the cure of FSGS. Scientists tell us that much more research needs to be done on the basic science behind the disease.

NFC would also like to see the Office of Rare Disease (ORD) to establish a FSGS Clinical Research Network within the Rare Disease Clinical Research Consortia. The development of a Clinical Research Network would allow for further collaboration between researchers and an expansion of the clinical understanding and treatment of FSGS.

NCF is also grateful to the NIDDK for issuing of a program announcement (PAs) that serve to initiate grant proposals on glomerular disease The PA, issued in March of 2006, is glomerular-disease specific. The announcement will utilize the R01 mechanism to award researchers funding.

We ask the Committee to encourage the ORD to establisht a FSGS Clinical Research Network to expand FSGS research. We also ask the NIDDK to continue to issue glomerular disease program announcements.

Too Little Education About a Growing Problem

When glomerular disease strikes, the resulting NS causes a loss of protein in the urine and edema. The edema often manifests itself as puffy eyelids, a symptom that many parents and physicians mistake as allergies. With experts projecting a substantial increase in nephrotic syndrome in the coming years, there is a clear need to educate pediatricians and family physicians about glomerular disease and its symptoms.

We also applaud the work of the NIDDK in establishing the National Kidney Disease Education Program (NKDEP), and we seek your support in urging the NIDDK to make sure that glomerular disease remains a focus of the NKDEP.

We ask the Committee to encourage the NIDDK to have glomerular disease receive high visibility in its education and outreach efforts, and to continue these efforts in conjunction

with the NephCure Foundation's work. These efforts should be targeted towards both physicians and patients.

Glomerular Disease Strikes Minority Populations

Nephrologists tell us that glomerular disease strikes a disproportionate number of African-Americans. No one knows why this is, but some studies have suggested that a genetic sensitivity to sodium may be partly responsible. DNA studies of African Americans who suffer from FSGS may lead to insights that would benefit the thousands of African Americans who suffer from kidney disease.

I ask that the NIH pay special attention to why this disease affects African-Americans to such a large degree. The NephCure Foundation wishes to work with the NIDDK and the National Center for Minority Health and Health Disparities (NCMHD) to encourage the creation of programs to study the high incidence of glomerular disease within the African American population.

There is also evidence to suggest that the incidence of glomerular disease is higher among Hispanic Americans than in the general population. An article in the February 2006 edition of the NIDDK publication *Recent Advances and Emerging Opportunities*, discussed the case of Frankie Cervantes, a six year old boy of Mexican and Panamian descent. Frankie has FSGS received a transplanted kidney from his mother. We applaud the NIDDK for highlighting FSGS in their publication, and for translating the article about Frankie into both English and Spanish. Only through similar efforts at cross-cultural education can the African-American and Hispanic-American communities learn more about glomerular disease.

We ask the Committee to join with us in urging the NIDDK and the National Center for Minority Health and Health Disparities (NCMHD) to collaborate on research that studies the incidence and cause of this disease among minority populations. We also ask that the NIDDK and the NCMHD undertake culturally appropriate efforts aimed at educating minority populations about glomerular disease.

Patient Registry and Biobank

Experts currently believe glomerular disease is increasing in frequency and it is often misdiagnosed or undetected and, as a result, is often unreported. Since many cases of glomerular disease are unreported, it is difficult to ascertain different aspects of the disease and to form more comprehensive data sets on the patient population.

It is also possible that the development of a biobank would be beneficial in understanding the genetic components of glomerular disease and their corresponding interactions with environmental factors.

We ask the Committee to support funding for the first-ever national database/registry for FSGS within NIDDK. Experts say that the incidence of FSGS is increasing and that the disease is often misdiagnosed, undetected or unrecorded. While databases and registries have helped defeat other diseases, one does not exist for FSGS. We also ask the Committee support the development of a biobank as a further means of understanding the causes of FSGS, both genetic and environmental.

Subcommittee on Labor, HHS, Education and Related Agencies

Witness Disclosure Requirement – "Truth in Testimony"
Required by House Rule XI, Clause 2(g)(4)

Your Name: *Dee Gailey Ryan*		
1. Are you testifying on behalf of a Federal, State, or Local Governmental entity?	Yes	(No)
2. Are you testifying on behalf of an entity other than a Government entity?	(Yes)	No
3. If your answer to question number 2 is yes, please list any federal grants or contracts (including subgrants or subcontracts) which you have received since October 1, 2005:		
4. Other than yourself, please list what entity or entities you are representing: *The NephCure Foundation*		
5. If your answer to question number 2 is yes, please list any offices or elected positions held or briefly describe your representational capacity with the entities disclosed in question number 4: *Volunteer*		
6. If your answer to question number 2 is yes, do any of the entities disclosed in question number 4 have parent organizations, subsidiaries, or partnerships to the entities for whom you are not representing?	Yes	(No)
7. If the answer to question number 2 is yes, please list any federal grants or contracts (including subgrants or subcontracts) which were received by the entities listed under question number 4 since October 1, 2005, including the source and amount of each grant or contract: *None*		

Signature: Dee Gailey Ryan Date: March 16 2008

Please attach this sheet, along with you curriculum vitae (résumé), to your written testimony.

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PROFESSIONAL

State Bar of Texas, Admitted, May 1993

EDUCATION

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Juris Doctor, February 1993
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Angelo State University, San Angelo, TX
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Wilbarger County & Vernon Abstract, JOC, Vernon, TX — August 1994-June 1996
Manager, Title and Abstract, Title insurance policies
Turner, Seaberry & Warford, Eastland, TX — May 1993-October 1993
Associate, Real Estate, Oil and Gas, Family Law
Kemp, Smith, Duncan & Hammond, PC, Midland, TX — Summer 1992
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Clerkship, Litigation and Oil & Gas Law

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Order of Barristers
Top Ten Speaker of Spring 1991 Moot Court Competition
Harvey M. Richey Moot Court Society
Bill Patterson Scholarship
Walter Umphrey Scholarship

Angelo State University
Alpha Chi National Honor Society, ASU chapter president, 1989-90
Alfred H. Nolle National Scholarship
University Symposium Committee
Pi Gamma Mu Outstanding Government Scholar
Presidential Scholar nominee, 1990

Mr. OBEY. Thank you very much. Let me first of all say to Jenna, you have been a very good girl, very patient. We appreciate that.

I want to thank all of you for sharing your stories with us. I know it is not an easy thing to do.

We are happy to have Congressman Burgess here this morning. I understand you were busy in another Committee, but we are happy to have you here.

Mr. BURGESS. If I might just——

Mr. OBEY. Sure.

Mr. BURGESS. My relationship with Jenna is——

Mr. OBEY. Would you pass the mic down?

Mr. BURGESS. And I appreciate the indulgence. Six years ago, when I was just a regular guy practicing medicine back in Texas, I delivered Jenna. She and her mother Dee are up here before you this morning to talk about her disease, nephrotic syndrome, which struck Jenna about four months ago. I thank the family for being here. I thank them for sharing their compelling story with you, and I hope the Committee will seriously take their recommendations.

I will not take any more of your time. Thank you.

Mr. OBEY. Thank you.

I appreciate your coming, again, and I just want to put in context the request, because NIH, I think every member of this Subcommittee cares deeply about what happens to NIH budget. In fact, some of us were out at NIH last Monday for a site visit for most of the day.

Last year, the Administration proposed to cut NIH by $475,000,000. The omnibus appropriation bill that we produced rejected that cut, adding $613,000,000 to the Administration's budget, but the White House vetoed an additional $771,000,000.

This year, the President has proposed to freeze the NIH budget, which would in effect mean about a $1,000,000,000 real cut, and we have been told by the chief at NIH, Dr. Zerhouni, that it would result in the loss of about 6,000 scientists who are presently working on NIH grants.

So we will do the best we can on this. A lot is going to depend on how much funding we are allowed under the budget resolution, which is up on the floor today.

But thank you all. I appreciate your coming and I am sure we wish you the very best of luck.

Mr. Walsh.

Mr. WALSH. I echo your comments.

Mr. OBEY. Thank you.

I have been told that we should expect a roll call between 11:00 and 11:30. It looks we are going to make it before we get devoured by one of those.

THURSDAY, MARCH 13, 2008.

NATIONAL INSTITUTES OF HEALTH FISCAL YEAR 2009 APPROPRIATIONS

WITNESS

ROBERT E. PALAZZO, PH.D., PRESIDENT, FEDERATION OF AMERICAN SOCIETIES FOR EXPERIMENTAL BIOLOGY, BETHESDA, MD, PROVOST, RENSSELAER POLYTECHNIC INSTITUTE, TROY, NY, DEPARTMENT OF HEALTH AND HUMAN SERVICES

Mr. OBEY. Next, the Federation of American Societies for Experimental Biology, Dr. Robert Palazzo.

Mr. PALAZZO. Mr. Chairman, thank you for the opportunity to testify today.

Mr. OBEY. Sure.

Mr. PALAZZO. It is an honor to come before you representing the 21 societies, more than 80,000 biomedical researchers of the Federation of American Societies for Experimental Biology. My name is Robert Palazzo. I am a Professor of Biology and the Provost of Rensselaer Polytechnic Institute, the oldest science and technology institute in the United States.

In the interest of time, I would like to give a brief summary of the longer comments that have been submitted for the record.

Although the members of this Committee are well aware, I think it bears repeating that the National Institutes of Health is the world's premier sponsor of medical research and is the Federal agency responsible for conducting and supporting the basic and clinical science that drives the development of treatments and cures for diseases and injury.

NIH funds more than 325,000 scientists at more than 3100 universities and institutions in every State across this Country. The researchers receiving NIH funds are united by a compelling desire to investigate the underlying biology of human disease and use this knowledge to improve our health and save lives.

Chairman Obey, you have asked on a number of occasions, "What have we lost by not adequately or fully funding programs like the medical research done at the NIH?" I think this is an important question, because it allows us to illustrate the sense of urgency felt by those of us who understand the critical mission of the NIH: emerging diseases and new health threats dominate our headlines, from drug-resistant staph infections to avian influenza and autism, all the while our aging population, under increasing pressure to meeting the challenges of Alzheimer's Disease, osteoporosis, macular degeneration, and many others.

During the next 25 years, the number of Americans with chronic diseases is projected to reach 46 million. That is roughly one in five Americans. Yet, just as the need to prevent diseases becomes greater and the opportunities to succeed become more numerous, I fear that our commitment to medical research may be dwindling.

Never before has science been more poised to advance the discoveries that will improve our health. Yet, never before have we been more in danger of squandering our scientific talent and delaying critical breakthroughs. Flat-funding of NIH, combined with the effects of inflation, has eroded the purchasing power of the agency by more than 10 percent. With every excellent idea left unfunded, we stand to miss or delay critical discoveries that could lead to therapies for our most debilitating health conditions.

The NIH funding situation threatens to affect an entire generation of young scientists. Young scientists watch their mentors struggle to maintain grant funding from the NIH and question whether they should invest in such a risky, albeit noble, career. Many of our best and brightest scientists are seeking more promising opportunities outside of the lab or in other nations like China

or Singapore. All these nations are increasing their investment in biomedical research even as we are pulling back.

Importantly, Mr. Chairman, applications for R01 grants from previously unfunded scientists seeking their first grant showed an appreciable drop in 2007, declining by nearly 600 applications from the 2006 level. This is a 6 percent to 7 percent drop in those junior people seeking their first NIH grant. This represents the loss of hundreds of scientists and all of the talent and intellectual capital that they bring to the system. We have moved past the point where scientists are spending more time filling out applications doing research, and now we are at the point where many may be giving up.

Congressmen, in closing, I would like to say that, without research, there is no hope. It was not long ago that a pronouncement of heart disease, AIDS, or breast cancer sounded a death knell. These are now treatable conditions and patients go on living long, happy lives years after the diagnosis. Infectious diseases that haunted our parents and grandparents—polio, measles, rubella, whooping cough—have been conquered by vaccines. Premature infants now survive to bring parents years of joy, rather than drawing their last desperate breath in the hospital.

We can help Jenna. We can conquer FSGS and many other diseases. The foundation for these cures lies in the NIH; lies in the support that this Congress has shown for this agency in the last 50 years. That hope is a direct result of your wisdom and the support of this House.

With that, I will simply close. I would be happy to take any questions.

[The information follows:]

TESTIMONY OF THE FEDERATION OF AMERICAN SOCIETIES FOR EXPERIMENTAL BIOLOGY (FASEB)

SUBCOMMITTEE ON LABOR, HEALTH & HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES

MARCH 13TH, 2008, 10:00 AM

NATIONAL INSTITUTES OF HEALTH
FY 2009 APPROPRIATIONS

ROBERT E. PALAZZO, PH.D.

PRESIDENT, FASEB, BETHESDA, MD
PROVOST, RENSSELAER POLYTECHNIC INSTITUTE, TROY, NY

HTTP://OPA.FASEB.ORG

FASEB is composed of 21 societies with more than 80,000 members, making it the largest coalition of biomedical research associations in the United States. FASEB enhances the ability of biomedical and life scientists to improve—through their research—the health, well-being and productivity of all people. FASEB's mission is to advance biological science through collaborative advocacy for research policies that promote scientific progress and education and lead to improvements in human health.

The National Institutes of Health (NIH) is the world's premiere sponsor of medical research and is the federal agency responsible for conducting and supporting the basic and clinical science that drives development of treatments and cures for disease and injury. A component of the Department of Health and Human Services, NIH comprises 27 Institutes and Centers, which collectively fund more than 325,000 scientists at more than 3,100 universities and institutions in every state. The researchers receiving NIH funds are united by a compelling desire: **to investigate the underlying biology of human disease and use this knowledge to improve our health and save lives.**

Research funded by the NIH also contributes to the nation's economic strength and competitiveness, which is driven by basic science generating commercially viable products and technologies. Biomedical research advances scientific knowledge while also creating a high-technology workforce that enhances innovation at the country's private sector companies.

Through its competitive peer review system, which is admired and emulated throughout the world, NIH ensures support of the highest quality research and seeks input from more than 30,000 scientists and members of the public who serve on NIH advisory boards, review groups, and expert panels. Scientists funded by NIH lay claim to 122 Nobel Prizes, including the 2007 Nobel Prize recipients in physiology or medicine: Mario R. Capecchi, Ph.D., of the University of Utah School of Medicine and Oliver Smithies, Ph.D., of the University of North Carolina. Drs. Capecchi and Smithies, together with their colleague, Sir Martin Evans, Ph.D., of Cardiff University, developed the immensely powerful gene "knockout" technology, which allows scientists to create animal models of human disease and study gene function. Over the past 50 years, the research supported by NIH has been and continues to be responsible for the revolutionary medical and health advances that have taken place.

NIH Research Has Led to Improved Health

Thanks to NIH-funded scientists, working at universities and institutions across the nation and on the NIH campus in Bethesda, Maryland, we have transformed many previously deadly or debilitating diseases into manageable conditions. Below are only a few select examples of how the research funded by NIH has saved and improved the lives of millions of Americans and provided doctors with tools to prevent and/or treat disease:

- More than one million lives per year are saved due to therapies to prevent death from **heart attack and stroke**, resulting in a nearly four-year gain in American life expectancy. Decades of NIH-supported fundamental research on cholesterol synthesis, clot-busting agents, and the basic biology of the cardiovascular system has culminated in blockbuster drugs such as statins that are utilized worldwide and have improved the health of more than 25 million Americans. The recent discovery that the anti-cancer drug Taxol, when used to coat the wire-mesh stents used during angioplasty, can prevent blockage of arteries, is expected to substantially reduce the number of open-heart bypass surgeries.

- Since 2002, deaths from **cancer** have been steadily reduced, dropping an average of two percent per year. In December, 2005, as a result of the work of hundreds of NIH-funded scientists studying strategies to block the cell signals that cause tumors to grow, Sorafenib was identified as a promising treatment for **kidney cancer**. Less than a year later, the FDA approved the use of a vaccine against human papillomavirus (HPV) which has the potential to prevent 70% or more of **cervical cancer**, the cause of 300,000 deaths per year. The connection between HPV and cervical cancer which led to development of the vaccine was made through the research of NIH-supported scientists. And in one of NIH's most powerful success stories, the survival rate for **childhood cancers**, which not long ago claimed the lives of more than half their victims, is now nearly 80% and improving.

- NIH-funded discoveries elucidating the fundamental nature of the immune system and the diseases that challenge it have vastly improved the quality of life for patients with conditions ranging from **rheumatoid arthritis** to **multiple sclerosis** to **HIV/AIDS**. Drugs which block the actions of tumor necrosis factor alpha (TNF-α) have dramatically improved the quality of life for some rheumatoid arthritis patients, eliminating symptoms, increasing energy, and decreasing inflammation while halting the progression of joint destruction and promoting repair of tissue damage. For those suffering the debilitating effects of multiple sclerosis, several new treatments that modulate the immune system are available, their discovery and development having been funded in part by NIH. HIV/AIDS, once a terminal illness, has been transformed through drug therapy into a chronic disease, with AIDS drugs estimated to have saved three million years of life in the United States alone.

- NIH-funded research on the effects of lifestyle changes is helping to teach Americans how to prevent **diabetes**, reverse serious **heart disease** risk factors, and slow the signs of aging. Diet and exercise changes have been shown to reverse diabetes and metabolic syndrome, strengthen bones and prevent **osteoporosis,** and even reduce the risk of **dementia**. Studies have shown that people who exercise regularly in middle age are one-third as likely to get **Alzheimer's disease** in their 70s as those who did not exercise. And even people who begin exercising in their 60s have their risk reduced by half.

Investment in NIH Brings Hope, Treatments on the Horizon

Arguably, the two trends of greatest consequence for American health in the twenty-first century are the rapid aging of the population and the unprecedented progress in medical research that is helping us to live longer, healthier lives. The life sciences revolution that has taken place over the past two decades has led us to the brink of developing new treatments and strategies for confronting our greatest health challenges, including those of the over-65 population, soon to number 70 million. Investment in NIH has already unlocked the secrets of the human genome and allowed scientists to gain new insight into how disease works at the most basic levels within our bodies. Researchers are arming themselves with this knowledge to identify targets for new drugs, therapies, and vaccines, which can halt the progression of disease before irrevocable damage occurs:

- ***Blindness:*** The prospect that it may someday be possible to restore vision in some people who have lost most or all of their eyesight was strengthened when scientists were able to help blind mice regain some ability to see after receiving transplants of cells taken from the eyes of other mice. NIH-supported researchers showed for the first time that light-detecting cells in the retina can orient themselves properly after being injected into a blind eye, connect to other nerve cells and communicate appropriately with visual centers in the brain. Moreover, researchers have discovered the genetic flaws that underlie a major type of glaucoma, a leading cause of blindness. Similarly, scientists have identified a genetic abnormality that accounts for up to 50 percent of **Age-Related Macular Degeneration (AMD)** cases, a blinding disease for which more than 8 million older Americans are at risk. By pinpointing what goes wrong in these conditions, these findings may provide a basis for devising new treatments.

- ***Alzheimer's disease:*** A team of NIH-funded scientists have developed a test that was about 90 percent accurate in distinguishing the blood of people with Alzheimer's from the blood of those without the disease. The test was about 80 percent accurate in predicting which patients with mild memory loss would go on to develop Alzheimer's disease two to six years later. In addition, basic and genetic studies describe some of the processes involved in Alzheimer's, revealing numerous targets for new drug development. Such discoveries shed light on why toxic molecules build up in the brain, what leads to the plaques and tangles characteristic of Alzheimer's, and how brain cell signaling systems affecting memory are disrupted.

- ***Drug resistant tuberculosis and staph:*** Nearly one-third of the world's population is infected with *Myobacterium tuberculosis*, the infectious agent that causes TB, and more than one million people die of this disease each year. In recent years, TB has presented even more serious challenges, with the emergence of multiple drug-resistant and extensively drug resistant TB. NIH has developed a drug known as SQ109, in partnership with the biotech company Sequella, which is currently undergoing FDA-approved clinical testing for treatment of drug-resistant TB. The recent epidemic of Methicillin-resistant (drug resistant) *Staphylococcus aureus* (MRSA) has underscored the critical importance of research to seek new ways to counter and prevent the emergence of "super bugs."

The American Public Supports Medical Research

Polls have shown that Americans are extremely concerned about their health and health care, setting these as priorities above keeping their jobs, paying their mortgage, or even being protected from a terrorist attack[1]. The popular press, from television to newspapers and magazines to Internet blogs, is filled with reports of new medical research findings and advice about staying healthy. NIH drives the engine of medical research discovery, addressing public health priorities and funding the cutting edge science that captures our national attention. This is why the people of the United States overwhelmingly support medical research:

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[1] Kaiser Family Foundation. (2003-2007) *Kaiser Health Poll Report.* http://www.kff.org/healthpollreport/currentedition/index.cfm?CFID=19610911&CFTOKEN=77244741

- Surveys have found that 83 percent of Americans would be **more likely to vote** for a candidate that supports increased funding for research to find cures for and prevent disease[2].
- A majority of Americans (78%) choose medical research as the best strategy for **reducing health care costs**[3]. Data supports their belief: NIH-funded advances in coronary heart disease alone are estimated to have generated $2.6 trillion in economic return for a total cost of about $110 per American over a 30 year span[4].
- More than three-quarters (76%) of U.S. respondents thought that it was very important that the **U.S. remain a global leader** in scientific research[5].

New Threats Emerge as Funding Lags Behind

Emerging diseases and new health threats dominate our headlines – from **drug resistant staph infections** ("MRSA") to **SARS**, **West Nile Virus**, and **avian influenza** – while our aging population lends a new sense of urgency to meeting the challenges of **Alzheimer's disease**, **osteoporosis**, and **macular degeneration**. Yet even as the need to prevent disease becomes greater and the opportunities to succeed become more numerous, our nation has begun to neglect our commitment to medical research. Never before has science been more poised to advance the discoveries that will improve our health, yet never before have we been more in danger of squandering our scientific talent and delaying critical breakthroughs:

- Flat funding of NIH, combined with the effects of inflation, has eroded the purchasing power of the agency by 10% or more. With every excellent unfunded idea, **we stand to miss or delay the critical discovery** leading to therapies for our most debilitating health conditions.
- The NIH funding situation **threatens to affect an entire generation of young researchers**. The 60,000 postdoctoral researchers, or "postdocs," who represent America's scientific future and are on the path to a lifelong career in research are being negatively affected by the decline in NIH's budget. Specifically, the funding cuts are resulting in fewer hires, lower salaries and increased layoffs. Many of the postdocs see their scientific mentors struggle to maintain grant funding from NIH and are beginning to question whether they should invest in such a risky career. Many of **our best and brightest scientists** are seeking more promising opportunities outside of the lab or in other nations.
- Applications for R01 grants, the gold standard of scientific discovery at NIH, from previously unfunded scientists (**"new investigators") showed an appreciable drop** in 2007, declining by nearly 600 applications from the 2006 level. This represents a **loss of**

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[2] Research!America (2006) *America Speaks: Poll Data Summary, Volume 8,* http://www.researchamerica.org/publications/AmericaSpeaks/AmericaSpeaksV8.pdf
[3] *Ibid*
[4] National Institutes of Health, http://www.nih.gov
[5] Research!America (2006) *America Speaks: Poll Data Summary, Volume 8,* http://www.researchamerica.org/publications/AmericaSpeaks/AmericaSpeaksV8.pdf

hundreds of new scientists and all of the talent and intellectual capital that they bring to the system.

- Over the past generation, the average age at which American biomedical researchers with Ph.D. degrees succeed in obtaining their first research project grant award (R01) from the NIH has **increased from 34.2 to 41.7 years of age**. Furthermore, in 2008 it is predicted that only 19% of the grant applications will receive funding, a figure well below the optimal rate of 30% that was achieved in 2003. While a career in medical research may always be riskier than other career paths, some **hope for a sustainable future** is essential to attract and retain talented individuals.

We Must Fulfill the Promise: NIH at the Crossroads

Over the past 50 years, NIH and its grantees have played a major role in the explosion of knowledge that has amounted to a revolution in biology. This knowledge has led to an unprecedented number of medical breakthroughs and discoveries that promise to improve the health and extend the lives for millions of people.

The good news is that – mainly due to medical advances in the treatment of heart disease, cancer and stroke – we're living longer and healthier lives. In September 2007, the National Center for Health Statistics said a baby born in the U.S. in 2005 should expect to live nearly 78 years on average. That's a record, up nearly three percent from a decade earlier, and only the most recent rise in a consistent gain in life expectancy.

During the next 25 years, the number of Americans with chronic diseases is projected to reach 46 million. If we are to successfully confront the health care challenges associated with a growing elderly population, it's going to require sustained support for basic and clinical research.

In the last five years, however, the NIH budget has failed to keep up with inflation, and we are in danger of sacrificing our nation's dominance in biomedical research and biotechnology as well as risking the status of our research institutions as the envy of the world. New opportunities for path-breaking research are going unfunded, and there is a real chance that the number of new therapies under development will begin to decrease. Therefore, it is imperative that we renew our commitment to medical research and to fulfill the hope of the American people by making NIH a national priority.

In order to fulfill the extraordinary scientific and medical promise of biomedical research, FASEB urges Congress to make the National Institutes of Health a priority and respectfully requests that NIH receive $ 31.1 billion in FY 2009.

Mr. OBEY. Well, thank you very much. We appreciate your time, and I certainly agree with the points that you made.

We just made it. So let me thank everybody for their patience. We will reconvene at 2:00 this afternoon for another round. Thank you.

AFTERNOON SESSION

THURSDAY, MARCH 13, 2008.

TESTIMONY OF INTERESTED INDIVIDUALS AND ORGANIZATIONS

Mr. OBEY. Well, thank you, everyone for coming. This is the second panel of public witnesses that we have heard from today. In the first hearing, we were very lucky. We were halfway through the testimony of the last witness when the bells rang for a vote. We are not going to be so lucky this time. We are supposed to have a vote in about 15 minutes, and we may have more than one.

But before I ask the witnesses to proceed, let me simply try to make a couple points and set the context.

First of all, as I said in the first hearing, please do not take silence on this side of the table as an indication of disinterest. We are going to be very squeezed to get all these witnesses in, in between roll calls, and so we have had plenty of time to talk through the first part of this year. We are going to largely listen to you. I may make a comment from time to time to put in context what each of the witnesses is saying, but outside of that we will try to restrain ourselves.

Secondly, I want people to understand what the position of this Subcommittee is. We do not have authority to put together any bill that we want. We have to live within the limits that are assigned to us by the budget resolution which is on the floor today.

To put that in context, last year, the President succeeded, in his view, in holding the line against our bills which means that we wound up putting into law, appropriation bills which were approximately $22,000,000,000 below those that the Committee reported out initially. The President vetoed the flagship domestic bill which is this Labor-Health-Education Bill, and that resulted in substantially less funding for this bill.

This year, the President is proposing a budget which, when you take into account the various offsets that we used last year that would not be available to us this year, what it means is that the President is, in essence, cutting the bills that he signed last year in terms of the accounts that we provided last year by roughly $26,000,000,000.

The budget resolution today would allow us to restore most of those cuts, to fill most of those holes, but the White House is making quite clear that they will not sign bills at that enhanced level.

So that is the context in which we have to make decisions, and that is the context in which you are testifying today. I do not especially like it, but I have a habit of facing reality.

So, with that, let me simply turn to Mr. Walsh for whatever comments he might make before we introduce the witnesses.

Mr. WALSH. Thank you, Mr. Chairman, and thank you for bringing in all these expert witnesses from all around the Country.

This is a very important part of the process because the decisions that we make do affect things. This bill especially has historically been referred to as the People's Bill because there are more things that affect people and our quality of life in this bill than any other than the Congress works on.

All of you are here because you appreciate the fact that democracy is not just a spectator sport. You have to roll up your sleeves and put on your sneaks or wingtips, whichever, and come down and fight for what you believe in. So we appreciate your coming here today.

I agree with the Chairman. I am glad that the Congress has the power of the purse. I think we should fight for that power. The Constitution gave it to us. It does not belong at the White House. It belongs here. I believe that we are closer to the people.

So we will listen to your priorities. We may not be able to meet them, but we will listen to them, and we will give you our best effort to create a bill that meets the needs of the Country.

Mr. Chairman, with that, I yield back.

Mr. OBEY. All right. I understand you want to introduce our first witness.

Mr. WALSH. If you will, yes. Thank you, Mr. Chairman.

It is my great pleasure to introduce Dr. Michael Miller from the State University of New York, Upstate Medical University in my hometown of Syracuse, New York. It is a marvelous hospital. It is also a teaching hospital and soon to have a children's hospital attached, which we are very excited about.

Dr. Miller is a Professor and Chair of the Neuroscience and Physiology Department.

Dr. Miller, thank you very much for coming today. We welcome your testimony.

THURSDAY, MARCH 13, 2008.

SUNY UPSTATE MEDICAL CENTER

WITNESS

DR. MICHAEL W. MILLER

Dr. MILLER. Well, good afternoon, and it is indeed an honor to speak to all of you. I would like to express a special appreciation to Mr. Walsh for his decades of service to Upstate New York and to our Country and for his inviting me to speak today.

I speak on behalf of my institution, biomedical researchers across the Country and for what I believe is the health and well being of citizens of the United States.

Seventy-eight years ago, Congress established the National Institutes of Health. It was a bold experiment, and I think we can all agree that it was a successful and continues to be a successful experiment.

NIH continues to have a number of successes. It discovers new knowledge and treatments that improve the health and save lives. It helps drive down the costs of healthcare, and it is an engine for economic growth.

It returns approximately $7 on the investment dollar, and it is one of the few areas that I think we can argue where we have a leadership role in the world.

Support for NIH has national impact. It is not just an entity that supports just medical schools. The extramural programs support the 150, roughly, allopathic and osteopathic medical schools, but it is not restricted to these institutions.

It is also supporting activities that are going on at small schools like Hamilton College, Clarkson College and small places Upstate New York as well as larger institutions such as Binghamton University. These are places outside of districts that are covered in the areas where there are just the medical schools.

All citizens benefit from NIH research, supported research: Improved life expectancy, work efficiency and quality of life of the citizens of the United States.

About 10 years ago, Congress took a bold step and decided to double the NIH budget. This was a wonderful opportunity, and it was in response to a lot of successful arguments that people had made, saying that we would be able to have cures within five years for neurodegenerative disease, cancer, diabetes, virtually any disease of your choice.

In essence, we told you what you wanted to hear. It may have been done innocently. People genuinely believe that because of the molecular biology revolution, that things were going to be going much faster.

But I think that it was naive on the part of scientists and on Congress' part, and the claims were foolhardy and shortsighted. We could not deliver within five years.

It takes a considerable amount of time for drug development to occur. Just if you have a drug and you want to develop, it takes five to seven years just for that process alone, not to mention the time it takes to prepare with the basic science research that underlays that drug development. So really, from beginning to end, from concept to care delivery, it takes about 20 years.

It could not be done within five years, and I think that it was not a good situation. Basically, Rome was not built in a day and what we need to do is to take a longer term view of things, and that is what I have come here to try and encourage Congress to take that view.

I just want to give an example of some of the activities that I am involved with. I am the head of a new center on developmental exposure to alcohol research, and what that is involved with is the effects of alcohol on the fetus and on adolescents.

I think that we can all agree that is a major clinical issue. In fact, alcohol costs the economy a quarter of a trillion dollars a year in all of its ramifications.

Fetal Alcohol Spectrum Disorder affects 2 percent of all children that are born. Adolescent exposure to alcohol, three-quarters of the adolescent population has reported taking alcohol as an adolescent.

The cost of just that is $58,000,000,000 to the economy. It is not a small activity.

The problem has been known since the 1970s, Fetal Alcohol Spectrum Disorder, but yet it has taken us 30 years to get to a point where we now have biomarkers to be able to understand the process and are now starting to develop approaches to be able to deal with ameliorating the problems. It takes a long time for this to happen.

So what I am asking Congress to do are three things: Provide global support for biomedical research; to support dependable, reliable growth of the research enterprise; to return to the central precept that the original charter of the NIH delegation, the original charter which is to delegate and to trust NIH to be able to operate. Congress should appropriate the funds for NIH and then to let the people at NIH figure out the best way to use those funds.

At the risk of suggesting that the research enterprise is the enemy, I would also argue that Congress should trust but verify. It should just not hand out the money willy-nilly. They also have to take responsibility for making sure that it is spent properly. So I think it is a handshaking operation, and we need both sides.

As a final comment, I would just like to say that the expectations of immediate returns from investment was not well taken on either part of the equation, us as scientists or on Congress' side. What we need for the best benefit of everybody is a consistent long-term commitment to biomedical research.

I thank you for your time.

[The information follows:]

The research community is ready and willing to take on the difficult problems.

This community is diverse.

It includes high powered big research machines (e.g., Harvard, Hopkins, and UCSF) and smaller institutions with particular strengths (e.g., Upstate).

Each setting provides (a) distinct training opportunities for medical and graduate students and (b) focus on different subpopulations- rural and urban communities

One example is Upstate Medical University. At Upstate we have expertise in developmental neuroscience and substance abuse. Indeed, we have generated a unique national resource for examining the consequences of early exposure to alcohol- during fetal and adolescent periods. Our research center coordinates research at Upstate in Syracuse, SUNY- Cortland, and Binghamton University (three separate Congressional districts; 22nd, 24th, and 25th).

Just some numbers about the scope of the problem-

Alcohol use disorder directly affects 19 million people. This is 3X that of the people abusing all other drugs combined.

It is a tremendous expense to the US- direct and indirect use of alcohol costs the US economy 276 billion dollars annually.

FASD affects as many as 2% or more of all children.

Adolescent use is rampant- more than 3/4 of high school students report using alcohol. The total cost of this use is $58 billion.

Alcoholism is not a social issue - - - it is a disease. There is a genetic predisposition for alcoholism and it has biological etiologies.

Though the problem of fetal exposure has been known since the early 1970's, acceptance among the clinical community and the deliberate activities of devoted researchers has only brought us to the point of recently having biomarkers to document alcohol use during pregnancy and strategies to address the neuropsychiatric consequences.

All of this diversity is essential for the stability and vitality of the research community

That said, the community is at risk. Science and math education in the elementary and high schools is not attracting enough qualified talent. Over the last few years the growth of the research budget at NIH

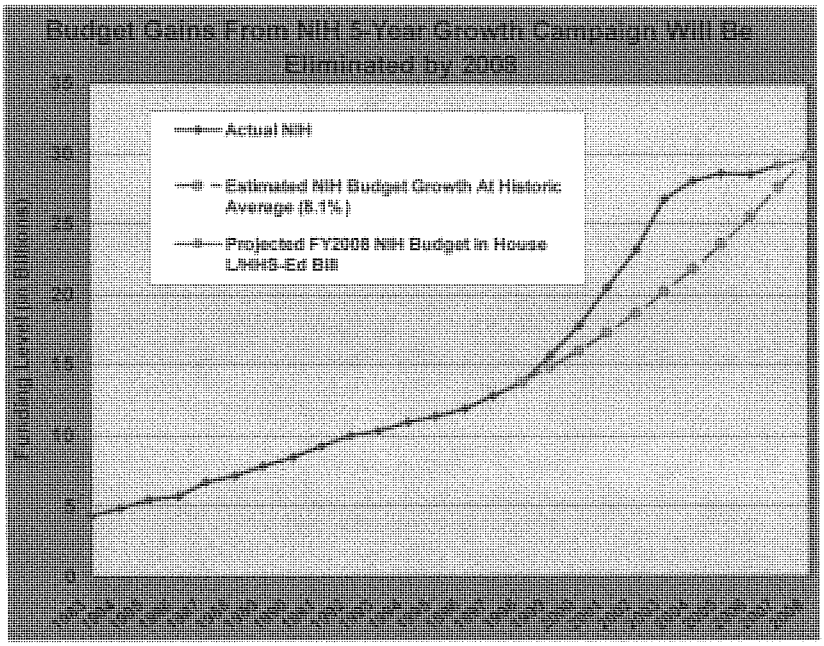
Though tempting, I am not asking for targeted funding of our research activities or for our university. Instead I am asking Congress to do two things-

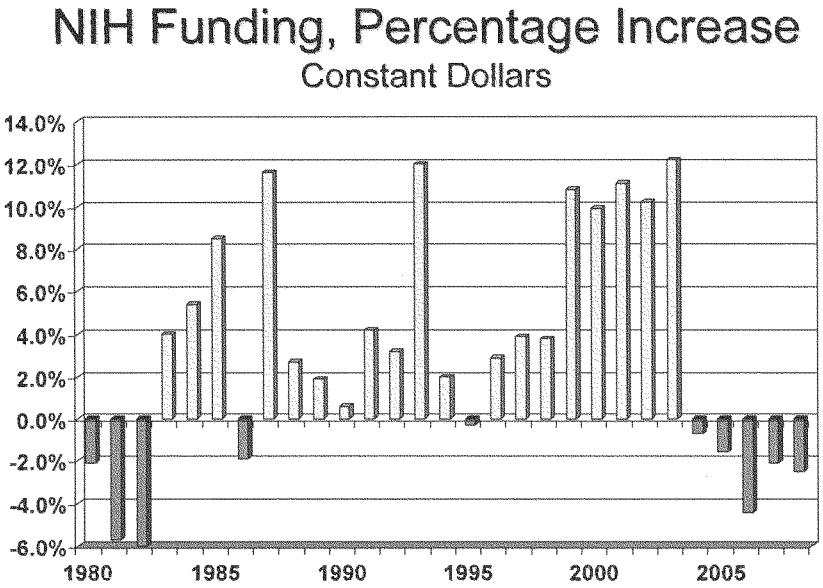
1. to provide global support for biomedical research, and
2. to return to a central precept of the original charter for NIH: to appropriate funds for NIH and then to let the people at NIH decide how to best use those funds.

The promise of improved health and well being of our citizens is great. This can emerge from biomedical research, That said, the expectations of "immediate returns from investment" (in terms of new cures and treatments) must be recalibrated and the support must be consistent and long-term.

Thank you for your time.

Respectfully,
Michael W. Miller


Budget Gains From NIH 5-Year Growth Campaign Will Be Eliminated by 2008
Actual NIH
Estimated NIH Budget Growth At Historic Average (8.1%)
Projected FY2008 NIH Budget In House LHHS-Ed Bill


NIH Funding, Percentage Increase
Constant Dollars
14.0%
12.0%
10.0%
8.0%
6.0%
4.0%
2.0%
0.0%
-2.0%
-4.0%
-6.0%
1980
1985
1990
1995
2000
2005

ALCOHOLISM: CLINICAL AND EXPERIMENTAL RESEARCH

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The Alcoholism Generator

Michael W. Miller and Linda P. Spear

Alcohol exposure largely affects 3 populations: fetuses, adolescents, and adults. These 3 developmental stages are inextricably intertwined such that elevated alcohol exposure at any time increases the probability of exposure at the others. This circular interdependency is called the alcoholism generator. Furthermore, exposure to large amounts of alcohol at these 3 times can cause cognitive dysfunction, largely through mechanisms of alcohol-induced perturbations in neurogenesis and synaptogenesis. Breaking this cycle is key to reducing problem alcohol drinking and the associated sequelae.

Key Words: Alcohol Abuse, Adolescent, Development, Fetal Alcohol Syndrome, Fetal Alcohol Spectrum Disorder, Fetal Programming, Teen Alcohol.

> Stop the individual chain reaction before it starts. Help chemically dependent women . . . not replicate the error, not perpetuate a syndrome which they themselves may suffer.
> Michael Dorris, Congressional testimony March 5, 1992

PREVALENCE OF ALCOHOL-INDUCED PROBLEMS

ALCOHOL ABUSE AND dependency are major health problems in the United States. Both are situations in which alcohol use shapes behavior. Alcohol dependence is characterized by a craving for alcohol, a loss of control for drinking, physical dependence on alcohol, and a tolerance to alcohol (American Psychiatric Association, 2000). Alcohol abuse is defined as a pattern of drinking associated with at least 1 of the following: a failure to complete responsibilities, drinking in physically risky situations, having repeated alcohol-related legal problems, and the need to continue drinking even though personal relationships are compromised by alcohol-induced behaviors. Alcohol abuse and dependency have been grouped under the rubric of alcohol use disorder (AUD).

Alcohol use disorder directly affects an estimated 19 million people in the United States each year. Substance abuse annually is responsible for more deaths and disabilities in the United States than any other cause (Institute for Health Policy, 2001). To put the scope of the incidence of AUD in perspective, the number of people abusing alcohol is 3 times the number of people abusing all other substances—licit and illicit drugs—combined. Moreover, the problem is becoming worse (Grant et al., 2004). It is estimated that in 1991 to 1992, 5.6 million people abused alcohol and an additional 8.2 million were alcohol dependent. Similar data were accumulated 10 years later. In 2001 to 2002, 9.7 and 8.9 million people were identified as being alcohol abusers and alcohol dependents, respectively. Thus, during this decade there was an increase of 4.8 million people developing problems with alcohol consumption—a 35% increase.

Alcohol use disorder affects people of all ages. For adults, the direct effects include adverse health consequences and lowered effectiveness in society. Alcohol use can also have indirect and broad effects; for example, there are negative effects on the health of family and friends and on innocent bystanders such as victims of people driving while intoxicated. Among adolescents, AUD also has both direct and indirect effects. Not only is illegal alcohol consumption one expression of the elevated risk-taking behavior of adolescents, but alcohol drinking itself may increase risk taking, e.g., unintended and unprotected sexual activity, contributing to the increased mortality rates seen during this stage of life (Irwin and Millstein, 1992). Regardless of the age of the alcohol user, a common component of AUD is cognitive dysfunction. The direct and indirect costs that can be attributed to AUD are estimated to be $276 billion per year (Institute for Health Policy, 2001). Thus, AUD costs the American economy more than cancer, heart disease, and diabetes combined.

Developmental (Fetal and Adolescent) Alcohol Exposure

The offspring of women who abused alcohol during their pregnancies often are the victims of alcohol abuse.

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These children can have a broad constellation of problems lescribed as fetal alcohol spectrum disorder (FASD). A subset of the children with FASD exhibit a stereotypical set of facial dysmorphologies, mental dysfunction, and growth retardation. These children are identified as having fetal alcohol syndrome (FAS). It is estimated that 1% to 3% of all children have FASD (Cook et al., 1990; Sampson et al., 1997). The numbers for FAS are lower, but still profound. Overall, the incidence of FAS is 1 to 2 per 1,000 live births and as high as 10.3 per 1,000 live births in selected populations such as communities of native Americans (Burd and Moffatt, 1994; Duimstra et al., 1993; May et al., 2004; Russo et al., 2004). A salient feature of FASD is brain dysfunction including learning and memory deficits, hyperactivity, and motor disorders. In fact, FAS is a principal known cause of mental retardation in the United States (Abel and Sokol, 1992).

A component of AUD among adolescents is deficits in learning and memory, e.g., reduced ability to retrieve verbal and nonverbal information, compromised ability to attend, and diminished function in visuospatial tasks (Brown and Tapert, 2004; Tapert and Schweinsburg, 2005). Such findings are disturbing because alcohol consumption among adolescents is widespread, with heavy alcohol use emerging in some. An estimated 10 million Americans who are 12 to 20 years old had at least one drink in the past month and two-thirds of them were binge drinkers (defined in this survey as the consumption of 5 or more drinks in a single drinking episode) (Johnston et al., 2005). Alcohol use often begins at an early age and becomes prevalent during adolescence. In 2003, nearly half of the surveyed eighth graders consume alcohol at least once per month and the vast majority of high school seniors (77%) report using alcohol. Indeed, nearly two-thirds of high school seniors self-report that they have been drunk and one-third of all seniors claim to have binged in the past 2 weeks. Alcohol use is associated with the 3 leading causes of death and injury among adolescents: suicides, homicides, and motor vehicle crashes (Centers for Disease Control, 1990). In 1999, it was estimated that the total cost resulting from alcohol use by adolescents was > $58 billion per year (Levy and Stewart, 1999).

Like fetal and adolescent exposure to alcohol, adult alcohol use/abuse can alter cognition and, in the most severe situations, it can cause dementia (Harper and Matsumoto, 2005; Pinder and Sandler, 2004; Vik et al., 2004). Multiple mechanisms underlying this dysfunction have been forwarded, including neuronal death and dendritic atrophy, i.e., the "reversal" of developmental events. A most intriguing mechanism of alcohol-induced brain dysfunction involves a component of the hippocampus. Exposure to alcohol (in infants, adolescent, and adults) affects the generation of new neurons that are eventually incorporated into the dentate gyrus (He et al., 2005; Miller, 1995; Nixon and Crews, 2002). Alterations in neurogenesis in the dentate gyrus can directly affect the ability to form short-term memories (Gould et al., 1999; Shors et al., 2001).

INTERDEPENDENCY OF FASD, ADOLESCENT ALCOHOL USE, AND ADULT ABUSE DISORDERS

The etiology of FASD, the consequences of adolescent alcohol consumption, and adult alcoholism are inextricably interrelated. Indeed, they are parts of a self-perpetuating cycle of alcohol abuse (Fig. 1). More specifically, adolescence is the time of initiation of alcohol use patterns, patterns that can lead to abuse (National Institute on Alcohol Abuse and Alcoholism, 1998). The age of initiation is key to the prognosis for alcoholism as an adult. Children who begin to drink before they are 15 years old are 4 times more likely to be addicted to alcohol than are people who have their first drink when they are 21 years old.

Alcohol use disorder among adults and the consequences of fetal exposure are intertwined. Adults with AUD are the prime source of children with FASD (Alvear et al., 1998; Jacobson et al., 1996, 1998; May et al., 2004). In turn, children with FASD are among those initiating alcohol use as young adolescents and with the highest incidence of developing AUD. Indeed, "prenatal alcohol exposure was more predictive of adolescent alcohol use and its negative consequences than was history of alcohol problems" (Baer et al., 1998). This association has been extended to adults (Baer et al., 2003). And the cycle continues.

The perpetuating cycle of AUD is stoked by parental consumption of alcohol that may serve as a model for

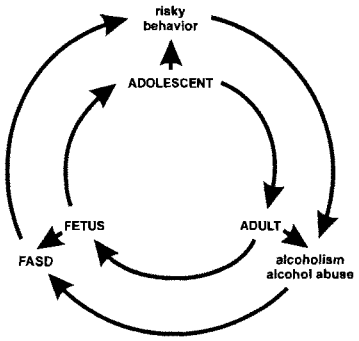

Fig. 1. The alcoholism generator. The inner and outer circles show the life cycle and the pattern of alcohol-related disorders, respectively. Initiation of alcohol use often begins in preadolescents and adolescents. The earlier the alcohol use, the more likely the habit will develop into a long-term pattern of problem drinking/alcoholism. Young adults are the most common source of children with fetal alcohol spectrum disorder (FASD). Children with FASD are likely to initiate alcohol consumption at an early age.

adolescent alcohol use and abuse (Weinberg, 1997). In short, a prime risk factor for AUD among adults, and for having children with FASD is the pattern of adolescent alcohol consumption (Grizenko and Fisher, 1992; Streissguth, 1997). We call this cycle the *alcoholism generator*.

BREAKING THE ALCOHOLISM GENERATOR

The effects of alcohol on the brain provide a framework for approaches to disrupt the cycle. Complementary approaches are necessary to break the alcoholism generator. First, basic researchers and care deliverers must work together to search for treatment/prevention strategies by relying on our understanding of brain development and structure as strategic guides. Second, a holistic approach to understanding AUD is required. Third, AUD must be viewed, at least in part, as a developmental disorder. In this context, the continuum of development from the fetal through the adolescent period into adulthood and the production of the next generation must be considered.

As described above, the brain is a prime target of fetal, adolescent, and adult alcohol exposure. Potential strategies to disrupt the generator must target neurodevelopmental events relevant to the timing of the exposure, keeping in mind that these events vary with age. Although some new neurons are produced throughout life, development during the fetal period is chiefly a period of brain assembly and the adolescent and adult periods are primarily times of brain remodeling. Ameliorative/preventive strategies must be based on the ongoing neural phenomena. An obvious approach is to reduce the incidence of FASD—a laudable, but challenging goal. More reasonable potential strategies for breaking the alcoholism generator focus on postfetal events. Two examples are described below.

One strategy is to maintain the population of cells that is produced during fetal development, which ultimately will have an effect on the bounty of connections in the adolescent and adult. After all, events occurring during early development have long-term effects on later life. During infancy, preadolescence, and adolescence, brain circuitry is established and optimized. This involves a selective (Darwinian) loss of connections. An overabundance (reserve) of connections established during preadolescence is winnowed and remodeled during adolescence. Thus, a reserve of connections is established in early development. If the loss of a connection(s) exceeds a threshold, a clinical condition results. Such depletion can occur naturally with aging or as a result of an exposure to an exacerbating factor such as a toxin. This type of loss likely contributes to neurodegenerative conditions such as Parkinson's disease and Alzheimer's disease.

The number of neurons created during early development presumably is a defining feature for the number of possible connections. Conceivably, having a lower number of neurons at the end of fetal development (be it by a reduction in cell proliferation or an increase in cell death) would reduce the reserve of axons available for forming neural circuits and thereby compromise the optimization of circuitry that occurs during adolescence. Thus, one strategy is to design treatments that retain the reserve by minimizing the loss of cells/connections during preadolescence or at least delay the losses so that they do not reach clinical levels until after adolescence is complete. A potential approach is to enrich the environments of children with FASD because such manipulations lead to improved circuitry and performance in certain behavioral tasks, an approach that has shown some success in rats (Klintsova et al., 2000, 2002).

From a clinical-psychosocial perspective, a particularly promising approach is to target adolescents: find ways to delay the time of initiation, discourage binge drinking, and alter the culture that promotes/glorifies alcohol use. Regardless of the approach, it is critical that future approaches to address the problem of adult alcohol consumption be conceived in the context of fetal and adolescent alcohol exposure serving as a source of later problematic alcohol use.

The current limitation to developing strategies to break the alcoholism generator is our ignorance of the dynamic changes in brain structure and function. Adolescence is not a heterogeneous period; neural plasticity in early adolescence appears to differ from that in late adolescence (e.g., Sisk and Zehr, 2005; Smith, 2003; Spear, 2000). Research into the bases of other psychiatric disorders, e.g., schizophrenia, highlight this malleability and show that the refinement of cerebral circuitry (and particular components such as local circuit neurons) is vulnerable to insults. Potentially, similar studies on alcohol-affected adolescent brains may provide insight into approaches for reducing adolescent alcohol use and breaking the alcoholism generator.

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Mr. OBEY. Thank you for your time.

Let me simply point out that the President's fiscal year 2008 budget proposed a $479,000,000 reduction to NIH compared to the appropriation level we provided in the fiscal year 2007 joint resolution.

The bill the President vetoed provided for an $899,000,000 increase. The final omnibus bill still provided $133,000,000 over fiscal year 2007 which was $613,000,000 over the President's request.

The President's fiscal year 2009 budget request fails to provide any increase at all for NIH, freezing the NIH budget at $29,200,000,000 which, as I indicated this morning, Dr. Zerhouni has told us will cost us the services of 6,000 scientists in the coming year.

Thank you for coming.

Dr. MILLER. Thank you.

Mr. OBEY. Next, Mr. Terry Peel.

THURSDAY, MARCH 13, 2008.

BOSTON UNIVERSITY AMYLOID TREATMENT AND RESEARCH PROGRAM

WITNESS

TERRY R. PEEL

Mr. PEEL. Some friends have joined me. Is that okay?

Mr. OBEY. Well, I do not mind the two people on the ends, but I am concerned about the fellow in the middle. [Laughter.]

Mr. PEEL. I understand this is your last hearing of the year and, recalling my prior service up here, this is a great day for the members but even a better day for the staff.

Mr. Chairman, I appreciate the opportunity to appear today to talk to you about the rare disease and the troubling disease of amyloidosis. Appearing with me today is my wife, Ann, who has successfully undergone treatment for this disease.

This Committee, the House Labor HHS Committee, starting with Mr. Regula as Chairman and now continuing with you, Mr. Obey as Chairman, has taken steps that have significantly changed the knowledge of this disease among the American public and also at NIH. We are asking you today to continue your efforts in providing report language that encourages NIH and the Centers for Disease Control to recognize this disease and work on the treatment, the care and prevention.

Until Ann was diagnosed with this disease, we had never heard of amyloidosis, and that is true of most of the American public. In fact, most people die of amyloidosis before they even know that they have it, and others are diagnosed too late to have the treatment.

The only treatment right now for amyloidosis is stem cell transplant and high dose chemotherapy. So, once you are diagnosed with this disease, you go through the risk of this type of procedure. Left untreated, the life expectancy for amyloidosis patients is 15 months.

Ann has successfully obtained treatment for amyloidosis, and she has moved through a life and death struggle. We are now devoting our time to use this experience to help others.

Dr. David Seldin is with us today. He is the Director of the Boston University Amyloid Treatment and Research Program, and it was Dr. Seldin and his team of professionals that actually saved Ann's life.

Now what is amyloidosis? Amyloidosis is a protein-folding disease in which proteins fold and clog up the organs in the simple explanation. They will clog up the heart, the kidney, the liver to a point where death occurs.

The treatment, as I have said, there is no cure for it, but the treatment is high dose chemotherapy and stem cell transplant where the patient's own stem cells are harvested in order to recover from the high dose of chemotherapy which brings you down to near death.

What needs to be done about this disease? Only through more research is there hope of further increasing the survival rate and finding treatments to help more patients. Timely diagnosis is also of great concern to us, and early treatment is the key to success.

Without a very sharp doctor here in Washington, identifying this disease, I am not sure Ann would be sitting here today.

Through the leadership of this Committee, there has been increased basic and clinical research on amyloidosis. There has been increased funding for equipment and research, and the National Institutes of Health have now increased their involvement and interest in amyloidosis and identified it as a rare disease.

What we are asking for you to do, Mr. Chairman, in the next steps is to continue the language that you have had in the report over the last several years, to continue to encourage the Centers for Disease Control and NIH to educate the American public and physicians, to provide funding in 2009 for research equipment and, finally, to assure that NIH is following through on the recommendations of the Committee.

Treatment has proven very effective for Ann. We want to turn what has been a life-threatening experience for her into hope for others.

Could Ann just say a couple words?

Ms. PEEL. When you have your health, you have everything which is one of the most important things I learned during my experience. What began as a devastating diagnosis ended in treatment, resulting in my remission.

One of my goals is to allow more people, early diagnosis and treatment, so they can lead healthy lives. The actions taken by this Committee are helping to do just that.

Thank you.

[The information follows:]

STATEMENT BY

TERRY R. PEEL

PRIVATE CITIZEN, BETHESDA, MARYLAND

BEFORE

THE SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,

EDUCATION AND RELATED AGENCIES

COMMITTEE ON APPROPRIATIONS

U.S. HOUSE OF REPRESENTATIVES

CONCERNING

AMYLOIDOSIS

March 13, 2008

2:00 PM

Summary: The testimony asks the Committee to include report language calling for additional steps to be taken on the diagnosis, treatment and research on the rare and deadly disease amyloidosis. The testimony also asks that additional research and treatment equipment for amyloidosis be provided for the Amyloid Treatment and Research Program at the Boston University School of Medicine and the Boston Medical Center.

Mr. Chairman, I appreciate the opportunity to appear before the Committee this afternoon to address the life threatening disease amyloidosis. Appearing with me today is my wife Ann, who has successfully undergone treatment for this disease. We ask that you continue to include language in the Committee's report for fiscal year 2009 drawing attention to amyloidosis. We also request that you recommend assistance for the Amyloid Treatment and Research Program at the Boston University School of Medicine and the Boston Medical Center.

Until my wife was diagnosed with primary amyloidosis, we had never heard of the disease. We were not alone. It is a disease that is often misdiagnosed or diagnosed too late.

Less than one percent of the U. S. population has been identified to have this disease. Many feel that the disease is vastly under diagnosed, especially in the African-American community.

Amyloidosis, which is often fatal, leads to heart, kidney, liver and other organ failure.

Thousands of people die because they were diagnosed too late to obtain effective treatment. Thousands of others die never knowing they had amyloidosis. The small number of those with amyloidosis who are lucky enough to obtain treatment face the risk of high dose chemotherapy and stem cell replacement.

Amyloidosis can literally kill people before they know what hit them. Left untreated there is an average survival rate from the time of diagnosis of about 15 months.

My wife has successfully obtained treatment for amyloidosis. She has moved through a life and death struggle. We are now devoting our time to use this experience to help others.

With us at the hearing are two of the people who enabled Ann to make this remarkable recovery: Dr. David Seldon, the Director of the Boston University Amyloid Treatment and Research Program, and Dr. Martha Skinner, a world renowned expert on amyloidsis, now the senior advisor on amyloidosis at the Boston Center.

WHAT IS AMYLOIDOSIS?

Amyloidosis occurs when cells malfunction and produce proteins that deposit on organs, such as the heart, kidney and liver. These misfolded proteins clog the organs until they no longer are able to function—sometimes at a very rapid pace.

In addition to primary amyloidosis, there are also cases of inherited or familial amyloidosis and secondary or reactive amyloidosis. All three types of amyloidosis, left undiagnosed or untreated, are fatal.

There is also no explanation for how or why amyloidosis develops.

Amyloidosis has no known cure.

HOW IS AMYLOIDOSIS TREATED?

Until thirteen years ago, the average survival rate for individuals undergoing treatment for amyloidosis was about a year. There was little that could be done to effectively stop amyloidosis—only two percent of patients responded well to low doses of oral chemotherapy treatment.

Boston University School of Medicine and other centers for amyloidosis treatment have found that large dose intravenous chemotherapy followed by stem cell replacement, or rescue, is an effective treatment in many patients. Abnormal bone marrow cells are killed through high dose chemotherapy and the patient's own extracted blood stem cells are replaced in order to improve the recovery process.

My wife has been part of a clinical trial and has undergone this procedure twice. This procedure has literally saved her life and for this we will be forever grateful to Dr. Skinner, Dr. Seldon and the entire team associated with the Boston University Amyloid program.

The high dose chemotherapy and stem cell rescue has increased the remittance and long term survival rate dramatically: increasing from two percent to almost 50 percent the number of patients with total remission.

WHAT NEEDS TO BE DONE?

Only through more research is there hope of further increasing that survival rate, and finding treatments to help more patients. Specifically, research needs to be done to develop targeted treatments that will specifically attack the amyloid protein produced in the bone marrow. Additional funding for research and equipment is needed to accomplish this task.

Timely diagnosis is also of great concern to us. Fortunately, Ann was diagnosed at an early stage by an alert doctor here in Washington. However many people are diagnosed after the point that they are physically able to undertake treatment.

Early treatment is the key to success. More needs to be done in this area to alert health professionals to identify this disease.

WHAT STEPS HAVE BEEN TAKEN?

Through the leadership of this Committee and the further involvement of the U. S. Government, a number of positive developments have occurred.

- There has been increased basic and clinical research at the Amyloid Treatment and Research Program: a model for the disease is under development; factors that cause protein misfolding are being identified; and new clinical trials are underway.

- Increased Federal funding for equipment for research and treatment has been another important element. This has been of key importance to speed the pace of discovery for basic research.

- The National Institutes of Health hosted a workshop at NIH in 2006 on amyloidosis and issued a report. NIH also supported an International Symposium on amyloidosis that took place in 2007 in Woods Hole, Massachusetts.

- The National Institutes of Health have identified amyloidosis as a rare disease and are in the process of pursuing additional research on it through the Office of Rare Diseases.

- Medicare has acknowledged that aggressive treatment for amyloidosis has proven to be effective, opening this treatment to patients previously unable to afford it.

WHAT ARE THE NEXT STEPS?

Mr. Chairman, we ask that the Committee do four things to help address this deadly disease.

- First, continue language in your report identifying amyloidosis as an important concern and encourage more research to find a cure.

- Second, continue to encourage the Centers for Disease Control and the National Institutes of Health to educate the American public and medical profession on the need to diagnose this disease at an early stage.

- Third, provide fiscal year 2009 funds within the Department of Health and Human Services for equipment and related assistance at the Amyloid Treatment and Research Program at the Boston University School of Medicine and the Boston Medical Center to assist in methods for treating and curing this tragic disease.

- Finally, assure that NIH is following through on the recommendations made by the Committee in past Committee reports.

Treatment has proven effective for my wife. We want to turn what has been a life threatening experience for her into hope for others.

Thank you for your consideration.

Mr. OBEY. Well, thank you.

Let me just ask the doctor one quick question. What percentage of physicians throughout the Country, do you think, are sufficiently aware of the disease and aware of the manifestations that would enable them to make a diagnosis?

Dr. SELDIN. I think most physicians are aware, Mr. Chairman. I think the internet has made a great difference for patients with rare disease and their ability to seek out centers for treatment, but it is only through the support of the Congress and funding of National Institutes of Health research that we can continue to make advances.

I think there are thousands of people alive today with this and other rare diseases because of what you have allowed NIH and the biomedical research community to do, millions of people living with cancer today, who would not be here without that support, and I hope you can continue the momentum to improve things for the American people in the future.

Thank you.

Mr. OBEY. Thank you.

Next, PKD Foundation, Michael Haggard.

THURSDAY, MARCH 13, 2008.

PKD FOUNDATION

WITNESS

MICHAEL HAGGARD, BOARD MEMBER, POLYCYSTIC KIDNEY FOUNDATION

Mr. HAGGARD. Thank you. Good afternoon, Mr. Chairman and members of the Subcommittee.

My name is Michael Haggard, and I am on the Board of Trustees of the Polycystic Kidney Foundation. I am also a patient with polycystic kidney disease.

The disease has run through my family as it does all who have PKD for generations. My maternal grandmother died when my mother was in college. I never met her.

My uncle was diagnosed and became a nephrologist to find a cure for the disease. He died after receiving a kidney transplant from my grandfather, and my mother died of polycystic kidney disease three years ago this week.

I am not here for myself. It is too late for me. I am here for Madison and Carson who are my two children, who have a 50 percent chance of receiving the gene from me and being diagnosed with PKD. I am here for all the children who cannot control the genes that their parents pass on to them.

Polycystic kidney disease affects 600,000 Americans, 12.5 million people across the globe, and it is one of the world's most prevalent life-threatening genetic diseases. Put another way, there are 1,400 PKD patients in each one of your congressional districts.

The majority of PKD patients will experience kidney failure, making dialysis or a kidney transplant the only way that they can survive.

PKD is the number one genetic cause of kidney failure and costs the Federal Government $2,000,000,000 annually in the Medicare

budget. As Congress knows, end-stage renal disease is the number one increasing item in Medicare.

I want to thank this Committee, as previous folks have testified, for your commitment to research, to the NIH because you have had a dramatic impact. Two years ago, the PKD Foundation testified before this Committee, and that was before we had 15 clinical trials ongoing right now. This gene was only discovered, the gene that causes PKD, 13 years ago. Right now, currently we have 17 clinical trials going on.

The PKD Foundation, which works with the NIH, has developed public and private partnerships to develop the research for this disease. Congress has responded. This Committee has responded with ever more progressive appropriations report language for PKD for 18 consecutive years.

Research in the PKD field is now at the point where we hope this Committee will include the proposed fiscal year 2009 report language which calls for the establishment of PKD centers and diagnostic treatment centers. We believe that these centers are really the next step in the progression of PKD research.

They would increase the new diagnostic methods to treat PKD, the application of new therapeutic regimens, conduct pilot studies and these clinical trials, and coordinate all that data with the public and private partnerships, and streamline the appropriate clinical applications of effective treatments.

We are pleased to report that Dr. Starr, who gave a speech to us last week at our awareness center, said PKD research is one of the most prevalent and most exciting research going on at the NIDDK and they have approved our report language.

My time before you obviously is limited and there is an incredible group of folks to testify after me and before me. So we have submitted the written testimony.

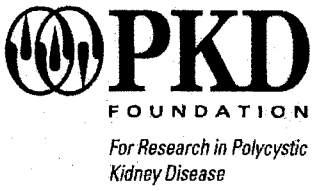
We realize that it is important for Congress, especially in light of everything that the Chairman has talked about with the freeze in funding, to see a return on investment. When you look at the return on investment in just a short time for PKD research, it is really one of those diseases that we are on the cusp of making a difference in. It is vitally important that this investment go on and we do not lose the scientific momentum that we have achieved.

I do not want to leave behind the legacy for my family and generations to become this disease. The blessing and the cursing of this disease come in the genetic form, in the gene. Every night when I put my two kids to bed, one of the thoughts I always have is: Did I pass this disease on to them?

The blessing of this disease is the genes because the scientists, because it is genetic, because of their discoveries, feel that they can make the advances and put it into clinical trials, which they have done, and get to the point where they can slow the progression of this disease.

Thank you so much for all your efforts in the past, and I thank you for my time today. If you have any questions, I will be happy to answer them.

[The information follows:]



Written Testimony of Mr. Michael Haggard, Esq.

Board of Trustee Member and PKD Patient

PKD Foundation
Kansas City, Missouri

Before the U.S. House Appropriations Subcommittee for Labor, Health and Human Services, Education and Related Agencies

2 p.m., March 13, 2008

Summary: This testimony describes the personal impact of PKD on a patient and summarizes the significant scientific momentum achieved to date in the field of Polycystic Kidney Disease (PKD) research through technological innovation, cutting edge science and collaboration between private entities and the National Institutes of Health (NIH).

Good morning, Mr. Chairman and members of the Subcommittee. My name is Michael Haggard, a Board of Trustee Member for the Polycystic Kidney Disease Foundation and a PKD patient living in Miami.

My entire family has been affected by this disease. My maternal grandmother died when my mother was still in college. My uncle then was diagnosed and went on to become a nephrologist so he could learn more about PKD and possibly find a cure. Unfortunately, after my grandfather gave him a kidney, my uncle died in the mid 1980s before significant progress had occurred in the research to cure PKD. My mother also unfortunately carried the gene for PKD and died three years ago this week.

I am not here for myself. I am here for Madison and Carson, my two children, who each have a 50 percent chance of becoming afflicted with this disease that has ravaged my family. I am here for all the future generations of children who have no choice in what genes their parents pass on to them.

I am one of the 600,000 Americans and 12.5 million people across the globe that have PKD, one of the world's most prevalent, life-threatening genetic diseases. Put another way, there is an average of 1,400 PKD patients in each of the nation's 435 Congressional Districts. This is a disease that does not discriminate based on gender, race, age or geography.

PKD is dominantly inherited and doesn't skip generations. The majority of PKD patients will experience End Stage Renal Disease or kidney failure, making survival dependent on dialysis or a kidney transplant. PKD is the number one genetic cause of kidney failure and the number four cause, overall. PKD patients occupy approximately 5,000 spots on the kidney transplant waiting list. PKD costs the federal government almost $2 billion annually in Medicare expenses for dialysis, transplantation, and related drug therapies. And, as Congress knows, ESRD is one of the fastest growing areas of the Medicare budget.

Many Members of Congress are frustrated that National Institutes of Health has generated too few treatments and cures, despite the significant budget increases the agency received in the 1990s. The NIH has invested $241 million in PKD research from 1993-2006, a relatively small sum when compared to the NIH's investment in other common, but far less prevalent, genetic diseases. In turn, the PKD Foundation has itself invested almost $11 million in research and medical programs since 2005 alone. However, the investment by Congress, the NIH and the PKD Foundation in PKD research has had a dramatic impact.

PKD is devastating to the families it affects, and there is significant cost to the federal government, but the opportunity to find an effective treatment for this disease is within reach. Two years ago, when the PKD Foundation last testified before this Committee, there were only a handful of clinical trials. But rapid research progress has pushed the number of clinical trials to 15 and counting—and it was only 13 years ago that the genes that caused PKD were discovered.

The PKD Foundation has worked hard to create unique public and industry partnerships to stimulate PKD research. In addition, PKD families across the nation have become more engaged in grass roots advocacy efforts. Their efforts, along with the unprecedented scientific momentum

currently underway in PKD research, have prompted Congress to adopt increasingly supportive Congressional Appropriations report language for PKD for 18 consecutive years.

This report language, in turn, has prompted the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) to establish PKD Centers of Excellence and issue special RFAs and Program Project Announcements, and conduct several International PKD Strategic Planning Meetings.

For FY 2009, I hope that the Appropriations Committee will include the proposed PKD Report Language which calls for the establishment of PKD Clinical and Diagnostic Treatment Centers. The PKD Foundation believes these Centers are the next step in the progression of PKD research. They would increase the application of new diagnostic methods to patients at risk for PKD; increase application of new therapeutic regimens; conduct pilot studies and clinical trials; and coordinate data and streamline appropriate clinical application of effective treatments.

I am pleased to report to you that the response from the NIDDK has been very positive to this proposal.

In addition to report language, the NIDDK's efforts have led to the development of innovative imaging technology for PKD – called CRISP (Consortium for Radiological Imaging Studies in Polycystic Kidney Disease) – that is so accurate and sensitive it reduces by 24 times the number of participants needed for clinical drug trials. The NIDDK also has been a leader in establishing the HALT-PKD clinical trials network, a research project jointly funded by the NIH and the PKD Foundation.

Commensurately, research funded by the PKD Foundation has discovered a class of drugs called "V2 receptor antagonists" that may stop a key hormone from causing cyst growth. Research has shown these drugs are highly effective in slowing disease progression in laboratory animals with PKD with little or no side effects.

Finally, last May, the PKD Foundation sponsored a workshop with the FDA that focused on using kidney and cyst volume, rather than the traditional "Glomerular Filtration Rate (GFR)," for measuring the progression of PKD in patients. Normally, a drop in GFR is an indication of kidney disease and is accepted as an outcome measure in clinical trials for kidney drugs. However, GFR is not a good measure of disease progression in PKD because as cysts continue to form and grow, and the kidneys enlarge, GFR remains normal because the kidney can compensate, up to a point. Eventually, as cysts continue to form and increase in size, GFR begins to fall quickly and the kidneys fail—but at that point it is too late to begin treatment to slow or stop disease progression.

I realize that Congress needs to see a "return on investment" in the funding it spends on disease research, and PKD has consistently offered a tremendous return for the relatively low levels of funding it has received.

I urge Congress to consider restoring the overall investment in disease research at the NIH, which has received little growth over the past five years, a period when PKD research funding decreased by about 15 percent.

Secondly, I call on Congress to look at adopting objective priority setting standards for the NIH that account for disease prevalence; morbidity, mortality, cost to the Federal government; scientific momentum; private/public/industry efforts; therapeutic opportunity; and collateral benefits to other research efforts like PKD.

I hasten to add, however, that if NIH resources are not directed toward such promising areas of scientific momentum and therapeutic opportunity, then promising therapies for PKD will be in jeopardy.

This effort is vitally important for hundreds of thousands of individuals with PKD, including my children. I want the legacy I leave them and future generations of my family to not include the suffering caused by PKD.

Thank you – and I'd be happy to answer any questions you may have.

PKD Research Update: Clinical Initiatives

The following is a summary of current clinical initiatives in the field of PKD research:

HALT PKD Study--To assess the effectiveness of anti-hypertensive drugs telmisartan and lisinopril on PKD progression and its cardiovascular complications in two different levels of kidney function, GFR more than 60 mL/min/1/73m^{2}and GFR between 25-60 mL/min/1/73m^2.

Tolvaptan Tempo 3 / 4 Trial--To evaluate the long-term effectiveness and safety of Tolvaptan by monitoring total kidney volume and cyst volume by magnetic resonance imaging and measuring a composite of clinical markers in ADPKD patients.

Efficacy, Safety and Tolerability of Everolimus in Preventing End-Stage Renal Disease in Patients with ADPKD--To evaluate the anti-proliferative drug Everolimus as a means to slow disease progression in PKD by measuring total kidney and cyst volumes and changes in renal function.

ADPKD Pain Study--To evaluate the effectiveness of VSPL procedure for pain management in patients with ADPKD

Pilot Study of Rapamycin as Treatment for ADPKD--To compare the effects of an anti-proliferative, anti-angiogenesis and tumor-progression-blocking agent on disease progression in ADPKD. Due to the intensive and frequent testing schedule, enrollment is limited to local patients only.

Sirolimus (Rapamune) for ADPKD--To investigate whether a low dose of sirolimus retards cyst growth and slows renal functional deterioration in patients with ADPKD.

Sirolimus Treatment in Patients with ADPKD: Renal Efficacy and Safety--To determine if the addition of sirolimus to conventional high blood pressure therapy can prevent a further increase in or can reduce total kidney and cyst volumes in ADPKD adults with normal and mild to moderate renal insufficiency.

Somatostatin in Polycystic Kidney: A Long-Term Three Year Follow-up Study--To compare the effects on disease progression of a three year treatment regimen using long-acting somatostatin or placebo in patients with ADPKD and normal renal function or mild to moderate renal insufficiency.

Octreotide in Severe Polycystic Liver Disease--To evaluate the effect of Octreotide LAR on liver volumes of patients with severe polycystic liver disease who are not candidates for or decline surgical treatments such as liver cyst fenestration or liver transplantation.

Effect of Statin Therapy on Disease Progression in ADPKD--To determine the effect of pravastatin treatment on renal and cardiovascular disease over a 3-year study period in children and young adults aged 8-21 years with ADPKD.

The Effect of High and Low Sodium Intake on Urinary Aquaportin-2 in ADPKD--To examine the effect of high and low diets on kidney function and on hormones that affect the kidney.

CCB Safety Study in Treatment of Hypertension in ADPKD--To evaluate the safety and efficacy of calcium channel blocker Candesartan in treatment of hypertension in ADPKD patients.

Evaluation of ARPKD and Congenital Hepatic Fibrosis--To collect comprehensive date on kidney and liver disease in ARPKD/CHF and follow patients over time to provide the groundwork for more focused studies and novel therapeutic interventions.

Chronic Kidney Disease in Children Prospective Cohort Study (CKiD)--To determine the risk factors for decline in kidney function and to define how a progressive decline in kidney function impacts neurocognitive function and behavior; the risk factors for cardiovascular disease; growth failure and its associated morbidity.

Transplant Registry: Patients Who May Require Transplantation and Those Who Have Undergone Transplantation of Liver, Kidney and/or Pancreas--To make a systematic review of medical records of patients (with patient consent) in the Virginia Commonwealth University Health System who have received a liver, kidney or pancreas or who may require one and to enter the data into a secure database.

Biographical Information for Michael Haggard

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Date/Place of Birth:	May 20, 1970, Fort Sumter, South Carolina
Education:	Florida State University, Bachelor of Science (1992) --Dean's List Scholar, President --Interfraternity Council (1991-1992) --Greek Man of the Year (1992) --Order of the Omega --Omicron Delta Kappa University of Miami School of Law (J.D., 1995) --Book Award --Advanced Litigation Skills
Civic Memberships and Associations:	Board of Directors: Florida State University Alumni Assoc. Volunteer: Community Partnership for the Homeless Volunteer: Habitat for Humanity Member: Coalition for Family Safety Member: Guardian Ad Litem Program Member National Advisory Board, National Crime Victims Bar Association Board of Trustees: Polycystic Kidney Disease Foundation

Mr. OBEY. Thank you very much. I appreciate your time.

Mr. HAGGARD. Thank you, Mr. Chairman.

Mr. OBEY. Let me say to Committee members, any time you want to ask a question, I am going to keep moving through witnesses unless somebody pulls my chain and lets me know they want to ask a question.

All right. I understand that the gentlewoman from California would like to introduce the next witness.

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

Mr. Chairman, I would like to introduce Dr. Randy Pausch who will be testifying about the critical importance about funding pancreatic cancer research. Dr. Pausch is an award-winning teacher, researcher and computer scientist at Carnegie Mellon University.

He is, more importantly, a husband, a father of three young children and a courageous and outspoken individual who is living with pancreatic cancer. In what time he has left, Dr. Pausch is trying to make a meaningful contribution to pancreatic cancer science.

Just a couple of days ago, Dr. Pausch was discharged from the hospital, and I also understand on his way over here he was in an automobile accident. So it has taken him a great deal of strength and determination to be here to share his message with us today.

So, thank you, Randy, for your courage and your unselfish giving of your precious time to share your story before this Subcommittee in hopes of saving the lives of others.

THURSDAY, MARCH 13, 2008.

PANCREATIC CANCER ACTION NETWORK

WITNESS

DR. RANDY PAUSCH

Dr. PAUSCH. Thank you.

I am here on behalf of the Pancreatic Cancer Action Network.

Pancreatic cancer is a terrible, terrible disease. I became sort of an accidental celebrity because after I was diagnosed, and I want to be very clear, I am a terminal cancer patient. I am not even supposed to be alive today.

In August, I was given three to six months. I have had a very fortunate response to the palliative chemo, but this is not going to last too much longer.

As you said, I was in the hospital last Monday. I was diagnosed with congestive heart failure and renal failure. I said to the doctors, can I get healthy enough to go to D.C. on Thursday?

We do not have advocates for this disease because they do not live long enough. We do not have a Michael J. Fox because people die too fast. Pancreatic cancer is absolutely ruthless.

I became an accidental celebrity because I gave a lecture at Carnegie Mellon after I was diagnosed, as an academic tradition of the last lecture. Hypothetically, if you were going to die, what would you tell your students? I got to do it for real.

I gave a lecture for my children, but I gave it in an academic setting. It got loose on YouTube and damned if six million people have not watched it.

But I want you to understand that pancreatic cancer is one of those unusual diseases. The statistics are pretty clear. If you get it, you are dead within a year with a 75 percent chance. When you talk about survival, 4 percent of people make it to 5 years.

When I presented first with symptoms, we thought I had hepatitis. When we got the diagnosis, my wife said, gee, I guess you would trade for hepatitis.

I said, honey, I would trade for AIDS in a heartbeat, in a flash. I would love to trade for AIDS.

This Subcommittee is pretty familiar with AIDS. You were some of the first funding that was provided. I do not think we have beaten AIDS, but I think we have made huge progress against the disease that many people thought would be impossible.

Pancreatic cancer right now is the fourth leading killer amongst cancers. More interestingly, it is one of the only cancers you can point to and say, in the last 30 years, we have made no progress. That is terrible.

There are so many cancers where you can see, particularly with childhood cancers, where the 4 percent survival became 90 percent survival. It makes me feel really good to be an American to see the researchers let loose and win like that.

With pancreatic cancer, I learned a new word, nihilistic. It means given up, too hard. I do not believe in too hard.

I believe that by funding pancreatic cancer research, we will be going after the hardest problem, and I am a trained researcher. I know that if you go after the hardest problem, you cannot go for the halfway solutions.

I mean not that I am not a fan of chemotherapy and radiation, they have kept me alive, but the real answers are going to be in genetics and things like pancreatic cancer force you into those kinds of solutions because the halfway measures just are not good enough against that strong of a disease.

This is a disease you cannot protect yourself against. I never smoked. I never drank. I exercised every day. I tried to eat right. It just comes like a thunderbolt out of the blue.

Part of my job is to put a face on the disease. At the risk of being a little bit overly dramatic, I want to show you a picture. This is my family.

This is Dylan. He is six years old. He loves dinosaurs.

This is Logan. He is four. He is Super Logan. He has a cape. He runs around the house, saving everyone.

This is Chloe. In May, she turns two.

And, this is my widow. That is not a grammatical construction you get to use every day, but it is not many diseases where you know it will be fatal.

I have metastasized to the liver and spleen which means that I have 100 percent chance of dying, and there is not anybody in the medical community who will not bet that I will not be dead by the end of the year.

This woman is going to raise these three children by herself, very bravely, because I will not be there to help her.

All I can ask today is that everyone keep in their minds that pancreatic cancer is a disease that I think we can beat, but it is going to take more continued courage and funding from our govern-

ment to help protect us from the things that we cannot protect ourselves from.

Thank you.

[The information follows:]

March 11, 2008

Testimony of Dr. Randy Pausch
Professor of Computer Science, Human-Computer Interaction and Design
Carnegie Mellon University
Chesapeake, Virginia

On the Behalf of the Pancreatic Cancer Action Network

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

On the Importance of Increasing Federal Funding for Pancreatic Cancer Research

Contact: Megan Gordon Don
Director of Government Affairs
Pancreatic Cancer Action Network
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Pancreatic Cancer Action Network

Mr. Chairman and members of the Subcommittee-

My name is Dr. Randy Pausch. I am here on behalf of the Pancreatic Cancer Action Network and the thousands of Americans who have suffered from this deadly disease.

In the way of background, I am Professor of Computer Science, Human-Computer Interaction and Design at Carnegie Mellon University. I had the good fortune of being named an NSF Presidential Young Investigator, spending time at Walt Disney's Imagineering and Electronic Arts, and co-founding the University's Entertainment Technology Center. That may sound like a boring resume to you, but to a geek like me, it's nirvana!

My father always advised me that if there is an elephant in the room, introduce it. In September 2006, at the age of 45, I was diagnosed with pancreatic cancer. I have some of the best doctors in the world, but even they couldn't stop what was happening. Last year I was told that my cancer had spread to my liver and spleen and that I had three to six months to live. According to the statistics, seventy-five percent of people diagnosed with pancreatic cancer die within the first year. So, for me, being here today is a milestone of sorts.

In the academic world it's become a common practice to invite professors to deliver a "last lecture," the premise being, what knowledge would you impart to your students if you were delivering your last lecture? Last September I had the opportunity to deliver my last lecture at Carnegie Mellon. I talked about fulfilling childhood dreams, and how we go about enabling the dreams of others. I thought perhaps my testimony today could be a different take on those subjects.

For me and the 37,680 Americans who will be diagnosed with pancreatic cancer this year, the dream is to find a cure or a way to prevent what is the most lethal form of cancer. I say that because only five percent survive more than five years and the survival rate beyond that is even lower. Pancreatic cancer is truly the deadliest cancer and yet it is also the fourth leading cause of cancer related death. It seems strange to be talking about rankings in this context, but pancreatic cancer kills more people than prostate cancer and is just behind breast cancer. In other words, this is not a "little" disease. It just hasn't received a lot of attention to date.

The money this Subcommittee has invested in cancer research over the years has paid off in so many wonderful ways. The result has been that the death rates associated with many types of cancers have declined.

Not so with pancreatic cancer. In fact, the chances of surviving this unmerciful disease are about the same as they were over 30 years ago. Pancreatic cancer is where breast cancer was in the 1930's—little understanding of the causes, no early detection, few effective treatments and single digit survival rates. It is not only the fourth leading

cause of cancer death in the US, but the number of people diagnosed with pancreatic cancer and the number of deaths it causes are going up—not down and have been even in the years when overall cancer deaths have decreased.

So how do we enable the dream of living without the threat of pancreatic cancer? How do we reverse the trend that will cause more Americans to suffer pain and anguish, and more families to bear the physical, emotional and financial burden of pancreatic cancer?

I am sure you can guess that the easy answer is, more money. The more accurate answer is, more money that is better targeted.

While I realize that Congress is reluctant to direct how NIH allocates research dollars, I would argue that something is wrong when one of the deadliest types of cancer receives so little attention. You may be surprised to learn that of the $4.8 billion this Subcommittee appropriated for the National Cancer Institute, less than two percent—or about $74 million—was spent on pancreatic cancer research. In fact, pancreatic cancer research receives the least amount of NCI funding of any of the top cancer killers. Please see the attached chart of NCI funding for the top five cancer killers and the survival rates for the same cancers. There is no question that funding levels and survival rates are linked.

Of the more than 5,000 research grants awarded by the National Cancer Institute in 2006, only 134 grants, approximately 3 percent, were focused primarily on pancreatic cancer research.

And of the 160 cancer research centers NCI supports, only three specialize in pancreatic cancer research.

We have heard repeatedly from the brightest scientific minds in the country that pancreatic cancer research is an area that holds great promise – the ideas are there, we just need the funds to pursue them.

I believe that Congress and NIH have a leadership role to play—as you did in the 1970s, when the war on cancer was declared; in the 1980s, when this Subcommittee provided the first appropriation to combat HIV/AIDS; at the start of this decade, with the launch of a bioterrorism research initiative and as you have done many times over the years for other cancers.

Ironically, the National Cancer Institute developed a pancreatic cancer research plan back in 2001. The problem is it was never fully implemented. In fact, only 5 of the plan's 39 recommendations were acted upon.

Last year, the Pancreatic Cancer Action Network gathered together the leading experts on this disease, many of whom crafted that original plan, and asked them to

update it. What they came up with is a detailed plan called *The National Plan to Advance Pancreatic Cancer Research*, that

- calls for a coordinated research initiative to support very specific research objectives, including finding more precise diagnostic methods and more innovated clinical trials testing;
- supports more pancreatic cancer research centers to serve as a staging area for highly targeted research on pancreatic cancer;
- takes the steps necessary to draw more scientists into this particular field of research; and
- promotes greater awareness among physicians and the general public.

The initial cost of what we call *The National Plan to Advance Pancreatic Cancer Research* would be $170 million. While I recognize that that seems like a large number, please remember what I said about pancreatic cancer research being stuck in the 1930s. We need to bring it into the 21st Century.

I have supplied the Subcommittee with a copy of this plan. Many of you may have learned about the National Plan from one of the 220 advocates who were here earlier this week for Pancreatic Cancer Action Network's Advocacy Day. I urge you to support the implementation and funding of the National Plan.

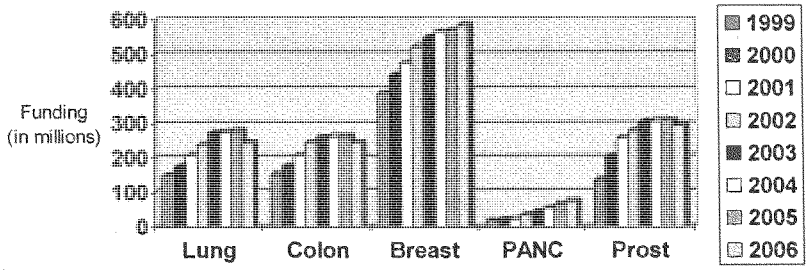
I should also point out that we strongly support increasing the overall budget for the NCI. Therefore, we are also joining our partners in the One Voice Against Cancer (OVAC) Coalition in calling for a 9.5% increase over Fiscal Year 2008 levels.

My mother always liked to refer to me as her son, the doctor, but not the type of doctor who helps people. I hope that by being here today, I will help people by shining a spotlight on this disease and urging you to provide necessary research funding for this disease.

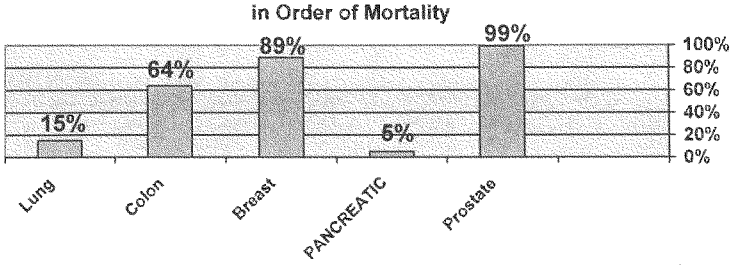
I will be glad to answer any questions you have, and thank you for the opportunity to present this testimony.

Pancreatic Cancer Action Network

NCI Funding for Top 5 Cancer Killers
(listed in order of mortality rates)



Five Year Survival Rates for Top Five Cancer Killers, in Order of Mortality



Pancreatic Cancer Action Network

Mr. OBEY. Thank you very much for sharing your story. If I may simply say, I am somewhat familiar with the problem because my brother-in-law died of pancreatic cancer.

Dr. PAUSCH. Sorry to hear that.

Mr. OBEY. He worked for the Department of Transportation in State Government in Wisconsin, and he decided to take early retirement so he could spend full-time working for Tin Can Sailors, an organization that he helped set up after the Vietnam War.

Before he retired, he took one last physical. Expecting no problems, he was shocked and his doctor simply said, I have a bad surprise for you. He spent the next two years, struggling before he was finally overcome by the disease.

So I know how hard it is, and I think virtually everybody on this panel knows someone who has been in a similar situation. I simply want to assure you that we will do everything we possibly can to try to shape a bill that recognizes that it is more important to put funding into medical research than it is to put $51,000,000,000 in the pockets of millionaires in the form of a tax cut this year.

I would simply point out again, to put this in context, between 2007 and 2006, the number of NIH new and competing grants dropped by 891 grants. In 2007, this Committee added 1,194 grants to the NIH budget, but that change is being eroded this year by the loss of some 6,000 scientists that will occur if we pass the President's budget.

So I want to assure you we will do everything we can to try to change that picture. I admire your courage, and we all wish you very well.

Anyone else have any other comment?

Mr. Honda.

Mr. HONDA. You are advocating more research and more study among the scientific community and the physicians. Where does one start?

Reading the information here, there does not seem to be a starting point. Is there a starting point?

Are there areas of research that should be looked at but are not being looked at, using computer science and the genome? Where do you start?

Dr. PAUSCH. I think you put your finger on it. The human genome is the wildcard. Every researcher I have talked to has said that is an asset that we did not have even a couple of years ago.

The thing that I find most tragic is when I talk to the young. I am a researcher myself, and I am trying to become the most informed pancreatic cancer patient in the world. I go and talk to the researchers, researcher to researcher.

I will tell you it pretty much stinks when I meet a hotshot researcher, and I know I can just ask the question, which parent? We would not have gotten very far with breast cancer research if we had only limited it to people who went into it because they lost their mother.

People right now who are young researchers are not heading toward pancreatic cancer research because it is wildly underfunded and it has always been underfunded.

I think part of the trick is to seed the junior hotshots with the kind of grants that are provided for young researchers. I think this

is going to be cracked by somebody younger, somebody who comes at it with a genomic approach. There are a lot of good vaccine-based approaches that are quite exciting.

But I think it is going to have to be a breakthrough. I do not think it is going to be another chemotherapy or radiation tweak. I firmly believe that there are plenty of bright people out there that want to attack it. What they need is they need the strong sense that the funding is there because I have been a junior researcher and I have looked over in computer science, what shall I work on, and I know that the smart people work on what there is money to work on because they are pretty ruthless in their careers and they should be.

So I do not think it is at all the same game it was even 10 or 15 years ago. I think that we have already made some strides in figuring out some of the genetic precursors, and there is no doubt there is a genetic component to this. As the previous speaker said, do not think I do not go to sleep every night without worrying about are these kids going to get my genes.

People say, are you worried?

I say, well, the good news is pancreatic cancer does not normally strike until later. If the money is there, I would bet everything that by the time my kids are my age, we will have it licked. If the money is not there, then I would not be very confident at all.

I do not know if that answered your question or not.

Mr. OBEY. Let me interrupt to simply say we have six minutes left to make the vote. So I think we are going to have to leave.

Thank you again for your testimony.

Dr. PAUSCH. Thank you.

Mr. OBEY. We will have a 15 minute vote on the floor, and then after that we are told another 15 minute quorum call. So I hope we can be back here in about 20 minutes.

[Recess.]

THURSDAY, MARCH 13, 2008.

HEPATITIS B FOUNDATION

WITNESS

DR. TIMOTHY M. BLOCK, PRESIDENT, HEPATITIS B FOUNDATION

Mr. OBEY. Let's see where we were.

Mr. Block.

Mr. BLOCK. Mr. Chairman and Committee members, I am accompanied by my wife, Joan, who is a nurse.

Mr. OBEY. Good first name.

Mr. BLOCK. We are off to a good start.

Mr. Chairman, thank you and the Committee for the opportunity to speak today about the problem of hepatitis B.

May I also note that Congressman Honda has been particularly sympathetic to the problem, and I hope after my testimony, others on the Committee, if not already, will also be convinced.

My name is Dr. Timothy Block, and I am the volunteer President of the Hepatitis B Foundation which my wife, Joan, and I and another couple from Pennsylvania founded more than 18 years ago

because someone very close to us was affected. I am also a professor at Drexel University College of Medicine.

The hepatitis B virus is the world's major cause of liver cancer and, while other cancers are declining in rate in the United States, liver cancer is the fastest growing in incidence. If you can stop hepatitis B, you can stop most liver cancer.

The numbers of people who are chronically infected with hepatitis B will knock your socks off. In the world, there are more than 400 million people who are chronically infected, and most of these people were infected at birth from their mothers and they are unaware of their infection.

Without intervention, as many as 100 million to 140 million of these individuals will die from an awful liver disease, most notably liver cancer, but pancreatic cancer has also increased in those with hepatitis B.

In the United States, there are perhaps two million Americans who are chronically infected. Asians and African Americans are disproportionately affected.

Every time I speak to a group this size, it turns out that someone in the room has been affected or knows someone who has but the news, of course, is not all grim, thanks to the work that has been done largely by the CDC and the National Institutes of Health. There is a vaccine to prevent infection.

But for those people who are already infected, the vaccine is too late. They are not helped by that. Of course, there are now medications to control the disease, but for half the people who have hepatitis B, those medications do not work.

One more thing, not everybody who is infected becomes sick. So if you know you have hepatitis B, that is still not enough. You do not know if you are going to get sick or not. The disease takes decades to declare itself. It is like having a time bomb inside you.

This is probably because most cases of cirrhosis and liver cancer, which is caused by hepatitis B, are diagnosed late. The current methods to treat liver cancer are in the dark ages. In fact, there really are not any, and early diagnosis is also primitive.

So we are just getting close to some solutions, but the decline in public health measures and scientific research that is happening today is threatening to allow these problems to come roaring back.

May I give you just a few examples of what I am talking about? There was a recent crisis in a Nevada clinic where as many as 40,000 people were placed at risk for infection with hepatitis B and other blood pathogens. This is a problem the Centers for Disease Control thinks might just be the tip of the iceberg.

The frightening increase in liver cancer is another example of a threat. In the United States, there were 20,000 babies born to mothers with hepatitis B last year alone, and 1,200 of them will develop chronic hepatitis, this while there is an effective vaccine.

So may I now call your attention to requests regarding the two Federal agencies that are most critical in our opinions to control hepatitis B.

We strongly support Senator Reid's request for supplemental funding dedicated to the Centers for Disease Control. We believe that the Division of Viral Hepatitis, DVH as it is called, is at great-

est need for this increase. DVH has had flat funding for the past 5 years, and we request a supplement of $7,000,000.

In 2009, we ask that the CDC budget be restored to $7,400,000,000 with $50,000,000 dedicated to the Division of Viral Hepatitis. If this is too big an ask, we ask that at least $5,000,000 be increased in the DVH budget which is really the minimum.

Finally, the National Institutes of Health, we request a 6.7 percent increase in the fiscal year 2009 budget with $40,000,000 dedicated in addition for hepatitis B research. Right now, there is only $40,000,000 spent on hepatitis B compared to billions for HIV, which is so important, I know, and billions for biodefense. Forty million dollars for hepatitis B in addition will be transformational.

In summary, may I just leave you with the words of Dr. Jay Hoofnagle of the NIH who said, we have this disease cornered. He said, at a recent meeting, we ask you that you not let it get away.

I was just reading, before you guys came in, the quotes behind you by Dwight D. Eisenhower and Hubert Humphrey. I could have read those as my closing statement if I had enough time, but I thank you very much for the opportunity to speak.

Thank you.

[The information follows:]

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CAUSE FOR A CURE
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STATEMENT
OF
TIMOTHY M. BLOCK, PH.D.
PRESIDENT AND CO-FOUNDER

ON BEHALF OF THE
HEPATITIS B FOUNDATION
DOYLESTOWN, PA

PRESENTED
TO
THE UNITED STATES HOUSE OF REPRESENTATIVES
COMMITTEE ON APPROPRIATIONS

SUBCOMMITTEE ON LABOR,
HEALTH AND HUMAN SERVICES,
EDUCATION AND RELATED AGENCIES

WASHINGTON, D.C.

THURSDAY, MARCH 13, 2008
2:00 PM

This testimony is being provided to highlight the urgent need to address the public health challenges of chronic hepatitis B by strengthening programs at the Centers for Disease Control and Prevention, and the National Institutes of Health.

Mr. Chairman and Members of the Subcommittee, thank you for giving the Hepatitis B Foundation

(HBF) the opportunity to testify as the Subcommittee begins to consider funding priorities for Fiscal Year (FY) 2009. We are grateful to the Members for their interest and note how members, such as Congressman Honda, have shown particular concern for hepatitis B.

Today I would like to speak about the urgent need to address the challenge to the public health of hepatitis B. The good news is that there have been great advances and we were getting close to very effective solutions. The worrisome news is that we may be letting down our guard, and the problem is coming back as bad as or worse than ever. I will discuss some of the evidence for this. I will finally speak about ways that we can solve the problem of hepatitis B, which can be accomplished in our lifetime.

My name is Dr. Timothy Block, and I am the volunteer President and Co-founder of the Hepatitis B Foundation (HBF) and its research institute. I am also 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 more than 18 years ago because someone very close to us was affected.

Today, the HBF is still 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; outreach staff manages a comprehensive website which receives almost one million visitors each year and a national patient conference; and public health professionals implement research-based 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 in rate, liver cancer is the fastest growing in incidence in the U.S. The numbers of people chronically infected with HBV will knock your socks off: there are 400 million people worldwide. Without intervention, as many as 100 million will die from an awful 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.

Every time I speak to a group this size, it turns out someone in the room - or "someone you know" - has been affected.

Most people were infected with HBV from their moms at birth. And most people who are infected are unaware of their infection. Even for people infected at birth, illness, when it happens, doesn't occur until the individual is in their prime at age 30-50 years. So, you see how tragic this can be. Having chronic HBV is like having a time bomb inside, because you are usually infected for years before suddenly becoming ill, and you don't know if or when you will become ill.

Additionally, although all ethnic groups are affected - and we started the HBF because of a tragic problem in Bucks County, PA, a very "low risk" place - it disproportionately affects Asians and Africans. That is, nearly 1 in 10 Asian Americans are chronically infected with hepatitis B. That's an incredible number for a community!

But, the news is not all grim. There have been tremendous advances in research and in the control and treatment of hepatitis B over the past 30 years. There is a good vaccine to prevent infection; although, there is now a question as to how long lasting the protection is, if given in infancy. Unfortunately, for the 400 million people already infected worldwide, the vaccine is too late.

For those already infected, there are now several medications that can be taken to control viral replication and prevent disease progression to end-stage liver disease and/or liver cancer; thereby, reducing mortality and the need for liver transplantation. However, most cases of cirrhosis or liver cancer are diagnosed in the late stages, and current methods to treat liver cancer are in the dark ages, literally, and early diagnosis of liver disease is also primitive. HBV screening as part of liver cancer prevention and detection is thought to be one of the best hopes for effective management.

Thus, we were getting close to solutions, but lack of sustained support for public health measures and scientific research is threatening to allow the problems to come roaring back. Clearly, the nation is faced with a major public health challenge that cannot be ignored. If we don't act with urgency, more and more people will suffer. Let me share just a few examples to dramatize the risks to us all.

The recent crisis in a Nevada clinic, where as many as 40,000 people were placed at risk for infection with HBV, HCV and HIV, is a problem that the Centers for Disease Control and Prevention (CDC) thinks might just be the "tip of the iceberg". The Nevada incident highlights critical deficiencies with national surveillance of chronic hepatitis B and C infections that are needed to rapidly identify problems such as the one that occurred in the Nevada clinic.

The frightening increase in the incidence of liver cancer, while most other cancer rates are on the decline, represents another example of shortcomings in our system. In the U.S., 20,000 babies are born to mothers infected with hepatitis B 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.

But, fortunately, there is a good and proven way to avoid these tragedies. The vaccine and medications were the result of successful innovation and public/private partnerships between industry, academia and the government. People concerned about this problem continue to turn to Congress and the CDC and the National Institutes of Health (NIH). The CDC and NIH have formulated plans and have the ability to, if not solve the problem, get it entirely under control.

Mr. Chairman, may I now turn attention to requests regarding two federal agencies that are critical in our effort to help people concerned with hepatitis B: the CDC and the NIH.

THE CENTERS FOR DISEASE CONTROL, DIVISION OF VIRAL HEPATITIS

We believe a strong, well equipped CDC is our best hope to manage the public health problem of hepatitis B. The HBF strongly supports U.S. Senator Reid's interest for urgent, supplemental funding dedicated to the CDC, and we believe that a FY 2008 supplemental of at least $7 million for the Division of Viral Hepatitis (DVH) is needed to address and prevent an incident like what

occurred
at the Nevada clinic.

The DVH has had "flat funding" for the past five years, despite the urgency and growth of this problem. 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. Currently, DVH focuses primarily on acute hepatitis A, B and C. While that's been very successful in decreasing new infections, little has been done about chronic hepatitis B and C, which impacts more than 6 million Americans and if left untreated, often leads to fatal liver failure or liver cancer.

The HBF calls for a "zero tolerance" policy against new HBV infections, particularly among newborns, and against leaving infected pregnant women uneducated and unprotected. All pregnant women who test positive for hepatitis B should be referred to appropriate follow-up care and treatment. With a safe vaccine and six approved therapies for hepatitis B, no woman or child should be left behind. HBF also urges an expansion of cooperative agreements to test and validate evidence-based interventions focused on the mother-child transmission issue, and the prevention and management of HBV in high-risk ethnic communities.

The HBF supports increased resources to build the capacity for the Division of Viral Hepatitis to improve public health interventions by building a robust national active surveillance of chronic HBV and HCV, strengthening state and local viral hepatitis prevention networks, and educating the community and providers to raise awareness about the importance of early detection and intervention of chronic hepatitis. Strengthening chronic hepatitis B education, testing, and referral to care programs will make an enormous difference in decreasing new infections and decreasing the mortality and morbidity associated with chronic viral hepatitis.

Both Drs. Kevin Fenton and John Ward, of the CDC, have shown great leadership and spoken eloquently on the state of hepatitis B in the U.S. Dr. Ward, for example, has observed that "Hepatitis B is the deadliest disease that can be prevented through infant vaccination." Dr. Ward also recognizes the need for recommendations to ensure HBV-infected pregnant women are educated and referred to care, rather than treated merely as vessels of disease. More investment in DVH, however, is required to bolster their programs to address the problems of chronic viral hepatitis.

To meet these needs, we request $50 million in FY 2009 for the DVH. This would allow for a comprehensive, aggressive approach. However, an additional annual increase of at least $5 million, beginning in FY 2009, is considered the minimum increase needed to sustain existing program and allow for minor reinforcements, in particular, to fund an Institute of Medicine Study to characterize and document the true burden of chronic viral hepatitis disease in the U.S., which is urgently needed.

Overall, the HBF joins with the CDC Coalition, a nonpartisan coalition of more than 100 groups, in supporting $7.4 billion for the Centers for Disease Control and Prevention in FY 2009. The CDC programs are crucial to the health of all Americans and key to maintaining a strong public health infrastructure to protect us from threats to our health. At a time when the CDC is faced with

unprecedented challenges and responsibilities ranging from chronic disease prevention, eliminating health disparities, bioterrorism preparedness, to combating the obesity epidemic the Administration has cut the CDC's budget by $412 million. We urge the Committee to restore this cut and fund the CDC at $7.4 billion.

THE NATIONAL INSITUTES OF HEALTH

We depend upon the U.S. NIH to search for new interventions to treat people with hepatitis B and liver cancer.

In FY 2008, NIH is expected to spend approximately $42 million on hepatitis B funding overall. Although it is unseemly to compare one disease with another, since for anyone affected it is the disease that afflicts them that is the most important, it may be useful to know that the NIH currently spends $2.9B on HIV and billions on biodefense. Current estimates predict that HBV research funding will be flat or decline for FY 2009.

Please help correct this situation. There are good plans that show how an additional $40 million per year can make transformational beneficial advances for HBV research. If this is not possible in the current funding climate, we urge that the level of funding for HBV research be increased by at least 6.7% in FY 2009.

Mr. Chairman, I would like to take this opportunity to commend the leadership of NIH, and especially the leadership of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), the National Cancer Institute, and the National Institute of Allergy and Infectious Diseases for their continued interest in liver disease research. They have performed admirably with the limited resources they are provided; however, more is needed.

The NIH published a 10 year Liver Disease Research Action Plan in 2004, and to date, NIDDK has succeeded in several important areas such as funding a network of HBV Clinical Research Centers and hosting the first HBV Consensus Conference focused on identifying best treatment practices for chronic hepatitis B infections. The growing number of treatment options is encouraging and suggests a strong rationale for conducting a consensus conference to provide state-of- the- art treatment guidelines for the practicing physician community.

Mr. Chairman, HBF joins the Ad Hoc Group for Medical Research Funding, a coalition of some 300 patient and voluntary health groups, medical and scientific societies, academic research organizations and industry, in recommending $31.2 billion (6.7% increase) for the National Institutes of Health in FY 2009. The FY 2009 Administration budget request for NIH is flat compared to FY 2008 funding levels, which is due to the effects of biomedical inflation, and translates to a cut. In the five years through 2008, NIH has lost approximately 11% in purchasing power due to inflation. Therefore, if the President's FY 2009 request becomes law, NIH will have lost one-seventh of its purchasing power due to inflation.

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 than proposed by the Administration.

In the words of Dr. Jay Hoofnagle, Director of the Liver Branch at NIDDK, "We have this virus by the legs." We ask that you not let it get away, since the consequences will be grave. This is a public health problem we can fix!

Mr. Chairman, we wish to thank the Subcommittee for its past leadership. I recognize Congressman Honda and others on this Subcommittee as having been sympathetic and helpful to the cause.

Significant progress has been made in developing better treatments and cures for the diseases that affect humankind due to your leadership and the leadership of your colleagues on this Subcommittee. Significant progress has also similarly been made in the fight against hepatitis B.

In conclusion, we specifically request the following funding for a FY 2008 supplemental and for FY 2009 programs:

- Provide at least $7 million in the FY 2008 supplemental to improve and expand the DVH chronic hepatitis surveillance program to help prevent problems such as what recently occurred at the Nevada clinic;
- In FY 2009, restore the CDC budget to $7.4 billion, with a $50 million increase to the Division of Viral Hepatitis (or at least an increase of $5 million) to strengthen the public health response to chronic viral hepatitis; and
- In FY 2009, provide a 6.7% increase for the NIH bringing the total funding level to $31.2 billion, including a $40 million increase per year for hepatitis B research.

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

Thank you.

Mr. OBEY. Thank you very much. I appreciate your time.

THURSDAY, MARCH 13, 2008.

UNITED STATES PSYCHIATRIC REHABILITATION ASSOCIATION

WITNESS

MARCIE GRANAHAM, CHIEF EXECUTIVE OFFICER, UNITED STATES PSYCHIATRIC REHABILITATION ASSOCIATION; ACCOMPANIED BY PETER ASHENDEN

Mr. OBEY. Next, U.S. Psychiatric Rehabilitation Association, Marcie Granaham.

Ms. GRANAHAM. Good afternoon, Mr. Chairman, members of the Committee. I am very pleased to be here today.

My name is Marcie Granaham. I am the Chief Executive Officer for the United States Psychiatric Rehabilitation Association, and I thank you for allowing me to speak today.

USPRA's mission is to improve the quality of psychiatric rehabilitation services, to educate the mental health workforce and to facilitate the community readjustment of people with psychiatric disabilities.

USPRA and its members, the constituencies they serve are very pleased that the President's 2009 budget will continue to fund programs that are critical to the mental health delivery system infrastructure, including those identified by both President Bush's New Freedom Commission on Mental Health and the Institute of Medicine.

However, our membership is extremely concerned with the overall proposed decrease in SAMHSA funding, specifically the proposed cuts to programs of regional and national significance.

USPRA believes that as a Federal Agency, SAMHSA is uniquely positioned to advance the transformation of our Nation's mental health system. SAMHSA and CMHS have been at the forefront of change from the funding that SAMHSA provides for progressive State programs to its investment in identifying evidence-based practices to its anticipation of future mental health workforce needs.

For the past 27 years, recovery from mental illness has been a priority of SAMHSA and the National Institute on Disability and Rehabilitation Research that is within the U.S. Department of Education.

To address this priority, NIDRR and SAMHSA established a decade-long interagency cooperative agreement to co-fund four centers called Rehabilitation Research and Training Centers whose mission is to conduct evaluations of services and systems and provide training and technical assistance to service providers and administrators. Two of those centers are mandated to focus on adult mental health illnesses, and the other two are on children's services.

These centers are internationally known for their substantive work in the area of mental illness and for their contributions to mental health policies, programs and systems. They have provided consultation to the White House, to members of Congress and to the Government Accountability Office.

Although USPRA does not personally receive CMHS funding under the programs of regional and national significance, I can attest to the value and the benefits that these programs provide. The Rehabilitation Research and Training Centers, also known as RRTCs, have been instrumental in conducting rigorous evaluations and studies designed to expand evidence-based practices as well as to identify newly emerging best practices.

The RRTCs are charged with conducting the necessary scientific inquiry to ensure that the government spends taxpayer dollars on services that are both effective and cost-efficient. Without SAMHSA's cofunding with NIDRR, these programs will end.

Another important group of programs that are funded with SAMHSA under the programs of national significance are the consumer and consumer-supported technical assistance centers. These are charged with advancing the recommendations of the New Freedom Commission and the IOM for self-directed care, recovery and consumer and family-centered services.

There are a total of five technical assistance centers that bring recovery-oriented illness self-management tools, such as the Wellness Recovery Action Planning or WRAP, into the mainstream.

This is critically important because the survey of State mental health authorities conducted by the National Association of State Mental Health Program Directors found that in fiscal year 2002 to 2003 the States spent less than 1 percent of their public mental health budgets on self-directed consumer-centered recovery-oriented services. In fact, a quarter of all States spend less than $200,000 a year on such services.

At this time, I would like to introduce to the Committee, Mr. Peter Ashenden, who is the Executive Vice President of the Depression and Bipolar Support Alliance and an officer of USPRA. Mr. Ashenden also happens to be a person in mental health recovery.

Mr. ASHENDEN. Good afternoon. Thank you very much for allowing me this opportunity to tell you my personal story.

I was diagnosed with mental health issues almost 25 years ago. I know what it is like to isolate. I know what it is like to be paralyzed with major depression and clinical depression. I know what it is like to have no hope, no connections and no future.

I have been there. I have done that.

Many traditional treatments did not work for me. However, as a result of the development of psychiatric rehabilitation, I can sit before you today.

I am the Executive Vice President of Depression and Bipolar Support Alliance, a national organization that has over 1,000 support groups, 450 chapters throughout the Country that are helping millions of people each and every year.

Today, I am no longer a drain on the taxpayers. Today, I am a taxpaying citizen which has been a real turnaround in my life.

You have the power to change the problem that we have identified. You have the power to save lives. You have the power to help individuals from being a drain on taxpayers, to being productive and taxpaying citizens.

These programs of regional and national significance assist us to lead productive, integrated lives in the communities of our choice

instead of living in institutions, jails or being a plight on communities through homelessness.

By assuring that these programs are not cut, you can help my peers to have their voice heard, to have safe and affordable housing, to have gainful and meaningful employment, to have social support and connections that so many of us want, and maybe even a date on a Saturday night as well as being a participant in our communities as fully taxpaying individuals.

My written testimony covers the importance of the research and the importance of funding these programs.

I ask you, please. I have a fear.

Excuse me, I have a far more important statement to make here. That is to please help save lives. Please allow my peers to experience the hope and connections that I have as a result of hard work and the right supports.

Please do not allow these cuts to occur. It will result in homelessness, institutionalization and death.

Thank you very much for allowing me to share my personal story with you.

[The information follows:]

USPRA US Psychiatric Rehabilitation Association

STATEMENT OF
MARCIE GRANAHAN, C.A.E.
CHIEF EXECUTIVE OFFICER
UNITED STATES REHABILITATION ASSOCIATION
AND
PETER ASHENDEN
ELECTED OFFICER OF THE USPRA BOARD OF DIRECTORS
BEFORE THE
COMMITTEE ON LABOR, HEALTH and HUMAN SERVICES,
EDUCATION and RELATED AGENCIES
UNITED STATES HOUSE OF REPRESENTATIVES
MARCH 13, 2008

Good afternoon, Mr. Chairman, Members of the committee, I am Marcie Granahan, the Chief Executive Officer for the United States Psychiatric Rehabilitation Association, better known as U.S.P.R.A., and I would like to sincerely thank you for allowing me to speak to the concerns that USPRA currently has with the proposed funding allocations in the President's 2009 budget pertaining to the Center for Mental Health Services (CMHS) of the federal Substance Abuse and Mental Health Services Administration (SAMHSA).

USPRA was founded to advance the role, scope, and quality of services designed to facilitate the community readjustment of people with psychiatric disabilities. USPRA's mission is to improve the quality of psychiatric rehabilitation services and programs, to educate the mental health workforce of service providers, and to strengthen the role of community-oriented psychosocial rehabilitation within mental health service delivery systems. USPRA brings together agencies, practitioners, families, and people with psychiatric disabilities.[1]

In short, USPRA and its members are on the frontlines of efforts to help people make full recoveries from psychiatric disabilities and, in doing so, to become fully-integrated and economically productive members of society. Providing USPRA representatives with time to speak before the committee will permit the Committee to hear directly from the people involved in delivering services and the people using those services.

[1] Gill, Kenneth J., Experience Is Not Always the Best Teacher: Lessons from the Certified Psychiatric Rehabilitation Practitioner Certification Program. American *Journal of Psychiatric Rehabilitation*, 8: 151–164

USPRA, its members, and the constituency that they serve are pleased that the President's 2009 Budget will continue to fund programs that are critical to the mental health delivery system infrastructure, including those identified by both President Bush's New Freedom Mental Health Commission and the Institute of Medicine (IOM). However our membership is extremely concerned with the overall proposed decrease in SAMHSA funding and specifically in regards to the cuts to the Programs of Regional and National Significance. These programs – including Rehabilitation Research and Training Centers and Consumer Technical Assistance Centers - support the states in carrying out activities that improve services for adults with psychiatric disabilities. This is especially the case for states that do not received federal dollars for transforming their systems from maintenance to a recovery orientation.

USPRA believes that, as a government agency, SAMHSA is uniquely positioned to advance the transformation of our nation's mental health system. SAMHSA and CMHS have been at the forefront of change, from the funding that SAMHSA provides for progressive state programs to its investment in identifying evidenced-based practices and its anticipation of future mental health workforce needs.

For the past 27 years, the recovery of adults and children with mental illness has been a priority for SAMHSA and the National Institute on Disability and Rehabilitation Research (NIDRR) within the U.S. Department of Education. To address this priority, NIDRR and SAMHSA established a decades-long, inter-agency cooperative agreement to co-fund four centers – called Rehabilitation Research and Training centers -- whose mission is to conduct evaluations of services and systems, and provide training and technical assistance to service providers and administrators.

Two of those centers are mandated to focus on adult mental illness and the other two were to focus on children's mental health. These Centers are internationally known for their substantive work in the area of mental illness and for contributions to mental health policies, programs and systems, as well as the development of innovative services for children and adults

with mental illness. These Centers are called upon to provide consultation by the White House, Congress and its investigational arm -- the Government Accountability Office, by federal agencies, and state authorities. These Center's research and training have helped to transform the world of mental health services for some of our most vulnerable children and adults by working closely with people with mental illnesses and or emotional disturbances, their families, and other advocates. This is also evidenced by the fact that faculty from the RRTCs were chosen as expert consultants to work with members of the New Freedom Commission on Mental Health and produced the reports on whicb much of the Commission's report is based.[2]

Although USPRA does not receive CMHS funding under these programs, it can attest to the benefits these programs provide. The Rehabilitation Research and Training Centers (RRTCs) have been instrumental in conducting rigorous evaluation studies designed to expand evidence-based practices, as well as to identify newly emerging best practices. The RRTCs are charged with conducting the necessary scientific inquiry to ensure that the government spends taxpayer's dollars on services that are both effective and cost efficient. This is not the kind of research funded by NIH with its emphasis on theoretically driven, academic studies. Instead, these Centers focus on translating research knowledge into clinical practice within psychiatric rehabilitation programs and the larger mental health system. This is exactly the strategy recommended by the New Freedom Commission on Mental Health and the Institute of Medicine for rebuilding our nation's public mental health system. Such a strategy would be severely compromised without the work of the RRTCs.

Another important group of programs known as Consumer and Consumer-Supported Technical Assistance Centers are charged with educating stakeholders at all levels regarding the recommendations of the New Freedom Commission and the IOM about approaches referred to as self-directed care, recovery, and consumer- and family-centered services. These five TA Centers bring recovery-oriented, illness self-management tools, such as Wellness Recovery

[2] Cook, J.A. Employment barriers for persons with psychiatric disabilities: a report for the President's New Freedom Commission, Psychiatric Services 57(10):1391-1405.

Action Planning or WRAP into the mainstream. This is critically important, because a survey of state mental health authorities conducted by the National Association of State Mental Health Program Directors found that, in FY 2002-2003, states spent less than one percent of their public mental health budgets on self-directed, consumer-centered, recovery-oriented services. In fact, a quarter of all states spent less than $200,000 a year on such services.[3]

Many of these technical assistance centers serve as conduits to ensuring a trained and educated mental health workforce. The Depression Bipolar Support Alliance, headquartered in Chicago, IL, is one of the five organizations that receive funding as a Consumer Technical Assistance Center, providing assistance and support for peer run programs throughout the United States. Elimination of programs such as these would be a terrible loss for the entire mental health community because there would no longer be an emphasis on self-help, self-management and peer-support that is so necessary to recovery.

At this time I would like to introduce to the committee Mr. Peter Ashenden, who is Executive Vice President of the Depression Bipolar Support Alliance located in Chicago, IL and a Member and Officer of USPRA's Board of Directors. Mr. Ashenden also happens to be a person in mental health recovery.

[3] State Mental Health Agency Profiling System, 2004. Alexandria, VA, National Association of State Mental Health Program Directors Research Institute, 2004. Available at www.nri-inc.org/profiles.

USPRA US Psychiatric Rehabilitation Association

{PETER ASHENDEN}

Mr. Chairman and Members of the Committee, I would like to thank you for taking the time today to listen to my story.

It is a great personal concern that those who are in need of psychiatric rehabilitation services will be unable to find the assistance that they require and will never find the path back to full citizenship. Without programs such as, supported employment, assertive community treatment and peer-to-peer support, are proven models for helping those with severe psychiatric disabilities re-enter the labor force, we are afraid that stories of the past will become the stories of the future.

As an individual who has been diagnosed with a mental health issue for the last twenty-five years, I am keenly aware of what it is like to be a drain on my fellow taxpayers being one today myself. If it had not been for the Psychiatric Rehabilitation Model, I am certain that I would not be sitting here before you today.

Prior to introduction to the psych rehab model, I had been through various treatment models that proved to be ineffective for me. During those times, I was isolating, unable to connect to my community and was paralyzed with fear and anxiety. By experiencing the benefits of a psychiatric rehabilitation model, I have moved from my isolation to become a person who now offers peer-support, advocacy, teaching skill building activities and other learning techniques to help my fellow brothers and sisters lead an engaged tax-paying community involved lifestyle.

The cuts that are planned for 2009 will seriously impact these vital services which are designed to aid us in bringing forth our voice in what goals we want to obtain and to go from being an institutionalized person to productive taxpaying members of our communities. The RRTCs that have already been cut, as my predecessor mentioned, is one of the only vehicles that examine, support and help to develop and substantiate the outcomes that we know work because

they are based on our strengths instead of medication compliance. I ask you not drive me back to a lifestyle of being unworthy, uncared for and a drain on the limited resources available to the system. Help me to maintain my active and engaged life.

Please do not cut funding and by doing so you will assist me in not having to return to lying in bed afraid of the world but instead allow me to continue to serve as the Executive Director of a national organization that is helping to create thousands other of taxpayers. I, as many others have done and can do, went from being a drain on the system to someone who contributes to it.

Together we can either build the US Treasury with more tax dollars from hard-working engaged individuals who have recovered from a mental illness or break the bank by tossing hundreds, if not thousands, back into emergency rooms, the penal system and homelessness.

Psychiatric rehabilitation programs are seriously underfunded and are lacking the resources that are required to help individuals' lead secured, successful and satisfying lives. Take, for example, supported employment programs, an evidence-based practice proven to help people with mental illness return to work. A survey conducted by the National Association of State Mental Health Program Directors (NASMHPD) Research Institute in 2004 found that only 36 of 50 state authorities used any state general revenue or federal Mental Health Block Grant monies to fund supported employment services. Not only that, but research tells us that pitifully few people with psychiatric disabilities have access to employment services. For example, a well-regarded study of individuals with psychiatric disabilities in two states found that only 23% of outpatients were receiving any vocational rehabilitation services.[4]

In a study of 2,749 adults with disabling mental disorders who received services in Vermont, only twenty-four percent received any employment services and more than half

[4] Lehman AF, Steinwachs DM, Dixon LB, et al: Translating research into practice: the Schizophrenia Patient Outcomes Research Team (PORT) treatment recommendations. Schizophrenia Bulletin 24:1–10, 1998

received fewer than six service contacts.[5] State mental health authorities have not traditionally viewed vocational rehabilitation as part of their mandate for this population. In a survey conducted by the National Alliance on Mental Illness in the late 1990s, only sixteen state mental health authorities required that treatment plans include vocational rehabilitation goals.[6] States have been notoriously slow to change, due to pressures such as fiscal crises and shifting political agendas.

As a result, we need Rehabilitation Research and Training Centers and Consumer Technical Assistance Centers to provide the impetus for change, and to be there with the research evidence and the educated constituencies necessary to transform our nation's mental health system.

[5] Pandiani JA, Banks SM, Simon MM: Employment services and employment outcomes for adults with serious mental illness. Research in Community and Mental Health 13:83–105, 2004

[6] Noble JH: Policy reform dilemmas in promoting employment of persons with severe mental illness. Psychiatric Services 49:778–781, 1998

Mr. OBEY. Well, thank you both for your testimony and thank you, specifically, for sharing your story with us.

Let me again point out the context in which you are testifying. The White House's fiscal year 2008 budget requested $807,000,000 for the Center for Mental Health Services at the Substance Abuse and Mental Health Services Administration. This was a cut of $77,000,000 or 9 percent below the level that we provided in the fiscal year 2007 joint resolution.

This Committee increased the appropriation for the center to $911,000,000, an increase of $104,000,000 or 13 percent above the President's level.

But, again, the President this year is proposing to decrease the funding to $784,000,000, a cut of $127,000,000 or 14 percent below the 2008 level.

That is the context in which you are testifying, and I appreciate your coming.

Mr. ASHENDEN. Thank you very much for allowing us.

Mr. OBEY. You bet.

I understand Dr. Weldon would like to introduce the next witness.

THURSDAY, MARCH 13, 2008.

NORTHWESTERN UNIVERSITY'S FEINBERG SCHOOL OF MEDICINE

WITNESS

DR. RICHARD BURT, CHIEF, DIVISION OF IMMUNOTHERAPY, NORTHWESTERN UNIVERSITY, CHICAGO, ILLINOIS; ACCOMPANIED BY BARRY GOUDY

Mr. WELDON. Yes. Thank you, Mr. Chairman.

It is a pleasure for me to introduce Dr. Richard Burt at Northwestern University. He brought along a patient.

I am very pleased that you have allowed the time for this.

Dr. Burt is doing some very fascinating work on treating essentially incurable patients, people who have failed standard therapy, using a variety of different adult stem cell transplant methods. Indeed, he is actually, in some instances, the person the NIH turns to when they have a case they cannot fix. So it is a real honor to have Dr. Burt here, and he brought along a fascinating patient.

Thank you for allowing the time for them to be here on the program, Mr. Chairman. I appreciate what you do.

Dr. BURT. Chairman Obey and honored members of the Committee, Congressmen and Dr. Weldon, thank you. It is my honor and my pleasure to be here.

I am the Chief of the Division of Immunotherapy at Northwestern University in the great City of Chicago.

What I am known for in my field is translational research in stem cells. So I go from the laboratory with stem cells to preclinical animal models that often take many years of work and from that experience to the bedside, designing protocols, not pharmaceutical protocols but our own through the IRB, through data safety monitoring boards, through the FDA and then initiate those treatments on patients.

What I am in my heart, though, is a patient advocate. I spend a great deal of my time fighting with insurance companies and looking for money to do the work that we need to do, to do what I love to do, and I am here to tell you about something that is succeeding.

At Northwestern University, we have treated over 200 patients now with autoimmune diseases with the blood stem cell. That is a type of adult stem cell that has been used for years to treat leukemias. It turns out it is also the immune stem cell.

So the concept I had 20 years ago was very simple, a basic concept. It is that we could reboot your immune system just like you reboot a computer. We could remove this police force that was supposed to protect you from pathogens and has turned around and attacked your own body and regenerate a new one from the immune compartment.

As it turns out, in the animal models and in human beings, by whatever design that is still being worked out, when it regenerates, the default is tolerance to self. We reestablish tolerance.

As I mentioned, we have been doing this in over, now, 200 patients. We currently have five patients going through transplant for autoimmune diseases in-house today.

We have treated patients and are treating patients with multiple sclerosis, systemic sclerosis, systemic lupus erythematosus, rheumatoid arthritis, Crohns disease, myasthenia gravis, chronic inflammatory demyelinating polyneuropathy, autoimmune-related retinitis and optic neuritis which causes blindness, polymyositis, different vasculitis, nerve vascular Behcet's, nerve vascular Churg-Strauss, Wegener's, primary biliary cirrhosis, we recently did a child with regressive autism, Devics and type 1 diabetes.

We have been using, for the most part, autologous and now we are moving into cord blood and sibling.

Before you, you should have some pictures of some patients just as evidence, pre-transplant and one year post-transplant of a patient with lupus.

Here is an example of another patient pre- and one year post-transplant. These patients had failed pretty much all therapy.

This is a patient suffering with severe ischemic ulcers throughout her body and internal organs. It was occurring in her heart as well, that would get infected, severely painful, on narcotic drips. Post-transplant, she has been in remission five years now.

Here is a patient with systemic sclerosis, whose lungs were very inflamed. It was destroying her lungs. You see on the next scan, post-transplant, to your right, that brown glass haze in the periphery of the lungs is gone. That destruction of the lungs is stopped and, in some cases, improved if we get it early enough.

I have put here a figure that we have just submitted to a journal of a patient who was going blind, referred to us from the University of California at Davis and Stanford. They had three different immune suppressive regimens. Her visual acuity was worsening. Got a transplant and since the transplant, off all therapy. Her vision is markedly improved.

I wanted a patient of mine who has MS, who you cannot put in a picture here, to briefly give you a description of his own experience from this.

Mr. GOUDY. Hi. My name is Barry Goudy. Mr. Obey, thank you for the invitation.

In 1995, I was diagnosed with multiple sclerosis. Though I received IV drips once a month and I also received weekly shots that I injected in myself, periodically I would fall out of remission and have exacerbations, go back into the hospital, and it would take more and more medicine to revive me and put me back out.

Since I met Dr. Burt, I went through a stem cell transplant in Chicago at Northwestern, and I have been MS-free now for five years.

I go back every year to Chicago for the protocol, and July 1st of this year will be the fifth year, and I live a normal, active, happy life. Stem cell research is very, very important.

Thank you.

[The information follows:]

Dr. Richard Burt

Chief of the Division of Immunotherapy for Autoimmune Diseases at Northwestern Memorial Hospital and Associate Professor of Medicine at Northwestern University's Feinberg School of Medicine.

Chicago, Illinois

Northwestern University's Feinberg School of Medicine

Labor, Health and Human Service, Education, and Related Agencies

Thursday March 13, 2008

2:00 p.m.

Division of Immunotherapy, Northwestern University

Mr. Chairman and Members of the Committee.

I am pleased to have the opportunity to share with you information about a rapidly developing field of stem cell therapy that we are using at Northwestern University to treat patients with autoimmune disease.

Stem cell research has generated excitement, promise, confusion and at times contradictory results in both the lay and scientific literature. Many types of stem cells show great promise but their current clinical application has lagged due to ethical concerns or difficulties in harvesting or safely and efficiently expanding quantities sufficient for clinical application. In contrast, the clinical indications for blood (peripheral blood or umbilical cord blood) and bone marrow stem cells, which can be easily and safely harvested, are rapidly increasing.

At Northwestern we have treated over 200 patients for autoimmune diseases with subsequent remission and improvement in the patients' disease. In autoimmune diseases the body's immune system attacks the body. We have effectively treated autoimmune disease by in essence "rebooting" the immune system, much like you do when your computer crashes.

Specifically, we have used blood stem cells to regenerate a new immune system—which no longer attacks itself-- in patients with multiple sclerosis, systemic sclerosis, systemic lupus erythematosus, rheumatoid arthritis, Crohns disease, myasthenia gravis, chronic inflammatory demyelinatig polyneuropathy, autoimmune related retinitis and optic neuritis, polymyositis, vasculitis, and recently primary biliary cirrhosis, regressive autism, Devics, and Type I diabetes. Based on pre-clinical animal models, we have also treated patients with peripheral vascular diseases whose only standard therapeutic option would have been amputation. Having pioneered and spoken on the use of stem cells for non-malignant diseases, we recently reviewed the world literature and published the results on use of marrow-derived and blood-derived stem cells in non-malignant diseases (that is, diseases other than malignant cancers) (Burt et al in JAMA Feb 27th, 2008).

Of 926 reports identified, 643 were reviews, editorials, commentaries, or ethical discussions. Another 323 were examined for feasibility and toxicity. This included reports with small numbers of patients, interim or sub-study reports, reports on multiple diseases, treatment of relapse, toxicity, mechanism of action, or stem cell collection. Outcome was reviewed in 69

reports. For autoimmune diseases, 26 reports representing 853 patients reported treatment related mortality (TRM) of < 1% (2/220 patients) for non-myeloablative regimens (that is regimens not used to treat cancer), < 2% (3/197) for dose-reduced myeloablative regimens, and 13% (13/100) for intense myeloablative regimens, i.e. regimens containing total body irradiation that would normally be used for cancer. These results indicate that stem cell treatments using a non-myeloablative approach, which has been the thrust and emphasis of our program at Northwestern University, can be performed safely for autoimmune diseases that are life- and / or organ-threatening with significant improvement in organ and patient function and disease amelioration.

For cardiovascular diseases, we found 17 reports on using blood or marrow-derived stem cells in acute myocardial infarction involving 1002 patients, 16 reports on chronic coronary artery disease involving 493 patients, 6 reports involving 169 patients with peripheral vascular disease, and 3 meta-analyses. The results indicate that stem cell transplantation may be performed safely in patients with coronary artery disease or peripheral vascular disease with modest improvement in cardiac function.

Our own experience and worldwide data indicate that stem cells harvested from blood or marrow can be, under appropriate conditions, used safely with disease-ameliorating effects in autoimmune and cardiovascular disorders. Like resetting a computer, blood or marrow stem cells regenerate a new immune system in autoimmune diseases, while in cardiac and vascular diseases these stem cells provide a local chaperone effect to support growth of new blood vessels, improving blood flow and organ function.

Mr. Chairman and members of the Committee, as you consider investments in medical research I would encourage you to ensure a robust focus on clinical research where we are working to find innovative and cutting edge approaches to effectively treating seriously debilitating and life-threatening diseases. Clinical research offers near term treatments for patients who are suffering today.

I have here with me a patient that we effectively treated and would ask him to take one minute to share what this treatment has meant to him.

Mr. OBEY. Thank you. Well, thank you both for testifying. I appreciate your dropping by yesterday, and I appreciate Dr. Weldon bringing you to the attention of the Committee. I am happy to hear what you are doing.

I am certainly happy to know what has happened to you.

Mr. GOUDY. Thank you.

Mr. OBEY. Any other comments?

Mr. WELDON. I just had a quick question. You said you did one autistic case?

Dr. BURT. Yes.

Mr. WELDON. What was the result from that?

Dr. BURT. I do not want this to become confused. The details are very important. This may not apply to the vast majority of autistic children.

But what we selected were kids with regressive autism who developed normally, normal milestones and then had a setback and developed severe autism on their CARS score and had abnormal immune parameters and specific cyalate in the blood and autoantibodies to Purkinge fibers.

We treated one such patient who, at this point, we have not yet published on but is behaving normally with no clinical manifestations of autism at this time.

This is unpublished data and probably not the best format for me to release it. I do not want the press to get on it. [Laughter.]

Mr. WELDON. Yes. Before you head back, if you could stop by my office, I may want to talk to you a little bit more about it. I meant to ask you about that earlier. Thanks.

Dr. BURT. Thank you, Dr. Weldon.

Mr. OBEY. Thank you both very much.

Dr. BURT. Thank you, Mr. Obey.

Mr. OBEY. You bet.

THURSDAY, MARCH 13, 2008.

AMERICAN ASSOCIATION FOR DENTAL RESEARCH

WITNESS

DR. MARC HEFT, PROFESSOR OF ORAL AND MAXILLOFACIAL SURGERY AND DIAGNOSTIC SCIENCES, UNIVERSITY OF FLORIDA

Mr. OBEY. I understand Mr. Simpson would like to introduce the next witness.

Mr. SIMPSON. Yes, I would like to welcome Dr. Heft to the Committee from the NIDCR and representing the dental profession and the work that the NIDCR does out of NIH.

Welcome to the Committee.

Mr. OBEY. I do not know that Mr. Simpson knows much about dentistry.

Mr. SIMPSON. Well, this morning in the Energy Subcommittee, we had Dr. Orbach there who is a physicist. Since you cannot ask them intelligent questions because they know so much, I had to ask him if he understood why it was important to brush your teeth before you eat rather than after you eat, and he did not get the point. [Laughter.]

Mr. OBEY. Please proceed.

Dr. HEFT. Mr. Chairman and members of the Committee, I am Mark Heft, Professor of Oral and Maxillofacial Surgery and Diagnostic Sciences at the University of Florida. My testimony is on behalf of the American Association of Dental Research.

I thank the Committee for the opportunity to testify about the exciting advances in oral health science.

Americans are living better and healthier lives into old age due to recent advances in healthcare including dental health and oral healthcare research. The National Institutes of Dental and Craniofacial Research has made this possible through research, research training and the dissemination of health information.

Concerned that scientific opportunities were outpacing funding at the NIH, the U.S. Congress doubled the NIH budget from 1998 through 2003 which led to a remarkable period of discoveries.

However, flat funding over the past six years for the NIH has left researchers and their institutions vulnerable to the rising costs of biomedical research. We are also in jeopardy of losing the pipeline of the next generation of scientists.

My testimony today will focus on our recent accomplishments in three areas and what still needs to be addressed in those areas.

The first area is salivary diagnostics. For many oral and systemic diseases, early detection before clinical symptoms appear offer the best hope for successful treatment. Fortunately, research funded by the NIDCR is developing highly sensitive and accurate methods to detect oral and systemic conditions at their earliest stage, using saliva as a noninvasive diagnostic fluid.

Saliva is easy and painless to collect, providing a major advantage over the use of blood or urine for diagnostics tests. The same biomarkers found in blood are also found in saliva.

We are close to marketability for a diagnostic test for oral cancer. Other diagnostics tests are in the pipeline.

The second area is tooth decay. Tooth decay continues to be a major health concern to millions of Americans. It is one of the main causes of poor oral health and pain throughout life and a major contributor to oral health disparities in this Country.

Early childhood carries is a painful, costly and severe form of tooth decay and is particularly common among Alaska Native and American Indian children. We are calling for $1,000,000 per year for 3 years to NIDCR's budget for research and clinical studies to address early childhood carries in cooperation with the Indian Health Service.

The third area is oral and systemic diseases. Oral health plays a substantial role in general health and well being. For example, oral disease and conditions can greatly affect systemic conditions such as diabetes, may be linked to cardiovascular diseases and play a role in initiating early delivery in pregnancy.

Oral bacteria associated with periodontal disease cause inflammation in the mouth. Scientists have uncovered a relationship between this inflammation and a higher risk of developing cardiovascular disease. Further, periodontal disease may also affect insulin resistance, glycemic control and the risk of developing other diabetic complications. Finally, preexisting gum disease in pregnancy is a risk factor for preterm or low birth weight babies.

NIDCR-funded research is evaluating these relationships.

As you can see, Mr. Chairman, there are many research opportunities with an immediate impact on patient care that need to be pursued. Additional funds can help greatly in bringing these opportunities to fruition. Imagine a world where disease can be detected at its earliest possible moment with a quick, painless and non-invasive salivary-based test.

Mr. Chair, a great amount of exciting research is underway, and the potential to improve oral health specifically and overall health in general is significant. Therefore, we are requesting a funding level of $438,000,000 for the NIDCR for fiscal year 2009.

Thank you for the opportunity to testify today.

Mr. OBEY. Thank you. I appreciate your time.

[The information follows:]

Statement of the American Association for Dental Research
before the
House Subcommittee on Labor, Health and Human Services and Education

Presented by
Marc Heft, D.M.D., Ph.D., Professor
Department of Oral & Maxillofacial Surgery
Diagnostic Sciences and
Director, Claude D. Pepper Center for Research
on Oral Health in Aging at the
University of Florida, Gainesville

Thursday, March 13, 2008

Summary

Dental research is concerned with increasing knowledge for the prevention, diagnosis, and treatment of diseases and disorders that affect the teeth, mouth, and jaws, and other systemic conditions. Dental health plays an important role in maintaining overall health throughout life. My testimony will cover what has been accomplished and what needs to be done in the following areas:

- Salivary diagnostics,
- Tooth decay, and
- Oral and systemic health.

Introduction

Mr. Chairman and members of the Committee, I am Dr. Marc Heft, D.M.D., Ph.D., Professor and Director of the Department of Oral & Maxillofacial Surgery and Diagnostic Sciences at the University of Florida. My testimony is on behalf of the American Association for Dental Research (AADR), a non-profit organization with over 4,000 individual members and 100 institutional members within the U.S. The AADR's mission is to advance research and increase knowledge for the improvement of oral health for all Americans.

I thank the committee for this opportunity to testify about the exciting advances in oral health science. Americans are living better and healthier lives into old age due to recent advances in health care, including dental care and oral health research. The National Institute of Dental and Craniofacial Research (NIDCR), the third Institute formed in 1948 by the National Institutes of Health and celebrating its 60th Anniversary this year, has made this possible through research, research training, and the dissemination of health information. Concerned that scientific opportunities were outpacing funding at the National Institutes of Health, the U.S. Congress decided to double the NIH budget from 1998 through 2003. This led to a dramatic acceleration of discovery and a remarkable period of discoveries, some of which I will highlight in my presentation.

However, flat funding over the last six years for the NIH has left researchers and their institutions vulnerable to the rising costs of biomedical research. The NIH has in fact *lost* over 10% of its purchasing power since 2003, and therefore, the opportunity to build on work accomplished during the doubling period is in serious jeopardy.

My testimony today will focus on our accomplishments in three areas and what still needs to be addressed in those areas:

- Salivary diagnostics,
- Tooth decay, and
- Oral and systemic health.

Salivary Diagnostics

For many oral and systemic diseases, early detection offers the best hope for successful treatment. Too often, a correct diagnosis may not be reached until clinical symptoms appear, and precious time for early intervention has been lost. Fortunately, research funded by the NIDCR is developing highly sensitive and accurate methods to detect oral and systemic conditions at their earliest stage, using saliva as a non-invasive diagnostic fluid. Saliva not only protects the oral cavity, but also combats the bacteria and viruses that enter the mouth and defends against oral and systemic diseases. Through the efforts of our researchers, we have learned that saliva also contains many compounds that indicate a person's overall health and disease status. Saliva is easy and painless to

collect, providing a major advantage over the use of blood or urine for diagnostic tests. The same biomarkers found in blood are also present in saliva.

Oral cancer affects nearly 30,000 Americans each year. Delayed diagnosis increases the death rate associated with this cancer. Early detection of oral cancer offers the best chance for successful treatment, helps cancer patients have a better quality of life, and can dramatically reduce health care costs. Early diagnosis and treatment is also the key to the avoidance of the disfiguring surgery that may occur when the malignancy is advanced and spread. NIDCR-funded research has produced a saliva test that can detect oral cancer, but further clinical studies are needed to produce and validate a diagnostic test with the accuracy required by the Food and Drug Administration.

Research is also being conducted to identify molecular determinants in saliva that may be used to diagnose other types of cancer, cardiovascular diseases, and various systemic conditions. It is our hope that such tests will soon be available to our patients for quick, accurate, and painless diagnoses. Dentists and physicians will be able to use portable devices that can diagnose diseases on site with just a sample of the patient's saliva. The test results would be available almost immediately, thus eliminating the need for sending blood or urine samples to an off-site lab and waiting days for results. Many research opportunities exist that may lead to the understanding of detectable changes in saliva that involve such areas as genetics, nutritional status, and age-specific changes.

The potential impact of this field of research is enormous.

Tooth Decay

Despite remarkable improvements since the 1950s, tooth decay continues to be a major health and quality-of-life concern to millions of Americans. It is one of the main causes of poor oral health and pain throughout life, and a major contributor to oral health disparities in this country. We have learned through dental research that tooth decay is caused by certain oral bacteria that release mineral-eroding acid, which, over sustained periods of time, destroys the enamel, leaving a 'cavity'. However, over the last 50 years, there have been outstanding discoveries and innovations aimed at treating and preventing tooth decay. In one recent innovation, a team of researchers supported by the National Institute of Dental and Craniofacial Research created a new 'smart' anti-microbial treatment that can be chemically programmed in the laboratory to seek out and kill a specific cavity-causing species of bacteria. This experimental treatment is known as a STAMP (Specifically Targeted Antimicrobial Peptides). Using this approach, scientists have found that they can eliminate the cavity-associated oral bacterium *Streptococcus mutans* within 30 seconds from an "oral biofilm", or dental plaque, with no collateral damage to related (but non-pathogenic) species attached nearby.

Still more is on the horizon. Scientists are now demonstrating ways to remineralize teeth, showing that the process of tooth decay *can* be reversed. Fiber optics and fluorescence methodologies are also being considered to detect the signs of tooth decay much earlier than x-rays and visual inspections, allowing for more effective and conservative treatment. With the necessary funding, scientists also have the potential to develop other

powerful diagnostic tools, such as an electronic probe designed to detect the early stages of tooth decay, when the disease process can be stopped or reversed.

Early childhood caries is a painful, costly, and severe form of tooth decay – an unfortunate reality for too many pre-school children in this country. Unfortunately, early childhood caries is particularly common among Alaska Native/American Indian children – with rates up to three times higher than those seen among other 2- to 5-year-olds. Addressing early childhood caries in the context of other barriers faced by Native American communities is very challenging; thus, we are calling for $1 million a year for 3 years of NIDCR's budget for research and clinical studies to address early childhood caries, in cooperation with the Indian Health Service.

Oral and Systemic Health

Oral health plays a substantial role in general health and well-being. Dental research has given way to discoveries showing the relationship of oral health to many medical conditions. For example, underlying oral diseases and conditions can greatly affect systemic conditions such as diabetes, may be linked to cardiovascular disease, and play a role in initiating early delivery in pregnancy.

Women who have had periodontal or gum disease during their pregnancy have a higher rate of delivering preterm or low-birth weight (PLBW) babies. However, scientists have shown that pregnant women who have received non-surgical treatment for their periodontal disease during their pregnancy did not significantly lower their risk of delivering PLBW babies. This suggests that the pre-existing gum disease at the onset of pregnancy may play a critical role in pregnancy outcomes. An NIH-funded study is under way to see if mothers with periodontal disease who receive periodontal treatment during the second trimester of pregnancy will experience a lower rate of preterm delivery and a higher mean birth weight of the premature infants.

Oral bacteria associated with periodontal disease cause inflammation in the mouth. Scientists have uncovered a relationship between inflammation within the mouth and a higher risk of developing cardiovascular disease. Scientists believe that inflammation caused by the body's own reaction to bacteria infects the blood stream, eventually causing arteries around the heart to thicken. The NIH is funding a project that will evaluate the relationship between periodontal disease and the incidence of peripheral arterial disease and ischemic stroke.

Inflammation is also a common link between periodontal disease and diabetes. Further research is under way to clarify how inflammatory periodontal diseases may affect insulin resistance, glycemic control, and the risk of developing other diabetic complications.

We are only beginning to understand the associations between oral and systemic diseases, but the implications for the health of the American people cannot be underestimated.

Conclusion

As you can see, Mr. Chairman, there are many research opportunities with an immediate impact on patient care that need to be pursued. Additional funds can help greatly in bringing these opportunities to fruition. Imagine a world where disease can be detected at its earliest possible moment with quick, painless, and non-invasive saliva-based tests. Imagine getting results from a test for oral cancer or systemic diseases without a two- or three-day wait. Or going to the dentist for a mineral-restoring rinse, instead of getting a filling. We would not only improve Americans' quality of life, but also save lives and better utilize the valuable resources that are currently burdening our health care system.

Mr. Chairman, a great amount of exciting research is under way, and the potential to improve oral health specifically and overall health in general, is significant. Therefore, we are requesting a funding level of $438 million for the NIDCR in Fiscal Year 2009.

Thank you for the opportunity to testify. I would be pleased to respond to any questions you may have.

THURSDAY, MARCH 13, 2008.

SCLERODERMA FOUNDATION

WITNESS

CYNTHIA CERVANTES

Mr. OBEY. Next, the Scleroderma Foundation, Cynthia Cervantes.

Ms. CERVANTES. Chairman Obey and the members of the Subcommittee, thank you for the opportunity to appear before you today, and I especially want to thank Congresswoman Sanchez and Congresswoman Roybal-Allard from the Los Angeles area.

I am Cynthia Cervantes, and I am 13 years old and in eighth grade. I live in Southern California.

Two years ago, I was diagnosed with scleroderma. Scleroderma literally means hard skin. What it does especially in my case, it causes my internal organs to harden and become smaller.

Two years ago, I began to experience sudden weakness. My body would ache and my vision was blurry. Some days it was so bad I could barely get myself out of bed and go to school.

I was taken to see a doctor after my feet became so swollen that calcium began to ooze out. It took the doctors one year to figure out exactly what was wrong with me because of how rare scleroderma is and how complicated the symptoms are.

Once again, I have been told that there is no known cause for scleroderma which affects three times as many women as men. Generally, women are diagnosed between the ages of 25 and 45, but sometimes kids like me are affected early in life. There is no cure for scleroderma, but there are treatments, treatments that have been delivered with the support of the National Institutes of Health.

Today, I have to take nine pills and one inhaler three times a day, and I always have to wear gloves and a sweater even on a hot day as part of my treatment.

Every month, I also have to go to the doctors to get some more shots, and I have to eat a special diet because my scleroderma is making my internal organs contract and slip at an angle, because it helps me digest my food.

I love to play basketball, but it is very difficult now because I become tired very quickly and it is hard to keep up with the other kids.

The Scleroderma Foundation's outreach program has been very helpful to me and my family. The Foundation provided us with materials to educate my teachers and others about my disease. Also, the local Southern California support groups the Foundation helped organize are helpful because they help show me that I can live a normal, healthy life and how to approach those who are curious about why I wear gloves even in hot weather.

It really means a lot to me to be able to interact with other people in the same situation as me because it helps me feel less alone.

Mr. Chairman, because no one knows what causes scleroderma and we have a great deal to learn about it in order to be able to effectively treat it, I respectfully ask you to please significantly in-

crease funding for the National Institutes of Health, so treatments can be found for other people like me who suffer from this sickness.

I also ask that you make it known to the leaders of NIH and the institute which studies skin disease, NIAMSD, that you consider scleroderma research to be a priority.

Mr. Chairman, on behalf of thousands of people suffering from scleroderma and the Scleroderma Foundation, I would like to thank you for the chance to speak before the Subcommittee and for your consideration of my request. Thank you.

[The information follows:]

STATEMENT OF THE SCLERODERMA FOUNDATION

ON

FISCAL YEAR 2009 APPROPRIATIONS FOR THE

DEPARTMENT OF HEALTH AND HUMAN SERVICES

SUBMITTED TO THE HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES

PRESENTED BY
CYNTHIA CERVANTES
SCLERODERMA FOUNDATION MEMBER AND PATIENT
HUNTINGTON PARK, CALIFORNIA

MARCH 13, 2008

SUMMARY OF RECOMMENDATIONS FOR FY09:

1) **A 6.5% INCREASE FOR THE NATIONAL INSTITUTES OF HEALTH AND THE NATIONAL INSTITUTE OF ARTHRITIS AND MUSCULOSKELETAL AND SKIN DISEASES.**

2) **INCREASED SCLERODERMA AWARENESS ACTIVITIES AT THE CENTERS FOR DISEASE CONTROL AND PREVENTION.**

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Cynthia Cervantes
Huntington Park, California
Scleroderma Foundation

Hearing: Thursday March 13, 2008 2:00 p.m.

Summary:
I am Cynthia Cervantes, I am 12 and in the eighth grade. I live in Southern California and in October 2006 I was diagnosed with scleroderma. Scleroderma means "hard skin" which is literally what scleroderma does and, in my case, also causes my internal organs to stiffen and contract. This is called diffuse scleroderma. It is a relatively rare disorder effecting only about 300,000 Americans.

About 2 years ago I began to experience sudden episodes of weakness, my body would ache and my vision was worsening, some days it was so bad I could barely get myself out of bed. I was taken to see a doctor after my feet became so swollen that calcium began to ooze out. It took the doctors (period of time) to figure out exactly what was wrong with me, because of how rare scleroderma is.

There is no known cause for Scleroderma, which affects three times as many women as men. Generally, women are diagnosed between the ages of 25 and 45, but some kids, like me, are affected earlier in life. There is no cure for scleroderma, but it is often treated with skin softening agents, anti-inflammatory medication, and exposure to heat. Sometimes a feeding tube must be used with a scleroderma patient because their internal organs contract to a point where they have extreme difficulty digesting food.

The Scleroderma Foundation has been very helpful to me and my family. They have provided us with materials to educate my teachers and others about my disease. Also, the support groups the foundation helps organize are very helpful because they help show me that I can live a normal, healthy life, and how to approach those who are curious about why I wear gloves, even in hot weather. It really means a lot to me to be able to interact with other people in the same situation as me because it helps me feel less alone.

Mr. Chairman, because the causes of scleroderma are currently unknown and the disease is so rare, and we have a great deal to learn about it in order to be able to effectively treat it. I would like to ask you to please significantly increase funding for the National Institute of Health so treatments can be found for other people like me who suffer from scleroderma. It would also be helpful to start a program at the Centers for Disease Control and Prevention to educate the public and physicians about scleroderma.

SCLERODERMA FOUNDATION
The Scleroderma Foundation is a nonprofit organization based in Danvers, MA with a three-fold mission of support, education, and research. The Foundation has 21 chapters nationwide and over 175 support groups.

The Scleroderma Foundation was established on January 1, 1998 through a merger between two organizations, one on the west coast and one on the east coast. Both organizations can trace their beginnings back to the early 1970s.

The Foundation provides support for people living with scleroderma and their families through programs such as peer counseling, doctor referrals, and educational information, along with a toll-free telephone helpline for patients and a quarterly magazine, *The Scleroderma Voice*.

The Foundation provides education about the disease to patients, families, the medical community, and the general public through a variety of awareness programs at both the local and national levels.

The Foundation awards over $1 million in peer-reviewed research grants annually to institutes and universities to stimulate progress in the search for a cause and cure for scleroderma.

The Foundation strives to boost awareness about the disease to patients, families, the medical community and the general public to not only generate more funding for medical research, but foster a greater understanding of the complications faced by people living with the disease.

Among the many programs arranged by the Foundation is the Annual Patient Education Conference held each summer. The conference brings together an average of 500 attendees and experts for a wide range of workshops on such topics as the latest research initiatives, coping and disease management skills, caregiver support, and exercise programs.

SCLERODERMA OVERVIEW
Scleroderma is an autoimmune disease which means that it is a condition in which the body's immune system attacks its own tissues. In autoimmune disorders, this ability to distinguish foreign from self is compromised. As immune cells attack the body's own tissue, inflammation and damage result. Scleroderma (the name means "hard skin") can vary a great deal in terms of severity. For some, it is a mild condition; for others it can be life threatening. Although there are medications to slow down disease progression and help with symptoms, there is as yet no cure for scleroderma.

WHO GETS SCLERODERMA?
There are many clues that define susceptibility to develop scleroderma. A genetic basis for the disease has been suggested by the fact that it is more common among patients whose family members have other autoimmune diseases (such as lupus). In rare cases, scleroderma runs in families, although for the vast majority of patients there is no other family member affected. Some Native Americans and African Americans get worse scleroderma disease than Caucasians.

Women are more likely to get scleroderma. Environmental factors may trigger the disease in the susceptible host. Localized scleroderma is more common in children, whereas scleroderma is more common in adults. However, both can occur at any age.

There are an estimated 300,000 people in the United States who have scleroderma, about one third of whom have the systemic form of scleroderma. Diagnosis is difficult and there may be many misdiagnosed or undiagnosed cases as well.

Scleroderma can develop and is found in every age group from infants to the elderly, but its onset is most frequent between the ages of 25 to 55. There are many exceptions to the rules in scleroderma, perhaps more so than in other diseases. Each case is different.

CAUSES OF SCLERODERMA

The cause is unknown. However, we do understand a great deal about the biological processes involved. In localized scleroderma, the underlying problem is the overproduction of collagen (scar tissue) in the involved areas of skin. In systemic sclerosis, there are three processes at work: blood vessel abnormalities, fibrosis (which is overproduction of collagen) and immune system dysfunction, or autoimmunity.

RESEARCH

Research suggests that the susceptible host for scleroderma is someone with a genetic predisposition to injury from some external agent, such as a viral or bacterial infection or a substance in the diet or environment. In localized scleroderma, the resulting damage is confined to the skin. In systemic sclerosis, the process causes injury to blood vessels, or indirectly perturbs the blood vessels by activating the immune system.

Research continues to assemble the pieces of the scleroderma puzzle to identify the susceptibility genes, to find the external trigger and cellular proteins driving fibrosis, and to interrupt the networks that perpetuate the disease.

TYPES OF SCLERODERMA

There are two main forms of scleroderma: systemic (systemic sclerosis, SSc) that usually affects the internal organs or internal systems of the body as well as the skin, and localized that affects a local area of skin either in patches (morphea) or in a line down an arm or leg (linear scleroderma), or as a line down the forehead (scleroderma en coup de sabre). It is very unusual for localized scleroderma to develop into the systemic form.

Systemic Sclerosis (SSc)

There are two major types of systemic sclerosis or SSc: limited cutaneous SSc and diffuse cutaneous SSc. In limited SSc, skin thickening only involves the hands and forearms, lower legs and feet. In diffuse cutaneous disease, the hands, forearms, the upper arms, thighs, or trunk are affected.

The face can be affected in both forms. The importance of making the distinction between limited and diffuse disease is that the extent of skin involvement tends to reflect the degree of internal organ involvement.

Several clinical features occur in both limited and diffuse cutaneous SSc. Raynaud's phenomenon occurs in both. Raynaud's phenomenon is a condition in which the fingers turn pale or blue upon cold exposure, and then become ruddy or red upon warming up. These episodes are caused by a spasm of the small blood vessels in the fingers. As time goes on, these small blood vessels become damaged to the point that they are totally blocked. This can lead to ulcerations of the fingertips.

People with the diffuse form of SSc are at risk of developing pulmonary fibrosis (scar tissue in the lungs that interferes with breathing, also called interstitial lung disease), kidney disease, and bowel disease.

The risk of extensive gut involvement, with slowing of the movement or motility of the stomach and bowel, is higher in those with diffuse rather than limited SSc. Symptoms include feeling bloated after eating, diarrhea or alternating diarrhea and constipation.

Calcinosis refers to the presence of calcium deposits in, or just under, the skin. This takes the form of firm nodules or lumps that tend to occur on the fingers or forearms, but can occur anywhere on the body. These calcium deposits can sometimes break out to the skin surface and drain whitish material (described as having the consistency of toothpaste).

Pulmonary Hypertension (PH) is high blood pressure in the blood vessels of the lungs. It is totally independent of the usual blood pressure that is taken in the arm. This tends to develop in patients with limited SSc after several years of disease. The most common symptom is shortness of breath on exertion. However, several tests need to be done to determine if PH is the real culprit. There are now many medications to treat PH.

Localized Scleroderma

Morphea

Morphea consists of patches of thickened skin that can vary from half an inch to six inches or more in diameter. The patches can be lighter or darker than the surrounding skin and thus tend to stand out. Morphea, as well as the other forms of localized scleroderma, does not affect internal organs.

Linear scleroderma

Linear scleroderma consists of a line of thickened skin down an arm or leg on one side. The fatty layer under the skin can be lost, so the affected limb is thinner than the other one. In growing children, the affected arm or leg can be shorter than the other.

Scleroderma en coup de sabre

Scleroderma en coup de sabre is a form of linear scleroderma in which the line of skin thickening occurs on the forehead or elsewhere on the face. In growing children, both linear scleroderma and en coup de sabre can result in distortion of the growing limb or lack of symmetry of both sides of the face.

CONCLUSION:

Unfortunately, support for scleroderma research at the National Institutes of Health over the past five years has been flat funded at $11 million, down from $13 million in 2003. These figures are extremely frustrating to our patients who recognize biomedical research as their best hope for a better quality of life. It is also of great concern to our researchers who have promising ideas they would like to explore if resources were available.

As Congress works to finalize the HHS appropriations bill for Fiscal Year 2009, we encourage you to support a 6.5 percent increase for the NIH. This funding recommendation has been endorsed by over 300 health care organizations and would ensure additional support for scleroderma research. The main institute responsible for scleroderma at the NIH is the National Institute of Arthritis and Musculoskeletal and Skin Diseases.

As you look ahead to next year's appropriations process, we would like to ask for your support of scleroderma specific recommendations in the HHS funding bill.

Mr. OBEY. Thank you.

Did either of you want to say anything?

Let me simply say, you are in eighth grade. You are doing a whole lot better in the eighth grade than I did. [Laughter.]

Mr. OBEY. I was kicked out of grade school when I was in eighth grade.

I will yield to you just a second. I just want to say that we appreciate your coming here today. You did a fine job testifying, and I am glad that people who know about this disease were smart enough to pick a really good spokesman to explain the situation today.

With that, let me yield to the gentlewoman from California.

Ms. ROYBAL-ALLARD. Mr. Chairman, it was during the break that I learned that Cynthia was going to be here, and I want to thank her for her testimony.

Also, she is a wonderful example of why I am so proud of the constituents of the 34th Congressional District. She is from the City of Huntington Park which I proudly represent.

So, thank you for being here, Cynthia.

Ms. CERVANTES. You are welcome.

Mr. OBEY. Let me just point out when the Secretary of Health and Social Services was here, we were talking about the fact that every time this Committee appropriates money, people will point to the cost of appropriating the money, but they very seldom talk about the cost of not appropriating the money.

As I understand it, if we take a look at what is being invested nationwide in this disease, it is about $12,000,000. That is a very small amount. If you compare that amount just to the economic cost of the disease, with everything from medical treatment to lost income to you name it, not to mention the human cost, I think it amply illustrates why we need to do far more than we are doing with respect not just to this disease but virtually everything else that NIH does.

Thank you very, very much.

Ms. CERVANTES. Thank you.

THURSDAY, MARCH 13, 2008.

PULMONARY HYPERTENSION ASSOCIATION

WITNESS

JOANNE SCHMIDT

Mr. OBEY. Next, Pulmonary Hypertension Association, Joanne Schmidt.

Ms. SCHMIDT. Good afternoon, Chairman Obey, members of the Subcommittee. On behalf of myself and the Pulmonary Hypertension Association, thank you for the opportunity to testify this afternoon.

My name is Joanne Schmidt. I am from Huntington, New York, and I have pulmonary hypertension.

Pulmonary hypertension refers to high blood pressure between the heart and the lungs, resulting in an enlarged heart that eventually loses its ability to pump. The disease is underdiagnosed,

deadly and incurable. PH can occur without a known cause or can be secondary to a number of other conditions including scleroderma, lupus and sickle cell.

In my case, this devastating condition runs in my family. My mom's sister was diagnosed with pulmonary hypertension in 1963 at the age of 23. She died within six months. My brother was diagnosed in 1995 at the age of 34. Three years later when I was 34, I began to develop symptoms of PH, and I knew immediately what they were.

I joined the Board of Trustees of the Pulmonary Hypertension Association in 2001. PHA is the Nation's oldest and largest nonprofit organization dedicated to the PH community.

I am also the founder and co-leader of the Long Island, New York support group. The group remains large and active. However, we unfortunately lose members to PH every year.

I would like to extend my sincere thanks to the Subcommittee for your past support of pulmonary hypertension programs at the National Institutes of Health, Centers for Disease Control and Prevention and Health Resources and Services Administration. These initiatives have opened up 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 pleased to report that we are making good progress in our fight against this deadly disease. Six new therapies for the treatment of PH have been approved by the FDA in the past ten years. However, there is still a long way to go on the road to a cure, and biomedical research holds the promise of a better tomorrow for our patients.

We are truly honored to have a great partner in the National Heart, Lung and Blood Institute, and I would like to take this opportunity to recognize the Director of NHLBI, Dr. Elizabeth Nabel, for all that she has done for our community. We are particularly excited about the two centers of excellence in PH that NHLBI initiated last year.

For fiscal year 2009, the Pulmonary Hypertension Association joins with other members of the research and patient community in recommending a 6.5 percent increase for the NIH. We are very aware of the strong need for robust support of the NIH.

A few years ago, leading PH researchers submitted a proposal to NIH, focused on the blood thinning drug, Warfarin, as a possible new treatment for PH. This concept was greeted enthusiastically within our community because it could reduce the cost of treating PH from hundreds of thousands of dollars a year to simply hundreds of dollars a year.

The proposal received an excellent score but did not make the declining NIH payline. It is critical that studies like these move forward in the future.

Finally, I would like to commend the Subcommittee for actively addressing the current backlog in Social Security Disability applications at the Social Security Administration. Many PH patients end up applying for disability coverage, and streamlining the benefits process would go a long way toward improving the quality of life for our most in need families.

Once again, Mr. Chairman, thank you so much for the opportunity to testify today.

I would like to close by saying a special thank you to a great champion of the PH community and a true friend of everyone on Capitol Hill, the late Congressman Tom Lantos. Representative Lantos became a tireless advocate for our cause after his beautiful granddaughter, Charity, was diagnosed with pulmonary hypertension a few years ago. We miss him terribly, and we honor his legacy today.

Thank you so much.

[The information follows:]

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TESTIMONY OF

MS. JOANNE SCHMIDT

MEMBER, BOARD OF TRUSTEES
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ON BEHALF OF THE

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REGARDING

FISCAL YEAR 2009 APPROPRIATIONS FOR THE DEPARTMENT OF HEALTH AND HUMAN SERVICES

BEFORE THE
HOUSE LABOR-HHS-EDUCATION APPROPRIATIONS SUBCOMMITTEE

MARCH 13, 2008 – 2:00PM

SUMMARY OF FY 2009 RECOMMENDATIONS:

- **A 6.5% increase for the National Heart, Lung and Blood Institute, and the National Institutes of Health overall.**
- **Continued support within the Centers for Disease Control and Prevention for a pulmonary hypertension awareness and education program.**
- **$25 million for the Health Resources and Services Administration's "Gift of Life" Donation Initiative, a $ 2million increase over FY08.**

Chairman Obey, Members of the Subcommittee, on behalf of myself and the Pulmonary Hypertension Association, thank you for the opportunity to testify this afternoon. My name is Joanne Schmidt, I am from Huntington, NY and I have pulmonary hypertension.

Pulmonary hypertension refers to high blood pressure between the heart and the lungs resulting in an enlarged heart that eventually loses its ability to pump. The disease is under-diagnosed, deadly, and incurable. PH can occur without a known cause or can be secondary to a number of other conditions including scleroderma, lupus, and sickle cell.

In my case, this devastating condition runs in my family. My mother's sister was diagnosed with pulmonary hypertension in 1963 at the age of 23. She died within six months. My brother was diagnosed in 1995 at the age of 34. Three years later, when I was 34, I began to develop symptoms of PH. I knew exactly what they were.

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For FY09, the Pulmonary Hypertension Association joins with other members of the research and patient community in recommending a 6.5% increase for the NIH. We are very aware of the strong need for robust support of the NIH. A few years ago, leading PH researchers submitted a proposal to NIH focused on the blood thinning drug warfarin as a possible new

treatment option. This concept was greeted enthusiastically within our community because it could reduce the cost of treating PH from *hundreds of thousands of dollars* a year to *hundreds of dollars* a year. The proposal received an excellent score, but did not make the NIH declining payline. It is critical that studies like these move forward in the future.

Finally, I want to commend the subcommittee for actively addressing the current backlog in Social Security Disability applications at the Social Security Administration. Many PH patients end-up applying for disability coverage, and streamlining the benefits process would go a long way toward improving the quality of life for our most in-need families.

Once again, thank you Mr. Chairman for the opportunity to testify today. I would like to close by saying a special thank you to a great champion of the PH community and a true friend of everyone on Capitol Hill, the late Congressman Tom Lantos. Rep. Lantos became a tireless advocate for our cause after his beautiful granddaughter Charity was diagnosed with pulmonary hypertension a few years ago. We miss him terribly and honor his legacy today. Thank you.

Mr. OBEY. Thank you very much.

Let me simply say that I have a very good friend who happened to have testified before this Committee last week whose wife has the same problem. So we have seen it affect good people, up and close.

You indicate that you want us to support an increase of 6.7 percent for NIH. I would dearly love to do that.

We have to face the reality that last year the bill that we sent to the President, that he vetoed, provided a relatively small increase in NIH funding of $770,000,000, and we came within four votes of being able to override his veto. We got 66.2 percent of the votes. We needed 66.7.

So we will be looking for ways to try to produce a bill which is veto-proof. If we cannot find that in this Congress, then we will have no choice but to simply pass a continuing resolution taking us through February, so we can get a new start with someone who will make compromises on these issues.

Thank you very much.

Ms. SCHMIDT. Thank you so much.

THURSDAY, MARCH 13, 2008.

TUBEROUS SCLEROSIS ALLIANCE

WITNESS

TOMMY LINDSEY, BOARD MEMBER, TUBEROUS SCLEROSIS ALLIANCE

Mr. OBEY. Next, the Tuberous Sclerosis Alliance, Tommy Lindsey.

Mr. LINDSEY. I did not have a chance, prior to coming in, to hand something over. Do you mind if I drop this off to you?

Mr. OBEY. That is fine. Thank you.

Mr. LINDSEY. First, I would like to say thank you for granting me this opportunity to speak before you today.

I would like to give a special thanks to Ranking Member Walsh, even though he is not in the room at the moment, for being so supportive of our organization in the past and hopefully in the future as well.

I would also like to make another point, that we have something in common. I was also kicked out of grade school. It was Catholic school and in kindergarten.

Mr. OBEY. We will form a union. [Laughter.]

Mr. LINDSEY. I am here today on behalf of the Tuberous Sclerosis Alliance. I am a current board member and, more importantly, a dad to a little boy, Tommy, who suffers from tuberous sclerosis.

Tuberous sclerosis is a rare genetic disorder that causes the formation of tumors in all your vital organs, causing severe mental and physical retardation, sometimes death. It affects every major organ in the body.

We all have these two genes that naturally suppress tumor growth. If either one or both happen to mutate, you lose the ability to fight off tumors. It is a one-third passed on mutation, two-thirds, spontaneous mutation.

My son happened to be a spontaneous. The sperm and the egg meet, the gene mutates, and you have this problem.

Tommy was born with numerous tumors in his brain, two in his heart, one in each eye, and he has a bunch on his skin. We have to get him scanned every six months to be sure that he does not have any new tumors growing in any other organs, and this is going to go on for the rest of his life.

They are benign in the sense that they are nonmalignant, but they are far from benign.

Tommy was first diagnosed at five weeks old from a series of epileptic seizures which progressed over time. We brought him into the hospital at five weeks old because of the, for better lack of a word, oftency of his disease, if that is a word.

It is very unknown even in the medical community. My wife and I were accused of shaken baby syndrome for three days because the medical doctors believed they were looking at blood spots in his brain. They did not realize they were looking at tumors. After a series of tests and MRIs, they realized they were looking at tumors, and Tommy was diagnosed with tuberous sclerosis.

The diagnosis was very bleak. I was told that Tommy would never work. He would never talk. He would be both severely and physically retarded and that I should consider an institution.

This was my five week old son. It was very hard to take. I was knocked on my butt.

Growing up, I just want to tell you a little bit about myself. I grew up in the city limits, one of the five boroughs in New York. My father left when I was four. I was on welfare, food stamps, the whole works. I have two older sisters and my mom. We struggled our whole lives, growing up, but we have all done pretty well for ourselves as adults.

I promised myself growing up that I would be a better father to my children once I had them, if that was at all possible, than my father was to me. Unbeknownst to me, I was going to wind up being this advocate and having a child handed to me that I was not prepared to be the advocate or father for.

There is no cure for tuberous sclerosis. I realized that right away. I never once said, why me?

I did say, why him, every day. I still do to this day because he bothered nobody. If anything, give it to me because I know that I can handle it from the way I was brought up and what I can deal with.

Tommy, himself, has gone through a series of brain surgeries to control his epilepsy. Back in 2003, he had three brain surgeries over eleven days, where they removed a large tumor from his right frontal lobe. Those are the pictures that I just handed to you now. That is actually my son in the OR. Those are not just pictures from a textbook.

He is on cocktails of anti-epileptic drugs on a daily basis. He has gone through 13, none with any help.

I cannot stress the fact that something has to be done. We need more money. We need it. So is everybody else who has a request in this room.

We are requesting we get—I am sorry. I am a little nervous. I am usually not nervous. I am usually a pretty big ham. I am also known as the Forest Gump of tuberous sclerosis.

You might remember me from three years ago. I was here with the Oscar-nominated actress, Julianne Moore, which I was fortunate enough to bump into in a chance meeting and get her to jump on board. She is now our national spokesperson.

But what we are asking for is an increase of 6.7 percent which a few other people have mentioned today, in the NIH funding to help do more research for tuberous sclerosis.

We have painted the Hill. Two weeks ago, we organized a march with constituents, family members, some members themselves who have tuberous sclerosis. We had a total of 290 meetings two weeks ago, asking the Appropriations Committee to appropriate $10,000,000 in the CDMRP for more research dollars for tuberous sclerosis.

We believe it is a very modest request. At the present time, we were granted $4,000,000 in 2007, but for 2008 we are hoping to get that increased to $10,000,000.

We are also asking that this Committee would be supportive and help us in funding a new program in the CDC to help us better understand the national prevalance of TSC and train individuals in the medical community to help us better understand tuberous sclerosis in general.

One example was what I gave you earlier is that you have people going to the doctors. I live in a city, New York City, where some people consider are the best doctors in the world, some of the best doctors in the world, and I am being accused of shaken baby syndrome and being told to put my child in an institution.

If we can better educate the medical community, the researchers in general, we can help treat these patients even if we cannot cure them which is obviously our main goal. We do not want to walk into a doctor's office where people are told that you have to put your child into an institution. We want them to have an idea of what needs to be done. We need some kind of protocol.

At the present time, everybody walks in like a guinea pig, and everybody just takes a shot in the dark to see what might work, what epileptic drugs. It is the number one genetic cause for epilepsy, number two genetic cause for autism.

We do have a pathway now. We know the two genes that have caused tuberous sclerosis. If we cure tuberous sclerosis, we might help many of the people that walk through these doors that are requesting for help as well.

The fact that it has a link to diabetes, there is a link to autism, a link to epilepsy, the link to cancer, the tumor gene itself. If we can find a way to cure or stop that tumor gene or somewhere down the line, we also will help find a way to stop and cure most cancers.

In some meetings with some of the hierarchy in NIH and other people on the Hill and researchers, we have been told in meetings that tuberous sclerosis is curable. We just need the funding. We are told that because of the strides that have been made in such a short period of time, we are kind of like the hot, sexy disease right now, if you want to call it that, if there is a hot, sexy disease.

Researchers are coming to the Tuberous Sclerosis Alliance, putting in grant applications that we cannot fund. Over the years, we have funded over $12,000,000 in research grants on our own as a private organization. So we are not looking for a handout. We are actually looking for a partner with the government, and hopefully together we can make a difference.

My son, Tommy, is my world. I never expected to get what was handed to me. I look at him every day, and I try to promise him.

I promised myself I would be a better dad than my dad was. Now I have to promise my son that he was not born with tuberous sclerosis for no reason at all. If anything else, even if I cannot cure him, at least I can help the people coming in behind him. If that is going to be his legacy, if it is just a rationalization to make myself feel better, at least it is doing something.

But I believe in this Committee. I believe in the United States Government because we do help people as a whole, even around the world, not just here. Everyone in this room, everyone on this Hill can make a difference.

If you look back and we needed to build the atomic bomb, what did we do? We put the right people in the room, gave them the funding and said, do not come out until it is done. It was done.

We wanted to send someone to the moon, same thing.

If we want to cure tuberous sclerosis, which in turn will cure many other diseases, we need to do the same thing and we need more funding. I greatly urge you to support our tasks here the best you can.

Thank you.

[The information follows:]

ORAL TESTIMONY BEFORE THE
HOUSE LABOR-HEALTH AND HUMAN SERVICES-EDUCATION SUBCOMMITTEE
Tommy Lindsey, Tuberous Sclerosis Alliance
March 13, 2008

- Good afternoon, Chairman Obey and Ranking Member Walsh, and thank you for giving me the opportunity to testify on behalf of the Tuberous Sclerosis Alliance.

- I am here today to tell you about my son Tommy, who suffers from tuberous sclerosis complex (TSC), a genetic condition that causes tumors in any of the body's vital organs, including the kidneys, lungs, liver, eyes, skin, and brain.

- **EXPLAIN TOMMY'S STORY HERE**

- I have painted a relatively bleak picture of what TSC patients and families must endure. However, I also have a good story to tell you today.

- Thanks to the efforts of this Committee, substantial investments have been made in tuberous sclerosis complex research at both the National Institutes of Health (NIH) and the Department of Defense (DoD).

- Thanks to this investment, researchers have made enormous breakthroughs that have a significant impact on our understanding not only of TSC but of more prevalent conditions like autism, epilepsy, cancer and diabetes. But more needs to be done to find a cure.

- The Tuberous Sclerosis Alliance supports a 6.7% increase for the NIH to help fund new research into finding a cure for TSC.

- We are also asking the DoD subcommittee to support an appropriation of $10 million for the Tuberous Sclerosis Complex Research Program – the world's largest single research program specifically devoted to TS research.

- And finally, we are asking this subcommittee to fund a new program at the Centers for Disease Control to help us better understanding the national prevalence of TS and train individuals to better diagnose this complex disorder.

- Last week, patients and families from around the country came to Washington, DC and met with the offices of 290 Members of the House and Senate to advocate for TS research funding.

- We sincerely hope your committee will continue its support for TSC research, not just for my son Tommy, but for the next generation of families that must cope with this devastating disorder.

Mr. OBEY. Well, thank you very much.

Let me simply say, I think you are a terrific father and a terrific spokesman.

I would simply make the point that what we are going to have to do is simply get enough votes to overcome the White House resistance or else get the White House to agree to make significant compromises in their budget because, as you mentioned, I have not heard a single person here come in and say, why do not you guys get your act together and cut cancer research, but that is what the Congress and the President did two years ago.

We just cannot afford many more years like that. Certainly, your son cannot. I know you cannot, but we appreciate your telling your story today. I know it is painful.

THURSDAY, MARCH 13, 2008.

AMERICAN ASSOCIATION OF COLLEGES OF NURSING

WITNESS

DR. JEANETTE LANCASTER, PRESIDENT, AMERICAN ASSOCIATION OF COLLEGES OF NURSING, DEAN, UNIVERSITY OF VIRGINIA SCHOOL OF NURSING

Mr. OBEY. The American Association of Colleges of Nursing, Dr. Jeanette Lancaster.

Dr. LANCASTER. Good afternoon, Mr. Chairman and Mr. Simpson. It is a pleasure to be here with this Subcommittee and the staff members who work so diligently to help you.

I am the President of the American Association of Colleges of Nursing and the Dean at the University of Virginia School of Nursing, and I am here to speak on behalf of increased funding for Title VIII which I know you are very familiar with and you have been supportive to funding for nursing in the past.

I guess the bottom line is we hear all of these difficult stories today that an investment in the profession of nursing is an investment in helping the people who have spoken today before me because without our graduates the care that they get will be severely limited compared to the care that they need.

I do understand the difficult situation, and there is so much of a need in NIH and in HRSA for both the workforce and the research to report the new recoveries and advancements.

As I think all of you know, we are in the middle of a decade-long nursing shortage. This is the most difficult shortage we have ever had. It is a complex shortage but to put it in the simplest terms, it is a total imbalance between demand and supply.

The demand for healthcare is growing and it will grow even further as those of us who, regrettably, are entering the baby boom generation will need more healthcare. That comes at a time when our ability to supply new nurses is diminished compared to those times in the past.

Now you might think well, that is because people do not want to become nurses, but that is really not the case at all. Last year, in our colleges of nursing, we documented the turning away of 40,000 students who wanted to become a nurse.

In my State of Virginia, we turned away over 1,400 students who wanted to become a nurse. At the University of Virginia, we will admit 56 students directly from high school and competing for those 56 spots are 404 candidates.

In every way you can, the school at which I am a dean, which is just reflective of the national situation, it is running this year a four to one to an eight to one ratio of those who wish to come and those who will be able to come.

So it is not that people do not have an appetite to become a nurse. It is that we do not have the faculty to enable us to increase more nursing students.

Historically, there are three things that prohibit us from increasing our class size: lack of clinical sites, lack of facilities to educate. Classroom seats, the fire marshal is very fussy about how many people you put in a classroom.

Those can be overcome. Faculty are creative, and you can find new ways to put chairs in rooms. But what cannot be overcome simply is finding enough faculty to teach the students, and that is where Title VIII has been a big help.

In fact, as I think back and I was thinking back a long time, I actually was supported in my master's program in psychiatric nursing through Federal funds, Federal training funds which paid for tuition and fees for students to get master's degrees in nursing. So many of us who are in the workforce now have been part of the Title VIII program.

Basically, this program provides the funding to prepare nurses who can provide primarily healthcare services and many are those nurse practitioners, nurse anesthetists. It also provides funding for people who want to become faculty. That, of course, as I have already said, is the chief problem that we have in front of us is just the lack of funds.

Just like NIH needs funds and not a single one of us in schools of nursing would deny that NIH does. We all know NIH needs funds, but the workforce development areas need funds as well. I do know that you know that.

We are respectfully asking as a nursing community for $200,000,000 to support Title VIII. We do appreciate your attention and your thoughtfulness and your help to us in the past, and we fully appreciate the dilemma you are in.

Thank you.

[The information follows:]

Testimony of Jeanette Lancaster, PhD, RN, FAAN on behalf of the American Association of Colleges of Nursing On Fiscal Year 2009 Appropriations for the Nursing Workforce Development Programs

Good morning, Mr. Chairman and distinguished members of the Subcommittee. I am Jeanette Lancaster, President of the American Association of Colleges of Nursing (AACN) and Dean and Professor of the School of Nursing at the University of Virginia. On behalf of AACN, I appreciate this opportunity to bring to the Subcommittee our FY 2009 funding priorities for the Nursing Workforce Development Programs authorized under Title VIII of the Public Health Service Act. These programs are a critical piece of the nation's effort to overcome the nursing shortage.

AACN and the nursing schools we represent deeply appreciate the Subcommittee's past support for the Title VIII programs. Through the dedicated work of this Subcommittee and your Senate colleagues last year, Title VIII saw its first significant funding increase since FY 2005. AACN certainly understands the difficult financial choices you must make regarding funding for health and education programs. Yet, at a time when the national nursing shortage is placing a constant strain on the healthcare delivery system, we implore you to invest more in the present and future nursing workforce to prevent further damage.

The Nationwide Nursing Shortage

The United States is in the midst of a decade-long shortage of Registered Nurses (RNs).[1] This shortage is expected to intensify as the baby-boomer population ages and the need for healthcare grows. According to the latest projections from the U.S. Bureau of Labor Statistics, more than 1.2 million new and replacement nurses will be needed by 2014.[2] Unless we act *now,* this shortage will further jeopardize access to quality patient care.

Healthcare delivery in the United States has experienced the negative effects of previous nursing shortages. During the 1940's, 1960's, and early 1970's[3], the nation's need for nurses greatly impacted patient care. While today's shortage shares some of the same contributing factors as those of the past, the aging nursing workforce, and fundamental changes in patient care such as length of stay and medical technology, further complicate the current demand for nurses.[3] Moreover, central to the present shortage, the nursing educational system is being threatened by a crippling shortage of nurse faculty, insufficient number of clinical placements and classroom space, and overall budget constraints.[4] According to AACN's 2007-2008 annual survey on baccalaureate and graduate programs, U.S. nursing schools turned away 40,285 qualified applicants, primarily due to a lack of faculty.[4]

Nursing and economic research clearly indicate that today's shortage is far worse than those of the past.[3] The current supply and demand for nurses demonstrates two distinct dilemmas. First, due to the present and looming demand for advanced health care by American consumers, the supply is not growing at a pace that will adequately meet long-term needs. This is further compounded by the number of nurses who will retire or leave the profession in the near future, ultimately reducing the supply of nurses. Second, the

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[1] Buerhaus, P.I., Donelan, K., Ulrich, B.T., Kirby, L., Norman, L., and Dittus, R. (2006). State of the Registered Nurse Workforce in the United States. *Nursing Economics.* 24(1), 6-12.

[2] Bureau of Labor and Statistics, (2005). *Occupational Projections to 2014.* Retrieved March 10, 2008 from http://www.bls.gov/opub/mlr/2005/11/art5full.pdf

[3] Nevidjon, B. & Erickson, J.I. (2006). The nursing shortage: Solutions for the short and long term. As cited in: Andrist, L.C., Nicholas, P.K., & Wolf (2006). *A History of Nursing Ideas.* Boston: Jones and Bartlett Publishers.

[4] American Association of Colleges of Nursing. (2008). *2007-2008 Enrollment and Graduations in Baccalaureate and Graduate Programs in Nursing.* Washington, DC.

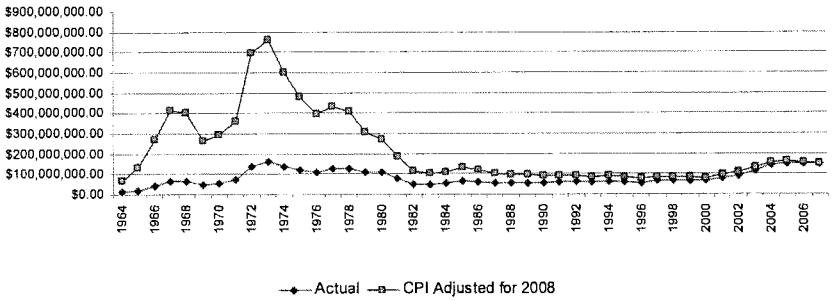
supply of nurses nationwide is stressed due to an ongoing shortage of nurse faculty. There is an enormous demand from individuals who wish to pursue a nursing education as evidenced by the thousands of qualified students turned away each year. However, the schools' ability to increase the nationwide supply of nurses is limited by the dwindling number of faculty. To address these related workforce issues, substantial efforts must be made to increase the number of faculty who will educate new nurses.

Nursing Workforce Development Programs: A Proven Solution

Congress has addressed past nursing shortages by creating the Title VIII authorities in 1964 and providing higher funding levels for the programs when the need for nurses was great. Unfortunately, due to a number of political and economic factors, funding for Title VIII over the last ten years has not increased to fully address the present nursing shortage.

In 1973, Congress appropriated $160.61 million to the Title VIII programs, the highest level of funding Title VIII has ever received. While this amount is close to the current funding level of $156.05 million, adjusting for inflation to address the 35-year difference, the current funding level would be $763.52 million (see Figure 1). More recently, stagnant funding levels for Title VIII between FY 2005 and FY 2007 have greatly impacted the purchasing power of these programs. In FY 2006 and 2007, $149.68 million was appropriated to Title VIII. The same allocation supported 91,198 nursing students and nurses in 2006 and only 71,729 in 2007.[5] This represents a loss of almost 20,000 nurses supported in one year.

Figure 1
Historical Funding for Title VIII Nursing Workforce Development Programs (in millions)



Source: Health Resources and Services Administration (HRSA), Division of Nursing, 2008 & Bureau of Labor and Statistics, Inflation Calculator, 2008

Given the projections that the nursing shortage will continue to worsen over the next decade, more must be done to help alleviate the barriers that have significantly slowed the growth of the RN workforce. ***Therefore, AACN respectfully requests $200 million for Title VIII Nursing Workforce Development Programs in FY 2009***, an additional $43.95 million over the FY 2008 level. New monies would expand nursing education, recruitment, and retention efforts to help resolve all aspects contributing to the shortage.

An Overview of the Title VIII Programs: Effective Approaches to Address the Shortage

Over the last 45 years, the Nursing Workforce Development programs have addressed all aspects of nursing shortages – education, practice, retention, and recruitment. As the largest source of federal funding

[5] Electronic Mail Communications from the Health Resources and Service Administration, Division of Nursing, 2008.

for nursing education, these programs bolster RN education from entry-level preparation through graduate study. The Title VIII programs award grants to nursing education programs, as well as provide direct support to nurses and nursing students through loans, scholarships, traineeships, and programmatic grants. By supporting the supply and distribution of qualified nurses, these programs help to ensure that nurses are available to provide care to individuals in all healthcare settings. Additionally, the Title VIII programs also favor institutions that educate nurses for practice in rural and medically underserved communities.

The Nursing Workforce Programs are effective and meet their authorized mission. In a 2008 survey by AACN, 729 Title VIII student recipients reported that these programs played a critical role in funding their nursing education. The four major themes identified in this qualitative study indicate that the programs decreased the students' financial burden, allowed them to achieve their career goals, shortened the length of time to obtain their degree, and the funding was greatly appreciated.[6] Still, many students stated that this support did not completely erase their educational debt and urged Congress to continue the funding.[6] As mentioned, the Title VIII programs address all aspects of the nursing shortage. A description of each Nursing Workforce Development program is provided below along with an explanation to illustrate how they help supply the RN demand.

Advanced Education Nursing (AEN) Grants (Sec. 811) support programs that prepare graduate-level nurses to be primary care providers and nurse faculty. These grants help schools of nursing, academic health centers, and other nonprofit entities improve the education and practice of nurse practitioners, nurse-midwives, nurse anesthetists, nurse educators, nurse administrators, public health nurses, and clinical nurse specialists. In FY 2007, the AEN grants supported 5,978 nursing students through grant funding. The AEN program also offers traineeships to nursing students.[5]

- AEN Traineeships assist students during their graduate nursing education. These traineeships provide full or partial support for the costs of tuition, books, program fees, and reasonable living expenses. Ninety-nine percent of the eligible applications were approved in FY 2007, which supported 7,941 students.[5]
- Nurse Anesthetist Traineeships (NAT) support the education of students in nurse anesthetist programs. Much like the AEN Traineeships, the NATs provide full or partial support for the costs of tuition, books, program fees, and reasonable living expenses. One-hundred percent of the eligible applications were approved in FY 2007, which supported 2,173 students.[5]

According to AACN's 2008 Title VIII study, 79 percent of student respondents received funding from AEN grants or traineeships.[6] The students who responded expressed great appreciation for the funding and stated how it directly helped them to attain their academic and professional goals. The major themes identified were that the AEN grants and traineeships allowed students to go to school full time, which in turn helped them to graduate and practice sooner, and alleviated the high financial burden of graduate school.[6] Because the AEN grants support the education of future nurse faculty and nurse practitioners who provide primary care to thousands of Americans, it is imperative that funding for the AEN grants continues in FY 2009.

Workforce Diversity Grants (Sec. 821) prepare students from disadvantaged backgrounds to become nurses. This program awards grants and contract opportunities to nursing schools, nurse-managed health centers, academic health centers, state or local governments, and nonprofit entities looking to increase

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[6] American Association of Colleges of Nursing. (2008). The Effectiveness of Nursing Workforce Development Programs. Washington, DC.

access to nursing education for disadvantaged students, including racial and ethnic minorities under-represented among RNs. Through grant programs and individual awards, 32,847 minority nursing students were supported in FY 2007.[5]

Diversity within the nursing population does not parallel the cultural and ethnic background of American healthcare consumers. HRSA reports that only 10.7 percent of the nursing workforce identify themselves as an ethnic or racial minority.[7] According to the National Advisory Council on Nurse Education and Practice, diversifying the nursing profession is essential to meeting the healthcare needs of the nation and reducing health disparities that exist among many underserved populations.[8] In response to the need to enhance diversity, schools of nursing have substantially increased their minority enrollment. In fact, minority students currently account for 26 percent of enrollees in entry-level baccalaureate nursing programs.[4] While nursing has made great strides in recruiting and graduating nurses that mirror the patient population, more must be done to keep pace with the changing demographics of our country to ensure that culturally sensitive care is provided. The Nursing Workforce Diversity Grants help to achieve this goal.

Nurse Education, Practice, and Retention Grants (Sec. 831) help schools of nursing, academic health centers, nurse-managed health centers, state and local governments, and health care facilities strengthen nursing programs. This program focuses on nursing education, practice, and workforce retention by offering:

- Education Grants to: a) expand enrollments in baccalaureate nursing programs; b) develop internship and residency programs to enhance mentoring and specialty training; and c) provide for new technology, including distance learning.
- Practice Grants to: a) expand practice arrangements in non-institutional settings to improve primary health care in medically underserved communities; b) provide care for underserved populations such as the elderly, HIV/AIDS patients, substance abusers, and domestic abuse victims; c) provide skills to practice in existing and emerging health systems; and d) develop cultural competencies.
- Retention Grants to: a) maintain the Career Ladder program supporting nursing education efforts assisting individuals in obtaining the education necessary to either enter the profession or advance within it; and b) enhance patient care delivery systems by increasing collaboration and improving communication among nurses and other healthcare professionals. These grant programs supported 21,145 nurses and nursing students in FY 2007.[5]

As evidenced by the increase in enrollment and the rising interest in nursing careers, substantial efforts have been made to recruit new nurses, including individuals who are changing careers to nursing. However, the nursing profession is still struggling to educate and retain nurses to meet the demand in all healthcare settings. HRSA projects that nursing schools must increase the number of graduates by 90 percent in order to adequately address the nursing shortage.[7] Research shows that the stress of being a nurse often makes it difficult to retain both the new and experienced nurses in our healthcare system.[9] The Nurse Education, Practice, and Retention Grants help to ensure that the current nursing population is highly educated, prepared to practice nursing care in all healthcare areas, and remains in the profession.

Nurse Loan Repayment and Scholarship Programs (Sec. 846) support students and new graduates:

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[7] Health Resources and Services Administration (2004). *National Sample Survey of Registered Nurses.* Accessed February 19, 2008 from http://bhpr.hrsa.gov/healthworkforce/reports/rnpopulation/preliminaryfindings.htm

[8] National Advisory Council on Nurse Education and Practice (2003). *Third Report to the Secretary of Health and Human Services and the Congress.* Accessed February 20, 2008 from ftp://ftp.hrsa.gov/bhpr/nursing/nacreport.pdf

[9] PricewaterhouseCoopers' Health Research Institute *(2007) What Works: Healing the Health care Staffing Shortage.*

- Loan Repayment: Repays up to 85 percent of nursing student loans in return for at least three years of practice in a designated healthcare facility with a critical shortage of nurses. In FY 2007, 4,845 nursing student applications were reviewed, but only 586 (12 percent) were accepted due to the lack of funding.[5]
- Scholarship: Offers individuals who are enrolled or accepted for enrollment as a full-time nursing student the opportunity to apply for scholarship funds. Upon graduation, a nurse is required to work in a healthcare facility with a critical shortage of nurses for at least two years. Due to a lack of funding in FY 2007, only 32 percent of the applications accepted were approved, which funded only 173 student scholarships.[5]

According to the AACN Title VIII study, students reported that their education debt can range from $60,000 to $100,000 after graduation.[6] This substantial debt can often delay graduation as nurses need to work while attending school to offset what they will owe in the future. The Nurse Loan Repayment and Scholarship Program lessens the financial burden for nurses. However, the awards made through this program are limited. Therefore, increased funding is essential.

Nurse Faculty Loan Program Grants (Sec. 846a) increase the number of qualified nurse faculty by creating a student loan fund within individual schools of nursing. Students must agree to teach at a school of nursing in exchange for cancellation of up to 85 percent of their educational loans, plus interest, over a four-year period. The cancellation rate for the first three years is 20 percent per year and 25 percent in the final year. These grants assisted the education of 729 future nurse educators in FY 2007.

The shortage of nurse faculty is the most critical element of the current nursing shortage. Without additional faculty to teach incoming nursing students, the shortage will continue. Requiring years to graduate new nurse faculty, steps must be taken now to increase the population of nurse educators. The faculty shortage is a nationwide epidemic, with an 8.8 percent vacancy rate at nursing schools with baccalaureate and/or graduate programs. In 2007, AACN found that only 531 students graduated with research-focused doctorates.[4] This is a concern, as the majority of vacant faculty positions require a doctorate in nursing or a related field. The Nurse Faculty Loan Program is the only Title VIII program solely dedicated to educating the next generation of nurse faculty. Unfortunately, this program is sorely underfunded at $7.86 million.

Comprehensive Geriatric Education Grants (Sec. 855) are awarded to eligible entities such as schools of nursing or healthcare facilities to educate nursing staff to provide better healthcare services for the elderly. These grants may be used to educate RNs who will provide direct care to older Americans, develop and disseminate geriatric curriculum, prepare faculty members, and provide continuing education. In FY 2007, no new grants were approved. Therefore, only 19 continuing grants were funded, which supported 157 nursing students. This is down from 1,531 in FY 2006.[5]

As the baby-boomer population ages, the need for health care will increase dramatically. The Comprehensive Geriatric Education Grants allow nurses not only to become experts in the practice of geriatric nursing, but also to discover new methods to create cost-effective, high-quality services for this increasing population.

Conclusion

AACN acknowledges the fiscal challenges within which the Subcommittee and the entire Congress must work. However, the Title VIII authorities provide a dedicated, long-term vision for educating the new nursing workforce and the next cadre of nurse faculty. To be effective, they must receive additional funding. AACN respectfully requests **$200 million for Title VIII programs in FY 2009**. Additional funding for these programs will assist schools of nursing to expand their programs, educate more nurse faculty, increase the number of practicing RNs, and ultimately improve the patient care provided in our healthcare system.

Mr. OBEY. Thank you.

Again, to put it in context, the President's fiscal year 2008 budget proposed to cut nurse training programs by $45,000,000. The House passed a bill last year and was able to add $60,000,000 to the President's request. A vetoed conference report would have provided $63,000,000 more than the President asked for.

The final bill that we were able to pass still contained $51,000,000 more than the President and $6,000,000 above the 2007 level, but for the coming fiscal year, the President proposes to cut nurse education programs by $46,000,000 or 30 percent below the current level. So we start out in the hole again with this as we do with so many other programs.

Dr. LANCASTER. That is right, and the cuts that the President is proposing are very heavily in advanced nursing education which would be the preparation of nurse practitioners and faculty, which are two huge demand needs in our Country.

So we thank you. We wish you to take your vitamins daily and have the strength to do what you need to do.

Mr. OBEY. My wife tells me that too. [Laughter.]

Dr. LANCASTER. Well, if you do not, you are in the same boat with Al Roker and Matt Lauer. They announced today they do not take vitamins. We need to get after them.

Mr. OBEY. Thank you very much.

THURSDAY, MARCH 13, 2008.

COALITION FOR HEALTH SERVICES RESEARCH

WITNESS

KENNETH E. THORPE, BOARD MEMBER, COALITION FOR HEALTH SERVICES RESEARCH; PROFESSOR OF HEALTH POLICY AT EMORY UNIVERSITY; EXECUTIVE DIRECTOR FOR THE PARTNERSHIP TO FIGHT CHRONIC DISEASE

Mr. OBEY. Lastly, the Coalition for Health Services Research, Kenneth Thorpe.

Mr. THORPE. Mr. Chairman, members of the Subcommittee, thank you for the opportunity to testify today on behalf of the Coalition for Health Services Research.

My name is Ken Thorpe. I serve as a board member of the Coalition. I am also a Professor of Health Policy at Emory University in Atlanta and serve as the Executive Director for the Partnership to Fight Chronic Disease.

The coalition represents the interests of 3,500 researchers and policy experts as well as 130 organizations that produce and use health services research.

On February 14th of this year, I had the pleasure of testifying in front of this Subcommittee about the escalating challenges we face in healthcare: high and rising healthcare costs, rising numbers of uninsured, uneven quality of healthcare. I also talked a little bit about the underinvestment that we make in research and development to find solutions to these problems.

For example, chronic diseases, as you have heard about many of these today, account for fully 75 percent of the over $2,000,000,000,000 we spend on healthcare. Healthcare spending

has been growing faster than our economy for many years and has projected to double in as little as 10 years.

Despite what we spend, research tells us that we only receive the appropriate care about half the time. The bottom line is America spends more on healthcare than any other nation, but we are in poorer health. We are simply not getting what we pay for, and we are not investing in healthcare wisely.

Health services research, the field in which I work, provides the data and evidence needed to make better decisions and develop effective policy to optimize healthcare financing, facilitating access to the delivery system and improve healthcare outcomes. Unfortunately, despite what we know and what we can learn from the health services research field, there is an erosion in Federal funding for this important field.

For the last five years, the Coalition has been collecting information on Federal funding for health services research and data. From what the Federal agencies report, we know that Federal expenditures have remained constant over this time period at about $1,500,000,000 a year. This equates to just 0.075 percent of the $2,000,000,000,000 we spend in healthcare annually.

Since 2003, the Federal funding has not increased. The field's purchasing power has continued to decline, despite the increased need for better information and more innovative and effective solutions.

If the Federal Government is going to start bending the cost curve and getting better care at better value, it will need to increase its investment in health services research. It is a true public good, provides essential tools to make needed improvements in our health system, improvements that will benefit all Americans. Most importantly, increasing Federal funding for health services will help us stave off the mounting challenges we face in healthcare and in healthcare entitlements.

We ask that the Subcommittee strengthen the capacity of the health services research field to address the challenges America faces in providing high quality, cost-effective healthcare.

AHRQ, the Agency for Healthcare Research and Quality, is the lead agency of our field, yet chronic underfunding combined with an increasingly earmarked budget threatens the agency's ability to achieve its important mission.

We recognize the budgetary context in which you are operating, yet we view these as substantial investments in finding solutions to our healthcare issues with respect to rising healthcare costs, reducing the number of uninsured and, indeed, providing better outcomes.

With these needs in mind, we, along with 100 members of the organization, the Friends of AHRQ, recommend an increase in funding. It is a modest increase from its current level, which has been flat at around $325,000,000 a year, to about $360,000,000 for fiscal year 2009. Again, the idea is to highlight the funding gap, again to raise, as the Chairman has already done, the critical issue of what the costs are of not funding these appropriate research services at the appropriate levels.

Taking your cue, another critical agency is the National Center for Health Statistics. This is a critical agency in terms of collecting

data and providing just essential information on births, deaths and other basic public health statistics. Again, we are asking for you to look seriously at increasing the funding for that organization as well.

As you know, Mr. Chairman, Medicare and Medicaid and SCHIP together provide coverage to nearly 100 million Americans, comprising 45 percent of America's total healthcare spending. It is imperative that we invest now in developing and testing new financing mechanisms to improve the cost and quality for the elderly, poor and other populations.

We recommend that you provide at least $45,000,000 in discretionary research and development funding to help CMS evaluate Federal programs and analyze pay for performance and payment methods and improve care models. Such work, we believe, will pay dividends as you and other policymakers look to expand care and healthcare coverage to all Americans.

Finally, I would like to discuss NIH as the principal funder of health services research, providing $921,000,000 or 3.3 percent of its entire budget for its work last year. While significant, this level is $17,000,000 less than the amount invested in the previous year.

We recommend that at least $1,000,000,000 for NIH health services research, which represents 3.3 percent of the nearly $31,000,000,000 that the broader health community is seeking for NIH.

In addition, we would hope NIH would increase the proportion of health services funding from 3.3 percent to 5 percent to assure that the discoveries from clinical trials that you have heard a lot of today are effectively translated into actual health services.

Mr. Chairman, the accomplishments of health services research would not be possible without your leadership and the support of this Subcommittee. We view these as critical investments in solving the rising costs of healthcare in this Country, in dealing with the entitlement crisis, in finding new and more effective ways of providing healthcare to all of our citizens.

We respectfully ask that you accept our recommendations, recognizing the substantial funding situation that you are dealing with, with the White House, for the Federal agencies that are funding health services research and health data.

Thank you for giving me the opportunity to be here today. I actually was happy to be the last person testifying here because it gave me an opportunity to hear and learn a lot about the challenges that we face, not only in solving the healthcare cost and quality problem but the challenges in just the basic research and investing in disease prevention and disease promotion. So, thank you for inviting us to testify.

[The information follows:]

Testimony of Kenneth E. Thorpe

Coalition for Health Services Research

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

Committee on Appropriations

U.S. House of Representatives

Thursday, March 13, 2008

Good morning, Mr. Chairman. I am Ken Thorpe, a member of the Board of Directors for the Coalition for Health Services Research (Coalition). I am the Executive Director of the Institute for Advanced Policy Solutions and the Robert W. Woodruff Professor and Chair of the Department of Health Policy & Management in the Rollins School of Public Health of Emory University in Atlanta, Georgia. In addition, I am the Executive Director of the Partnership to Fight Chronic Disease.

I am pleased to offer this testimony on behalf of the Coalition regarding the role of health services research in improving our nation's health. The Coalition's mission is to support research that leads to accessible, affordable, high-quality health care. As the advocacy arm of AcademyHealth, the Coalition represents the interests of 3,500 researchers, scientists, and policy experts, as well as 130 organizations that produce and use health services research.

Health care in the United States has the potential to improve people's health dramatically, but often falls short and costs too much. Health services research is used to understand how to better finance the costs of care, measure and improve the quality of care, and improve coverage and access to affordable services. It provides patients, providers, payers, and policymakers with the necessary tools to make health care:

- **Affordable**, by decreasing cost growth to sustainable levels.
- **Efficient**, by decreasing waste and overpayment and monitoring cost effectiveness of care.
- **Safe**, by decreasing preventable medical errors, monitoring public health, and improving preparedness.
- **Effective**, by evaluating programs and outcomes and promoting evidence-based innovations.
- **Equitable,** by eliminating disparities in health and health care.
- **Accessible,** by connecting people with the health care they need when they need it.
- **Patient-centered**, by increasing patient engagement in, and satisfaction with, the care they receive.

Indeed, health services research is changing the face of American health care, uncovering critical challenges facing our nation's health care system. For example, the 2000 Institute of Medicine (IOM) report *To Err is Human* found that up to 98,000 Americans die each year from medical errors in the hospital. Health services research also uncovered that disparities and lack of access to care in rural and inner cities result in poorer health outcomes. And, it found that obesity

accounts for more than $92 billion in medical expenditures each year and has worse effects on chronic conditions than smoking or problem drinking.

But health services research does not just lift the veil on problems plaguing American health care; it also seeks ways to address them. Health services research framed the debate over health care reform in Massachusetts—forming the basis for that state's 2006 health reform legislation—and continues to frame the debate on the national stage today. It offers guidance on implementing and making the best use of health information technology, and getting the best care at the best value across a menu of treatment options.

In fact, there are increasing examples that demonstrate how comparative effectiveness research—an emerging science in the broader field of health services research—provides the scientific basis needed to determine what treatments work best, for whom, and in what circumstances.

- The Agency for Healthcare Research and Quality (AHRQ) found that drugs can be as effective as surgery in management of gastroesophageal reflux disease (GERD)—where stomach acid enters the esophagus, causing heartburn and potential esophageal damage. GERD is one of the most common health conditions among older Americans and results in $10 billion annually in direct health care costs. Knowing that, for the majority of patients, drugs can be as effective as surgery in relieving the symptoms could result in significant health care savings and improved quality of life.

- The National Institute of Mental Health (NIMH) found that, within a class of antipsychotic drugs, the older, less expensive drug (Perphenazine) was just as effective and caused no worse side effects than the three newer, more expensive drugs in treating patients with schizophrenia. One of the newer drugs (Zyprexa) was slightly more effective in controlling systems than the other drugs, but at the cost of serious side effects.[i] This study enables greater flexibility in care and informs patients and providers about costs and quality of care.

As these examples suggest, health services research can contribute greatly to better health care at better value. It is a true public good, providing a basis for improvements in our health care system that will benefit the general public. Americans overwhelmingly agree. According to a 2005 *Research!America* survey, roughly 95 percent of Americas agree that it is important to support research that focuses on how well health care functions and how it can function better, and that health care delivery should be based on the best and most recent research available.[ii] After all, the investment in basic research and the development of new medicines and equipment is wasted if the health system cannot safely and effectively deliver that care.

For the last five years, the Coalition has been collecting data to track the federal government's expenditures for health services research and health data. From information provided to us by these funders—including AHRQ, National Institutes of Health (NIH), and the Centers for Disease Control and Prevention (CDC)—funding for this field has remained constant since 2003 and has not kept pace with inflation.

In stark contrast, spending on health care overall has risen faster than the rate of inflation—from $1.4 trillion in 2000 to nearly $2 trillion in 2005.[iii] The total federal investment in health services research and data by our estimates approaches $1.5 billion—representing just 0.075 percent of

the $2 trillion dollars we spend on health care annually.[iv] Health services research needs federal support—now more than ever—to help us spend our health care dollars more wisely.

We recognize the support the Subcommittee currently provides to federal agencies that fund health services research and now ask that the Subcommittee strengthen the capacity of the health services research field to address the pressing challenges America faces in providing access to high-quality, cost-effective care for all its citizens.

Agency for Healthcare Research and Quality
AHRQ is the lead federal agency charged with supporting unbiased, scientific research to to improve health care quality, reduce costs, advance patient safety, decrease medical errors, and broaden access to essential services.Yet chronic under-funding combined with an increasingly earmarked budget threatens the agency's ability to achieve this important mission—at a time when health care costs are at an all time high, and Americans' basic health status lags behind that of others around the world.

Before the targeted increase Congress provided last year to study the comparative effectiveness of health care interventions and Methicillin-resistant *Staphylococcus aureus* (MRSA), the agency's budget rose just 6.7 percent since FY 2002. Even with last year's increase, the agency has lost $19 million in purchasing power since FY 2005 due to inflation and years of flat funding. And under the President's budget, the agency stands to lose an additional $9 million.

This 'no growth' budget has a significant impact on the field of health services research and its ability to respond to the needs of policymakers. For example, investigator-initiated research, such as that undertaken by Lucian Leape in discovering the prevalence of medical errors (which provided the basis for the IOM's *To Err is Human)*, is now practically non-existent. Specifically, there has been a dramatic decline in the number of, and funding for, grants that support researcher innovation and career development; and based on the President's FY 2009 budget, support for these awards will hit new lows. AHRQ needs funding for new and competing grants to rejuvenate the free marketplace of ideas, and for supporting the next generation of researchers to ensure the field's capacity to respond to the growing public and private sector demand for research.

We join the Friends of AHRQ—a coalition of more than 100 health professional, research, consumer, and employer organizations that support the agency—in recommending a FY 2009 funding level of at least $360 million, an increase of $26 million over the FY 2008 level. This investment will allow AHRQ to restore its critical health care safety, quality, and efficiency initiatives; strengthen the infrastructure of the research field; and reignite innovation and discovery.

Centers for Disease Control and Prevention
Housed within CDC, the **National Center for Health Statistics** (NCHS) is the nation's principal health statistics agency, providing critical data on all aspects of our health care system. Thanks to NCHS, we know that too many Americans are overweight and obese, cancer deaths have decreased, average life expectancy has increased, and emergency rooms are over-crowded. We know how many people are uninsured, how many children are immunized, how many Americans are living with HIV/AIDS, and how many teens give birth.

Before the small increase Congress provided last year, NCHS had lost $13 million in purchasing power since FY 2005 due to years of flat funding and inflation. These shortfalls forced the elimination of data collection and quality control efforts, threatened the collection of vital statistics, stymied the adoption of electronic systems, and limited the agency's ability to modernize surveys to reflect changes in demography, geography, and health delivery.

Even amid deep cuts to CDC and health programs broadly, the President recognized the value of NCHS and its data to the health infrastructure, providing the agency nearly $125 million in his FY 2009 budget request. This level of funding is critical for sustaining uninterrupted collection of vital statistics from states. Without sustained support for these critical data systems, we are at risk of becoming the first industrialized nation unable to afford to continuously collect birth, death, and other vital health information. The Coalition joins the Friends of NCHS—a coalition of more than 100 health professional, research, consumer, industry, and employer organizations that support the agency—in supporting the President's funding request of $125 million to ensure uninterrupted collection of vital statistics; restore other important data collection and analysis initiatives; and modernize its systems to increase efficiency, interoperability, and security.

While significant funding has been provided to improve the public health system's capacity to respond to a terrorist attack or a public health crisis such as pandemic flu, insufficient funding has been provided to support research that evaluates the effectiveness of our preparedness interventions and seeks to improve the delivery of public health services. For example, how cost effective are public health and prevention programs? How can the medical care and public health delivery systems be better linked?

This important Public Health Research program has been flat funded since FY 2005 at a level of $31 million, and the President's budget requests this same amount in FY 2009. The Coalition requests at least $35 million for this program in FY 2009 to restore purchasing power to FY 2005 dollars.

Centers for Medicare and Medicaid Services (CMS)

The President's budget request for the Office of Research, Development and Information is $31 million—consistent the FY 2008 level. This level—a decrease of $26 million since FY 2006—hinders CMS' ability to meet its statutory requirements and conduct new research into Medicare, Medicaid, and SCHIP, public programs which together provide coverage to nearly 100 million Americans and comprise 45 percent of America's total health expenditures.[v] At a time when these programs pose an ever increasing threat to the nation's fiscal sustainability, it is critical that we adequately fund research to evaluate the programs' efficiency and effectiveness, and seek ways to curtail spending growth.

The Coalition supports a FY 2009 funding level of $45 million in discretionary research and development funding—in addition to funding for programmatic earmarks—as a critical down payment to help CMS recover lost resources and restore research to evaluate these programs, analyze pay for performance and other tools to update payment methodologies, and to further refine service delivery methods.

National Institutes of Health (NIH)
The NIH reported that it spent $921 million on health services research in FY 2007—roughly 3.3 percent of its entire budget—making it the largest federal sponsor of health services research. Nevertheless, this represents a $17 million decline over the previous fiscal year in the portion of NIH's total budget allocated to health services research.

For FY 2009, the Coalition recommends a funding level of at least $1 billion—3.3 percent of the nearly $31 billion the broader health community is seeking for NIH. We recognize the support various institutes now provide to fund health services research, but this level of funding should be viewed as our minimum request. We encourage NIH to increase the proportion of their overall funding that goes to health services research from 3.3 to 5 percent to assure that discoveries from clinical trials are effectively translated into health services. We also encourage NIH to foster greater coordination of its health services research investment across its institutes.

In conclusion, the accomplishments of health services research would not be possible without the leadership and support of this Subcommittee. As you know, the best health care decisions are based on relevant data and scientific evidence. Increased funding for health services research and health data will yield better information and lead to improved quality, accessibility, and affordability. We urge the Subcommittee to accept our FY 2009 funding recommendations for the federal agencies funding health services research and health data.

If you have questions or comments about this testimony, please contact Emily Holubowich, Director of Government Relations at 202.292.6743 or e-mail at emily.holubowich@academyhealth.org.

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[i] Lieberman, J.A., et. al. "Effectiveness of Antipsychotic Drugs in Patients with Chronic Schizophrenia," *New England Journal of Medicine*, Vol. 353, No. 12, pp.1209-1223 (Sept. 22, 2005). Available on the Web at http://content.nejm.org/cgi/content/abstract/353/12/1209

[ii] Woolley, M. and S. Propst. "Public Attitudes and Perceptions about Health-Related Research." *Journal of the American Medical Association*, Vol. 294, No. 11, p. 1382 (Sept. 21, 2005).

[iii] Catlin, A., et. al. "National Health Spending in 2005: The Slowdown Continues," *Health Affairs*, Vol. 26, No. 1, pp. 142-153 (Jan./Feb. 2007).

[iv] *Federal Funding for Health Services Research*, Coalition for Health Services Research (Feb. 2008). Available on the Web at www.chsr.org

[v] Catlin, A, et. al. "National Health Spending in 2005: The Slowdown Continues," *Health Affairs*, Vol. 26, No. 1, pp. 142-153 (Jan./Feb. 2007).

Mr. OBEY. Thank you.

Just two points, you mention that this Country spends more than any other country on healthcare. Paul Krugman, in his new book, has pointed out that I believe he said almost 30 percent of every dollar spent on healthcare in this Country is spent not to deliver healthcare but in an effort to deny someone healthcare. Given your comment about the cost, I thought we ought to put that in the record.

Secondly, again, in terms of the context, the President's budget request for 2008 increased funding for the agency by $11,000,000 or 3 percent. In the final 2008 appropriation bill, this Committee went a step further and provided a $5,000,000 or a 1.5 percent increase above the President. These are all very small numbers, but they are very important.

The President's request this year cuts the 2009 budget by $9,000,000 or a 2.7 percent reduction. To me, these expenditures are so small, but they are designed to tell us what works and what does not, which is fairly important if you are going to spend taxpayers' money, I would think.

To me, to cut this budget is penny-wise and pound-foolish.

Mr. SIMPSON. I do not know if I got the message. Did you support the President's actual bill?

Mr. OBEY. I did not.

Mr. SIMPSON. I am just kidding. As you know, I supported your actions to override the President's veto because I think it was foolish on the White House's part because this really is an investment in the future. I think, quite frankly, we do not do enough in healthcare research. We do not do enough in basic science research and other research as is necessary in this Country.

But I was just curious. A lot of the organizations and groups that have come up today and testified have asked for a 6.7 percent increase in NIH funding. Do you know where that 6.7 percent comes from?

I do not know where they came up with 6.7 percent.

Mr. OBEY. Well, you will have to ask them. My request has always been to avoid a specific number like that because it creates false expectations.

Mr. SIMPSON. Yes. Well, I was curious.

Mr. OBEY. Very frankly, when we passed the bill out of the House, there were a number of health organizations who spent more time arguing about what little piece of the pie they got and did not get than they spent working on the House and the Senate to build enough votes to overcome the President's veto.

Mr. SIMPSON. That is right.

Mr. OBEY. In the end, we wound up with a bill which was below the original House-passed bill. I tried to warn people that could happen.

Mr. SIMPSON. Well, I was curious. As you know, the VSOs in the veterans area come together with kind of a VSO budget that they would like to see passed. I was wondering if these groups got together and talked about what they think is necessary in NIH and stuff. I am not criticizing it or anything.

If that is where 6.7 percent came from, why is not it 5.5? Why not 9.5?

Mr. OBEY. I share their goal.

Mr. SIMPSON. As do I.

Mr. OBEY. But the question is under these circumstances, what is the best you can do without endangering your ability to deliver anything?

Mr. SIMPSON. Yes. One of the real things we learned the other day, we knew it beforehand, when we went out to NIH. Chairman Obey took several of us out there, and we took a tour of NIH and some of the institutes out there. They called it the doubling of the NIH budget, those years when we attempted for five years to double the NIH budget. Now it is the undoubling of the NIH budget, quite frankly, because we are losing ground.

If we had just gone up at a steady rate and had not looked at doubling, just gone up at a steady rate, a steady, modest rate, and done it over the full period of time, we would probably be ahead of where we are not. But we did the doubling and then everybody said, okay, that is done.

Mr. OBEY. That is the problem.

Mr. SIMPSON. Exactly.

Mr. OBEY. I mean it is appalling to me that we spent the money that we spent to map the human genome, and we have made a concerted effort to greatly increase the NIH budget while we were doing that, and now that we have completed the job, we have the keys that can open a lot of doors, but somehow we appear not very anxious to go through those doors.

Mr. SIMPSON. Exactly.

Mr. OBEY. That just makes no sense to me. After we spent all of the money in a preliminary effort to get us into a position to really make some progress, now we are saying, well, we think we will take the slow train.

Mr. SIMPSON. Well, I appreciate your leadership on this Committee and particularly in this area, Mr. Chairman.

Mr. OBEY. And I appreciate your support, too.

Thank you very much. We appreciate your coming.

Mr. THORPE. Thanks for having us.

STATEMENTS FROM RELATED AGENCIES ON FISCAL YEAR 2009 BUDGET

STATEMENT ON THE BUDGET REQUEST
FOR FISCAL YEAR 2009
DAVID EISNER
CHIEF EXECUTIVE OFFICER
CORPORATION FOR NATIONAL AND COMMUNITY SERVICE
HOUSE APPROPRIATIONS SUBCOMMITEE ON LABOR, HEALTH, AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES
March 2008

Chairman Obey, Ranking Member Walsh, and members of the Subcommittee, on behalf of my colleagues, I am grateful for the opportunity to submit testimony supporting the Fiscal Year 2009 President's Budget for the Corporation for National and Community Service (the Corporation). Through the programs of the Corporation, Americans of all ages and abilities are investing their time, energy, and talent to improve the lives of others, strengthen their communities, and foster a culture of civic engagement and responsibility across the nation.

In his recent State of the Union address, President Bush said that over the last seven years, more of our fellow citizens have "discovered that the pursuit of happiness leads to a life of service." Since the President's call to service in 2002 when he asked all Americans to give two years of their lives -- 4,000 hours of their time -- in service to others, Americans have answered that call. Indeed, Americans are now volunteering in record numbers tackling the tough problems of illiteracy, gang violence, homelessness, crime, hunger, drug abuse, children aging out of foster care, elder care, and the divide between the haves and the have-nots. As volunteers meet vital needs every day, they demonstrate that service is no longer something that is merely nice to do, but necessary to solving the intractable problems that face our society.

In FY 2007, over 2.1 million Americans served through the Corporation's programs – AmeriCorps, Senior Corps, and Learn and Serve America. Another 1.8

million volunteers were recruited, coordinated, or supported by our participants. Together, they gave over 228 million hours of service in communities around the country. To continue this important work, the President is requesting $829.7 million for Fiscal Year 2009 for the Corporation and its programs. The funds will support 75,000 AmeriCorps members, provide service opportunities for nearly 500,000 Senior Corps volunteers, and engage 1.3 million students in service-learning activities through Learn and Serve America.

The past several years have presented us with an unprecedented climate in which to foster volunteer national service. Our research shows that some volunteer rates are at a 30-year high, with Baby Boomers volunteering at their highest rate in a generation and at the highest rate of any age group. College student volunteering is up 20 percent and – one of the most significant trends – teens today are twice as likely to volunteer as teens did in the '70s and '80s. In addition, there's been increasing focus on civic engagement by government, foundations, corporations, and nonprofits all seeking to expand volunteer service. The Corporation itself has experienced bipartisan support, including the support of this Subcommittee.

The Corporation has capitalized on this once-in-a-generation opportunity to grow and sustain a significant upsurge in citizen engagement. In 2006, we adopted a strategic plan that set forward service goals for the Corporation for the next five years: mobilizing more volunteers; ensuring a brighter future for America's youth; engaging students in communities; and harnessing Baby Boomers' experience. We added a fifth strategic initiative – preparing for and responding to disasters – in 2007.

In addition to Corporation program operations, we have implemented several major activities to bolster progress towards our strategic goals.

The 2008 Martin Luther King Jr. Day of Service on January 21 was the largest ever with more than half a million volunteers serving in more than 5,200 projects in all 50 states. Volunteers built homes, delivered meals, read to children, signed up mentors and did so much more as they honored Dr. Martin Luther King, Jr. by continuing his ethic of service.

In an innovative and collaborative effort we joined the President's Council on Service and Civic Participation, the Points of Light & Hands On Network, the Taproot Foundation, UPS, and USA Freedom Corps, with support from Citi, the Committee Encouraging Corporate Philanthropy, and Target, to sponsor the Summit on Corporate Volunteerism on February 13, 2008. Many nonprofit organizations are tackling and succeeding in turning around the most vexing social problems, but lack the capacity to carry their programs to scale without the help of more skilled volunteers. The summit brought together 130 business, government, and nonprofit leaders to discuss their pro bono service efforts and map strategies to boost skilled volunteering in professions such as marketing, finance, technology, and management consulting.

The business and nonprofit leaders at the summit launched a three-year campaign to generate $1 billion of pro bono service to help nonprofits become more effective in meeting social and community needs. Major global companies committed to ramp up their pro bono efforts and eight companies announced specific pledges totaling more than $110 million.

We also looked for ways to improve and expand Corporation services and to reinvent volunteering in nonprofit organizations and expand opportunities to underserved communities. In October, we joined 21 other federal agencies as a participant in the DisabilityInfo.gov Web site, which will help us reach the 54 million Americans with disabilities, their friends, and families, with information on the many opportunities to participate in Corporation programs. We have committed over $50 million toward inclusion of persons with disabilities in our programs over the last ten years and are deeply committed to having more persons with disabilities serve in our programs.

In November, we came together with tribal leaders and volunteers at our annual tribal conference to help expand the reach and impact of tribal service programs in Native communities. At home, we are expanding our tribal outreach with new staff, technology, and resources.

We also funded four new grant recipients in 2007 to develop next-generation volunteer management tools and practices. The grants went to the Maine Commission on Community Service, the Girls Scouts of the USA, Nazarene Compassionate Ministries and America SCORES. Grantees were selected from more than 400 national and local applicants in a highly competitive process. The organizations are using the grants to professionalize their volunteer management practices and infrastructure, including collecting information on volunteers to best match their skill sets and preferences to the appropriate volunteer tasks. Through a one-time investment of about $650,000, and just three months into the grant period, we are already beginning to see the potential return.

The Corporation's Office of Research and Policy Development supports and conducts research and evaluation that undergirds policy development and decision-

making, not just for the Corporation, but for the entire nonprofit sector. The Volunteering in America survey results will be available later this year, and in May, we will release the results of the largest and most comprehensive study of AmeriCorps, *Serving Country and Community: A Longitudinal Study of Service in AmeriCorps.* This survey is designed to assess the longer-term effects of participation in AmeriCorps State and National and AmeriCorps NCCC. We will be happy to brief the Subcommittee on the results of this work.

These accomplishments, while significant, don't tell the full story of the effects our programs are having on the lives of individuals and communities across our nation. We are helping some of the 37 million Americans – including 13 million children – who live in poverty, reaching out to some of the 3.5 million Americans who have no place to live, creating opportunities for some of the more than 600,000 prisoners released into their communities annually, and mentoring their children.

The RSVP of Portage County and the Charles F. Fernandez Center for Alternative Learning in Stevens Point, Wisconsin operate an innovative program that has been building intergenerational relationships for over eight years. RSVP volunteer woodworkers teach students basic woodworking skills in a fully equipped workshop at the school. All of the students are considered high risk because of truancy, drug and alcohol dependency, dysfunctional home life, or having an incarcerated parent. During the 2007 school year, 20 RSVP volunteers worked a total of 990 hours with 52 students on a one-on-one basis. While these volunteers taught woodworking skills, at the same time they served as mentors and role models to the young people. Teachers and volunteers reported that the students demonstrated increased self-esteem and

social/emotional confidence as a result of the mentoring. One of the most amazing sidelights of this program is that its creator, Charles Fernandez, who is age 85 and a current RSVP volunteer, is now working with the Boys and Girls Club to start an auto body repair program for adjudicated juveniles.

AmeriCorps members with Lutheran Social Services of Illinois provide support services for children of prisoners and assist offenders with community re-entry. Members encourage and strengthen family connection programs in 16 prisons across the state. Activities include the Storybook Project, which allows prisoners to record reading a book to their children, and ensures that the family receives the recording. It also includes facilitated prison "visits to Mom and Dad," that strengthen family relationships and support family reunification. The program has served over 4,500 individuals and children during its first year of operations.

Service-learning projects find other innovative ways to reach young people. Students at Otterbein College in Westerville, Ohio, one of six schools recently recognized with the President's Community Service Honor Roll award, partner with Genoa Middle School in a service-learning project funded by Learn and Serve America called the Creative Literary Alliance. Otterbein's creative writing students serve as "poets in residence" at the middle school, teaching over 300 diverse and economically disadvantaged urban youth. This year, the middle school students wrote, directed, and acted in plays to raise community awareness about violence, bullying, positive relationships with teachers, and identity issues. The plays were performed for teens throughout the city extending the impact of the program far beyond the Genoa students. According to the principal at Genoa, Otterbein students helped the Genoa students

achieve a significant increase in Ohio standardized scores in reading. This observation has challenged to us to evaluate this service model, and we are hopeful that it holds promise for having positive impacts elsewhere.

The Save the Bay program sponsored by the Ocean State Environmental Education Collaborative has served over 9,800 students in Rhode Island's core cities, providing approximately 800 programs to supplement or enhance science programs. The program intentionally operates in communities with the highest poverty levels. Fifteen AmeriCorps members reach students through the classroom, after-school, summer camp and public outreach. The program demonstrates that the values taught in caring for the environment are intrinsic to caring about and improving lives generally and can help young people see that they can have an impact in their communities.

Our programs also focus on Americans at the opposite end of the age spectrum – the elderly. For example, ten RSVP volunteers in the Wayne County (New York) Action Program lead the RSVP Osteoporosis Exercise and Education Program, teaching specific exercises and weekly discussion groups on nutrition, lifestyle, and medication options to help mitigate or prevent osteoporosis. The NY Department of Health reported that at least 3 million men and women over age 50 either have osteoporosis or are at significant risk for the disease. Participants in the exercise and education program reported improved activity and energy levels, as well as an overall improvement in quality of life since they began the program. In the Pueblo of Isleta, New Mexico, the Legacy Corps AmeriCorps members provide in-home respite care service to frail and home-bound seniors and their caregivers, who are primarily Native Americans.

Homelessness and poverty exist in areas as different from one another as urban California and rural Montana. During the past year, the Hope for the Homeless Program in Los Angeles engaged 32 formerly homeless individuals as AmeriCorps members. These street-smart members served over 15,000 homeless individuals and families, successfully moving more than 5,000 individuals toward permanent economic self-sufficiency and stable housing. At the Veterans Service Center in Hamilton, Montana, a single RSVP volunteer schedules and supervises over 95 volunteers who operate the center five days a week and staff the yearly "Stand Down to Help Veterans" event. In 2007, they served 466 veterans and families, including more than 40 homeless veterans.

VISTA members with the GRID Alternatives Solar Affordable Housing Program in San Francisco train and lead teams of community volunteers to install solar electric systems and energy efficient upgrades for low-income California homeowners. For most of the program year, a single VISTA member served the program. But that one VISTA helped GRID exceed each of its proposed annual goals. Proving the ability of VISTA members to recruit and manage community volunteers, he helped add 520 newly trained community volunteers who contributed over 10,000 hours of service and installed 50 new solar electric systems. The VISTA indentified 12 new GRID clients, streamlined the volunteer database and was instrumental in expanding chapter offices to Los Angeles and Fresno. As a result of his work with the volunteers, many low-income Californians were able to reduce their heating and cooling costs.

Our national service members were also able to help other Americans regain their footing in the wake of a natural disaster. In Westchester, New York, eight AmeriCorps NCCC members partnered with the Westchester Habitat for Humanity to assist residents

recovering from flooding last spring. NCCC members refurbished damaged homes and helped community members move on with their day-to-day lives and look towards long term solutions against flooding. NCCC members helped 300 members of the local community, providing 1,700 hours of service.

In addition to providing direct service such as disaster relief, NCCC members recruited, or worked with organizations that recruited 138,000 volunteers last year to assist in their vital work—that is 130 volunteers per member. In 2009, we estimate that NCCC members will work with organizations that will mobilize 175,000 volunteers.

Since we believe that volunteering is essential to meeting the country's vital needs, we have successfully refocused our programs on recruiting community volunteers, in addition to the direct service they already provide. This is important because the volunteers themselves can reap tangible health benefits when they give back to their communities. The Corporation is noticing increasing numbers of studies and reports that suggest that volunteering to meet community needs has beneficial effects, including physical, emotional and mental well-being. Following up on these studies, the Corporation is interested in conducting research to determine the impact of citizens serving in national service programs. In addition to maintaining excellence throughout our programs, we are therefore committed to strengthening the volunteer sector through a continued focus on volunteer recruitment by our national service members.

The President's Fiscal Year 2009 Detailed Budget Request

The President's Fiscal Year 2009 budget request of $829.7 million for the Corporation will help grow volunteering in the United States, strengthen how service

meets local needs, and help nonprofits better engage the power of Americans to give back to their communities.

In addition to supporting volunteering and our national service programs, the budget supports the Corporation's further steps toward excellence as a well-managed, fully accountable organization that links strategic and operational goals, and continually improves its performance.

AmeriCorps

AmeriCorps engages members in full- and part-time service to strengthen communities and solve our nation's toughest problems in the areas of education, public safety, health, and the environment. In FY 2007, AmeriCorps proudly marked the enrollment of its 500,000th member since it began in 1994. For FY 2009, the proposed AmeriCorps request of $507.7 million supports the President's goal to provide funding that can support 75,000 AmeriCorps members serving in our three AmeriCorps programs:

$274.2 million for AmeriCorps State and National Grants

Grants to state service commissions and nonprofit organizations fortify the infrastructure of the nonprofit sector, increasing the scope and quality of services available at the state and local level. This funding will support nearly 67,000 members, or nearly 90 percent of the 75,000 AmeriCorps total. AmeriCorps members serving in these organizations multiply their effectiveness many times over through their ability to recruit, train, and deploy community volunteers. We project that these AmeriCorps members will help to mobilize 925,000 community volunteers in FY 2009.

$91.6 million for AmeriCorps VISTA

For more than 40 years, VISTA has fought poverty in some of our nation's poorest urban and rural areas by strengthening local organizations and communities and building permanent solutions to poverty rather than making it merely more tolerable. This request will support 6,900 VISTA members who will focus on mentoring disadvantaged youth and children of prisoners, assisting youth aging out of foster care, and engaging disadvantaged youth in service.

$9.8 million for AmeriCorps National Civilian Community Corps (NCCC)

AmeriCorps NCCC has a long history of involvement with disaster response. They have performed remarkable work in the Gulf, and since Hurricane Katrina, NCCC members have served 1.5 million hours on 610 relief and recovery projects associated with disasters across the country. The request of $9.8 million, plus $6.3 million in carryover funds, and an additional estimated $10 million in planned private sector giving, will support 1,120 members. NCCC will continue to emphasize disaster services and serve as the programmatic lead for our disaster service strategic initiative.

$132.1 million for the National Service Trust

The Trust provides funds for the Segal AmeriCorps Education Awards for eligible participants who complete AmeriCorps service. The awards can be used to pay for the member's college education or pay back eligible student loans. For a year of full-time service, the award is $4,725, with lesser awards for less than full-time service. Funding for the Trust comes from appropriations, earned interest, and proceeds from the sale or redemption of Trust investments. More than 400,000 AmeriCorps members have earned

Segal AmeriCorps Education Awards totaling over $1 billion since the program was launched in 1994.

Senior Corps

The FY 2009 budget request for Senior Corps is $174 million for the three Senior Corps programs – RSVP, Senior Companion, and Foster Grandparent programs. This funding will support nearly 500,000 participants age 55 and above, many of whom provide individual attention to the most vulnerable in our society – children and the frail elderly. Overall, Senior Corps programs expect to serve 241,000 children, and provide independent living and respite services to 416,660 seniors and their caregivers.

$59.7 million for RSVP

The largest and most flexible of the Senior Corps programs, RSVP, taps the skills, talents and interests of volunteers age 55 and over to meet a wide range of community needs – from tutoring to supporting independent living services to disaster response and recovery. Through its network of 741 grantees, this request will allow over 428,500 RSVP volunteers to expand the capacity of more than 65,000 community organizations nationwide.

$46.1 million for the Senior Companion Program

The Senior Companion Program provides an economical and necessary component to the continuum of care required for our nation's aging population, particularly the increasing number of frail elderly – age 85 and above – who wish to remain independent in their own homes. This request will allow the Corporation to support 15,200 Senior Companions, age 60 and over, who will continue to provide independent living services to over 60,000 clients and their caregivers.

$68.1 million for the Foster Grandparent Program

Foster Grandparents, age 60 and over, help address a critical challenge in America providing one-on-one mentoring, nurturing, and support to children with special or exceptional needs. In 2007, Foster Grandparents served 284,000 children and youth filling the need for a caring, consistent presence in the lives of these young people. Although the request is less than last year, the FY 2009 budget will support 19,800 Foster Grandparents who continue to provide valuable service to children across the country. This program continues to be the largest investment in the Senior Corps portfolio.

Learn and Serve America

Learn and Serve America provides an on-ramp to active citizenship and lifelong volunteering for over one million students, from kindergarten through college. Service-learning programs integrate hands-on community service with classroom activity, giving students an opportunity to identify and address community needs while improving their academic, civic, and social skills. For FY 2009, the Corporation requests $32 million for Learn and Serve America to engage 1.3 million service-learning participants, including a greater number of at-risk youth. In addition, the program will focus on the critical science, technology, engineering, and math (STEM) disciplines.

Management Excellence

The Corporation is fundamentally a different organization than it was four years ago. As the Subcommittee is aware, we have taken strong steps to improve our management and operations, increase cost-effectiveness, and create an organizational culture that promotes performance and accountability. By every indicator we have been

successful – with government surveys giving us high marks for customer service, and OPM surveys and employee retention demonstrating improved staff morale and high job satisfaction. I am also very pleased to report that we received an unqualified audit opinion on our FY 2007 financial statements for the eighth consecutive year, with no material weaknesses or reportable conditions.

Achieving this level of management excellence came as a result of the work of many people throughout the Corporation and our dedicated Board of Directors. But, I also want thank this Subcommittee for its support throughout the process, and especially for working with us on specific legislative policy changes that make our programs more effective and efficient. In particular, streamlining of our account structure provides us more flexibility in making budget adjustments and managing our programs more effectively.

The most significant policy changes allow AmeriCorps and its grantees greater flexibility in meeting local needs. Moving to one-year funding for formula funds allows state commissions to access the full amount of their formula allocation, even when they have not yet completed the state selection process. The Professional Corps' waiver language will enable Commissions to support AmeriCorps programs providing teachers, firefighters, police, and other professionals in shortage areas in ways that best meet the needs of their states and constituents. And, allowing AmeriCorps programs to have a single match of Corporation funds rather than two matches gives them flexibility to optimize their community's support for the program.

Chairman Obey, it has been a privilege to work with you and to serve with my Corporation colleagues in service to our country. You have expressed your desire that

what your committee does today will have positive effects on America ten years from now. In his State of the Union address, the President said that "we must trust the good heart of the American people and empower them to serve their neighbors in need." By making a strong investment in service and civic engagement now, we will empower the citizens of our great land to make a difference in their communities that will positively impact the lives of millions of Americans for years to come.

RAILROAD RETIREMENT BOARD
FISCAL YEAR 2009 BUDGET REQUEST

Statement for the Record, March 31, 2008

HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES

Michael S. Schwartz, Chairman of the Board

V. M. Speakman, Jr., Labor Member of the Board

Jerome F. Kever, Management Member of the Board

Mr. Chairman and Members of the Committee:

We are pleased to present the following information to support the Railroad Retirement Board's (RRB) fiscal year 2009 budget request.

The RRB administers comprehensive retirement/survivor and unemployment/sickness insurance benefit programs for railroad workers and their families under the Railroad Retirement and Railroad Unemployment Insurance Acts. The RRB also has administrative responsibilities under the Social Security Act for certain benefit payments and Medicare coverage for railroad workers. During fiscal year 2007, the RRB paid $9.8 billion in retirement/survivor benefits and vested dual benefits to about 616,000 beneficiaries. We also paid $74.6 million in net unemployment/sickness insurance benefits to about 29,000 claimants.

PRESIDENT'S PROPOSED FUNDING FOR AGENCY ADMINISTRATION

The President's proposed budget would provide $105,463,000 for agency operations in fiscal year 2009, which is about $4 million less than we originally requested. By comparison, the Consolidated Appropriations Act, 2008 (P.L. 110-161) provided about $101.9 million for RRB operations in 2008, which includes a rescission of $1.8 million.

At the President's proposed level of funding, the RRB would be able to maintain a staffing level of 910 full-time equivalent staff years (FTEs) in 2009. This represents a reduction of 8 FTEs from our current funded level, and continues a downward trend which has reduced the RRB's staffing by nearly half since 1993. This downward trend adversely impacts our succession planning efforts as it restricts our ability to replace employees who leave the agency.

The President's proposed budget would provide $2,370,000 for information technology (IT) investments. Nearly $1.5 million of this amount will be needed for network operations, emergency equipment replacement, IT tools and task order services. The remaining funds, totaling about $870,000, would be available for information security improvements, system modernization, and E-Government initiatives. At this budget level we would delay replacement

of desktop computing equipment in accordance with the agency's life cycle replacement schedules for the second year in a row. In addition, we would delay development of electronic personnel files, which is part of the Enterprise Human Resources Initiative.

AGENCY STAFFING

Like many agencies, the RRB has an aging workforce. Current estimates show that about one in three RRB employees will be eligible for retirement by fiscal year 2009. To prepare for the coming transition in our workforce, we have undertaken major initiatives related to training and succession planning.

In connection with these initiatives, the agency is looking at a variety of critical positions to identify any gaps in particular competencies or skills that exist within the workforce. In some cases, we have provided supplemental developmental and training opportunities to current employees so that the activities associated with these positions will continue effectively as more experienced employees leave the agency. We have also continued hiring to fill essential positions as funding levels permit. In fiscal year 2007, for the first time in many years, the RRB was able to hire entry-level employees for two claims examiner training classes. Given the expected increase in the agency's attrition rate, new employees such as these will be key to the RRB's long-term success in continuing to provide outstanding service to our customers.

Partially in response to recommendations and suggestions made by the Office of Personnel Management, the RRB is also in the process of developing more formalized human capital management and succession planning documents. We have created an internal succession planning task force, chaired by the Director of Human Resources, to provide coordination and consolidation of existing plans, as well as identify new initiatives to address this important area.

FIELD SERVICE MODERNIZATION

During fiscal year 2007, we restructured the RRB's field service operations along the lines of a hub-and-satellite configuration, which will enable the agency to maintain customer service by utilizing new technologies more effectively. The hub-and-satellite configuration will support telephone and face-to-face service for our customers, and will allow agency management to more effectively balance and share workloads among the offices in each network. By the end of fiscal year 2008, we will close the RRB's three regional offices and consolidate them into corresponding hub offices.

The field restructuring plan also calls for the possibility of using "virtual offices" and/or "co-located offices." In 2007, the agency began pilot-testing an arrangement to provide customer service through an off-site claims representative. The pilot, which is continuing, is designed to serve as a test environment to determine the kinds of procedures and technologies that would be needed to establish virtual offices in the future.

Work is continuing to build, test and implement technology infrastructure improvements for the field service. The completion of this infrastructure is contingent upon sufficient funding being made available. Ongoing initiatives include, among other things:

- Toll-free telephone service: Nationwide toll-free service is a key component of our field technology plans. In fiscal year 2007, we contracted with Qwest Government Services, Inc. (under the General Services Administration's Networx Universal) for development of the RRB's toll-free service. We plan to begin offering the service in 12 pilot offices between April and June 2008, as part of the initial proof-of-concept phase, and to complete overall implementation by December 31, 2008.

- Expansion of interactive voice response (IVR) service: After the implementation of toll-free telephone service, we also plan to expand the range of services that can be accessed through the IVR system. The IVR system will continue to be accessible to callers through the 800 number, but will also be substantially modified in the future to allow for more interactive transactions and better security. Initially, it will continue to provide all current services, plus an option for the caller to be able to speak to a field service representative at any time during the call.

- Additional Internet self-service options: By fiscal year 2009, we expect to implement a system that will enable railroad employees to file sickness insurance claims through the Internet. We also plan to provide expanded Internet reporting functions for rail employers.

- Document imaging: In fiscal year 2007, we conducted a pilot program involving the expansion of our existing document imaging system to four pilot field offices. During fiscal year 2008, we are expanding the use of document imaging to 25 additional offices. The remaining offices are scheduled for implementation during fiscal year 2009.

In March 2007, we also implemented an on-line system to allow our employees to track and record direct customer contacts. This system enhances our ability to handle telephone calls in a more effective manner, regardless of which field office answers the call. We are confident that the strategic use of technology in our telecommunications and other processes is the foundation needed for the most effective and efficient use of agency resources, allowing us to continue to provide the excellent service that our customers have come to expect.

The President's proposed budget includes $72 million to fund the continuing phase-out of vested dual benefits, plus a 2 percent contingency reserve, $1,440,000, which "shall be available proportional to the amount by which the product of recipients and the average benefit received exceeds the amount available for payment of vested dual benefits."

In addition to the requests noted above, the President's proposed budget includes $150,000 for interest related to uncashed railroad retirement checks.

FINANCIAL STATUS OF THE TRUST FUNDS

Railroad Retirement Accounts –The RRB continues to coordinate its activities with the National Railroad Retirement Investment Trust (NRRIT), which was established by the Railroad Retirement and Survivors' Improvement Act of 2001 to manage and invest railroad retirement assets. Through fiscal year 2007, the RRB transferred about $21.3 billion to the NRRIT for this purpose. During the same period, the NRRIT transferred approximately $5.0 billion to the Railroad Retirement Account for payment of retirement and survivor benefits. During fiscal year 2007, these transfers totaled $1.391 billion. As of September 30, 2007, the market value of NRRIT-managed railroad retirement assets was approximately $32.7 billion.

In June 2007, we released the annual report on the railroad retirement system required by Section 22 of the Railroad Retirement Act of 1974, and Section 502 of the Railroad Retirement Solvency Act of 1983. The report, which reflects changes in benefit and financing provisions under the Railroad Retirement and Survivors' Improvement Act of 2001, addresses the 25-year period 2007-2031 and contains generally favorable information concerning railroad retirement financing. The report includes projections of the status of the retirement trust funds under three employment assumptions. These indicate that, barring a sudden, unanticipated, large decrease in railroad employment or substantial investment losses, the railroad retirement system will experience no cash flow problems throughout the projection period.

Railroad Unemployment Insurance Account – The equity balance of the Railroad Unemployment Insurance Account at the end of fiscal year 2007 was $100.7 million, an increase of $3.4 million from the previous year. The RRB's latest annual report on the financial status of the railroad unemployment insurance system was issued in June 2007. The report indicated that even as maximum daily benefit rates rise 49 percent (from $57 to $85) from 2006 to 2017, experience-based contribution rates maintain solvency. The average employer contribution rate remains well below the maximum throughout the projection period, but a 1.5 percent surcharge, which is now in effect, is expected for calendar year 2009, and is likely for calendar year 2010. The report did not recommend any financing changes.

In conclusion, we want to stress the RRB's continuing commitment to improving our operations and providing quality service to our beneficiaries. Thank you for your consideration of our budget request. We will be happy to provide further information in response to any questions you may have.

MARTIN J. DICKMAN, INSPECTOR GENERAL, RAILROAD RETIREMENT BOARD

BEFORE THE
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES
OF THE COMMITTEE ON APPROPRIATIONS
U.S. HOUSE OF REPRESENTATIVES

TESTIMONY OF THE INSPECTOR GENERAL OF THE RAILROAD RETIREMENT BOARD

March 31, 2008

INTRODUCTION OF WITNESS

Mr. Chairman and Members of the Subcommittee:

My name is Martin J. Dickman and I am the Inspector General for the Railroad Retirement Board. I would like to thank you, Mr. Chairman, and the members of the Committee for your continued support of the Office of Inspector General.

BUDGET REQUEST AND BACKGROUND INFORMATION

I wish to describe our Fiscal Year (FY) 2009 appropriations request and our planned activities. The Office of Inspector General (OIG) respectfully requests funding in the amount of $7,806,000 to ensure the continuation of its independent oversight of the Railroad Retirement Board (RRB).

The agency's central mission is to pay accurate and timely benefits. During FY 2007, the RRB paid approximately $9.7 billion in retirement and survivor benefits to 600,000 beneficiaries. RRB also paid $73 million in net unemployment and sickness insurance benefits to almost 28,000 claimants during the benefit year ending July 30, 2007. The Railroad Medicare Part B carrier, Palmetto GBA, paid approximately $897 million in medical insurance benefits for more than 496,000 beneficiaries.

During FY 2009, the OIG will perform reviews of significant policy issues and program operational areas. We will coordinate our efforts with agency management to identify and eliminate operational weaknesses. We will also continue our investigation of allegations of fraud, waste and abuse, and refer cases for prosecution and monetary recovery action.

NATIONAL RAILROAD RETIREMENT INVESTMENT TRUST

The OIG respectfully requests oversight authority to conduct audits and investigations of the National Railroad Retirement Investment Trust (NRRIT). The sole purpose of the NRRIT is to manage and invest railroad retirement assets in a diversified investment portfolio in the same manner as those of private sector retirement plans. The NRRIT is responsible for the investment of approximately $32.7 billion in trust funds used to support Railroad Retirement Act benefit programs. We continue to express concerns about the RRB's passive relationship with the NRRIT. Federal oversight of the NRRIT does not include performance audits by an independent auditor such as the OIG, Government Accounting Office or a public accountant. The NRRIT plays a critical role in the financing and future solvency of the RRB program. If oversight authority is granted, my office would work to ensure sufficient reporting mechanisms are in place and that the NRRIT management is fulfilling their fiduciary responsibilities. The program and its public constituency would benefit from an OIG that is permitted to fulfill its statutory role by extending its oversight responsibilities to the NRRIT.

MANDATED REIMBURSEMENTS TO THE AGENCY

The OIG is currently required to reimburse the agency for office space, equipment, communications, office supplies, maintenance and other administrative services. We are the only federal OIG that cannot negotiate a service level agreement with its parent agency. The current mandate has resulted in a burdensome accounting and reconciliation process. Removal of the current language would permit a more efficient and fair negotiation between the RRB and the OIG.

OFFICE OF AUDIT

The Office of Audit (OA) conducts financial, performance and compliance audits to ensure the economy, efficiency and effectiveness of RRB programs. The OA efforts are directed primarily to fulfilling the financial audit and information security evaluation requirements mandated by law. As resources permit, audit staff will undertake to perform other audits, evaluations and monitoring activities that will add value to agency operations.

The OA conducts the annual audit of the RRB's financial statements. During FY 2009, the OA will complete the audit of the agency's FY 2008 financial statements and begin the audit of the FY 2009 statements. The annual financial statement audit is conducted using OA staff with technical assistance from actuarial specialists under contract to the OIG. Audit staff will continue to work with agency management to ensure that the necessary detailed, verifiable financial information is available from the NRRIT. This effort includes periodic stand-alone audits that support the office's overall financial audit responsibility.

Audit staff will also conduct the annual evaluation of the RRB's information security pursuant to the requirements of the Federal Information Security Management Act of 2002. This annual effort includes stand-alone audits of controls in various agency systems conducted during the year as well as the additional evaluation work required to respond to certain areas about which the Office of Management and Budget requires more specific information. The related area of privacy of sensitive and confidential information will remain a concern.

OA will continue to monitor agency actions in response to audit recommendations. As resources permit, the OA will work to identify potentially at-risk areas of agency responsibility, perform risk assessments and plan audits to disclose deficiencies in internal control, compliance with applicable laws and regulations, and fraud vulnerabilities in the benefit programs administered by the RRB.

The OA does not anticipate performance audits of the NRRIT because, as we have previously stated, it is our understanding that the OIG does not have a role in oversight of the NRRIT.

OFFICE OF INVESTIGATIONS

The Office of Investigations (OI) focuses its efforts on identifying, investigating and presenting cases for prosecution, throughout the United States, concerning fraud in RRB benefit programs. OI conducts investigations relating to the fraudulent receipt of RRB sickness, unemployment, disability or retirement benefits. OI also investigates railroad employers and unions when there is an indication that they have submitted false reports to the RRB. RRB Medicare oversight authority was reinstated to the OIG on December 26, 2007. This authority allows the OIG to investigate allegations of fraud, waste and abuse in the RRB Medicare program. Investigative efforts can result in criminal convictions, administrative sanctions, civil penalties and the recovery of program benefit funds.

OI initiates cases based on information from a variety of sources. The agency conducts computer matching of employment and earnings information reported to state governments and RRB benefits paid. Referrals are made to OI if a match is found. OI also receives allegations of fraud through the OIG Hotline, contacts with state, local and Federal agencies, and information developed through audits conducted by the OIG's Office of Audit.

OI's investigative results for FY 2007 are:

Civil Judgments	Indictments/Informations	Convictions	Recoveries/Collections
25	32	46	$4,655,049

OI anticipates an ongoing caseload of approximately 450 investigations in FY 2009. During FY 2007, OI opened 297 new cases and closed 295. At present, OI has cases open in 47 states, the District of Columbia and Canada with estimated fraud losses totaling almost $11 million.

OI will continue to concentrate its resources on cases with the highest fraud losses. We anticipate that these cases will relate to the RRB's disability, retirement, and Medicare programs. These cases involve more complicated schemes and result in the recovery of substantial funds. They also require considerable time and resources such as travel by special agents to conduct sophisticated investigative techniques such as surveillance and witness interviews. These fraud investigations are extremely document-intensive and involve sophisticated financial analysis.

OI will also continue to investigate fraud violations of railroad employees collecting unemployment or sickness insurance benefits while working and receiving wages from an employer. OI will also investigate retirement fraud which typically involves the theft and fraudulent cashing of U.S. Treasury checks or the withdrawal of electronically deposited RRB benefits. OI will also use the Department of Justice's Affirmative Civil Enforcement Program to recover trust fund monies from cases that do not meet U.S. Attorney's guidelines for criminal prosecution.

OI will also investigate complaints involving administrative irregularities and any alleged misconduct by agency employees.

In FY 2009, OI will continue to coordinate its efforts with agency program managers to address vulnerabilities in benefit programs that allow fraudulent activity to occur and will recommend changes to ensure program integrity. OI plans to continue proactive projects to identify fraud matters that are not detected through the agency's program policing mechanisms. Findings will be conveyed to agency management through OIG systemic implication reports to alert officials of operational weaknesses that may result in fraud against RRB programs. OI will also continue to work with RRB program managers to ensure the appropriate and timely referral of all fraud matters to the OIG.

SUMMARY

In FY 2009, the OIG will continue to focus resources on reviewing RRB program operations and ensuring the integrity of agency trust funds by aggressively pursuing individuals who engage in activities to fraudulently receive RRB funds. OIG will continue to keep the Subcommittee and other members of Congress informed of any agency operational problems or deficiencies. OIG sincerely appreciates its cooperative relationship with the agency and the ongoing assistance extended to its staff during the performance of their audits and investigations. Thank you for your consideration.

Martin J. Dickman

Martin J. Dickman was appointed Inspector General of the U.S. Railroad Retirement Board in October 1994. As Inspector General, he is responsible for promoting economy, efficiency and effectiveness, and for detecting waste, fraud or abuse in the programs and operations of the Board.

An independent Federal agency headquartered in Chicago, the Board provides retirement, survivor, disability, unemployment and sickness benefit payments totaling about $9.7 billion a year under the Federal Railroad Retirement and Unemployment Insurance Acts, for about 600,000 beneficiaries now on its rolls and 236,000 current rail employees.

Mr. Dickman is a member of the President's Council on Integrity and Efficiency, and has been an active member of the Association of Inspectors General since 1999.

Before his appointment to the Railroad Retirement Board, Mr. Dickman served from 1991 as a prosecutor for the Cook County, Illinois State's Attorney's Financial and Governmental Crimes Task Force. His responsibilities included the investigation, indictment and prosecution of criminal cases involving governmental and white collar crimes.

From 1972-91, Mr. Dickman was a member of the Board of Trade of the City of Chicago. At the Board of Trade, he served as the presiding judicial officer at Exchange judicial hearings, and as a Director and Member of the Executive Committee. He established policy, long-range strategic plans and international development for the multi-million dollar entity. He also developed legal and administrative policies, and approved budgets for over 800 staff employees and 3,000 members.

Mr. Dickman has conducted legal research and assisted in trial preparation as an Associate with the Law Firm of Peter Fitzpatrick and Associates in Chicago, 1973-89; and presided over tax-related disputes as a Hearings Referee for the Illinois Department of Revenue, 1976-80. He has also interpreted and drafted legislation as Legislative Counsel for the minority leadership of the Illinois House of Representatives, 1972-73; and represented the City of Chicago in various aspects of civil litigation as an Assistant Corporation Counsel, 1970-72.

A native of Chicago, Mr. Dickman is a graduate of the University of Illinois (B.S. 1966) and DePaul University College of Law (J.D. 1969).

STATEMENTS FROM PUBLIC WITNESSES ON FISCAL YEAR 2009 BUDGET

PUBLIC WITNESS TESTIMONY FOR THE RECORD: HOUSE COMMITTEE ON APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH & HUMAN SERVICES & EDUCATION, SUBMITTED BY ALEXA EGGLESTON, DIRECTOR OF PUBLIC POLICY, NATIONAL COUNCIL FOR COMMUNITY BEHAVIORAL HEALTHCARE

The National Council for Community Behavioral Healthcare appreciates the opportunity to submit testimony on behalf of its 1,400 members who serve nearly six million adults, children, and families in communities across America. National Council members offer a vital safety net to some of the poorest and most vulnerable in our society — Medicaid beneficiaries, the uninsured, the destitute and homeless, children in foster care, older adults, those with HIV/AIDS, veterans, and those in our criminal and juvenile justice systems. Our members offer a range of mental and substance use disorder prevention, treatment and recovery programs and therefore find the support federal funding dedicated to the Substance Abuse and Mental Health Services Administration (SAMHSA) in the Department of Health and Human Services, the Department of Education and the National Institutes of Health vitally important. Our testimony will focus on the need to expand federal funding for prevention, treatment, and research of substance use and mental health conditions.

Every Year Millions of People Need but Do not Receive Treatment for Mental and Substance Use Disorders

According to a recent Institute of Medicine Report[i], each year, more than 33 million Americans use health care services for their mental problems and illnesses or conditions resulting from their use of alcohol, non-medical use of prescription medications, or illegal drugs. About 28 million Americans aged 18 or older, received mental health treatment in an inpatient or outpatient setting in 2003 and more than 6 percent of American children and adolescents aged 5–17 had contact with a mental health professional in a 12-month period. More than 3 million (1.4 percent) of those aged 12 or older reported receiving some kind of treatment during 2003 for a problem related to alcohol or drug use but millions more reported that they needed treatment for mental/substance use conditions but did not receive it. *From 2001 to 2003, only 40.5 percent of those aged 18–54 who met a specific definition of severe mental illness received any treatment. And, in contrast with the more than 3 million Americans aged 12 or older who received treatment during 2003 for a problem related to alcohol or drug use, more than six times that number reported abusing or being physiologically dependent on alcohol or other drugs.*

Treatment Works: The Importance of Investing in Treatment for Mental Illness and Addictions

In the first-ever Surgeon General's report on mental health, published in 1999, mental health was recognized as fundamental to overall health. The report had a single explicit recommendation: all Americans should seek help if they have a mental illness or think they have symptoms of a mental disorder. While a range of treatments exist for most mental disorders and the efficacy of mental health treatment is well documented, concerns about the cost of care are among the primary reasons why people do not seek the mental health care they need. In Achieving the Promise: Transforming Mental Health Care in America, the final report of the President's New Freedom Commission on Mental Health, the importance of early detection of and access to treatment and supports for mental illness is emphasized as a means to impact the lives and health of people with mental illness. Emerging research indicates that early intervention can interrupt

the negative course of some mental illnesses and may in some cases lessen long-term disability. Research has shown that a spectrum of evidence-based pharmacologic and psychosocial treatments for people who have problems with or are dependent on substances produce results similar to or better than those obtained with treatments for other chronic illnesses. New medications, such as buprenorphine, are effective in reducing opioid use and can be prescribed routinely in physicians' offices. Naltrexone and acamprosate show efficacy in treating alcohol dependence. The efficacy of nonpharmacologic treatments for drug dependence—such as cognitive behavioral therapy, motivational enhancement treatment, and contingency management—has been demonstrated. Also effective are 12-step mutual-support groups, such as Alcoholics Anonymous, particularly as an adjunct to treatment and as a form of long-term aftercare. Brief advice from a physician and office-based counseling interventions can reduce the use of alcohol in problem drinkers. As a result of these and other advances, patients who remain in treatment for use of alcohol, opioids, or cocaine are less likely to relapse or resume their harmful substance use.[ii]

The Need to Support and Expand Federal Funding of Prevention, Treatment, Research and Recovery Programs is Critical

SAMHSA's Center for Mental Health Services (CMHS), Center for Substance Abuse Treatment (CSAT) and Center for Substance Abuse Prevention (CSAP) are the primary federal agencies to mobilize and improve mental health and addiction services in the United States. The National Institute of Mental Health (NIMH), the National Institute on Drug Abuse (NIDA), and the National Institute on Alcohol Abuse and Alcoholism (NIAAA) - three institutes at the NIH - are the leading federal agencies supporting basic biomedical and behavioral research related to mental illness and addiction disorders. Given the importance of such programs we encourage the Subcommittee to adopt the following funding recommendations:

- Substance Abuse Prevention and Treatment Block Grant (SAPTBG) -- $1,858.7 million
- Center for Substance Abuse Prevention (CSAP) Programs of Regional and National Significance -- $215.06 million
- Center for Substance Abuse Treatment (CSAT) Programs of Regional and National Significance -- $420.0 million
- CMHS, Community Mental Health Services Block Grant -- $482.9 million
- CMHS, Projects for Assistance in Transition from Homelessness (PATH) -- $61.1 million
- CMHS, Programs of Regional and National Significance (PRNS) -- $343.3 million
- SAMHSA Integrated Treatment for Co-occurring Serious Mental Illnesses and Substance Abuse Disorders -- $4.14 million
- CMHS Jail Diversion Program Grants -- $7.80 million
- Department of Education, State Grants portion of the Safe and Drug Free Schools and Communities (SDFSC) program -- $346.5 million

- NIH, National Institute on Drug Abuse (NIDA) -- $1,067.7 million
- NIH, National Institute on Alcohol Abuse and Alcoholism (NIAAA) -- $465.5m
- NIH, National Institute on Mental Health -- $1,498.6 million

The Substance Abuse and Mental Health Services Administration

Substance Abuse Prevention and Treatment Block Grant (SAPTBG) -- $1,858.7 million: As private insurance has come to play a smaller role in financing treatment for substance use disorders -- by 2003, less than 0.5 percent of private insurance spending was allocated to it -- the share of public financing has increased -- by 2003, 77 percent of treatment for substance use disorders was publicly financed. Much of the public financing occurs through the SAPT Block Grant, the cornerstone of the nation's drug and alcohol prevention and treatment system. The SAPTBG provides roughly half of all public funding for treatment services and distributes funds to 60 eligible States, Territories, the District of Columbia and the Red Lake Indian Tribe of Minnesota through a formula, based upon specified economic and demographic factors. Over 10,500 community-based organizations receive Block Grant funding from the States. In FY 2004, approximately 1.9 million individuals were served.

Center for Substance Abuse Prevention (CSAP) Programs of Regional and National Significance -- $215.06 million: In the United States in 2006, one third of adolescents aged 12 to 17 drank alcohol in the past year, one fifth used an illicit drug, and one sixth smoked cigarettes. Given that addiction is a developmental disease and that research shows that the earlier a person begins to use drugs the more likely they are to progress to more serious abuse, prevention is key. Current research shows that evidence-based substance abuse prevention is effective in preventing youth from initiating substance use and in reducing the number of individuals who become dependent. The 2006 Monitoring the Future survey of eighth, tenth, and twelfth graders showed gradually declining rates of students reporting use of any illicit drug in the past 12 months.

Center for Substance Abuse Treatment (CSAT) Programs of Regional and National Significance -- $420.0 million: CSAT continues to invest in critical programs to identify individuals with or at-risk for substance use-related problems for intervention prior to the need for more extensive or specialized treatment; increase the availability of clinical treatment and recovery support services; and support grant programs which focus on diversion and reentry for adolescents, teens and adults with substance use and mental disorders. Data indicates that screening and brief intervention for alcohol problems, delivered during routine patient visits to their doctor's office, can be just as effective as common preventative measures like childhood immunizations and advising patients to take aspirin to reduce the risk of stroke or heart attacks. Similarly, SAMHSA's support for programs that provide community-based treatment for court-involved individuals with substance use and mental health conditions are critical to ending the cycle of incarceration that plagues those who do not receive necessary services and we urge their continuation through CSAT's Drug Treatment Court initiative as well as through CMHS' Jail Diversion Program Grants. We also urge the Committee to support the continued expansion of recovery support services by encouraging SAMHSA to fund new grants under the Recovery Community Services Program (RCSP). RCSP grant projects design and deliver peer-to-peer

recovery support services to help individuals in their communities initiate and sustain recovery and gain overall wellness.

CMHS, Community Mental Health Services Block Grant -- $482.9 million: The Community Mental Health Services Block Grant is the principal federal discretionary program supporting community-based mental health services for adults and children. The Block Grant is a flexible source of funding that is used to support new services and programs, expand or enhance access under existing programs, and leverage additional state and community dollars. Despite increasing pressure from the federal government to expand community-based services for people with mental illnesses, the federal government's financial support is limited. Medicaid provides optional coverage for some services under separate Medicaid options, but technical barriers exist to states that want to use Medicaid waivers to provide these services. In addition, many essential elements of effective community-based care--such as housing, employment services, and peer support — are non-medical in nature and generally are not reimbursable under Medicaid. Therefore, Block Grant funding is the principal vehicle for federal financial support for evidence-based comprehensive community based services for people with serious mental illnesses.

CMHS, Projects for Assistance in Transition from Homelessness (PATH) -- $61.1 million: The Projects for Assistance in Transition from Homelessness (PATH) formula grant program provides funding to states, localities and non-profit organizations to support individuals who are homeless (or are at risk of homelessness) and have a serious mental illness and/or a co-occurring substance use disorder. Federal PATH funds, when combined with state and local matching funds are the only resources available in many communities to support the range of services needed to effectively reach and engage individuals with severe mental illness and co-occurring substance use disorders.

CMHS, Programs of Regional and National Significance (PRNS) -- $343.3 million:

Integrated Treatment for Co-occurring Serious Mental Illnesses and Substance Abuse Disorders -- $4.14 million: Research demonstrates that mental and addictions disorders are often inter-related, that integrated treatment is more effective than parallel and sequential treatment for co-occurring disorders, and that it is necessary to use clinical staff cross-trained in the treatment of both kinds of disorder. Individuals with severe levels of co-occurring disorders are more likely to experience a chronic course and to over-utilize health and expensive emergency room services than are those with either type of disorder alone. It is therefore critically important that Congress direct funding toward integrated treatment.

CMHS Jail Diversion Program Grants -- $7.80 million: Jail diversion programs provide an alternative to incarceration by diverting individuals with serious mental illness and co-occurring substance use disorders from jail to community-based treatment and support services. These programs include a variety of pre-booking programs, which divert individuals at initial contact with law enforcement officers before formal charges are brought, and post-booking programs, which identify individuals in jail or in court for diversion at some point after arrest and booking.

Department of Education, *State Grants portion of the Safe and Drug Free Schools and Communities (SDFSC) program -- $346.5 million:* The State Grants portion of the SDFSC program has historically served as the backbone of school based substance abuse prevention and

intervention efforts in the United States and has had a significant impact on helping to achieve the 24% overall decline in youth drug use over the past six years. Without this funding stream, the majority of school based prevention infrastructures currently in place will be decimated and many of the 37 million youth who are served annually by programs funded through SDFSC will no longer receive the prevention education they need.

National Institutes of Health: NIDA, NIAAA, and NIMH

National Institute on Drug Abuse (NIDA) -- $1,067.7 million: NIDA-supported scientific advances over the past three decades have revolutionized our understanding of drug abuse and addiction, informing the development of more effective prevention and treatment approaches. NIDA is committed to the principle that addiction is a preventable and treatable disease. Advances in genetics are identifying genes of vulnerability or protection so that interventions can be tailored for the greatest impact. Addiction results from the complex interplay of drugs, genes, and environmental and developmental factors and NIDA has made the study of these interactions a priority. Capitalizing on breakthrough discoveries showing the involvement of different brain systems in drug abuse and addiction—beyond the dopamine/reward system—NIDA's medications development program is pursuing a variety of emerging targets and treatment approaches.

National Institute on Alcohol Abuse and Alcoholism (NIAAA) -- $465.5 million: NIAAA funds 90 percent of all alcohol research in the United States. This research is designed to reduce the enormous health, social, and economic consequences caused by excessive drinking. Particularly promising areas of research include: new technologies to advance identification of the genes likely to influence the risk for alcoholism; advancing discovery of new behavioral treatments and medications development; longitudinal studies to expand understanding of alcohol effects on the developing adolescent brain; and determining how alcohol use affects development of co-morbid disorders.

National Institute on Mental Health -- $1,498.6 million: The mission of the National Institute of Mental Health (NIMH) is to reduce the burden of mental and behavioral disorders through research on mind, brain, and behavior. NIMH is committed to translating the discoveries made in scientific research into clinical practices that will predict who is at risk for disease; pre-empt the disease process by developing interventions; personalize interventions based on knowledge of individual biological, environmental, and social factors; and increase participation in clinical trials.

Thank you for the opportunity to comment on the importance of Federal funding in the FY 09 Labor-HHS spending bill for programs that prevent, treat, research and help people recover from mental and substance use disorders. For additional information, please contact Alexa Eggleston, Director of Public Policy at alexae@thenationalcouncil.org, 301-984-6200 ext.243.

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[i] Improving the Quality of Health Care for Mental and Substance-Use Conditions: Quality Chasm Series (2006), Board on Health Care Services (HCS)

[ii] Id.

Written Testimony By:
Phyllis Greenberger, MSW: President and CEO, Society for Women's Health Research
and
Jeanne Becker, Ph.D.: Chair, Women's Health Research Coalition

Before the House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Other Related Agencies
March 18, 2008
Submitted for the Record

On the behalf of the Society for Women's Health Research and the Women's Health Research Coalition, we are pleased to submit the following testimony in support of federal funding of biomedical research, and more specifically women's health research.

The Society for Women's Health Research is the only national non-profit women's health organization whose mission is to improve the health of women through research, education, and advocacy. Founded in 1990, the Society brought to national attention the need for the appropriate inclusion of women in major medical research studies and the need for more information about conditions affecting women disproportionately, predominately, or differently than men. In 1999, the Women's Health Research Coalition was created by the Society as a grassroots advocacy effort consisting of scientists, researchers, and clinicians from across the country that are concerned and committed to improving women's health research.

The Society and Coalition are committed to advancing the health of women through the discovery of new and useful scientific knowledge. We believe that sustained funding for biomedical and women's health research programs conducted and supported across the federal agencies is absolutely essential if we are to meet the health needs of the population and advance the nation's research capability.

National Institutes of Health

From decoding the human genome to elucidating the scientific components of human physiology, behavior, and disease, scientists are unearthing exciting new discoveries which have the potential to make our lives and the lives of our families longer and healthier. The National Institutes of Health (NIH) has facilitated these advances by conducting and supporting our nation's biomedical research. World-class researchers, scientists, and programs at NIH are dedicated to understanding how the human body works and to gaining insight into countless diseases and disorders. Congressional investment and support for NIH has made the United States the world leader in medical research and has provided a direct and significant impact on women's health research and the careers of women scientists over the last decade.

Great strides and advancements have been made since the doubling of the NIH budget from $13.7 billion in 1998 to $27 billion in 2003. However, we are concerned that the momentum driving new research has been eroded under the current budgetary constraints. Medical research must be considered an essential investment - an investment in thousands of newly trained and aspiring scientists; an investment to remain competitive in the global marketplace; and an investment in our nation's health. A large majority of Americans believe they are receiving the

highest quality and latest advancements in health care and they depend upon Congress to make a strong investment in biomedical research at NIH to continue that expectation.

Unfortunately, the Administration's proposed FY 2009 budget request of $29.2 billion for NIH is identical to the final approved budget for FY 2008. This trend of flat lining not only unravels the successes gained from the doubling of NIH's budget, but it directly contributes to decreasing NIH's purchasing power by almost 11% due to inflation. NIH only truly receives $28.3 billion in the proposed budget due to the transfer of $300 million to the Global Fund to Fight HIV/AIDS. Not only does the proposed decrease not keep pace with the inflation rate, but it is lower than that of the Biomedical Research and Development Price Index (BRDPI) which is indicative of how much funding the NIH needs to maintain purchasing power and compensate for the average yearly cost increases that occur in maintaining research activity at the previous year's level.

Without a robust budget, NIH will be forced to reduce the number of grants it is able to fund. The number of new grants funded by NIH has been dropping steadily since FY2003 and this trend must stop. This shrinking pool of available grants has a significant impact on scientists who depend upon NIH support to cover their salaries and laboratory expenses to conduct high quality biomedical research. Failure to obtain a grant results in reduced likelihood of achieving tenure. This means that new and less established researchers will be forced to consider other careers, the end result being the loss of the critical workforce so desperately needed to sustain America's cutting edge in biomedical research.

In order to continue the momentum of scientific advancement and expedite the translation of research findings from the laboratory to the patients who depend on these advances for improved health and welfare, the Society proposes **$31.1 billion for NIH**, an increase of $1.9 billion over the Fiscal Year 2008 funding level. In addition, we request that Congress strongly encourage the NIH to assure that women's health research receives resources sufficient to meet the health needs of all women.

Scientists have long known of the anatomical differences between men and women, but only within the past deeade have they begun to uncover significant biological and physiological differences. Sex-based biology, the study of biological and physiological differences between men and women, 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. It is imperative that research addressing these important differences between males and females be supported and encouraged. Congress clearly reeognizes these important sex-based differences and should support NIH at an appropriate level of funding and direct NIH to continue expanding research into sex-based biology.

Office of Research on Women's Health

The NIH Office of Research on Women's Health (ORWH) has a fundamental role in coordinating women's health research at NIH, advising the NIH Director on matters relating to research on women's health; strengthening and enhancing research related to diseases, disorders, and conditions that affect women; working to ensure that women are appropriately represented in research studies supported by NIH; and developing opportunities for and support of recruitment, retention, re-entry and advancement of women in biomedical careers. ORWH has a pivotal role

within the NIH structure and beyond to maintain and advance not only biomedical research in women's health but also to support careers of women in science and medicine. ORWH co-chaired a task force with the Director of NIH examining a report by the National Academies of Science regarding women in medicine and science. It is through ORWH that many initiatives can be achieved in strengthening the position of women scientists. Furthermore, ORWH strives to address sex and gender perspectives of women's health and women's health research, as well as differences among special populations of women across the entire life span, from birth through adolescence, reproductive years, menopausal years and elderly years.

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

The BIRCWH program 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. It is expected that each scholar's BIRCWH experience will culminate in the development of an established independent researcher in women's health. In 2007, ORWH funded 15 new or type II centers in the fourth round of BIRCWH. Previously, the BIRCWH has released four RFAs (1999, 2001, 2004, and 2006). Since 2000, 287 scholars have been trained (76% women) in the twenty-four centers resulting in over 882 publications, 750 abstracts, 83 NIH grants and 85 awards from industry and institutional sources. Each BIRCWH receives approximately $500,000 a year, most of which comes from the ORWH budget.

The SCOR program, administered by the National Institute of Arthritis and Musculoskeletal and Skin Diseases, was developed by ORWH in 2000 through an initial RFA that resulted in 11 SCOR Centers out of 36 applications. SCORs are designed to increase the transfer of basic research findings into clinical practice by housing laboratory and clinical studies under one roof. The eleven SCOR programs are conducting interdisciplinary research focused on major medical problems affecting women and comparing gender difference to health and disease. Each SCOR works hard to transfer their basic research findings into the clinical practice setting. Each program costs approximately $1 million per year.

ORWH has made significant strides in raising awareness for women's health issue. This past year it launched a national educational and awareness campaign on vulvodynia in collaboration with other DHHS agencies and non-Federal partners; co-sponsored the 8th International Association for Chronic Fatigue Syndrome conference; co-sponsored an agency-wide training session on sex/gender, race and ethnicity issues in clinical research attended by over 300 NIH staff members; awarded the co-funding of sixteen grants to 9 institutes and centers exceeding $3.8 million for the advancement of sex/gender specific biomedical research; and led the NIH observance of the National Women's Health week.

Despite the advancement of women's health research and ORWH's innovative programs to advance women scientists, it has been flat lined at $40.9 million for FY 2008 and 2009 after having also received a cut of $249,000 in FY 2006 and no additional funding in FY 2007. Flat

funding must not continue to happen. It imperative that the ORWH programs and research grants continue to thrive. This research is vital to women and men and we implore Congress to direct NIH to continue its support of ORWH and its programs.

Department of Health and Human Services

The Department of Health and Human Services (HHS) has several offices that enhance the focus of the government on women's health research, in addition to ORWH described above. Agencies with offices, advisors or coordinators for women's health or women's health research are the Department of HHS, the Food and Drug Administration, the Centers for Disease Control and Prevention, the Agency for Healthcare Quality and Research, the Indian Health Service, the Substance Abuse and Mental Health Services Administration, the Health Resources and Services Administration, and the Centers for Medicare and Medicaid Services. These agencies must be funded at levels adequate for them to perform their assigned missions. We ask that the Committee Report clarify that Congress supports the permanent existence of these various offices and would like to see them appropriately funded to ensure that their programs can continue and be strengthened in the coming fiscal year.

The focus on women's health within HHS has been critical to the advances made in women's health in communicating the appropriate message to patients and health care providers. Scientists have only just scratched the surface of understanding female biology, with new information forthcoming as a result of the recent sequencing of the human X chromosome. Now is the time to strongly press ahead with this vital research to continue making discoveries and educating women about their health and these offices are critical to the success of this effort. Although many important programs can be identified from these women's health offices, we would like to bring two such programs to your specific attention, as follows.

HHS 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. The OWH coordinates women's health efforts in HHS to eliminate disparities in health status and supports culturally sensitive educational programs that encourage women to take personal responsibility for their own health and wellness.

In 2007, the OWH led efforts to improve breastfeeding information available to women of all cultures by offering multilingual websites and helplines. They collaborated with other organizations to lead a conference on "Charting New Frontiers in Rural Women's Health," as well as hosting the third Minority Women's Health Summit to address the unique health issues many women of color experience. The OWH has continued their efforts to improve the health of young women by providing information on their website to address eating disorders and HIV/AIDS prevention for aldolescent girls, in conjunction with conducting their HIV/AIDS National Awareness Day.

Since the beginning of 2008, the OWH has led a series of Women's Heart Health Fairs nationwide. In addition, they will empower women across the country to get healthy by sponsoring the National Women's Health Week in May of 2008. In conjunction with families,

communities, business and other governmental and health organizations, the OWH will educate women on how they can improve their physical and mental health through various behavior modifications.

It is only through continued funding that the OWH will be able to achieve its goals. While the budget for FY 2008 increased the OWH budget by $2 million to a total of $30 million, it has been flat lined for FY 2009. This is, in essence, a decrease due to inflation. Considering the amount and impact of women's health programs from OWH, we urge Congress to provide an increase of **$2 million** for the HHS OWH.

Agency for Healthcare and Research Quality

The Agency for Healthcare Research and Quality (AHRQ) is the lead public health service agency focused on health care quality, including coordination of all federal quality improvement efforts and health services research. AHRQ'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. This important information provided by AHRQ is brought to the attention of policymakers, health care providers, and consumers all of whom make a difference in the quality of health care that women receive.

AHRQ has a valuable role in improving health care for women. Through AHRQ's research projects and findings, lives have been saved and underserved populations have been treated. For example, women treated in emergency rooms are less likely to receive life-saving medication for a heart attack. AHRQ funded the development of two software tools, now standard features on hospital electrocardiograph machines, which have improved diagnostic accuracy and dramatically increased the timely use of "clot-dissolving" medications in women having heart attacks.

While AHRQ has made great strides in women's health research, the Administration's budget for Fiscal Year 2009 could threaten such life-saving research. While AHRQ's FY 2008 budget received an $11 million increase, the President's proposed FY 2009 budget marks an almost $9 million decrease. With the cost of inflation and years of flat funding, AHRQ has lost $19 million in purchasing power since 2005. With the President's proposed budget of approximately $325 million, the agency stands to lose an additional $9 million. This Agency has been operating under a major shortfall for years. Decreased funding seriously jeopardizes the research and quality improvement programs that Congress mandates from AHRQ.

We encourage Congress to fund AHRQ at **$360 million for FY 2009,** an increase of $26 million over the FY 2008 level. This will ensure that adequate resources are available for high priority research, including women's health care, sex and gender-based analyses, Medicare, and health disparities.

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

Statement
of the
American Occupational Therapy Association

Presented to

The United States House of Representatives
Committee on Appropriations

Subcommittee on Labor, Health and Human Services, and Education

By

Frederick P. Somers
Executive Director

March 31, 2007

Mr. Chairman and Members of the Subcommittee, thank you for giving the American Occupational Therapy Association (AOTA) the opportunity to testify as the Subcommittee begins to consider funding priorities for Fiscal Year (FY) 2009. My name is Fred Somers and I am the Executive Director of the American Occupational Therapy Association, a nationally recognized professional association of more than 35,000 occupational therapists, occupational therapy assistants, and students of occupational therapy. AOTA has affiliate programs in all 50 states.

ABOUT OCCUPATIONAL THERAPY

Occupational therapy addresses the activity limitations of people experiencing health problems such as stroke, spinal cord injuries, cancer, congenital conditions, developmental disabilities, and mental illness. With interventions to develop and restore skills that are essential for independent functioning, health, well-being, and participation in society therapy interventions are available for people of all ages and occur in a wide range of settings including schools, hospitals, skilled nursing facilities, home health, outpatient rehabilitation clinics, psychiatric facilities, and community health programs. Occupational therapy programs promote healthy lifestyles for individuals who are at risk for health conditions and prevent secondary problems associated with chronic conditions or disabilities. The outcome of occupational therapy promotes independence in individuals who may otherwise require institutionalization or other long-term care and enables people with disabilities to be productive and contributing members of society. Lower health care costs and improved quality of life for individuals, families, and caregivers are also evident byproducts of occupational therapy services.

RECOGNIZING THE LEADERSHIP OF THE SUBCOMMITTEE

AOTA's testimony is in support of four major programs under the Subcommittee's jurisdiction: the Center for Disease Control and Prevention, especially the Center on Injury Control and Prevention's National Falls Prevention Program; the National Institutes of Health; the Health Resources and Services Administration's Health Professions Programs; and the Administration on Aging. Mr. Chairman, our specific recommendations for these and other areas of interest are summarized in a table at the end of this statement.

Mr. Chairman, AOTA appreciates your leadership and the leadership of this Subcommittee in supporting NIH in a time of fiscal austerity. Your leadership in supporting all of the programs mentioned in our statement are also greatly recognized and appreciated. These programs are important to our shared goals of improving the health and well being of the nation. We applaud the Subcommittee's leadership in addressing the needs of all of the programs under the jurisdiction of this Subcommittee during this time of fiscal constraints.

CENTERS FOR DISEASE CONTROL AND PREVENTION

AOTA joins with the CDC Coalition, a nonpartisan coalition of more than 100 groups, in supporting $7.4 billion for the Centers for Disease Control and Prevention in FY 2009. The CDC programs are crucial to the health of millions of Americans, they are key to maintaining a

strong public health infrastructure, and are essential in protecting us from threats to our health. At a time when the CDC is faces with unprecedented challenges and responsibilities ranging from chronic disease prevention, eliminating health disparities, bioterrorism preparedness, to combating the obesity epidemic the Administration's budget has cut the CDC's budget by $412 million. We urge the Committee to restore this cut and fund the CDC at $7.4 billion. Within that amount, we further request that the Committee provide a $20.7 million increase for the Falls Prevention Program in the Center for Injury Prevention and Control.

Mr. Chairman, AOTA applauds the CDC's Center for Injury Prevention and Control's initiative of preventing falls among older adults. Falls are a leading cause of mortality among adults age 65 and older; one of every three older Americans falls each year, and about 30% of those who fall require medical treatment. In 2005, in the United States, more than 16,000 older adults died from falls, approximately 1.8 million were treated in hospital emergency departments for unintentional fall-related injuries, and more than 430,000 of those were subsequently hospitalized. Falls and fall-related injuries represent an enormous burden to individuals, society, and to our health care system. CDC reports that the mortality rate from falls among older Americans has increased 39% between 1999 and 2005. Furthermore, a recent analysis by CDC determined that in 2000, among adults aged 65 and older, direct medical costs totaled $19.2 billion for nonfatal fall-related injuries.

Occupational therapy evaluates and treats many older adults who are at risks for falls. Both prevention and rehabilitation programs are available as part of occupational therapy services Occupational therapy addresses the physical and sensory impairments of aging, eliminates environmental barriers by promoting "universal design" and recommends safety practices in people's homes. But occupational therapy can also deal with the fear of falling, which contributes to isolation and seriously limits many older adults' participation in full community life.

CDC's ability to reduce the rate of falls among older Americans is substantially leveraged and increased by collaboration with states and organizations, such as Area Aging Agencies, and other partners with special access and expertise. AOTA, for example, with 35,000 national members and affiliates in all 50 states, we believe, is an ideal partner for effective program collaboration. In order to enhance CDC's outreach and collaboration with appropriate organizations, AOTA recommends a $20.7 million be appropriated to the CDC for elder falls prevention.

THE NATIONAL INSTITUTES OF HEALTH

Mr. Chairman, for the National Institutes of Health in FY 2009, we recommend an increase of $1.9 billion over the FY 2008 funding level. AOTA joins the Ad Hoc Group for Medical Research Funding, a coalition of some 300 patient and voluntary health groups, medical and scientific societies, academic research organizations and industry in making this recommendation. The Administration's FY 2009 request would provide $29.2 billion for NIH, representing the sixth consecutive year that the NIH budget has failed to keep pace with biomedical inflation. In the five years through 2008, a series of nominal increases and cuts has

amounted to flat funding for NIH, and NIH has lost approximately 11% in purchasing power due to inflation. If the President's FY 2009 request becomes law, NIH will have lost one-seventh of its purchasing power due to inflation. Furthermore, we urge the Subcommittee to provide a 6.5% base adjustment for medical rehabilitation research across all Institutes and Centers.

The National Center for Medical Rehabilitation Research (NCMRR), within NICHD, provides important leadership within the NIH for the 15 NIH Institutes and Centers which fund medical rehabilitation research. For FY 2009 the NIH projects that it will spend $344 million for medical rehabilitation research, which is the same as the FY 2007 actual NIH expenditure for this category of programs. AOTA recommends that these programs be increased to allow for a heightened focus on institutional and career development awards aimed at increasing the applicant success rate of the several under-represented health professions that contribute significantly to the field, such as occupational therapists.

The National Institute for Neurological Disorders and Stroke (NINDS) is providing important leadership in efforts to develop a consensus rehabilitation treatment protocol for stoke victims that will help insure the fullest possible recovery. AOTA strongly supports NINDS leadership to convene a Scientific Workshop to indentify the scientific questions that must be answered before such a consensus rehabilitation treatment protocol can be developed and we would urge the Committee to support this effort as well.

The Institute of Medicine report, *Enabling America: Assessing the Role of Rehabilitation Science and Engineering*, highlighted the national need for research advances to improve the effectiveness of rehabilitation services and the practices for promoting the health of people with disabilities. The incidence and prevalence of people with disabilities continue to mount in parallel with dramatic increases in medicine's ability to prevent deaths due to injury, disease, and conditions associated with aging. An estimated 49 million Americans, about one out of every seven, have disabling conditions so severe that they are unable to carry out the major activities of their age group, such as attending school, working, or providing self-care. Occupational therapy, as part of a medical rehabilitation team, provides the means for reducing the effects and societal costs of disability.

HRSA HEALTH PROFESSIONS PROGRAM

The AOTA urges the restoration of the funding reductions proposed by the Administration to HRSA's Health Professions programs. Many of these programs, such as the Area Health Education Centers Program, the Health Careers Opportunity Program, and the Centers of Excellence Program are all particularly effective in addressing faculty shortages, institutional barriers and other programs needed to support the cost of educating under-represented minority health practitioners and addressing the needs of underserved areas. These programs are particularly advantageous to Historically Black Colleges and Universities, where Departments of Occupational Therapy, for example, are at constant risk of closure. Adequate support from HRSA's health professions program is important for all institutions of higher education to meet our workforce needs.

ADMINISTRATION ON AGING

Mr. Chairman, the Administration on Aging (AoA) has developed a commendable vision and program structure that focuses on the importance of community based organizations to help adults as they age maintain their independence and well being in the community. AoA is to be commended for its development of a national network of Aging and Disability Resource Centers (ADRC). The ADRC initiative supports State efforts to develop "one stop shop" programs that help seniors make informed decisions about service and support options. AOTA is disappointed, however, in the very limited and diminishing discretionary program needed to fund and promote new and innovative options to help seniors remain independent. For example, AOTA is aware of the exciting and large array of pre-market assistive device technologies that need further research, development and testing before they can be appropriately promoted and used by our seniors. AOTA recommends increased funding for AoA in FY 2009.

DEPARTMENT OF EDUCATION

As the national association representing occupational therapy, a profession dedicated to maximizing independence and function for people throughout the lifespan, AOTA supports NIDRR's Long Range Plan's emphasis on rapidly transitioning research knowledge into policy and best practices that will improve the quality of life for people with disabilities. We urge Congress to fully fund these activities.
Two issues of particular interest for AOTA in this area are the Disability Rehabilitation Research Projects (DRRP) related to rehabilitation of children with traumatic brain injury and reducing obesity and obesity-related secondary conditions in adolescents and adults with disabilities.

AOTA also recognizes the translational research being conducted by the Institute of Educational Science, particularly the National Center for Special Education Research (NCSER) which published a request for proposals on the topic of special education related services. AOTA believes Congress should increase support for NCSER in order to promote research that delivers more evidence-based interventions into classrooms.

SUMMARY AND CONCLUSION

Mr. Chairman, we appreciate the opportunity to testify on the many important programs funded by this Subcommittee. A summary of our specific funding recommendations follows:

<u>CDC: +$20.7 Million for the Center for Injury Prevention and Control</u>
- Increased funding needed for CDC's Falls Prevention Program and Older Drivers Initiative.

<u>NIH and Medical Rehabilitation Research</u>
- 6.5% increase for NIH overall and a 6.5% increase for Medical Rehabilitation Research;

<u>HRSA: + $50.74 million to Restore Administration Cuts</u>
- Area Health Education Centers Program, the Health Careers Opportunity Program and the Centers of Excellence Programs

<u>AoA: +$5 million for programs to fund innovative options to help seniors remain independent.</u>

STATEMENT
OF
THE AMERICAN LIVER FOUNDATION

PRESENTED
TO
THE UNITED STATES HOUSE OF REPRESENTATIVES
COMMITTEE ON APPROPRIATIONS

SUBCOMMITTEE ON LABOR,
HEALTH AND HUMAN SERVICES,
EDUCATION AND RELATED AGENCIES

BY
JAMES L. BOYER, M.D.
CHAIRMAN OF THE BOARD

WASHINGTON, D.C.

March 31, 2008

Mr. Chairman and Members of the Subcommittee, thank you for giving the American Liver Foundation the opportunity to testify as the Subcommittee begins to consider funding priorities for Fiscal Year (FY) 2009. My name is Dr. James L. Boyer and I am the Chairman of the Board of Directors of the American Liver Foundation (ALF), a national voluntary health organization dedicated to the prevention, treatment and cure of hepatitis and other liver diseases through research, education and advocacy. I am also the Ensign Professor of Medicine and Director of the Liver Center at Yale University School of Medicine.

ALF has 25 Chapters nationwide and provides information to 300,000 patients and families. Over 70,000 physicians, including primary care practitioners and liver specialists and scientists also receive information from ALF. The ALF Board of Directors is composed of scientists, clinicians, patients and others who are directly affected by liver diseases. Every year ALF handles over 100,000 requests for information, helping patients and their families understand their illnesses, informing them about available services, and showing them that there are knowledgeable and concerned individuals to assist them in every possible way.

Mr. Chairman, ALF joins the Ad Hoc Group for Medical Research Funding, a coalition of some 300 patient and voluntary health groups, medical and scientific societies, academic research organizations and industry, in recommending $31.1 billion (6.5% increase) for the National Institutes of Health in FY 2009. The FY 2009 Administration budget request for NIH is flat compared to FY 2008 funding levels, which due to the effects of biomedical inflation, translates to a cut. If the President's budget were implemented, this funding level would mean NIH's ability to conduct and support life-saving research will be cut by more than 11 percent in inflation-adjusted dollars since FY 2003

While the ALF recognizes the demands on our nation's resources, we believe the ever-increasing health threats and expanding scientific opportunities continue to justify higher funding levels than proposed by the Administration. To ensure that NIH's momentum is not further eroded, and to ensure the fight against diseases and disabilities that affect millions of Americans can continue, ALF supports a minimum increase of 6.5% for the NIH in FY 2009 and a minimum increase of a 6.5% for the National Institute for Diabetes and Digestive and Kidney Diseases and for liver disease research across all NIH Institutes.

In addition to the NIH, there are a number of programs within the jurisdiction of the subcommittee that are important to ALF including the Centers for Disease Control's Division of Viral Hepatitis and HRSA's Division of Transplantation. Mr. Chairman, our specific recommendations for these and other areas of interest are summarized in a table at the end of this statement.

RECOGNIZING THE LEADERSHIP OF THE SUBCOMMITTEE

Mr. Chairman, ALF appreciates your leadership and the leadership of this Subcommittee in supporting NIH in a time of fiscal austerity. Your leadership in supporting CDC and HRSA's

Division of Transplantation are also greatly recognized and appreciated. These programs are important to our shared goals of improving the public health response to the threats of hepatitis and liver disease and to increasing the rate of organ donation. We applaud the Committee's leadership in making progress in these important areas and to allocating increased funding to these programs during periods of fiscal austerity.

RECOGNIZING THE LEADERSHIP OF THE NIH

Mr. Chairman, I would also like to take this opportunity to commend the leadership of NIH, and especially the leadership of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) for their strong support of liver disease research. In the summer of 2002, a member of this Subcommittee, Congressman Dan Miller, introduced a piece of legislation titled the Liver Disease Research Enhancement Act. The legislation, reintroduced in the 110th Congress by Congressmen Stephen Lynch and Peter King, was introduced after several months of deliberation and consultation with the leadership of NIH, with the intention of creating a center within NIDDK focused solely on liver and liver-related diseases. This bill will streamline the study and funding of liver disease research by creating a Liver Disease Research Advisory Board that will include preeminent scientists at the NIH, and from across the country to develop a Liver Disease Research Action Plan to guide future NIH funding decisions and help the liver research community prioritize research efforts. In addition the bill provides new authorities necessary to help insure that the scientific opportunities identified by the Liver Disease Research Action Plan are adequately funded.

After the bill was first introduced, the NIH independently implemented many of the provisions of this legislation, including the establishment of a Liver Disease Branch and the creation of a Liver Disease Research Action Plan, which the NIH continues to update each year. The Research Action Plan is an important blueprint for the future of liver disease research; however, ALF is concerned that without the authorities included in the legislation, implementation of the plan will proceed slowly. We recommend the Liver Research Enhancement Act to the Subcommittee as necessary steps needed to improve the rate of scientific discovery thus leading to cures and better treatment for liver disease.

We would also like to commend the leadership of the NIDDK on their decision to host a consensus conference focused on best treatment practices for individuals with hepatitis B. The growing number of treatment options is encouraging and suggests a strong rationale for conducting a consensus conference to provide state of the art treatment guidelines for the practicing physician community.

FUNDING THE LIVER DISEASE RESEARCH ACTION PLAN

Mr. Chairman, in December of 2004, the NIDDK released the Liver Disease Research Action Plan outlining major research goals for the various aspects of liver disease. Working with the

leading scientific experts in the field, the plan is organized into 16 chapters and identifies numerous areas of research important to virtually every aspect of liver disease, including: improving the success rate of therapy of hepatitis C; developing noninvasive ways to measure liver fibrosis; developing sensitive and specific means of screening individuals at high risk for early hepatocellular carcinoma; developing standardized and objective diagnostic criteria for major liver diseases and their grading and staging; and decreasing the mortality rate from liver disease. Each year, the plan is reviewed and updated. The ALF urges the Committee to provide adequate funding and policy guidance to NIH to urge continued implementation of the plan.

CDC'S DIVISION OF VIRAL HEPATITIS

ALF joins with the CDC Coalition, a nonpartisan coalition of more than 100 groups, in supporting $7.4 billion for the Centers for Disease Control and Prevention in FY 2009. The CDC programs are crucial to the health of millions of Americans, they are key to maintaining a strong public health infrastructure, and are essential in protecting us from threats to our health. At a time when the CDC is facing unprecedented challenges and responsibilities ranging from chronic disease prevention, eliminating health disparities, bioterrorism preparedness, to combating the obesity epidemic the Administration's budget has cut the CDC's budget by $412 million. We urge the Committee to restore this cut and fund the CDC at $7.4 billion. Within that amount, we further request that the Committee provide a $5 million increase for the Division of Viral Hepatitis.

The Division of Viral Hepatitis (DVH) is included in the National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention at the CDC, and is responsible for the prevention and control of viral hepatitis, a disease which impacts over 6 million Americans and often leads to liver cancer and liver failure. The DVH provides the scientific and programmatic foundation for the prevention, control and elimination of hepatitis virus infections in the U.S. and also assists the international public health community in these activities. DVH works with state and local health departments to provide the guidance and technical expertise needed to integrate hepatitis prevention services such as hepatitis A and B vaccine, hepatitis B and C counseling, and testing and referral to existing public health programs serving individuals at high risk.

Mr. Chairman, ALF requests that an increase of $5 million, be included to address the public health crisis of Hepatitis A, B & C and the large growing HIV co-infection rates.

INCREASING THE SUPPLY OF ORGANS FOR DONATION

As the Subcommittee knows, even with advances in the use of living liver donors, the increase in the demand for livers needed for transplantation will continue to exceed the number available. The need to increase the rate of organ donation is critical. Each day approximately 78 people receive an organ transplant, but another 18 people die because organ demand far outweighs the supply and the gap continues to widen. For example, in 2007, while 5,940 liver transplants were performed, there were over 17,122 individuals on the list waiting for liver transplantations and

about 1,421 people died due to the lack of a donor liver. Despite this demonstrated need, the Division of Transplantation has received cuts or level funding over the past four fiscal years.

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, no additional funding has been provided to implement this legislation. To address these needs, ALF recommends that the Division of Transplantation receive a $2 million increase in FY 2009.

SUMMARY AND CONCLUSION

Mr. Chairman, again we wish to thank the Subcommittee for its past leadership. Significant progress has been made in developing better treatments and cures for the diseases that affects mankind due to your leadership and the leadership of your colleagues on this subcommittee. Significant progress has also similarly been made in the fight against liver disease. For FY 2009 we recommend a 6.5%, increase for NIH above the level of the FY 2008 funding levels, with the level of liver disease research also increased by at least 6.5%. We also urge a $5 million increase for CDC to strengthen the public health response to hepatitis and liver disease and a $2 million increase to HRSA's Division of Transplantation necessary to increase the rate of organ donation. Mr. Chairman, if this country is to maintain its leadership role in health maintenance, disease prevention, and the curing of diseases, adequate funding for NIH, CDC and HRSA is paramount. The ALF appreciates the opportunity to provide testimony to you on behalf of our constituents and yours.

ALF RECOMMENDATIONS FOR FISCAL YEAR 2009 FUNDING

NIH and the Liver Disease Research Action Plan

- 6.5% increase for NIH overall and 6.5% for the National Institute of Diabetes and Digestive and Kidney Diseases;
- +$25 million to implement the Liver Research Action Plan

CDC: National Hepatitis C Prevention Strategy, Public Health Information, HAV & HBV Vaccinations

- + $5 million to support expansion of CDC's National Hepatitis C Prevention program;
- +$1 million to increase the public health information regarding liver diseases.

HRSA: Expanding the supply or organs

- + $2 million to start funding the Organ Donation and Recovery Act provisions.

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NCAI TESTIMONY TO HOUSE LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES SUBCOMMITTEE ON FY 2009 APPROPRIATIONS

On behalf of the tribal nations of the National Congress of American Indians (NCAI), we are pleased to present testimony to the House Committee on Appropriations, Subcommittee on Labor, Health and Human Services, Education, and Related Agencies for the Fiscal Year 2009 Budget.

At the recent State of Indian Nations address, NCAI President Joe Garcia spoke about the special place of honor children hold in American Indian and Alaska Native cultures. He discussed the community's sacred obligation to instill in them the traditional knowledge of past generations so their innocence and laughter may develop into wisdom as they become the leaders of the future. He stressed our belief that every Indian child should have the right to community-based, culturally appropriate services that help them grow up safe, healthy, and spiritually strong–free from abuse, neglect, and poverty. Unfortunately, all too often Native children are born into circumstances that may be rich in culture and love, but fail to meet their basic needs of health, shelter, safety, and education. Our communities have a vision of a restored, safer, healthier Indian Country for our children, but President Bush's budget request fails to move us in the direction of that vision and will leave Indian children in poverty and at risk.

This NCAI FY2009 testimony highlights key aspects of the vision tribal leaders have expressed to create a safe, healthy Indian Country for our children. In developing these recommendations we recognize that chipping away at the years of under-funding and backlogs that plague Indian Country can only be accomplished over time. The requests that follow do not reflect the full need in Indian Country, but rather are achievable first steps that we believe Congress and the President should be able to support this year.

Education

One of the President's major focuses of the FY 2009 Education budget was closing the achievement gap. However, the numerous decreases proposed for programs that support Indian children's education government-wide does not support this claim. A standard argument of the current administration for eliminating tribal education programs is that they are duplicative, claiming that our students are eligible for funding through both the Department of Education and the Bureau of Indian Education. However, each of these offices provide different and essential services to ensure that our students are able to achieve the same challenging academic standards as other students.

Funding levels for Indian education under the Office of Indian Education remained stagnate at FY08 levels. Of major concern is the elimination of discretionary funding for Strengthening Tribally Controlled Colleges and Universities (TCUs) and Strengthening Alaska Native and Native Hawaiian Serving Institutions. One of the

primary arguments for their elimination was the substantial increase in mandatory funding from 2007. However, this increase is a result of funds made available from the College Cost Reduction and Access Act and were meant to supplement ***not*** supplant TCU funding. This decision was not made in consultation with the Tribes.

The Administration proposed eliminating five tribal-specific programs at the Department of Education: Education for Native-Hawaiians ($33.3 million), Alaska Native Education Equity Assistance ($33.3 million), Strengthening Alaska Native, Native Hawaiian Serving Institutions ($11.6 million), Strengthening Tribal Colleges ($23.2 million), and Tribally Controlled Postsecondary Institutions ($7.4 million).

- **Restore the 5 Indian specific programs eliminated by the DOE in the FY 2009 budget.**
  - **Strengthening Tribal Colleges ($23.2 million)**
  - **Tribally Controlled Postsecondary Institutions ($7.4 million)**
  - **Education for Native-Hawaiians ($33.3 million)**
  - **Alaska Native Education Equity Assistance ($33.3 million)**
  - **Strengthening Alaska Native, Native Hawaiian Serving Institutions ($11.6 million)**

- **Increase funding 10% for 2 programs that remained stagnate in DOE FY 2009 budget.**
  - **Impact Aid ($1,365)**
  - **Indian Education Act, Title VII ($132 million)**

Health and Human Services

ADMINISTRATION ON AGING

The aging of our nation's population will challenge federal programs such as those in the Older Americans Act. The tribal service delivery systems, with social service programs and delivery systems already stretched beyond capacity, face an impending human and financial crisis. The crisis is exacerbated by inadequate funding, remoteness of the areas, inadequate healthcare funding, increased training needs for program staff, and lack of resources. According to the National Indian Council on Aging, inadequate funding has made it impossible for many Tribes to meet the five days a week home-delivered meal requirement and has forced them to provide congregate meals only two or three days a week.

- **Increase Older Americans Act, Title VI funding to $50 million to help older American Indian elders to remain independent in their homes and communities.**
- **Provide funding support of not less than $10 million to the Older Americans Act, Title VI Native American aging programs to support one-on-one counseling and enrollment assistance regarding Medicare and Medicaid services.**
- **Provide funding support of $10 million for the Older Americans Act, Title VII, Subtitle B "Native American Provision for Prevention of Elder Abuse and Neglect" and the "Allotment for Vulnerable Elder Rights Protection Activities" to protect elder rights and implement elder rights activities in tribal communities.**

ADMINISTRATION FOR CHILDREN AND FAMILIES

Head Start: Indian Head Start programs are vital to many Native communities, providing support to needy families, strengthening revitalization efforts for tribal culture and language, and contributing greatly to community-based healthcare strategies. Of the approximately 562 federally recognized tribes, only 188 have Head Start programs. That means 374 tribes do not have Head Start available for their children. Indian Head Start has been receiving a declining percentage of Head Start funds, now currently at about 2.7%. As funding for Head Start over the last seven years has failed to keep pace with inflation we continue to support efforts to increase funding for Head Start by $1.072 billion in the coming year.

- **To meet the expansion commitment made to the Indian Head Start program in the reauthorization bill, increase Head Start funding by no less than $155 million in FY 2009.**

ADMINISTRATION FOR NATIVE AMERICANS

Native Languages: Throughout Indian Country tribes are combating the loss of traditional languages by advocating for and instituting language programs within their communities. Created to reverse centuries of federal policies meant to destroy Native languages, Native language programs prevent the loss of tribal traditions and cultures while assisting students in their academic endeavors. The tribal students in immersion programs perform substantially better academically, including on national tests, than Native students who have not gone through such programs.

- **Maintain or increase the $2 million provided for the Esther Martinez Native American Languages program in the Administration for Native Americans.**

SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION (SAMHSA)

Tribal youth between the ages of 15 and 24 commit suicide at a rate more than three times the national average. In Alaska, Native youth ages 19 and younger make up 19% of the population but comprise 60% of the suicides in that age group for the entire state. More than half of those who committed suicide in Indian country had never been seen by a mental health provider, yet 90% of all teens who die by suicide suffer from a diagnosable mental illness at the time of death.
American Indian and Alaska Native Grant Program: The American Indian and Alaskan Native specific grant program within SAMHSA was authorized to award grants to Indian health programs to provide the following services: prevention or treatment of drug use or alcohol abuse, mental health promotion, or treatment services for mental illness in the amount of $15 million. To date, these funds have never been appropriated.

- **Fully fund the American Indian and Alaska Native specific grant program at $15 million.**

Circles of Care: Circles of Care is the only grant program in SAMSHA where tribes do not need to compete with the States to receive funding. This grant program was designed specifically to respond to the inequity that tribes experience in trying to access federal behavioral health services funding compared to states and the lack of programming that is specifically designed to respond to tribal communities and their service delivery system realties.

- **Fund Circles of Care at $5 million.**

Labor

The unemployment rate among American Indians is twice that for the total US population at 8.6% according to the US Census Bureau. On some reservations, the rate is drastically high. For example, according to the Bureau of Indian Affairs, the Blackfeet Tribe face a 69% unemployment rate and the San Carlos Apache Tribe struggle with 81% of their population being unemployed.

Denali Commission: The Employment and Training Administration (ETA) provides tribes with grants to offer these valuable services to their members. The purpose of the Denali Commission is to provide critical utilities, infrastructure and economic support to distressed rural communities in Alaska. This funding stream is being terminated in the President's budget.

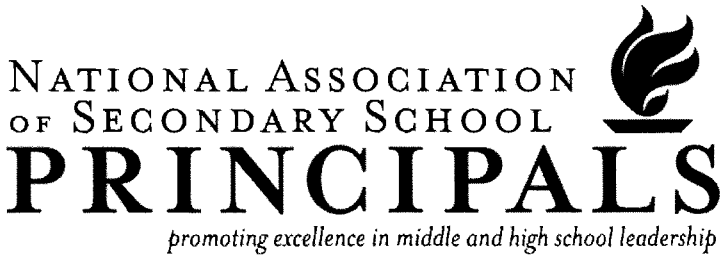
- **Restore funding to Denali Commission $6,755,000.**

Native American Programs: One of the ETA's priorities for the Native American Section 166 program in FY 2009 will be to integrate the program with the One-Stop Career Center system. The One-Stop Career Center System does not allow flexibility for cultural barriers and disability barriers to employment.

- **Fully fund Native American Programs at $53 million.**

Conclusion

NCAI realizes Congress must make difficult budget choices this year. As elected officials, tribal leaders certainly understand the competing priorities that you must weigh over the coming months. However, the federal government's constitutional and treaty responsibility to address the serious needs facing Indian Country are unique. These responsibilities remain unchanged, whatever the economic climate and competing priorities may be. We at NCAI urge you to make a strong, across-the-board commitment to meeting the federal trust obligation by fully funding those programs that are vital to the creation of vibrant Indian Nations. Such a commitment, coupled with continued efforts to strengthen tribal governments and to clarify the government-to-government relationship, truly will make a difference in helping us to create stable, diversified, and healthy economies in Indian Country.



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

"Supporting Long-Term Economic Growth and Prosperity by Investing in Education"

March 13, 2008

Written Testimony Submitted by the National Association of Secondary School Principals

In existence since 1916, the National Association of Secondary School Principals (NASSP) is the preeminent organization of and national voice for middle level and high school principals, assistant principals, and aspiring school leaders from across the United States and more than 45 countries around the world. The mission of NASSP is to promote excellence in middle level and high school leadership.

No Child Left Behind Act (NCLB)
In 2001, Congress enacted the No Child Left Behind Act (NCLB), ushering in an era of increased accountability for the success of all students. As school leaders, our members accept accountability for results, however to ensure the success of all students, the federal government must invest greater resources into schools and the principals that lead them.

Increasing Enrollment; Declining Investment
Enrollment in K – 12 education has increased significantly since 1991, and the U.S. Department of Education expects this trend to continue well through the 2014, 100% student proficiency deadline. At the same time however, the federal government's investment in education has been on a steady decline since 2003, and accounts for only about 9% of per-pupil spending. Moreover, since 2001, Congress has underfunded NCLB by more than $85 billion, and this year 59% of all Title I school districts will receive less funding for education of the disadvantaged than they did in the previous school year, according to the Committee for Education Funding. Additionally, while the number of students in special education has increased by 30% over the past 10 years, the federal investment in special education is only 17% - well short of its 40% commitment – generating a shortfall of $10.9 billion for state and local school districts.

Investing in School Leadership
A recent study by the Southeast Center for Teaching Quality (2005) found that high-quality leadership was the single greatest predictor of whether or not high schools made adequate yearly progress (AYP). Yet funding for the School Leadership program was cut in FY 2008, and for the seventh year in a row, President Bush targeted the program for elimination. The School Leadership program provides competitive grants to help districts in high-need areas recruit and retain principals and assistant principals. Grants may be used to offer financial incentives for aspiring new principals, provide stipends to principals who mentor new principals, and carry out professional development programs in instructional leadership and management.

The School Leadership program is the only federal initiative that directly addresses the difficulty of attracting and retaining high-quality candidates to positions as principals in high-need districts. Although there is an allowable use of Title II funds for principal training, this funding has not been effective in ensuring that principals are included in ongoing professional development and mentoring activities. As a result, there is also a need for a dedicated funding stream for principal training and professional development.

As the instructional leader of a school, the principal plays a unique and important role in implementing reform and creating a climate that fosters excellence in teaching and learning. In today's achievement-focused atmosphere, in which the U.S. continues to lag behind other

industrialized nations on international math and reading tests, the stewardship provided by the principal of a school is even more crucial.

Investing in Secondary Education is Cost-Effective
Historically, Congress has invested in the elementary grades and higher education, but has paid too little attention to the nation's secondary schools. Despite significant increases over the past several years to Title 1 of NCLB (the primary source of support for K – 12 schools), secondary schools receive far less funding under this program than elementary schools. In fact, based on U.S. Department of Education statistics, of the 2004-05 Title 1 appropriation, only approximately 14% was directed to middle schools, and only about 10% was directed to the high school level. Consequently, low-income secondary school students receive considerably less federal funds than do low-income elementary students.

NASSP strongly supports strategies of early intervention; however investments made at the elementary level do not inoculate children from later academic and learning difficulties. Investments must also be made at the middle level, where students at risk of dropping are often first identified, and this investment must follow through to high school.

In addition to the moral imperative of preparing all students for success, an increased investment in secondary education is cost-effective, and would more than pay for itself. According to a 2007 report by the Center for Benefit-Cost Studies at Columbia University, if the number of high school dropouts was cut in half, the government would see an additional $45 billion in tax revenues and reduced welfare, health care, and criminal justice payments.

If we are truly serious about improving our schools, we must provide the resources that address the problems and challenges of school reform in a comprehensive manner from pre-kindergarten and elementary through high school and beyond.

Closing
A few final thoughts: Principals, teachers, and other staff members in the vast majority of schools are working hard to improve and meet the standards of NCLB. They are implementing new strategies, improving teaching methods, and working with parents to achieve higher student learning. Many schools are actively seeking to accomplish what has been asked of them.

NASSP strongly supports the ideals embodied in NCLB, and principals are optimistic that given adequate resources, all students can achieve high levels of success. But our optimism has too often been dampened in the past when federal budget proposals reflect education as so low a priority. Experience teaches us the new provisions in NCLB will be impossible to implement without full funding. We therefore strongly urge you to commit to your nation's schools in budget as much as in law and ensure that the necessary level of funding is appropriated.

NASSP promotes the improvement of secondary education and the role of principals, assistant principals, and other school leaders by advocating high professional and academic standards, addressing problems school leaders face, providing a "national voice," building public confidence in education, and strengthening the role of the principal as instructional leader. NASSP promotes the intellectual growth, academic achievement, character development, leadership development, and physical well-being of youth through its programs and student leadership services, including the National Honor Society™, the National Association of Student Councils™, and the National Association of Student Activity Advisers™.

TESTIMONY ON THE FY 2009 BUDGET OF
THE NATIONAL INSTITUTES OF HEALTH
before the
Subcommittee on Labor, Health and Human Services, and Education
Committee on Appropriations
United States House of Representatives

THE HONORABLE DAVID OBEY, CHAIR
March 31, 2008

Organization: Association for Psychological Science
Witness: Amy S. Pollick, PhD, Director of Government Relations

SUMMARY OF RECOMMENDATIONS

- As a member of the Ad Hoc Group for Medical Research Funding, **APS recommends $31.1 billion for NIH in FY 2009.**

- **APS requests Committee support for behavioral and social science research and training as a core priority at NIH** in order to: better meet the Nation's health needs, many of which are behavioral in nature; realize the exciting scientific opportunities in behavioral and social science research, and; accommodate the changing nature of science, in which new fields and new frontiers of inquiry are rapidly emerging.

- Given the critical role of basic behavioral science research and training in addressing many of the Nation's most pressing public health needs, **we ask the Committee to ensure that the National Institute of Mental Health coordinates with other NIH Institutes to provide support for basic behavioral science research.**

- **APS encourages the Committee to review behavioral science activities at individual institutes.** Examples are provided in this testimony to illustrate the exciting and important behavioral and social science work being supported at NIH.

Mr. Chairman, Members of the Committee: My name is Dr. Amy Pollick, and I am speaking on behalf of the Association for Psychological Science. Thank you for the opportunity to provide this statement on the FY 2009 appropriations for the National Institutes of Health. As our organization's name indicates, APS is dedicated to all areas of scientific psychology, in research, application, teaching, and the improvement of human welfare. Our 20,000 members are scientists and educators at the Nation's universities and colleges, conducting NIH-supported basic and applied, theoretical and clinical research. They look at such things as: the connections between emotion, stress, and biology and the impact of stress on health; they look at how children grow, learn, and develop; they use brain imaging to explore thinking and memory and other aspects of cognition; they develop ways to manage debilitating chronic conditions such as diabetes and arthritis as well as depression and other mental disorders; they look at how genes and the environment influence behavioral traits such as aggression and anxiety; and they address the behavioral aspects of smoking and drug and alcohol abuse.

As a member of the Ad Hoc Group for Medical Research Funding, APS recommends $31.1 billion for NIH in FY 2009, an increase of 6.5% over the FY 2008 appropriations level. This increase would halt the erosion of the Nation's public health research enterprise, and help restore momentum to our efforts to improve the health and quality of life of all Americans.

Within the NIH budget, APS is particularly focused on behavioral and social science research and the central role of behavior in health. The remainder of my testimony concerns the status of those areas of research at NIH.

HEALTH AND BEHAVIOR: THE CRITICAL ROLE OF BASIC AND APPLIED PSYCHOLOGICAL RESEARCH

Behavior is a central part of health. Many leading health conditions – such as heart disease; stroke; lung disease and certain cancers; obesity; AIDS; suicide; teen pregnancy; drug abuse and addiction; depression and other mental illnesses; neurological disorders; alcoholism; violence; injuries and accidents – originate in behavior and can be prevented or controlled through behavior.

As just one example: stress is something we all feel in our daily lives, and we now have a growing body of research that illustrates the direct link between stress and health problems: chronic stress accelerates not only the size but also the strength of cancer tumors; mounting evidence indicates that chronic stressors weaken the immune system to the point where the heart is damaged, paving the way for cardiac disease; children who are genetically vulnerable to anxiety and who are raised by stressed parents are more likely to experience greater levels of anxiety and stress later in life; animal research has shown that stress interferes with working memory; and stressful interactions may contribute to systemic inflammation in older adults, which in turn extends negative emotion and pain over time.

None of the conditions or diseases described above can be fully understood without an awareness of the behavioral and psychological factors involved in causing, treating, and preventing them. Just as there exists a layered understanding, from basic to applied, of how molecules affect brain cancer, there is a similar spectrum for behavioral research. For example, before you address how to change attitudes and behaviors around AIDS, you need to know how attitudes develop and change in the first place. Or, to design targeted therapies for bipolar disorder, you need to know how to understand how circadian rhythms work as disruptions in sleeping patterns have been shown to worsen symptoms in bipolar patients.

Prevention and Health: Changing Behavior

In Subcommittee hearings earlier this year, Members asked health experts why Americans, who know they need to stop smoking, eat better and exercise to be healthy, continue to engage in these detrimental behaviors. As the Partnership to Fight Chronic Disease has said, it all boils down to changing behavior. In this era of flat funding for NIH and a severely restricted discretionary budget, preventive health care that has real cost offsets have received a great deal of attention. The Centers for Disease Control and Prevention has said that "the United States cannot effectively address escalating health care costs without addressing the problem of chronic diseases," and the Milken Institute estimates the annual economic impact of preventable chronic diseases on the U.S. economy to be more than $1 trillion. Fully 75% of our current healthcare spending goes towards chronic diseases, the vast majority of which could be better prevented or managed.

Only a tiny fraction of health-care spending is devoted to the promotion of healthier behavior, even though health care experts agree that moderate improvements in prevention would result in enormous savings to the economy. The Milken Institute's major policy recommendations include promoting healthy lifestyles and disease prevention. If we can reduce obesity and smoking in this country, we'd save $60 billion over the next 15 years. The Partnership to Fight Chronic Disease agrees that behavioral factors play a critical role in this surging trend, and that prevention focusing on these factors should be the starting point of any campaign to reduce the incidence of these debilitating conditions.

Let me illustrate how critical behavioral research is to prevention: Basic decision science research elucidates the cognitive, emotional, and social factors that influence judgment and choice, and how judgment and decision-making can be predicted and improved. This research plays a central role in health education by identifying the most effective ways to frame messages that will encourage behavior change. For example, fundamental cognitive research has shown that for certain kinds of prevention efforts, public health information is best conveyed in a "gain-framed" message (e.g., "if you regularly apply sunscreen you'll help prevent skin cancer," versus "if you don't apply sunscreen, you increase your risk for skin cancer"), whereas early detection strategies should be conveyed in a "loss-framed" way (e.g., "if you don't get a mammogram, tumors can't be detected early, and the later the detection of cancer, the fewer the treatment options."). Additional research has shown that the influence of message framing on health behavior is also related to the type of behavior being promoted: People are risk-seeking when they consider losses and risk-averse when they consider gains, which is directly applicable to decision making related to health. This finding has been the basis for a new generation of tailored health-related public service messages that advance the goal of encouraging people to protect their health.

While "prevention" has been the buzzword in Congress and health advocacy circles, and there are well-intended programs aimed at reducing health problems, we need to ensure that health promotion strategies are grounded in scientific understanding of how people process information and make decisions.

Next, I'd like to talk about the status of research into the fundamental processes underlying health behaviors.

Basic Behavioral Science Research Needs A Stable Infrastructure

Broadly defined, behavioral research explores and explains the psychological, physiological, and environmental mechanisms involved in functions such as memory, learning, emotion, language, perception, personality, motivation, social attachments, and attitudes. Within this, ***basic*** behavioral research aims to understand the fundamental nature of these processes in their own right, which provides the foundation for ***applied*** behavioral research that connects this knowledge to real-world concerns such as disease, health, and life stages. Basic behavioral research continues to fare poorly at NIH, a circumstance that jeopardizes the success of the entire behavioral research enterprise. Let me remind you of the current situation:

Traditionally, the National Institute of Mental Health (NIMH) has been the home for far more basic behavioral science than any other institute. Many basic behavioral and social questions were being supported by NIMH, even if their answers could also be applied to other institutes. In recent years, NIMH has begun to aggressively reduce its support for many areas of the most basic behavioral research, in favor of translational and clinical research. This means that previously funded areas now are not being supported.

NIMH's abrupt decision to narrow its portfolio came without adequate planning and is happening at the expense of critical basic behavioral research. We favor a broader spectrum of support for basic behavioral science across NIH as appropriate and necessary for a vital research enterprise. But until other Institutes have the capacity to support more basic behavioral science research connected to their missions, programs of research in fundamental behavioral phenomena such as cognition, emotion, psychopathology, perception, and development, will continue to languish. The existing conditions for basic behavioral science research undermine the scientific community's efforts to address many of the Nation's most pressing public health needs. We ask the Committee to ensure that NIMH coordinates with other NIH Institutes to support basic behavioral research and training at NIH.

Despite the clear central role of behavior in health, behavioral research has not received the recognition or support needed to prevent, or reverse the effects of, behavior-based health problems in this Nation. APS asks that you continue to help make behavioral research more of a priority at NIH, both by providing maximum funding for those institutes where behavioral science is a core activity, by encouraging NIH to advance a model of health that includes behavior in its scientific priorities, and by encouraging stable support for basic behavioral science research at NIH.

BEHAVIORAL SCIENCE AT KEY INSTITUTES

In the remainder of my testimony, I would like to highlight examples of cutting-edge behavioral science research being supported by individual institutes.

National Cancer Institute (NCI): NCI's Behavioral Research Program continues to make excellent progress, supporting basic behavioral research as well as translational research on the development and dissemination of interventions in areas such as tobacco use, dietary behavior, sun protection, and decision-making. With current focus on prevention in health care, NCI's ongoing program in decision-making exemplifies the relationship between basic and applied behavioral research. One study this program funds is testing health behavior interventions that can be broadly applied across sociodemographic populations. Researchers are experimenting with methods of communicating risk and statistics information to women at high risk for breast cancer. These messages draw from a foundation of basic behavioral and social science research into such issues as how people learn and remember health information, how they perceive health risks, and how they are persuaded to adopt healthy behaviors. APS asks Congress to support NCI's behavioral science research and training initiatives and to encourage other Institutes to use these programs as models.

National Institute on Aging (NIA): One of NIA's major initiatives is the ACTIVE (Advanced Cognitive Training for Independent and Vital Elderly) trial, which aims to halt the decline of cognitive functioning in older adults. Without good mental capabilities, this population will lose its ability to live independently, which in turn places an enormous burden on an already stressed healthcare system. This landmark study showed that brief mental exercises produced long-lasting improvements years later, which has profound implications for intervention design. These results show that basic behavioral and cognitive science, when it underlies sound interventions that help people in real time, has a very real impact. APS asks the Committee to support NIA's behavioral science research efforts and to increase NIA's budget in proportion to

the overall increase at NIH in order to continue its high quality research to improve the health and wellbeing of older Americans.

National Institute on Drug Abuse (NIDA): By supporting a comprehensive research portfolio that stretches across basic neuroscience, behavior, and genetics, NIDA is leading the Nation to a better understanding and treatment of drug abuse. We still know very little about the ways in which social influences interact with the unique adolescent brain to increase vulnerability to drug abuse. New research supported by NIDA is examining events in brain development that change with exposure to drugs as well as to risky behavior. Researchers are asking how these behavioral and neurobiological changes during this stage of development may be uniquely sensitive to the problems of drug abuse behavior. If we can better understand the effects structural brain changes have on functions like thinking, decision-making, sensation and perception we will be able to better develop targeted and more likely effective prevention strategies from the brain development perspective. APS asks this Committee to support this and other critical behavioral science research at NIDA, and to increase NIDA's budget in proportion to the overall increase at NIH in order to reduce the health, social and economic burden resulting from drug abuse and addiction in this Nation.

National Institute of Dental and Craniofacial Research (NIDCR): Several Institutes are increasingly recognizing the value and relevance of basic behavioral research to their mission. NIDCR is to be particularly commended for their support of behavior and oral health research. As we've made explicit throughout this testimony, behavior impacts every aspect of health, and oral health is no exception – to that end, NIDCR is funding basic research on theoretical models that get beyond simple cause-and-effect relationships in behavior. By identifying new ways to conceptualize behavioral and social contributors to oral health, researchers can better identify potential targets for more efficient interventions to help Americans maintains good oral health. APS asks Congress to support NIDCR's emerging behavioral science research portfolio and to encourage other Institutes to use this program as a model for how basic behavioral research can greatly facilitate achieving their research goals.

It's not possible to highlight all of the worthy behavioral science research programs at NIH. In addition to those reviewed in this statement, many other institutes play a key role in the NIH behavioral science research enterprise. These include the National Institute for Child Health and Human Development, the National Institute of Mental Health, the National Institute on Alcohol Abuse and Alcoholism, the National Heart, Lung, and Blood Institute, and the National Institute of Diabetes and Digestive and Kidney Diseases. Behavioral science is a central part of the mission of these institutes, and their behavioral science programs deserve the Committee's strongest possible support.

This concludes my testimony. Again, thank you for the opportunity to discuss NIH appropriations for FY 2009 and specifically, the importance of behavioral science research in addressing the Nation's public health concerns. I would be pleased to answer any questions or provide additional information.

Written Testimony

FY09 Funding: National Institute for Dental and Craniofacial Research

Prepared for presentation to the U.S. House of Representatives
Appropriations Subcommittee on Labor, Health & Human Services, Education, and Related Agencies

Submitted By:

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March 31, 2008

Mr. Chairman and distinguished Members of the Committee, the members of the **Friends of the National Institute of Dental and Craniofacial Research (FNIDCR),** a leading coalition of individuals, corporations, and institutions that understands the importance of dental, oral, and craniofacial health to our society, are requesting that FY09 funding for the **National Institute of Dental and Craniofacial Research (NIDCR)** be appropriated at our recommended level of $425 million. As it stands, the president's recommended level of FY09 funding for NIDCR, $390,535,000, is woefully inadequate and it is $6 million below FY08 funding that Congress passed last year.

NIDCR: A Renown Leader in Research

For 60 years, NIDCR has been the leading sponsor of research and research training in biomedical and behavioral sciences. Its mission is to *"improve oral, dental and craniofacial health through research, research training, and the dissemination of health information."*

NIDCR meets its mission by:

- Performing and supporting basic and clinical research;
- Conducting and funding research training and career development programs to ensure an adequate number of talented, well-prepared and diverse investigators is sustained;

- Coordinating and assisting relevant research and research-related activities among all sectors of the research community; and

- Promoting the timely transfer of knowledge gained from research and its implications to health professionals, researchers, and policy-makers; and on the overall well-being of our society.

NIDCR Research Benefits Society

Proper federal funding of NIDCR will transform the future of medical and dental practice to the benefit of our society and ease the burden on our nation's healthcare system. Examples of where NIDCR research has benefited, and will continue to benefit, society are:

Tooth Decay. Fluorides and sealants have cut the rate of the number of American adults, aged 45 and older, who are without teeth by more than half since 1950s.

Oral Cancer Detection. Twenty-two Americans die each day from oral cancer, and 39,000 people develop it every year. Survival rates are among the lowest of all the major cancers. It is difficult to detect and hard to predict its outcome.

NIDCR-supported research has yielded initial success with developing a fully-automated, all-in-one test device that can alert dentists if oral cancer is in the early stages of development in a patient. The portable device, which probes cells brushed from the mouth for a common sign of oral cancer, yields results in under ten minutes. Currently, a painful tissue biopsy is the method used to detect oral cancer and the results take days; not minutes.

Salivary Diagnostics. The promising prospect of using saliva as a diagnostic fluid to identify an emerging disease is an example of the type of cutting-edge research being conducted and supported by NIDCR. Salivary Diagnostics possesses advantages over traditional blood testing, including the absence of needles and the ability to be administered on-the-spot.

Genome-wide Association Studies. NIDCR is supporting the first genome-wide association studies on cleft lip/cleft palate and dental carries. This is being done in collaboration between epidemiologists, geneticists, informatics experts, and environmental scientists. The studies offer significant potential for understanding the molecular and genetic basis of cleft lip/cleft palate and dental carries with the goal of improving the ability to predict and manage them.

Moreover, NIDCR research benefits millions of Americans with:

- Periodontal Disease
- Chronic Dry Mouth

- Chronic Facial and Oral Pain, and
- Bone and Cartilage Regeneration

All of these diseases and ailments lead to two million hospitalizations and 100,000 deaths annually at a cost of $100 billion to our nation's healthcare system.

Oral Health Disparities Centers

Finally, through community-based disparities research funded by NIDCR, a difference is being made in meeting the health needs of our nation's low-income, underserved, and high-risk populations. Sadly, this need was made apparent with the tragic passing of 12-year-old Deamonte Driver who died from a tooth infection in 2007.

NIDCR is committed to eventually eliminating oral health disparities by planning to fund Centers to Reduce Oral Health Disparities this summer. The Centers will continue to perform interventions to determine the best methods for preventing oral disease and applying research findings in communities with health disparities.

Recommendation

Simply stated, proper funding of the National Institute for Dental and Craniofacial Research is essential to the overall health and well-being of our fellow Americans. Moreover, we firmly contend that medical discoveries and advances from NIDCR funding lead to improvements in dental practices and change the scope of public health policies across the nation. Whether it is detecting a clear link between bacteria in the mouth and heart disease—or discovering how saliva can be used as an indicator of how healthy a human being is—we all benefit when we make oral health research a priority.

Therefore, based upon the merits of the research conducted by NIDCR, we respectfully request the Subcommittee to fund NIDCR at **$425 million** so that it can realize the full potential of its worthy mission.

Thank you for the opportunity to present our written testimony before the Subcommittee.

Testimony of the Friends of SAMHSA

Before the House Committee on Appropriations
Subcommittee on Labor, HHS, and Education
March 31, 2008
Prepared by Andrew Kessler
Slingshot Solutions LLC

Mr. Chairman, thank you for the opportunity to testify before the committee. The Friends of SAMHSA is a new organization, a coalition of associations, corporations and individuals, with one united goal; to support the mission of the Substance Abuse and Mental Health Services Administration. Officially formed in November 2007, the Friends of SAMHSA has members across the country, in places such as New York, California, Texas, Nebraska, Wyoming, and Oregon.

SAMHSA's goals go far beyond simple treatment. Their creed is "a life in the community for everyone." Treatment for mental health and addiction disorders is an ongoing process, one that goes far beyond therapy and rehabilitation. An individual in recovery does not seek solely sobriety or sanity, but a complete life as well. A job, a home, a family. Behavioral health problems can hinder the road to these privileges. Yet once someone receives treatment, not every aspect of life immediately falls into place. SAMHSA's programs and grants are aimed at helping those who suffer from behavioral health disorders achieve these goals.

This testimony is the first time that Friends of SAMHSA has taken a public position on the budget of SAMHSA. The President's budget for FY 2009 requests a budget decrease for SAMHSA in the amount of $198 million. At a time when such incredible advances are being made in the field of behavioral health treatment, a budget decrease of this size would turn the clock back years, or perhaps even decades on the progress that has been made. The President himself has said "Americans with mental health disorders deserve our understanding, and they deserve excellent care." The proper funding of SAMHSA will go a long way towards fulfilling this sentiment.

This committee has been responsible for supporting great achievements in the fields of addiction and mental health. The doubling of the NIH budget completed earlier this decade was an outstanding accomplishment, and has funded research that has led and will lead to incredible advances in treatment. Yet if our country is to see the results of the research brought about by this budget increase, to truly reap the fruits of this labor, we must see the same commitment to funding services as we do to funding research. After all, what good is research if it is not translated into treatment? SAMHSA was established in 1992 to be the leading federal agency on the treatment of behavioral health disorders, yet it is often overlooked.

This Congress has made clear how much it supports the treatment of substance abuse and mental health. The House has passed the Paul Wellstone Mental Health and Addiction Equity act, and both chambers of Congress have passed the Second Chance Act. In the wake of these developments, Congress has an opportunity to finally make a difference in the lives of millions of people suffering from behavioral health disorders. Without proper funding for agencies such as SAMHSA, it will be difficult to realize the vision and the spirit of these landmark pieces of legislation. If the cuts implemented by the President's budget are not restored, SAMHSA will be forced to cut several programs that are critical to its mission. SAMHSA's Center for Substance Abuse Treatment (CSAT) funds a

program for pregnant and postpartum women. The Center for Substance Abuse Prevention (CSAP) funds an underage drinking initiative. These programs are just two examples of what stands to be eliminated. SAMHSA's Programs of Regional and National Significance in mental health, drug abuse treatment, and drug abuse prevention also face significant cuts.

SBIRT

There is no doubt that the best way to treat a behavioral disorder is to find it in its earliest stages. Screening and brief interventions are critical. The SBIRT (Screening & Brief Intervention and Referral to Treatment) program at SAMHSA is a paradigm shift in the provision of treatment for substance use and abuse. The services are different from specialized or traditional treatment, but work well in compliment with them.

The SBIRT Initiative targets those with non-dependent substance use conditions and provides effective strategies for intervention prior to the need for more extensive or specialized treatment. It involves implementation of a system within community and medical settings, which include physician offices, hospitals, educational institutions, and mental health centers. The system screens for and identifies individuals with or at-risk for substance use-related problems. Screening determines the severity of substance use and identifies the appropriate level of intervention. The system provides for brief intervention or brief treatment within the community setting or motivates and refers those identified as needing more extensive services than provided in the community setting to a specialist setting for assessment, diagnosis, and appropriate treatment.

As of August 2007, SBIRT grantees funded by SAMHSA have screened over half of a million people. Through the efforts of SAMHSA grantees, researchers are learning how to integrate SBIRT into primary care. To date, SAMHSA grantees have implemented SBIRT in trauma centers, emergency rooms, community clinics, federally qualified health centers, and school clinics.

Suicide Prevention

One of SAMHSA's top priorities is suicide prevention. There are close to 30,000 suicides in the United States each year. Youth suicide early intervention and prevention efforts should continue to be a national priority and states, tribes, and colleges and universities must have the resources needed to address this important public health problem. Congress has shown its commitment to this cause, by passing the Garrett Lee Smith Memorial Act, and can continue to show its commitment through funding SAMHSA's programs in this field. The Garrett Lee Smith Memorial Act (GLSMA) created a program within the Substance Abuse and Mental Health Services Administration, which enhances suicide prevention efforts on a state, tribal, local, and campus level.

Under the act, grants are also be provided to institutions of higher education, in order to coordinate the implementation of State-sponsored statewide or tribal youth suicide early

intervention and prevention strategies; finally, SAMHSA will be able to collect and analyze data on State-sponsored statewide or tribal youth suicide early intervention and prevention services that can be used to monitor the effectiveness of such services and for research, technical assistance, and policy development

The act authorizes a total of $210 million over five years to help states and tribes develop and implement statewide youth suicide early intervention and prevention strategies, raise awareness, educate people about mental illness and the risk of suicide, help identify young people with mental illnesses, and allow states to expand access to treatment options. Also, the bill authorizes a total of $31 million over five years to fund a matching-grant program to colleges and universities to help raise awareness about youth suicide, as well as enable those institutions to train students and faculty to identify and intervene when youth are in crisis, and develop a system to refer students for care. Finally, the bill authorizes a total of $25 million over five years to fund a suicide prevention technical assistance center. We urge this committee to commit to funding this act at a full and complete level.

SAMHSA's Centers

SAMHSA funds programs that focus on both short-term response and long-term care. SAMHSA's Helpline, a 1-800 number, is a National, toll-free referral service for locating drug and alcohol abuse treatment programs that is operated by SAMHSA's Center for Substance Abuse Treatment (CSAT). According to SAMHSA administrator Terry Cline, the helpline receives between twenty-five thousand and thirty thousand calls per month. Other CSAT resources include: methadone and brupenorphine locators, so that heroin addicts may find treatment close to them, and; treatment center locators, including private and public facilities that are licensed, certified, or otherwise approved for inclusion by their State substance abuse agency, as well as treatment facilities administered by the Department of Veterans Affairs, the Indian Health Service, and the Department of Defense. Any cuts to SAMHSA's budget, and in turn to CSAT, will diminish the effectiveness of the aforementioned services. Treatment cannot improve if CSAT cannot continue to reach more people who are in desperate need of their help.

SAMHSA's Center for Substance Abuse Prevention (CSAP) works with States and communities to develop comprehensive prevention systems that create healthy communities in which people enjoy a quality life. This includes supportive work and school environments, and drug- and crime-free neighborhoods. The Center for Mental Health Services (CMHS) leads national efforts to improve prevention and mental health treatment services for all Americans. CMHS pursues its mission by helping States improve and increase the quality and range of treatment, rehabilitation, and support services for people with mental health problems, their families, and communities.

Other programs

We cannot emphasize enough the importance of the grants under projects of regional significance, most notably the Consumer Networks Grant, and Statewide Family Network

Grants. These are pivotal if we are to build and maintain family and consumer voices, so that we may further implement recommendations from the President's New Freedom Commission on Mental Health. This program must at a minimum be retained, and we are hopeful it will grow in the very near future.

The Statewide Family Networks program exists to enhance State capacity and infrastructure to be more oriented to the needs of children and adolescents with serious emotional disturbances, as well as their families. The programs goals are to strengthen organizational relationships; foster leadership and business management skills among families of children and adolescents with serious emotional disturbance and; identify and address the technical assistance needs of children and adolescents with serious emotional disturbances and their families.

Consumer network grants help consumer organizations around the country work with policymakers and service providers to improve services for persons living with serious mental illnesses. Grantees are encouraged to work in partnership with their state's Mental Health Transformation State Incentive Grant staff toward achieving common statewide consumer network goals. Grants funds are used to support activities such as: Improvement of community services to include creating individualized plans of care; developing anti-stigma initiatives; interacting with the criminal justice system; supporting employment programs; developing supports for returning veterans); Improvement of cultural competence issues, which include rights protection; responsiveness to diverse needs of racial and ethnic minorities; outreach to rural, minority, and older adult populations.

As our nation's health care continues to evolve, behavioral health services are playing a larger and larger role. If SAMHSA is not allowed to grow at the same pace as the rest of the country's health services, it is the American public that will pay the price. We urge you to restore the President's cuts, and increase SAMHSA's budget to a level 5% greater than that of FY 2008.

Appendix A

Members of the Friends of SAMHSA

Alcoholism and Substance Abuse Providers of New York State

California Association of Drug and Alcohol Abuse Counselors (Sacramento, CA)

California Network of Mental Health Clients

Center For Health Care Services (San Antonio, TX)

Central City Concern (Portland OR)

Entertainment Industry Council (Reston, VA)

International Certification & Reciprocity Consortium (Harrisburg PA)

Suicide Prevention Action Network (Washington DC)

Trichotillomania Learning Center (Santa Cruz, CA)

Uplift (Cheyenne, WY)

Dr. Nancy Speck, Houston, TX

Dr. Alan Tomkins, University of Nebraska

Angela L. Sharpe, Deputy Director for Health Policy, Consortium of Social Science Associations

Statement of the Coalition for the Advancement of Health Through Behavioral and Social Science Research (CAHT-BSSR) on FY 2009 Funding for the National Institutes of Health submitted for the record to the Subcommittee on Labor, Health and Human Services, Education and Related Agencies, Committee on Appropriations, U.S. House of Representatives
The Honorable David Obey, Chair, March 31, 2008

Mr. Chairman and Members of the Subcommittee, the Coalition for the Advancement of Health Through Behavioral and Social Science Research (CAHT-BSSR) appreciates and welcomes the opportunity to comment on the Fiscal Year (FY) 2009 appropriations for the National Institutes of Health (NIH). CAHT-BSSR includes 12 professional organizations, scientific societies, coalitions, and research institutions concerned with the promotion of and funding for research in the social and behavioral sciences. Collectively, we represent more than 120 professional associations, scientific societies, universities, and research institutions.

The behavioral and social sciences regularly make important contributions to the well-being of this nation. Due in large part to the behavioral and social science research sponsored by the NIH, we are now aware of the enormous contribution behavior makes to our health. At a time when genetic control over diseases is tantalizingly close but not yet possible, knowledge of the behavioral influences on health is a crucial component in the nation's battles against the leading causes of morbidity and mortality: obesity, heart disease, cancer, AIDS, diabetes, age-related illnesses, accidents, substance abuse, and mental illness. As a result of the strong Congressional commitment to the NIH in years past, our knowledge of the social and behavioral factors surrounding chronic disease health outcomes is steadily increasing. The NIH's behavioral and social science portfolio has emphasized the development of effective and sustainable interventions and prevention programs targeting those very illnesses that are the greatest threats to our health, but the work is just beginning.

Unfortunately, the President's request over the past few years has not allowed us to fully reap the research opportunities that the doubling campaign have made available. In recent years, NIH has been unable to keep pace with the biomedical rate of inflation. The agency's purchasing power has decreased by more than 13 percent since FY 2003. **To fulfill the extraordinary scientific promise of biomedical, behavioral and social science research, the Coalition joins the Ad Hoc Group for Medical Research in respectfully requesting a FY 2008 appropriation of $31.1 billion for the NIH.** This level of funding will provide adequate resources to regain the momentum of set in place by the completed campaign to double the nation's investment in the promising research supported and conducted by the NIH.

The grandest challenge we face is understanding the brain, behavior, and society -- from global warming to responding to short term pleasures; from self destructive behavior, such as addiction, to life style factors that determine the quality of life, infant mortality rate and longevity. Nearly 125 million Americans are living with one or more chronic conditions, like heart disease, cancer, diabetes, kidney disease, arthritis, asthma, mental illness and Alzheimer's disease. The Centers for Medicare and Medicaid Services (CMS) recently reported that health care spending in the United States rose to $1.6 trillion in 2002, up from $1.4 trillion in 2001 and $1.3 trillion in 2000. Health expenditures per person averaged $5,440 in 2002, up from $5,021 in 2001 and $4,670 in 2000. Today, it is even more.

Significant factors driving this increase are the aging of the U.S. population, and the rapid rise in chronic diseases, many caused or exacerbated by behavioral factors: for example, obesity, caused by sedentary behavior and poor diet; addictions and resulting health problems caused by tobacco and other drug use.

Behavioral and social sciences research supported by NIH is increasing our knowledge about the factors that underlie positive and harmful behaviors, and the context in which those behaviors occur. NIH supports behavioral and social science research throughout most of its 27 institutes and centers. Numerous reports by the National Academy of Sciences (e.g. *The Aging Mind, New Horizons in Health: An Integrative Approach*, and *Health and Behavior*) have presented cutting edge research agendas and made eloquent cases for the applicability of the social and behavioral scientific disciplines to the myriad, complex problems of prevention, treatment and cure of diseases as well as the enhancement of quality of life.

The NIH Office of Behavioral and Social Sciences Research (OBSSR), authorized by Congress in the NIH Revitalization Act of 1993 and established in 1995, purpose is to serve a convening and coordinating role among the institutes and centers at NIH. OBSSR focuses on cross-cutting behavioral and social research issues (e.g. "Long-term Maintenance of Behavior Change") using its modest budget to seed cross-institute research initiatives. OBSSR has spurred cutting edge research in areas such as measures of community health, socioeconomic status, and new methodology development.

OBSSR's recently released strategic plan emphasizes a Systems Science approach to health. In FY 2009, the Office is planning to support an initiative on the development and application of systems integrative science approaches to study how multiple factors – behavioral, social, and biological – interact with each other and change over time to influence health. It is the intent of the Office that these approaches can be incorporated into two additional programs that it plans to support in FY 2009: 1) research to improve adherence to treatments and 2) research to reduce or eliminate health disparities. The areas represent two persistent public health problems that have been resistant to solution. OBSSR plans to issue a new Funding Opportunity Announcements (FOA), Using Systems Science Methodologies to Protect and Improve Population Health, which will call for applicants to use one or more specific system science methodologies to address one or more specific opportunities to protect and improve population health. The initiative follows OBSSR's success in attracting large global audiences for its webcasts of its 2007 Symposia Series on Systems Science and Health, and the 2007 Conference on Complex Approaches to Population Health.

Another strategy for OBSSR for FY 2009 consists of continuing to fund transdisciplinary research on prevention, policy, and health care, three broad areas influencing health disparities. The Office also intends to continue to fund multi-year programs which support its mission and goals, including community-based participatory research (CBPR) with new CBPR programs which apply intervention research methods to disease prevention and health promotion while targeting medically-served areas. Health literacy research is another area that the OBSSR plans to provide continued support, along with support for the NIH Blueprint for Neuroscience, its annual summer training institutes (behavioral interventions in randomized clinical trials and social work research methods); add new training programs in genetics for behavioral and social scientists, and in integrative systems science methodology. A second annual trans-NIH conference on dissemination

and implementation science is also being planned by the Office. The OBSSR also plans to initiate a program to support research on how interactions among social, behavioral, and genetic factors influence health. **CAHT-BSSR supports an appropriation of $28.4 million for OBSSR.**

As highlighted by NIH Director Elias Zerhouni on the occasion of OBSSR's 10th anniversary in June 2006: ***"the OBSSR has been a tremendous asset to NIH throughout its first ten years . . .we are faced with an enormous and evolving national burden of disease and disability, much of which has roots in personal behavior or socioeconomic influences. The need for behavioral and social research and intervention has never been greater, and its impact has never been clearer. We need but look at recent decreases in rates of cancer, largely due to dramatic decreases in tobacco use. We can point to a remarkable demonstration of the pronounced benefits of diet and exercise – more effective than drug therapy – in preventing the onset of type 2 diabetes among high-risk individuals. These are but two among many shining examples of the widespread benefits to public health realized through our investment in basic and applied behavioral and social science research, so critical to our understanding of health and disease."***

The following research ***Achievements Of The Social And Behavioral Sciences: Improving Health at Home and Abroad*** compiled by the OBSSR research further illustrate why behavioral and social sciences research is a critical component in generating scientific knowledge to prevent, treat or cure illnesses or enhance health in a broader context.

Reducing Tobacco Use -- The biggest public health success story of the 20th century may very well be the reduction in tobacco use and related diseases. Behavioral and social science research has demonstrated successes in preventing youth uptake of smoking as well as in developing powerful behavioral and pharmacological interventions that help smokers quit. As a result, in 2006, overall cancer death rates dropped for the first time in a century, driven largely by the dramatic 50 percent reduction in male smoking from 47 percent in the 1960's to less than 23 percent today. While smoking still kills more women than breast cancer, rates are slowing as women quit and fewer adolescents start. Without this research, 40 million Americans might still be smoking today with about 12 million additional premature deaths and billions of dollars in excess cost.

Improving Mental Health -- Over the past 30 years, our understanding of the bio-behavioral mechanisms and treatment of mental disorders has advanced dramatically. Effective and cost-effective therapies that combine behavioral and pharmacological treatments are now available for treatment of depression, anxiety disorders, and the abuse of nicotine, alcohol and other drugs.

Understanding Mind/Body Interactions -- It is now widely recognized that stress plays an important role in heart disease, decreased immune system functioning, and premature aging. In addition, there is strong evidence that stress and social involvement are related to the progression of cancer and vice versa. In addition, other research has demonstrated that cognitions (attitudes, beliefs values), social support, prayer, and meditation can reduce psychological stress and contribute to positive health outcomes.

Preventing Diabetes -- For many years, scientists believed that medication was the only tool to prevent and treat diabetes. The Diabetes Prevention Program demonstrated that lifestyle interventions – modest weight loss and regular physical activity – can reduce the risk of developing type 2 diabetes

in high-risk adults by 58 percent, compared to 31 percent reduction with diabetes medication. These findings led to "Small Steps, Big Rewards", the first national diabetes prevention campaign.

Reducing Sudden Infant Death Syndrome (SIDS) -- SIDS is the leading cause of death among infants who are 1 month to 1 year old, and claims the lives of about 2,500 infants each year in the United States. One of the leading risk factors for SIDS is entirely behavioral – stomach sleeping. Behavioral and social science research on communication, diffusion, and behavior change led to the nationwide *Back to Sleep Campaign* which promotes infant back sleeping to prevent SIDS. Since the campaign was launched in 1994, back sleeping increased from 26.9 percent to 72.8 percent and SIDS has declined by more than 50 percent.

Reducing the Health Burden of Poverty: Discoveries in the behavioral and social sciences can inform life-saving environmental and policy changes. One example is the PROGRESA study (Programa Nacional de Educacion, Salud, y Alimentacion), an anti-poverty program begun in 1997 that provides aid to 2.6 million poor Mexican families. This study is comprised of an impressive collaboration across disciplines including biomedical, social/behavioral sciences, economics, epidemiology, and demography. The results have been dramatic, showing that the trajectory of health outcomes associated with poverty may be altered within a generation. The PROGRESA intervention was associated with better growth and lower rates of anemia in low-income, rural infants and children in Mexico. This large-scale, real-world study has demonstrated that antipoverty programs that combine education, health, and nutrition interventions can improve the capacity of families to pull themselves out of poverty and adverse health effects that often ensnare generations.

Slowing the HIV/AIDS Epidemic -- Although still devastating, HIV/AIDS is no longer the epidemic it once was in the U.S. thanks to research breakthroughs in the biological, behavioral, and social sciences. Mother-to-child-transmission of HIV has fallen dramatically due to the widespread use of new antiretroviral drugs during pregnancy and labor. Socio-behavioral studies of risky behavior have improved our ability to prevent risk through improved screening and adherence to treatment. Large scale educational campaigns have been delivered effectively. Lessons learned are being provided to other countries. The impact of these innovations is dramatic. Previously, 1500 to 1800 babies in the United States were born infected with HIV. Today, fewer than 50 HIV-infected babies are born each year. It is estimated that 16,000-20,000 lives have been saved by preventing mother-to-child transmission of HIV in the U.S. Globally, 280,000 cases of HIV infection in children could be averted each year using this effective psychosocial and drug therapy combination.

Increasing Life Expectancy and Quality of Life -- In the last century, life expectancy has extended by an astounding amount—from 47 years in 1900 to 77.5 years in 2003. While medical advances increasingly contribute to living longer and healthier lives, the vast majority of improvements in the quality of life have come from changes in our social, economic, and physical environments.

Slowing the Cognitive Effects of Aging -- Recent research has led to dramatic advances in knowledge of the psychosocial determinants of premature aging and effective interventions to slow degeneration and improve cognitive fitness and memory as we age.

Understanding the Links Between Social and Cultural Factors and Health: Social scientists have made significant strides in shedding light on the basic social and cultural structures and processes that

influence health. Social and cultural factors influence health by affecting exposure and vulnerability to disease, risk-taking behaviors, the effectiveness of health promotion efforts, and access to, availability of, and quality of health care. Social and cultural factors also play a role in shaping perceptions of and responses to health problems and the impact of poor health on individuals' lives and well-being. In addition, such factors contribute to understanding societal and population processes such as current and changing rates of morbidity, survival, and mortality.

Improving Health Literacy: Health literacy is defined as the "degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions." In order for health care and public health systems to serve individuals and populations more effectively and to reduce health disparities in the population, it is critical to understand the nature of health literacy and its relationship to healthy behaviors, illness prevention and treatment, chronic disease management, health disparities, risk assessment of environmental factors, and health outcomes. Behavioral and social scientists have made great strides in improving knowledge of interventions that can strengthen health literacy and improve the positive health impacts of communications between healthcare and public health professionals.

Finally, CAHT-BSSR applauds the NIH's recognition that the "scientific challenges in developing an integrated science of behavior change are daunting." The recent designation of the **"Science of Behavior Change"** in the third cohort of the Common Fund Programs is to be commended. We agree with the goals of this Roadmap Pilot to "establish the groundwork for a unified science of behavior change that capitalizes on both the emerging basic science and the progress already made in the design of behavioral interventions in specific disease areas. By focusing basic research on the initiation, personalization, and maintenance of behavior change, and by integrating work across disciplines, this Roadmap effort and subsequent trans-NIH activity could lead to an improved understanding of the underlying principles of behavior change. This should drive a transformative increase in the efficacy, effectiveness, and (cost) efficiency of many behavioral interventions."

CAHT-BSSR would be pleased to provide any additional information on these issues. We have attached a list of coalition member societies to the end of the testimony. We thank the Subcommittee for its generous support of the National Institutes of Health and for the opportunity to present our views.

CAHT-BSSR

American Educational Research Association
American Psychological Association
American Sociological Association
Association of Population Centers
Center for the Advancement of Health
Consortium of Social Science Associations
Gerontological Society of America
Institute for the Advancement of Social Work Research
National Association of Social Workers
Population Association of America
Society for Research in Child Development
The Alan Guttmacher Institute (AGI).

The Coalition for the Advancement of Health Through Behavioral and Social Science Research

Testimony for Submission

Laura Hanen
Coalition Director
Hepatitis C Appropriations Partnership

To the House Committee on Appropriations
Subcommittee on Labor, HHS, Education and Related Agencies
For FY2009

The Hepatitis C Appropriations Partnership, whose members advocate for increased federal support for hepatitis C prevention, testing, education, research, and treatment, respectfully submits testimony for the record regarding federal funding for federal adult hepatitis programs in the FY2009 Labor, HHS and Education Appropriations legislation. HCAP appreciates the Committee's past support for these important public health programs.

As you craft the FY2009 Labor, HHS and Education Appropriations legislation, we urge you to consider the following critical funding needs to appropriately address the HCV epidemic:

- Include $50 million for the Centers for Disease Control and Prevention's (CDC) Division of Viral Hepatitis (DVH);
- Continue $20 million for hepatitis B vaccination for adults through the Section 317 Vaccine Program;
- Continue funding commitment for Community Health Centers;
- Increase funding for the Ryan White Program to support additional case management, provider education and the coverage of HCV drug therapies; and
- Increase funding for the National Institutes of Health to support their *Action Plan for Liver Disease Research.*

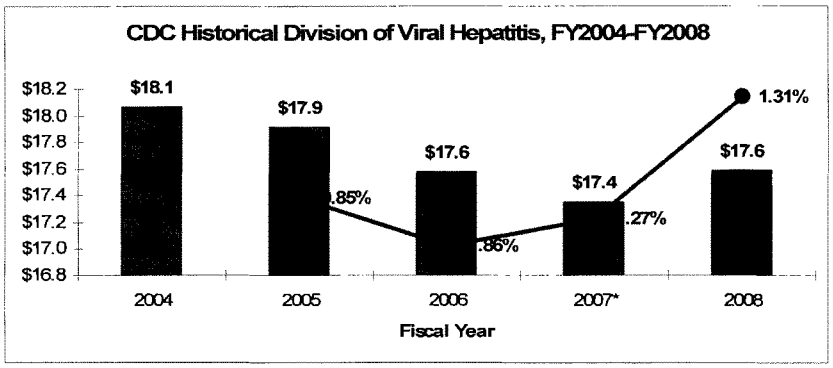
Approximately 6.25 million Americans are infected with the hepatitis C virus (HCV) and hepatitis B virus (HBV). Chronic viral hepatitis is now one of the leading killers of Americans living with HIV/AIDS. In addition, chronic viral hepatitis is the leading cause of liver cancer, now among the top 10 killers of Americans over the age of 25 years. Overall, the death rate for HCV-related deaths in the U.S. is expected to triple by 2019.

It is critical that Americans know whether they are hepatitis C-infected in order to mitigate disease burden and to prevent transmission. These include simple steps like abstaining from

alcohol use, exercising and maintaining a healthy diet. There are effective pharmaceutical treatment options available as well.

Prevention

HCAP requests a minimum increase of $32.4 million in FY2009 for the Centers for Disease Control and Prevention's (CDC) Division of Viral Hepatitis (DVH) to enable state and local health departments to provide basic core public health services. Of this increase, we request a doubling of funding for state adult viral hepatitis prevention coordinators from $5 million to $10 million. DVH currently receives $17.6 million to address hepatitis C, of which states receive an average award of $90,000 to fund a coordinator. The coordinator position receives precious little above personnel costs, leaving little to no money for the provision of public health services such as education programs for the public and health professionals, hepatitis counseling, testing, and referral, or hepatitis A and B vaccine for adults. In addition, there are no funds for surveillance of chronic viral hepatitis, which would allow states to better target their limited resources. Due to lack of funding, CDC treats hepatitis outbreaks as sentinel events rather than systematically addressing hepatitis B and C epidemics with over 6 million Americans infected. Addressing one outbreak at a time is neither cost-effective nor is it prevention. Simply put, in the absence of an HCV vaccine the government can invest in prevention now or wait until public systems are overwhelmed by the costs of chronic liver disease, including liver transplantation.



The greatest remaining challenge for hepatitis A and B prevention is the vaccination of high-risk adults. High-risk adults account for more than 75 percent of all new cases of hepatitis B infection each year and annually result in an estimated $658 million in medical costs and lost wages. In FY2007, CDC allowed states to use $20 million of 317 Vaccine funds to vaccinate high risk adults for hepatitis B. States are integrating vaccination into service programs for persons with risk factors for infection (e.g., STD clinics, HIV counseling and testing sites, correctional facilities and drug treatment clinics). By targeting high-risk adults, including those with hepatitis C, for vaccination, the gap between children and adults who have not benefited

from routine childhood immunization programs can be bridged. **HCAP requests a continuation of $20 million in FY2009 for hepatitis B vaccination.**

Treatment
Access to available treatments and treatment support services are critical to combat co-infection morbidity. While there are no dedicated funding streams for medical management and treatment of hepatitis C, low-income patients can and do seek services at Community Health Centers (CHCs). **HCAP supports your continued commitment to increasing resources for CHCs.**

Many low-income individuals co-infected with HCV and HIV can obtain services through the Ryan White Programs and because of that, **HCAP urges you to provide increased Ryan White resources.** Only half the state's AIDS Drug Assistance Programs (ADAP) are able to provide HCV and HIV treatments to co-infected clients. Increased resources are also needed to improve provider education on HCV medical management and treatment, to cover additional case management for patients undergoing treatment and to allow more states to add HCV therapies and HCV viral load tests to their ADAP formularies.

Research
Finally, research is needed to increase understanding of the pathogenesis of hepatitis C, improve HCV treatments that are currently difficult to tolerate, develop clinical strategies to slow the progression of liver disease among persons living with HCV, and develop a vaccine to prevent HCV infection. The Liver Disease Branch, located within the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) at the National Institutes of Health (NIH), has developed an Action Plan for Liver Disease Research. **HCAP requests full funding for NIH to support the recommendations and action steps outlined in this *Action Plan for Liver Disease Research*.**

A strong public health response is needed to meet the challenges of this infectious disease impacting over four million Americans. We welcome the opportunity to work with you and your staff on this important issue.

As you craft the FY2009 Labor-HHS appropriations bill, we ask that you consider all of these critical funding needs. It is essential that the United States continue to demonstrate its commitment to fighting the ongoing domestic and global HIV/AIDS, viral hepatitis, and STD epidemics. The National Alliance of State and Territorial AIDS Directors thank the Chairman, Ranking Member and members of the Subcommittee, for their thoughtful consideration of our recommendations.

Testimony for Submission

Julie M. Scofield
Executive Director
National Alliance of State and Territorial AIDS Directors

To the House Committee on Appropriations
Subcommittee on Labor, HHS, Education and Related Agencies
For FY2009

The National Alliance of State and Territorial AIDS Directors (NASTAD), whose members are responsible for administering state HIV/AIDS prevention and care programs nationwide, respectfully submits testimony for the record regarding federal funding for federal HIV/AIDS and adult hepatitis programs in the FY2009 Labor, HHS and Education Appropriations legislation. NASTAD appreciates the Committee's past support for these important public health programs.

As you craft the FY2009 Labor-HHS-Education Appropriations legislation, we urge you to consider the following critical funding needs of HIV/AIDS, STD and viral hepatitis programs:

- $1.4 billion for the Ryan White Part B Program, including $481.9 million for the Part B base and $943.5 million for the AIDS Drug Assistance Program (ADAP);
- $1.3 billion for CDC's HIV/AIDS Prevention Program, including an additional $28 million to restore cuts to the state and local health department cooperative agreements since FY2004, an additional $35 million to shore up state and local HIV/AIDS surveillance systems, and $45 million for the continuation of CDC's HIV Testing Initiative targeting communities of color;
- $50 million for CDC's Viral Hepatitis Prevention Program, including a doubling of resources for the Adult Viral Hepatitis Prevention Coordinator Program to $10 million.
- $20 million for hepatitis B vaccination for high-risk adults through the Section 317 Vaccine Program;
- $167 million for CDC's STD Prevention Program for prevention, treatment and surveillance cooperative agreements with state and local health departments; and
- $610 million for the Minority AIDS Initiative to enhance capacity in communities of color.

HIV/AIDS Care and Treatment Programs

NASTAD respectfully requests a minimum increase of **$230 million** in FY2009 for state Ryan White Part B grants, including an increase of at least **$95 million** for the Part B Base and at least **$135 million** for AIDS Drug Assistance Programs (ADAPs). The President's budget provides an increase of $8.2 million for Part B Base programs. The Part B Base was cut by $19 million in FY2008 and at a minimum those funds must be restored. These funds provide care and support services across the United States and are necessary to ensure there are not large funding shifts resulting from formula changes in the reauthorized law.

While only one state currently has a waiting list, the present fiscal condition remains fragile and is not guaranteed beyond FY2007. The President's budget included an increase of $6 million, which is insufficient to meet continuing demand for these programs. The elimination of waiting lists is largely due to state funding increases, $39.4 million in FY2007 ADAP Supplemental grants, transfers of Part B Base funding into ADAP, and program savings from the Medicare Part D Prescription Drug Benefit. Shifts in funding as a result of reauthorization of the Ryan White Program and one-time additional funding to Part B in FY2007 render the fiscal future of ADAPs uncertain. Additionally, CDC estimates that their newly implemented HIV testing initiative will find 20,000 new infections over the next year. Three new therapies were approved in 2007 and early 2008. ADAPs will be adding these to their formularies thus increasing costs.

HIV/AIDS Prevention and Surveillance Programs

NASTAD respectfully requests a funding increase of **$608 million** for total funding of **$1.3 billion** for CDC's HIV prevention and surveillance programs. The President's budget cuts CDC's HIV prevention and surveillance programs by $1 million. CDC is on the verge or releasing revised estimates of HIV incidence that will show that there have been more new infections each year than previously thought. Funding has not kept pace and has in fact been cut since FY2003. State and local HIV prevention cooperative agreements have been cut by $28 million between FY2003 and FY2008 (this includes an estimated rescission amount for FY2008). In FY2007, CDC awarded $35 million to 18 states and 5 cities to support routine testing in clinical settings particularly targeted to settings that see a large number of African Americans. NASTAD requests the maintenance of these grants to continue the testing initiative. Additionally, core HIV/AIDS surveillance funding has eroded over the last decade, while the importance of this data has become paramount for targeting prevention efforts and directing Ryan White resources. **$35 million** is needed to shore up state and local HIV/AIDS surveillance systems.

In addition, we urge you not to fund the Early Diagnosis Grant Program in Section 209 of the *Ryan White Treatment Modernization Act of 2006*. Funds should not be directed to fund this provision as it redirects scarce HIV prevention resources away from the ever

shrinking state and local prevention cooperative agreements. At a minimum, the impact and scope of this provision should be reduced.

The nation's prevention efforts must match our commitment to the care and treatment of infected individuals. State and local public health departments know what to do to prevent new infections, they just need the resources. First and foremost we must address the devastatmg impact on racial and ethnic minority communities. We must expand outreach and HIV testing efforts targeting high-risk populations including racial and ethnic minority communities, young gay men of color, substance users, women and youth. But, testing alone can never end the epidemic. All tools in the prevention arsenal must be supported. Additional resources must be directed to build capacity and provide technical assistance to enable community-based organizations and health care providers to implement evidence-based behavior change interventions, ensure fiscal responsibility and refer partners of HIV-positive individuals to counseling and testing services.

Viral Hepatitis Prevention Programs

NASTAD respectfully requests an increase of $36.4 million for a total of **$50 million** in FY2009 for the CDC's Division of Viral Hepatitis (DVH) to enable state and local health departments to provide basic core public health services. DVH currently receives $17.6 million to address chronic viral hepatitis B and C impacting 6.2 million Americans. This is $7.4 million less than its peak funding of $25 million in FY2001. The President's budget cuts DVH funding by $80,000. Of the DVH funding, $5.2 million is used to fund the Adult Viral Hepatitis Coordinator Program with an average award to states of $90,000. Doubling this program to $10 million would allow states to implement a hepatitis prevention strategy. The coordinator position receives precious little above personnel costs, leaving little to no money for the provision of public health services including public education, hepatitis counseling, testing, and hepatitis A and B vaccine. In addition, there are no funds for surveillance of chronic viral hepatitis, which would allow states to better target their limited resources. Given the recent hepatitis public health crises in Nevada and New York, the government has a choice - invest in prevention now or wait until public systems are overwhelmed by a lack of infrastructure to address future outbreaks.

The greatest remaining challenge for hepatitis A and B prevention is the vaccination of high-risk adults. High-risk adults account for more than 75 percent of all new cases of hepatitis B infection each year and annually result in an estimated $658 million in medical costs and lost wages. In FY2007, CDC allowed states to use $20 million of 317 Vaccine funds to vaccinate high risk adults for hepatitis B. States are integrating vaccination into service programs for persons with risk factors for infection (e.g., STD clinics, HIV counseling and testing sites, correctional facilities and drug treatment clinics). By targeting high-risk adults, including those with hepatitis C, for vaccination, the gap between children and adults who have not benefited from routine childhood

immunization programs can be bridged. NASTAD requests a continuation of the **$20 million** in Section 317 Vaccine funds in FY2009 for hepatitis B vaccination for high-risk adults.

STD Prevention Programs

NASTAD supports a minimum increase of **$15 million** for a total of $167 million in FY2009 for STD prevention, treatment and surveillance activities undertaken by state and local health departments. The President's budget cut STD prevention program funding by $680,000. STD prevention programs at CDC have been cut or flat-funded since FY2003 while the number of persons infected continues to climb. The U.S. has the unwanted distinction of having the highest rates of STDs of all industrial nations. In 2006 for the second consecutive year, the United States experienced record increases of the three leading STDs– Chlamydia (5.6%), Gonorrhea (5.5%), and Syphilis (13.8%).

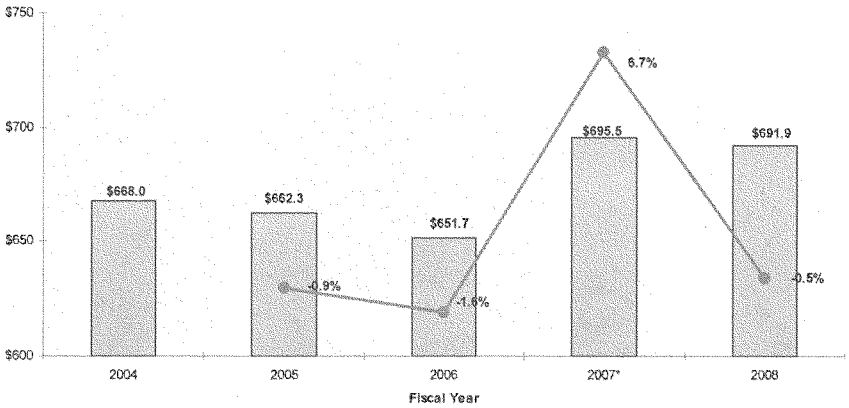
Minority AIDS Initiative

NASTAD also supports a **$210 million** increase for a total of $610 million for the Minority AIDS Initiative (MAI) in FY2009. The President's budget flat funds these important programs. The MAI provides targeted resources to address the HIV/AIDS epidemic in hard-hit communities of color. The data from CDC on the disproportionate impact on African Americans continues to be alarming. Support for the MAI along with the traditional funding streams that serve these populations is essential.

As you craft the FY2009 Labor-HHS appropriations bill, we ask that you consider all of these critical funding needs. It is essential that the United States continue to demonstrate its commitment to fighting the ongoing domestic and global HIV/AIDS, viral hepatitis, and STD epidemics. The National Alliance of State and Territorial AIDS Directors thank the Chairman, Ranking Member and members of the Subcommittee, for their thoughtful consideration of our recommendations.

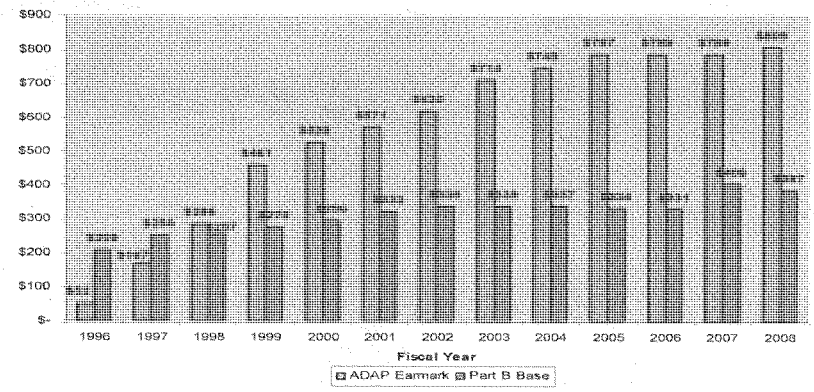
Appendix A

CDC Historical HIV/AIDS Prevention & Surveillance Funding, FY2004-2008



*$45 million in additional funding was added to the FY2007 appropriated amount for the HIV Testing Initiative *"Expanded and Integrated HIV Testing for Populations Disproportionately Affected by HIV, Primarily African Americans."*

Historical Growth of Part B Base and ADAP Earmark



Written Statement of

Wanda O. Wilson, CRNA, PhD, MSN, President

American Association of Nurse Anesthetists

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House Appropriations Subcommittee
On Labor, Health and Human Services, and Education

2358 Rayburn Building
Washington, DC
March 31, 2008

FY 2009 Appropriations Request Summary

	FY08 Actual	FY09 Budget	AANA FY 09 Request
HHS / HRSA / BHPr Title VIII Advanced Education Nursing, Nurse Anesthetist Education Reserve	Awaiting grant allocations—in FY07 awards amounted to approx. $3.5MM	Grant allocations not specified	$4 MM for nurse anesthesia education
Total for Advanced Education Nursing, from Title VIII	$61.8MM for Advanced Education Nursing	$0 for Advanced Education Nursing	$67 MM for advanced education nursing
Title VIII HRSA BHPr Nursing Education Programs	$156,046,000	$109,853,000	$200,000,000

The AANA is the professional association for more than 37,000 Certified Registered Nurse Anesthetists (CRNAs) and student nurse anesthetists, representing over 90 percent of the nurse anesthetists in the United States. Today, CRNAs are directly involved in delivering 30 million anesthetics given 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 as well as providing acute and chronic pain management services. CRNAs provide anesthesia for a wide variety of surgical cases and are the sole anesthesia providers in almost 100 percent of rural hospitals, affording these medical facilities obstetrical, surgical, and trauma stabilization, and pain management capabilities. CRNAs work in every setting in which anesthesia is delivered, including hospital surgical suites and obstetrical delivery rooms, ambulatory surgical centers (ASCs), pain management units and the offices of dentists, podiatrists and plastic surgeons.

Nurse anesthetists are experienced and highly trained anesthesia professionals whose record of patient safety in the field of anesthesia was bolstered by the Institute of Medicine report in 2000, which found that anesthesia is 50 times safer than 20 years previous. (Kohn L, Corrigan J, Donaldson M, ed. *To Err is Human.* Institute of Medicine, National Academy Press, Washington DC, 2000.) Nurse anesthetists continue to set for themselves the most rigorous continuing education and re-certification requirements in the field of anesthesia. Relative anesthesia patient safety outcomes are comparable among nurse anesthetists and anesthesiologists, with Pine having recently concluded, "the type of anesthesia provider does not affect inpatient surgical mortality." (Pine, Michael MD et al. "Surgical mortality and type of anesthesia provider." *Journal of American Association of Nurse Anesthetists.* Vol. 71, No. 2, p. 109 – 116. April 2003.)

Even more recently, a study published in *Nursing Research* indicates that obstetrical anesthesia, whether provided by Certified Registered Nurse Anesthetists (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's data showed that CRNAs and anesthesiologists are substitutes in the production of surgeries, and it is important to note that through continual improvements in research, education, and practice, nurse anesthetists are vigilant in their 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. In May 2003 at the beginning of "Operation Iraqi Freedom," 364 CRNAs were deployed to the Middle East to ensure military medical readiness capabilities. For decades, CRNAs have staffed ships, remote U.S. military bases, and forward surgical teams without physician anesthesiologist support.

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 $67 million for advanced education nursing from the

Title VIII program. We feel that this funding request is well justified, as we are seeing a vacancy rate of nurse anesthetists in the United States impacting people's healthcare. The Title VIII program, which has been strongly supported by members of this Subcommittee in the past, is an effective means to help address the nurse anesthesia workforce demand. This demand for CRNAs is something that the nurse anesthesia profession addresses every day with success and also with the critical assistance of federal funding through HHS' Title VIII appropriation.

The AANA is very concerned that the President's FY 2009 budget proposal eliminates funding for Advanced Education Nursing Programs, which seek to increase the number of providers in rural and underserved America and are the master's and doctoral prepared providers who are eligible to serve as faculty. Therefore, cuts to this program in Title VIII present a two-fold loss—reducing the number of providers who are trained as clinicians to fill the nursing shortage and reducing the number of eligible faculty to alleviate the faculty shortage.

Increasing funding for advanced education nursing from $61.8 million to $67 million is necessary to meet the continuing demand for nursing faculty and other advanced education nursing services throughout the United States. Only a limited number of new programs and traineeships can be funded each year at the current funding levels. 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 meeting the nursing workforce needs of Americans who require healthcare.

In 2007, the AANA conducted a nurse anesthesia workforce study that found a 12.6% vacancy rate in hospitals for CRNAs, and a 12.5% faculty vacancy rate. The supply of clinical providers has increased in recent years, stimulated by increases in the number of CRNAs trained. Between 2003-2007, the number of nurse anesthesia educational program graduates nearly doubled. However, the nurse anesthetist vacancy rate remained steady at around 12%, which is likely due to increased demand for anesthesia services as the population ages, growth in the number of clinical sites requiring anesthesia services, and CRNA retirements.

The problem is not that our 108 accredited programs of nurse anesthesia are failing to attract qualified applicants. It is that they have to turn them away by the hundreds. The capacity of nurse anesthesia educational programs to educate qualified applicants is limited by the number of faculty, the number and characteristics of clinical practice educational sites, and other factors. A qualified applicant to a CRNA program is a bachelor's educated registered nurse who has spent at least one year serving in an acute care healthcare practice environment. Nurse anesthesia educational programs are located all across the country including the following states:

State	*# of Accredited Nurse Anesthesia Programs*
CA	3
CT	3
FL	9
IL	5
MD	3
MN	4

NY	4
OH	5
PA	12
RI	2
TX	5
WI	1

Recognizing the important role nurse anesthetists play in providing quality healthcare, the AANA has been working with the 108 accredited nurse anesthesia educational programs to increase the number of qualified graduates. In addition, the AANA has worked with nursing and allied health deans to develop new CRNA programs.

The Council on Certification of Nurse Anesthetists (CCNA) reports that in 1999, our schools produced 948 new graduates. In 2005, that number had increased to 1,790, an 89 percent increase in just five years. This growth is expected to continue. The CCNA projects CRNA programs to produce over 2,000 graduates in 2008.

To truly meet the nurse anesthesia workforce challenge, the capacity and number of CRNA schools must continue to expand. With the help of competitively awarded grants supported by Title VIII funding, the nurse anesthesia profession is making significant progress, expanding both the number of clinical practice sites and the number of graduates.

The AANA is pleased to report that this progress is extremely cost-effective from the standpoint of federal funding. Anesthesia can be provided by nurse anesthetists, physician anesthesiologists, or by CRNAs and anesthesiologists working together. As mentioned earlier, the study by Pine et al confirms, "the type of anesthesia provider does not affect inpatient surgical mortality." Yet, for what it costs to educate one anesthesiologist, several CRNAs may be educated to provide the same service with the same optimum level of safety. Nurse anesthesia education represents a significant educational cost-benefit for supporting CRNA educational programs with federal dollars vs. supporting other 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 in 2003 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, who provide care to patients during and following their education. Moreover, they reported producing additional CRNAs that went to serve in rural or medically underserved areas. Under both of these circumstances, an increased number of student nurse anesthetists and CRNAs are providing healthcare to the people of medically underserved America.

We believe it is important for the Subcommittee to allocate $4 million for nurse anesthesia education for several reasons. First, as this testimony has documented, the funding is cost-effective and very needed. Second, the Title VIII authorization previously providing such a reserve expired in September 2002. Third, this particular funding is important because nurse

anesthesia for rural and medically underserved America is not affected by increases in the budget for the National Health Service Corps and community health centers, since those initiatives are for delivering primary and not surgical healthcare. Lastly, 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 a growing coalition of nursing organizations, including the Americans for Nursing Shortage Relief (ANSR) Alliance and representatives of the nursing community, and others in support of the Subcommittee providing a total of $200 million in FY 2009 for nursing shortage relief through Title VIII. This amount is approximately $44 million over the FY 2008 level and $90 million above the President's FY 2009 budget.

Every district in America is familiar with the importance of nursing. The AANA appreciates the support for nurse education funding in FY 2008 and past fiscal years from this Subcommittee and from the Congress.

The need for increasing nurse educational funding to strengthen our healthcare is clear. According to the Office of the Actuary at the Centers for Medicare & Medicaid Services, America spent about $2.1 trillion on healthcare in 2006, which is the most recent year for which the agency had records. About $401 billion of that was from Medicare outlays. Medicaid spending was $309 billion. It is estimated that Medicare directs over $8.7 billion of its outlays to Graduate Medical Education (GME), of which more than $2.3 billion goes to Direct GME. Approximately 99 percent of that educational funding helps to educate physicians and allied health professionals, and about 1 percent is allocated to help educate nurses.

In the interest of patients past and present, particularly those in rural and medically underserved parts of this country, we ask Congress to reject cuts from federal investments 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 nurse education will improve patient access to quality services and strengthen the nation's healthcare delivery system.

Thank you.

# # #

Testimony for the Record
House Committee on Appropriations Subcommittee on Labor, Health, & Human Services, Education and Related Agencies

Dorothy Stoneman, PhD
Chairperson, National YouthBuild Coalition
March 31, 2008

Introduction
Thank you Chairman Obey, Ranking Member Walsh, and members of the Committee for allowing me to submit this statement for the record. I want to bring to your attention to the powerful role the federal YouthBuild program can be as part of the solution to the crisis of high school dropouts in America.

A few statistics released recently at a national summit on dropouts tells the grim story:

- More than one million American high school students leave high school every year without a diploma.
- Nearly half of all African Americans, Hispanics and Native Americans fail to graduate with their high school classes.
- 1.7 million low income youth are both out of school and out of work, likely to be the parents of the next generation raised in poverty and despair.
- Another 225,000 are in prison or jail, soon to return home with no prospects for jobs.

The need for additional resources for YouthBuild is clear. Over 32 percent of America's youth are dropping out of high school with no prospect of becoming gainfully-employed contributing members to society. In inner-city communities, that percentage rises to fifty percent. Annually, States are spending at least $36,000 per inmate to incarcerate 365,000 16 to 24 year olds, 65 percent of whom did not complete high school.

YouthBuild Description and History
YouthBuild began in East Harlem in 1978. It was replicated in New York City and across the country before being authorized as a federal program in 1992 under the jurisdiction of the US Department of Housing and Urban Development. Since 1994, when HUD YouthBuild funds first reached communities, more than 76,000 YouthBuild students have produced over 17,000 units of low-income housing. Today, there are 226 YouthBuild programs in 42 states, engaging approximately 8,000 young adults each year in America's poorest urban, rural and tribal communities.

In September, 2006, at the recommendation of the Bush Administration, YouthBuild was transferred by unanimous consent in Congress to the jurisdiction of the US Department of Labor because the Department of Labor said that YouthBuild was consistent with its vision of engaging the most disadvantaged youth in high demand careers through comprehensive programming. The National YouthBuild Coalition of nearly 1,000 organizations cooperated with this move in the hope that it was the precursor to a major expansion that would use YouthBuild's proven approach to reconnect more of America's lost youth.

YouthBuild is a uniquely comprehensive, full-time, non-residential, community-based program that offers at-risk youth an immediately productive role rebuilding their communities. Students spend half their time attending basic education classes and half their time receiving job skills training in the construction field while building affordable housing. YouthBuild is also on the cutting edge of education reform for drop-outs and effective re-entry for offenders. Over forty YouthBuild programs have now been authorized to provide high school diplomas.

YouthBuild programs work because they put equal emphasis on education, employment skills, and community service in a supportive setting. While attending basic education classes for 50% of program time for approximately 11 months, students also receive job skills training in the construction field, personal counseling from respected mentors, a supportive peer group with positive values, help in building assets through IDA programs, and experience in civic engagement. The young people help address the need for affordable housing by building houses for homeless and low-income people while earning their GED or high school diploma.

Research on nine hundred YouthBuild graduates, several years after they had completed the program, showed that more than seventy-five percent of them are either employed at an average wage of $10/hour or attending college and are positively contributing to their communities. The recidivism rate is also stunningly low – between 15 to 20 percent. This is a much lower rate than the 68 percent recidivism rate for most prison systems.

How YouthBuild Works: the Formula to "Flip the Script"

YouthBuild is not the only program that works. However, it is the only national program that reaches a highly disadvantaged population with a comprehensive community-based program that puts equal emphasis and commits equal time to education and job training, that offers job training in the form of creating a profoundly valuable community service, and that is committed to teaching leadership skills and values through engaging the young people in helping to develop the policies that affect them. There are precious few pipelines for low-income youth to become good citizens, to take on active leadership roles in their communities.

The formula to do what the young people call "flip the script" of their lives, taking them from a negative direction to a positive direction, includes all of the following elements:

- a way for young adults to resume their **education** toward a high school diploma and college
- **skills training** toward decent-paying jobs
- an **immediate visible role contributing to the community** that earns respect from family and neighbors
- **stipends or wages** to support themselves and their children
- **personal counseling** from admired, deeply-caring role models who are committed to these young adults and who also firmly challenge self-defeating attitudes from a basis of love
- **positive peer support with a clear value system** strong enough to compete with the streets
- **a mini-community that offers a sense of belonging** and a foundation young people can believe in – with everyone committed to everyone else's success

- **a role in governance** and the ability to participate in important decisions about staff and policies in their own programs
- **leadership development and civic education** offering a vision of the important role young adults can play in their neighborhoods and society to change conditions that have harmed them and the people they love – and the skills to do so
- **assistance in managing money and building assets** such as individual development accounts, scholarships, financial literacy training, and budgeting
- **placements with colleges and employers**
- **support after graduation** with continued counseling and the opportunity to belong to a supportive community.

The extraordinarily successful public/private partnership between YouthBuild USA and the US Department of Labor builds on the successes of the national non-profit with which DOL contracts to provide training and technical assistance to its YouthBuild grantees, merging the best of both governmental and non-profit capacity.

The Voice and Experience of Disconnected Youth, One Story Representing Tens of Thousands:

When he was just 11 years old in Columbus, Ohio, Mike Dean cut hair to put food on the table for his four younger siblings – often just Ramen noodles. Their mom was hooked on drugs and alcohol and was gone frequently for a day or two at a time. Mike had to get his sisters and brothers ready for school. At age 16, he fled his home life and spent the next few years crashing at different friends' homes. He often skipped school for weeks at a time. He wasn't a gangster or a bad kid – just one without direction. At age 17, he got his 15-year-old girlfriend pregnant. When the basketball coach found out Mike was a runaway, he was cut from the team. Behind academically, Mike dropped out of school completely and hung out with the wrong crowd, drinking and getting high. He tried working at McDonalds but saw how much his drug dealer friends were earning so he joined their ranks. He was arrested and went to the workhouse for a few weeks. But when he got out, he returned to his old ways again.

Mike's girlfriend saw an ad for YouthBuild, and they both applied. In YouthBuild, Mike suddenly found people who showed him genuine love, a new experience for him. "Eventually, YouthBuild became my family, and I let a lot of my old friends go," he says. "These people really gave me a chance, despite all that had transpired. There were people who actually showed they cared." Today, Mike is 30. He earned his GED through YouthBuild. He earned more than $10 an hour at union construction jobs. Today, he is a construction manager at YouthBuild, helping other young people who were once like him. He is vice president of the national YouthBuild alumni council. He's starting his own construction business.

In your own states, your own communities, you have young men – and women – who were just like Mike Dean. They are adrift, floundering, and heading downhill fast. You can play a major role in determining whether they turn their lives around.

YouthBuild Demographics and Outcomes
YouthBuild students are disconnected and disadvantaged youth for whom the public schools did not work. 100% are poor; 91 percent are high school dropouts; 72 percent are young men; 48% are African American, 22% Latino, 22% White, 3% Native American; 44% have been adjudicated, 10% in foster care; 30% have been homeless. They are both urban and rural. Twenty six percent are already young parents themselves.

YouthBuild programs have demonstrated the principles and practices that work to reconnect most youth and to create pathways to higher education, careers, and citizenship. What we have learned is that every disconnected youth is yearning to become somebody that other people will welcome and respect, and if given the right conditions they will transform their own lives and play a constructive role in society.

The 226 existing YouthBuild programs, all based on the same philosophy and model, have been highly successful. Although 91 percent of the students were previously high school dropouts and all of them are poor, nearly 70 percent complete the program, 52 percent obtain their GED or high school diploma, and 71 percent of graduates go on to college or jobs earning an average of nearly $9 an hour. The recidivism rate for graduates previously convicted of a felony is less than 33 percent. Imagine the social and economic impact across the country of simultaneously helping over 50 percent of high school dropouts complete their GED or diploma while drastically reducing the recidivism rate of youthful offenders!

Demand:
The challenge for the YouthBuild network is quite simply this: DOL currently has only enough resources to serve a fraction of the young people who seek a second chance, in this nation that believes in second chances. In 2007 alone, over 200 communities were denied YouthBuild funding. Each year YouthBuild programs turn away 14,000 youth for lack of funds: 800 in North Philadelphia, 500 in Harlem, 400 in Newark, 800 in Madison, and so on. Furthermore, over 1000 community-based organizations have applied to HUD since 1994 to bring this proven and inspiring program to their neighborhoods. The demand is equally great from young people--in 2006 local programs turned away 14,000 applicants for lack of funds. Currently 151 existing YouthBuild programs lack federal funding; about 30 are in danger of closing by the end of June if some new resource is not found quickly.

In Closing:
We know what works. We simply need the resources to expand so we can engage tens of thousands more young people in programs such as YouthBuild. In 2007, researchers highlighted that every dollar spent on YouthBuild generated at least $5 in value to society. This is a sound investment with high return that we as a nation cannot afford not to make. All the YouthBuild programs with waiting lists should be supported to open their doors to all the youth who are knocking. They are leaving the public schools and lining up outside the doors of programs that offer them a sense of belonging to a caring community, skills for jobs and college, and clear pathways to a hope-filled and meaningful future.

I would also like to underscore that YouthBuild is an investment that yields a high return. Since its inception 76,000 youth participants have built over 17,000 units of affordable housing. The

$755 million that has been appropriated through the Department of Housing and Urban Development and the Department of Labor since 1993 have leveraged over $1.3 billion of additional public and private investment at the local level due to the resourcefulness of local leaders and the high demand for YouthBuild programs.

Recommendation:
I am writing to respectfully request that the FY09 Labor, Health and Human Services, Education bill include at least $100 million for the national YouthBuild program. For over a decade, YouthBuild has demonstrated outstanding ability to provide opportunities for stability, employment, education and civic engagement to the most disadvantaged urban and rural youth, who have dropped out of high school or been adjudicated.

For the long run, Congress should establish an eight-year plan in partnership with DOL and YouthBuild USA, to expand the federal YouthBuild program to full scale. This successful network could grow from 8,000 low-income, disadvantaged youth in 226 communities to 50,000 youth in 850 communities.

The federal YouthBuild program has developed a public/private partnership that has coupled the long-term commitment, knowledge, and leveraged resources of YouthBuild USA with the know-how and capacity of several federal agencies. The federal government has built the infrastructure with an investment of $650M; YouthBuild USA has brought an additional $114M into the mix; and local YouthBuild programs have raised over $1B of matching funds. Together we have the knowledge, infrastructure, commitment, capacity, and demand to grow dramatically. It would take a steady annual increase to an appropriation of $1B in the eighth year, at a 12-month annual cost per full-time youth participant of $20,000. This includes a $5,000 stipend for each youth to compensate for their hard work and service producing affordable housing.

Part of this growth plan should include a federal incentive for states to join in, by offering competitive points for every proposal that brings state funds for adjudicated young people to participate in YouthBuild programs as a diversion or re-entry program. In Wisconsin, California, and Newark state governments have already noticed YouthBuild and begun to invest in it as a re-entry program. States could save millions of dollars and many lives by lowering the recidivism rates through YouthBuild.

Thank you very much for this opportunity to submit this statement to this subcommittee.

Fiscal Year 2009 Budget Request

Public Witness Testimony for the Record of the
House Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

Brian Blackwell
Indialantic, Florida

March 14, 2008

Testimony summary:
I am submitting testimony on a congenital brain disorder called Dandy-Walker Syndrome that affects my youngest son. Dandy-Walker Syndrome is the most common congenital malformation of the cerebellum and its causes are largely unknown. This community did not have any active organization advocating on their behalf until 2007, when the Dandy-Walker Alliance was formed. The Dandy-Walker Alliance, which I am representing, gives a voice to a community affected by this brain disorder.

I am asking the Committee to please introduce language into the fiscal year 2009 House Appropriations bill for the Centers for Disease Control and Prevention to conduct an epidemiological study or surveillance program capable of producing an accurate estimate of prevalence for the spectrum of abnormalities classified as Dandy-Walker Syndrome, Dandy-Walker Malformation and Dandy-Walker Variant.

I am also asking the Committee to please introduce language into the fiscal year 2009 House Appropriations bill for the National Institutes of Health to disclose historical annual funding levels for Dandy-Walker Syndrome research based on actual grants, contracts, and research conducted at NIH and other mechanisms of support.

Thank you, Mr. Chairman and Members of the Subcommittee, for this opportunity to submit written testimony on the congenital brain disorder Dandy-Walker Syndrome. The cause of this disorder is largely unknown and the rate of occurrence is suspect.

My name is Brian Blackwell and the youngest of my five children, Samuel, was diagnosed with Dandy-Walker Syndrome at eighteen weeks gestation. We were basically told that we should not continue with the pregnancy because most of the research that is available paints a very grim picture of the affects of Dandy-Walker Syndrome. Over the past four years, I have found thousands of individuals who are thriving and contradict the information that is readily available. It's not always been an easy road with all of the doctor, physical therapy, occupational therapy, and teacher appointments, but I am here to state that my son is one of those individuals who is thriving and is leading a "normal" life.

As the father of a child with Dandy-Walker, I see it as my duty and my social obligation to speak on behalf of millions of Americans who, until last year, had no national voice, who are affected directly or indirectly by Dandy-Walker and cannot advocate for themselves. My goal is to share some of my experiences with you, so that you may have some insight into what is needed by people with Dandy-Walker and submit to you two ways in which you can help.

Dandy-Walker is present from birth and may be diagnosed in-utero, provided that appropriate prenatal care is received. The treatment for individuals with Dandy-Walker generally consists of treating the associated problems versus the syndrome itself. Seizures will manifest in 30 percent of patients with Dandy-Walker Syndrome and up to 90 percent have or will develop a condition called hydrocephalus. While seizures may be treated with pharmacological solutions, hydrocephalus is treated today the same way that was developed in 1952, by inserting a special tube called a shunt into the brain to drain off excess cerebral spinal fluid. Unfortunately, there have been no major technological advances in shunt systems and it continues to have an extremely high failure rate. My son has had to endure seven shunt revision surgeries within three and half years. Research to improve this antiquated, yet life saving, medical device would not only help individuals affected by Dandy-Walker Syndrome, but assist those Americans who live with hydrocephalus, as well as our wounded soldiers returning from Afghanistan and Iraq who are suffering from Traumatic Brain Injury (TBI) and now require a shunt system.

Rather than passive acceptance of this diagnosis, based on the limited information available, our family has chosen to turn this diagnosis into an opportunity to educate and raise awareness for Dandy-Walker Syndrome. Our goal is to prevent other families from having to make uninformed choices based on limited information. That is why I ask that the Committee to please introduce language into the fiscal year 2009 House Appropriations bill for the Centers for Disease Control and Prevention to conduct an epidemiological study or surveillance program capable of producing an accurate estimate of prevalence for the spectrum of abnormalities classified as Dandy-Walker Syndrome, Dandy-Walker Malformation and Dandy-Walker Variant.

We also need disclosure of efforts to research this brain disorder. That is why I am also asking the Committee to please introduce language into the fiscal year 2009 House Appropriations bill for the National Institutes of Health to disclose historical annual funding levels for Dandy-Walker Syndrome research based on actual grants, contracts, and research conducted at NIH and other mechanisms of support.

I understand that balancing the policy needs of our nation is a difficult job. I also believe that understanding the true prevalence of Dandy-Walker Syndrome, that presently is estimated to occur in 1 out of every 5,000 children that are born alive, and knowing the amount of public funding expended to research the causes of this brain disorder will help to spur further scientific interest and promote opportunities for the research community to collaborate with medical practitioners, private industry representatives, advocates and people affected by Dandy-Walker. With your leadership, guidance and support we have the opportunity to act on behalf of millions of disabled members in society who can not advocate for themselves.

Mr. Chairman, my goal in submitting testimony is to seek your help in raising the national profile of Dandy-Walker Syndrome and ultimately find the causes of and hopefully the cure for this brain disorder that affects my four-year-old son Samuel. I want simply to give Samuel and other individuals affected by this syndrome the same full access, possibilities and experiences as any other person.

All I respectfully ask is that you partner with me in asking the CDC and NIH to help us determine the true prevalence of and disclose the public funding expended researching Dandy-Walker.

Thank you.

EXPERIENCE WORKS WRITTEN TESTIMONY SUBMISSION TO THE HOUSE LABOR-HHS APPROPRIATIONS SUBCOMMITTEE ON BEHALF OF FY 09 FUNDING FOR THE SENIOR COMMUNITY SERVICE EMPLOYMENT PROGRAM

My name is Cynthia A. Metzler. I am the President and CEO of Experience Works, a national, charitable, community-based organization that helps seniors get the training they need to find good jobs in their local communities. We began in 1965 as Green Thumb, a rural demonstration project that provided work for poor farmers. We have grown to be a leader in providing training, job placement and community service for low-income older people. We offer programs designed to primarily help disadvantaged mature individuals enter the workforce, secure better and new jobs, or supplement their incomes. Central to our service offerings is the Senior Community Service Employment Program (SCSEP); we are the largest of the 18 national SCSEP grantees and operate in 30 states and Puerto Rico.

I appreciate the opportunity to provide testimony to the House Labor, Health and Human Services, Education, and Related Agencies Appropriations Subcommittee about the impact that a reduced investment in the SCSEP, in the President's proposed 2009 budget, will have on older workers and communities nationwide. We have greatly appreciated the bipartisan Congressional support for SCSEP, which was reauthorized in 2006 on a nearly unanimous basis in both the House and Senate. However, we are deeply concerned that the President's FY 2009 budget request does not reflect this strong bipartisan support for SCSEP, but instead proposes to cut the program by 23,016 based on current authorized positions (39 percent) and investments by $171,625,000 (33 percent) compared to FY 2008 enacted level.

We firmly believe that a reduced investment in the SCSEP will erode earnings and services to some of our most vulnerable citizens – low income older people. Most SCSEP participants are over 60. All of them are poor; about 86 percent of the SCSEP participants had family incomes below the poverty level when entering the program.[1] On average, a participant's income increased by $5,054 while performing community services.[2] These older Americans spend the wages they earn, stimulating local economies.

The President's FY 2009 budget proposal would cut $171,625,000 from the PY 2008 enacted appropriations level. The 33 percent reduction in authorized positions would result in a loss of 19,886 authorized positions, and denying work and service opportunities to more than 28,469 older, poor Americans[3]; a reduction of 4,744 SCSEP participants who obtain unsubsidized

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[1] SCSEP Quarterly Progress Report; estimates are calculated for PY 2007 using the first six months of performance data. (PY 2006 data is not used since the Department only recorded nine months of data for the SCSEP program operated by the national grantees. 60,446 positions were authorized for SCSEP in PY 2007.

[2] A conservative estimate, this is calculated based upon the expectation that the average SCSEP participant works 18 hours per week for 48 weeks at the federal minimum wage of $5.85 per hour. Twenty-nine states pay a minimum wage above the federal minimum wage.

[3] The 19,886 number is the authorized positions of 60,446 reduced by 32.9 percent (the gap in needed funding from FY 2008 appropriations to the Presidents Budget for FY 2009). DOL's service level performance measure is 162 percent of modified positions. The 28,469 number of positions that cannot be served is determined by taking 162 percent times the modified number of positions lost. The modified positions is determined by taking 88.37 percent times the 19,886 authorized positions times which equals 17,573. Modified positions are 88.37 percent of the authorized or funded positions. Because many state's have a minimum wage higher than the federal minimum wage, positions were modified for performance purposes due to the fact that the SCSEP funding, based on the federal minimum wage, is not adequate to cover the full cost of participant wages and fringe benefits in states with a higher minimum wage. Therefore, it is not possible to achieve performance requirements based on funded positions. Modified positions are determined by the percentage the federal minimum wage is of the state minimum wage and multiplying the authorized positions by that percentage. The result is modified positions that performance measures can be more fairly measured against.

employment and raise their income to just above the poverty level[4]; and a loss of 14,129,852 of community service hours to thousands of non-profit community organizations and public organizations.

Another way of calculating the impact of the reduced investment is to examine the funding level needed in FY 09 to maintain the current number of authorized positions versus the President's FY 09 request - $578,189,000 will be necessary in FY 09 to maintain the PY 2007 current level of authorized positions (60,446). The President's proposed budget for FY 2009 for the SCSEP is $350,000,000, which leaves a shortfall of $228,189,000. The additional funding in FY 09 is necessary to fully support the last installment of the federal minimum wage increase. The President's request is a 39% cut below what is needed to support the PY 07 authorized position level of 60,446 and if enacted would result in a loss of 23,857 funded positions denying work and service opportunities to more than 34,154 older, poor Americans; and a loss of 16,770,000 hours of community service hours to approximately 19,500 non-profit community organizations and public organizations.

These losses would have detrimental effects on communities. For example, in the current Program Year 2007-2008, during the first six months SCSEP participants provided 21,473,940 hours of community service -- or an annualized total of 42,947,880 hours of service. About 72 percent of these hours (30,922,474 hours) are targeted to the general community with SCSEP participants serving as teacher's aides, library aides, day care providers, employment and training providers, park maintenance workers, and clerical assistants. About 28 percent of the service hours (12,025,406 hours) are focused on supporting the elderly as SCSEP participants serve as transportation drivers, nutrition site assistants, meals on wheels drivers, and health care and outreach aides. Each participant will contribute an average of 500 hours of community services to their local communities in PY 2007. [5]

The importance of the role of community service as a lifeblood to keeping valuable services running is illustrated by the example of the Spring Valley Shelter in Seymour, Indiana, which provides shelter and supportive services to homeless families and individuals. The shelter's director, Tom Isakson, had long depended on volunteers for help, but the volunteers can only be depended on to work 4 to 8 hours every few weeks. Experience Works SCSEP participants proved to be the solution he needed, working at the shelter, a consistent 20 hours a week. "The participants want to work," he says. "They are motivated, punctual and really appreciate the opportunity to train." They proved so valuable; he's hired two of them. "If it wasn't for Experience Works, I don't know how I'd keep the shelter running."

SCSEP community service is also valued by agencies providing services to seniors. An Ohio Department of Aging executive in 2006 said, "If the community service element of SCSEP is dropped from the program, we conservatively estimate that 330-400 FTEs (full time equivalents) that directly support Older Americans Act activities and programs will be lost".[6]

Most importantly, the President's proposed FY 09 cuts to SCSEP will have a devastating affect on the low income older people with multiple barriers to employment, which the program effectively serves each day. For example, after looking for a job for over a year, Delores McDonald, age 67, enrolled in the SCSEP. Besides a lack of skills, Delores' health problems,

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[4] the number of lost jobs is determined by reducing the annualized number of participants to be placed into jobs by 32.9 percent which is the percentage of funding gap from the FY 2008 appropriations to the FY 2009 President's Budget

[5] SCSEP Quarterly Progress Report ETA 5140.

[6] Statement of Elise Geig, before the Subcommittee on Select Education Committee on Education and the Workforce, Field Hearing on "The Older Americans Act: Improving Quality of Life for Aging Americans", April 28, 2006.

which lead to surgery, also jeopardized her ability to find work. She found that without computer and clerical skills, even though she was bilingual, it was nearly impossible to find work. Delores was helped immediately once she enrolled in Experience Works' SCSEP. Delores was assigned to the judge's office where she provided needed interpretative services while improving her office skills and using her Spanish-speaking abilities. Six months later, the judge hired Mrs. McDonald as a full-time employee for $30,000 a year with benefits.

Another SCSEP participant whose life has changed as a result of the program is Pat Roberts, 55 of Charleston, South Carolina. A series of hard knocks landed Ms. Roberts in a homeless shelter. She tried to get a job, but the more she was rejected, because of her age, the lower her self esteem dropped. Enrollment in the Experience Works SCSEP set her on a life changing course. At the local YWCA she participated in employability and basic computer-skills training. Next, through "Dress for Success", she upgraded her work image and obtained some clothes. From her training assignment at the Vanderhorst-Koinonia Ministries, she learned to greet clients in crisis, do office work, and stock the food pantry. Since she began her training assignment, Ms. Roberts has moved out of the homeless shelter and into public housing. Her self-esteem, confidence and health improved. She says, "I feel like a new person. I feel like I stand a chance at getting a job."

At 78, La Von Yeske, La Cross, Wisconsin is another example of a person desperately seeking employment who turned to the SCSEP for assistance. When Ms. Yeske lost her husband, she also lost most of her income. Her age and lack of current skills weren't her greatest job barrier; she also had never graduated from high school. Experience Works assigned her to train at the Wisconsin Job Center to update her clerical skills. She was also enrolled in a GED program. At age 81, she received her GED from Western Technical College. With her degree and updated skills, she can now take the next step to get a job off the Senior Community Service Employment Program.

Older people with sky-rocketing medical expenses and debt are desperate for help making ends meet. Some want to work but need specialized assistance to prove they can be assets to employers. A cancer survivor and amputee, wheelchair-bound Wanda Johnson-Schell of Cayuga, Indiana, came to Experience Works desperate for a way to pay her medical bills after her husband's death. She completed SCSEP training as an elementary school teachers' aide then attended Experience Works' Job Club. She learned the techniques for transitioning into employment so well that she was asked to conduct the Job Club sessions herself, and now helps other SCSEP participants turn their lives around. Knowing first-hand how hard it is to deal with a disability, hardship, and the discouragement of being unemployed, she works with other older people to create resumes, do online job searches, prepare for interviews and ultimately get jobs and become self sufficient.

In conclusion, in these difficult economic times, the SCSEP is a program that works as Congress intended. It augments federal funds by helping low-income older people serve their communities, build their skills and self-esteem, and contribute to their local economies through wages earned and spent while on the program and after employment off the program. However, the program has not kept pace with the ever-growing needs of the older population. I respectfully request that the committee reject the Administration's short-sighted proposal to reduce funding by 39% and provide a minimum of $578 million in FY 09 to ensure we can maintain current SCSEP participant levels. Thank you for your consideration.

Public Witness Testimony for the Record

House Appropriations Subcommittee on Labor, Health & Human Services,

Education and Related Agencies

March 30, 2008

Submitted by John Twomey, President USA Works!

810 1st Street, NE

Washington, DC 20002

Introduction

Chairman David Obey, Mr. Walsh and the other distinguished members of this Subcommittee, my name is John Twomey, and I am the president of the USA Works! In my other life, I am the CEO of New York's workforce association, NYATEP.

In my testimony, I will discuss very briefly, *USA Works'* views regarding:

- The effects of the $250 Million Workforce Investment Act (WIA) rescission adopted by the Congress in the Omnibus Appropriation Bill in December 2007;
- Our observations on the federal funding commitment to building a globally competitive workforce from the local perspective; and
- *USAWorks!* Recommendations for FY 2009 funding for the Workforce Investment Act and funding for the Employment Service.

We hope that this information will be helpful to the Subcommittee as you make very difficult decisions, balancing important priorities in a time of war, large deficits, and an increasing economic crisis.

The United States Labor Market

Our nation is confronting both a serious short term deterioration of the economy, as well as a profound structural change in the labor market.

Certainly the Congress is well aware that the United States is teetering on the edge of a recession. You have enacted one stimulus package and are considering second. The housing market is stalled; consumer confidence and spending are weak.

The presidential campaigns in Ohio and Pennsylvania have acutely focused on off-shoring of jobs and the belief that NAFTA is unfairly constructed. At USAWorks! we believe that off-shoring of jobs is real, and is causing great pain to workers, businesses, communities, and the country.

But we also believe that a much larger cause of job loss is replacement of high paying jobs through widespread adoption of new technologies. Some experts believe that this technological replacement of workers by technology is responsible for 85% to 90% of job loss. Recently the

USA Today newspaper February 29,2008 ran an editorial stating that since 1993 the United States' manufacturing output had increased by +66% even though the number of manufacturing workers has deeply and steadily declined.

This has led to the phenomenon where we have an excess of able-bodied, low skilled workers for a diminishing pool of jobs, while at the same time we have critical shortages in good paying "middle skill" jobs.

We have reached a perilous juncture in our ability to be globally competitive. If we do not increase our investments in helping the workers with low skills acquire the skills that will allow them to fill these middle skill jobs, two things will happen. First, these workers, their families, and their communities will be unlikely to reach the American middle class dream. Just last week, Randall Stephenson, CEO of A T&T commented to Reuters on his company's inability to find workers with the skills they need to fill jobs in the United States, "We're able to do new product engineering in Bangalore as easily as we're able to do it in Austin Texas. I know you don't like to hear that, but that's the way it is." In other words, if American workers don't have the skills we need, we will go anywhere in the world where we can get those skilled workers.

In his testimony before this Subcommittee February 26, 2008, addressing this funding issue, Professor Harry Holzer of Georgetown said "One of the great ironies of workforce policy in the past few decades has been the extent to which federal investments in training have consistently and dramatically declined, even while the labor market places an ever-higher premium on skills."

Holzer also testified at that time that "the demand in the labor market for workers in "middle-skill" jobs remains fairly strong and is likely to remain so in the future. These are jobs that require some significant postsecondary education or training but less than a bachelor's degree; though the educational requirements for these jobs are not very high, most low-income workers cannot meet them. The jobs are frequently found in health care, construction, manufacturing, transportation, and many other sectors of the economy; they include technician, maintenance and repair, and many other occupations".

USA Works! agrees. We face a classic mismatch, unemployed low skilled workers on one hand and at the same time companies that want to do business in the United States who can't find the middle skill workers they need to do that work here.

Before discussing the recently enacted $250 Million WIA rescission, and taking a look at the effects of years of federal disinvestment in federal worker preparation, USA Works! would like to again acknowledge the extremely difficult choices the Subcommittee and the Full Appropriations Committee face this year. Certainly, every single day, a host of worthwhile groups beseech the Congress to invest in their issues for the good of the country. Nevertheless, this disinvestment over a sustained period of time has brought the nation's workforce development system to a place where it does not have the capacity to most effectively deal with the short term surge in jobseekers caused by the current severe downturn, nor the longer term ability to upskill the workers needed to fill these good paying middle skill jobs.

The $250 Million WIA Rescission, a Bad Idea at the Wrong Time

For the past several years, USDOL has argued that there are as much as $1.1 Billion in unspent funds in the WIA system, and that rescinding these funds would have no effect on services.

USA Works! strongly disagrees with that premise, and this belief is reinforced by Local Workforce Investment Boards (WIBs) across the country being forced to radically reduce the very services for workers and businesses that they know yield a very positive return on investment as a result of the recently enacted rescission.

USA Works! is not alone in its' belief that USDOL's theory on vast unspent funding is completely erroneous. In his June 28, 2007 testimony before the House Subcommittee on Higher Education, Lifelong Learning, and Competitiveness, GAO's then Director of Education, Workforce, and Income Security Issues, Sigurd Nilsen, stated that:

- USDOL's "focus on expenditures without including obligations overestimates the amount of funds available to provide services at the local level."
- "The process used to determine states' available funds considers only expenditures and does not take into account the role of obligations in the current program structure. Our (GAO's) analysis of Labor's data from program year 2003 and beyond indicates that **states are spending their WIA funds within the authorized 3 year period."**
- "In fact, almost all program funds allocated in program year 2003 were spent by states within 2 years."
- Finally, Nilsen said that USDOL's "Office of the Inspector General (OIG) recently concurred, noting that obligations provide a more useful measure for assessing states' WIA funding status if obligations accurately reflect legally committed funds, and are consistently reported."

Under USDOL's definition, the following are two examples of "unexpended" funds that could be recaptured with no negative effect on services to workers or businesses:

- Where a WIB approves 2 year training at a community college but has only paid for the first semester, USDOL's methodology considers the other funding, as "unexpended", available for recapture with no effect on services instead of prudently set aside to cover a commitment.

- For a busy One Stop Career Center that has a staff of 35 and a long-term lease, expenses for rent and staff salaries can only be reported month-by-month, as they are paid. So after month one in a year, only one month of salary or rent are "expended". In spite of this accounting quirk, the other 11 months of expenses have to be set aside and cannot be spent on other activities.

Obviously, when these WIA funds were rescinded based on this faulty interpretation, this translated into deep, painful, reductions in services.

In fact, although this WIA rescission was proposed in June 2007 and adopted into law when President Bush signed the Omnibus Appropriations Bill in December 2007, USDOL only issued the guidance needed to implement this rescission March 25, 2008. **This means that this onerous rescission has to be offset by real cuts in services in the 3 month period between today and June 30, 2008.** In reality, these are severe cuts that would be very harmful in any time, but they hit at the very time when: the country has moved into recession; when the unemployment rate is

rising; when TANF rolls are increasing; when the traffic at One Stop Career Centers throughout the United States is increasing every week.

I asked Local WIBs in New York, and across the country what this rescission will mean to service delivery, this is a partial list of what they have told me over the past few weeks:

- For nine months we have been uncertain as to the size of the impending rescission we will face at the local level, making us very tentative in funding training
- Although the economy has stalled we had to slow down our know the size of the cut
- We stopped approving training for employed workers who need skill upgrading
- Reluctantly we are cutting way back on services to our business customers
- We are looking at reducing the number of One Stop Centers, which will require laid off workers top drive long distances with gasoline at $3.45 a gallon
- We will have to stop paying support services like transportation
- Our computers are old and won't run some of the software we need, but we did not buy new more powerful computers for our customers, we cut additional skill development programs, we shelved a planned e-learning program
- Staff morale has greatly suffered, we know what needs to be done but think we won't be able to do it

These comments were widespread. This list from Onondaga County New York is reflective of opportunities missed. Several important community training collaborations are currently in limbo:

- Built on Pride, Syracuse City School District initiative to provide pre-apprenticeship opportunities. This has been a great tool for helping individuals underrepresented in the workforce move into skilled trades
- Training and Upgrade Fund, collaboration with SEIU 1199 and health care management to help develop, train, and upgrade the health care workforce
- Southside Innovation Center- collaboration with Syracuse University's Center for Business Information Technology and the Southside Innovation Center to provide PC Support Technology training; this training is specifically designed to support a regional economic driver.

Appropriate Resources to Meet the Challenges in this Economy

The chart below shows how severe the national disinvestment in workforce development has been in my State, New York since we began to implement WIA in July 2000. While this chart would vary state-to-state, overall funding has been reduced so significantly that the local workforce development system's ability to meet the country's current economic challenges has been severely compromised.

WIA Funding
Program Years 2000 to 2008
New York State Allocations

Program	Program Year		New York State Allocations
WIAA Adult, Dislocated Worker and Youth	2000		$ 304,953,605
	2001		$ 257,333,620
	2002		$ 217,667,870
	2003		$ 216,044,909
	2004		$ 223,356,562
	2005		$ 234,418,297
	2006		$ 197,433,309
	2007		$ 190,776,050
	2008		$ 159,224,210
	Difference 2000-2008		**$ (145,729,395)**
	% Difference 2000-2008		**-47.79%**

To again quote Professor Holzer's testimony to this Subcommittee last month, "since 1979, expenditures on these programs have declined in real terms by nearly 70 percent and, relative to the size of the U.S. economy by 85 percent. This share is far lower than what is spent on active labor-market policy by almost any other industrialized nation."

As you know, the Department of Labor's FY 09 budget request includes $1.2 billion in cuts to employment and training programs, including $515 million in cuts to the TES account and the elimination of the $703 million Employment Service state grants. USDOL continues to argue that these cuts can be made without the diminution of services to jobseekers impacted by the economic downturn.

USA Works! strongly disagrees with this assessment and argues that USDOL proposed continued disinvestment in employment and training programs, if enacted, would further undermine our ability to both assist jobseekers impacted by the economic downturn and train our workforce in an increasingly global economy. A recessionary environment is the wrong time to cut funding for programs targeted to assist workers most heavily impacted by it. We respectfully request the Subcommittee restore the Administration's proposed cuts to the Workforce Investment Act; fully fund the Employment Service; and begin the process of reversing years of disinvestment.

Again, we know you have very difficult choices to make and limited funding to meet the overwhelming needs on the Subcommittee. However, the workforce system is at a breaking point, economic security is real national security, and there is a cost to disinvesting in America's workers. I can be reached at 518 -433-1200 if you would like any clarification. Thank you.

NATIONAL ORGANIZATION OF STATE OFFICES OF RURAL HEALTH

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June 27, 2008

Mr. Chairman and members of the Subcommittee. On behalf of the National Organization of State Offices of Rural Health (NOSORH), I am pleased to submit this testimony.

NOSORH is a non-profit organization representing the 50 State Offices of Rural Health (SORHs). The creation of 50 State Offices of Rural Health was a federal initiative undertaken more than a decade ago that has been enormously beneficial to rural communities throughout the United States.

There are numerous federal programs that support initiatives to improve access to quality health care in rural communities. Our comments will focus in on just a few of the programs that we consider vitally important:

- State Office of Rural Health
- Rural Hospital Flexibility Grants
- Rural Outreach/Network Grants
- Research and Policy

1. STATE OFFICE OF RURAL HEALTH

These offices vary in size, scope, organization, and in the services and resources they provide. Most SORHs are organized within the state health departments, but some are located in universities or not-for-profit organizations.

The general purpose of each SORH is to help their individual rural communities build health care delivery systems. While funding levels and sources also vary, every state receives a portion of their funding from the Federal Office of Rural Health Policy through the SORH Grant program, begun in 1991. With this grant, a SORH is expected to:

- Collect and disseminate information;
- Coordinate rural health resources and activities state-wide;
- Provide technical assistance;
- Encourage recruitment and retention of health care professionals; and
- Strengthen state, local, and federal partnerships.

While the roles and responsibilities of individual state offices of rural health vary from state-to-state, it can be universally stated that each State Office of Rural Health is a vital resource in their state.

Here are some examples of how State Offices of Rural Health have been instrumental in their communities:

In Pennsylvania, the State Office of Rural Health was successful in using the FLEX (rural hospital flexibility program) and SHIP (state health insurance assistance program) to complement one another. The Critical Access Hospitals in Pennsylvania have agreed to use their SHIP grant funds to subscribe to rural performance management (RPM), an on-line performance and benchmarking system that uses the balanced scorecard as a framework. The FLEX program grant dollars are then used to assist these hospitals in both collaborative and hospital specific performance improvement initiatives that have been identified by the data from RPM.

In Wisconsin, with the assistance of the State Office of Rural Health, sixty rural hospitals are funded in Wisconsin for small quality improvement and HIPAA compliance projects. Three SORH staff members are partially funded with the federal matching funds. As a result, these staff can provide a variety of support mechanisms for rural health care in Wisconsin, such as:

- provide a daily news feed of rural health information (emerging federal and state news, legislation, regulations, events and funding opportunities);
- maintain a "virtual library" of resources for rural health care: online courses and seminars, toolkits, articles, useful website links, research, etc.;
- serve as a voice for rural needs in statewide health care planning and resource allocation; and
- serve as a coordinating entity for rural health projects, to better utilize meager resources and avoid duplication and confusion.

NOSORH recommends $12 Million FY '09 appropriation for State Offices of Rural Health

2. RURAL HOSPITAL FLEXIBILITY GRANTS (FLEX) AND SMALL RURAL HOSPITAL IMPROVEMENT PROGRAM (SHIP)

The Rural Hospital Flexibility (FLEX) program is a federal initiative that provides funding to state governments to strengthen rural health. The FLEX program allows small hospitals the flexibility to reconfigure operations and be licensed as Critical Access Hospitals (CAHs). FLEX encourages the development of rural-centric health networks and offers grants to states to help implement a CAH program in the context of broader initiatives to strengthen the rural health care infrastructure. The funding in this account also provides support for the small rural hospital improvement grant program (SHIP).

In Missouri, the FLEX grant funds are used to improve access to health care for rural citizens. This is accomplished through initiatives to improve CAHs performance outcomes utilizing the balanced scorecard and to support CAHs' staff attendance at Advanced Cardiac Life Support (ACLS) courses. Further, it provides equipment and training, as well as hosting a technical assistance program for key personnel within the CAHs.

FLEX funds also support the strengthening of EMS systems and staff trainings. FLEX funds are essential to improving hospital financial operations and patient care.

SMALL RURAL HOSPITAL IMPROVEMENT GRANT PROGRAM (SHIP)

The purpose of the small rural hospital improvement grant program is to help small rural hospitals do any or all of the following:

- pay for costs related to implementation of prospective payment systems (PPS);
- comply with provisions of the health insurance portability and accountability act (HIPAA) of 1996; and
- reduce medical errors and support quality improvement (QI).

In Missouri, two major items were identified as needs related to compliance with the Health Insurance Portability and Accountability Act (HIPAA). First was the storage of medical records (both electronic and paper) to ensure patient privacy. Many rural facilities are exploring the use of imaging systems to replace paper medical records with scanned documents. Not only will this approach resolve the storage space constraints these small facilities have, but will also provide a greater level of security and privacy.

The second issue, more ongoing or maintenance in nature, is the training of personnel on HIPAA compliance. Due to the need for continuing education (reiteration/reinforcement) and initial training (new employees), HIPAA training will continue to be a large part of the support provided through SHIP. Quality improvement (QI) is the largest emphasis of SHIP in Missouri. QI needs as expressed in the responses from eligible hospitals made up sixty-seven percent (67%) of the total needs identified. The needs for QI in eligible hospitals include program consultation, reference materials, new positions, equipment, and software, especially in the area of medical or medication error reduction.

Without these grants, rural hospitals would be adversely affected. These hospitals already are stretched in staffing and financial capacities. Grants such as these provide additional resources and technical assistance vital to their operation.

NOSORH recommends $39.2 Million FY '09 appropriation for the FLEX and SHIP programs

3. RURAL OUTREACH/NETWORK GRANTS

The emphasis of the Rural Outreach and Network Development grant program is on service delivery through creative strategies. This program requires the grantee to form a network with at least two additional partners.

The Network Development Grant program is specifically designed to further ongoing relationships among health care organizations by funding rural health networks that focus on integrating clinical, information, administrative, and financial systems across members.

In order to assist and encourage these types of collaborative relationships, applicants can submit a grant application for a Network Development Planning Grant. Planning grants provide one year of funding to rural communities needing assistance in the development of an integrated health care network. The planning grants are used to develop a formal network with the purpose of improving the coordination of health services in rural communities and strengthening the rural health care system as a whole.

This past year, the Florida Office of Rural Health awarded $216,409 towards the development of a pharmacy health information technology initiative. As a result of this grant, nine rural hospitals are collaborating to improve pharmacy services and the quality of health care they provide. The grant is intended to encourage these (and eventually other) hospitals to implement information technologies identified as having a significant impact on preventing medication errors. The total cost for the equipment to be acquired by the hospitals is over $484,000 and includes pharmacy computers, automated medication dispensing cabinets, and computerized medication infusion pumps.

NOSORH recommends $ 53.9 Million FY '09 appropriation for Rural Outreach and Network Development Grants

4. RURAL RESEARCH AND POLICY

The Office of Rural Health Policy (ORHP) helps shape rural health policy in a variety of ways. The Office advises the Secretary of Health and Human Services on major issues such as the effects of Medicare and Medicaid on rural citizens' access to health care. Since its inception, ORHP staff has worked with the Centers for Medicare & Medicaid Services on the development and review of Medicare and Medicaid regulations. ORHP also has established working relationships with other federal agencies in the development of policy and regulatory decisions.

The Rural Health Research Center Program in the Department of Health and Human Services Office of Rural Health Policy is the only Federal program dedicated entirely to producing policy-relevant research on health care in rural areas.

In addition to the Rural Policy work, ORHP manages and oversees the Rural Health Research Centers (RHRCs) Cooperative Agreement Program. Recipients of cooperative agreements establish Rural Health Research Centers that conduct and disseminate policy-relevant health services research on issues of national significance with a specific topic of concentration (e.g., Medicare, health workforce, uninsured).

Specific examples of the types of projects supported by ORHP include:

- Develop a Roadmap for the Adoption of Health Information Technology in Rural Communities.
- Prepare policy briefs identifying the number of rural beneficiaries enrolled in various types of Medicare Advantage plans as a percent of all rural beneficiaries, and rural beneficiaries as a percent of all enrollees in each type of Medicare Advantage plan. The data from this analysis were used during discussions among policy makers of the costs of the Medicare Advantage program and impacts of changing federal payment to Medicare Advantage plans.

- Development and field-testing of an Emergency Department Transfer Communication measure for small rural hospitals.

NOSORH recommends $9.7 Million FY '09 appropriation for Rural Outreach and Network Development Grants

On behalf of the 50 State Offices of Rural Health and the rural residents we serve, we appreciate your consideration of these recommendations and we would be happy to provide you with any additional information or answer any questions you may have regarding our work.

Sincerely,

Karen A. Madden
President
National Organization of State Offices of Rural Health

Submitted on behalf of CAEAR Coalition:

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On behalf of the tens of thousands of individuals living with HIV/AIDS to whom the members of the Communities Advocating Emergency AIDS Relief (CAEAR) Coalition provide care, I want to thank Chairman David Obey and Ranking Member Jerry Lewis for affording CAEAR Coalition the opportunity to submit this written testimony for the record regarding increased funding for the Ryan White HIV/AIDS Program.

CAEAR Coalition is a national membership organization which advocates for federal appropriations, legislation, policy and regulations to meet the care, treatment, support service and prevention needs of people living with HIV/AIDS and the organizations that serve them. CAEAR Coalition's proactive national leadership is focused on the Ryan White Program as a central part of the nation's response to HIV/AIDS. CAEAR Coalition's members include Ryan White Program Part A, Part B, and Part C consumers, grantees, and providers.

A Wise Investment in a Program That Works

The Ryan White Program works. Those on the epidemic's frontlines know this to be true, and that faith received a ringing endorsement from the White House Office of Management and Budget (OMB). In its 2007 Program Assessment Rating Tool (PART), OMB gave the Ryan White Program its highest possible rating of "effective"—a distinction shared by only 18% of all programs rated. According to OMB, effective programs "set ambitious goals, achieve results, are well-managed and improve efficiency." Even more impressively, OMB's assessment of the Ryan White Program found it to be in the top 1% of all federal programs in the area of "Program Results and Accountability." **Out of the 1,016 federal programs rated—98 percent of all federal programs—the Ryan White Program was one of seven that received a score of 100% in "Program Results and Accountability."**

The passage of the Ryan White HIV/AIDS Treatment Modernization Act in December 2006 extended the Ryan White Program for another three years and requires a renewed commitment to providing the funding demanded by the scope of the domestic HIV/AIDS epidemic. As you are aware, the Ryan White Program serves as the indispensable safety net for thousands of low-income, uninsured or underinsured people living with HIV/AIDS.

- Part A provides much-needed funding to the 56 major metropolitan areas hardest hit by the HIV/AIDS epidemic with severe needs for additional resources to serve those living in their communities.
- Part B assists states and territories in improving the quality, availability, and organization of health care and support services for individuals and families with HIV disease.

- The AIDS Drug Assistance Program (ADAP) in Part B provides urgently needed medications to people living with HIV/AIDS in all 50 states and the territories.
- Part C provides grants to 362 faith and community based primary care health clinics and public health providers in 49 states, Puerto Rico and the District of Columbia. These clinics play a central role in the delivery of HIV-related medical services to underserved communities, people of color, and rural areas.
- Part F AETC supports training for health care providers to identify, counsel, diagnose, treat, and manage individuals with HIV infection and to help prevent high-risk behaviors that lead to infection. It has 124 program sites in 46 states.

We thank you in advance for your consideration of our comments and our request for:

- $840.4 million for Part A to support grants to the cities hardest hit by HIV/AIDS so they can provide quality care to people with HIV/AIDS (an increase of $213.2 million);
- $482 million for Part B base to provide additional needed resources to the states in their efforts to address the HIV/AIDS epidemic (an increase of $45 million).
- $943.5 million in funding for the ADAP line item in Part B so uninsured and underinsured people with HIV/AIDS can access the prescription therapies they need to survive (an increase of $135 million)
- $299.3 million for Part C to support grants to community-based organizations, agencies, and clinics that provide quality care to people living with HIV/AIDS (an increase of $100.5 million).
- $50 million to fund the 11 regional centers funded under by Part F AETC to offer specialized clinical education and consultation on HIV/AIDS transmission, treatment and prevention to frontline healthcare providers (an increase of $15.9 million).

The increases CAEAR Coalition seeks in the current funding for Part A, Part B base and ADAP, Part C, and Part F AETC reflect the reality that the HIV/AIDS epidemic and the health care and social service needs of people with HIV/AIDS require significantly more federal resources than those provided in recent years. Although Part A, Part B ADAP, and Part C saw funding increases in FY 2008, these increases fail to keep pace with the growing demand for services, especially given the burden of stagnant and rescissionary funding over the past seven years CAEAR Coalition is also deeply concerned by cuts to the Part B base in FY 2008 and Part F AETC. Like other components of the program, the Part B base and the AETCs need more, not fewer resources to fulfill their crucial mandate to improve access to high quality HIV/AIDS care.

Growing Needs, Diminishing Resources

In 2005, CDC revised upward its estimate of persons living with HIV/AIDS in the U.S. from 1,039,000-1,185,000 (as of 2003). Approximately one-half of those people have yet to access HIV-related medical care and there is a projected influx of newly diagnosed individuals into care as a result of CDC initiatives to promote routine HIV testing. CDC also estimates an additional 43,000 new cases of HIV every year. Ryan White Program Part A , Part B base and ADAP, Part C, and Part F AETCs must receive adequate increases to meet the health care and supportive services needs of individuals already in care and those newly identified HIV patients entering care—many of whom will require comprehensive medical treatment and supportive services at the time of diagnosis.

Last year saw the expansion of the Ryan White Program to include five new Part A–funded jurisdictions. These five cities—Baton Rouge, Charlotte, Indianapolis, Memphis, and Nashville—are home to nearly 20,000 people living with HIV/AIDS. Each time new jurisdictions have joined Part A in the past there have been commensurate increases in Part A appropriations. Those resources weren't allocated in FY 2007, and 56 jurisdictions were forced to share the same amount of funds previously used to support services in 51 jurisdictions, requiring painful cuts to vital care provided in jurisdictions across the country. The Part A programs welcome the FY 2008 funding increase that addressed this oversight and funded the program expansion for the five new jurisdictions while beginning to reverse some of the devastation wrought by years of stagnant funding. Additional increases are desperately needed to address the growing demand for services, offset the rising cost of care, and help the many jurisdictions forced year after year to make service reductions and eliminations to rebuild their programs.

The Part B base was cut by nearly $20 million in FY 2008. That funding must be restored, and additional resources provided so that the fifty states, the District of Columbia, Puerto Rico, Guam and the US Virgin Islands can address the demand for care, treatment and support services by the ever-growing population of those living with HIV/AIDS.

ADAP waiting lists and other cost-containment measures, including limited formularies, reducing eligibility, or removing already enrolled people from the program, are clear evidence that the need for HIV-related medications continues to outstrip availability. ADAPs are forced to make difficult trade-offs between serving a greater number of people living with HIV/AIDS with fewer services or serving fewer people with more services. Additional resources are needed to reduce and prevent further use of cost-containment measures to limit access to ADAPs and to allow all state ADAPs to provide a full range of HIV antiretrovirals and treatment for opportunistic infections.

The number of clients entering the 362 Part C community health centers and outpatient clinics has consistently increased over the last five years. Over 224,000 persons living with HIV and AIDS receive medical care in Part C–funded community health centers and clinics each year. These community- and faith-based HIV/AIDS providers are staggering under the burden of treatment and care after four years of funding cuts prior to the modest increase in FY 2008. The CDC has implemented a number of initiatives designed to promote routine HIV testing to identify people living with HIV. Their success continues to generate new clients seeking care at Part C–funded health centers and clinics with no commensurate increase in the funds necessary to provide access to comprehensive, compassionate treatment and care.

Increasing Testing Requires Increasing Access to Care

In 2003, despite the cuts to key parts of the Ryan White Program, the CDC announced an ambitious initiative that seeks to bring people with HIV not currently in care into the HIV care system. According to CDC Director Dr. Julie Gerberding, this initiative aims "to open up the door to [HIV] testing so that people can learn their status and get the appropriate treatment and prevention services that they deserve and need." Last March, CDC unveiled a more focused plan

to address high rates of HIV among African Americans and this past fall funded a large expansion of HIV testing efforts in communities across the country.

CAEAR Coalition supports efforts to help identify those individuals infected with HIV but do not know their status. However, CAEAR Coalition is concerned that without the simultaneous allocation of additional resources for treatment, these CDC initiatives have resulted in a significant increase in the demand for HIV/AIDS services without the capacity in place to provide that care.

Increased demand for services has placed a severe strain on the HIV/AIDS safety net and forced community-based providers to stretch already scarce resources even further to address growing needs. This additional pressure on an already overburdened system will leave many of the 200,000+ HIV-infected individuals who do not know their HIV status without access to the care they need. CAEAR Coalition urges Congress and the Administration to provide a commensurate increase for treatment programs to meet the demand that has resulted from CDC prevention programs.

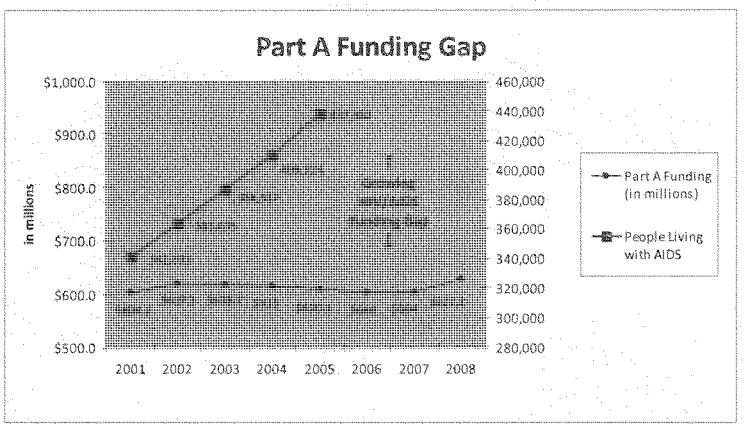
Sufficient Funding for Ryan White Programs Saves Money and Saves Lives

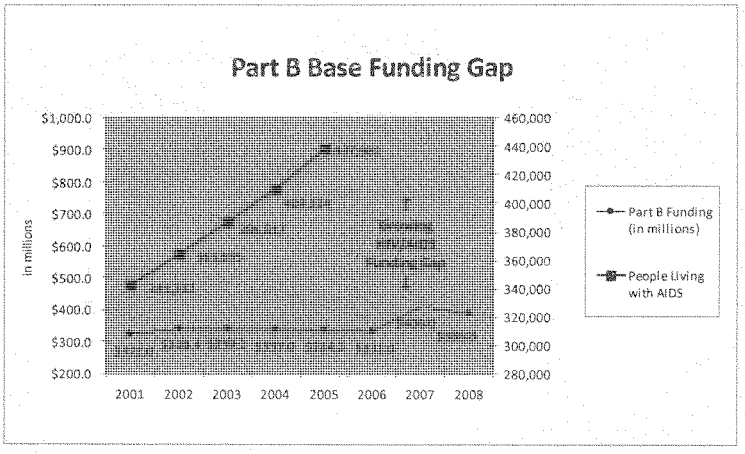
Increased funding for Ryan White Programs will reap a significant health return for minimal investment. Data show that Part A and Part C programs have reduced HIV-related hospital admissions by 30 percent nationally and by up to 75 percent in some locations. The programs supported by the Ryan White HIV/AIDS Treatment Modernization Act also have been critical in reducing AIDS mortality by 70 percent. Taken together, the Ryan White Program works – resulting in both economic and social savings by helping keep people healthy and productive.

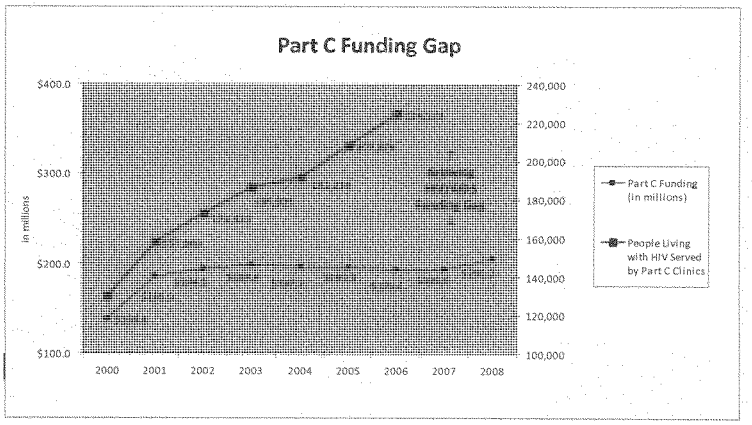
The Administration and the Congress have made a commitment to increase funding for the AIDS epidemic around the world, have made good on that commitment, and are to be commended. CAEAR Coalition is eager to work with Congress to meet the challenges posed by the HIV/AIDS epidemic here at home. Congress and the Administration must do more to address the grim reality that the domestic epidemic is not static; it is continuing to grow at a significant rate and more federal resources are needed to prevent it from becoming a public health catastrophe similar to what we are witnessing in the developing world. Already, some communities in the United States have infection and death rates similar to those in Africa. We must make a commensurate domestic investment to care for people in our own communities. CAEAR Coalition looks forward to working with the Committee and the Congress to help meet the needs of Americans living with HIV/AIDS as the appropriations process moves forward.

Given the Ryan White Program's stellar history of accomplishments, the vast need for more resources to address unmet need, and such strong praise from the federal government's most stringent and assiduous assessors, we hope the committee will act to provide these relatively modest funding increases.

Growing HIV/AIDS Funding Gaps, 2001-2008







Testimony of
John Anderson
Chairman, Advocacy Committee
American Diabetes Association

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

March 14, 2008

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Introductory Remarks

Thank you Chairman Obey, Ranking Member Walsh and Members of the Committee for your work to provide the first increase since Fiscal Year 2005 for education and prevention programs at the Centers for Disease Control and Prevention (CDC) and diabetes research at the National Institutes of Health (NIH). As the nation's leading nonprofit health organization providing diabetes research, information and advocacy, we appreciate the opportunity to submit testimony on the importance of federal funding for vital diabetes programs and the devastating effect diabetes is having on our nation.

Background Information

There are currently 20.8 million Americans who have diabetes, 7 percent of the population. Of the 20.8 million, 6.2 million are unaware that they have diabetes. Additionally there are 54 million more Americans with pre-diabetes[1] meaning their blood glucose levels are higher than normal and are at increased risk of progressing to diabetes unless they take steps to reduce their risk. Together, this means that 25 percent of the U.S. population either has, or is at risk for developing, this serious disease. Federal funding for diabetes prevention and research efforts are critical to facing this epidemic.

Diabetes is serious. It is a chronic condition that impairs the body's ability to use food for energy. The hormone insulin, which is made in the pancreas, helps the body change food into energy. In people with diabetes, the pancreas either does not create any insulin, which is type 1 diabetes, or the body doesn't create enough insulin and/or cells are resistant to insulin, which is type 2 diabetes. If left untreated, diabetes results in too much glucose in the blood stream. Type 1 individuals account for 5 to 10 percent of all diagnosed cases; type 2 diabetes accounts for 90 to 95 percent of diabetes cases. Diabetes is the leading cause of kidney disease, adult-onset blindness and lower limb amputations as well as a significant cause of heart disease and stroke.[2] Every 21 seconds someone is diagnosed with diabetes. More than 4,000 people will be diagnosed in 24 hours. During this same time frame there will be 230 amputations, 120 people will enter end-stage kidney disease programs, and 55 people will go blind all due to diabetes.[3]

Diabetes is costly. The total annual economic cost of diabetes in 2007 was estimated to be $174 billion. Medical expenditures totaled $116 billion and were comprised of $27 billion for diabetes care, $58 billion for chronic diabetes-related complications, and $31 billion for excess general medical costs. Indirect costs resulting from increased absenteeism, reduced productivity, disease-related unemployment disability, and loss of productive capacity due to early mortality totaled $58 billion. This is an increase of $42 billion since 2002. **A 32% increase, meaning that the dollar amount has grown over $8 billion each year**. In fact, approximately one out of every five health care dollars is spent caring for someone with diagnosed diabetes, while one in ten health care dollars is attributed to diabetes.[4] Additionally, approximately one-third of Medicare expenses are associated with treating diabetes and its complications.[5]

Diabetes is deadly. It is the fifth leading cause of death by disease, compromising of an estimated 224,092 deaths each year. Diabetes is likely to be underreported as a cause of death. Studies have found that less than half of individuals with diabetes had it listed on their death certificate. The risk for death among people with diabetes is about twice that of people without diabetes of similar age.[6] Having diabetes lowers the average life expectancy by up to 15 years.[7]

Unfortunately, while the death rate due to diabetes has increased by about 45 percent since 1987 while death rates from cancer, heart disease, and stroke have declined. [8]

The American Diabetes Association's Funding Requests

Diabetes is one of the greatest U.S. public health crises of the 21st century. To stem the tide of this epidemic, it is essential that diabetes prevention and outreach efforts expand and scientists and researchers be enabled to continue their work towards finding a cure. Therefore, we are requesting:

- **$83.5 million for CDC's Division of Diabetes Translation (DDT).** This would be a $20.8 million increase, one dollar for each American suffering from diabetes. This program received an $880,000 increase in FY08. This year the Administration has requested a reduction of $257,000 to this essential prevention and education program.

- **$1.818 billion for the National Institute for Diabetes, Digestive and Kidney Diseases (NIDDK) at the NIH.** This would add $112.6 million to NIDDK and represent a 6.6 percent increase over FY08 funding. The additional funding would provide a 3 percent increase over biomedical inflation which continues to eat into the purchasing power of research funding. The Administration has requested an increase of $2 million for FY09.

Diabetes Interventions at the Centers for Disease Control and Prevention

The CDC's Division of Diabetes Translation is critical to our national efforts to prevent and manage diabetes because DDT literally translates research, like that done at NIH, into real solutions and practices. Appropriated funds to DDT are focused on: defining the diabetes burden through the use of public health surveillance; translating research findings into clinical and public health practice; developing and maintaining state-based diabetes and prevention programs; and supporting the National Diabetes Education Program. Our request of $20.8 million will allow these critical programs at DDT to expand and more adequately meet the growing demands of the diabetes epidemic to prevent or delay this destructive disease.

The research findings that are translated into practice identify and detail the public health implications of results from clinical trials and scientific studies. These findings are applied in health care systems and within local communities. Areas of translational research include: access to quality care for diabetes, especially within managed care organizations; cost-effectiveness of diabetes prevention and control activities; effectiveness of health practices to address risk factors for diabetes; and demonstration of primary prevention of type 2 diabetes.

DDT provides support for 59 state and territorial-based Diabetes Prevention and Control Programs (DPCPs). These programs work to increase outreach and education, and to reduce the complications associated with diabetes. Due to funding constraints, DDT currently funds 28 states at a higher level of support called basic implementation. At this level, states are able to devise and execute community-based programs on a broader scale. The remaining 22 states, 8 territories, and the District of Columbia are funded at the lower, capacity building level. This level of funding establishes a presence in a state, but does not allow them to develop much in the

way of intervention. The level of funding proposed by the President's budget would not allow for adequate increases in the amount individual states are provided.

The following are funded at the lower, capacity building, amounts:

- Alabama
- Arizona
- Connecticut
- District of Columbia
- Georgia
- Hawaii
- Idaho
- Indiana
- Iowa
- Louisiana
- Maine
- Maryland
- Mississippi
- Nebraska
- Nevada
- New Hampshire
- North Dakota
- Oklahoma
- South Dakota
- Tennessee
- Vermont
- Virginia
- Wyoming

The DDT conducts additional activities which work to eliminate the preventable burden of diabetes and to educate communities. The Diabetes Primary Prevention Initiative, which was created from an initial NIH clinical trial, is an effort to plan and create pilots focusing on health implementation of diabetes primary prevention programs. This program is currently funded in five states as demonstration projects and is expected to end this year. Additional funds would be needed to translate primary prevention in all 50 states.

In a joint cooperative CDC is working with NIH, and over 200 partners, to jointly sponsor the National Diabetes Education Program (NDEP), which seeks to improve the treatment and outcomes of people with diabetes, promote early detection, and prevent the onset of diabetes. In FY08 the NDEP focused on minority populations who bear a disproportionate burden of diabetes.

Diabetes Research at the National Institutes for Health

The National Institute for Diabetes, Digestive and Kidney Diseases is one of the 27 institutes housed at the NIH. Through its valuable work, NIDDK is poised to make major discoveries that could prevent or reverse the autoimmune destruction of insulin-producing cells. While there is no cure for diabetes, researchers at NIH are working on a variety of projects that represent hope for the millions of individuals with type 1 and type 2 diabetes. The list of advances in treatment and prevention is thankfully long, but it is important to understand what has been, and what can be achieved for Americans with diabetes with additional funding.

A generation ago, 20 percent of individuals diagnosed with type 1 diabetes died within 20 years of diagnosis and over 30 percent died within 25 years. Thanks to research at NIDDK, patients now use a variety of insulin formulations, such as rapid or long acting insulin, insulin pumps, or inhaled insulin to control their blood glucose. Even components of an artificial pancreas are being tested in clinical studies.[9]

Researchers have already learned a great deal about the biology of diabetes, and they now understand much more about the loss of islet cell function. These discoveries have led directly to islet cell transplants, which have given some individuals more than a year of freedom from insulin administration. Scientists are now working on ways to keep the islet cells functioning longer by suppressing the body's natural immune response to the transplanted cells.[10]

Recognizing the growing problem of obesity and its increasing prevalence among youth, the NIDDK is focusing on paths to prevention. The clinical trial, the Diabetes Prevention Program (DPP) focused on discovering whether diet and exercise or an oral diabetes drug could prevent or delay the onset of type 2 diabetes in people with impaired glucose tolerance. The trial found that with modest lifestyle interventions individuals can reduce their risk of developing type 2 diabetes by **58 percent**, the oral diabetes medication also reduced risk, although less dramatically.[11]

Additionally, scientists have found that timely laser surgery and appropriate follow-up can reduce the risk of blindness for a person with diabetic retinopathy by 90 percent. This is significant as diabetes is the leading cause of new cases of blindness among adults aged 20-74 years. Another major clinical trial, the Diabetes Control and Complications Trial, showed that intensive glucose control dramatically delays or prevents the eye, nerve, kidney, and heart complications of type 1 diabetes.[12]

Conclusion

As you are considering the FY09 appropriation, we ask you to keep in mind that diabetes is a burgeoning epidemic with a rising morbidity rate that will create a financial and socioeconomic burden of even greater proportion in the very near future. If left unchecked it will overwhelm our healthcare system as well as tragically affect millions of American families. The CDC translational programs and NIH research go hand in hand in the effort to combat the diabetes epidemic. Our Nation can more rapidly move toward curing, preventing, and managing this disease by increasing funding for diabetes education, programs and research.

The American Diabetes Association strongly urges the Subcommittee and the Senate to provide a $20.8 million increase for the CDC's Division of Diabetes Translation. With 58 percent of type 2 diabetes being preventable this is a smart investment in the well being of our nation. Additionally, we urge the Subcommittee to increase NIH funding by 6.6 percent allowing for a continued and expanded commitment to diabetes research.

We must have a proactive approach to this disease, rather than merely reacting to its consequences. Your continued leadership on this growing epidemic is essential to accomplishing this goal. Again, thank you for your proven commitment to the diabetes community and for the opportunity to submit this testimony. The American Diabetes Association is prepared to answer any questions you might have on these important issues.

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Ovarian Cancer National Alliance

Written Testimony of the Ovarian Cancer National Alliance
Regarding Fiscal Year 2009 Ovarian Cancer Related Funding
House Subcommittee on Labor-Health and Human Services-Education and Related Activities
March 31, 2008

Submitted on behalf of the Ovarian Cancer National Alliance by:

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On behalf of the Ovarian Cancer National Alliance (the Alliance), thank you for this opportunity to submit comments for the record regarding the Alliance's fiscal year (FY) 2009 funding recommendations. We believe these recommendations are critical to ensure that advances can be made to help reduce and prevent suffering from ovarian cancer. For 11 years, the Alliance has worked to increase awareness of ovarian cancer and advocated for additional federal resources to support research that would lead to more effective diagnostics and treatments.

As an umbrella organization with 45 state and local organizations, the Alliance unites the efforts of survivors, grassroots activists, women's health advocates and health care professionals to bring national attention to ovarian cancer. Our sole mission is to conquer ovarian cancer.

According to the American Cancer Society, in 2008, more than 22,000 American women will be diagnosed with ovarian cancer and approximately 15,000 will lose their lives to this terrible disease. Ovarian cancer is the fifth leading cause of cancer death in women. **Currently, more than half of the women diagnosed with ovarian cancer will die within five years**. While ovarian cancer has early symptoms, there is no early detection test. Most women are diagnosed in Stage III or Stage IV, when survival rates are low. If diagnosed early, more than 90 percent of women will survive for five years, but when diagnosed later, less than 30 percent will.

In addition, only a few treatments have been approved by the Food and Drug Administration (FDA) for ovarian cancer treatment. These are platinum-based therapies and women needing further rounds of treatment are frequently resistant to them. More than 70 percent of ovarian cancer patients will have a recurrence at some point, underlying the need for treatments to which patients do not grow resistant.

Ovarian Cancer National Alliance

For all of these problems, we urgently call on Congress to appropriate funds to find solutions.

As part of this effort, the Alliance advocates for continued federal investment in the Centers for Disease Control and Prevention's (CDC) Ovarian Cancer Control Initiative. The Alliance respectfully requests that Congress provide $10 million for the program in FY 2009.

The Alliance also fully supports Congress in taking action on ovarian cancer through its recent passage of Johanna's Law: The Gynecologic Cancer Education and Awareness Act [P.L. 109-475]. The Alliance respectfully requests that Congress provide the remaining $10 million to implement Johanna's Law in FY 2009.

Further, the Alliance urges Congress to continue funding the Specialized Programs of Research Excellence (SPOREs), including the four ovarian cancer sites. These programs are administered through the National Cancer Institute (NCI) of the National Institutes of Health (NIH). The Alliance respectfully requests that Congress provide a 9.5 percent increase to NCI in FY 2009.

Centers for Disease Control and Prevention

The Ovarian Cancer Control Initiative

As the statistics indicate, late detection and, therefore, poor survival are among the most urgent challenges we face in the ovarian cancer field. The CDC's cancer program, with its strong capacity in epidemiology and excellent track record in public and professional education, is well positioned to address these problems. As the nation's leading prevention agency, the CDC plays an important role in translating and delivering at the community level what is learned from research, especially ensuring that those populations disproportionately affected by cancer receive the benefits of our nation's investment in medical research.

Prompted by efforts from leaders of the Alliance and championed by Representative Rosa DeLauro – with bipartisan, bicameral support – Congress established the Ovarian Cancer Control Initiative at the CDC in November 1999. Congress' directive to the agency was to develop an appropriate public health response to ovarian cancer and conduct several public health activities targeted toward reducing ovarian cancer morbidity and mortality.

Through the OCCI, the National Comprehensive Cancer Control Program is helping states address issues related to ovarian cancer. The program current funds efforts in California, Florida, Michigan, New York, Pennsylvania, Texas and West Virginia. These projects are working to develop ovarian cancer health messages for the general public and for health care providers.

Ovarian Cancer National Alliance

Johanna's Law: The Gynecologic Cancer Education and Awareness Act

It is critical that women and their health care providers are aware of the signs, symptoms and risk factors of ovarian and other gynecologic cancers. Often, women and providers mistakenly confuse ovarian cancer signs and symptoms with those of gastrointestinal disorders or early menopause. While symptoms may seem vague – bloating, pelvic or abdominal pain, increased abdominal size and bloating and difficulty, eating or feeling full quickly, or urinary symptoms (urgency or frequency) – they can be deadly without proper medical intervention.

In recognition of the need for awareness and education, Congress unanimously passed Johanna's Law in 2006, enacted in early 2007. This law provides for an education and awareness campaign that will increase providers' and women's awareness of all gynecologic cancers including ovarian. Together, Johanna's Law and the Ovarian Cancer Control Initiative will help increase awareness and understanding of ovarian cancer and work to reduce ovarian cancer morbidity and mortality.

Already, with only a small amount of seed money, the CDC has launched the *Inside Knowledge: Get the Facts About Gynecologic Cancer* campaign to raise awareness of the five main types of gynecologic cancer: ovarian, cervical, uterine, vaginal and vulvar. Many fact sheets, including the ovarian cancer fact sheet, are already available on the CDC's Web site for download. The CDC plans to develop broadcast advertisements, posters – such as dioramas for bus stops – and other print materials, a comprehensive brochure on gynecologic cancers, and materials aimed at health care providers.

National Cancer Institute

Specialized Programs of Research Excellence in the National Institutes of Health

The Specialized Programs of Research Excellence were created by the NCI in 1992 to support translational, organ site-focused cancer research. The ovarian cancer SPOREs began in 1999. There are four currently funded Ovarian Cancer SPOREs located at the MD Anderson Cancer Center, the Fred Hutchinson Cancer Research Center, the Fox Chase Cancer Center and the Dana Farber/Harvard Cancer Center.

These SPORE programs have made outstanding strides in understanding ovarian cancer, as illustrated by their more than 300 publications as well as other notable achievements, including the development of an infrastructure between Ovarian SPORE institutions to facilitate collaborative studies on understanding, early detection and treatment of ovarian cancer.

Clinical Trials

The National Cancer Institute supports clinical research – the only way to test the safety and efficacy of potential new treatments for ovarian cancer. Two recent studies from NCI clinical trials show the impact of intraperitoneal chemotherapy in treating ovarian

cancer (when chemotherapy is introduced directly into the woman's abdominal cavity, rather than her bloodstream) and the importance of ultrasound expertise in properly diagnosing the disease.

NCI supports the Gynecology Oncology Group, a more than 50-member collaborative focusing on cancers of the female reproductive system. In 2007 alone, GOG published 23 articles about ovarian cancer.

A Sustained Commitment to Fund Cancer Research

When funding stagnates or does not keep pace with inflation, progress in critical research programs is halted or slows significantly. Inadequate funding for the NIH and the NCI means smaller "trickle down" occurs for the lesser-known or less frequently occurring – yet terribly devastating – diseases such as ovarian cancer.

From FY 2005 to FY 2006, NCI funds decreased by only two percent, while the number of ovarian cancer research grants decreased by 20 percent. From FY 2006 to FY 2008, the NCI budget was flat, and the number of ovarian cancer research grants dropped 15 percent in the first year, and look to drop even more significantly for FY 2008.

To ensure adequate funding for all types of cancer, particularly those most deadly and least understood, the Alliance joins the cancer community in asking for a 6.5 percent increase for NIH and a 9.5 percent increase for NCI in FY 2009.

Summary

The Alliance maintains a long-standing commitment to work with Congress, the Administration, and other policy makers and stakeholders to improve the survival rate for women with ovarian cancer through education, public policy, research and communication. Please know that we appreciate and understand that our nation faces many challenges and that Congress has limited resources to allocate; however, we are concerned that without increased funding to bolster and expand ovarian cancer education, awareness and research efforts, the nation will continue to see growing numbers of women losing their battle with this terrible disease.

On behalf of the entire ovarian cancer community – patients, family members, clinicians and researchers – we thank you for your leadership and support of federal programs that seek to reduce and prevent suffering from ovarian cancer. Thank you in advance for your support of $10 million in FY 2009 funding for the CDC's Ovarian Cancer Control Initiative and $10 million in FY 2009 funding for Johanna's Law as well as your continued support of the SPORES program, a 9.5 percent increase for NCI.

THE **AIDS** INSTITUTE

March 28, 2008

WRITTEN STATEMENT OF DR. GENE COPELLO, EXECUTIVE DIRECTOR, THE AIDS INSTITUTE, TO THE SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES
HOUSE COMMITTEE ON APPROPRIATIONS

Dear Chairman Obey and Members of the Subcommittee:

The AIDS Institute, a national public policy research, advocacy, and education organization, is pleased to comment in support of critical HIV/AIDS and Hepatitis programs as part of the FY2009 Labor, Health and Human Services, Education and Related Agencies appropriation measure. We thank you for your consistent support of these programs over the years, and trust you will do your best to adequately fund them in the future in order to provide for, and protect the health of many Americans.

HIV/AIDS

HIV/AIDS remains one of the world's worst health pandemics in history. Worldwide, some 33.2 million people are infected with this incurable infectious disease, and more than 6,800 new infections occur each day. Tragically, AIDS has already claimed the lives of over 25 million. Here in the U.S., according to the CDC, 984,155 people have been diagnosed with AIDS, and 550,394 people have died. It is estimated there are more than 40,000 new infections in the U.S. each year, although this number may soon be revised to as high as 55,000 to 60,000. At the end of 2005, an estimated 1.2 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 12% of the US population, account for half of the HIV/AIDS cases. HIV/AIDS also disproportionately affects the poor, and about 70 percent of those infected rely on public health care financing.

The U.S. government has played a leading role in fighting AIDS, both here and abroad. The vast majority of the discretionary programs supporting HIV/AIDS efforts domestically and a portion of our Nation's contribution to the global AIDS effort 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 and global AIDS programs. The AIDS Institute asks that you do your best to adequately fund these programs at the requested level.

We are keenly aware of budget constraints and competing interests for limited dollars. Unfortunately, despite the growing need, several domestic HIV/AIDS programs have

experienced cuts in recent years including HIV prevention funding at the CDC and some parts of the Ryan White HIV/AIDS Program.

This year, the President has proposed to cut CDC HIV Prevention even more, and increase Ryan White programs by a mere .004 percent, while cutting some parts of the program. The AIDS Institute asks you to reject these cuts and increase the entire program at the community requested level. Below are the program requests and supporting explanation by The AIDS Institute:

Centers for Disease Control and Prevention-HIV Prevention and Surveillance

FY 2008:	$692 million
FY 2009 President's Request:	$691 million
FY 2009 Community Request:	$1,300 million

While the CDC has reported for many years the number of new HIV infections in the U.S. is estimated to be 40,000 each year, they have announced they will release new incidence numbers in the near future in which, according to press reports, indicate the number is more like 55,000 to 60,000. While the current numbers are enough to cause alarm, the new estimates will hopefully convince Congress there is a heightened immediate need for increased funding, rather than additional cuts.

The increase in new infections is particularly occurring in certain populations, such as the poor, African- Americans, men who have sex with men, Latinos, substance users and the incarcerated. In order to address the specific needs of these populations, CDC is going to need additional funding.

Investing in prevention today will save money tomorrow. Every case of HIV that is prevented saves, on average, $1 million of lifetime treatment costs for HIV. One recent study concluded the cost of new HIV infections in the US in 2002 was estimated at $36.4 billion, including $6.7 billion in direct medical costs and $29.7 billion in productivity losses. Another study concluded preventing the estimated 40,000 new HIV infections in the U.S. each year would avoid obligating $12.1 billion annually in future medical costs.

Despite the savings of lives and costs that prevention provides, the Congress cut the program by $3.5 million in FY08 and the Administration is proposing to cut it in FY09 by another $1 million. Cuts of greater magnitude have been occurring for actual direct prevention programming while increases have gone for HIV testing. Since one quarter of the over one million people living with HIV in the U.S. are unaware of their HIV status, The AIDS Institute supports increased testing programs. However, we do not support funding these efforts at the expense of prevention intervention programs.

The Administration is also proposing $30 million to implement the Early Diagnosis Grant Program. The AIDS Institute does not support this request and urges that the money should be directed instead to CDC HIV/AIDS prevention programs.

Ryan White HIV/AIDS Programs

FY 2008:	$2,167 million
FY 2009 President's Request:	$2,168 million
FY 2009 Community Request:	$2,782 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 reaches over 531,000 low-income, uninsured, and underinsured people each year.

In FY08, the program overall received an increase of $29 million, although some parts of it experienced cuts, including an unprecedented $19 million cut for Part B, which provides money to the states. The President has proposed a .004 percent increase for Ryan White in FY09, or only $1.1 million. Within this request, some parts of the program would receive minor increases, while others would receive decreases. The AIDS Institute urges you to reject this budget proposal and instead provide substantial funding increases to all parts of the Ryan White Program. Consider the following:

1) Caseload levels are increasing. People are living longer due to lifesaving medications; there are at least 40,000 new infections each year; and increased testing programs, according to the CDC, will identify 12,000 to 20,000 new people infected with HIV each year. All of this will necessitate the need for more Ryan White services and medications.

2) The price of healthcare, including medications, is increasing and state and local budgets are experiencing cutbacks due to the economic downturn.

3) There are significant numbers of people in the U.S. who are not receiving life-saving AIDS medications. An IOM report concluded that 233,069 people in the U.S. who know their HIV status do not have continuous access to Highly Active Antiretroviral Therapy. A CDC study concluded 212,000 or 44% of eligible people living with HIV/AIDS, aged 15–49 in the US, are not receiving antiretroviral therapy.

Given these factors, cuts in funding or flat or minor increases are unacceptable. 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 urge you to reject the President's proposed cut of $7.7 million and instead request an increase of $213 million, for a total of $840 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 $95 million increase, for a total of $482 million.

The **AIDS Drug Assistance Program (ADAP)** provides life-saving HIV drug treatment to over 100,000 people; the majority of whom are people of color (60%) and very poor

(80% are at or below 200% of the federal poverty level). Due to a lack of funding, states have not been able to include all necessary drugs on their formularies, have limited eligibility and capped enrollment. In order to address the 386 new ADAP clients each month and drug cost increases, we are requesting an increase of $134.6 million for a total of $943.5 million.

Part C provides early medical intervention and other supportive services to over 225,000 people at over 360 directly funded clinics. We are requesting a $100.5 million increase, for a total of $299 million.

Part D provides care to over 53,000 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 $48.8 million increase, for a total of $122.5 million.

Part F includes the AIDS Education and Training Centers (AETCs) program and the Dental Reimbursement program. We are requesting a $15.9 million increase for the AETC program, for a total of $50 million, and a $6 million increase for the Dental Reimbursement program, for a total of $19 million.

The AIDS Institute supports increased funding for the **Minority AIDS Initiative** (MAI). MAI funds services nationwide that address the disproportionate impact that HIV has on communities of color.

National Institutes of Health-AIDS Research

FY 2008:	$2.9 billion
FY 2009 President's Request:	$2.9 billion
FY 2009 Community Request:	$3.35 billion

Through the NIH, research is conducted to understand the AIDS virus and its complicated mutations; discover new drug treatments; develop a vaccine and other prevention programs such as microbicides; and ultimately, a cure. Much of this work at the NIH is done in cooperation with private funding. 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 best HIV can be prevented in various affected communities. We ask the Committee to fund critical AIDS research at the community requested level of $3.35 billion.

Administration for Children & Families: Community Based Abstinence Education

Efforts to improve prevention methods and weed out non-effective programs should be a constant undertaking and be guided by science and fact based decision-making. It is for these reasons The AIDS Institute opposes abstinence-only-until-marriage programs,

for which the President requested a $28 million increase. While we support abstinence-based prevention programs as part of a comprehensive prevention message, there is no scientific proof that abstinence-only programs are effective. On the contrary, they reject proven prevention tools, such as condoms, and fail to address the needs of homosexuals, who can not marry, and who remain greatly impacted by HIV/AIDS.

Substance Abuse and Mental Health Services Administration

Many persons infected with HIV also experience drug abuse and/or mental health problems, and require the programs funded by SAMHSA. Given the growing need for services, we are disappointed by proposed funding cuts at SAMHSA, including $63 million for the Center for Substance Abuse Treatment, $36 million for the Center for Substance Abuse Prevention, and $126 million for the Center for Mental Health Services. We ask the Committee to reject these cuts, and adequately fund these programs.

Viral Hepatitis

Viral Hepatitis, whether A, B, or C, is an infectious disease that also deserves increased attention by the federal government. According to the CDC, there are an estimated 1.25 million Americans chronically infected with Hepatitis B, and 60,000 new infections each year. Although there is no cure, a vaccine is available, and a few treatment options are available. An estimated 4.1 million (1.6%) Americans have been infected with Hepatitis C, of whom 3.2 million are chronically infected. Currently, there is no vaccine and very few treatment options. It is believed that one-third of those infected with HIV are co-infected with Hepatitis C.

Given these numbers, we are disappointed the Administration is calling for a decrease in funding for Viral Hepatitis at the CDC. The program is currently being funded at a level that is substantially less than what it was funded in FY03 and falls short of the $50 million that is needed. These funds are needed to establish a program to lower the incidence of Hepatitis through education, outreach, and surveillance, and to support such initiatives as the CDC National Hepatitis C Prevention Strategy and the 2002 NIH Consensus Statement on the Management of Hepatitis C and accompanying recommendations.

The AIDS Institute asks that you give great weight to our testimony and remember it as you deliberate over the FY2009 appropriation bill. Should you have any questions or comments, feel free to contact Carl Schmid, Director of Federal Affairs, The AIDS Institute (202) 462-3042 or cschmid@theaidsinstitute.org. Thank you very much.

Susie Novis, President
International Myeloma Foundation
FY 2009 Written Testimony Regarding Myeloma Research Programs
March 31, 2008

The International Myeloma Foundation (IMF) appreciates the opportunity to submit written comments for the record regarding fiscal year (FY) 2009 funding for myeloma cancer programs. The IMF, the oldest and largest myeloma foundation, is 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 they need and deserve, the IMF advocates on-going 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

Myeloma is a cancer in the bone marrow affecting production of red cells, white cells and stem cells. It is also called "multiple myeloma," because multiple areas of bone marrow may be involved. Myeloma is the second most common blood cancer after lymphomas, affecting an estimated 750,000 people worldwide and its prevalence appears to be is increasing significantly.

No one knows the exact causes of myeloma. Doctors can seldom explain why one person develops this disease and another does not. Research has shown that people with certain risk factors such as age and race are more likely than others to develop myeloma. Growing older increases the chance of developing multiple myeloma as most people with myeloma are diagnosed after age 65. However, in recent years the diagnosis of myeloma in people 40 years of age and younger appears to have become more common as our ability to detect and diagnose this disease has improved. The risk of myeloma is highest among African Americans and lowest among Asian Americans.

Scientists are studying other possible risk factors for myeloma. Toxic chemicals (for example, agricultural chemicals and Agent Orange used in Vietnam), radiation (including atomic radiation), and several viruses (including HIV, hepatitis, herpes virus 8, and others) are associated with an increased risk of myeloma and related diseases.

According to the American Cancer Society, 19,920 Americans will be diagnosed with myeloma and 10,690 will lose their battle with this disease in 2008. Even while they live with the disease, myeloma patients can suffer debilitating fractures and other bone disorders, severe side effects of their treatment, and other problems that profoundly affect their quality of life, and significantly impact the cost of their health care. Despite these grim statistics, significant gains in the battle against myeloma have been made through our nation's investment in cancer research and its application. Research holds the key to improved myeloma prevention, early detection, diagnosis, and treatment, but such breakthroughs are meaningless unless we can deliver them to all Americans in need.

Sustain and Seize Cancer Research Opportunities

Our nation has benefited immensely from past federal investment in biomedical research at the National Institutes of Health (NIH). The IMF has joined with the broader health community in advocating a $30.81 billion budget for NIH in FY 2009. This will allow NIH to sustain and build on its research progress resulting from the recent doubling of its budget while avoiding the severe disruption to that progress that would result from a minimal increase. Myeloma research is producing extraordinary breakthroughs – leading to new therapies that translate into longer survival and improved quality of life for myeloma patients. Although myeloma was once considered a death sentence with limited options for treatment, today there are dozens of drugs in clinical trials for myeloma in the United States alone, and several recently-developed drug regimens can be used in sequence to help myeloma patients maintain their daily routines for years and even decades. To that end, the IMF calls upon Congress to allocate $5.26 billion to the National Cancer Institute (NCI) in FY 2009 to continue our battle against myeloma and its sequelae.

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 joins with our partners in the cancer community – including One Voice Against Cancer (OVAC) – in calling on Congress to provide additional resources for the CDC to support and expand much-needed and proven efforts in such areas as cancer prevention, early detection, and risk reduction. Specifically, the IMF advocates the appropriation of $445.5 million in FY 2009 for CDC's cancer prevention and control initiatives.

Within that allocation, the IMF specifically advocates $5.5 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 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 $5.5 million in FY 2009 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.

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 2009 funding levels necessary to ensure that our nation continues to make gains in the fight against myeloma.

STATEMENT BY THE MONTGOMERY COUNTY STROKE ASSOCIATION
FLORA INGENHOUSZ, BOARD MEMBER
FY 2009 APPROPRIATIONS FOR LABOR-HHS-EDUCATION
(NIH)

I am Flora Ingenhousz, a psychotherapist in private practice in Silver Spring, Maryland. I have always been in excellent health and live an active, healthy lifestyle. Doctors always commented on my low blood pressure and my excellent cholesterol numbers. But I suffered a stroke two years ago. It was a shock to me and my family, friends and clients.

One morning two years ago, when doing a load of laundry, I had no idea how to set the dials, despite the fact that I had used them weekly for the last ten years. I stood there for what seemed an eternity before I figured out how to set the dials.

Next I went to do yoga. In one of the poses, I noticed my right arm was hanging limp. When my husband asked me a question, my answer was just the opposite of what I wanted to say. I caught my error and tried again, but it soon became clear that something was wrong. My symptoms kept getting worse.

When we walked into the ER, my right leg was weak, and I could not sign my name at the desk. Twelve hours later, I could not move my right side, and my speech was reduced to yes and no. Not a good thing for a psychotherapist, where language is a primary tool!

In the ER, a CT scan showed a hemorrhagic or bleeding stroke where an artery burst, destroying millions of brain cells within minutes, affecting my speech and my ability to perform activities like dressing in the correct order. Also, my right arm and leg were extremely weak. However, I could understand everything, and I was never completely paralyzed. But, I was scared.

I was in intensive care for four days of observation and lots of testing, but the tests provided no answers. Two days after my stroke, while still in intensive care, I started occupational, physical and speech therapy. It was extremely challenging to feed myself with my right hand, requiring all my concentration. After a meal or brushing my teeth, I was exhausted. Speaking was the hardest of all. My brain seemed devoid of words.

After being stabilized, I was transferred to the National Rehabilitation Hospital. For a week, I endured speech, physical, occupational and recreational therapies.

Speech therapy was the hardest, but also the most important given my profession. Several times, the speech therapist challenged me to the brink of tears.

After a week at the Rehabilitation Hospital, I went home and to outpatient therapies. Speech therapy lasted the longest. After being discharged from speech therapy, I still had deficits in my organizational skills and abstract thinking.

As I struggled with starting to see my clients again, I slid into a deep depression. I was not confident that I could continue to practice. For months, I saw no point in living. Recovery from my post-stroke depression was harder than the recovery of my arms and legs and even speech!

Being a psycho-therapist, I know how to treat depression, so I went to a psychiatrist who prescribed anti-depressant medication and, I also found a psychotherapist.

After months on anti-depressants and excellent psychotherapy, my depression began to lift. I continue on the drugs and to see my psychotherapist. Emotionally, the aftermath of my stroke cut deep.

I am fortunate that two years post-stroke, I am back to my practice full-time. I lead support groups for stroke survivors and caregivers through the Montgomery County Stroke Association and serve on its Board. I now lecture on stroke, stroke prevention and stroke recovery. I also founded "hope for stroke"--individual and family counseling for stroke survivors and caregivers. In addition, I have participated in a NIH study about stroke recovery.

Once again, I am in excellent health and have resumed my active life style. I thank my brain for having the capacity to work around the dead cells. But most of all, I thank my therapists for my recovery. Their ability to zero in so effectively would not have been possible without NIH research.

Because stroke is a leading cause of death and disability and major cost to society, I urge you to provide stroke research with a significant funding increase. I am concerned that NIH continues to invest only 1 percent of its budget in stroke research.

Thank you.

STATEMENT BY THE MENDED HEARTS, INCORPORATED
ROBERT A. SCOTT, NATIONAL ADVOCACY CHAIRMAN
FY 2009 APPROPRIATIONS FOR LABOR-HHS-EDUCATION
(NIHI)

I am Robert A. Scott, National Advocacy Chairman for Mended Hearts Inc., a heart disease support group with more than 300 chapters across the United States and Canada. In 2007, accredited Mended Hearts volunteers visited about 3,000 heart patients in more than 400 hospitals throughout the United States.

As a walking testimony of the benefits of NIH-supported heart research, I would like to share my story. In 1998, at age forty-eight, I suffered my first heart attack while playing volleyball. While at Woonsocket, Rhode Island's Landmark Medical Center, doctors diagnosed me as suffering a so called silent heart attack. I learned that as many as 4 million Americans experience this type of episode—a heart attack with no warning.

After being stabilized, I was transferred to Roger Williams Hospital, in Providence, Rhode Island for a heart catheterization—the gold standard for diagnosis of heart problems. The procedure showed that I had a blockage in my artery that required a stent to open it. Also, it showed that the lower chamber of my heart was damaged, resulting in congestive heart failure that could be controlled with medicine. A stent was inserted in my artery in Rhode Island Hospital.

In 1999, I received another heart catheterization in Miriam Hospital because of the damage to my heart from the silent heart attack. However, this time, I was told that my artery could not be repaired with a stent and that I needed heart bypass surgery the next morning. Calling me a high risk patient because of my age and my weakened heart, my surgeon encouraged me to find a doctor in Boston because my heart might not start again. However, he assured me that if this happens they had a device that could keep me alive for only seven hours. Thank goodness, he told me that in Boston they had another device that could keep me alive for seven months while they located a replacement heart. In less then ten hours, I went from the possibility of needing another stent, heart bypass surgery, and a heart transplant. My journey with heart disease continued.

My next stop was to visit my local cardiologist in Woonsocket who estimated my survival rate at 20%, but he thought I would survive the heart bypass surgery. Thankfully, he was right and I survived heart bypass surgery.

But my journey didn't end there. My congestive heart failure was causing my heart to beat irregularly, so an implantable defibrillator was inserted to control the problem in 2002. However, this device had to be replaced nearly four years later. My story continues in 2007 where I started experiencing daily chest pain and shortness of breath. Yet another heart catheterization showed that I needed an additional stent, but this time in Miriam Hospital. After the procedure, the doctor told me the original heart bypass surgery was no longer effective. Although I was scared, my doctors comforted me by explaining that a new medical innovation could save my life—a drug eluting stent. They explained that it could open up the

original blockage from my silent heart attack. My doctor explained that if these state-of-the art stents had been available in 1998, I would not have had to have heart bypass surgery.

Today, heart attack, stroke and other cardiovascular diseases remain our Nation's most costly and No. 1 killer and a major cause of disability. Thanks to medical research supported by the NIH, I am alive today. I am concerned that NIH continues to invest only 7% of its budget on heart research and a mere 1% on stroke research when there are so many people in our country just like I am. Enhanced NIH funding dedicated to heart and stroke research will bring us closer to a cure for these often deadly and disabling diseases.

STATEMENT BY THE AMERICAN HEART ASSOCIATION FY 2009 APROPRIATIONS FOR LABOR-HHS-EDUCATION
(NIH, CDC, HRSA, AHRQ)

Although heart disease and stroke remain our nation's No. 1 and No. 3 killers respectively, death rates are on the decline. Thanks in large measure to advancements in medical research, treatment and prevention programs, death rates from coronary heart disease have plummeted by almost 26 percent since 1999 and stroke mortality has fallen by 24 percent. If this positive trend holds, a total of 240,000 lives will be spared in 2008 alone.

But while the battle against heart disease and stroke has been successfully joined, the war is far from won. Heart disease, stroke and other forms of cardiovascular disease (CVD) still claim more than 860,000 lives in the United States each year and the costs associated with this disease are projected to exceed $448 billion in 2008. Moreover, any gains we have achieved could be eroded by a rise in often preventable and certainly treatable risk factors, such as high blood pressure, cholesterol, diabetes, obesity and a lack of physical exercise. Continued progress in the fight against CVD is not guaranteed. We must work at it every day through increased research, better access to treatment and reinvigorated prevention efforts.

Sadly, the President's FY 2009 budget turns a blind eye to these challenges. Funding for NIH fails to keep pace with medical research inflation for the sixth year in a row, curtailing work on promising breakthroughs. Increased emphasis on preventing CVD is critical too, but programs that teach Americans how to build healthier lives free of heart disease and stroke are cut or eliminated. Access to quality care and treatment is also jeopardized, by cuts in programs that develop evidence-based information to improve health care outcomes, comparative effectiveness research, and advances in health information technology.

FUNDING RECOMMENDATIONS: INVESTING IN THE HEALTH OF OUR NATION
When adjusted for medical research inflation, the NIH budget is roughly 11% lower in FY 2008 than in FY 2003, and funding for CVD research is 15% lower for that same time period. Prevention also suffers. Funding for the Centers for Disease Control and Prevention's Heart Disease and Stroke Prevention Program and the WISEWOMAN screening and evaluation program are cut. Less than a third of all states receive federal resources to carry out these critical prevention initiatives.

Where you live could determine if you survive a sudden cardiac arrest. The Rural and Community Access to Emergency Devices Program provides grants to rural areas and communities to buy automated external defibrillators (AEDs), place these life-saving devices in schools, churches, fire stations and other sites, and train lay rescuers and first responders in their use. This successful program is terminated in the President's budget.

With CVD risk factors on the rise, it is clearly not the time to retreat and slash investments that prevent and treat America's leading and most costly killer. If we fail to take deliberate and focused action now, we will pay much more in the future in lost lives and higher health care costs. Our recommendations address this crisis in a comprehensive but fiscally responsible way.

Summary of Recommendations	
National Institutes of Health	$31.1 billion
National Heart, Lung, and Blood Institute	$3.1 billion
National Institute of Neurological Disorders and Stroke	$1.6 billion
Agency for Healthcare Research and Quality	$360 million
Centers for Disease Control and Prevention	$7.4 billion
Heart Disease and Stroke Prevention Program	$70 million
WISEWOMAN	$25 million
National Center for Health Statistics	$125 million
Health Resources and Services Administration	
Rural and Community Access to Emergency Devices Program	$8.9 million

Funding Gap for the National Institutes of Health (NIH)

NIH-supported research has revolutionized patient care and holds the key to finding new ways to prevent, treat and cure CVD, resulting in longer, healthier lives and lower health care costs. NIH research also generates economic growth and preserves our nation's position as the world leader in pharmaceuticals and biotechnology. However, the President's FY 2009 budget request for NIH is flat. When adjusted for medical research inflation, the gap between the funding levels achieved with the doubling of NIH's budget between 1999 and 2003 and the current request now approaches a 14% decline in support for the NIH.

***The American Heart Association Recommends*:** AHA joins the research and patient advocacy communities in advocating for a FY 2009 appropriation of $31.1 billion for NIH, representing a 3% increase over the 3.5% in medical research inflation for a total funding increase of 6.5%. This 3% increase over medical research inflation in consistent with the average NIH appropriation over the past 30 years (excluding the "doubling" period). Such a sustained and stable funding stream will allow NIH to take advantage of burgeoning scientific opportunities and protect past congressional investments in research that have saved millions of lives.

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

The decline in the death rates from CVD can be directly linked to NIH heart and stroke research – with more life-saving treatments and prevention tactics on the horizon. For example, recent NIH research has determined that post-menopausal hormone therapy is not useful in the

prevention of heart disease and stroke, has defined the genetic basis of dangerous responses to essential blood-thinners, and funded the early work of the 2007 Nobel Prize winners in Physiology or Medicine for their development of the technology of gene targeting.

Beyond lives saved, NIH research also produces tangible cost savings. For example, the original NIH tPA drug trial resulted in a 10-year net $6.47 billion reduction in stroke health care costs. And the Stroke Prevention in Atrial Fibrillation Trial 1 produced a 10-year net saving of $1.27 billion. But despite such solid returns on investments and other successes, NIH heart and stroke research remains disproportionately under-funded. In fact, only 7% of its budget goes to heart disease research, and a mere 1% is devoted to stroke. That must change.

Cardiovascular Disease Research: National Heart, Lung, and Blood Institute (NHLBI)
Under the President's budget proposal, funding for CVD research does not keep pace with medical research inflation and cannot adequately support current activities or allow investments in promising research opportunities. The loss of purchasing power over the past few years has reduced the ability of the NHLBI to fund meritorious investigator-initiated research and has necessitated cutbacks in Institute programs. Continued cutbacks will limit the pace at which the new NHLBI strategic plan can be implemented. Areas in which research could lag include the ability to translate basic research on human behavior into real world ways to reduce obesity and promote cardiovascular health; studies examining genetic susceptibility in the Framingham population, followed for 3 generations, and further research into the best methods for saving lives of those suffering from cardiac arrest.

Stroke Research: National Institute of Neurological Disorders and Stroke (NINDS)
An estimated 780,000 Americans will suffer a stroke this year, and more than 143,000 will die. Many of the 5.8 million stroke survivors face physical and mental disabilities, emotional distress and huge costs – a projected $66 billion in medical expenses and lost productivity in 2008.

The NINDS-sponsored Stroke Progress Review Group has issued a long-term, stroke research strategic plan. A variety of research initiatives have since been undertaken, but more funding is needed to fully implement the plan. Indeed, the FY 2009 request for NINDS stroke research falls about 50% short of the plan's target and additional resources are needed for programs such as:

- *Stroke Translational Research* – Translational studies are essential to providing cutting-edge stroke treatment, patient care and prevention. However, due to budget shortfalls, NINDS has been forced to scale back by 30% its Specialized Programs of Translational Research in Acute Stroke from a planned 10 centers to only seven.
- *Genetic Repository* – NINDS could better understand genetic risk factors associated with stroke by helping more researchers contribute data and findings to an NIH-funded genetic repository and to study available samples.
- *Neurological Emergencies Treatment Trials Network* – NINDS has established a clinical research network of emergency medicine physicians, neurologists and neurosurgeons to develop more and improved treatments for acute neurological emergencies, such as strokes. However, the number of trials will be limited by available funding.

The American Heart Association Recommends: AHA supports an FY 2009 appropriation of $2.260 billion for NIH heart research; $3.112 billion for the NHLBI; $362 million for NIH stroke research; and $1.644 billion for the NINDS. This represents a 6.5% increase over FY 2008 – commensurate with the Association's overall recommended funding increase for NIH.

Increase Funding for the Centers for Disease Control and Prevention (CDC)
With so many risk factors on the rise, prevention is the best way to protect the health of Americans and ease the economic burden of heart disease and stroke. However, many effective prevention strategies and programs are not being implemented for lack of funds.

For example, CDC's Division for Heart Disease and Stroke Prevention funds only 13 states to implement programs to reduce risk factors for heart disease and stroke, improve emergency response and quality care, and end treatment disparities. An additional 20 states receive funds for planning such prevention programs; however, there are no funds for actual implementation.

This Division also administers the WISEWOMAN program that screens uninsured, under-insured and low-income women ages 40 to 64 in 14 states for heart disease and stroke risk. They receive counseling, education, referral and follow-up as needed. Since January 2000, more than 70,000 women have been screened and more than 170,000 lifestyle interventions have been conducted. The program should be expanded to cover the other 36 states, but the President's budget contains no such funding.

The American Heart Association Recommends: AHA joins with the CDC Coalition in support of an appropriation of $7.4 billion for CDC, including increases for the Heart Disease and Stroke Prevention and WISEWOMAN programs. Within that total, we recommend $70 million for the Heart Disease and Stroke Prevention Program, allowing CDC to: (1) add nine unfunded states to develop state-tailored plans; (2) increase funding for up to18 states with current Heart Disease and Stroke Prevention Programs; (3) continue to support the remaining funded states; (4) maintain the Paul Coverdell National Acute Stroke Registry; (5) increase the capacity for national, state and local heart disease and stroke surveillance; and (6) provide additional assistance for prevention research and program evaluation. AHA also advocates $25 million to expand WISEWOMAN to additional states and joins with the Friends of the NCHS in recommending $125 million for NCHS to restore funding lost and to continue the collection of important public health data.

Restore Funding for Rural and Community Access to Emergency Devices (AED) Program
About 94% of cardiac arrest victims die outside of a hospital. Receiving immediate CPR and the use of an AED can more than double your chance of survival. Communities with comprehensive AED programs have achieved survival rates of 40% or higher. The Rural and Community AED Program provides grants to states to buy and place AEDs and train lay rescuers and first responders to use them. During its first year, 6,400 AEDs were purchased, and placed and 38,800 individuals were trained. Despite this success, the President yet again terminates the program in his proposed FY 2009 budget.

***The American Heart Association Recommends*:** For FY 2009, AHA advocates restoring the 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 helps develop evidence-based information to improve health care decision-making. Through its *Effective Health Care Program*, AHRQ supports research focused on outcomes, comparative clinical effectiveness and the appropriateness of pharmaceuticals, devices and health care services for conditions such as heart disease, stroke and high blood pressure.

On another front, AHRQ's health information technology (HIT) plan will help bring health care into the 21st century. Through more than $130 million in grants since 2004,AHRQ and its partners have begun work that can help identify: challenges to HIT adoption and use; solutions and best practices; and tools that aid hospitals and clinicians successfully integrate HIT. This must continue.

The American Heart Association Recommends: AHA joins with Friends of AHRQ in advocating a $360 million appropriation for the Agency. By restoring AHRQ to FY 2005 levels, we can improve health care, reduce medical errors and expand access to outcomes information.

CONCLUSION

Although heart disease, stroke and other forms of cardiovascular disease are largely preventable, they continue to exact a deadly and costly toll on our nation. However, adequate funding of research, treatment and prevention programs will save lives and reduce rising health care costs. The American Heart Association urges Congress to consider these recommendations during its deliberations on the FY 2009 budget. We believe that they are a wise investment for our nation and the health and well-being of this and future generations of Americans.

Statement of the Coalition of Northeastern Governors
to the Subcommittee on
Labor, Health and Human Services, Education and Related Agencies
Committee on Appropriations
United States House of Representatives
Regarding FY 2009 Appropriations for
the Low Income Home Energy Assistance Program
March 31, 2008

The Coalition of Northeastern Governors thanks you for this opportunity to provide testimony for the record to the House Subcommittee on Labor, Health and Human Services, Education, and Related Agencies regarding FY 2009 appropriations for the Low Income Home Energy Assistance Program (LIHEAP). The Governors appreciate the Subcommittee's continued support for the LIHEAP program and recognize the considerable fiscal challenges facing the Subcommittee this year. However, the skyrocketing cost of home energy has made this program more crucial than ever. The Governors request that regular FY 2009 LIHEAP block grant funding be appropriated at the full $5.1 billion level as authorized by the Energy Policy Act of 2005. The Governors also ask the Congress to appropriate additional contingency funds to address unforeseen energy emergency situations.

Funding the LIHEAP block grant at the $5.1 billion level will help restore some of the purchasing power of the program, provide greater certainty for program planning, and enable states across the nation to provide meaningful assistance to more citizens struggling to pay unaffordable home energy bills.

LIHEAP is a vital safety net for many of our nation's most vulnerable citizens. The program has served as a foundation of other assistance programs provided by utilities and the private sector, such as shutoff moratoria and other direct assistance. The highest level of LIHEAP assistance is provided to households with the lowest incomes that pay a high proportion of their income for home energy. These low-income households spend an average of 14 percent of annual income on home energy, compared to 3.6 percent for all other households. In 2004, elderly households in receipt of Supplemental Security Income paid nearly 19 percent of their income for energy, leaving few remaining funds to pay for food, shelter or medication. LIHEAP provides vital assistance to elderly households struggling to survive on fixed incomes, as 41 percent of LIHEAP recipient households include at least one elderly member.

Adding to the economic stress on these low-income households are the rapidly escalating costs of heating fuels that have eroded the purchasing power of the LIHEAP dollar. According to the Energy Information Administration (EIA), the national average cost of heating a home has risen from $704 during the winter of 2003-2004 to a projected $981 this winter – a 39 percent increase. This increase has far outpaced the growth in income for this population. Faced with

simply unaffordable energy bills, these households take drastic measures such as keeping their homes at unhealthy or unsafe temperatures, using unsafe alternative heating options, or accumulating high levels of home energy debt and the possibility of utility service shut-off.

At the same time that home energy prices are escalating, the average LIHEAP benefit has decreased and the number of households receiving assistance has declined since the peak of FY 2006. Approximately 5.7 million households – less than 16 percent of those eligible – now receive LIHEAP assistance (down from 5.8 million in FY 2006), and the average LIHEAP benefit has decreased from $464 to $378.

The recent price increases are especially troubling for households that rely on delivered fuels such as home heating oil and propane. According to the Department of Energy, roughly 69 percent of the nation's 5.3 million households that use home heating oil are in the Northeast. EIA estimates that households heating primarily with home heating oil will pay $1,990 this year, or 35.6 percent more than last year and a 66 percent increase over three years. Without an adequate benefit that can meet the minimum delivery requirement, these households face the prospect that a dealer will not make a delivery or will require a surcharge, further reducing the purchasing power of the LIHEAP benefit.

Households that use natural gas are also struggling with dramatically increasing home energy costs. While the cost has increased at a slower rate than home heating oil, households using natural gas are expected to pay 7.2 percent more than last year, and 32 percent more than during the winter of 2003-2004. The rising utility bills result in many of these households accumulating substantial arrearages and facing the prospect of shutoffs as the moratoria period in some states ends. A recent report by the American Gas Association found that the percentage of past due accounts rose from 16.5 percent in 2001 to 21 percent in 2006, and the total amount of uncollectible expenses rose 39 percent between 2003 and 2006. LIHEAP funds can be instrumental in helping these households stay out of debt or get their utilities reconnected.

If federal resources remain level or decline as home energy prices continue to rise, states face the difficult decision of serving fewer households in order to maintain some of the purchasing power of the LIHEAP grant for the program's poorest families, or reducing the level of benefits to recipients. To deliver maximum program dollars to households in need, states in the Northeast have incorporated various strategies to minimize the program's administrative costs including using uniform application forms to determine program eligibility, establishing a one-stop shopping approach for the delivery of LIHEAP and related programs, sharing administrative costs with other programs, and using mail recertification. However, opportunities to further reduce LIHEAP administrative costs are limited, since they are already among the lowest of the human service programs. In spite of these state efforts to stretch federal and state LIHEAP dollars, the need for the program is far too great. Increased, predictable and timely federal funding is vital for LIHEAP to assist the nation's vulnerable, low-income households faced with exorbitant home energy bills.

An increase in the regular LIHEAP appropriation to the $5.1 billion level for FY 2009 as well as the appropriation of additional contingency funds will enable states across the nation to help

mitigate the potential life-threatening emergencies and economic hardship that confront the nation's most vulnerable citizens. With these additional funds, states can provide assistance to more households in need, offer benefit levels that provide meaningful assistance, lessen the need for emergency crisis relief, plan and operate a more efficient program, and again make optimal use of leveraging and other cost-effective programs.

We thank the Subcommittee for this opportunity to share the views of the Coalition of Northeastern Governors, and we stand ready to provide you with any additional information on the importance of the Low Income Home Energy Assistance Program to the Northeast and the nation.

Written Testimony Submitted to the House of Representatives
Labor, Health and Human Services, and Education Appropriations Subcommittee
Regarding FY 2009 Funding for Malaria Related Programs

Claire Panosian, MD, DTM&H
President, American Society of Tropical Medicine and Hygiene

Overview

The American Society of Tropical Medicine and Hygiene (ASTMH) appreciates the opportunity to submit written testimony to the House Labor, Health and Human, Services, and Education Appropriations Subcommittee. With more than 3,300 members, ASTMH is the world's largest professional membership organization dedicated to the prevention and control of tropical diseases. We represent, educate, and support tropical medicine scientists, physicians, clinicians, researchers, epidemiologists, and other health professionals in this field.

We respectfully request that the Subcommittee provide the following allocations in the fiscal year (FY) 2009 Labor, Health and Human, Services, and Education Appropriations bill to support a comprehensive effort to enhance malaria control programming globally:

- $18 million to the Centers for Disease and Control and Prevention (CDC) for malaria research, control, and program evaluation efforts with a $6 million set-aside for program monitoring and evaluation;
- $31.1 billion to National Institutes of Health (NIH);
- $4.3 billion to the National Institute of Allergy and Infectious Diseases (NIAID); and
- $71 million to the Fogarty International Center (FIC).

We very much appreciate the Subcommittee's consideration of our views, and we stand ready to work with the Subcommittee Members and staff on these and other important global health matters.

ASTMH

ASTMH plays an integral and unique role in the advancement of the field of tropical medicine. Its mission is to promote world health by preventing and controlling tropical diseases through research and education. As such, the Society is the principal membership organization representing, educating, and supporting tropical medicine scientists, physicians, researchers, and other health professionals dedicated to the prevention and control of tropical diseases. Our members reside in 46 states and the District of Columbia and work in a myriad of public, private, and non-profit environments, including academia, the U.S. military, public institutions, federal agencies, private practice, and industry.

The Society's long and distinguished history goes back to the early 20th century. The current organization was formed in 1951 with the amalgamation of the National Malaria Society and the American Society of Tropical Medicine. Over the years, the Society has counted many distinguished scientists among its members, including Nobel laureates. ASTMH and its members continue to have a major impact on the tropical diseases and parasitology research carried out around the world.

ASTMH aims to advance policies and programs that prevent and control those tropical diseases which particularly impact the global poor. ASTMH supports and encourages Congress to expand funding for – and commitments to – national and international malaria control initiatives. As part of this effort, ASTMH recently conducted an analysis of federally funded tropical medicine and disease programs and developed FY 2009 funding requests based on this assessment.

Tropical Medicine and Tropical Diseases

The term "tropical medicine" refers to the wide-ranging clinical work, research, and educational efforts of clinicians, scientists, and public health officials with a focus on the diagnosis, mitigation, prevention, and treatment of diseases prevalent in the areas of the world with a tropical climate. Most tropical diseases are located in either sub-Saharan Africa, parts of Asia (including the Indian subcontinent), or Central and South America. Many of the world's developing nations are located in these areas; thus tropical medicine tends to focus on diseases that impact the world's most impoverished individuals.

The field of tropical medicine encompasses clinical work treating tropical diseases, work in public health and public policy to prevent and control tropical diseases, basic and applied research related to tropical diseases, and education of health professionals and the public regarding tropical diseases.

Tropical diseases are illnesses that are caused by pathogens that are prevalent in areas of the world with a tropical climate. These diseases are caused by viruses, bacteria, and parasites which are spread through various mechanisms, including airborne routes, sexual contact, contaminated water and food, or an intermediary or "vector" – frequently an insect (e.g. a mosquito) – that transmits a disease between humans in the process of feeding.

Malaria

Malaria is a global emergency affecting mostly poor women and children; it is an acute and sometimes fatal disease caused by the single-celled *Plasmodium* parasite that is transmitted to humans by the female *Anopheles* mosquito.

Malaria is highly treatable and preventable. The tragedy is that despite this, malaria is one of the leading causes of death and disease worldwide. According to the CDC, as many as 2.7 million individuals die from malaria each year, with 75 percent of those deaths occurring in African children. In 2002, malaria was the fourth leading cause of death in children in developing countries, causing 10.7 percent of all such deaths. Malaria-related illness and mortality extract a significant human toll as well as cost Africa's economy $12 billion per year perpetuating a cycle of poverty and illness. Nearly 40 percent of the world's population lives in an area that is at high risk for the transmission of malaria.

Fortunately, malaria can be both prevented and treated using four types of relatively low-cost interventions: (1) the indoor residual spraying of insecticide on the walls of homes; (2) long-lasting insecticide-treated nets; (3) Artemisinin-based combination therapies; and (4) intermittent

preventive therapy for pregnant women. However, limited resources preclude the provision of these interventions and treatments to all individuals and communities in need.

Requested Malaria-Related Activities and Funding Levels

CDC Malaria Efforts

ASTMH calls upon Congress to fund a comprehensive approach to malaria control, including adequately funding the important contributions of the CDC. The CDC originally grew out of the WWII "Malaria Control in War Areas" program, and since its founding the Atlanta-based agency has maintained a strong role in efforts to research and mitigate malaria. Although malaria has been eliminated as an endemic threat in the United States for over fifty years, CDC continues to be on the cutting edge of global efforts to reduce the toll of this deadly disease.

CDC efforts on malaria falls into three broad areas – prevention, treatment, and vaccines – and CDC performs a wide range of basic research within these categories. This includes investigations of the biology of host-parasite relationships; immune response to malaria; host genetic factors associated with malaria; parasite genetic diversity and drug resistance; HIV and malaria interaction; the efficacy of insecticide-treated nets in preventing illness and deaths; malaria and pregnancy; public health strategies for improving access to antimalarial treatment and delaying the appearance of antimalarial drug resistance; improved transmission reduction strategies; vaccine development and evaluation; and many other topics.

Although endemic malaria has been eradicated in the United States it remains one of the leading causes of death and disease around the world, and a significant proportion of CDC's malaria-focused work involves working in and with foreign countries to prevent the spread of malaria, and to assist in the treatment of those who have contracted the disease. CDC funding in FY 2008 for global malarial activities is $8.7 million, which includes CDC's contribution to the $1.2 billion President's Malaria Initiative.

CDC participates in several global efforts, including:

- *The President's Malaria Initiative (PMI)* – The PMI is a $1.2 billion, five-year effort led by the U.S. Agency for International Development (USAID) in conjunction with CDC and other government agencies to lower the incidence of malaria in 15 targeted countries in sub-Saharan Africa by 50 percent.
- *Amazon Malaria Initiative (AMI)* – This program works with countries in South America to combat the reemergence of malaria in that part of the world.
- *West Africa Network Against Malaria During Pregnancy* – CDC works with countries in Francophone West Africa to encourage the use of intermittent preventive treatment with sulfadoxine-pyrimethamine (IPTp/SP) to prevent anemia and death in pregnant women and malaria-related low-birthweight in their newborns.
- *Preventing and Controlling Malaria During Pregnancy in Sub-Saharan Africa* – CDC works with many partners to prevent and control malaria among pregnant women and their newborns in sub-Saharan Africa.

- *International Red Cross and the Expanded Program for Immunizations* – CDC works with these groups to implement and evaluate the effectiveness of distributing ITNs during immunization campaigns and during routine vaccine visits.

CDC collaborations support treatment and prevention policy change based on scientific findings; formulation of international recommendations through membership on World Health Organization (WHO) technical committees; and work with Ministries of Health and other local partners in malaria-endemic countries and regions to develop, implement, and evaluate malaria programs. In addition, CDC has provided direct staff support to the WHO; UNICEF; the Global Fund to Fight AIDS, Tuberculosis, and Malaria; and the World Bank – all stakeholders in the Roll Back Malaria (RBM) Partnership.

NIH Malaria Programs

As the nation's and world's premier biomedical research agency, the NIH and its Institutes and Centers play an essential role in the development of new anti-malarial drugs, better diagnostics, and an effective malaria vaccine. NIH estimates that its FY 2007 spending on malaria research will total $101 million while malaria vaccine efforts will receive $45 million. ASTMH urges that NIH malaria research portfolio and budget be increased by at least 6.6% in FY 2009. To support a comprehensive effort to control malaria, ASTMH respectfully requests the following funding:

- $31.1 billion to NIH
- $4.3 billion NIAID
- $71 million to the Fogarty International Center for training that supports U.S. efforts targeting malaria and other neglected tropical diseases.

National Institute of Allergy and Infectious Diseases (NIAID)

Malaria continues to be among the most daunting global public health challenges we face. A long-term investment is needed to achieve the drugs, diagnostics and research capacity needed to control malaria. NIAID, the lead institute for malaria research, plays an important role in developing the drugs and vaccines needed to fight malaria. ASTMH urges the committee to increase NIAID funding so that present malaria research efforts be maintained and new areas explored such as: increasing fundamental understanding of the complex interactions among the malaria parasites, the mosquito vectors responsible for their transmission and the human host; developing new diagnostics, drugs, vaccines, and vector management approaches; and enhancing both national and international research and research training infrastructure to meet malaria research needs.

Fogarty International Center (FIC)

While biomedical research has provided major advances in the treatment and prevention of malaria, these benefits are often slow to reach the people who need them the most. While highly-effective anti-malarial drugs exist and when patients receive these drugs promptly their lives can be saved. FIC plays a critical role in strengthening science and public health research

institutions in low-income countries, specifically in malaria, TB, and neglected tropical diseases. By promoting applied health research in developing countries, the FIC can speed the implementation of new health interventions for malaria, TB, and neglected tropical diseases.

FIC works to strengthen research capacity in countries where populations are particularly vulnerable to threats posed by malaria and neglected tropical diseases. FIC's efforts that strengthen the research workforce in-country – including collaborations with U.S.-supported global health programs – which help to ensure that programs are continuously improved and adapted to local conditions, and that the impact of U.S. investments is maximized, are critical to fighting malaria and other tropical diseases.

The FIC addresses global health challenges and supports the NIH mission through myriad activities, including: collaborative research and capacity building projects relevant to low- and middle-income nations; institutional training grants designed to enhance research capacity in the developing world, with an emphasis on institutional partnerships and networking; the Forum for International Health, through which NIH staff share ideas and information on relevant programs and develop input from an international perspective on cross-cutting NIH initiatives; the Multilateral Initiative on Malaria, which fosters international collaboration and co-operation in scientific research against malaria; and the Disease Control Priorities Project, which is a partnership supported by FIC, The Gates Foundation, the WHO, and the World Bank to develop recommendations on effective health care interventions for resource-poor settings.

ASTMH urges the Subcommittee to allocate additional resources to the FIC in FY2009 to increase these efforts, particularly as they address the control and treatment of malaria.

Conclusion

Thank you for your attention to these important global health matters. We know that you face many challenges in choosing funding priorities and we hope that you will provide the requested FY 2009 resources to those agencies programs identified above. ASTMH appreciates the opportunity to share its views, and we thank you for your consideration of our requests.

National Psoriasis Foundation
Written Testimony to the House Labor-Health and Human Services Appropriations Subcommittee
Regarding Fiscal Year 2009 Psoriasis and Psoriatic Arthritis Research Funding
Submitted by: Pam Field, Acting CEO National Psoriasis Foundation
March 31, 2008

Introduction and Overview

The National Psoriasis Foundation (the Foundation) appreciates the opportunity to submit written testimony for the record regarding federal funding for psoriasis and psoriatic arthritis research for Fiscal Year (FY) 2009. The Foundation serves as the nation's largest patient-driven non-profit voluntary association committed to improving the quality of life for the millions of people affected by psoriasis and psoriatic arthritis.

As part of our mission, we educate health professionals, the public and policymakers to increase public awareness and understanding of the challenges faced by people with psoriasis and psoriatic arthritis. Moreover, the Foundation maintains a strong commitment to securing public policies and programs that support its focus of education, advocacy and research toward better treatments and a cure. The Foundation specifically seeks to advance public and private efforts to improve treatment of these diseases, identify a cure and ensure that all people with psoriasis and psoriatic arthritis have access to the medical care and treatment options they need to live the highest quality of life possible.

The Foundation stands ready to work with policymakers at the local, state and federal levels to advance policies and programs that will reduce and prevent suffering from psoriasis and psoriatic arthritis. Specifically, the Foundation advocates that the National Institutes of Health (NIH) be given additional resources to support new investigator-initiated research grants for genetic, clinical, and basic research related to the understanding of the cellular and molecular mechanisms of psoriasis and psoriatic arthritis, as well as studies to understand co-morbidities such as obesity, depression, and heart disease that may be associated with inflammation in the skin and joints. Specifically, we respectfully call upon Congress to boost psoriasis and psoriatic arthritis research efforts by allocating a 6.6% increase in FY 2009 (to $31.1 billion) to NIH and its institutes and centers that play an integral role in psoriasis and psoriatic arthritis research:

- The National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS);
- The National Institute of Allergy and Infectious Diseases (NIAID);
- The National Human Genome Research Institute (NHGRI);
- The National Institute for Environmental Health Systems (NIEHS);
- The National Institute of Mental Health (NIMH);
- The National Center for Complementary and Alternative Medicine (NCCAM); and
- The National Center for Research Resources (NCRR).

In addition, the Foundation urges the Subcommittee to encourage the Centers for Disease Control and Prevention (CDC) to strengthen patient data collection on psoriasis to improve the knowledge base of the longitudinal impact of these diseases on the individuals they affect. The Foundation believes that a greater investment in NIH, NIAMS, NIAID, NHGRI, NIEHS, NIMH, NCCAM, NCRR, and CDC will lead to the development of new, safe, effective and long-lasting treatments and a cure for psoriasis and psoriatic arthritis.

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March 31, 2008

The Impact of Psoriasis and Psoriatic Arthritis

According to the NIH, as many as 7.5 million Americans have psoriasis – an immune-mediated genetic, chronic, inflammatory, painful, disfiguring, and life-altering disease that requires life-long sophisticated medical intervention and care, and imposes serious adverse effects on the individuals and families affected. On average, 17,000 people with psoriasis live in each Congressional District.

Psoriasis most often first strikes between the ages of 15 and 25 and lasts a lifetime. Unfortunately, psoriasis often is overlooked or dismissed because it typically does not cause death. It is commonly and incorrectly considered by insurers, employers, policymakers, and the public as a mere annoyance – a superficial problem, mistakenly thought to be contagious and/or due to poor hygiene. Yet, together psoriasis and psoriatic arthritis impose significant economic costs on individuals and society. Each year, Americans with psoriasis lose approximately 56 million hours of work and spend $2 billion to $3 billion to treat the disease.

There is mounting evidence that people with psoriasis are at elevated risk for myriad other serious, chronic and life-threatening conditions. Although data are still emerging on the relationship of psoriasis to other diseases and their ensuing costs to the medical system, it is clear that psoriasis goes hand-in-hand with co-morbidities such as Crohn's disease, diabetes, metabolic syndrome, obesity, hypertension, heart attack, cardiovascular disease, liver disease and psoriatic arthritis – which occurs in up to 30 percent of people with psoriasis. Of serious concern is that studies have shown that psoriasis causes as much disability as other major chronic diseases and individuals with psoriasis are twice as likely to have thoughts of suicide as people without psoriasis or with other chronic conditions.

Despite some recent breakthroughs, many people with psoriasis and psoriatic arthritis remain in need of improved quality of life and effective, safe, and affordable therapies, which could be delivered through an increased federal commitment to genetic, clinical and basic research. Research holds the key to improved treatment of these diseases, better diagnosis of psoriatic arthritis and eventually a cure for both conditions.

Federal Psoriasis and Psoriatic Arthritis Research

While our nation has benefited from past federal investment in the NIH, unfortunately psoriasis and psoriatic arthritis research progress has not keep pace with other chronic conditions. An analysis of longitudinal federal funding data shows that, on average over the past decade, NIAMS has spent less than $1 per person with psoriasis per year. At the historical and current rate of psoriasis funding, NIH funding is not keeping pace with research needs.

Meetings and correspondence with NIAMS and other Institutes and Centers at NIH indicates that the three principal agencies involved in psoriasis and psoriatic arthritis research are NIAMS, NCRR and NHGRI, the Foundation knows from meetings at NIH that other federal research agencies – such as NIAID, NIEHS, NIMH, and NCCAM – have important roles to play in psoriasis and

National Psoriasis Foundation
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Submitted by: Pam Field, Acting CEO National Psoriasis Foundation
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psoriatic arthritis and understanding their health and psychosocial impact on affected individuals. The Foundation has joined with the broader health community in advocating $31.1 billion for the NIH in FY 2009. This level of investment will allow NIH to sustain and build on its research progress resulting from the recent NIH budget doubling effort while avoiding the severe disruption to that progress that would result from a minimal increase. More than ever, a greater investment today in psoriasis and psoriatic arthritis will go farther faster and help the nation turn the corner on finding a cure for these two life-altering, disfiguring diseases.

We hope that the Subcommittee will provide all seven of the aforementioned institutes and centers with increased FY 2009 funding specifically, we urge the Subcommittee to provide NIH and the aforementioned institutes and centers with a 6.6% increase in FY 2009 funding and encourage them to undertake and/or expand psoriasis and psoriatic arthritis research so they can undertake the following:

- Make efforts to understand the reasons for the co-morbidities associated with psoriasis and psoriatic arthritis such as obesity, depression, heart disease and heart attack and the interplay between inflammation and such co-morbidities found disproportionately among individuals with psoriasis. Individuals with psoriasis are at elevated risk for other chronic and debilitating health conditions, such as heart attacks and diabetes and the risk of mortality is 50% higher for people with severe psoriasis.
- Conduct research within the Institutes and Centers associated with these co-morbidities with particular focus on biomarkers for psoriasis and psoriatic arthritis and shared molecular pathways with comorbid conditions.
- Support NIAMS in its interest in a strong follow-up study to the Genetic Association Information Network grant. Research is beginning to identify the immune cells involved in psoriasis; this knowledge will help scientists understand which cells or molecular processes should be targeted for more effective treatments and eventually a cure.
- Undertake research relating to genetics, immunology, and animal models relating to psoriasis and psoriatic arthritis.
- Expand basic research including how genetic variation gives rise to differences in treatment responses and mechanisms that link skin and joint inflammation.
- Study the immune cells and inflammatory process as it relates to the pathogenesis of psoriasis.
- Conduct research to better the understanding between psoriasis and mental health, including identifying any underlying biologic reason for mental health issues associated with psoriasis, as well how negative social and psychological effects impact psoriasis. It is estimated as many as 52 percent of psoriasis patients report clinically significant psychiatric symptoms (such as depression) and that individuals with psoriasis are twice as likely to have thoughts of suicide as people without psoriasis or with other chronic conditions.
- Study how environmental triggers interact with different genetic susceptibility factors to better understand psoriasis disease development and response to treatment to provide insight in psoriasis and prevention of psoriasis and psoriatic arthritis.

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- Evaluate of the effectiveness of complementary and alternative therapies for the treatment of psoriasis and/or psoriatic arthritis.

The Role of CDC in Psoriasis and Psoriatic Arthritis Research

The Foundation is concerned that there have been very few efforts to collect epidemiological and other related data on individuals with psoriasis and psoriatic arthritis. Researchers and clinicians continue to be limited in their longitudinal understanding of these conditions and their effects on individual patients. The Foundation hopes that the Subcommittee will encourage the CDC to add psoriasis and psoriatic arthritis specific epidemiological studies where appropriate as part of its research plan. In addition, we ask that the Subcommittee encourage the National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) within the CDC to examine and develop options and recommendations for the creation of a National Psoriasis and Psoriatic Arthritis Patient Registry in FY 2009. A national patient registry that collects longitudinal patient data will help researchers to learn about key attributes such as response to treatment, substantiating the waxing and waning of psoriasis, understanding associated manifestations like nail disease and arthritis, and the relationship of psoriasis to other public health concerns.

Conclusion

On behalf of the Foundation's Board of Trustees and the millions of individuals with psoriasis and psoriatic arthritis who we represent, thank you for this opportunity to submit written testimony regarding the FY 2009 funding levels necessary to ensure that our nation adequately addresses psoriasis and psoriatic arthritis and to make gains in improving therapies and eventually attaining a cure. We thank you in advance for encouraging the CDC and the NCCDPHP to become more engaged in psoriasis and psoriatic arthritis data collection. We believe that additional research undertaken at the NIH coupled with epidemiologic efforts at the CDC together will help advance the nation's efforts to improve treatments and identify a cure for psoriasis and psoriatic arthritis. 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 our requests.

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Friends of the National Institute on Aging
Testimony on FY 2009 National Institutes of Health Appropriations

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

Submitted by:
Mr. Daniel Perry, Alliance for Aging Research, Chair

March 31, 2008

Chairman Obey and members of the Subcommittee, thank you for the opportunity to submit testimony on the important role that the National Institute on Aging (NIA) plays among the National Institutes of Health (NIH) and the urgent need for increased appropriations to advance research supported by the NIA.

The Friends of the NIA is a coalition of 50 academic, patient-centered and not-for-profit organizations that conduct, fund or advocate for scientific endeavors to improve the health and quality of life for Americans as we age. We support the continuation and expansion of NIA research activities and seek to raise awareness about important scientific progress in the area of aging research currently guided by the Institute. Our testimony highlights recent advances resulting from NIA funding, as well as negative consequences that could occur if Congress does not provide sufficient appropriations for NIA research and training activities in FY 2009.

As you know, the NIA leads national research efforts to better understand the nature of aging and to maintain the health and independence of Americans as they grow older. NIA's mission is to support and conduct a range of genetic, biological, clinical, social and economic research related to aging processes and diseases of the aged. One area where this mission is clearly reflected is in the research efforts of NIA investigators aimed at extending an individual's years of healthy life. Projects focused on achieving this goal include studies assessing the beneficial age-related effects of reducing caloric intake in laboratory animals, as well as the testing of compounds in these subjects with the potential to extend the years of disease-free life. Both approaches have produced promising results in a number of animal species, and may lead to insights into potentially beneficial human applications. By capitalizing on such successful studies and the identification of genes that influence longevity, investigators hope to delay the onset of disease and disability associated with human aging.

Many challenges will arise as Americans reach retirement age in increasing numbers. Currently, there are approximately 36 million Americans aged 65 and older. That group is expected to double in size within the next 25 years, at which time at least 20% of the U.S. population will be older than 65. Of particular concern is the dramatic growth that is anticipated among those age 85 and over. By 2050, 19.4 million Americans will be over the age of 85. If rapid discoveries are not made now to reduce the prevalence of debilitating age-related disorders, the health-related costs associated with caring for the oldest and sickest Americans will place an

unmanageable burden on patients, their families, and our fragile health care system. However, with proper investment further advances in the area of longevity science could yield tremendous health and economic benefits by shortening the period during which humans suffer from costly, debilitating diseases.

The single largest driver of healthcare costs in the United States is Alzheimer's disease. The NIA has been a leader in basic, translational, and clinical research focused on facilitating early diagnosis of Alzheimer's disease and developing more effective therapies and strategies for Alzheimer's prevention. NIA-supported research in this area remains focused on efforts to speed delivery of novel Alzheimer's therapies to patients. In FY 2009 the NIA will continue its pre-clinical drug development program and pilot trials initiative, along with a cooperative agreement to conduct new clinical trials through the Alzheimer's Disease Cooperative Study. In addition, the NIA will advance work under the Alzheimer's Disease Neuroimaging Initiative (ADNI), which has provided necessary neuroimaging tools to view disease processes and assist researchers in developing and monitoring emerging treatments. NIA will also continue the Alzheimer's Disease Genetics Initiative (GI), which was established to identify the genes that contribute to the most common form of AD, late-onset. The need for progress in these areas becomes ever more important as the extraordinary costs to patients and families continue to grow.

Medicare spending on beneficiaries with Alzheimer's climbs steadily, reaching more than $189 billion over the next decade. Adequate sustained resources must be provided in order for these programs to one day provide relief to the 5.2 million patients and their families currently living with Alzheimer's. If the onset of Alzheimer's could be delayed by five years, the projected population that is expected to suffer from the disease could be cut in half. If researchers are successful in achieving a modest delay in the rate of aging, health and economic benefits would be achieved that are greater than what would result from the elimination of cancer or heart disease alone. To achieve these powerful results, meaningful investments in aging research must be made now. Scientists are poised to make breakthroughs in the prevention and treatment of a host of age-associated diseases and conditions, but without sufficient funding for aging research, Americans are unlikely to see these breakthroughs occur during their lifetime.

Healthy longevity and Alzheimer's disease are just two of the NIA's important focus areas. Other promising research efforts supported by the NIA include projects to discover new Parkinson's and neurological disease susceptibility genes; to study the environmental risk-factors and genetic predisposition to obesity; and to uncover how the interplay between neurons and inflammatory immune cells can be harnessed to improve stroke outcomes. All of these conditions are prevalent among older adults and take a tremendous toll in health costs and lost quality of life.

Other work of critical importance conducted and funded by the NIA is in the area of behavioral and social science research. The NIA's behavioral and social science research programs have been instrumental in providing essential data on the socioeconomic and demographic implications of an aging population. These data are used by policymakers at all levels of government, including, at the Federal level, the Social Security Administration, Centers for Medicare and Medicaid Services, and Department of State, to inform the development and

evaluation of public policy. Much of the productivity of the BSR program is attributable to researchers supported via its network of research centers, such as the Demography of Aging Centers, Roybal Centers for Applied Gerontology and Resource Centers for Minority Aging Research. The BSR program also supports large, accessible datasets utilized by scientists worldwide. One of the largest datasets, the Health and Retirement Study (HRS), is the leading source of combined data on health and financial circumstances of Americans over age 50 and a valuable resource to follow and predict trends for an aging America. NIA also partners with the U.S. Census Bureau on joint demographic studies of the elderly population and the Federal Forum on Aging, which is composed of 13 federal departments and agencies, and collects, provides, and analyzes aging-related data. Data from these surveys are particularly important for understanding the budgetary impact of population aging. They also help Congress in budgetary considerations of population aging as it deliberates potential changes to public programs such as Social Security, Medicare, and Medicaid. With consistent funding, these surveys can continue to be seminal sources of information on the health and socioeconomic status of older Americans.

In the area of geriatrics and clinical gerontology, the NIA's work this year will be centered on reducing disease and disability among older people. This is critically important because the U.S. spends approximately $26 billion per year on Medicare beneficiaries who lose the ability to remain fully independent. As individuals age, their risk for suffering from many diseases and disabling conditions increases dramatically. NIA's Geriatrics and Clinical Gerontology (GCG) Program examines age-related physical changes and their relationship to health outcomes, the maintenance of health and the development of disease, and specific age-related risk factors for disease. In FY 2009 the NIA plans to initiate studies to determine why the elderly develop dangerous blood clots in their veins and arteries; to continue research increasing understanding of the unidentifiable causes of anemia in the elderly; and to conduct studies in nutrition, weight loss and exercise to measure their role in preventing age-related diseases like heart disease and certain cancers.

Since the end of the NIH's budget doubling in 2003, funding has been on a downward trajectory and many of the areas of research mentioned earlier have been impacted despite prioritization by the NIA. In the five years through 2008, a series of nominal increases and cuts has amounted to flat funding for NIH, and as a result it has lost approximately 11% in purchasing power due to inflation alone. For the NIA specifically, flat budgets are to blame for a 12.9% reduction in constant dollars for the Institute between FY 2003 and FY 2009. To operate in this environment the NIA and other institutes have not been able to fund increasing numbers of high-quality research grants each year. Those that are funded are subject to cost containment policies that decrease the funding level of new grants and reduce the funding level of existing grants. The NIA in particular must implement an 18% cut on average in recommended funding for individual competing grants.

NIH is the primary funder of biomedical research in this country. Approximately 85% of its budget goes to support investigators at universities and medical centers across the U.S. But declining budgets are impeding progress. Because of a scarcity of resources, the overall success rate for NIH research grant applications has fallen from 32% to 24% since 1999. This means that only one in four research proposals can be funded by the NIH and fewer of them are funded on the first submission. The effect of this has been reluctance on behalf of new investigators to submit truly ground-breaking research proposals for consideration. While we recognize that there

is enormous competition for Congressional appropriations each year, we believe that a continued slowdown in funding for the NIH will have a devastating impact on the rate of basic discovery and the development of interventions that could have the significant public health benefits for our aging population.

The Friends of the NIA supports a 6.6 percent increase in funding to $31.1 billion for the NIH in FY 2009. Such an increase would prevent the estimated 3.6 percent loss that the NIH will experience this year without an inflationary increase. This increase would begin to restore the NIH's ability to pursue new basic, translational, and clinical research opportunities. The $31.1 billion would also allow the National Institute on Aging specifically to increase support of new and existing investigator initiated research projects and better facilitate the acceleration of discoveries to prevent, treat, and potentially cure a wide range debilitating age-related diseases and conditions among our growing population of older Americans.

Mr. Chairman, the Friends of the NIA thanks you for this opportunity to outline the challenges and opportunities that lie ahead as you consider the FY 2009 appropriations for the NIH and we would be happy to furnish additional information upon request.

Contact Information

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GENE R. CARTER, EXECUTIVE DIRECTOR

Written Testimony of
Dr. Gene R. Carter
Executive Director/CEO
The Association for Supervision and Curriculum Development (ASCD)
Submitted to the
Committee on Appropriations Subcommittee on Labor, Health & Human Services, Education, and Related Agencies
March 31, 2008

Chairman Obey, Ranking Member Walsh, and Honorable Members of the Subcommittee:

Thank you for the opportunity to share ASCD's priorities for federal funding. My name is Dr. Gene Carter, and I am Executive Director and CEO of the Association for Supervision and Curriculum Development (ASCD).

ASCD is a nonprofit, nonpartisan organization representing 175,000 educators. ASCD members are found in schools throughout this country. They are superintendents, deputy superintendents, principals, teachers, professors of education, and school board members. With the exception of teacher unions, we represent more principals, superintendents, and educational leaders than any singular principal association or school administrator association. Formed in 1943, ASCD advocates for educational excellence and equity. As ASCD has grown in membership, our mission has evolved and expanded to address all aspects of effective teaching and learning—including professional development, educational leadership, capacity building, and effective pedagogy. ASCD membership is driven by best practices in the classroom to provide our children with the skills necessary to compete in the 21st century. We want the best policies to develop and educate the whole child.

ASCD believes that through effective program changes and increased flexibility education can thrive in this country. We also believe that accountability is as critical to education as textbooks. Although the proper accountability framework is a subject of debate, ASCD firmly believes in high standards and effective indicators that demonstrate progress towards those standards. Furthermore, ASCD is unique in that we have not previously submitted testimony to this committee asking for more resources. We have cautioned our membership against simply requesting more money when speaking with their members of Congress. We do not believe money alone will solve the problems facing education. However, we do believe that a lack of money exacerbates the difficulties schools face when preparing our children to succeed in this global economy. We offer the following recommendations for your consideration:

Funding Gaps: Authorization Versus Appropriations
Many in Congress believe legislative authorizations are a guardrail to restrain spending for federal programs. Given the tremendous gap between authorized amounts and the appropriated amounts, especially in Title I and IDEA, the need for such a "guardrail" is not readily apparent. ASCD appreciates that several members of this subcommittee and the full committee decried the

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inadequate funding and put forth tremendous efforts to provide significant education increases for both NCLB and IDEA. Unfortunately, the gap persists, and educators across this country—those charged with implementing and complying with the requirements of NCLB and IDEA—are finding their work seriously impacted by the lack of federal funds.

Looking at three significant and important programs—Title I, Title II, and IDEA—there is a federal funding difference of $19.6 billion between the authorized and appropriated amounts. This gap is exacerbated when combined with an inflation rate of 4.3 percent. In addition, student enrollment is expected to grow by almost 5 percent through 2014, the time frame included in the NCLB legislation. This gap requires schools to find crucial resources through state or local tax increases. Adding further pressure to this situation is the dismal fiscal outlook among the states for the next two years. Eighteen states are projecting budgetary shortfalls totaling $14 billion for FY 08, and 17 states are projecting shortfalls of $31 billion for FY 09—leading to either greater pressure on local taxpayers or drastic reductions in services to children.

We believe that the federal government has an obligation to support our schools and to pay for a larger share of the requirements associated with compliance of federal programs. Although we do not expect to see an increase of $19.6 billion, this funding gap illustrates a fundamental obstacle in the education of children. We urge the members of this committee to consider this situation when developing the funding legislation. We are hopeful this subcommittee will continue the promising support expressed by the House Budget Resolution, which contained a $7.1 billion increase over the President's FY09 discretionary funding request for education, training, and social services programs.

Looking ahead to FY 2009

ASCD urges you to provide the funding levels necessary to educate the whole child. Listed below are several programs we believe will make a substantial difference in helping schools, communities, educators, and policymakers to provide the necessary support and resources to ensure all children are healthy, safe, engaged, supported, and challenged.

Title I

Title I enables schools to better serve the neediest student populations. This program provides critical funds and learning resources to help compensate for the difficulties faced by disadvantaged children. Additional programs and learning materials help students, and schools continue to narrow the achievement gap. However, given increasing costs and growing student populations, funding for Title I has been inadequate. We know that schools are capable of doing much more, but we recognize that they are presently bound by their lack of resources. A significant increase in Title I funding will provide schools the flexibility to use the resources for assisting targeted student populations.

Title II

The correlation between teacher and school leader quality and student success is well documented. ASCD believes funding for Title II Teacher Quality Grants should be significantly higher than in previous years. It is time we begin to provide incentives, including salaries and professional development opportunities that better reflect the importance of teachers and educational leaders. We applaud past efforts by this committee to provide increased funds for

Title II. However, to ensure that our teachers are well prepared to meet growing demands, we must provide the programs and opportunities that enable more professional development opportunities. We also believe effective programs like the Teacher Incentive Fund and other grant programs—enabling schools to offer financial and professional incentives for high-quality educators to serve in high-need areas—is a critically important role that should receive increased funding.

High School Redesign

Our high schools are in crisis. We lose over one million students every year. One student drops out every 30 seconds. Beginning in the middle grades, the signs are clear as to which students are prone to dropping out. Students with low attendance, increasing academic difficulty or a failing grade, and decreasing or minimal engagement with educators all signify a danger of dropping out. Academic difficulty is not the only reason kids drop out; many students leave because they are not challenged or engaged by educators.

Yet, the answers exist. Pockets of successful schools graduate students and prepare them for high achievement in the real world or at advanced educational institutions. These solutions are not cheap. Effective high schools include personalized learning and mentoring to engage students. They have rich and relevant curricula that challenge students. The educators in these schools receive extensive professional development that is innovative and flexible. These high schools are also free to develop alternative scheduling options for fulfilling the Carnegie unit, including the length of the school day and school year. Yet additional resources are needed for many schools to develop and effectively implement these approaches.

Although there may be some hesitancy to invest significant resources now, given the difficult financial situation we face, consider numerous studies that demonstrate the hundreds of billions in dollars lost in productivity, taxes, and wages of high school dropouts. From a societal standpoint, dropouts are also associated with drastically higher medical and health care costs. High school dropouts also have higher incarceration rates. I am happy to share the extensive research on this topic. This committee faces a fundamental question: Do we spend this money now and invest in the future? Or does the country pay for our lack of funding in the future? Fortunately, a dedicated fund for secondary school improvement was unanimously approved as part of the Senate's 2009 Budget Resolution, signaling broad support for this investment. We are hopeful that this amendment remains as part of the final 2009 Budget Resolution. As such, it is our hope that this subcommittee will take the next step by including funding for high school redesign in the legislation.

Community Schools

One of the most cost-effective and innovative approaches to addressing not only educational needs but also the needs of local communities is full-service community schools. Full-service community schools facilitate collaboration among public schools, community-based organizations, and public and private partnerships, resulting in comprehensive educational, social, and health services provided to children and families. This approach does not saddle schools with the financial or service requirements of other agencies; instead these agencies use the school as the site or location to provide the relevant services. Full-service community schools create the school as the hub of the community and the centralized location to provide a

multitude of services by relevant professionals. These schools not only address the health and social needs of many students, but also they provide extensive resources for other community members that achieve broader societal goals, including job training, career counseling, medical assistance, and linkage with social service programs. We request the subcommittee do its part in providing more resources to support these schools and the related services provided.

Children's Heath and Learning

Among the many important choices facing the subcommittee, we encourage you to support those programs like Head Start that provide early childhood access to health services and pre-kindergarten education. Like high schools, the studies are numerous and overwhelming that children's health is an important factor in high academic achievement. The same is true of effective pre-kindergarten programs. If we truly want to close the achievement gap and prepare our children for success in the 21st century, we must provide these critical services.

Conclusion

We recognize that the nation's economy is currently under tremendous strain, and we fully comprehend the need to be fiscally responsible in a time of growing budget deficits and economic downturns. However, ASCD believes important domestic priorities like education are not an expense, but an investment. Our children's education, health, and our teachers' professional development are three of the most proven methods of maintaining our strength and competitiveness in a global economy. It is apparent now more than ever that our funding choices today will lay the foundation for our country's success tomorrow. To ensure that we educate our children and prepare them to be tomorrow's leaders; we need to make the investment in our children and students today.

Thank you again for the opportunity to share ASCD's positions. We look forward to working with you in the coming days to craft sound public policy for the good of our children and our future. Please contact me at 1-703-575-5494 with any questions or concerns. Thank you for your consideration.

STATEMENT OF
HOPE BARTON
DIRECTOR, CENTRAL TECHNICAL SERVICES
UNIVERSITY OF IOWA LIBRARIES

ON BEHALF OF THE
MEDICAL LIBRARY ASSOCIATION
AND THE
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REGARDING FISCAL YEAR 2009 APPROPRIATIONS FOR THE NATIONAL LIBRARY OF MEDICINE

SUBMITTED TO THE
HOUSE COMMITTEE ON APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES

MONDAY, MARCH 31, 2008

SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2009:

1) **A MINIMUM 6.5% FUNDING INCREASE FOR THE NATIONAL INSTITUTES OF HEALTH AND THE NATIONAL LIBRARY OF MEDICINE.**

2) **SUPPORT FOR THE NATIONAL LIBRARY OF MEDICINE'S URGENT FACILITY CONSTRUCTION NEEDS.**

3) **CONTINUED SUPPORT FOR THE MEDICAL LIBRARY COMMUNITY'S ROLE IN THE NATIONAL LIBRARY OF MEDICINE'S OUTREACH, TELEMEDICINE, DISASTER PREPAREDNESS AND HEALTH INFORMATION TECHNOLOGY INITIATIVES.**

On behalf of the Medical Library Association (MLA) and the Association of Academic Health Sciences Libraries (AAHSL), thank you for the opportunity to present testimony regarding fiscal year (FY) 2009 appropriations for the National Library of Medicine (NLM).

MLA is a nonprofit, educational organization with more than 4,500 health sciences information professional members worldwide. Founded in 1898, MLA provides lifelong educational opportunities, supports a knowledgebase of health information research, and works with a global network of partners to promote the importance of quality information for improved health to the health care community and the public.

AAHSL is comprised of the directors of the libraries of 142 accredited American and Canadian medical schools belonging to the Association of American Medical Colleges (AAMC). AAHSL's goals are to promote excellence in academic health sciences libraries and to ensure that the next generation of health professionals is trained in information-seeking skills that enhance the quality of healthcare delivery.

Together, MLA and AAHSL address health information issues and legislative matters of importance through a joint legislative task force and a Government Relations Committee.

As you are aware, recent years of near level-funding at the National Institutes of Health (NIH) has negatively impacted the mission of NLM, as well as many other NIH Institutes and Centers. Consistent with years past, Senators Tom Harkin (D-IA) and Arlen Specter (R-PA) have once again added substantial budget authority for health programs in the Senate's budget resolution. They have also expressed their interest in seeing this recommended infusion of funds translate to an urgently needed 10% funding increase for NIH and NLM as the FY 2009 appropriations process continues. Recognizing current budgetary constraints, MLA and AAHSL are urging this Subcommittee to work with its counterpart in the Senate in pursuing such a substantial and essential funding increase. For FY 2009, MLA and AAHSL are recommending a funding increase of at least 6.5% for NIH and NLM.

A 6.5% funding increase would allow NLM to adequately address 5 key areas that are at the core of its mission. They are: 1) the growing demand for NLM's basic services, 2) NLM's expanding outreach and education services, 3) NLM's role in emergency preparedness and response, 4) NLM's health information technology initiatives and 5) NLM's facility needs.

1) THE GROWING DEMAND FOR THE NLM'S BASIC SERVICES

It is a tribute to NLM that the demand for its services and expertise continues to grow. As the world's foremost digital library and knowledge repository in the health sciences, NLM provides the critical infrastructure in the form of data repositories and integrated services such as GenBank and PubMed that are helping to revolutionize medicine and advance science to the next important era—individualized medicine based on an individual's unique genetic differences.

As the world's largest and most comprehensive medical library, services based on NLM's traditional and electronic collections continue to steadily increase each year.

These collections stand at more than 11.4 million items-books, journals, technical reports, manuscripts, microfilms, photographs and images. By selecting, organizing and ensuring permanent access to health science information in all formats, NLM is ensuring the availability of this information for future generations, making it accessible to all Americans, irrespective of geography or ability to pay, and ensuring that each citizen can make the best, most informed decisions about their healthcare. NLM is a national treasure and support for its programs and services could not be more important at the present time. I can tell you that without NLM our nation's medical libraries would be unable to provide the quality information services that our nation's health professionals, educators, researchers and patients have all come to expect.

2) OUTREACH AND EDUCATION

NLM's outreach programs are of particular interest to both MLA and AAHSL. These activities are designed to educate medical librarians, health professionals and the general public about NLM's services.

NLM has taken a leadership role in promoting educational outreach aimed at public libraries, secondary schools, senior centers and other consumer-based settings. Furthermore, NLM's emphasis on outreach to underserved populations assists the effort to reduce health disparities among large sections of the American public. One example of NLM's leadership is the "Partners in Information Access" program which is designed to improve the access of local public health officials to information needed to prevent, identify and respond to public health threats. With nearly 6,000 members in communities across the country, the National Network of Libraries of Medicine (NNLM) is well positioned to ensure that every public health worker has electronic health information services that can protect the public's health.

Currently at the University of Iowa is the Empowering Public Health/Patient Safety Outreach through Community Partnerships program. This program provides train-the-trainer sessions in local settings to instruct public health educators and community program planners on developing patient safety programming for consumers. University of Iowa Librarians are partnering with health providers to present sessions that will include demonstrations and suggested presentations, along with tips for the development of consumer focused patient safety programming.

With help from the Congress, NLM, NIH and the Friends of NLM, launched NIH MedlinePlus Magazine in September 2006. This quarterly publication is distributed in doctors' waiting rooms, and provides the public with access to high quality, easily understood health information. NLM also continues to work with medical librarians and health professionals to encourage doctors to provide MedlinePlus "information prescriptions" to their patients. This initiative also encourages genetics counselors to prescribe the use of NLM's Genetic Home Reference website.

"Go Local" is another exciting feature of MedlinePlus that enables local and state agencies and others to participate by creating sites that link the MedlinePlus information seeker to local pharmacies, doctors and other health and social services. This service further enhances the value of NLM and MedlinePlus, not just for medical librarians and health professionals, but also for health consumers. It also provides a platform for

enhancing public access to the information needed to prepare for and respond to disasters and emergencies. For example, University of Iowa librarians have begun a project to link MedlinePlus health topic pages to local health resources by geographic areas, including hospitals, physicians, nursing homes, support groups, health screening providers and many others. This will allow health consumers to link directly from a health topic, for example asthma, to local services such as clinics, pulmonary specialists, and support groups in the geographic area selected.

Yet another service is NLM's clinical trials database, which was launched in February of 2000, and lists more than 53,000 U.S. and international trials for a wide range of diseases. The clinical trials database is a free and invaluable resource to patients and families who are interested in participating in cutting-edge treatments for serious illnesses. Last September, the Congress took a major step to improve the transparency of clinical trials for drugs and devices by passing legislation that greatly expands mandatory registration of clinical trials in ClinicalTrials.gov, requires submission of summary trial results data for the first time, and imposes significant penalties for non-compliance. NLM moved quickly to modify ClinicalTrials.gov to accommodate the expanded registration requirements and is working with others at NIH, FDA, and the Office of the Secretary of HHS to implement the other clinical trials reporting provisions.

MLA and AAHSL thank the Congress for their efforts to improve public access to information about the results of clinical trials, but we are concerned that no additional funds have been appropriated to support this major new NLM responsibility.

MLA and AAHSL applaud the success of NLM's outreach initiatives, particularly those initiatives that reach out to medical libraries and health consumers. We ask the Committee to encourage NLM to continue to coordinate its outreach activities with the medical library community in FY 2009.

3) EMERGENCY PREPAREDNESS AND RESPONSE

MLA and AAHSL are pleased that NLM has established a Disaster Information Management Research Center to expand NLM's capacity to support disaster response and management initiatives, as recommended in the *NLM Board of Regents Long Range Plan for 2006-2016*, we ask the Subcommittee to show its support for this initiative, which has a major objective ensuring continuous access to health information and effective use of libraries and librarians when disasters occur. Following Hurricane Katrina, NLM worked with health sciences libraries across the country to provide health professionals and the public with access to needed health and environmental information by: 1) quickly compiling web pages on toxic chemicals and environmental concerns, 2) rapidly providing funds, computers and communication services to assist librarians in the field who were restoring health information services to displaced clinicians and patients and 3) rerouting interlibrary loan requests from the afflicted regions through the National Network of Libraries of Medicine. Libraries are a significant, but underutilized resource for community disaster planning and management efforts, which NLM can help to deploy.

4) HEALTH INFORMATION TECHNOLOGY AND BIOINFORMATICS

NLM has played a pivotal role in creating and nurturing the field of medical informatics, most notably through the creation of GenBank and a wide array of related scientific data and analysis tools which provide critical infrastructure for the nation's researchers. This critical infrastructure will be key to advances in medicine in the future.

For nearly 35 years, NLM has supported informatics research and training and the application of advanced computing and informatics to biomedical research and healthcare delivery including a variety of telemedicine projects. Many of today's informatics leaders are graduates of NLM-funded informatics research programs at universities across the country. Many of the country's exemplary electronic health record systems benefited from NLM grant support.

A leader in supporting, licensing, developing and disseminating standard clinical terminologies for free US-wide use (e.g., SNOMED), NLM works closely with the Office of the National Coordinator for Health Information Technology (ONCHIT) to promote the adoption of interoperable electronic records.

MLA and AAHSL encourage the Subcommittee to continue their strong support of NLM's medical informatics and genomic science initiatives, at a point when the linking of clinical and genetic data holds increasing promise for enhancing the diagnosis and treatment of disease. MLA and AAHSL also supporting health information technology initiatives in ONCHIT and the Agency for Healthcare Research and Quality (AHRQ) that build upon initiatives housed at NLM.

5) NLM'S FACILITIES NEEDS

Over the past two decades NLM has assumed many new responsibilities, particularly in the areas of biotechnology, health services research, and high performance computing and consumer health. As a result, NLM has had tremendous growth in its basic functions related to the acquisition, organization and preservation of an ever-expanding collection of biomedical literature and expanded staff. NLM now houses 1,100 staff in a facility built to accommodate only 650. This increase in the volume of biomedical information and in the number of personnel has led to a serious space shortage. Digital archiving–once thought to be a solution to the problem of housing physical collections–has only added to the challenge, as materials must often be stored in multiple formats and as new digital resources consume increasing amounts of storage space. As a result, the space needed for computing facilities has also grown, further squeezing out staff. In order for NLM to continue its mission as the world's premier biomedical library, a new facility is urgently needed. The NLM Board of Regents has assigned the highest priority to supporting the acquisition of a new facility. Further, Senate Report 108-345 that accompanied the FY 2005 appropriations bill acknowledged that the design for the new research facility at NLM had been completed, and the Committee urged NIH to assign a high priority to this construction project so that the information-handling capabilities and the good of biomedical research are not jeopardized.

MLA and AAHSL encourage the Subcommittee to provide the resources necessary to construct a new facility for NLM.

Thank you for the opportunity to present the views of the medical library community.

Testimony of Daniel Paul Perez, President & CEO of the FSH Society before the Subcommittee on Labor, Health and Human Services, Education and Related Agencies on the Subject of FY2009 Appropriations for National Institutes of Health (NIH) Research on Facioscapulohumeral Muscular Dystrophy (FSHD)
March 20, 2008

Mr. Chairman, thank you for the opportunity to testify.

I am here to remind you that muscular dystrophy (MD) is still taking its toll. As a patient with facioscapulohumeral muscular dystrophy (FSHD), I have experienced the constant loss of function this disease leaves in its wake.

We request this year in FY2009, help for those of us coping with and dying from MD and FSHD, as we did in FY2008. **Specifically we ask that Congress and the Appropriations Subcommittee on Labor, HHS, Education and Related Agencies consider:**

1. Resuming the five year doubling of the National Institutes of Health (NIH) budget. Over the past year the research funding situation has gone from bad to worse and we have lost opportunities to fund excellent research.

2. Appropriating $80 million to MD research at the NIH in FY2009 and steadily increasing this amount to at least $125 million annually over the next five years.

3. Making NIH funding comprehensive for basic research in each of the nine types of MD as well as creating an equitable distribution for each MD across the Senator Paul Wellstone Cooperative Research Centers network, program projects, clinical research, and translational research programs.

Last year, the Honorable Chairman Rep. David Obey asked us to go back to the districts and tell fellow citizens that many of these programs cannot be funded due to the current tax cuts. Five years prior, I testified before this same committee and the exact same thing was said. Given the extent of my physical disability and the Herculean effort it takes me to be present, I personally found this advice very painful. It is irresponsible of Congress to ask those of us who are sick and dying to compensate for the actions of the Congress and the Administration. It simply is not right for Congress to put the burden back on the shoulders of those with disability, disease and little means to effect decisions made by the Congress. Let me be on record that the Boston Globe did an interview with us and ran a story on our testimony and on Mr. Obey's request to us to help get his message out. We have done what you requested of us.

Our first request calls for increasing the NIH budget and resuming the five year doubling. The wars in Iraq, Afghanistan, tax cuts and the turmoil in the financial markets have essentially halted any progress in biomedical research. We all know that America has fallen far behind in biomedical research funding. As a person with a disease it is hard to reconcile the generosity of the Congress towards the wars, tax cuts to the wealthy, and bailing out institutions that have put us all at financial risk, against the lack of action on behalf of sick and dying citizens. The NIH budget at $29.2 billion is a miniscule fraction of these other expenses. Doubling a tiny fraction is still a tiny fraction. For those in Congress who ask the NIH where are the cures – consider that the NIH budget of $29.2 billion covering countless thousands and thousands of diseases is a fraction of the market capitalization of a large pharmaceutical company covering a few disease areas. Consider also that the main job of NIH is basic science, not drug development, and that the pharmaceutical companies, the American public and people

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.

throughout the world benefit directly from the NIH investment in science. Please act now to refocus spending on American infrastructure before trust and confidence is lost.

Our second request calls for NIH to build and grow its MD disease area funding to a level commensurate with diseases of similar burden. A wide disparity still exists in funding for MD. This is a matter for both Appropriations and for the NIH, with its wide discretion on funding for diseases. More funding would help balance out these disparities and accelerate treatments and cures for diseases. We request that the Director of the NIH consider a more commensurate and equitable amount for MD that is solidly in line with its disease peers at $80 to $125 million.

Our third request asks the Appropriations Committee to request that the Director of NIH increase the amount of FSHD research and projects in its portfolios using all available mechanisms and interagency committees. Given the knowledge base and current opportunity for breakthroughs in treating FSHD it is inequitable that only two of the twelve NIH institutes covering muscular dystrophy have a handful of research grants for FSHD and that FSHD research is virtually non-existent in the Senator Paul Wellstone MD Cooperative Research Centers (CRCs). This funding should include projects from NIH roadmap, extramural programs, intramural programs, Senator Paul Wellstone MD CRCs and similar program projects that have a major focus on FSHD.

FSHD is the second most prevalent adult muscular dystrophy. The incidence of the disease is conservatively estimated to be 1 in 20,000. The prevalence of the disease, those living with the disease ranges from 15,000 to 40,000 Americans based on our increasing experiences with the disease and accurate diagnostic tests. For men, women, and children the major consequence of inheriting FSHD is a lifelong progressive and severe loss of all skeletal muscles. FSHD is a terrible, crippling and life shortening disease. It is genetically transmitted to children and it affects entire family constellations.

The Appropriations Committee is no stranger to asking the National Institutes of Health (NIH) for more research on facioscapulohumeral muscular dystrophy (FSHD). More than eight years ago, on February 15, 2000 the House Appropriations Committee questioned Dr. Ruth Kirschstein, then the Director of NIH, on why FSHD research has been slow to develop. In addition, Dr. Gerald Fischbach, then the Director of the National Institute of Neurological Disorders and Stroke (NINDS), was asked to respond to questions about the NIH non-response to developing FSHD on February 29, 2000. This inquiry followed a period of five or six years of miniscule growth in FSHD research portfolios at the NIH.

In late 2000, we shifted our efforts to the authorization track. It was an honor, then, to help the late Senator Paul Wellstone rewrite portions of the Muscular Dystrophy Community Assistance, Research and Education Amendments of 2001 (the MD-CARE Act, Public Law 107-84) to include all nine types of muscular dystrophy, including women, adults and not just children with Duchenne muscular dystrophy (DMD). We also added patient representative and input at the inter agency level via the Muscular Dystrophy Coordinating Committee (MDCC) advisory committee. The MD-CARE Act was passed mandating the NIH and other applicable federal agencies to immediately expand and intensify research on each form of muscular dystrophy.

How is facioscapulohumeral muscular dystrophy (FSHD) research at NIH doing in 2008, seven years after the MD CARE Act 2001 was passed, and, fifteen years after our first testimony in person before the late Representative Natcher, a former Chairman of this honorable Committee?

We applaud Dr. Story Landis, Director, National Institute of Neurological Disorders and Stroke (NINDS), and, Chairman of the MDCC; Dr. Stephen Katz, Director, National Institute of Arthritis and Musculoskeletal Disorders (NIAMS) and past-Chairman of the MDCC; Dr. John Porter, Program Director Muscular Dystrophy, NINDS and Executive Secretary of the MDCC, and; Dr. Glen Nuckolls, Program Director Muscular Dystrophy, NIAMS for their extraordinary comprehension, insight, accuracy and speed with which the NIH Action Plan for Muscular Dystrophy was researched, compiled, written, and approved. The NIH is making significant investments to understand muscular dystrophy research needs and has made excellent choices in recruiting program staff with the ability to understand the extremely complex nature of MD.

Between fiscal year 2006 and 2007, NIH overall funding for muscular dystrophy increased from $39,913,000 to $47,179,000, an 18 percent increase. Figures from the NIH Appropriations History for Muscular Dystrophy show that from the inception of the MD CARE Act funding has doubled for muscular dystrophy.

Between fiscal year 2006 and 2007, NIH funding for facioscapulohumeral muscular dystrophy (FSHD) increased from $1,732,655 to 4,108,555. In fiscal 2007, FSHD was 8.7% of the total muscular dystrophy funding ($4.109M / $47.179M).

National Institutes of Health (NIH) Appropriations History
Source: NIH/OD Budget Office & NIH OCPL (Dollars in millions)

Fiscal Year	NIH Overall Dollars	MD Research Dollars	FSHD Research Dollars	FSHD % of MD
2000	$17,821	$12.6	$0.4	3%
2001	$20,458	$21.0	$0.5	2%
2002	$23,296	$27.6	$1.3	5%
2003	$27,067	$39.1	$1.5	4%
2004	$27,887	$38.7	$2.2	6%
2005	$28,494	$39.5	$2.0	5%
2006	$28,587	$39.913	$1.7	4%
2007	$28,899	$47,179	$4.109	8.7%
2008	$29,230Est	$47,221Est	-	-

FSHD is the second most prevalent adult muscular dystrophy after myotonic muscular dystrophy (DM). We are very concerned about the wide disparity in funding between the most widely recognized pediatric muscular dystrophy (DMD) and the entire group of the other eight types of MD. DMD has exclusive funding from the Centers for Disease Control (CDC), Department of Defense (DoD) and more than half (>50%) of NIH funding for MD. This is astounding considering FSHD and DM are each more prevalent than DMD and each received 5% and 15% respectively of total MD dollars as last reported by the NIH to Congress!

Between 2006 and 2007, the NINDS became the lead institute for funding in MD. Historically, the NIAMS in its mission statement has been primarily responsible for and has been the lead institute for muscle disease research. The Center for Scientific Review (CSR) routes the majority of MD grant applications to NIAMS based on its mission. In fiscal year 2007, NIAMS was the second largest contributor, followed by NICHD as third, and NHLBI as fourth. It should be concerning that muscular dystrophy spending has declined significantly in several key institutes that could bring tremendous impact to these devastating diseases.

National Institutes of Health (NIH) Muscular Dystrophy Funding by Institute FY2007
Source: NIH/OD Budget Office (Dollars in millions)

Participating ICs	FY 2006 Actual	FY 2007 Actual	Change
NINDS	12.697	19.347	+51.6%
NIAMS	16.576	17.734	+7%
NICHD	4.818	4.591	-4.7%
NHLBI	2.270	2.458	+8.3%
NIA	1.865	1.882	+0.9%
NCRR	0.770	0.679	-11.8%
NCI	0.495	0.426	-13.9%
NHGRI	0.391	0.161	-58.8%
NINR	0.031	-	-
NEI, NIMH, FIC, OD	0.0	0.0	0%

NINDS: In fy2007, NINDS spent $2,612,994 on FSHD and $19,247,940 on MD. 47 projects, including Wellstone CRC components for a total of $19,247,940 were funded. FSHD was 13.6 percent of NINDS MD funding. The NINDS funded, for FSHD, three research grants, one research fellowship, one research contract, one-quarter of a Wellstone MDCRC center and one-half of a Translational Research Center research grant for a total of six projects. NINDS funding for FSHD went up by $1,191,398 or 83.8%. Total funding for MD by NINDS increased over the year by $6,551,266 or 51.6%.

NIAMS: In fy2007, NIAMS spent $1,495,561 on FSHD and $17,734,317 on MD. This comprises 89 projects, including Wellstone MDCRC components for a total of $17,734,317. FSHD was 8.4 percent of NIAMS MD funding. The NIAMS funded, for FSHD, four research grants, one research contract, 2% of a Translational Research Center for a total of six projects. NIAMS funding for FSHD went up by $1,184,502 or 381%. Total funding for MD by NIAMS increased over the year by $1,158,000 or 7%.

NICHD: In fy2007, NICHD spent $0 on FSHD and of $4,591,826 on all MD. 17 projects, including three Wellstone MDCRC centers were funded. FSHD was zero percent of NICHD MD. Total funding for FSHD by NICHD was $0. Total funding for MD by NICHD decreased over the previous year by $225,756 or 4.7%.

NHLBI: In fy2007, NHLBI spent $0 on FSHD and $2.458 million on MD. FSHD was zero percent of NHLBI fy2007 MD funding. Total funding for FSHD by NHLBI remained at zero dollars. This should be of grave concern as respiratory insufficiency and failure is becoming increasingly recognized as a cause of poor quality of life and, even more significantly, of death in FSHD.

The MD CARE Act 2001 mandates the Director to intensify efforts and research in the muscular dystrophies, including FSHD, across the entire NIH. It should be very concerning that only two of the institutes at the NIH are funding FSHD. NICHD, NHLBI, NHGRI, NCI and NCRR are all aware of the high impact each could have on FSHD. FSHD is certainly still far behind when we look at the breadth of research coverage NIH-wide.

Centers of excellence -- Wellstone MD Cooperative Research Centers (MDCRCs, U54s) are mandated by the MD CARE Act and, to date, have not been established to cover each of the nine types of MD. There is an inequitable distribution of each of the muscular dystrophies across the Wellstone centers with almost two-thirds of the entire center network, four out of six centers, focusing on DMD. FSHD has about a five (5) percent share of the entire current Wellstone centers

portfolio. Today, the NIH has six Wellstone centers, but they have almost no presence for FSHD, and nothing at all for related dystrophies such as Emery-Dreifuss Muscular Dystrophy (EDMD) and Oculopharyngeal muscular dystrophy (OPMD).

I am here once again to remind you that FSHD is taking its toll on your citizens. FSHD illustrates the disparity in funding across the muscular dystrophies and recalcitrance in growth over twenty years despite consistent pressure from appropriations language and Appropriations Committee questions, and an authorization from Congress mandating research on FSHD.

We request that Congress resume the doubling of NIH funding every five years. Under the current budget, research funding percentiles have reached the top tenth percentile and higher. With funding pay lines at ten percent, plus or minus a few percent, excellent research proposals are going unfunded. We request that the Appropriations Committee to act now to restore the lifeline to biomedical research in the United States to avoid an accelerated loss of researchers and clinicians.

We request that $80 million to $125 million annually be appropriated for MD. We all know that for a disease area to grow -- grant applications must be received and grant applications must be funded. The majority of growth in any disease area at the NIH is obtained through unsolicited applications. In the widest sense, in order for NIH to increase the MD portfolio across the missions of applicable and participating institutes more funding is needed for the NIH. We request the Appropriations Committee help increase the number of unsolicited FSHD and MD grants awarded by lowering the pay lines with an increase in the overall pool of funds NIH works with.

We have learned from experience that the FSH Society as a volunteer health agency and the patients it represents serve a vital function in developing research. We develop an area of research to a point where the NIH could then push the research to much greater heights. The FSH Society has invested over $2 million in the last nine years into nearly seventy post-doctoral and research fellowships and grants. In the last two years, our understanding of how FSHD mechanistically works has dramatically increased. This, in turn, allows researchers to fill the gaps between mechanistic knowledge to translational research to clinical trials. This knowledge has dramatically increased thanks to the efforts of patients, the FSH Society, researchers, clinicians and the NIH. Investments from small non-profits like the FSH Society have allowed the global funding and initiation of novel challenging and promising research in FSHD. Two of the three research projects funded by NINDS are past FSH Society research fellows (5-R01-NS048859-04 M. Ehrlich, 5-R01-NS047584-05 R.G. Tupler). Three of the four research projects funded by NIAMS are past FSH Society research fellows (1-R01-AR-52027-01-A2 Y.W. Chen, 1-R01-AR-56129-01-A2 R.G. Tupler, 1-R21-AR-55876-01 S. van der Maarel) and the fourth project came from FSH Society patient networking activities (1-R01-AR-55877-01 P.L. Jones).

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

Thanks to your efforts and the efforts of your Committee, Mr. Chairman, the Congress, the NIH and the FSH Society are all working to promote progress in facioscapulohumeral muscular dystrophy. We are pleased to see FSHD funding from the NIH and federal research agencies gaining traction. FSHD funding is just now beginning to grow. Our successes are just beginning and your support must continue and increase.

We ask you to fund biomedical research, fund NIH, fund MD, and fund FSHD.

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.

TESTIMONY TO

HOUSE LABOR, HEALTH & HUMAN SERVICES, EDUCATION AND RELATED AGENCIES APPROPRIATIONS SUBCOMMITTEE

SUBMITTED BY

MEIR KRYGER, MD, FRCPC
CHAIRMAN, BOARD OF DIRECTORS
NATIONAL SLEEP FOUNDATION
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REGARDING

FISCAL YEAR 2009 FUNDING FOR THE DEPARTMENT OF HEALTH AND HUMAN SERVICES

MARCH 31, 2008

SUMMARY OF FY 2009 RECOMMENDATIONS

- Provide $11 million in funding for sleep activities within the Community Health Promotion account within the Chronic Disease Program at the Centers for Disease Control and Prevention (CDC). Expanded funding for sleep and sleep disorder-related activities would allow the CDC to create education and training materials for current and future health professionals; build and test public health interventions; expand surveillance and epidemiological activities; create fellowship and research opportunities; and enhance public awareness and education.

- Encourage CDC to continue to take a leadership role in partnering with other federal agencies and voluntary health organizations in the National Sleep Awareness Roundtable to create collaborative sleep education and public awareness initiatives. In view of CDC's success with similar initiatives, encourage the CDC to financially support the Roundtable and its initiatives.

Mr. Chairman and members of the Subcommittee, thank you for allowing me to submit testimony on behalf of the National Sleep Foundation (NSF). I am Dr. Meir Kryger, Chairman of the NSF Board of Directors and Director of Sleep Medicine Research and Education, Gaylord Hospital, Wallingford, Connecticut. NSF is an independent, non-profit organization that is dedicated to improving public health and safety by achieving understanding of sleep and sleep disorders, and by supporting sleep-related education, research, and advocacy. We work with sleep medicine and other health care professionals, researchers, patients and drowsy driving victims throughout the country as well as collaborate with many government, public and private organizations with the goal of preventing health and safety problems related to sleep deprivation and untreated sleep disorders.

Sleep problems, whether in the form of medical disorders or related to work schedules and a 24/7 lifestyle, are ubiquitous in our society. It is estimated that sleep-related problems affect 50 to 70 million Americans of all ages and socioeconomic classes. Sleep disorders are common in both men and women; however, important disparities in prevalence and severity of certain sleep disorders have been identified in minorities and underserved populations. Despite the high prevalence of sleep disorders, the overwhelming majority of sufferers remain undiagnosed and untreated, creating unnecessary public health and safety problems, as well as increased health care expenses. Surveys conducted by NSF show that more than 60 percent of adults have never been asked about the quality of their sleep by a physician, and fewer than 20 percent have ever initiated such a discussion.

Additionally, Americans are chronically sleep deprived as a result of demanding lifestyles and a lack of education about the impact of sleep loss. Sleepiness affects vigilance, reaction times, learning abilities, alertness, mood, hand-eye coordination, and the accuracy of short-term memory. Sleepiness, as a result of untreated disorders or sleep deprivation, has been identified as the cause of a growing number of on-the-job accidents and automobile crashes.

According to the National Highway Traffic Safety Administration's *2002 National Survey of Distracted and Drowsy Driving Attitudes and Behaviors*, an estimated 1.35 million drivers have been involved in a drowsy driving crash in the past five years. According to NSF's 2008 *Sleep in America* poll, 64% of respondents report that they have driven drowsy at least once in the past year. In fact, 32% say they drive drowsy once a month or more! A large number of academic studies have linked work accidents, absenteeism, and poor school performance to sleep deprivation and circadian effects.

The 2006 Institute of Medicine (IOM) report, *Sleep Disorders and Sleep Deprivation: An Unmet Public Health Problem,* found the cumulative effects of sleep loss and sleep disorders represent an under-recognized public health problem and have been associated with a wide range of negative health consequences, including hypertension, diabetes, depression, heart attack, stroke, and at-risk behaviors such as alcohol and drug abuse – all of which represent long-term targets of the Department of Health and Human Services (HHS) and other public health agencies. Moreover, the personal and national economic impact is staggering. The IOM estimates that the direct and indirect costs associated with sleep disorders and sleep deprivation total hundreds of billions of dollars annually.

Sleep science and government reports have clearly demonstrated the importance of sleep to health, safety, productivity and well-being, yet studies continue to show that millions of Americans are at risk for serious health and safety consequences of untreated sleep disorders and inadequate sleep. Unfortunately, despite recommendations in numerous federal reports, there are no on-going national educational programs regarding sleep and fatigue issues aimed at the general public, health care professional, underserved communities or at-risk groups.

NSF believes that every American needs to understand that good health includes healthy sleep, just as it includes regular exercise and balanced nutrition. We must elevate sleep to the top of the national health agenda. We need your help to make this happen.

Our biggest challenge is bridging the gap between the outstanding scientific advances we have seen in recent years and the level of knowledge about sleep held by health care practitioners, educators, employers, and the general public. Because resources are limited and the challenges great, we think creative and new partnerships are needed to fully develop sleep awareness, education, and training initiatives. Consequently, the NSF is spearheading two important initiatives to raise public and physician awareness of the importance of sleep to the health, safety and well-being of the nation.

First, for the last four years, Congress has recommended that the CDC support activities related to sleep and sleep disorders. As a result, CDC's National Center for Chronic Disease Prevention and Health Promotion has been collaborating with more than twenty voluntary organizations and federal agencies to form the National Sleep Awareness Roundtable (NSART), which was officially launched in March of 2007. NSART is currently working to develop a National Action Plan. This document will address what is required to organize a successful collaboration to implement effective public and professional awareness and education initiatives to improve sleep literacy and healthy sleep behaviors. NSART is seeking to expand its membership by reaching out to new organizations and state and federal agencies that are interested in raising awareness of sleep issues and implementing NSART's National Action Plan.

In FY 2008, Congress provided $818,000 for activities related to sleep and sleep disorders, including CDC's participation in NSART and incorporating questions on sleep and sleep-related disturbances into established CDC surveillance systems. The President's FY 2009 budget request currently includes $818,000 for these programs.

With FY 2008 funding, CDC plans to provide grants to at least 15 states to include several sleep questions in their data collection through the Behavioral Risk Factor Surveillance System. CDC also plans to include one core sleep question in its national data collection efforts. This new data will provide important information on the prevalence of sleep disorders and enable researchers to better address the complex interrelationship between sleep loss and comorbid conditions such as obesity, diabetes, depression, hypertension, and drug and alcohol abuse.

CDC also plans to provide support for the goals and activities of the National Sleep Awareness Roundtable.

Although the CDC has taken initial steps to begin to consider how sleep affects public health issues, the agency needs additional resources to take appropriate actions, as recommended by the IOM and other governmental reports.

Expanded funding for sleep and sleep disorder-related activities would allow the Center to create education and training materials for current and future health professionals; build and test public health interventions; expand surveillance and epidemiological activities; create fellowships and research opportunities at state universities; and enhance public awareness and education on sleep and sleep disorders. The following are detailed scenarios for various funding levels.

- **$2 million:**
  - **Expand Surveillance on BRFSS**. CDC could double the number of grants it provides to states to use the optional sleep module and include more core questions in the nationwide data collection through the Behavioral Risk Factor Surveillance System (BRFSS). CDC would also expand its participation in and funding of the goals and activities of the National Sleep Awareness Roundtable.

- **$5 million** – All activities detailed in the $2 million scenario, plus:
  - **Public Education.** CDC could support the development of public education and awareness initiatives that use targeted approaches for delivering sleep-related messages.
  - **Training Materials.** Tools could be developed for current and future health professionals to increase the diagnosis and treatment of sleep disorders. Today, most health care professionals receive no such training, which increases the nation's health burden.

- **$11 million** – All activities detailed in the $5 million scenario, plus:
  - **Initiate Surveillance on YRBSS.** CDC could implement questions on the Youth Risk Behavior Surveillance System (YRBSS). This will further build the evidence base for the prevalence of sleep-related conditions that commonly afflict the American population, such as obstructive sleep apnea, in addition to increasing data collection on sleep-related practices and public awareness of their importance across the life stages.
  - **Fellowship and Research Opportunities.** Additional funding would also allow the CDC to support the development of targeted approaches for delivering sleep-related messages and increasing public education and awareness on this important issue. Fellowship opportunities could be increased to attract promising researchers into the field of sleep epidemiology.

NSF and members of the National Sleep Awareness Roundtable believe that a partnership with CDC is critical to address the public health impact of sleep and sleep disorders. We ask that the Committee encourage CDC to continue to take a leadership role in partnering with other federal agencies and voluntary health organizations in the National Sleep Awareness Roundtable to create collaborative sleep education and public awareness initiatives. We hope that the Committee will provide funding of $11,000,000 to the CDC to execute programs as outlined here

and to financially support efforts developed by NSART through a cooperative agreement similar to other roundtables in which CDC participates.

Thank you again for the opportunity to present you with this testimony.

TESTIMONY OF THE PENNSYLVANIA ASSOCIATION OF WORKFORCE INVESTMENT BOARDS

TO THE

U.S. HOUSE APPROPRIATIONS COMMITTEE SUBCOMMITTEE ON LABOR, HEALTH & HUMAN SERVICES, EDUCATION AND RELATED AGENCIES

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Introduction

The Pennsylvania Association of Workforce Investment Boards (WIBs), comprised of all 22 local workforce investment boards in the Commonwealth of Pennsylvania, is seriously concerned about the reduced levels of funding for workforce development services proposed in the Administration's Fiscal Year 2009 Budget request.

We believe the President's request does not adequately recognize the negative impact of the steady and cumulative reductions in funding already imposed over the last 6-7 years. It does not demonstrate any understanding of the actual on-the-ground relationships between Workforce Investment Act (WIA) and Wagner-Peyser Act (Employment Service) services in the context of the nation's One Stop systems. It ignores the critical role of local workforce investment boards in building partnerships to maximize resources, and it does not recognize the changing nature of the labor market and the skill sets workers need to succeed and companies need to remain competitive in a global economy. It certainly does not anticipate the economic conditions we are likely to face in the next 3-5 years.

Where We Are

Every year for the past six years, funding for WIA and Wagner-Peyser programs has been reduced. Those reductions have, of course, been accompanied each year by admittedly modest but nevertheless ultimately significant cost inflation for personnel wages and benefits, facilities, technology, education and training, and for all the things that generally increase the cost of doing business. At the same time, we have been strongly encouraged to spend down even

fiscally responsible amounts of "carryover" funds to dispel the mistaken notion that there were "excess" monies in the system.

We are now at the point, as with the classic story of placing a frog into a very slowly heating pot of water, where the workforce development system has discovered it is being "parboiled". More reductions at this time will be disastrous for the nation's employment and training system.

WIA funding has now declined by 30 percent since 2002, not even taking into account the effect of inflation. The President's Fiscal Year 2009 budget proposal would make another $484 million cut in WIA while simultaneously eliminating $703 million (100 percent) from Wagner-Peyser, on top of a $250 million rescission of funds that the system has yet to absorb.

Cuts of that magnitude cannot be made without severely reducing services, capacity and effectiveness, and that is what we are facing now. This is no longer alarmists crying, "The sky is falling". It just hit us on the head, and at the worst possible time.

What Local WIBs Are Facing

The situation is already tenuous. Even during the current 2007-08 Program Year, more than half of the local WIBs in Pennsylvania have reported to our Association that they have made significant reductions in services and/or cuts in staffing levels. Wagner-Peyser funded positions have also declined, with positions becoming vacant through retirements and not being refilled. Staff in these positions assist individuals in finding employment and help businesses recruit and hire qualified workers. Our total WIA funding for Pennsylvania in PY 2007 was cut by nearly 12 percent from the previous year, and the recently announced allotments to states for PY 2008 indicate an additional cut to Pennsylvania of nearly 9 percent.

As mentioned above, these reductions have already adversely impacted services. Access to WIA-funded training has been severely reduced; employment preparation and school retention programs for economically disadvantaged youth have been, in many cases, discontinued; fewer staff are available to provide services in the one-stops (known as "PA CareerLinks"); and the cycle perpetuates itself. As there are fewer staff to conduct outreach to businesses or service employers' accounts, job orders from employers decrease.

The effect is also felt directly by our PA CareerLinks. The "mandated partners" envisioned by the Workforce Investment Act have never met the expectations of the law and have not been pressed to do so by their funding sources. A very disproportionate share of the financial burden of operating one-stops has been borne by WIA and Wagner-Peyser, and only the close coordination and cooperation of these two systems has enabled the one-stop system to work.

In that context, it is appropriate and necessary to flatly dispute the allegations that WIA and Wagner-Peyser are duplicative. They are not. In Pennsylvania, these services are not only located together in PA CareerLinks but are often functionally integrated with teams comprised jointly of WIA and Wagner-Peyser staff working together on business outreach, job development and screening and referral of applicants. The idea that funding for Wagner-Peyser can be elimi-

nated with no negative impact on job seekers and employers is a fantasy. It could be possible, however, to consolidate the systems, and local WIBs might find that gave them added flexibility, but not if total funding was cut.

Pennsylvania's Response and Implications for Workforce Development

The Commonwealth of Pennsylvania has responded to changing economic and workforce conditions with a complete paradigm shift to a demand-driven system. The process included a proactive partnership between the state and local workforce investment boards. Some of the early best practices of local boards, especially around industry cluster analyses, were adopted and institutionalized into statewide practices. This is a dynamic and changing process that is very much data driven. As the key clusters and industries are defined, high priority occupations are identified, all with opportunity for input at the local level and from industry. Occupations are analyzed in terms of the supply demand balance and for their ability to produce a self-sufficiency wage or a career ladder or lattice to such a wage.

State funding has been provided to form industry partnerships at the regional level and to facilitate training of the incumbent workforce. At the same time, the local CareerLinks are enlisted to meet demand for qualified employees and to provide career information, direction and access to relevant training.

Pennsylvania's initiatives also require the formation of regional consortia but give the local WIBs the option to decide, for example, that their partnership around healthcare may be with two to three other WIBs that have similar requirements and issues, while a logistics and transportation partnership may have a different geographical configuration for that industry.

Pennsylvania's major financial investment in the creation and growth of a demand-driven system runs the risk of being undercut by the reductions in federal funding to support the system's very foundation and infrastructure. The PA CareerLinks, for example, need adequate funding to provide training for workers whose skills are not in demand in a changing economy as well as sufficient staff to help these workers with skills assessment, career direction and an informed choice of training opportunities. Even when the cost of training is borne by the federal Trade Act, the "up-front" cost comes out of WIA funds, resulting in efficiency and better informed and appropriate choices.

That process also requires the WIBs to work with the industry partnerships and training providers like community colleges to develop the capacity to provide the training necessary for the incumbent workforce as well as new entrants or retrained dislocated workers. That training is usually considerably more expensive, even in the community colleges, than what can be accomplished with a $3,000 Career Advancement Account (CAA) as proposed by the Administration. There is more to making the proper placement in training and getting workers' skills up to the market's expectation than setting up a $3,000 Automated Teller Machine (ATM) for training providers.

We need adequately staffed (with WIA and Wagner-Peyser funds) one stop systems. We need to keep kids in school, see that they have current and relevant career information, and pro-

vide a "second chance" system for young people who have made unwise choices. We need to provide training which can really prepare workers for a new career, not just provide a quick fix path to another job which will not last. We need WIBs with enough resources to be the conveners, facilitators and neutral brokers which can manage the workforce development issues in their regions. We need to have the federal government make the kind of substantive investment in the system that Pennsylvania has with State funding, and to respect the experience and judgment of local WIBs and the practitioners who support them.

Faced with an imminent economic downturn, if not a recession, now is certainly not the time to accelerate the disassembly of our basic workforce development infrastructure.

Now, in fact, is the time for a comprehensive recommitment to validating the federal, state, local partnership around Workforce Development.

The Pennsylvania Association of Workforce Investment Boards greatly appreciates the opportunity to present its views and respectfully but strongly encourages a renewal of commitment to workforce development through the restoration of full funding to the Workforce Investment Act and Wagner-Peyser Act programs.

National Labor Relations Board Union
26 Federal Plaza, Room 3614
New York, New York 10278-0104

Telephone: (212) 264-0319
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March 31, 2008

The Honorable David Obey, Chairman
U.S. House of Representatives
Appropriations Subcommittee on Labor,
Health and Human Services,
Education and Related Agencies
2314 RHOB
Washington, D.C. 20515

Re: National Labor Relations Board
Fiscal Year 2009 Appropriation

Dear Chairman Obey:

The National Labor Relations Board Union urges the Subcommittee to approve OMB's Fiscal Year 2009 appropriations request of $262.6 million for the National Labor Relations Board.

The National Labor Relations Board Union represents approximately 1000 Field Attorneys, Field Examiners and Support Staff employed by the National Labor Relations Board. Our members work in Washington D.C. and 51 metropolitan areas throughout the Nation, including Alaska, Hawaii and Puerto Rico. As a responsible collective-bargaining agent, we are concerned that the Board receives adequate funding in the appropriations process.

The OMB proposed a FY 2009 appropriation of $262,595,207. Funding at this level is critical to continue the efficient and effective operation of the NLRB. Unlike other federal agencies, the NLRB does not fund grants or programs that can be reduced in years of inadequate appropriations. At the NLRB, reductions in appropriations necessarily result in personnel reductions and have resulted in curtailed or deferred benefits and training. To date the Agency has been successful in holding off RIFs or furloughs through normal attrition and filling only vacancies in "critical" positions. Reduced appropriations could lead to further FTE reductions which would negatively impact the Agency's ability to serve the public in FY 2009 and beyond.

As in the past, even the $262.6 million FY 2009 appropriation request would represent a reduction in the Agency's real appropriation after accounting for any COLA increases and increases in fixed costs over the past four years. Taking into account basic inflationary increases and COLA increases, any funding at less than the Administration's appropriation request would result in a reduction of our current service level to the public. Operational gains achieved as the result of responsible funding will be lost. In the past, service cuts resulting from inadequate appropriations required the public to engage in extensive travel to give testimony and participate in Board proceedings, caused delays in case processing and hearings, and resulted in a deterioration of the quality of investigations and trial preparation. When funding has not been sufficient in the past, employee benefits enjoyed throughout the government were denied to dedicated Board employees who deserve equitable treatment. The Agency has deferred and/or curtailed employee recognition programs every year for the past five years. It is likely that the Agency would, once again, balance its budget on the backs of its employees should Congress reduce the Agency's appropriation.

Without sufficient funding Employee training may also be curtailed, significantly damaging the Board's ability to enforce the Act. Even though the cost of training programs is very small, approximately $400,000 per fiscal year, in four out of the past five fiscal years, the Agency deferred and/or curtailed training programs. With a reduction in funding for FY 2009 the public will be unable to rely on the Board to execute its mission with quality and efficiency through a properly trained workforce.

We understand a Democratic controlled Congress's reluctance to fully fund an Agency in a Republican Administration. Unfortunately the people who would be hurt by withholding funds are the dedicated public servants who work through Administrations liberal and conservative and the public they serve. We urge you fund the Agency at the full level in the Administration's request.

Even funding Board operations at the level of $262.6 million will require continued fiscal discipline by the Board's managers and employees in order to carry out the mission of the Act. However, an appropriation of less cannot but curtail Board operations and result in a deterioration in the level of service to the public. This is not to say that the Agency cannot improve its budget management. The Agency's Inspector General has recommended implementation of tighter budget controls to insure that the Agency obligate all the funds the Congress has appropriated. We have, and we will continue to urge that the Agency implement the budget monitoring changes recommended by the Inspector General, and hope that Congress will do the same.

If you require further information, the NLRB Union will make every effort to comply with your request, including face-to-face meetings with you or your staff. Please contact me at (212) 264-0319 at the above address if you require anything further. In my absence, feel free to contact Legislative Co-Chairs Bert Dice-Goldberg at (973) 645-3536, or David Schaff at (907) 271-0350.

Thank you for your very kind attention.

Very truly yours,

Eric Brooks
President

D.J. Ida, Ph.D. ~ Executive Director, National Asian American Pacific Islander Mental Health Association (NAAPIMHA)

Public Witness Testimony for the Record

Mental Health in Asian American, Native Hawaiian and Pacific Islander communities:

Mental health is the topic that no one likes to talks about. Few provide resources for it and yet it is something that impacts each of us on a daily basis. It permeates every aspect of our lives but is ignored until we reach a crisis. If it is big enough we hear about it on the evening news. The shootings at Virginia Tech by Seung Hui Cho and the suicide of noted author Iris Chang made headlines around the world. It shocked many Asian American, Native Hawaiian and Pacific Islanders (AANHOPI) and pulled back the covers to reveal that mental health problems do exist in our communities. There is agreement that both situations are tragic but for very different reasons.

At Virginia Tech, the tragedy was the incomprehensible loss of innocent lives at the hand of an individual who had a long history of mental health problems. It is impossible to calculate the pain and devastation that the victim's family and friends felt. Cho's own family were also victims and are trying to cope with the unbearable pain brought on by Seung Hui's actions. It might also be said that Cho himself was a tragic figure whose mental health problems drove him to such an unthinkable act.

In the case of Ms. Chang, the tragedy was the loss of a talented writer who used her gift with words to expose the inhumane treatment of one society over another. In addition to writing the book The Rape of Nanking, she wrote of the Chinese American experience and topics that highlighted the inequalities in life. When Ms. Chang took her life, she also took with her the promise of a bright future. Maybe saddest of all, her death silenced forever a voice that tried to make this world a little more tolerant.

As public as these two cases are, the real tragedy for Asian Americans, Native Hawaiians and Pacific Islanders is the private stories that never make the news. It is story of the young student in Denver who fears he cannot be perfect and chooses to end his life. It is the overwhelming depression of the elder Chinese woman who finds herself in a nursing home in Houston. Isolated and surrounded by people who do not speak her language, she wonders when her adult children will come to visit her. It is the father in Los Angeles who agonizes over the diagnosis of schizophrenia given to his son and he wonders "why me?"

All is not well in paradise either as an increasing number of young Hawaiians and Pacific Islanders turn to drugs to help cope with their problems. The Asian American experience includes the Hmong father who watches his son become involved with gangs on the streets of Minneapolis. It is also about the Cambodian woman whose health is deteriorating because she remains distraught over the loss of her entire family at the hands of Pol Pot. Her emotional trauma makes it almost impossible to take care of herself, even thirty years later. When the National Cambodian Health Advocates, Inc. held a national townhall meeting in 2006, the number one health concern that was cited by the 400 participants was mental health.

Belying the myth of the model minority, the following statistics provide a glimpse into the lives of AANHOPIs living in the United States:

National Asian American Pacific Islander Mental Health Association
1215 19th St. Suite A ~ Denver, Colorado 80202 ~ 303.298.7910 ~ djida@naapimha.org

- ⇨ 17% of Asian American boys in grades 5 through 12 reported physical abuse, as compared to 8% among white boys, in a survey by the Commonwealth Fund. (The Health of Adolescent Boys: A Commonwealth Fund Survey. The Commonwealth Fund, 1998)

- ⇨ 30% of Asian American girls in grades 5 through 12 reported depressive symptoms, as compared to white girls (22%), African American girls (17%), or Hispanic girls (27%), in a survey by the Commonwealth Fund. (The Commonwealth Fund Survey of the Health of Adolescent Girls. The Commonwealth Fund, 1998)

- ⇨ Asian American women have among the highest suicide mortality rate among all women between 15-24 years of age. (Center for Disease Control and Prevention)

- ⇨ 73.3% of Asian Americans speak a language other than English. (An Invisible Crisis: The Educational Needs of Asian Pacific American Youth. Asian Americans/Pacific Islanders in Philanthropy, 1997)

- ⇨ 14% of Asian Americans live below the poverty line, compared to 13% of the U.S. population. (An Invisible Crisis: The Educational Needs of Asian Pacific American Youth. Asian Americans/Pacific Islanders in Philanthropy, 1997)

- ⇨ In the city of Westminster in Orange County California, approximately 17% of all juvenile delinquency and 48% of all Asian delinquency involve Asian gangs (U.S. Dept of Justice of Juvenile Justice and Delinquency Prevention, Fact Sheet February 2000 #1)

- ⇨ In a report on domestic violence in Massachusetts, 39% of the Vietnamese respondents and 47% of Cambodian respondents reported that they know a woman who has been physically abused or injured by her partner (Yoshioka, M.R., Dang, Q., Shewmangal, N., Chan, C., & Tan, C.I. (2000). *Asian family violence report: A study of the Cambodian, Chinese, Korean, South Asian and Vietnamese Communities in Massachusetts.* Boston, MA: Asian Task Force Against Domestic Violence, Inc.

Disparities in quality care

The disparities in quality care for communities of color, including Asian Americans, Native Hawaiians and Pacific Islanders is well documented. The President's New Freedom Commission on Mental Health (2003) concluded in their report Achieving the Promise: Transforming Mental Health Care in America that:

> *"The current mental health system has neglected to incorporate, respect or understand the histories, traditions, beliefs, languages and value systems of culturally diverse groups. Misunderstanding and misinterpreting behaviors have led to tragic consequences, including inappropriately placing individuals in the criminal and juvenile justice systems. There is a need to improve access to quality care that is culturally competent".*

The Institute of Medicine's 2002 report *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, concluded that:

"Communities of color bear a disproportionately high burden of disability from behavioral health disorders. The burden cannot be attributable to only a greater frequency or increased severity in these populations but rather a lack of quality care, and in many instances they are the recipients of poorer quality care. Even when communities of color receive mental health services, they are usually of substandard quality and not equal to that of the white population."

Workforce Issues:

The need to improve the workforce and increase the number of bicultural and bilingual service providers is at the core of how to eliminate disparities in quality care. There remains, however, a glaring discrepancy between the number of Latinos, African Americans, Asian American/Pacific Islanders and Native Americans and the number of service providers from each of these communities. In 2002, SAMHSA awarded four Eliminating Disparities Through Workforce Development grants in an effort to rectify this situation. In spite of an overwhelming response to the RFP, new funds were never appropriated and there continues to be a major outcry for additional dollars.

According to the 2000 Census, the four major ethnic groups comprised 30% of the population and by the year 2025 will represent almost 40% of the US population. They are, however, greatly underrepresented in the number of mental health service providers that are available. The majority of psychologists and psychiatrist continue to be Caucasian, only 13% of social workers, 18% of counselors, 5% of psychiatric nurses, 5% of marriage and family therapists, and 16% pastoral counselors are from communities of color (Center for Mental Health Services, 2004). The number for any of the specific ethnic populations and particularly those with the appropriate language skills is even smaller, leaving the most vulnerable population without proper care.

Increasing individuals from these communities is in and of itself insufficient. Being bi-lingual does not guarantee clinical competence. By the same token, having a doctorate degree does not guarantee cultural competence. The majority of training programs fail to address the cultural and language issues that impact the mental health of AANHOPIs which in turn can have dire consequences. The lack of proper training can result in misdiagnosis, poor treatment, inappropriate use of medications, early termination or an increase in symptoms that can lead to costly hospitalizations that could have been avoided if proper treatment had been given. .

The Annapolis Coalition for Workforce Development established the national strategic plan to address mental health workforce issues with funding from the US Department of Health and Human Services, Substance Abuse Mental Health Services Administration – SAMHSA. The Cultural Competence Subcommittee goal and recommendations are:

Goal: ***Reduce and eliminate disparities in the healthcare of communities of color through the development of a culturally competent workforce***

Recommendation 1: Reduce barriers to the recruitment and retention of people of color which includes the use of para-professionals, consumers, family members, natural healers and trained interpreters.

Recommendation 2: Identify, develop, implement and evaluate culturally competent training curricula for service providers, consumers, family members, and para-professionals, including traditional/indigenous healers and trained interpreters.
Recommendation 3: Cultural competency training should be a requirement for licensure and certification of professionals and certification of interpreters.
Recommendation 4: Appropriate rates of reimbursement will be established for use of trained, culturally competent para-professionals and interpreters.

Integrating primary health and mental health.
Research shows that there is a direct relationship between primary health and mental health. The key mental health policy reports conclude that in order to reduce healthcare disparities, it is necessary to integrate primary health, mental health and substance abuse. It is estimated that untreated mental health problems cost between $74 and $102 billion dollars each year. Integrating services is particularly important for AANHOPIs who tend to enter the service delivery system through their primary care doctor. Unfortunately most are not trained to assess for mental health or substance use disorders. In response to this need, HRSA initiated the Primary Care Integration project that has been implemented in Federally Qualified Health Centers or Community Health Centers throughout the country. Funding, however, continues to be inadequate with no resources available to the mental health settings.

Failure to address the mental health needs of an individual increases the risk for physical problems. A person who is seriously depressed may not eat properly, is under greater stress, may fail to follow through with self care activities, including taking medications and following doctors order. Diabetes doubles the risk of depression compared to those who are not depressed. According to the National Institutes for Health, the chances of becoming depressed increase as diabetes complications worsen. Research over the past two decades show that people with heart disease are also more likely to suffer from depression than otherwise healthy people, and conversely, that people with depression are at greater risk for developing heart disease. Furthermore, people with heart disease who are depressed have an increased risk of death after a heart attack compared to those who are not depressed. Depression and anxiety disorders may affect heart rhythms, increase blood pressure, and alter blood clotting. While there is no evidence to support a causal role for depression in cancer, depression may impact the course of the disease and a person's ability to participate in treatment. Individuals who are depressed may have difficulty taking medications and following through with their treatment plans.

Limited English Proficiency and Mental Health
According to the 2000 US Census, 88% of Asian Americans are foreign born or have at least one foreign born parent. This has tremendous implications for access to and delivery of mental health services. Many immigrants and refugees have limited proficiency in English, which presents challenges for the provision of culturally and linguistically competent services.

Effective communication is essential for quality care. Language barriers can lead to miscommunications, resulting in inaccurate assessment and diagnosis, development of inappropriate treatment plans, early termination and overall poor quality of services. The need for culturally competent mental health services far exceeds the available number of

bilingual and bicultural mental health professionals. Therefore, the use of interpreters is vital to bridge the language and cultural gap. Far too frequently a clerical member of the staff or a family member is asked to interpret. This is a highly unethical practice which can seriously compromise the quality of care an individual receives.

Title VI of the Civil Rights Act of 1964, requires that "no person in the United states, shall, on grounds of race, color, or national origin, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance". This includes receiving care that is linguistically appropriate since failure to communicate effectively does not constitute access to services. In recent years, legislators in many states and administrative agencies have begun to recognize the growing need for linguistically appropriate health care and adapt measures that require or encourage service providers to take steps to overcome language barriers.

Although many organizations already use interpreters, at least three major problem exist:

- Most interpreters are not properly trained in the art of interpreting in mental health settings.
- Most providers may not be skilled in using interpreters
- Most non-English speaking clients are ill- informed about their right to receive service in their native language.

SUMMARY;

Serious mental health problems do exist within the diverse Asian American, Native Hawaiian and Pacific Islander communities. Stigma and shame are only partly responsible for the failure to receive proper services. The lack of properly trained bi-lingual and bi-cultural service providers is a major contributing factor for disparities in quality care. For those who do seek treatment, they are at risk for misdiagnosis, poor assessment and development of inappropriate treatment plans that can result in unnecessary costs and unavoidable hospitalizations. It is important for AANHOPIs to realize that mental health is a normal part of all our lives, people do get better, recovery is possible and prevention and early intervention can save dollars, untold heartache and lives. Developing a culturally and linguistically competent workforce is imperative if we are to make any real headway in improving quality of services for vulnerable and under served AANHOPI populations.

RECOMMENDATIONS:

- *Enforce Title VI of the Civil Rights Act, 1964 that guarantee access to government-funded services*

Request $ 1.2 million to reduce mental health disparities and improve quality of services by:

- *Developing, implementing and evaluating a culturally and linguistically competent workforce, including the integration of mental health and primary health*
- *Reimbursing mental health interpretation and translation services*
- *Developing training models for mental health interpreters to work in the primary health and mental health settings*
- *Developing anti-stigma campaigns that are culturally sensitive and linguistically appropriate for the diverse AANHOPI communities.*

Dr. T. Alan Hurwitz
National Technical Institute for the Deaf (NTID), Rochester Institute of Technology (RIT)
Vice President of RIT for NTID, CEO and Dean of NTID

Mr. Chairman and Members of the Committee:

I am pleased to present the FY 2009 budget request for NTID, one of eight colleges of RIT, in Rochester NY. Created by Congress, we provide university technical education serving 1,185 deaf and hard-of-hearing students from across the nation and 158 hearing students, totaling 1,343 students.

NTID has fulfilled our mission with distinction for 40 years.

BUDGET REQUEST: This request details the importance of obtaining our full FY 2009 request of **$62,027,000**. We ask for **$60,852,000** for continuing operations and **$1,175,000** for construction for phase two of replacing aging mechanical systems. The NTID request and the President's are:

	Operations	Construction	Total
NTID Request	$60,852,000	$1,175,000	$62,027000
President's Request	$58,020,000	$1,175,000	$59,195,000
Difference	**$2,832,000**	**$0**	**$2,832,000**

We respectfully request your support of our full appropriation request. We do not request new operations funding for academic programs or headcount; instead, we commit to fund increases, if any, through reallocating resources. We commit because we consistently restrain requests. From FY 2003 through FY 2007 we documented $6,200,000 of savings by reducing/reallocating headcounts and increasing revenues. These difficult savings controlled requests while improving programs and expanding in areas like speech-to-text services for deaf and hard-of-hearing students who benefit from this service.

We are proud of those accomplishments; however, they leave limited flexibility in what we respectfully submit is inadequate funding in the President's budget. To meet the President's request level we will need to reduce important programs and services. The following are not all inclusive but exemplify the actions we will be required to undertake if we are funded at the President's level.

1. **Technology**. Student curriculums demand state-of-the-art technology. Our students depend on

technology updates to be prepared for work. For deaf and hard-of-hearing students, instructional delivery technology is critical. We require $1,000,000 per year to assure we remain current.

2. **Endowment.** The Education of the Deaf Act authorizes matching private gifts from appropriations, reducing dependence on federal funds. In FY 2007 we matched over $800,000; we expect to match $1,000,000 in FY 2008. We want to continue matching; otherwise we will severely limit donor commitments.
3. **Outreach** and **Enrollment.** Approximately $500,000 supports programs that: attract junior/senior high school students; create a community college referral program to enhance college preparation and transferability; and revamp English programs to help students to improve their reading and writing skills. All increase future enrollments. Limited funding may impact these efforts.
4. **Open Positions.** Current and future position openings will not be filled. The impact of a freeze depends on where vacancies appear. The position reduction we planned and implemented from FY 2003 through FY 2007 leaves few options today that will not directly impact services to students.

Our FY 2009 operations request represents costs driven by increases in salary, health benefits, and energy costs, as well as RIT service charges that have the same inflationary pressures. We do not ask for funds to address program modifications; we will reallocate to meet those needs. Our experience from FY 2003 to FY 2007 proves we can and will do this without additional appropriations.

Adding to our concerns for FY 2009 is that after our submission RIT learned it was not in compliance with some provisions of the Fair Labor Standards Act. RIT reclassified many salaried positions to hourly positions including 122 full-time NTID interpreters who now receive overtime pay.

This finding affected about 140 NTID employees, and others who worked for NTID in the last six years. Forty additional NTID positions are now being evaluated for potential reclassification. We may be required to pay these individuals for past overtime and if reclassified, for future overtime.

The reclassification of these positions has already added $800,000 to FY 2008 overtime

expenditures and is expected to grow to $1,000,000 in FY 2009 and beyond. We are unsure if we can support this at our request level much less at the amount recommended in the President's budget.

Unanticipated salary pressures also impact FY 2009. We budgeted for a 3% salary increase; however, only two months ago RIT increased faculty salaries by 4.5%, almost a $300,000 impact on us. We also face a necessary increase in interpreter salaries for FY 2009 to compete with video relay service centers established in Rochester which have significantly increased local pay scales.

Our FY 2009 request was submitted 15 months before the fiscal year; needs changed in the interim, not an unusual occurrence, as expenditures increased significantly. But there are also decreases; our original construction request for $1,640,000 has been reduced by nearly 30% to $1,175,000. We accomplished this by negotiating cost-sharing with RIT for two projects in the original submission.

NTID has a long history of successful stewardship of federal funds and is committed to provide exemplary education for deaf and hard-of-hearing students in a cost-effective manner.

ENROLLMENT: Total enrollment is at 1,343 for school year 2007-08 (FY 2008), and was 1,250 students last year. This dramatic increase of 93 students (7.4%) brings us to the second largest enrollment in our 40-year history, just 15 students below our peak 24 years ago. NTID anticipates maintaining or increasing enrollment for school year 2008-09 (FY 2009). A five-year history follows.

NTID Enrollments: Five-Year History								
	Deaf/Hard-of-Hearing Students				Hearing Students			Grand Total
School Year	Undergrad	Grad RIT	MSSE	Sub-Total	Interpreting Program	MSSE	Sub-Total	
2003-4	1,064	45	41	1,150	92	28	120	1,270
2004-5	1,055	42	49	1,146	100	35	135	1,281
2005-6	1,013	53	38	1,104	116	36	152	1,256
2006-7	1,017	47	31	1,095	130	25	155	1,250
2007-8	1,103	51	31	1,185	130	28	158	1,353

The number of students in our interpreting program has grown substantially in recent years. The number in our graduate secondary teacher preparation program (MSSE) has fluctuated (totaling both MSSE columns above), and the total of deaf and hard-of-hearing students increased dramatically from

1,095 in 2006-7 to 1185 in 2007-8 an increase of 90 students (8.2%).

STUDENT ACCOMPLISHMENTS: Our placement rate is 95% placed in jobs commensurate with the level of their education (using the Bureau of Labor Statistics methodology). Over the last five years, 64% were employed in business and industry, 26% in education/non profits, and 10% in government.

In FY 2005, NTID, the Social Security Administration, and Cornell University examined over 13,000 NTID applicants. We learned NTID graduation has significant economic benefits. By age 50, deaf and hard-of-hearing baccalaureate graduates earn on average $6,021 more per year than those with associate degrees, who in turn earn $3,996 more per year on average than those who withdraw. Students who withdraw earn $4,329 more than those who are not admitted. Students who withdraw also experience twice the rate of unemployment as graduates.

The same studies show 60% of students at NTID receive Supplemental Security Income benefits, but when they are at 50, less than 3% draw these benefits. Graduates also access Social Security Disability Insurance (an unemployment benefit), at far lesser rates than withdrawals; by age 50, withdrawals were twice as likely to be receiving these benefits as graduates. A large percentage of school leavers without a degree will continue to depend heavily on federal income support throughout their lives. But NTID graduates have significantly reduced dependence on welfare programs.

Considering the added taxes graduates pay as a result of their increased earnings and the savings derived from reduced dependency on the federal income support programs, the federal investment in NTID returns significant societal dividends.

NTID clearly makes a significant, positive difference in earnings, and in lives.

NTID BACKGROUND: *Academic Programs:* NTID offers high quality, career-focused, associate degree programs preparing students for specific well-paying technical careers. A cooperative education component ties closely to high demand employment opportunities. Expanding transfer associate degree programs better serve the higher achieving segment of our student population who seek bachelors and

masters degrees in an increasingly demanding marketplace. These transfer programs provide seamless transition to baccalaureate studies. We support students in RIT baccalaureate programs. One of NTID's greatest strengths is our outstanding track record of assisting high-potential students gain admission to and graduate from the other colleges of RIT at rates that are better than their hearing peers.

Research: The research program is guided and organized according to these general research areas: language and literacy, teaching and learning, socio-cultural influences, career development, technology integration, and institutional research. All benefit the deaf and hard-of-hearing population.

Outreach: Extended outreach activities to junior/senior high school students, expand their horizons regarding a college education. We also serve other universities and post-college adults.

Student Life: The new Student Development Center, funded by a $2,000,000 private gift and $1,500,000 FY 2005 federal appropriations has opened. Our activities foster student leadership and community service, and provide opportunities to explore other educational interests.

SUMMARY: It is extremely important that our funding be provided at the full level requested particularly in light of the unanticipated impact of the FLSA requirements described above; even at this level, some service reductions may be necessary should we be unable to offset these costs.

We will continue our mission of preparing deaf and hard-of-hearing people to enter the workplace and society.

Our alumni have demonstrated that they can achieve independence, contribute to society, earn a living, and live a satisfying life as a result of NTID. Research shows that NTID graduates over their lifetimes are employed at a much higher rates, earn substantially more (therefore paying significantly more in taxes), and participate at a much lower rate in federal welfare programs than those who withdraw or who apply but do not attend NTID.

We are hopeful that the members of the Committee will agree that NTID, with its outstanding record of service to deaf and hard-of-hearing people, remains deserving of their support and confidence.

American Public Health Association

Working for a Healthier World

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Testimony of the American Public Health Association (APHA)
Concerning the Public Health Budget for Fiscal Year 2009
Submitted for the Record to the House Appropriations Subcommittee on Labor, Health and Human Services and Education
March 31, 2008

The American Public Health Association (APHA) is the nation's oldest, largest and most diverse organization of public health professionals in the world, dedicated to protecting all Americans and their communities from preventable, serious health threats and assuring community-based health promotion and disease prevention activities and preventive health services are universally accessible in the United States. We are pleased to submit our views on federal funding for public health activities in fiscal year 2009.

Recommendations for Funding the Public Health Service

APHA's budget recommendation for overall funding for the Public Health Service includes funding for the Centers for Disease Control and Prevention (CDC), the Health Resources and Services Administration (HRSA), the Substance Abuse and Mental Health Services Administration (SAMHSA), the Agency for Healthcare Research and Quality (AHRQ), and the National Institutes of Health (NIH), as well as agencies outside the Subcommittee's jurisdiction—the Food and Drug Administration (FDA) and the Indian Health Service (IHS).

Centers for Disease Control and Prevention (CDC)

APHA believes that Congress should support CDC as an agency—not just the individual programs that it funds. We support a funding level for CDC that enables it to carry out its mission to protect and promote good health and to assure that research findings are translated into effective state and local programs.

In the best judgment of APHA—given the challenges and burdens of chronic disease, a potential influenza pandemic, terrorism, disaster preparedness, new and reemerging infectious diseases, increasing drug resistance to critically important antimicrobial drugs, and our many unmet public health needs and missed prevention opportunities—we believe the agency will require funding of at least $7.4 billion (including funding for the Agency for Toxic Substances and Disease Registry) for CDC's core programs in FY09. This request does not include the mandatory funding provided for the Vaccines for Children Program (VFC).

APHA appreciates the Subcommittee's work over the years, including your recognition of the need to fund chronic disease prevention, infectious disease prevention and treatment, programs to combat racial, ethnic and geographic disparities in health and health care and environmental health programs at CDC. 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 risk of a potential onset of an influenza pandemic, in addition to the many other natural and man-made threats that exist in the modern world, CDC has become the nation's—and the world's—expert resource and response center, coordinating communications and action and serving as the laboratory reference center. States and communities rely on CDC for accurate information and direction in a crisis or outbreak.

CDC's budget has actually shrunk since 2005 in terms of real dollars – by almost 4 percent. If you add inflation, the cuts are even worse – and these are cuts to the core programs of the agency. The current administration request for FY 09 cuts the CDC budget by $475 million below the FY08 level including cuts to state and local preparedness funding, chronic disease programs, infectious disease detection and control and elimination of the Preventive Health and Health Services Block Grant. This request is inadequate and many of the cuts appear to be arbitrary in nature. Since 2005, CDC has sustained a total cut to core budget categories of over half a billion dollars. We are moving in the wrong direction, especially in these challenging times when public health is being asked to do more, not less. It simply does not make any sense to cut the budget for CDC's core public health programs at a time when the threats to public health are so great. Funding public health outbreak by outbreak is not an effective way to ensure either preparedness or accountability. Until we are committed to a strong public health system, every crisis will force trade offs.

CDC serves as the lead agency for bioterrorism preparedness and must receive sustained support for its preparedness programs in order for our nation to meet future challenges. In the best judgment of CDC Coalition members, given the challenges of terrorism and disaster preparedness, and our many unmet public health needs and missed prevention opportunities we strongly oppose the President's proposed $135.5 million cut to the state and local capacity grants. While we understand that this cut is part of a realignment of the grant funding cycles, we are concerned that this funding must now be restored in the FY2010 budget. We ask the Subcommittee to restore these cuts to ensure that our states and local communities can be prepared in the event of an act of terrorism or other public health threat this year and in future years. Unfortunately, this is not a threat that is going away.

Public health programs delivered at the state and local level should be flexible to respond to state and local needs. Within an otherwise-categorical funding construct, the Preventive Health and Health Services (PHHS) Block Grant is the only source of flexible dollars for states and localities to address their unique public health needs. The track record of positive public health outcomes from PHHS Block Grant programs is strong, yet so many requests go unfunded. Unfortunately, the President's budget once again proposes the elimination of the PHHS Block Grant. We greatly appreciate the work of the Subcommittee to at least partially restore the fiscal year 2008 elimination of the Block Grant. Nevertheless, the cut to the Block Grant in fiscal year 2006 reduces states' ability to tailor federal public health dollars to their specific needs.

We must address the growing disparity in the health of racial and ethnic minorities. CDC's Racial and Ethnic Approaches to Community Health (REACH), is helping states address serious disparities in infant mortality, breast and cervical cancer, cardiovascular disease, diabetes, HIV/AIDS and immunizations. Our members are committed to ending the disparities. We encourage the

Subcommittee to reject the president's proposed cuts and to provide adequate funds for CDC's REACH program.

We also encourage the Subcommittee to provide adequate funding for CDC's Environmental Public Health Services Branch to revitalize environmental public health services at the national, state and local levels. The agencies that carry out these services are fragmented and their resources are stretched. These services are essential to protecting and ensuring the health and well being of the American public from threats associated with West Nile virus, terrorism, E. coli and lead in drinking water. We encourage the Committee to provide at least $50 million for CDC's Environmental Health Tracking Network and to provide $11.1 million to CDC's environmental health activities to develop and enhance CDC's capacity to help prepare for and adapt to the potential health effects of climate change. This funding would allow CDC to establish a climate change program within the agency to develop staff expertise, to fund academic and other institutions in their efforts to research the impacts of climate change on public health, to create a Center of Excellence at CDC to serve as a national resource for government leaders and the public on climate change science and health, to improve global disease detection capabilities and to conduct outreach and education for our state and local public health workers.

Health Resources and Services Administration (HRSA)

Through its programs in thousands of communities across the country, HRSA provides a health safety net for medically underserved individuals and families, including 47 million Americans who lack health insurance, 50 million Americans who live in neighborhoods where primary health care services are scarce, and more than one million people living with HIV/AIDS. HRSA funding goes where the need exists, in communities all over America and especially among populations experiencing racial/ethnic and rural/urban disparities in health status. We support a growing trend in HRSA programs to increase flexibility of service delivery at the local level, necessary to tailor programs to the unique needs of America's many varied communities, as well as HRSA long-time commitment to enhancing the health resources that lay the foundation for health care delivery across the country. The agency's overriding goal is to achieve 100 percent access to health care, with zero disparities. In the best professional judgment of APHA, to respond to this challenge, the agency will require an overall funding level of at least $7.9 billion for FY 2009.

APHA is gravely concerned about the President's budget recommendation of $992 million in cuts for FY 2009, including over 20 program eliminations. These proposed cuts would considerably undermine the agency's ability to achieve its goals of improving access and eliminating disparities. A significantly greater investment is necessary to adequately fund HRSA's many programs and new initiatives that help millions of Americans live healthier, more productive lives. In the 21st century, rapid advances in research and technology promise unparalleled advances in the nation's health care delivery system. HRSA could be well positioned to meet these new challenges in providing needed health care to the nation's most vulnerable citizens.

The Bureau of Health Professions received the largest cut - $542 million - in the President's budget. This cut includes the proposed elimination of most Health Professions Programs authorized under Titles VII and VIII of the Public Health Service Act and the Children's Hospital Graduate Medical Education Program. The budget eliminates all Title VII health professions programs and provides only $110 million for the Title VIII nursing workforce development programs. These programs are an essential component of America's healthcare safety net, bringing healthcare providers to underserved communities and filling

the gaps in the health professions supply not met by traditional market forces. The Title VII and VIII programs work in concert with the Health Centers Program and the National Health Service Corps to strengthen the healthcare safety net by enhancing the supply, distribution and diversity of the health professions workforce. They are the only federal programs designed to train providers in interdisciplinary settings to meet the needs of underserved populations and increase minority representation in the health professions workforce. Through loans, scholarships, and grants to academic institutions and non-profit organizations, these programs provide support for the training of primary care physicians, nurses, dentists, physician assistants, advanced practice nurses, public health personnel, psychologists, pharmacists, healthcare educators, and other allied health providers. Cuts to the Health Professions Programs threaten to disrupt the pipeline of new providers that Health Centers and other safety-net health facilities need to meet the long-term needs of underserved communities. Cuts also will impede the recruitment of underrepresented minorities and students of disadvantaged backgrounds into the health professions, which will intensify health disparities. Furthermore, we are concerned about the impact health professions cuts will have on children's care, through the elimination of the Children's Hospital Graduate Medical Education Program, and our aging Baby Boomer generation, though the elimination of Title VII geriatric education programs. We strongly encourage the Subcommittee to restore funding to these vital programs.

The Office of Rural Health Policy received a $150 million cut in the President's FY 2009 budget, an 86 percent reduction over FY 2008. This Office promotes better healthcare services for the almost one quarter of our population that lives in rural communities. These communities suffer from inadequate access to quality healthcare and experience the higher rates of illness associated with a lower socioeconomic status. The proposed cuts include the elimination of the Rural Access to Emergency Devices, the Rural Hospital Flexibility Program, Rural Outreach grants, the Denali Commission, and the Delta Health Initiative. The Rural Access to Emergency Devices grant program helps rural communities purchase automated external defibrillators (AEDs) and provides first responders training in their use and maintenance. Sudden cardiac arrest strikes over 160,000 Americans each year and these devices can more than double a victim's chance of survival. The Rural Hospital Flexibility Program provides grants to State governments for a variety of purposes such as to develop and implement Rural Health Plans, stabilize rural hospitals and help them obtain designation as "Critical Access Hospitals", improve and integrate emergency medical services, and improve the quality of care in rural communities. Rural Outreach grants support the development of new and innovative healthcare delivery systems in rural communities that lack essential healthcare service. These grants fund a variety of programs that provide care to at least two million rural citizens across the country that would not otherwise have access to these services, including hospice, pediatric dental care and prenatal care. The Denali Project supports health infrastructure development in Alaska by providing resources for the planning, design and construction of primary healthcare facilities. Finally, the Delta Health Initiative funds rural organizations to address local healthcare needs in the rural Delta region. Programs funded through the Initiative have provided services to over 300,000 people including chronic disease management, access to pharmacy services, practice management services, oral health, school-based health services, mental health/substance abuse services, and teenage pregnancy prevention. We encourage the Subcommittee to restore funding to these important programs that address the many unique healthcare needs of rural communities.

The President's budget cuts funding for the Poison Control Centers by a devastating 63 percent, $17 million under the FY 2008 level. These centers are a critical resource for people, health professionals and organizations. Poisoning can happen to anyone, at anytime in any place and can lead to serious illness or even death. Each year, more than two million possible poisonings are reported to the nation's poison centers. On average, poison centers handle one possible poisoning every 13 seconds. These critical centers cannot afford to lose any resources and we encourage the subcommittee to fully fund this program.

Through its many programs and initiatives, HRSA helps countless individuals live healthier, more productive lives. As leaders of our nation, this Subcommittee decides what direction we will go in terms of delivering health care to those who need it most. APHA believes that with adequate resources, HRSA is well positioned to meet these challenges as it continues to provide needed health care to the nation's most vulnerable citizens. Restore the funds to these important public health programs.

Agency for Healthcare Research and Quality (AHRQ)

We request a funding level of at least $360 million for AHRQ for fiscal year 2009. 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. The cuts proposed in the administration's budget will severely hamper these efforts.

Substance Abuse and Mental Health Services Administration (SAMHSA)

APHA supports a funding level of $3.85 billion for SAMHSA for fiscal year 2009. 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.

National Institutes of Health (NIH)

APHA supports a funding level of $31.1 billion for the NIH for fiscal year 2009. 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. While we have said this before, in the post-September 11th era, we need to include a commitment to public health in our spending growth in terrorism and disaster preparedness as well. We must think in a broad and balanced way, leveraging homeland security programs and funding whenever possible to provide public health benefits as a matter of routine, rather than emergency.

We thank the subcommittee for the opportunity to present our views on the FY 2009 appropriations for public health service programs.

Statement of the

NATIONAL ASSOCIATION OF COUNTY AND CITY HEALTH OFFICIALS

Submitted for the record to the
Subcommittee on Labor, Health and Human Services, Education and Related Agencies
Committee on Appropriations
United States House of Representatives

FY 2009 Appropriations for Public Health Programs

March 28, 2008

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SUMMARY

The proposed cuts in the FY 2009 budget for the Centers for Disease Control and Prevention (CDC) submitted by the President continue a pattern of reduced funding for public health that gravely worries the nation's local health departments. The National Association of County and City Health Officials (NACCHO) is particularly concerned about two funding streams that directly benefit local health departments, although the range of reductions in CDC's budget threaten overall work in prevention that we fully support.

The President's budget requests $609 million in FY09 for state and local capacity building for public health preparedness in FY09 and eliminates the Advanced Practice Center program. This represents a cut of 18% from FY08. The Preventive Health and Health Services (PHHS) block grant program, the other major source of CDC funding to health departments, received funding of $97 million in FY08 and is eliminated in the President's budget. Taken together, these reductions will seriously compromise the ability of the nation's governmental public health

system to fulfill its mission of protecting and promoting health.

Local public health departments work every day on the front lines to combat threats to the health of their communities. They cannot afford substantial reductions in federal support for their roles as first responders to natural disasters, acts of bioterrorism and other public health emergencies. Moreover, local public health departments receive about 40% of the PHHS funds. In states where local health departments rely exclusively on these funds to conduct prevention programs for which no other sources of funding are available, activities to reduce the burdens of preventable disease will cease. Prevention is critical to slowing the astronomical growth in chronic diseases like obesity and diabetes as well as protecting the public from hazards such as lead poisoning and infectious diseases like tuberculosis. An investment in prevention improves both length and quality of life.

At a time when the nation is engaged in urgent work to protect the homeland from terrorists and natural disasters, as well as to stop the growth in chronic disease, it is profoundly counterproductive and irrational to reduce support for local programs that are the first line of defense against the greatest threats to the health of communities. NACCHO urges Congress to continue funding these two CDC programs at levels no less than those in FY 2005. Those levels are $919 million for state and local public health emergency preparedness and $131 million for the Preventive Health and Health Services block grant. NACCHO urges Congress to continue funding for pandemic flu preparedness at $350 million for FY09. In addition, NACCHO advocates for new funding of $10 million in FY09 to inaugurate two new workforce programs within the National Health Service Corps in the Health Resources and Services Administration (HRSA) that would benefit local public health and address workforce shortages.

Progress Has Been Made in Bolstering the Readiness of Local Health Departments to Respond to Emergencies

A report released by CDC on February 20, 2008, *Public Health Preparedness: Mobilizing State by State,* documents progress made by preparedness funding grantees. According to the report, preparedness funding has allowed state and local health departments to have a more focused and effective response to actual emergencies, not just to plan for a hypothetical future emergency. These real-life situations have provided an opportunity for local health departments to exercise their response plans and to learn where improvements can be made. Preparedness is not simply a matter of theoretical planning for a future catastrophe. Rather, it makes a difference in how well health departments can respond to public health problems daily.

CDC reports improvements in preparedness across the country made possible by federal funding. For instance, in Wisconsin in 2006, public health officials working with public health laboratories were the first in the nation to identify the bacterial strain that sickened hundreds and caused three deaths in the spinach *E. coli* O157:H7 outbreak. In New York City, public health preparedness funds have helped the health department bring together a wide array of partners to prepare for a possible pandemic flu outbreak and to exercise their response in a scenario involving an avian flu outbreak in the city's poultry markets.

CDC's report confirmed the findings of a 2007 NACCHO survey of LHDs, which found that three-quarters of local health departments (LHDs) reported that they had improvements in preparedness but that more improvement is needed. Virtually all local health departments had developed a plan for mass vaccination, as well as an all-hazards preparedness plan, had implemented the National Incident Management System (NIMS), trained their workforce in new emergency response skills, conducted public education campaigns, and improved their communication systems.

Public health officials have also made advances in pandemic flu planning supported by federal funding. For example, in Oregon, public health officials conducted an exercise involving the state health department, more than 30 local public health departments, 50 hospitals, two tribal health departments, the Oregon Board of Pharmacy, Oregon National Guard, and state agencies of emergency management, administrative services, education, transportation, and the fire marshal. This wide range of partners allowed relationships to be built and sustained well in advance of an actual emergency. Similar exercises take place regularly across the nation.

Strengthening the Governmental Public Health System to Protect Local Communities Requires Sustained Funding

Since Fiscal Year 1999, Congress has provided funding to strengthen the nation's capacity to respond to an act of bioterrorism or other public health emergency. After 9/11 and the anthrax attack in the fall of 2001, Congress increased this funding markedly and included $940 million for building state and local capacities, of which about $870 million was made available to states and localities. Federal funds for improving state and local public health preparedness have declined from $919 million in FY05 to $746 million in FY08. The President's budget would provide $609 million for FY09, and would cut the grant year to slightly more than nine months. In FY10, a $129.6 million increase in funding would be required to maintain level, full-year funding.

The downward slope in federal preparedness funding has severely hampered LHDs in sustaining current activities and in building an experienced preparedness workforce. LHDs experienced an average **20%** funding reduction in 2007 and further reductions are expected when HHS distributes FY08 funds. Already, more than one-quarter of LHDs have reduced their preparedness activities, delayed completion of plans, and/or delayed acquisition of equipment and supplies as a result of reduced funding. Notwithstanding the federal cuts, LHDS continue to contribute their share to this national effort. Nearly half of all LHDs make use of city or county funds to pay directly for preparedness activities. All contribute additional in-kind resources, principally staff time diverted from other activities.

The safety and well-being of America's communities is dependent on maintenance of the capacity of their health departments to respond in any emergency that threatens human health. Every community now has a public health emergency plan in place, but plans must be supported by public health responders who engage in continuous training and exercising. In its recent

report, CDC listed challenges that remain with regard to public health emergency preparedness. Among them were the need for state and local health departments to sustain a system of all-hazards planning, training, exercising, and improving. In order to continue this essential cycle of continuous improvement, LHDs need consistent funding The nation cannot afford to backslide or lose its investment by failing to sustain federal funding that helps health departments continue their progress and address new and emerging threats.

The President's budget eliminates the Advanced Practice Center (APC) program, which provides funds to eight local health departments to develop innovative field-tested tools and models to help other LHDs meet emergency preparedness goals. The products produced by the APCs are disseminated to other local health departments nationwide, saving them the expense and trouble of designing from scratch. A cost effective investment of $5.4 million will allow this program to continue and to have a much greater impact than the numbers alone would suggest.

Media attention to the threat of pandemic flu may have waned, but experts say that it remains a real threat. A flu pandemic will likely break out at multiple sites simultaneously and could go on for months, in a series of waves across the country. The effect could be disruption of businesses, schools and delivery of services throughout communities. Preparation at the local level is the surest way to respond to such an event and to forestall panic.

The CDC has stated, "The local level is where the effects will be felt and where the response needs to occur." Development of a vaccine for pandemic influenza can take six months or more. Therefore, public education and engagement in preventing the spread of disease and local response to early cases will be vital to controlling a pandemic. Emergency supplemental funds in the amount of $600 million appropriated in FY06 for pandemic influenza preparedness have been distributed and ongoing funding is needed to make sure that the enormous job of preparing every community continues. Meaningful progress requires a continuous process of training, exercising and improvement that involves not merely public health responders, but all community partners that are part of any response, including law enforcement, emergency management, hospitals, schools, and a host of private sector partners. This is not a one-time project.

The nation has a long way to go before every citizen enjoys the best possible protection by disease detection and response systems that work as quickly as possible. Providing this protection is the job of the governmental public health system. No other entity can do it. NACCHO urges Congress to reverse the cuts in funds available to local public health departments, the nation's first responders to bioterrorism and other public health emergencies.

The PHHS Block Grant is a Linchpin for Prevention

Local public health departments receive approximately 40% of the Preventive Health and Health Services block grants nationally. The proportion received by local health departments varies among states from less than five percent to almost 100 percent. The block grant funds fulfill three critical purposes. First, they enable states to address critical unmet public health needs.

The coexistence of other federal categorical public health funds does not mean that sufficient funds are available to address all public health needs. They are not. Improving chronic disease prevention through screening programs and programs that promote healthy nutrition and physical activity are prime examples of activities to which many jurisdictions devote PHHS funds.

Second, PHHS funds provide flexible funding to address unexpected problems or problems unique to a particular geographic area. West Nile virus, a fully preventable disease spread to humans by mosquitoes, is one good example. Third, PHHS funds provide leverage for more funds and in-kind resources from non-federal sources. In one southern state, local health departments collectively used $2.77 million in block grant funds to establish new prevention programs and generate $5 million in additional resources for those programs.

According to the National Association of Chronic Disease Directors, elimination of the PHHS block grant would cause a loss of $40.8 million for chronic disease programs and $11.2 million for infectious disease programs. In those states where local health departments receive a significant amount of PHHS funds from the state, local prevention efforts will diminish. As health care costs escalate, reducing the nation's commitment to prevention by eliminating the PHHS block grant, weakening state and local public health departments, is unwise and uneconomic.

Workforce Shortages Threaten the Strength of Local Public Health

According to NACCHO's 2005 Profile of Local Health Departments, public health professionals in short supply include public health nurses, epidemiologists, environmental health scientists, and health educators. Nearly half of all LHDs experienced problems hiring public health nurses in 2005 and 60% expected to have trouble recruiting nurses in 2008. Staff attrition and retirement are the most frequently cited factors causing uncertainty and concern about future workforce capacity.

NACCHO advocates new funding of $10 million in FY09 to begin addressing public health workforce shortages. In 2006, the Pandemic and All-Hazards Preparedness Act created two new programs within the National Health Service Corps in the Health Resources and Services Administration (HRSA). One program would allow expansion of the National Health Service Corps on a trial basis to include loan repayment for individuals who complete their service in a state, local, or tribal health department that serves health professional shortage areas or areas at risk of a public health emergency. The second program establishes grants to states to create loan repayment programs. As the public health role has expanded to include greater involvement in emergency preparedness, in addition to the more traditional public health activities like immunization and chronic disease prevention, it is essential that there be a workforce trained to carry out these tasks.

The National Association of County and City Health Officials (NACCHO) is the organization representing the 2860 local public health departments in the United States.

FY 2009 Written Testimony for the Labor, Health and Human Services, and Education Subcommittee of the House Appropriations Committee

By Ronald Johnson, Deputy Executive Director
AIDS Action

I am pleased to submit this testimony to the Members of this committee on the importance of increased funding for the Fiscal Year (FY) 2009 HIV/AIDS portfolio. Since 1984, AIDS Action Council, through its member organizations and the greater HIV/AIDS and public health communities, has worked to enhance HIV prevention programs, research protocols, and care and treatment services at the community, state and federal level. AIDS Action represents many AIDS service organizations located in the nation's HIV epicenters, local health departments, smaller service providers, faith-based organizations, substance abuse treatment centers, and education and advocacy organizations from all over the country. AIDS Action's goals are to ensure effective, evidence-based HIV care, treatment, and prevention services; to encourage the continuing pursuit of a cure and a vaccine for HIV infection; and to support the development of a public health system which ensures that its services are available to all those in need. On behalf of AIDS Action Council's diverse membership I bring your attention to issues impacting funding for FY 2009.

Over 25 years since it was first identified, the HIV/AIDS epidemic in the US is characterized by needless mortality, inadequate access to care, persistent levels of new infection, and stark racial inequalities. Despite the good news of improved treatments, which have made it possible for people with HIV disease to lead longer and healthier lives, stark realities remain. Consider that in the United States…

- Every year, over 40,000 people are newly infected with HIV – **one new infection every 13 minutes**. According to the Centers for Disease Control and Prevention (CDC) the HIV infection rate has not fallen in 15 years.
- Over a million people are living with HIV or AIDS; an **estimated half of people living with HIV/AIDS are not in care.**
- Between 14,000 – 16,000 people die from HIV related causes each year.
- African Americans represent **13% of the population but nearly half of all newly reported HIV infections.**
- In 2005 **Hispanics/Latinos with only 13% of the population accounted for 20% of newly reported cases of HIV.**
- **The percentage of newly reported HIV/AIDS cases in the U.S. among women tripled from 8% to 27% between 1985 and 2007.**
- AIDS is the **leading cause of death among black women aged 25-34**
- HIV is **the #1 health care risk for gay men.**
- Almost **half of all Americans who are newly diagnosed are identified too late in their disease progression to fully benefit from lifesaving therapies.**
- There is neither a cure nor a vaccine for HIV and current treatments do not work for everyone.

The federal government's commitment to funding prevention, research, and care and treatment for those living with HIV is critical. We would be unable to respond to this epidemic without the federal government's increased commitment to funding HIV programs at home. However, we are not doing enough. The unsatisfactory outcomes from our country's response to AIDS have serious human and economic costs. A study published in 2003 found that failure to meet the government's then goal of reducing HIV infections by half would lead to $18 billion in excess expenses through 2010. We need more prevention, more treatment and care and more research if we are ever to slow and eventually reverse this epidemic.

It is AIDS Action's hope that the Congress, through the good work of this subcommittee, will recognize and address the true funding needs of the programs in the HIV/AIDS portfolio. HIV is a 100% preventable disease that can be lessened with a focused, concentrated effort and increased funding. The community has come together under the umbrella of the AIDS Budget and Appropriations Coalition with the community funding request for the HIV/AIDS domestic portfolio for FY 2009. The numbers requested represent that community work. These requests have been submitted to the committee.

According to CDC estimates contained in the agency's March 2006 HIV/AIDS Surveillance Report, 1,014,797 cumulative cases of AIDS have been diagnosed in the United States, with a total of 565,927 deaths since the beginning of the epidemic. As noted above, the CDC estimates that between 1.1 and 1.2 million people are living with HIV/AIDS and that 250,000 -350,000 people are unaware of their status and could unknowingly transmit the virus to another person. As funding has remained essentially flat for more than seven years, money has shifted to new and needed HIV testing efforts and initiatives. As a result, grants to states and local communities have significantly decreased and new infections have stubbornly remained at the level of over 40,000 per year. The CDC is expected to release new incidence data this year, revealing rates over 40,000 new infections annually. Dr. David Holtgrave, chair of the Johns Hopkins Bloomberg School Department of Health, Behavior and Society, has convincingly shown that there is a strong correlation between the lack of funding increases and the failure to reduce the number of new HIV infections. **Therefore, AIDS Action Council and the HIV community estimates that the CDC HIV Prevention and Surveillance programs will need $1.3 billion, an increase of $608 million, in FY 2009 to address the true unmet needs of preventing HIV in the United States.**

Now in its eighteenth year, The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, administered by the Health Resources and Services Administration (HRSA) and funded by this subcommittee, provides services to more than 533,000 people living with and affected by HIV throughout the United States and its territories. It is the single largest source of federal funding solely focused on the delivery of HIV services; it provides the framework for our national response to the HIV epidemic. CARE Act programs have been critical to reducing the impact of the domestic HIV epidemic. Yet in recent years, CARE Act funding has not kept pace with the epidemic and has decreased through across-the-board rescissions. In FY 2008 some CARE Act programs received modest increases, while others were decreased. Part B (Title II) base, The AIDS Education and Training Centers, and the Dental Program were significantly cut. It is important to remember that CARE Act programs are designed to compliment each other. It is necessary that all parts of the CARE Act receive increased funding to ensure the success of the program. **AIDS Action and the HIV/AIDS community estimate that the entire Ryan White**

CARE Act portfolio needs $2.7816 billion in FY 2009 to address the true needs of the hundreds of thousands of people living with HIV who are uninsured, underinsured, or who lack financial resource for health care.

Part A (Title I) of The Ryan White CARE Act now includes five additional Transitional Grant Areas (TGAs). Some of the services provided under Title I include physician visits, laboratory services, case management, home-based and hospice care, and substance abuse and mental health services. Under the most recent reauthorization these services are even more dedicated towards funding core medical services and to ensuring the ability of patients to adhere to treatment. These services are critical to ensuring patients have access to, and can effectively utilize, life-saving therapies. **AIDS Action along with the HIV/AIDS community recommends funding Part A/Title I at $840.4 million, an increase of $213.25 million.**

Part B (Title II) of the CARE Act ensures a foundation for HIV related health care services in each state and territory, including the critically important AIDS Drug Assistance Program (ADAP). Title II base grants (excluding ADAP) received a decrease of $19.25 million in FY 2008. **AIDS Action along with the HIV/AIDS community recommends funding for Part B/Title II base grants at $481.9 million, an increase of $95.3 million.**

The AIDS Drug Assistance Program (ADAP) provides medications for the treatment of individuals with HIV who do not have access to Medicaid or other health insurance. According to the 2007 National ADAP Monitoring Project, ADAP provided medications to approximately 96,121 clients in 2006. **AIDS Action along with the HIV/AIDS community recommends $943.5 million, an increase of $134.6 million, for ADAP for FY 2009.** This "community need" number is derived from a pharmacoeconomic model to estimate the amount of funding needed to treat ADAP eligible individuals in upcoming federal and state fiscal years. The need number represents the amount of new funding required to allow state ADAPs to provide a minimum clinical standard formulary of HIV/AIDS medications to ADAP clients under the current eligibility rules for each state.

Part C (Title III) of the Ryan White CARE Act awards grants to community-based clinics and medical centers, hospitals, public health departments, and universities in 22 states and the District of Columbia under the Early Intervention Services program. These grants are targeted toward new and emerging sub-populations impacted by the HIV epidemic. Part C (Title III) funds are particularly needed in rural areas where the availability of HIV care and treatment is still relatively new. Urban areas continue to require Part C (Title III) funds as emerging populations as grantees struggle to meet the needs of previously identified HIV positive populations. **AIDS Action, along with the HIV/AIDS community, requests $299.3 million, an increase of $100.5 million, for Part C (Title III).**

Part D (Title IV) of the Ryan White CARE Act awards grants under the Comprehensive Family Services Program to provide comprehensive care for HIV positive women, infants, children, and youth, as well as their affected families. These grants fund the planning of services that provide comprehensive HIV care and treatment and the strengthening of the safety net for HIV positive individuals and their families. **AIDS Action and the HIV/AIDS community request $122.5 million, an increase of $48.8 million, for Part D (Title IV).**

Under Part F, the AIDS Education and Training Centers (AETCs) is the training arm of the Ryan White CARE Act; they train the healthcare providers, including the doctors, advanced practice nurses, physicians' assistants, nurses, oral health professionals, and pharmacists. The role of the AETCs is invaluable in ensuring that such education is available to healthcare providers who are being asked to treat the increasing numbers of HIV positive patients who depend on them for care. Additionally, the AETCs have been tasked with providing training on Hepatitis B and C to CARE Act grantees and to ensure inclusion of culturally competent programs for and about HIV and Native Americans and Alaska Natives. However no funding has been added for additional materials, training of staff, or programs. The AETCs were cut by $600,000 in FY 2008. **AIDS Action and the HIV/AIDS community request $50 million, a $15.9 million increase, for this program.**

Also under Part F, Dental care is another crucial part of the spectrum of services needed by people living with HIV disease. Oral health problems are often one of the first manifestations of HIV disease. Unfortunately oral health is one of the first aspects of health care to be neglected by those who cannot afford, or do not have access to, proper medical care removing an opportunity to catch early infections of HIV. **AIDS Action and the HIV/AIDS community request $19 million, a $6.14 million increase, for this program.**

Finally under Part F, rising infections and strapped care systems necessitate the research and development of innovative models of care. The SPNS program is designed for this purpose and must continue to receive sufficient funding.

The Minority AIDS Initiative directly benefits racial and ethnic minority communities with grants to provide technical assistance and infrastructure support and strengthen the capacity of minority community based organizations to deliver high-quality HIV health care and supportive services to historically underserved groups. HIV/AIDS in the U.S. continues to disproportionately affect communities of color. The Minority AIDS Initiative provides services across every service category in the CARE Act and was authorized for inclusion within the CARE Act for the first time in the 2006 CARE Act reauthorization. It additionally funds other programs throughout HHS. **AIDS Action and the HIV/AIDS community request a total of $610 million for the Minority AIDS Initiative.**

Research on preventing, treating and ultimately curing HIV is vital to the domestic and global control of the disease. The research agenda for HIV prevention science at the Office of AIDS Research (OAR), part of the National Institutes of Health (NIH), targets interventions to at-risk individuals, both infected and uninfected, to reduce HIV transmission. It is essential that OAR continue its groundbreaking research in both basic and clinical science to develop a preventative vaccine. Research on microbicides, gels, creams or other substances that prevent the sexual transmission of HIV and other sexually transmitted infections (STIs) when applied topically, is also critical.

The research at NIH on new medications for drug resistant strains of HIV is also critical. The current success of treatment for people living with HIV and AIDS is due in large part to early research investments in new drugs. The United States must continue to take the lead in the research and development of new medicines to treat current and future strains of HIV. Primary prevention of new HIV infections must remain a high priority in the field of research.

Finally, behavioral research to increase knowledge of sexual behavior and research to help individuals delay the initiation of sexual relations, limit the number of sexual partners, limit the consumption of alcohol and drugs prior to sexual relations, and move from drug use to drug treatment are all critically important in finding a solution to the spread of HIV in the United States. NIH's Office of AIDS Research is critical in supporting all of these research arenas. Increased funding is necessary to ensure that the resources needed to address all the research concerns are available both now and in the future. Commitment in research will ultimately decrease the care and treatment dollars needed if HIV continues to spread at the current rate. **AIDS Action requests that the National Institutes of Health be funded at $33.58 billion in FY 2009 and that the AIDS portfolio must be funded at $3.35 billion**

The Housing Opportunities for People with AIDS (HOPWA) program, administered by the U.S. Department of Housing and Urban Development (HUD), is another integral program in the HIV care system. Stable housing is absolutely critical to the ability of people living with HIV to access and adhere to an effective HIV treatment plan. Without housing, one cannot appropriately store medicine or food and often cannot consistently access clean water or clean bathrooms needed to manage the side effects of medication. Furthermore, when one has no housing, the need for shelter rises above the need to take care of one's HIV infection, which places the individual at higher risk of becoming ill and infecting others. Finally, stable housing plays a key role in HIV prevention; lack of housing is a known risk factor for HIV. Although HOPWA is not part of the Labor, Health and Human Services Appropriations bill, AIDS Action urges all Appropriations Committee members to support this critical program. **AIDS Action requests that $470 million be appropriated to the HOPWA program for FY 2009.**

HIV is a continuing health crisis in the United States. We must continue to work to fully fund our domestic prevention, treatment and care, and research efforts. On behalf of all HIV positive Americans, and those affected by the disease, AIDS Action Council urges you not to accept the President's suggested cuts but rather to increase funding in each of these areas of the domestic HIV/AIDS portfolio. Help us save lives by allocating increased funds to address the HIV epidemic in the United States.

Respectfully submitted,
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AIDS Action
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Testimony Submitted on behalf of
Melanoma Research Foundation

C. RANDY LOMAX, MS, MFT
CHAIRMAN OF THE BOARD
MELANOMA RESEARCH FOUNDATION

March 31, 2008

Mr. Chairman and Members of the Subcommittee, I thank you for providing me the opportunity to testify before the House Labor, Health and Human Services Appropriations Subcommittee.

I am Randy Lomax, and I appear before you as a melanoma survivor and as Chairman of the Board of the Melanoma Research Foundation.

Melanoma Research Foundation

The Melanoma Research Foundation (MRF) is committed to research, education and advocacy in our national battle to find more effective treatments and, ultimately, a cure for this disease. We are the primary US non-profit organization serving the melanoma community and welcome your partnership and support of our efforts.
Our programs and services include:

- *Research.* In 2008 we are investing one million dollars to fund melanoma research grants. These include 14 Career Development Awards ($50,000 per year for a maximum of two years) and 3 Established Investigator Awards ($100,000 per year for a maximum of two years). We are committed to attracting the best and brightest young scientists to melanoma research and to funding long-term scientists on the cutting edge of finding answers. We are also supporting the Society for Melanoma Research, the international organization of melanoma scientists, through an annual grant which supports ongoing efforts as well as their annual educational convention.

- *Education.* In addition to this website, we manage the Melanoma Patients Information Page (www.MRF.org), the international chat room for the melanoma community; and distribute a quarterly newsletter of information, activities and resources. MRF also sponsors educational symposia around the United States. I encourage you to check our website to see where and when these symposia will be held in 2008. In 2007 we initiated a "Melanoma 101" teleconference with a leading melanoma clinician that provided a personal opportunity to both learn more about this disease, as well as asking questions of a leading physician in the melanoma field. We will continue these teleconferences in 2008.

- *Advocacy.* MRF is active in Washington DC. We work to keep melanoma awareness a high priority with elected officials and to encourage their support of research funding. As

well, we are in ongoing communications with the National Cancer Institute of the National Institutes of Health. To increase our presence with federal officials, MRF spearheaded the creation of a Melanoma Alliance of all melanoma organizations in the United States and is the primary supporter of this new organization.

Melanoma and Skin Cancer Facts

The statistics on melanoma and skin cancer are staggering and impact all Americans. The following background information on melanoma has been taken from the introductory section of the National Cancer Institutes' "Community-Oriented Strategic Action Plan for Melanoma Research":

- *Incidence of melanoma is high and is increasing.* The American Cancer Society estimated that in 2007, there were almost 60,000 new cases of melanoma, the most serious form of skin cancer, and more than 8,000 deaths. The NCI has documented a 619% increase in the annual incidence of melanoma and a 165% increase in the annual mortality from 1950 to 2000. Melanoma continues to be the fifth leading type of new cancer diagnosis in the United States. The mortality rate of melanoma for persons ages 16-29 is exceeded only by breast cancer, cervical cancer and non-Hodgkin's Lymphoma. Furthermore, while the death rates for other common cancers such as breast, colon, and prostate cancer are declining, death rates for melanoma have increased over the past 25 years
- *Melanoma results in lost years in the lives of Americans.* Melanoma primarily affects individuals in the prime of their lives—the mean age for diagnosis of melanoma is 50, while for many other cancers it is 65 to 70. Advanced melanoma takes a greater toll than other solid tumors in terms of productive life-years lost. Approximately $1.5 billion is spent in the United States each year on treatment of melanoma.

Despite these alarming statistics, there is no cure for melanoma. There has been progress in the clinical management of melanoma, but the only curative treatment available is surgery to remove the primary tumor or lymph nodes prior to metastasis. For patients with advanced melanoma, their median lifespan is less than one year.

Skin Cancer Prevention and CDC

Research funding for the prevention of skin cancer has been disproportionately low. Skin cancer stands alone as the cancer for which incidence and mortality are rising unabated while the best means for combating the disease, prevention and early detection, continues to be severely underutilized. In part, this is related to the fact that less than 2% of the Centers for Disease Control and Prevention's cancer control budget is devoted to prevention of skin cancer. For Fiscal 2009, we are requesting that the CDC's skin cancer prevention program receive $5 million dollars for public and professional education.

Melanoma Research and the NIH

The Melanoma Research Foundations joins the biomedical advocacy community within urging

the Appropriations Committee to provide a 6.5% increase in funding for the National Institutes of Health in its Fiscal 2009 Labor, Health and Human Services, Education and Related Agencies Appropriations bill.

However, we understand the challenges facing the Appropriations Committee, and the problems created by the President's proposed budget for non-defense discretionary spending, which fails to offer any increase for NIH over the Fiscal 2008 enacted level. For that reason, we respectfully request the Committee's support for report language encouraging the National Cancer Institute to be more strategic in investing the limited dollars for melanoma research that it does receive.

By way of background, we at MRF have been working with Congress, the NCI, and the extramural research community, to develop a strategic plan for melanoma research. The Fiscal 2007 Senate Appropriations Committee (Senate Report No. 109-287) requested that the NCI to convene a panel of extramural and intramural scientists and consumers to identify the current shortfalls and promise of melanoma research and develop a 5-year strategic plan for melanoma research that recommends new directions and targets for future research.

In response to that language, the NCI convened a workshop in February 2007, and from the recommendations of that meeting prepared a "Community-Oriented Strategic Action Plan for Melanoma Research," which was submitted to Congress in July of last year. This Strategic Plan identified three over-arching transformational melanoma research opportunities: reducing melanoma mortality through prevention and early detection; streamlining the development of personalized melanoma diagnosis and treatment; and improving melanoma survival. The panel also identified three cross-cutting, resource-building initiatives that are needed to support efforts to address the three transformational research opportunities: creating a Melanoma Investigators Consortium; promoting sharing of melanoma biospecimens, cell lines, animal models, and research data; and creating a critical mass of researchers in melanoma.

The Congress renewed its interest in NCI's progress in implementing the recommendations of the "Strategic Plan for Melanoma Research" in the Fiscal 2008 Senate Appropriations Committee Report. That report "strongly encourage[d] the NCI to devote sufficient funds in the areas of research opportunity identified by the plan and issue program announcements in those areas." The Appropriations Committee went on to request the Cancer Institute "to report by July 1, 2008, on steps it has taken to implement the plan."

Mr. Chairman, the melanoma advocacy and extramural research community have been working with NCI and we agree that there are specific opportunities NCI can take advantage of to advance melanoma research. Those opportunities are:

- targeted therapies in melanoma, including searching for the genes that drive melanoma, inhibiting pathways that drive melanoma, and developing biomarkers for classification, detection, risk assessment and therapy selection;
- host response in melanoma, including developing strategies to target inhibitory immune cells and to augment the specific and innate immune response; and
- melanoma prevention, including identification of mechanisms by which intense sun exposure lead to the development of melanoma, developing applications of imaging

technology for early detection, and making progress toward facilitating a randomized trial of screening for melanoma.

We have included language for the Fiscal 2009 Committee Report that encourages the NCI to invest its melanoma research dollars on the strategic areas identified above.

Thank you, Mr. Chairman, for providing me the opportunity to represent the community of people affected melanoma and to present written testimony before the Committee on the need for increased funding for NIH and NCI and ensuring that the dollars NCI has for research in melanoma are strategically used according to the plan developed by the research community.

NATIONAL CANCER INSTITUTE

Melanoma. The Committee is aware of the ongoing dialogue between the National Cancer Institute and the advocacy and extramural research community on prioritizing NIH-funded melanoma research, starting with the 2005 *Roadmap for New Opportunities in Melanoma Research* and most recently with the 2007 *Community-Oriented Strategic Action Plan for Melanoma Research.* The Committee is further aware of the advocacy and research community's effort to further prioritize melanoma research into three categories: targeted therapies in melanoma (basic), host response in melanoma (clinical); and prevention, including exploring the feasibility of a randomized trial of screening for melanoma. In a period of limited resources, the Committee encourages the NCI to better target its funds to those areas of research opportunity identified above – basic, clinical, and prevention—and utilize all available mechanisms, including program announcements, to target research in those areas. The Committee requests the NCI to report by July 1, 2009, on steps it has taken to implement those strategic investments in melanoma research.

Testimony by Dr. Harel Weinstein
President of the Biophysical Society
&
Chairman, Department of Physiology and Biophysics
Chair, Graduate Program in Physiology, Biophysics and Systems Biology
Weill Medical College of CORNELL University (WCMC)

Submitted for the written record
on behalf of the Biophysical Society

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

Concerning FY 2009 Appropriations for the National Institutes of Health

March 31, 2008

The Biophysical Society appreciates the opportunity to present this testimony in support of $31.1 billion in funding for the National Institutes of Health (NIH) for FY 2009.

The Biophysical Society is a professional scientific society representing nearly 8000 scientists throughout the United States and the world. Members teach and conduct research in colleges, universities, laboratories, government agencies, and industry. The testimony I am submitting on behalf of the Society focuses on the critical importance of funding for the National Institutes of Health. The Biophysical Society strongly urges this subcommittee to provide the NIH with $31.1 billion, an increase of $1.9 billion, or 6.6 %, above the FY08 enacted level and the President's request for FY 2009. Even in these admittedly difficult fiscal times, one must maintain the seed corn. This increase is needed to sustain our world leadership in biomedical research and innovation and to continue to improve health outcomes for our citizens.

As the most influential federal research agency in the world, the NIH strives to increase its already enormous treasure of biomedical knowledge. Responsible for incommensurable advances in medicine, for fostering growth in medical and pharmaceutical industries and continuous progress in diagnosis of disease and medical techniques, the NIH gives hope to those patients who depend on its innovation and efficiency. NIH also provides strong support for dissemination of knowledge to the public. With a wealth of information from global literature and research it oversees the development and support of medical libraries and databases, training of medical librarians, and other health information specialists. Determined to pursue its goal of discovering new knowledge that can be used to prevent, understand and cure a wide range of disabilities and diseases, NIH research is conducted in its own laboratories among 26 institutes and centers. In addition, scientists at universities, hospitals, and research institutions across the

nation and abroad receive NIH funding on a competitive basis, judged by significance, innovation and expected impact on the NIH mission. Because NIH is the largest federal supporter of research and development (after the Department of Defense), cities and towns across the country (as well as the international community) have been adversely affected by flat NIH funding in the past five years.

According to Research!America, the $29.5 billion appropriation for the NIH represents only 5.5% of the $2.1 trillion in total U.S. healthcare spending. Steady investment in quality research is directly linked to improved prevention and treatment; both are key to reducing healthcare spending. The standstill budget hinders scientific inquiry into pressing biomedical research topics like chronic illness, which is the greatest contributor to rocketing healthcare costs. Seven of the most common chronic illness (including cancer, diabetes, hypertension and stroke) affect 162 million Americans combined and cost the U.S. $1.3 trillion per year. Large increases in NIH funding during the late 1990's resulted in evident biomedical progress with several notable breakthroughs. New technologies developed include a saliva test that detects four molecules which identify oral cancer with 90% accuracy, the clot-busting drug t-PA that became the only FDA-approved emergency therapy to reduce disability from stroke, and treatments that reduced U.S. mother-to-child HIV transmission from 25% to 1%.

Since 2003, lack of budget increases has eroded the purchasing power of the NIH by more that 15%. According to the US Department of Commerce's Bureau of Economic Analysis (BEA), the NIH budget will need to increase by 3.5% in FY 2009 to simply maintain its existing purchasing power. An additional $1.9 billion will provide a financial boost to begin to alleviate the loss of trained scientific personnel, recover the declining morale in scientific labs, and maintain training of the next generation of scientific talent. As science has progressed towards solving complexities at the molecular and nanoscale levels, traditional divisions among scientific disciplines are becoming less relevant; and interdisciplinary research, especially between the life sciences and physical sciences holds much potential for new discovery. The NIH has recognized this important change in health science over the past decade, and has established several NIH Roadmap Initiatives, a series of awards that makes funding for interdisplinary search more accessible. However, lack of funding threatens to compromise cutting-edge interdisciplinary research. After inflation adjustment, the stagnant FY 2009 budget leaves NIH funding 8 % below FY 2004.

Currently only 1 in 4 original research applications is funded. Limited access to funding stifles creativity, while stressful competition for fewer grants promotes intellectual conservatism. Novel ideas that challenge current paradigms cannot be pursued in a climate that funds mainly safe and certain research. But scientists face increasing obstacles to innovation and ingenuity. More time is now spent writing and rewriting grant proposals, with less time to focus on scientific research and peer review. Furthermore, high-quality research often requires expensive technology and equipment: mass spectrometers, which characterize the composition of cells in diseased tissues, and detect impurities or contaminants, cost $450,000 to $750,000. The limited number of small grants cannot support the purchase and use of such equipment.

Limited funding has created yet additional problems for young researchers, who are taking even longer to attain their first grant, from an average age of 34.2 years in 1970 for the first grant, to

today's average of 41.7 years (source: NIH). Diminished prospects of a successful biomedical career have left many discouraged young investigators searching elsewhere for opportunities, such as work in China, India, Singapore, or are forcing them to abandon science altogether. The funding environment also stifles the creativity of established researchers, as scientists do not have the funding to explore new areas of study created by the advances we have produced with successful initiatives like the Human Genome Project or Nanotechnology.

The ability to maintain and enhance the health of its population is an important identifier of a nation's prosperity. The correlation between basic medical research and societal benefit was once recognized and maintained in the U.S. However, countries of the E.U. and Asia now seem to have a greater understanding of the necessity for achieving biomedical leadership to secure improved national health and economic well-being. An increase in the NIH FY 2009 budget will help to restore the balance between America's current economic state and quality of life, and also will provide the appropriate investment for a prosperous future.

Eric Lee Cole
President, Dandy-Walker Alliance, Inc.
Kensington, Maryland

Public Testimony for the Fiscal Year 2009 Public Record Submitted to the House Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

March 15, 2008

Testimony summary:
Dandy-Walker Syndrome is the most common congenital malformation of the cerebellum. The causes of this brain defect are largely unknown and the rate of occurrence is suspect but stated to occur in 1 out of every 5000 live born infants.

I respectfully ask the Committee to please introduce language into the fiscal year 2009 House Appropriations bill for the Centers for Disease Control and Prevention to conduct an epidemiological study or surveillance program capable of producing an accurate estimate of prevalence for the spectrum of abnormalities classified as Dandy-Walker Syndrome, Dandy-Walker Malformation and Dandy-Walker Variant.

I also respectfully ask the Committee to please introduce language into the fiscal year 2009 House Appropriations bill for the National Institutes of Health to disclose historical annual funding levels for Dandy-Walker Syndrome research based on actual grants, contracts, research conducted at NIH and other mechanisms of support.

Thank you, Chairman Obey and Members of the Subcommittee, for this opportunity to submit written testimony on the congenital brain defect Dandy-Walker Syndrome. The causes of which are largely unknown and for which the rate of occurrence is suspect.

My name is Eric Cole and I serve as President of the Dandy-Walker Alliance, the only not-for-profit organization advocating for the brain defect Dandy-Walker and recognized as tax-exempt under Internal Revenue Code section 501(c)(3). However, my proudest title is that of "Dad" to a 2-year-old son who happens to live with this brain defect.

As the father of a child with Dandy-Walker, I see it as my duty and my social obligation to speak on behalf of all Americans with Dandy-Walker and cannot advocate for themselves. My goal is to share with you what is needed by people with Dandy-Walker and submit to you two ways in which you can help.

Dandy-Walker is present from birth and may be diagnosed in-utero, provided that appropriate prenatal care is available and received. The treatment for individuals with Dandy-Walker generally consists of treating the associated problems versus the syndrome itself.

Seizures will manifest in 30 percent of patients with Dandy-Walker. Up to 90 percent of individuals with Dandy-Walker have or will develop a condition called hydrocephalus which is sometimes referred to as water-on-the-brain.

While seizures may be treated with pharmacological solutions with varying degrees of success, hydrocephalus is treated today the same way that was developed in 1952, by inserting a special tube called a shunt into the brain to drain off excess fluid.

There is no definitive answer on how common Dandy-Walker is but some medical journals suggest that it is more common than 1 in every 5000 live born infants. That is why I respectfully ask that the Committee please introduce language into the fiscal year 2009 House Appropriations bill for the Centers for Disease Control and Prevention to conduct an epidemiological study or surveillance program capable of producing an accurate estimate of prevalence for the spectrum of abnormalities classified as Dandy-Walker Syndrome, Dandy-Walker Malformation and Dandy-Walker Variant.

We also need disclosure of efforts to research this brain defect. That is why I am also asking the Committee to please introduce language into the fiscal year 2009 House Appropriations bill for the National Institutes of Health (NIH) to disclose historical annual funding levels for all Dandy-Walker research based on actual grants, contracts, research conducted at NIH and other mechanisms of support.

I understand that balancing the policy needs of our nation is a difficult job. I also believe that understanding the true prevalence of Dandy-Walker, that presently is estimated to occur in 1 out of every 5000 children that are born alive, and knowing the amount of public funding expended to research the causes of this brain defect will help to spur further scientific interest and promote opportunities for the research community to

collaborate with medical practitioners, private industry representatives, advocates and people affected by Dandy-Walker. With your leadership, guidance and support we have the opportunity to act on behalf of millions of disabled members in society who can not advocate for themselves.

Mr. Chairman, my goal in submitting testimony is to seek your help in raising the national profile of Dandy-Walker and ultimately find the causes of and hopefully the cure for this brain defect that affects my 2-year-old son Ryan. I want simply to give Ryan and other individuals affected by this brain defect the same full access, possibilities and experiences as any other person.

All I respectfully ask is that you partner with me in asking the CDC and NIH to help us determine the true prevalence of and disclose the public funding expended researching Dandy-Walker.

Thank you.

John Rogers, MD, MPH, MEd
President, Society of Teachers of Family Medicine

Michael K. Magill, MD
President, Association of Departments of Family Medicine

Mark Robinson, MD
President, Association of Family Medicine Residency Directors

Allan Dietrich, MD
President, North American Primary Care Research Group

Public Witness Testimony for the Record
House Appropriations Labor/HHS/Education Subcommittee
March 31, 2008

FY 2009 FUNDING LEVELS
SECTION 747 PRIMARY CARE MEDICINE AND DENTISTRY CLUSTER
AGENCY FOR HEALTHCARE RESEARCH AND QUALITY
NATIONAL INSTITUTES OF HEALTH

Mr. Chairman, the Society of Teachers of Family Medicine, the Association of Departments of Family Medicine, the Association of Family Medicine Residency Directors, and the North American Primary Care Research Group, thank you for the opportunity to provide this statement for the record on behalf of funding for family medicine training, the Agency for Healthcare Research and Quality (AHRQ) and the National Institutes of Health (NIH).

Health Professions: Primary Care Medicine and Dentistry (Title VII, Section 747)
We request that this committee return funding of the Primary Care Medicine and Dentistry Cluster (Section 747 of Title VII) to its earlier (FY02) funding level of $93 million. Since FY2004, this program has lost more than 50% of its funding. Currently (FY2008), the program is funded at less than $48 million. The President's budget for FY09 continues to zero out funding for this cluster.

Primary Care in Crisis:
Why should Congress restore funding for this program? Primary care in the United States is in crisis. The United States Government Accountability Office (GAO) testified before the Senate HELP Committee in February of this year. It described the difficulties of increasing the number of primary care physicians in the United States and the benefits to the nation of doing so. One of its findings concluded:

> "Health professional workforce projections that are mostly silent on the future supply of and demand for primary care services are symptomatic of an ongoing decline in the nation's financial support for primary care medicine."[1]

Data from the Congressional Research Service (CRS) also show that reduced funding for the primary care medicine and dentistry cluster had a deleterious impact on the effectiveness of these programs – at a time when more, rather than less primary care is needed. For example, "In FY2006, the program supported a total of 17,870 individuals in clinical training in underserved areas, a decrease from the support of 31,153 individuals in FY2005."[2] This is a decrease of almost 43%.

Additional testimony before the Senate HELP Committee last month clarified the problems that primary care in the United States currently faces. Kevin Grumbaugh, MD, Professor and Chair, UCSF Department of Family and Community Medicine, and a recognized expert in workforce research, put it this way:

> "The primary care infrastructure in the United States is crumbling, and patient access to primary care is suffering throughout the nation. From 1997 to 2005, the number of US medical school graduates entering careers in family medicine residencies dropped by 50%, as did the number of internal medicine residents planning careers in primary care rather than specialty medicine. In a 2006 survey of 92 large or medium-sized physician groups, 94% of the respondents ranked internists or family physicians as the most difficult to recruit. Federally funded community health centers reported more than 750 vacant positions for primary care physicians in 2004. In 2007, 29% of Medicare beneficiaries reported a problem finding a primary care physician, up from 24% in 2006."

The Primary Care Payoff[3]

According to a report prepared by the National Association of Community Health Centers, The Robert Graham Center, and Capitol Link, "There is a growing consensus among the nation's political and industry leaders that the U.S. health care crisis has shifted from the realm of the poor and disenfranchised, to the doorstep of middle-class America." Additionally, they cite the following:

> "If every American made use of primary care, the health care system would see $67 billion in savings annually. This reflects not only those who do not have access to primary care, but also those who rely extensively on costly specialists for most of their care, leading to inefficiencies in the

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[1] Testimony before the Committee on Health, Education, Labor, and Pensions, U.S. Senate. Primary Care Professionals: Recent Supply Trends, Projections and Valuation of Services. Statement of A. Bruce Steinwald, Director Health Care, United States Accountability Office.February 12, 2008 GAO-08-472T

[2] CRS Report to Congress. February 7, 2008 Title VII Health Professions Education and Training: Issues in Reauthorization (Order Code RL32546)

[3] Access Granted: The Primary Care Payoff, August 2007, National Association of Community Health Centers, The Robert Graham Center, Capitol Link (pgs 1-2)

> system. More specifically, the expansion of Medical homes can even more dramatically facilitate effective use of health care, improve health outcomes, minimize health disparities, and lower overall costs of care. "

The GAO also cites the importance of primary care in terms of quality and cost:

> "Ample research in recent years concludes that the nation's over reliance on specialty care services at the expense of primary care leads to a health care system that is less efficient. At the same time, research shows that preventive care, care coordination for the chronically ill, and continuity of care --- all hallmarks of primary care medicine – **can achieve improved outcomes and cost savings."** [4][emphasis added]

An April, 2004 *Health Affairs* article found the quality of health care lower in states with higher levels of Medicare spending. The authors suggest that more specialists and fewer primary care physicians mean higher costs and lower quality. A small increase in the number of primary care physicians in a state was associated with a large boost in that state's quality ranking.

The Success of Title VII, Section 747

A 2006 study by the University of California San Francisco and the Robert Graham Center shows that medical schools that receive primary care training dollars produce more physicians who work in Community Health Centers (CHCs) and serve in the National Health Service Corps (NHSC) compared to schools without Title VII primary care funding. This finding is particularly true for family physicians. Without funding for primary care training, fewer family physicians will be trained to work in CHCs and serve in the Corps. Almost 4,000 family physicians and general practitioners exposed to Title VII funding during medical school subsequently chose to work in a CHC. Without this exposure, we would anticipate a decrease of over 750 family physicians working in a CHC in 2003. The JAMA article mentioned below shows 600 current vacancies for family physicians in CHCs. Without Title VII dollars, these data point to twice as many vacancies.

The Health Resources and Services Administration (HRSA) has provided some new data regarding the success of Title VII programs as part of the FY09 budget justification document published by the Administration. It directly counters the Administration's claims of ineffectiveness of these programs, and shows the folly of zeroing out these programs. Below are some selected excerpts:

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[4] Testimony before the Committee on Health, Education, Labor, and Pensions, U.S. Senate. Primary Care Professionals: Recent Supply Trends, Projections and Valuation of Services. Statement of A. Bruce Steinwald, Director Health Care, United States Accountability Office.February 12, 2008 GAO-08-472T

> "During the [PART] review Health Professions developed new long-term and annual performance measures and established baseline data and has since begun regularly collecting data and reporting on performance. In 2007, 57 percent of graduates and program completers of Titles VII and VIII supported programs were underrepresented minorities and/or from disadvantaged backgrounds. This exceeded the target by 17 percent. The proportion of trainees in Titles VII and VIII supported programs training in medically underserved communities was 43 percent in 2007 which exceeded the target of 41 percent. The percentage of health professionals supported by the program entering practice in underserved areas was 35 percent in 2007. This exceeded the target by 14 percent."

We have demonstrated 1) the nation needs more primary care physicians, 2) the efficacy of primary care in reducing costs and promoting quality, and 3) the success of Title VII programs in producing more primary care physicians. Based on these factors, we recommend that the Committee reinvigorate these programs by increasing the Primary Care Medicine and Dentistry funding to a previous level of $93 million.

The Agency for Health Care Research and Quality (AHRQ)

We request funding of $360 million for AHRQ in FY09. This is an increase of $25 million over FY08, and $34 million more than the President's FY09 Budget request. For the last several years, even with an increase in FY08, funding for AHRQ has remained relatively stagnant, while it's portfolio of work has increased dramatically. Our researchers are finding that investigator-initiated grants are very difficult to obtain.

It should be noted that a much larger investment should be made, as recommended by The Institute of Medicine's report, *Crossing the Quality Chasm: A New Health System for the 21st Century* (2001). It recommended $1 billion a year for AHRQ to "develop strategies, goals, and actions plans for achieving substantial improvements in quality in the next 5 years..." The report looked at redesigning health care delivery in the United States. AHRQ is critical to retooling the American health care system.

One of the hallmarks of the patient centered medical home is evidence-based medicine. Comparative effectiveness research, which compares the impact of different options for treating a given medical condition, is vital to improving the quality of health care. Studies comparing various treatments (e.g. competing drugs) or differing approaches (e.g. surgery and drug therapy) can inform clinical decisions by analyzing not only costs but the relative medical benefits and risks for particular patient populations.

Comparative effectiveness research holds out the promise of reducing health care costs while improving medical outcomes. AHRQ's Effective Health Care Program is critical if we are to realize that promise. Although the President's budget request proposed to hold this important program at $30 million, the same as FY 2008, we hope that the Congress will increase our investment in comparative effectiveness research.

National Institutes of Health (NIH)
Historically, the research at NIH has failed to pose the questions asked by family doctors in primary care practice regarding treatment of their patients. We are encouraged by the development of the NIH Roadmap and the Clinical and Translational Science Awards (CTSA), along with the establishment, in statute, of a funding stream for the common fund that demonstrates the willingness of NIH to become a more fertile arena for family medicine and other primary care research. Hence, we support the Ad Hoc Group for Medical Research and others' call for an increase in NIH funding. In addition, we would like to see some report language that would help NIH ensure that the promise of bench to bedside research truly becomes bench to bedside to community – and back.

We support the inclusion of the following language in the report to accompany the Labor/HHS appropriations bills for FY08.

"Translational Research has been identified by the Director of the National Institutes of Health (NIH) as a road map initiative. The committee supports this effort and encourages NIH to integrate such research as a permanent component of the research portfolio of each institute and center. The committee urges NIH to begin discussions to determine how best to facilitate progress in translating existing research findings and to disseminate and integrate these findings at the practice level. Translational research should also include the discovery and application of knowledge within the practice setting using such laboratories as practice-based research networks. This research spans biological systems, patients, and communities, and arises from questions of importance to patients and their physicians, particularly those practicing primary care. The Committee requests that the Director of NIH include a progress update in next year's Budget Justification."

Conclusion:
We hope that the committee will be able, with the more generous figures included in the FY09 House and Senate Budget Resolutions this year, to fund increases in these three important programs: health professions primary care medicine and dentistry training, AHRQ, and NIH. Certainly, at a minimum, we request that funding cuts to the health professions primary care medicine and dentistry training program be restored to at least FY05 levels of $88.8 million. However, these programs were funded at a historic high of $93 million in FY2002, and we support a return to that figure.

Vicki Modell
Co-Founder
The Jeffrey Modell Foundation

Mr. Chairman and Members of the Subcommittee:

Thank you for the opportunity to present this testimony to the Subcommittee. My name is Vicki Modell and, along with my husband Fred, we created the Jeffrey Modell Foundation (JMF) in 1987 in memory of our son, Jeffrey, who died at the age of 15 as a result of a life long battle against one of the estimated 140 primary immunodeficiency (PI) diseases.

The Jeffrey Modell Foundation is an international organization with its headquarters in New York City. In the 21 years since we established it, the Foundation has grown into the premier advocacy and service organization on behalf of people afflicted with primary immunodeficiency diseases. As a demonstration of the extent to which the JMF leads in the field, please consider the following:

- The Foundation has created Jeffrey Modell Research and Diagnostic Centers at 38 academic and teaching hospitals from coast to coast in the United States and throughout the world. The Centers funded by the Jeffrey Modell Foundation are located in Boston, Los Angeles, New York City, Philadelphia, Seattle, Stanford, San Francisco, Miami, Milwaukee, Dallas, Chicago, and others. The JMF Referral Network includes 350 physicians at 180 Centers in 53 countries spanning 6 continents.

- The Foundation conducts a national physician education and public awareness campaign, currently funded with approximately $2.9 million appropriated by this subcommittee to the Centers for Disease Control and Prevention (CDC) and awarded by contract to the JMF. To date, the Foundation has leveraged the federal money to generate in excess of $90 million in donated media with hundreds of thousands of placements on television, radio, print, and other public media, as well as a 30-minute program produced for PBS. The campaign has also included physician symposia, conducted for CME credits in locations throughout the country. It has also included mailings to physicians in a variety of specialist and primary care fields, including pediatrics and several pediatric specialties, family practice, and internal medicine, as well as school nurses, clinical and registered nurses and daycare centers.

- In addition, the Foundation has long been a provider of direct patient services such as KIDS Days that give young people an opportunity to meet and share experiences with others similarly situated in their communities in a fun atmosphere that encourages a feeling of normalcy in patients. This was something that Jeffrey never experienced and one of the things we wanted to address from the beginning of the Foundation. We also offer a hotline that serves patients 24 hours a day.

First and foremost, Mr. Chairman, I am here today to thank you and all the members of this subcommittee on both a personal and a professional level. Personal because whenever Fred and

I come to Washington, whether it is to testify here before the committee or to meet with the members of the subcommittee individually in their offices, every Member of Congress and every member of your staffs are unfailingly polite, courteous, interested and caring. The response that we receive, and the warmth and understanding that we enjoy, makes this a labor of love for us.

And, professional because over the sixteen years that we have been coming to Washington, we have been given the opportunity to build a partnership with the Congress, the Centers for Disease Control and Prevention, the National Institutes of Health, as well as with our own supporters in the private sector, including industry and other concerned donors. We believe that we have maximized the benefits for patients from the support that this subcommittee has afforded us. I would like to take a few minutes to discuss where we are and, more importantly, where we are going with your continued support.

The Centers for Disease Control and Prevention

This subcommittee is currently funding CDC with $2.9 million for physician education and public awareness of immune deficiencies. I am delighted to report that the President's recommended budget for FY09 continues the program at its FY08 level. The Jeffrey Modell Foundation operates the program under a contract with CDC, with whom we have a very strong relationship.

Since the campaign's inception, it has generated nearly $100 million in donated media, including television and radio spots, magazine ads, billboards, airport signs and other print media. It has also enabled us to raise additional funding from the private sector – both individuals and the pharmaceutical industry. To this point, every $1 provided by the subcommittee to this program has been leveraged into more than $10 for this education and awareness program. Also, visits to the website have increased by more than 50 percent from approximately 600,000 per month to over 900,000 per month. Continuing to incorporate "new media" into the campaign will extend its reach, particularly to young parents and others.

Most importantly, Mr. Chairman, I am delighted to report to you that the program that this subcommittee has funded is having exactly the impact that all of us hoped it would when it was created. Allow me to give you some specifics. This data was recently published in the scientific journal *Immunology Research.*

169 physicians from 85 Jeffrey Modell Diagnostic and Referral Centers responded to a survey relating to PI. Baseline reports for the period before the Education and Awareness program and reports for the year following the program were compared. The results were striking.

- The number of patients diagnosed at these centers went from approximately 5,900 at baseline to over 31,000 in the follow up, an annual increase of 132%.
- Patient referrals from generalists to specialists increased by 87%.
- The number of diagnostic tests performed went up by an astounding 656%.

- There was a 102% annual increase in the number of patients receiving treatment.

- Finally, patients receiving intravenous immunoglobulin went up by 81%.

But, it is fair of this subcommittee to ask "so what?" What difference does it make to the to the health of these patients if they are now in treatment? What is the real impact in a real world sense on the patients that are found?

Eighty five centers responded to a survey assessing 532 patient records and again the data are amazing. Comparing patients' charts for the year before diagnosis and the year after diagnosis, the following conclusions are reached:

- Acute infections are down 72%.
- Physician/hospital/ER visits are down 83%.
- Severe infections are down 86%.
- Pneumonias are down 79%.
- Days with chronic infections are down 72%.
- Time on antibiotics is down 56%.
- Days in the hospital are down 73%.
- School/work days missed are down 74%.

But, again, the subcommittee might ask, "How does diagnosing and treating patients improve the public health and help reduce health care costs?" That is a fair question and one we are prepared to answer.

The economic impact of PI diagnosis was carefully assessed comparing the costs of treatment before diagnosis and after. In round numbers what we learned was that the average annual cost of health care for an undiagnosed patient is $103,000 per year. The same costs for the same patients in the year after diagnosis are $23,000. The gross annual savings is $80,000 per patient. The NIH estimates that at least 500,000 cases of PI are undiagnosed in the United States, thus the economic impact of undiagnosed PI patients to the healthcare system of the United States totals over $40 billion dollars annually.

Mr. Chairman, this program is working. We are respectfully requesting that the funding level in the President's budget receive just a five percent cost of living increase so that we can continue to build on the success we have had to date.

Newborn Screening Program

As described above, early diagnosis is critical to the health of patients and to saving the healthcare system money. And, there are few better examples of early diagnosis than newborn screening. The JMF has worked long and hard to support the development of a newborn screening program for Severe Combined Immune Deficiency (SCID), the most severe and deadly form of PI.

Early detection of SCID through newborn screening is vital because bone marrow transplants cure over 98 percent of infants who have the procedure before developing any serious infections. The treatment costs less than $10,000. However, if an infant receives a transplant after developing severe infections, the success rate is only between 50 and 60 percent; the costs associated with the treatment of these infants can be as high as $1 million.

After working with NIH and a private company to develop a screening test for SCID, we collaborated with the CDC to hold a meeting in Atlanta on this topic with scientists and public health officials from around the country. The result was a commitment from the State of Wisconsin to run a pilot program for SCID testing. The pilot program screened 10,000 babies in 2007. I am delighted to report that this program developed into general population screening effective January 1, 2008. Every baby born in Wisconsin is being tested for SCID. Next year, Mr. Chairman, I hope to report on the success of this project.

The Wisconsin project was funded by the state, Children's Hospital and the JMF. The FY08 Omnibus Appropriations bill contains $1.0 million to expand this pilot program to at least two additional states. We hope to have results for you on this next year as well. And, Mr. Chairman, we are asking that the $1.0 million be restored to the FY09 appropriations bill so that this life-saving and money-saving endeavor can go forward in more states.

National Institutes of Health

Mr. Chairman, in addition to CDC, the Jeffrey Modell Foundation has a long history of working closely with the National Institutes of Health on the scientific research issues that surround primary immunodeficiencies. We have long enjoyed a strong collaborative relationship with several institutes and want to inform the subcommittee of the exciting new initiative we are undertaking.

In our frequent meetings with the world's top researchers in this field, we have become increasingly concerned that the constraints on the NIH budget are having a negative impact on researchers' ability to stay in this field and to develop the next generation of PI researchers.

After doing a series of meetings around the NIH, we have reached an agreement to enter into a collaborative research program. The JMF will bring its resources to the NIH and match federal funding on a research initiative that will be targeted at jumpstarting the field and moving the science forward through the normal peer-review channels.

Our partners in this endeavor – NIAID, NICHD, NHLBI and NIDDK – are working now to craft the announcement of the availability of this funding. We are envisioning a multi-institute, multi-disciplinary program that will generate up to $14 million in new research. There remains so much to learn, particularly when it comes to the causes and cures at the molecular level. For this program, all we are seeking is a strongly encouraging paragraph of report language that has been submitted by at least two of your colleagues.

Again, this is an initiative that we are looking forward to coming back to you next year with good news about the success we anticipate we will be having by the time your committee reconvenes.

Conclusion

With the support the Jeffrey Modell Foundation has received from this subcommittee over the years, we have been able to increase the public's awareness of PI and most importantly improve and save lives. We are grateful for your past and continued support. While we understand that the subcommittee must make difficult decisions in this fiscal environment, please remember that the Foundation has successfully leveraged federal dollars to expand the reach of all of our activities. Frankly, the collaboration between the federal government and the Jeffrey Modell Foundation has been a model for successful public-private collaborations. The impact of every federal dollar spent on the education and awareness campaign, on newborn screening, and on research has been exponentially increased by our commitment to bring the Foundation's resources to bear. This is a real working partnership, because as always we ask only for a hand, never for hand-out.

Mr. Chairman, again, we are delighted to have the opportunity to present to the subcommittee and stand ready to continue to work with you.

Frank Somma
National President
Cooley's Anemia Foundation

March 31, 2008

Mr. Chairman and Members of the Subcommittee:

Thank you for the opportunity to present this testimony to the Subcommittee today. My name is Frank Somma. I live in Holmdel, New Jersey and I am honored to serve as the National President of the Cooley's Anemia Foundation. As many members of this subcommittee know, Cooley's anemia, or thalassemia, is an incurable, fatal genetic blood disorder.

Over the years, this subcommittee has been a consistent supporter of the programs that exist to improve the lives of our children – children who suffer from thalassemia. We are very grateful for all that you have done to help over the years and again, we are asking that you continue to support the research and the programs that will help lead to a cure for this dreaded disease.

I could bog you down in a detailed scientific explanation of what happens physiologically when the human body cannot produce red blood cells in adequate numbers and of adequate quality to sustain life or the danger and pain of bi-weekly blood transfusions I am not going to do that. **The important thing for members of this Subcommittee to remember about Cooley's anemia is that it is an incurable, *fatal* genetic blood disorder. Period.**

In my testimony, I am going to address the following three issues in what I hope is a clear and succinct manner.

- The first is the immediate need to provide a five percent increase to the CDC's Division of Blood Disorders to fund the thalassemia blood safety surveillance network. This program works for thalassemia patients, and for all Americans, *by providing a mechanism to take immediate actions to keep the blood supply safe when a threat emerges.* The President's budget recommends $1.85 million; we are requesting $1.95 million.

- The second issue is the equally critical need for this Subcommittee to commit our government through the NIH – and more specifically through NHLBI – to the development of a vigorous, ethical, progressive and focused gene therapy program that is designed to *cure single- gene disorders in the shortest possible time.*

- The third issue is the urgent need to increase funding for the NIH by a minimum of 6.5 percent this year and to *assure the continuation of desperately needed research through the Thalassemia Clinical Research Network, which is based at NHLBI.*

Blood Safety Surveillance:

Mr. Chairman, when a baby is diagnosed with Cooley's anemia, or thalassemia major, the standard of treatment is to begin that child on blood transfusions. I want to be very clear here that the treatment is not to give the child a blood transfusion; it is to begin a lifetime treatment regimen of this most invasive and dangerous intervention. *Once diagnosed, our children receive a blood transfusion every two weeks for the rest of their lives.*

Because Cooley's anemia patients are transfused so regularly and so often, they represent an "early warning system" for problems in the blood supply. If there is an emerging infection or other problem with the blood supply, it is our patients that will get it first and, because of their fragile health, will likely suffer more critically from secondary complications.

Please understand, for example, that nearly every patient over the age of 18 today who has thalassemia major also has HIV or hepatitis C, or both, as a result of their transfusions – or did have it before the combination of the infectious disease and their underlying genetic disease killed them.

Blood safety is a major national issue. Surgical and trauma patients often have no choice but to be transfused. And, it is done on an emergency basis everyday in hospitals in your states and districts. Nothing is more important to the patient at the time of transfusion than that they can be confident that the blood being pumped into their veins is free from infectious agents – HIV, HCV, or something that none of us have yet heard and doctors have yet to identify.

The blood safety surveillance program is currently operating very effectively through the Division of Blood Disorders in the National Center for Birth Defects and Developmental Disability (NCBDDD) with about $1.86 million in funding. We are pleased that the President's budget recommends continuing it, although at a $1.85 million level.

We are respectfully urging that the Subcommittee increase this funding to $1.95 million to reflect inflationary pressures in order to continue to protect Americans from unnecessary infections and diseases that may occur in the blood supply. Also, we are requesting that the Subcommittee and its staff remain vigilant in protecting this program from unjustified and unjustifiable assaults as we saw after the passage of the FY07 Continuing Resolution.

Gene Therapy:

Mr. Chairman, as you know, in the last year or two we have begun to see evidence of some very good news about gene therapy. After decades of overblown promises and false starts, we can now see a pathway for scientists to follow to help make the *promise* of gene therapy become the *reality* of cures. The problem to this point in the long saga that is gene therapy has not been one of science; it has been one of expectations. As a society, we all forgot that science requires trial and error and that experiments are just that – experiments. Sometimes they succeed, but often

they fail. And, when they fail, we need to analyze what happened and identify how to correct it...*and then try again.*

Today, gene therapy is advancing at a rapid pace in the rest of the world. Exciting work is being undertaken in Japan and China, in the UK and in France. Unfortunately, it is showing less progress the United States of America...and that is not right. We are the international leaders in scientific research and, in a field like this – fraught with financial, scientific and ethical minefields – it is essential that America demonstrate its continued leadership to the world. We set the highest ethical and moral standards on every one of these issues. We protect human subjects best. The future of gene therapy as a means of curing disease is simply too important to leave it to anyone else.

For persons with a single cell mutation disorder like thalassemia or sickle cell disease or "boy in the bubble" disease (SCID), gene therapy holds tremendous promise for a cure. We are now learning so much about how to deliver healthy genes to unhealthy cells that we cannot turn back – nor can we as a nation afford to let down the scientists in this country who have such a depth of knowledge and experience. Our friends in Europe and Asia are leaping ahead of us in this critical area of biomedical research and gene therapy.

We hope that this Congress – speaking through this subcommittee – will do what we have done and dare the NIH and its grantees to "cure something." You are investing nearly $29 billion of taxpayer money in this agency that houses the "best and the brightest" in Bethesda and that funds "the best and the brightest" throughout the nation. We as Americans must never stop striving to reach previously unimaginable heights. If that means that we have to shake up the status quo and create a new funding mechanism, let's do it. But let's not continue to follow the slow going incremental, some might say "glacial," path of the past.

We need to spend our tax dollars in a coordinated and focused manner that will maximize the chances that science will unlock the secrets of how to correct single gene defects. We are gaining direct knowledge of how to safely proceed, with an experiment currently being conducted – in France – that may be a breakthrough. **It is time for the US to step up and lead the world in this life-saving area of research. We are counting on our representatives in Congress to lead the way.** As I said, this research is being done in other places around the world. In the US I have detected a reticence to proceed because of safety concerns which made news years ago. If we are truly concerned with safety, doesn't it make sense to embark on gene therapy here where we know the IRB's will ensure that patients come first?

NIH and the Thalassemia Clinical Research Network:

Mr. Chairman, eight years ago, working closely with members of this Subcommittee from both sides of the aisle, the CAF convinced the NHLBI of the need to create a Thalassemia Clinical Research Network. The purpose of the Network is to create an infrastructure that would enable the top researchers in the field to collaborate on desperately needed research projects using common protocols. Today, the Network is up and running and is the focal point for thalassemia research, most of which takes place in academic medical centers, literally spread from coast to coast.

However, there remains a cloud hanging over this, and all other, research at NIH. As the Biomedical Research and Development Price Index continues to escalate, the buying power of an NIH that has been flat-funded for five years continues to decrease. There would be nothing wrong with this if we had cured thalassemia, hemophilia, cystic fibrosis, and all other genetic and non-genetic diseases. But that is not the case.

There is an enormous amount of work to be done, treatments to be developed and cures to be found. And there is no one else to do it but our National Institutes of Health, with the support of our Congress and President.

I urge the Subcommittee to make a commitment this year in this bill to at the very least a 6.5% increase for the National Institutes of Health. This level of funding will help to restore some of the purchasing power that has been lost since the end of the five year doubling. It is time to commit to undo the damage that has been done in the last 5 years. I also urge the committee to assure that NIH shows no diminution of support the Thalassemia Clinical Research Network.

Conclusion:

As I indicated at the outset, Mr. Chairman, the Cooley's Anemia Foundation has three priorities this year:

- Funding the blood safety surveillance program at CDC at $1.95 million;
- An enhanced focus on gene therapy designed to cure something; and,
- At least a 6.5% increase in NIH funding and the continuation of the Thalassemia Clinical Research Network.

Mr. Chairman, every night when I watch my beautiful, smart, talented 23 year old daughter Alicia suffer from the complications of thalassemia such as osteoporosis and as I watch her endure daily 8-10 hours of painful drug infusions to remove the excess iron in her system from her bi-weekly blood transfusions, I know we can do better than what we are doing now.

Please excuse my passion, but this is the United States of America. I know we can prevent this disease from happening in newborns. I know we can improve the lives of those who currently have it. And, most importantly, I know that we can cure it once and for all.

It is long past time to demand the very best from the very best – our scientists, our government, and ourselves.

Thank you for your very kind attention and for all the support this committee has shown to our patients and their families over the years.

Public Witness Testimony for the Fiscal Year 2009 Public Record
March 31, 2008

Testimony of:

David Ward, president of the American Council on Education and co-chairman of the Student Aid Alliance
David Warren, president of the National Association of Independent Colleges and Universities and co-chairman of the Student Aid Alliance

On behalf of the Student Aid Alliance, a coalition of organizations representing students, parents, colleges and universities and others who believe that all qualified students should be able to go to college regardless of their financial resources, we appreciate the opportunity to submit this testimony for the record.

Since the G. I. Bill was enacted in 1944, the federal government has taken the lead in making the American dream of a college education possible. The combined impact of grant, work-study and loan programs is what makes the difference for low-income students. Without the partnership between the federal government, states, institutions and families, millions of students would not be able to go to college.

The Pell Grant program is central to this partnership and it plays a unique role in promoting economic and social mobility in the United States. It is the nation's largest single source of need-based grant assistance, serving more than 5 million students—one in every three undergraduates—annually. Everything we know about the effects of higher education suggests that Pell Grant recipients will be better prepared for 21st century jobs and will earn higher wages than their peers who are not able to pursue postsecondary education. They also will be more likely to participate actively in their communities, to vote and to send their own children on to higher education. The relatively small public investment in the Pell Grant program reaps huge rewards in increased prosperity, reduced reliance on public assistance and enhanced civic life.

In the first session of the 110th Congress, the College Cost Reduction and Access Act (CCRAA) shifted $20 billion from student loan providers in order to lower student loan interest rates and to provide additional Pell Grant increases for the next five years. CCRAA's stated goal is to augment the discretionary appropriation for Pell in order to reach a maximum grant of $5,400 in five years. This temporary, five-year infusion of mandatory funds to the Pell Grant program

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Invest in futures. Theirs and ours.

should not be used to camouflage a lack of growth in the discretionary maximum award. Last year, the House took the lead on increasing Pell Grant appropriations, but budget battles whittled away the appropriated maximum grant from $4,310 to $4,241. We applaud the House for recognizing that, without annual appropriations increases, not only will the Pell Grant program fail to reach the target $5,400 maximum in five years but, if discretionary funds decline or stay level, there will be a massive reduction in the maximum award students receive six years years from now when the mandatory funds vanish.

In the second session, we urge Congress to recommit to increasing student aid appropriations. With a federal budget of $3 trillion, a shaky economy and the national need to remain globally competitive, this is an especially important time for the federal government to make an investment in college students' futures. Some of the trends that support such an investment are familiar: increased enrollment, including a two-year spike in the growth of the very lowest income students; an increase in enrollment among unemployed workers who are attempting to retrain for new jobs; and disinvestment in higher education at the state level as budgets are slashed in state after state.

However, as if these factors alone were not sufficient cause for an investment in federal student aid, there is a new and ominous trend on the horizon: turbulence in the student loan markets. While this trend is still evolving and its full ramifications are not yet clear, it is safe to say that if there is a sizable disruption in the student loan industry, the result could be students lacking the funds they need for college this fall. To date, dozens of lenders have discontinued their participation in the federal student loan programs. A recent estimate suggests that out of 2,000 current lenders who participate in the Federal Family Education Loan Program (FFELP), none of the not-for-profit lenders and only about 15 private lenders will remain in the program by next year. Other lenders—those who issue private loans to students—are stating that they will institute added charges or require credit checks or co-signers for certain groups of borrowers. At a recent hearing of the House Education and Workforce Committee to assess the impact of these trends, Chairman George Miller asked the witnesses what steps Congress should take and was told that increasing grant funds and Perkins Loan capital would be welcome steps.

Reflecting that urgent request, we urge that the FY 2009 appropriation should provide a significant increase for student aid. Not only do our nation's students deserve a college education, but our nation's competitive and economic health depends on it.

Pell Grants

The maximum Pell Grant should be $5,100. Pell Grants provide basic college assistance to financially disadvantaged students. The grants are the foundation of a low-income student's aid package. More than 5.3 million students with a median family income of less than $20,000 received Pell Grants in FY 2007.

During his 2000 campaign, candidate George W. Bush called for a $5,100 Pell Grant maximum award, saying, "College is every parent's dream for their children and we should make this

opportunity available to all students." As Democrats campaigned to retake the majority in Congress, a $5,100 Pell Grant was one of their "6 for '06" priorities. In FY 2009, Congress and the president should achieve this bipartisan goal.

To get there, the appropriated maximum grant should be increased by $369. A $4,610 appropriated maximum grant, plus the additional $490 from mandatory funds, would achieve a $5,100 Pell Grant maximum this year.

Campus-based and state aid

Erosion of campus-based and state aid programs should stop. These programs were created to ensure that institutions of higher education and states are partners in helping low-income students go to college. Over the last seven years, the Supplemental Educational Opportunity Grant (SEOG), Federal Work Study (FWS), Perkins Loan, and Leveraging Educational Assistance Partnerships (LEAP) state grants have been cut by a cumulative $158 million. With across-the-board cuts in five of the last seven years and level funding patterns, low-income college students have seen the erosion of their opportunities to secure additional grant aid, low-interest loans and work study positions. These students are now borrowing more or working more off-campus to make up for lost aid. This pattern should not continue if Congress wants our nation's brightest students—regardless of their income—to succeed in today's global economy.

The campus-based and state aid programs should be increased by $685 million. Campus-based federal dollars are matched at a ratio of at least 1-to-3 by participating institutions. LEAP federal dollars are matched at a ratio of at least 1-to-1 by participating states.

SEOG should be funded at $1 billion. As the Pell Grant's sister program, the SEOG program provides up to an additional $4,000 in grant assistance to Pell Grant recipients in order of need. SEOG expands college options for these students. With a $1 billion federal investment, more than 1.3 million students would receive at least $1.3 billion in additional grant aid.

Federal Work Study should be funded at $1.25 billion. FWS provides students with money to pay for college through jobs on campus, in the community and in the private sector. This self-help program encourages 810,000 financially disadvantaged students to develop strong work habits and gain exposure to potential employment opportunities.

Federal Perkins Loan Capital should be restored to $100 million. In the pending Higher Education Act reauthorization, Congress has signaled its support for the Perkins Loan program by reauthorizing this low-interest loan program, with the House raising the authorized contribution from $250 million to $350 million. Federal capital contributions have not been made to this program in four years. With the tightening credit market, low-income students could be unable to borrow for college without a renewed investment in the Perkins Loan program. Capital invested in Perkins loans is matched by schools and recycled again and again to help future generations.

Perkins Loan cancellation reimbursements should be increased to $120 million to fully reimburse colleges for loans forgiven for students who pursue public service careers. Years of under-funding is depleting campuses' Perkins Loan revolving funds, hurting future generations of students who may want to take public service jobs. Higher Education Act reauthorization legislation is expected to add three additional public service jobs to the list of those eligible for forgiveness, putting further strain on Perkins Loan funds.

LEAP should be funded at $100 million. The LEAP program encourages states to continue to expand their own grant programs and improve college access for low-income students. States match each federal dollar with at least one state dollar. In FY 2005, federal funding of $65.6 million generated more than $840 million in matching state funds, making possible nearly 800,000 awards to students. Since then, LEAP funding has declined to $63 million. Funding at $100 million would generously improve state grant funding.

Early intervention programs

Funding for the early intervention programs TRIO and GEAR UP should be increased by $167 million. As aspirations for college-going continue to grow in our society, so do the number of first-generation college students. These students need extra help to prepare for, enter, and graduate from college.

For years, TRIO and GEAR UP have placed higher education within reach of our nation's most historically underrepresented students and families. TRIO and GEAR UP provide students with academic assistance, mentoring, financial aid awareness and other support services to ensure they are prepared both academically and financially to succeed in and graduate from college. TRIO and GEAR UP help bridge the transition between K-12 and higher education for the most disadvantaged students, many of whom will rely on continuity of services, Pell grants and other federal financial aid throughout their postsecondary education.

Despite the accomplishments of TRIO and GEAR UP, funding for these programs has remained stagnant over the past five years, resulting in a decrease in the number of students being served. To continue building upon the success of these programs in encouraging low-income, first-generation students to stay on the path towards obtaining a college degree, adequate funding must be allocated to support these programs.

TRIO should be funded at $948.2 million. The TRIO programs help first-generation, low-income students overcome non-financial barriers to higher education by providing academic tutoring, personal counseling and other vital support services. Two-thirds of TRIO students come from families with incomes of less than $24,000 and in which neither parent graduated from college. As TRIO has not had an increase since 2004, the programs can only serve seven percent of the eligible population. The TRIO programs currently serve more than 870,000 students in all 50 states and many U.S. territories. An increase of $120 million would allow for approximately 85,600 additional students to be served in 2009.

GEAR UP should be funded at $350 million. GEAR UP provides students and families from low-income communities with the necessary academic skills and aspirations to prepare for and succeed in college. GEAR UP fosters cooperation among K-12 schools, institutions of higher education, state higher education entities, businesses and community-based organizations and leverages private matching resources to supplement the federal investment in pre-college awareness and preparation. Since its enactment in 1998, GEAR UP has served millions of students in 48 states, the District of Columbia and four territories.

Recent data from the U.S. Department of Education shows that 89.8 percent of the first class of GEAR UP students graduated from high school in 2005. This remarkable graduation rate is well above those of other low-income students (64.1 percent) and all students nationally (73.9 percent). Despite GEAR UP's demonstrated success in improving high school graduation rates, college enrollment rates and college readiness among low-income learners, the program is only serving a fraction of eligible students. An appropriation of $350 million in FY 2009 would allow GEAR UP to serve an additional 175,000 college-aspiring students.

Graduate Programs

Graduate level programs should be increased to $49.5 million. Graduate Assistance in Areas of National Need (GAANN) strengthens U.S. economic competitiveness by supporting graduate student traineeships in critical fields of study. GAANN should be funded at $32 million, excluding any set-asides for priority areas designated outside the established process. The Jacob Javits Fellowship program recognizes superior academic ability and is the only federal program that supports graduate students in the humanities and arts. Javits should be funded at $12.5 million. The Thurgood Marshall Legal Educational Opportunity Program, which should be funded at $5 million, helps disadvantaged students gain access to, and complete law school. Additionally, the Ronald E. McNair Postbaccalaureate Achievement Program (funded under the TRIO programs) prepares undergraduates from disadvantaged backgrounds for doctoral studies. McNair should be funded at $50 million. Our nation needs highly skilled professionals to ensure continued innovation and prosperity. All these programs have been flat-funded or cut for at least six years; adjusting for inflation, their buying power has been severely compromised.

We thank the House Appropriations Subcommittee on Labor, Health & Human Services, Education, and Related Agencies for the opportunity to submit this statement for the public record and we look forward to working with the committee members as the appropriations process proceeds.

TESTIMONY FOR THE HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION: FY 2009 FUNDING FOR ALCOHOL AND DRUG PREVENTION, TREATMENT, RECOVERY AND RESEARCH PROGRAMS

Submitted by Gabrielle de la Gueronniere, Deputy Director for National Policy, Legal Action Center, on behalf of the State Associations of Addiction Services and Legal Action Center
236 Massachusetts Avenue, NE, Suite 505, Washington, DC 20002
March 31, 2008

State Associations of Addiction Services (SAAS) and the Legal Action Center (LAC) appreciate the opportunity to submit testimony on FY 2009 funding for substance abuse prevention and addiction treatment, recovery, and research programs. SAAS is a national organization representing state provider associations and community-based alcohol and drug abuse prevention and addiction treatment programs in 43 states. The mission of SAAS is to ensure the availability and accessibility of quality drug and alcohol treatment, prevention, education, and research programming. The Legal Action Center is a non-profit law and policy organization that works to expand services for people with alcohol and/or drug addictions, people living with HIV/AIDS, and people with criminal records.

Alcohol and drug addiction is a preventable and treatable disease – just like cancer, diabetes, and heart disease. People with addictions can and do recover and have a meaningful life in the community – if they get the help they need. However, while addiction afflicts one in ten Americans and affects one of every four children, only *12% of the 23.6 million* people who need treatment for alcohol and drug problems receive it. Additionally, millions of young people never benefit from proven substance abuse prevention strategies that are successful and cost-effective.

FIELD RECOMMENDATIONS FOR SUBSTANCE ABUSE PREVENTION, TREATMENT, EDUCATION AND RESEARCH FUNDING FOR FY 2009

The unmet need for alcohol and drug treatment services in America is overwhelming and we respectfully request that Congress increase funding for key alcohol and drug programs in order to meet this incredible need. In partnership with other prevention and treatment advocates, we urge Congress to adopt the following funding levels in FY 2009 for alcohol and drug prevention, treatment, recovery and research programs in the Substance Abuse and Mental Health Services Administration (SAMHSA), the Department of Education, and the National Institutes of Health. These investments will provide desperately needed services in communities across the country:

- **$1.8587 billion** for the Substance Abuse Prevention and Treatment Block Grant
- **$420 million** for the Center for Substance Abuse Treatment (CSAT)
- **$215 million** for the Center for Substance Abuse Prevention (CSAP)
- **$346.5 million** for the Safe and Drug Free Schools and Communities State Grants program
- **$465.5 million** for the National Institute on Alcohol Abuse and Alcoholism (NIAAA)
- **$1.0678** billion for the National Institute on Drug Abuse (NIDA)

CLOSING THE PREVENTION AND TREATMENT SERVICES GAP

According to SAMHSA, in 2006 23.6 million Americans, or 9.6 percent of the population aged 12 or older, needed treatment for an illicit drug or alcohol use problem. Of these, just 2.5 million individuals received treatment at a specialty facility, leaving 21.2 million persons in need of these

life-saving services. Over forty percent of those who tried to get help for their addiction were denied treatment because of cost or insurance barriers. Such barriers mean that for many people, federal- and State-funded programs are the only means available to obtain treatment and prevention services. In many States, public spending accounts for more than 60% of the annual support for treatment and prevention services. The shortage of addiction treatment services results in waiting lists in many places, sometimes as long as six months.

It can be especially difficult for members of special populations, such as our veterans and youth, to obtain necessary drug and alcohol treatment and recovery support services. For example, according to SAMHSA, in 2002 an estimated two million veterans were dependent on or abusing alcohol or illicit drugs. However, funding for healthcare services through the VA has significantly decreased. According to the VA Committee on the Care of Veterans with Serious Mental Illness, VA spending on addiction and mental health services declined by 8 percent between 1998 and 2004, and by 25 percent when adjusted for inflation. With hundreds of thousands of American soldiers and sailors currently on active duty in Afghanistan, Iraq and other areas of conflict, it is expected that the need for alcohol and other drug addiction treatment services for veterans will increase significantly.

It is also essential that we invest in our nation's youth by ensuring that they have access to quality substance abuse prevention and addiction treatment services. Alcohol remains the most heavily abused substance by America's youth. Although there has been a significant decline in tobacco and illicit drug use among teens, underage drinking has remained at consistently high levels. In addition, although rates for non-medical prescription drug use among adults are largely unchanged the past year, these rates have risen for young adults. The number of young adults using prescription drugs non-medically increased from 5.4 percent in 2002 to 6.3 percent in 2005. Recent studies have shown that one in five teens, roughly 4.5 million young people, report abusing prescription pain medications; one in five teens report abusing prescription stimulants and tranquilizers; and one in ten teens, 2.4 million youth, have abused cough medicine.

ADDICTION IS AN ILLNESS THAT CAN BE PREVENTED AND TREATED WITH SERVICES THAT WORK AND SAVE MONEY

Numerous studies have demonstrated the effectiveness of substance abuse prevention and addiction treatment services in reducing alcohol and drug addiction and use. Addictions treatment has been shown to cut drug use in half, reduce crime by 80 percent and reduce arrests up to 64 percent. Addiction treatment is also sustainable; addictions treatment is significantly associated with a 67% reduction in weekly cocaine use, a 65% reduction in weekly heroin use, a 52% decrease in heavy alcohol use, a 61% reduction in illegal activity, and a 46% decrease in suicidal ideation one year post treatment. Moreover, these outcomes are generally stable for the same clients five years post treatment.

Prevention also has been shown to be effective in reducing alcohol and drug use and the risk of addiction, and in effecting academic achievement. A recent University of Washington study found that the level of peer substance use in schools has a substantial impact on academic performance; students whose peers avoided substance use had test scores that were on average 18 points higher for reading, and 45 points higher for math. The Center for Substance Abuse Prevention (CSAP) has identified numerous models of prevention programs backed by research findings of effectiveness that empower communities to meet their unique needs.

In addition to reducing drug use, treatment and prevention are cost-effective. According to SAMHSA, for every dollar the United States Government spends on addictions treatment it saves

$7 to $25 in other costs. A number of state studies have also demonstrated the cost-effectiveness of treatment and prevention. One study found that in Ohio, every $1 spent on addiction treatment saved $11 in other health care costs. A Washington state study showed a 50 percent decrease in all other medical expenses for those receiving treatment. In Minnesota, a recent study showed that one year after alcohol and drug treatment, 67 percent of investment from reductions in all other health care costs was recovered. In addition, a Washington state study of school-based prevention programs found that a number of these programs resulted in a $70.34 benefit for each dollar of programming spent for each participating young person. These savings resulted from increased productivity and reduced health care, criminal justice, and social services costs.

FEDERAL FUNDING IS ESSENTIAL TO PREVENT SUBSTANCE ABUSE AND TREAT ADDICTION

Programs that serve people with alcohol and drug addiction depend nearly exclusively on public funds. According to SAMHSA's recent National Expenditure Report, public funding provides the vast majority of substance abuse expenditures, increasing from 62 percent in 1991 to 76 percent in 2001. Private insurance represented only 13 percent of addiction treatment expenditures in 2001, while it covered 36 percent of all health care expenditures. However, although the alcohol and drug addiction treatment system relies heavily on public funds, an extremely small percentage of health care spending is used for treatment. In 2001, of the $1.4 trillion spent on health care, an estimated $18 billion was devoted to treatment of alcohol and drug addiction. This amount constituted just 1.3 percent of all health care spending and a fraction of the economic and social costs of substance use and addiction; in 1998, the total economic costs of alcohol and drug addiction were estimated to total $328 billion. These costs include medical consequences, lost earnings linked to premature death, lost productivity, motor vehicle crashes, crime, and other social consequences. Expenditures on addiction treatment grew 1.7 percentage points less than the growth rate of all health care.

THE ENTIRE CONTINUUM OF PREVENTION, TREATMENT, AND RESEARCH PROGRAMMING MUST BE ADEQUATELY FUNDED

We urge Congress to improve access to, and the effectiveness of, life-saving drug and alcohol services and research by increasing support for the following programs:

- **$1.8587 billion for the Substance Abuse Prevention and Treatment Block Grant**

Funding for the Substance Abuse Prevention and Treatment (SAPT) Block Grant, the foundation of the publicly supported prevention and treatment system in this country, has been cut by over $20 million over the past several years. As the cornerstone of the nation's prevention and treatment system, the SAPT Block Grant must receive increased funding in order to meet current demand and increase access to services. SAMHSA's most recent data indicates that the SAPT Block Grant serves nearly 2 million people every year, providing roughly half of all public funding for treatment services. Over 10,500 community-based organizations receive Block Grant funding from the states. The Block Grant also provides crucial support for the states' prevention programs, designating 20 percent of the total funding for this purpose.

In many local jurisdictions, individuals can wait long periods before they are able to access appropriate drug and alcohol treatment. This access problem is caused in part by the fact that private and public insurance frequently do not cover the cost of treatment and states face unprecedented financial pressures, making treatment funding even more scarce and increasing the importance of the Block Grant. Funding the full continuum of services is extremely difficult for many jurisdictions given the limited amounts of funds that are available, the pressures facing other funding streams, such as Medicaid, and the restricted coverage provided by private insurance.

Additional Block Grant funding would help alleviate the pressure on services and provide greater access to high-quality drug and alcohol prevention and treatment services.

- **$420 million for the Center for Substance Abuse Treatment (CSAT)**

Although the FY 2009 proposes a $62.8 million cut to CSAT, sustaining and increasing funding for CSAT programming is essential to close the treatment gap. Funding for CSAT's Programs of Regional and National Significance supports States and communities to carry out an array of activities for service capacity expansion, service improvements and other priority needs. These programs are critical in order to ensure that what is learned about addiction through scientific research is effectively shared with the treatment provider community.

We also support the innovative approaches that SAMHSA has developed to expand the continuum of services offered and the range and capacity of providers. Peer recovery support services, provided through CSAT's Access to Recovery and Recovery Community Services Programs, are integral to recovery-oriented systems of care. We support building on these program's successes, including providing additional support for recovery support services critical to helping individuals stay healthy and drug-free.

In addition, funding for CSAT's Capacity category of programming that support services that are tailored to address specific and emerging drug epidemics and/or underserved populations, such as youth, pregnant and parenting women, and communities of color must be strengthened. Unfortunately, under the FY 2009 budget, these programs would be cut by $48.5 million from last year. These CSAT funds are critical and enable states and regions dealing with emerging needs, such as veterans returning home in need of essential addiction treatment services, to appropriately address them. Another key program we urge support for within CSAT is the Screening, Brief Intervention, and Referral to Treatment (SBIRT) program which helps to link primary care and emergency services providers with treatment programs.

- **$215 million for the Center for Substance Abuse Prevention (CSAP)**

Addiction is a disease that begins in adolescence; young people who start drinking before the age of 15 are five times more likely to have alcohol problems later in life than those who begin drinking at age 21 or older. Research by the National Institute on Drug Abuse (NIDA) has shown that if we can stop use and abuse before age 25, we will significantly reduce the prevalence of addiction. Under the proposed budget, CSAP would receive a cut of $36 million. Prevention efforts are effective in deterring young people from using illicit drugs and alcohol. We strongly support CSAP's Strategic Prevention Framework to promote the use of performance measurement by providers, expand collaboration across community agencies, and support implementation of effective prevention programs at the State and community levels. Unfortunately, the President's request would cut funding for this critical program by $9.3 million. CSAP's Strategic Prevention Framework is helping communities to promote youth development, reduce risk-taking behaviors, build assets and resilience, and prevent problem behaviors across the life span and needs increased funding to continue and to expand its reach.

- **$346.5 million for the Safe and Drug Free Schools and Communities State Grants program**

The Safe and Drug Free Schools and Communities (SDFSC) State Grants Program is the backbone of school-based prevention efforts in the United States, and supports community-based prevention programming throughout this country. According to recent data, upwards of 37 million youth are served annually by programs funded through SDFSC. The SDFSC program has had a significant impact on helping to achieve the 17 percent overall decline in youth drug use over the past three years, documented by the 2004 Monitoring the Future survey, and is having a significant impact in many states. We strongly urge the Subcommittee to support this program and to protect its funding. The President's budget proposes funding of $100 million for the SDFSC State Grants program, a crippling cut of nearly $195 million. Cutting the SDFSC program will leave millions of American children without any drug prevention education.

- **$465.5 million for research at the National Institute on Alcohol Abuse and Alcoholism (NIAAA) and $1.0678 billion at the National Institute on Drug Abuse (NIDA)**

Research into the causes, costs, treatment, and prevention of alcoholism and drug addiction plays an essential role in improving the quality of services. Increasing the support available for research on drug and alcohol addiction would allow future research to focus on additional effective prevention strategies, medications development, and treatment and service delivery throughout the criminal justice system.

NIAAA and NIDA are both taking steps to promote the transfer of new research to practice, including collaboration with SAMHSA, state agencies and providers. Over the past several years, NIDA has made extraordinary scientific advances in understanding the nature of addiction, such as those made through the use of imaging technologies like positron emission tomography (PET scans), and through the development of the new treatment technologies and medications. Additionally, NIDA's Criminal Justice Drug Abuse Treatment Studies (CJ-DATS) research is designed to improve outcomes for people with substance use disorders by improving the integration of drug abuse treatment with other public health and public safety systems. Research on addiction as a disease has been useful in the development and testing of new science-based therapies. NIAAA also has conducted breakthrough research that has improved clinical practice, with much of this research focusing on the genetics, neurobiology, and environmental factors that underlie alcohol addiction. NIAAA also has sought to use new information about alcohol use to promote education and an effective public health response to this problem.

CONCLUSION

Our nation is spending only a fraction of what is necessary to prevent alcohol and drug abuse and treat addiction – a total of $18 billion from all sources of funds, compared to social and economic costs estimated well in excess of $300 billion. Public funding supports three-fourths of those expenditures, and funding appropriated by Congress is the critical foundation for prevention, treatment, education, and research. State Associations of Addiction Services and the Legal Action Center urge the Committee to approve the funding levels that we and other organizations in the field have recommended.

Thank you for your consideration.

Statement by

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

on the Fiscal Year 2009 funding for the Office of Museum Services
at the Institute of Museum and Library Services

Submitted to the Subcommittee on Labor, Health and Human Services, Education
and Related Agencies
Committee on Appropriations
U.S. House of Representatives

March 31, 2008

Chairman Obey, Representative Walsh and distinguished members of the Subcommittee, the American Association of Museums appreciates the opportunity to submit testimony on the Fiscal Year 2009 budget for the museum program at the Institute of Museum and Library Services (IMLS).

The American Association of Museums (AAM) is the only organization representing the full scope of museums—art museums, history museums, science centers, children's museums, zoos and aquariums, public gardens and many specialty museums—along with professional staff and volunteers who work for and with museums. AAM currently represents more than 15,000 individual museum professionals and volunteers, 3,000 institutions and 300 corporate members. Our membership is as diverse as the collections contained in the museums we represent.

We respectfully request your approval of $46.3 million for grants to museums administered through the Office of Museum Services (OMS) at the Institute of Museum and Library Services (IMLS) and the agency's overall budget request of $500,000 for museum data collection.

Museums and libraries are the most trusted sources of online information among adults of all ages, education levels, races and ethnicities. According to a recent IMLS report, museums and libraries rank higher in trustworthiness than all other information sources, including government, commercial and private websites. This report highlighted the vital role of museums in supplementing formal education and providing informal learning opportunities.

There are more than 17,500 museums in America. As vibrant community assets and sources of civic pride, museums perform an essential function in the creation of America's social and cultural fabric. Museums are all about connections to the natural world; to the science that explores the workings of the universe; to the documents, artifacts and places that make up our history; and to the greatest achievements of humankind. Museums also connect Americans to the future, fostering innovation and sparking creativity. Indeed, education is the central purpose of museums.

However, unlike schools and libraries, most museums operate as private, nonprofit organizations with nominal government funding. According to AAM's most recent financial survey, nonprofit museums receive approximately 24 percent of their budget from local, state and federal funding. The bulk of their income is derived from private philanthropy in the form of donations, grants and corporate sponsorships and earned income from admissions and gift shop sales.

Preserving Our Past

Museums preserve and present to the public the collections that helped make America a great nation. Our society has bequeathed to the care of museums the documents and artifacts, scientific specimens and works of art that are the cornerstones of our civilization. The care of these objects is critical to their preservation for future generations. Toward that end, IMLS funded the Heritage Health Index, the first comprehensive survey ever conducted of the condition and preservation needs of our nation's collections, in museums, libraries, archives, historical societies and scientific research organizations. The survey produced two startling facts: These collections are visited more than 2.5 billion times a year, yet 630 million artifacts, encompassing works of art, photographs, historic objects, natural science specimens, books and periodicals, are currently at risk.

One result of this survey was a multifaceted plan to manage, protect and preserve these valuable objects. "Connecting to Collections" is an IMLS-supported initiative, through which grants fund statewide planning on preserving a state's collections. This initiative also addresses the need for emergency preparedness planning and sharing information with key constituents.

For example, the Leigh Yawkey Woodson Art Museum in Wausau, Wisconsin, received an IMLS grant of $18,825 in 2007 that enabled it to conduct a detailed condition survey of more than 1,300 works on paper in the institution's permanent collection. These objects, encompassing watercolors, pastels, woodcuts and pencil and ink drawings, included works by such renowned naturalist-artists as John James Audubon.

IMLS assists museums with efforts to examine, document, treat, stabilize and restore their collections through the consultation services of the Conservation and Museum Assessment Programs and with financial assistance through the Conservation Project Support program. But the Conservation Project Support program's resources never meet the demand. In FY 2008 IMLS received 172 applications and made a total of 65 grants (for a total of $4.9 million).

An example of a state anticipating these needs and of the effectiveness of "Connecting to Collections" grants is the effort underway in Rhode Island. A $40,000 grant to the Rhode Island Office of Library and Information Services in 2008 enabled it to define and inventory the universe of statewide heritage collections, institute an online disaster planning program, train stakeholders in its use and share this knowledge with state and local emergency management agencies, first responders and heritage stakeholders. To date, 19 similar statewide grants have been awarded.

IMLS funds have also enabled the Martin Art Gallery at Muhlenberg College in Muhlenberg, Pennsylvania, to give more serious attention to collections management. They are currently

moving approximately 50 percent of the Tanner Collection (works on paper) to storage in a climate-controlled storage area. In addition, a large 1868 painting is slated for conservation, and there is an increase in awareness about the responsibilities of holding collections in trust for the public.

Educating the Public

As state and local public education mandates have changed, students' access to education in the arts, history and other subjects has been reduced. Museums have helped fill the void with invaluable learning experience for K–12 students. As school budgets have been cut, especially for off-site field trips, many museums have aggressively brought their institutions and collections directly to the students.

The Peabody Museum of Natural History at Yale University in New Haven, Connecticut, received a 2007 IMLS grant of $144,030 to launch the Evoking Learning and Understanding Through Investigations of the Natural Sciences (EVOLUTIONS), an after-school program for a group of 90 students, grades 8–12, drawn from New Haven's economically disadvantaged communities. The program emphasizes STEM learning (Science, Technology, Engineering and Math), as well as requisite skills for success such as communication and computer training. The program includes internships in the laboratories of many Yale scientists, demonstrating to the students that not only can they "do" science, they can also pursue careers as scientists.

Current efforts by the Yellowstone Art Museum in Billings, Montana, exemplify the educational role of museums. In 2007 the museum obtained a $117,825 IMLS grant to expand its programs in the Billings public schools, solidifying its position as the preeminent art education source for the city's students. The museum took the innovative approach of relating art education to other core subjects. The result has been better integration of art education into the regional school curriculum and into the daily lives of children and their families.

Supporting Research

The U.S. needs a robust program of research in order to understand the larger impact of museums nationwide. Important areas of future research include:

- measuring the educational and social influence of museums at the national level while building the capacity of institutions to measure how they affect their communities
- studying what skills are needed to be a successful 21st-century museum professional, and what training is needed to nurture leaders in the field
- supporting the ongoing collection of core data about museums, such as financial benchmarks, attendance patterns and long-term social impacts, and
- examining areas of special interest to the museum field, such as collections stewardship and the relationship between museums and both formal and informal learning.

Striving for Excellence

Museums must consistently strive to improve if they are to retain the public trust and fulfill their mission of education and public service. IMLS has been integral to that ongoing effort, in numerous ways. One of the most critical is its support of the Museum Assessment Program (MAP), a program that brings fresh, experienced, outside eyes to a museum's operations and collections management. MAP is a consultative initiative, through which museums are assisted

in setting and meeting their own goals and priorities. Participants also learn how their institution compares to current standards and best practices in the field. MAP participants come to understand their strengths and weaknesses, learning how to improve overall operations and set institutional priorities. These museum improvements directly benefit the public they serve.

Celebrating Diversity
While IMLS funds a wide range of programs and efforts at a broad range of institutions, two of the newest programs help ensure that museums reflect our nation's diversity. AAM supports the continuation of the Native American/Native Hawaiian Museum Services grants and Museum Grants for African American History and Culture. These institutions are among the newest specialized type of museums and must be supported to ensure that the public has access to the broadest interpretation and representation of the history and culture of our nation.

Training Museum Leaders and Educators
To further connect museums and their public to the future, IMLS has led the way in supporting the 21st Century Museum Professionals program, an initiative designed to empower future museum leaders to face a field that is rapidly changing.

In years past, museum boards often sought out relevant scholars to head their institutions. Today, the demands of a museum director are such that boards search for candidates who are strategic thinkers, excellent communicators and talented fundraisers, as well as having an entrepreneurial spirit and energy that will enable them to bridge the worlds of commerce and scholarly pursuits. Moreover, these directors need to have qualified and able staffs. According to a 2006 AAM survey of museum finances, the average museum has a staff of six full-time employees and four part-time employees. This includes curators, educators, registrars, accountants and marketing and development professionals, with many filling more than one role. Museums rarely have the resources to train and develop their staff members. We anticipate that the pool of qualified, professional candidates is getting smaller. Like many other nonprofits, museums have also struggled to identify diverse pools of qualified workers.

IMLS works to fill this void via the 21st Century Museum Professionals program. While still in its infancy, this initiative already has drawn the attention of those who aspire to a career in museums and their mission of serving the public. In its first two years of existence, the program has attracted 97 applicants for only 19 fundable spots. The agency's FY 09 request would allow IMLS to fund approximately 20 more applications in FY 09 than were funded in FY 07 or will be funded in FY 08. IMLS received far more quality applications for this program than there are funds to grant. We urge the subcommittee to consider increasing future investment in the development of a diverse, talented and qualified workforce of museum professionals.

Building Communities
Museums are iconic entities in their communities. Communities value museums for their contributions to civil society; their support of education, both school-age and lifelong; and their role as a refuge for safe, substantive family activities. Citizens take pride in their local museums. Museum-focused programs supported by IMLS strengthen these community ties while also serving a useful civic role, the benefits of which may reach well beyond local boundaries.

A compelling example comes from St. Paul, where the Minnesota Historical Society used a 2002 IMLS grant of $125,389 to initiate a program designed to further integrate the Twin Cities' sizeable Somali population into their new host culture. Somali women are often isolated due to religious and cultural strictures. This program trained 15 Somali women in the use of digital technology, resulting in a compelling film, Two Homes, One Dream: The Somalis in Minnesota. For the film the women did historical research; conducted oral history interviews with peers, elders, educators and community leaders; and filmed events across the Twin Cities. Some four years after its completion, Two Homes, One Dream is still requested and featured in public screenings throughout the region, as its themes of cultural identity and the immigrant experience continue to resonate with a diverse group of Minnesotans.

Conclusion

We realize how difficult it is to prioritize how resources are allocated among all the worthy programs that are within this subcommittee's jurisdiction. Our appeal is that, in making these important choices, you consider the vital contribution museums make in communities nationwide. Whether they address our past or our future, compelling historical artifacts or the wonders of science, the natural world or worlds springing from the imaginations of great artists, museums add meaning to American life. Investing in museums is investing in our traditions, our culture, our heritage and in the American spirit of creativity and independence. By way of evidence, we offer this story of two Philadelphians for whom museums have been both an inspiration and a lifeline (first reported in February 2008 in the Philadelphia Inquirer):

Bill McLaughlin and Dick Hughes are World War II veterans. Both are in their 80s. They attend the same church in Philadelphia, but were not really close friends.

When Bill's wife was losing her battle with Alzheimer's, Dick thought it was his "Christian duty" to pull Bill out of his despondency. They spent an afternoon at the Academy of Natural Sciences in Philadelphia. They enjoyed it, for the intellectual stimulation and for the way it diverted their attention from other pressing matters. The following week, they visited the battleship New Jersey. And they continued to visit Philadelphia-area museums and historic sites for three years and a total of 203 museums. The result was a handy guide they recently published, entitled Travels with Dick and Bill, sales of which benefit their church. But more importantly, these travels cultivated their love for museums, an appreciation of their hometown and an enduring friendship that will undoubtedly last the rest of their lives.

This is a poignant example of how museums bring us together, and of how these public institutions served two men who had served their country so nobly. With the continued support and leadership of an increased investment of federal funding in museums, and by working with our partners in the private sector, museums can continue to strive for the highest standards in fulfilling their mission of educating the public and preserving our heritage—and perhaps even more importantly, in continuing to touch American lives like those of Bill McLaughlin and Dick Hughes.

NATIONAL MARFAN FOUNDATION

JOSEPHINE GRIMA, PH.D.
VICE PRESIDENT OF RESEARCH AND LEGISLATIVE AFFAIRS

TESTIMONY SUBMITTED TO THE HOUSE OF REPRESENTATIVES APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES

REGARDING FY09 APPROPRIATIONS FOR THE DEPARTMENT OF HEALTH AND HUMAN SERVICES

Chairman Obey and Ranking Member Walsh, thank you for the opportunity to submit testimony regarding the FY2009 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 support of the NIH and CDC, particularly as it relates to life-threatening genetic disorders such as Marfan syndrome. Thanks in part to your leadership we are at a time of unprecedented hope for our patients.

It is estimated that 200,000 people in the United States are affected by Marfan syndrome or a related condition. Marfan syndrome is a genetic disorder of the connective tissue that can affect many areas of the body, including the heart, eyes, skeleton, lungs and blood vessels. It is a progressive condition and can cause deterioration in each of these body systems. The most serious and life-threatening aspect of the syndrome the 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.

NATIONAL HEART, LUNG AND BLOOD INSTITUTE

A) Pediatric Heart Network Clinical Trial

NMF applauds the National Heart, Lung and Blood Institute for its leadership in advancing a landmark clinical trial on Marfan syndrome. Under the direction of Dr. Lynn Mahoney and Dr. Gail Pearson, the Institute's Pediatric Heart Network has spearheaded a multicenter study focused on the potential benefits of a commonly prescribed blood pressure medication (losartan) on aortic growth in Marfan syndrome patients.

NHLBI Director Dr. Elizabeth Nabel describes this promising research well.....

> *"After the discovery that Marfan syndrome is associated with the mutation in the gene encoding a protein called fibrillin-1, researchers tried for many years, without success, to develop treatment strategies that involved repair of replacement of fibrillin-1. Then a major breakthrough occurred with the discovery that one of the functions of fibrillin-1 is to bind to another protein, TGF-beta, and regulate its effects. After careful analysis revealed aberrant TGF-beta activity in patients with Marfan syndrome, researchers began to concentrate on treating Marfan syndrome by normalizing the activity of TGF-beta. Losartan, which is known to affect TGF-beta activity, was tested in a mouse model of Marfan syndrome and the results showed that drug was remarkably effective in blocking the development of aortic aneurysms, as well as lung defects associated with the syndrome.*
>
> *Based on this promising finding, the NHLBI Pediatric Heart Network, has undertaken a clinical trial of losartan in patients with Marfan syndrome. About 600 patients aged 6 months to 25 years will be enrolled and followed for 3 years. This development illustrates the outstanding value of basic science discoveries, and identifying new directions for clinical applications. Moreover, the ability to organize and initiate a clinical trial within months of such a discovery is testimony to effectiveness of the NHLBI Network in providing the infrastructure and expertise to capitalize on new findings as they emerge."*

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 fibrillin-1 and TGF-beta play 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.

NMF is also proud to actively support the losartan clinical trial in partnership with the Pediatric Heart Network. Throughout the life of the trial we will provide 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.

Finally Mr. Chairman, we would like to take this opportunity to thank the Pediatric Heart Network for its recent decision to add eight additional sites to the losartan trial. These new sites will help ensure that patient recruitment stays on schedule and that all regions of the country have access to this exciting research.

B) NHLBI "Working Group on Research in Marfan Syndrome and Related Conditions"

In April 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. Mr. Chairman, for fiscal year 2009 NMF joins with other professional and patient organizations in recommending a 6.7% for NHLBI.

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. 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 clinical trial moves forward, we hope to expand our partnership with NIAMS to support ancillary 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 in support of this research in the coming year.

For FY09, NMF recommends a 6.7% increase for NIAMS.

CENTERS FOR DISEASE CONTROL AND PREVENTION

Mr. Chairman, we are grateful for the Subcommittee's encouragement last year of collaboration between the CDC and the Marfan syndrome community. 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.

Despite our ongoing efforts to raise awareness among the general public and health care providers, we know of too many families who have lost a loved one because of a missed diagnosis.

Last year, we were pleased that the acting director of CDC's Division of Human Development and Disability (within the National Center on Birth Defects and Developmental Disabilities) attended our annual patient conference in Palo Alto, California. We have discussed a variety of potential collaborations with the CDC focused on education and early diagnosis. We ask the Subcommittee to continue to encourage CDC to work with us to initiate these activities in fiscal year 2009.

For FY09, NMF joins with the CDC Coalition in recommending an appropriation of $7.4 billion, an increase of $1 billion over FY08, for the agency.

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.

For more information please contact;

The National Marfan Foundation
22 Manhasset Avenue
Port Washington, NY 11050
1-800-8MARFAN

CROHN'S AND COLITIS FOUNDATION OF AMERICA

TESTIMONY SUBMITTED TO THE HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES

BY: KENNETH EDMONDS, MEMBER, CCFA NATIONAL BOARD OF TRUSTEES

REGARDING FY09 APPROPRIATIONS FOR THE DEPARTMENT OF HEALTH AND HUMAN SERVICES

Chairman Obey and Ranking Member Walsh, thank you for the opportunity to submit testimony on behalf of the Crohn's and Colitis Foundation of America (CCFA). We greatly appreciate your leadership and the opportunity to work with you to improve the quality of life for our patients and families.

My name is Kenneth Edmonds and I serve on the National Board of Trustees for the CCFA, the nation's oldest and largest voluntary organization dedicated to finding a cure for and to seeking to prevent Crohn's disease and ulcerative colitis. I also have the privilege of serving as Chief of Staff for Congressman Jesse Jackson, Jr. (D-IL).

Through research, education and support, CCFA is committed to improving the quality of life of children and adults affected by these diseases, collectively known as inflammatory bowel disease (IBD). I am one of them.

IBD is a chronic disorder that causes inflammation of the digestive tract. It affects approximately 1.4 million Americans, 30% of whom are diagnosed in their childhood. IBD can cause persistent diarrhea, severe abdominal pain, fever, and, at times, rectal bleeding. If complications develop, it also can lead to, among other conditions, anemia, liver disease and colorectal cancer.

Indeed, inflammatory bowel disease can be painful and debilitating. And, its impact is perhaps most devastating for children and adolescents, whose diagnoses often make them stand out at a time when they most want to fit in. Their disease can make them not only feel different, but look different as some adolescents with IBD may have delays in physical growth and puberty, causing them to appear younger and smaller than their peers. But, at any age, being diagnosed with IBD can bring change and challenge.

The news of my diagnosis came not in one, sudden rush, but rather in a long, gradual backslide -- and into a hospital bed. In retrospect, I exhibited typical signs of IBD as early as 1993 while a student in college. But, unfortunately, I responded to those signals like too many adolescents and young adults -- I overlooked them.

At the time, I experienced acute abdominal pain so sharp and sudden that I would double over. These cramps often came without warning, creating an intense urge to use the nearest bathroom.

On these occasions and others, my stools had traces of blood.

But, because I was young and active, I didn't think that much about it. And, I certainly didn't talk about it, to anyone. I chalked these brief episodes up to my regimen, rather than my abdomen. I figured that I just needed to add more greens to my diet and add more hours to my sleep.

But, by 1996, after moving to Chicago, my symptoms had become too persistent, too serious and too severe to ignore. By the summer of that year, I had developed sores or ulcers on my tongue, making it difficult and painful to eat. I lost appetite and lost weight.

In addition to the persistent diarrhea and acute cramps, I also had developed a tear (a fissure) in the lining of my anus, which caused excruciating pain and bleeding during bowel movements. I also suffered from severe exhaustion.

As you can imagine, this was an agonizing predicament: I was losing weight, but could not eat. I was fatigued, but could not sleep. I had frequent, sudden bowel movements, but they caused sharp, piercing pain. Indeed, I had deteriorated dramatically; my condition relegating me to somewhere between bedridden and bathroom-bound.

A misdiagnosis, three, long, withering weeks, and a plane ride later, I found myself in the Washington Hospital Center under the care of my uncle, a gastroenterologist here in the District. After a series of tests, X-rays and examinations, I was diagnosed with Crohn's colitis and prescribed medications for my symptoms. Since my hospitalization ten years ago, I am pleased to report that the disease has been in remission and I have enjoyed relatively good health.

But, Mr. Chairman, IBD is a life-long disease. While there are drug therapies to treat symptoms, there is no medical cure. And, its cause is unknown.

That's why CCFA's work has been so critical and groundbreaking.

RECOMMENDATIONS FOR FISCAL YEAR 2009

1) 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.

To further accelerate genetic research and advance understanding of IBD, NIDDK issued a

research solicitation to establish an IBD Genetics Consortium approximately 7 years ago. This effort was informed by recommendations from external experts. Funding for the Consortium's six centers began in 2002, and intensive data and sample collection, genetic analysis, and recruitment of new patients and their families have been under way. In 2006, the Consortium published the major discovery of a new IBD gene. Some sequence variations in this gene, called *IL23R,* were found to increase susceptibility to IBD, while another variant actually confers protection. This gene was known previously to be involved in inflammation, and its newly-discovered association with IBD may lead to the development of better therapies for IBD. In recognition of the success of the Consortium's large-scale collaborative effort, NIDDK decided to continue support for the program beyond its initial 5-year period which was slated to end last year.

Renewed funding in FY08 has enabled the Consortium to continue its genetic studies and recruit additional patients and relatives (as well as subjects without IBD for comparison). This expansion will facilitate the identification of additional predisposing genes and enable genetic analyses of certain patient subgroups, such as those from minority populations or those who experience an early-onset form of IBD. These findings may then be used to pursue genetically-based diagnostic tests that allow for earlier diagnosis and treatment intervention. In addition, the data can be used to identify new molecular targets for therapeutic development that are specifically targeted to a unique subset of patients.

Mr. Chairman, we are grateful for the leadership of Dr. Stephen James, Director of NIDDK's Division of Digestive Diseases and Nutrition, for pursuing this and other opportunities in IBD research aggressively. Fortunately, the field of IBD is widely viewed within the scientific community as one of tremendous potential. CCFA's scientific leaders, with significant involvement from NIDDK, have developed an ambitious research agenda entitled "Challenges in Inflammatory Bowel Disease" that seeks to address many opportunities that currently exist. We look forward to working with NIDDK and the Subcommittee to pursue these research goals in the coming years.

To help capitalize on these opportunities, CCFA recommends that the Subcommittee provide a 6.7% increase in funding for NIDDK and NIAID in FY09. Moreover, CCFA requests that the Subcommittee encourage these two institutes to expand their IBD research portfolios at a similar rate.

2) CENTERS FOR DISEASE CONTROL AND PREVENTION

INFLAMMATORY BOWEL DISEASEEPIDEMIOLOGY PROGRAM

Mr. Chairman, CCFA estimates that 1.4 million people in the United States suffer from IBD, but there could be many more. We do not have an exact number due to these diseases' complexity and the difficulty in identifying them.

We are extremely grateful for your leadership in providing funding over the past four years for an epidemiology program on IBD at the Centers for Disease Control and Prevention. This program is yielding valuable information about the prevalence of IBD in the U.S. and increasing our knowledge of the demographic characteristics of the IBD patient population. If we are able to generate an accurate analysis of the geographic makeup of the IBD patient population, it will provide us with invaluable clues about the potential causes of IBD.

For FY09, CCFA encourages the Subcommittee to continue its strong support for the IBD Epidemiology Program at the current level of funding ($667,000). This represents an increase of $3,000 over the the President's request.

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 FY09.

Once again Mr. Chairman, thank you for the opportunity to submit written testimony. Please do not hesitate to contact me or the Crohn's and Colitis Foundation of America should you have any questions or require additional information.

Testimony of William R. Green, Ph.D., The American Association of Immunologists, Submitted to the House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies, Regarding the FY 2009 Budget for the National Institutes of Health – March 28, 2008

The American Association of Immunologists (AAI), a not-for-profit professional society representing more than 6,500 of the world's leading experts on the immune system, appreciates having this opportunity to submit testimony regarding Fiscal Year (FY) 2009 appropriations for the National Institutes of Health (NIH). The vast majority of our members - research scientists and physicians who work in academia, government, and industry - depend on NIH funding and the research it supports to advance their own work and the broader field of immunology.[1] With approximately 83% of NIH's $29.2 billion budget awarded to scientists throughout the United States and around the world, NIH funding advances not only immunological and biomedical research, but also regional and national economics.[2]

Why immunology?

HIV/AIDS. Cancer. Influenza. Malaria. Diabetes. Rheumatoid arthritis. Smallpox. West Nile Virus. Lupus. Organ Transplants. Asthma. Treatments and cures for all of these - and for many more infectious and chronic diseases - depend on our understanding of the immune system. And yet, the study of immunology is relatively new. Although scientists developed the first vaccine in 1798 (to protect against smallpox), most of our basic understanding of the immune system has only come about in the past 30-40 years, and new discoveries are being made every day.

And what advances have been made! Vaccines protect us from childhood diseases that historically caused millions of childhood deaths and contributed to lower life expectancy.[3] Advances in understanding challenges to the immune system enable us to better control environmental threats. And progress in our urgent quest to study the immune response to natural infectious organisms that can be modified for use as agents of bioterrorism (including plague, smallpox, and anthrax) or that threaten to be the next pandemic (including avian influenza) may soon protect us against these dangerous pathogens. For all of these pressing needs and more, basic research on the immune system provides a crucial foundation for prevention, treatment, and cure through the development of diagnostics, vaccines, and therapeutics.[4]

Recent scientific discoveries: blockbusters and hope

Vaccines are arguably the most successful immunotherapeutics that mankind has produced. Effective in preventing and all but eliminating a wide range of childhood and adult infectious diseases, their usefulness in cancer and chronic infectious disease has not been fully realized. That all may change due to the discovery of Toll-like Receptors (TLR). These receptors recognize products (like DNA, lipids, lipoproteins, and flagella) present in pathogens such as bacteria, viruses, and parasites, and mount an intense immune response against these foreign invaders. This discovery could lead to the creation of a whole new generation of vaccines for cancer and chronic infectious disease.

As has been widely reported, a highly effective vaccine against cervical cancer caused by Human Papillomavirus (HPV) was recently approved by the Food and Drug Administration. HPV infects over 8% of women aged 15-50; the new vaccine ("Gardasil") is efficacious in preventing primary infection and therefore in reducing the incidence of cervical cancer. More recently, a TLR immune adjuvant called MPL is being used as an adjuvant in a newer HPV vaccine; results from early clinical trials indicate that the adjuvant induces a more robust immune response in older adults and a faster response in young adults than does Gardasil.

In 2007, B lymphocytedepleting therapies were shown to be a revolutionary advance in the treatment of autoimmune diseases. In Rheumatoid Arthritis (RA), the anti-CD20 monoclonal antibody, rituximab, was shown to induce clinical remissions in patients that had been previously unresponsive to all available prior agents. Subsequently, rituximab was shown not only to improve signs and symptoms of RA, but also to prevent structural damage in this severely affected patient population. Rituximab therapy is now being applied with impressive success to the treatment of an ever-expanding list of autoimmune diseases such as idiopathic thrombocytopenic purpura (ITP, a condition in which blood does not clot properly), pemphigus (which causes blistering of the skin and mucous membranes), and systemic lupus erythematosus (in which the immune system attacks healthy cells and tissues by mistake, resulting in multi-organ/tissue damage). In patients with relapsing remitting Multiple Sclerosis (MS), rituximab has enabled control of inflammation and further brain damage within one month. Several other very promising MS therapeutics based on monoclonal antibodies are currently in trials [Ocrelizumab and alemtuzemab (campath)]; and evidence to date is that (compared to current treatments) these treatments may be novel, highly effective, and safe therapies for those patients with refractory autoimmune diseases. Another potentially important treatment that has shown remarkable efficacy in relapsing MS is FTY720 (fingolimod). A profound reduction in MRI activity and relapse rate has been observed in ongoing clinical trials.

Immunologists have also made progress in understanding why the immune system does not work well to clear persistent virus infections such as HIV and Hepatitis C Virus (HCV). Thus, by injecting specific antibodies (to IL-10, PD-1, or PD-1's receptors) into mice, the immune system can be reactivated, which then clears the persistent virus. Other important research advances include the development of additional therapeutic monoclonal antibodies, increasingly recognized as the most promising mode of treatment for a myriad of human diseases (including autoimmune diseases and cancers), and the use of pre-transplant conditioning and administration of bone marrow to eliminate the need for immunosuppression following organ transplantation. Each of these is a potentially important therapeutic avenue that needs support in order to be further developed.

The NIH budget continues to erode

AAI is very grateful to this subcommittee and the Congress for its successful bipartisan effort to double the NIH budget from FY 1999 to FY 2003. With this unprecedented commitment from the Congress, biomedical scientists were able to grow the research enterprise and train new young investigators, preparing them to take on today's scientific challenges and become tomorrow's teachers and leaders. Although the NIH budget has grown since the doubling ended (from $27.067 billion in FY 2003 to $29.2 billion in FY 2008), ***sub-inflationary budget increases since FY 2003 have resulted in a loss of purchasing power of more than 13%.*** Last year, AAI warned this subcommittee that such a loss in purchasing power was already beginning to have a devastating effect; this year, AAI can testify to the inordinate stress and life-altering consequences this has had on so many of our researchers whose work continues to be excellent but whose grant applications simply cannot be funded under these conditions:

1. Key NIH Institutes have already dropped their RO1 paylines to as low as 10-14%, significantly below the approximately 22% during the doubling period. Success rates [the percentage of reviewed Research Project Grant (RPG) applications receiving funding computed on a fiscal year basis] dropped to 21% in FY 2007, the lowest since 1970, and to 19% in FY 2008. With funding so low, many senior investigators with outstanding, innovative ideas - many of whom support (through their NIH grants) entire laboratories filled with younger faculty, post-doctoral fellows, and technicians - cannot retain their NIH funding. Even the most successful senior investigators are typically not being funded on their first renewal grant submission, forcing them to spend valuable time on revising and resubmitting their applications.

Under these circumstances, it is particularly disturbing that the Administration claims it has "proposed increases for each Institute and Center [IC] at NIH." (Written testimony of Secretary of Health and Human Services Mike Leavitt to the House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies, February 14, 2008, p. 3) The ICs were given such miniscule "increases" as to be insignificant [e.g., 0.17% for the National Institute of Allergy and Infectious Diseases (NIAID); 0.1% for the National Cancer Institute (NCI); and 0.09% for the National Institute on Aging (NIA)], particularly since they are well below the rate of biomedical research inflation projected for FY 2009 (3.5%).

2. The President's budget would provide no inflationary increases for direct, recurring costs in non-competing RPGs for the 4th straight year.

3. The President's budget would permit inadequate increases (~1%) to already inadequate stipends and benefits for pre-doctoral and post-doctoral fellows, whose work is critical to today's established investigators and who will be the principal scientists of tomorrow.

The President's FY 2009 budget would increase the long-term adverse repercussions on Americans' health and the national economy: in addition to their terrible human toll, disease and disability cost society trillions of dollars annually in medical care, lost wages and benefits, and lost productivity.[5] The President's budget would also jeopardize the future of the biomedical research enterprise: our brightest young people will be deterred from pursuing biomedical research careers if their chances of receiving an NIH grant, or of being able to sustain a career as an NIH-funded scientist, do not improve. If we are unable to attract and retain the best young minds, the United States will lose more of its senior scientists, as well as its preeminence in medical research, science, and technology, to nations (including India, Singapore, and China) that are already investing heavily in this essential economic sector.

AAI recommends a 6.5% budget increase for FY 2009

AAI urges the subcommittee to increase the NIH budget by 6.5% ($1.9 billion) in FY 2009, to $31.1 billion. This increase, which is only 3% above the projected rate of biomedical research inflation, would begin to restore both the loss in purchasing power that has occurred since the NIH budget doubling ended in FY 2003[6] and the confidence of young scientists that a career in biomedical research is possible.

Other key NIH Issues

Influenza and bioterrorism

Seasonal influenza leads to more than 200,000 hospitalizations and about 36,000 deaths nationwide in an average year. Moreover, an influenza pandemic as serious as the one that occurred in 1918 could result in the illness of almost 90 million Americans and the death of more than 2 million, at a projected cost of $683 billion.[7] AAI strongly believes that the best preparation for a pandemic is to focus on basic research to combat seasonal flu, including building capacity, pursuing new production methods (cell based), and seeking optimized flu vaccines and delivery methods. For bioterrorism, the focus should also be on basic research, including identifying new and potentially modified pathogens, understanding the immune response, and developing tools (including new and more potent vaccines) to protect against the pathogen.

The NIH "Common Fund"

The NIH Reform Act of 2006 established within NIH a "Common Fund" (CF) to support trans-NIH initiatives (including those funded under the "Roadmap for Medical Research"). The President's budget would increase the CF by $38 million, or 7.66%. While AAI recognizes the value of interdisciplinary

research, we believe that the funds allocated to the CF should not grow faster than the overall NIH budget, and that all CF awards and grants must be awarded through a transparent and rigorous peer review process.

The "NIH Public Access Policy"

AAI respectfully requests that the subcommittee require that NIH report on the cost of implementing the NIH Public Access Policy (Policy). To the best of AAI's knowledge, NIH has never reported the cost of the former voluntary Policy or the projected cost of the new mandatory Policy, and there is no requirement in law that NIH ever do so. AAI therefore requests that the subcommittee require NIH to publicly report by April 2009: 1) the total funds expended on implementing the voluntary Policy (May 2, 2005 - January 11, 2008); 2) the cost anticipated for implementation of the mandatory Policy in FY 2009; and 3) how much of the cost anticipated for FY 2009 will be a one-time implementation cost, and how much will be an annual cost. AAI further requests that NIH report all costs incurred by the National Library of Medicine (NLM) as well as the various NIH Institutes, Centers, and Offices involved, including: a) the number of FTEs and contracted services used to implement this Policy; b) the cost of personnel and administrative services (including associated space for infrastructure and personnel); c) time spent directly on the promotion, management, enforcement, and assessment of the Policy to/by NIH grantees and the public; and d) all costs associated with network infrastructure improvements including but not limited to bandwidth capabilities, server capacity, and equipment.

AAI continues to believe that the Policy will duplicate, at great cost to NIH and to taxpayers, publication services which are already provided cost-effectively and well by the private sector. The private sector, including not-for-profit scientific societies, already publishes - and makes publicly available - thousands of scientific journals that report cutting-edge research funded by both NIH and other public and private entities. AAI urges that, rather than creating a new government bureaucracy (a particular burden in this era of severe budget constraints), NIH should partner with these publishers to develop a plan that enhances public access while also addressing publishers' key concerns, which include respecting copyright law and ensuring journals' continued ability to provide quality, independent peer review of NIH-funded research.

Preserving high quality peer review

NIH has recently conducted a "Self-Study" of its peer review system, soliciting the views of a wide range of stakeholders in an effort to improve what is already the world's best system. AAI applauds, and has participated fully in, this important effort. Nevertheless, AAI has some concerns that NIH has not adequately considered the importance of transparent evaluation and urges the subcommittee to ensure that NIH: 1) provides adequate time for stakeholder review and input on all final recommendations; and 2) conducts timely and transparent evaluation of all pilot projects and permanent changes, with ample opportunity for public comment. Even as NIH seeks to make needed improvements, it is essential that changes to our extraordinary peer review system, already the envy of the world, must first "do no harm".

Ensuring the independence of science

Millions of lives - as well as the prudent use of taxpayer dollars - depend on the willingness of government officials to accept the best, most independent scientific advice available. AAI urges the subcommittee to ensure that funds expended protect the ability of scientists to provide independent scientific advice, whether through government advisory panels, through the peer review process, or by supporting the vitality of independent scientific journals that provide expert peer review of taxpayer-funded research.

Ensuring NIH operations and oversight

AAI urges the subcommittee to explore whether the President's proposed sub-inflationary increase of $20 million (1.49%) for Research, Management, and Services, which supports the management, monitoring,

and oversight of all research activities (including peer review), is adequate to ensure NIH supervision of a portfolio of increasing size and complexity, as well as to ensure that NIH funds are properly spent.

Conclusion

AAI greatly appreciates this opportunity to submit testimony and thanks the Chairman and members of the subcommittee for their strong support for biomedical research, the NIH, and the scientists who devote their lives to preventing, treating, and curing disease.

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[1] The majority of AAI members receive grants from the National Institute of Allergy and Infectious Diseases (NIAID), the National Cancer Institute (NCI), and the National Institute on Aging (NIA).

[2] NIH funding supports "more than 300,000 scientists and research staff at more than 3,000 universities, medical schools, and other research institutions in every state and around the world". FY 2009 Director's Budget Request Statement: Fiscal Year 2009 Budget Request, Witness appearing before the House Subcommittee on Labor-HHS-Education Appropriations, Elias A. Zerhouni, M.D., Director, National Institutes of Health (March 5, 2008)

[3] Scientists estimate that "vaccination with 7 of the 12 routinely recommended childhood vaccines prevents an estimated 33000 deaths and 14 million cases of disease ...[and] saves $10 billion in direct costs in each birth cohort... and saves society an additional $33 billion costs that include disability and lost productivity." Roush et al. "Historical Comparisons of Morbidity and Mortality for Vaccine-Preventable Diseases in the United States." The Journal of the American Medical Association, Vol. 298, No. 18, pp. 2155-2163 (2007)

[4] The immune system works by recognizing and attacking "foreign invaders" (e.g., 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 attacking and destroying the virus, bacterium, or tumor cell - or partially, resulting in a less serious illness. It is also responsible for the rejection responses observed following transplantation of organs or bone marrow. The immune system can malfunction, allowing the body to attack itself instead of an invader (resulting in an "autoimmune" disease, such as Type 1 diabetes, multiple sclerosis, or rheumatoid arthritis).

[5] National health expenditures cost $3.28 trillion in 2006 and are projected to be $4.1 trillion in 2016. U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services National Health Expenditure Data
http://www.cms.hhs.gov/NationalHealthExpendData/downloads/proj2006.pdf
http://www.cms.hhs.gov/NationalHealthExpendData/downloads/highlights.pdf

[6] According to the Biomedical Research and Development Price Index ("BRDPI"), a U.S. Department of Commerce annual estimate of the cost of inflation for biomedical research, the projected rate of biomedical research inflation for FY 2009 is 3.5%. NIH funding increases since FY 2003 have all been below the BRDPI. National Institutes of Health memo dated February 4, 2008: "Biomedical Research and Development Price Index: FY 2007 Update and Projections for FY 2008-2013"
http://officeofbudget.od.nih.gov/UI/2008/BRDPI_Proj_2008_final.pdf

[7] A report issued by Trust for America's Health ("Pandemic Flu and the Potential for U.S. Economic Recession") predicts that a severe pandemic flu outbreak could result in the second worst recession in the United States since World War II, resulting in a drop in the U.S. Gross Domestic Product of over 5.5%.

Association of
American Cancer Institutes

**Written Testimony to the United States House of Representatives
Appropriations Committee, Subcommittee for
Labor, Health and Human Services, Education and Related Agencies
Regarding FY 2009 Cancer-Related Funding
Submitted March 31, 2008**

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The Association of American Cancer Institutes (AACI), representing 91 of the nation's premier academic and free-standing cancer centers, appreciates the opportunity to submit this statement for consideration as the Labor, Health and Human Services Appropriations Subcommittee plans the fiscal year (FY) 2009 appropriations for the National Institutes of Health (NIH) and the National Cancer Institute (NCI).

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. Years of flat funding for the NIH and NCI have eroded these institutions' ability to maintain their robust research programs. For FY 2009, the AACI joins its colleagues in the biomedical research community in recommending an appropriation of $31.1 billion for NIH (an increase of $1.9 billion over FY 2008 levels). Further, AACI respects the professional judgment of the NCI in requesting an appropriation of $5.26 billion (an increase of $455 over FY 2008 levels). AACI will work to ensure that Congress approves the maximum possible appropriations for NIH and NCI.

The Growing Cancer Burden

In 2008, there will be approximately 1.44 million new cases of cancer in the United States and approximately 565,650 deaths due to the disease.[1] The human toll of cancer is staggering, as is its financial toll; the NCI reports that in 2006, $206.3 billion was spent on healthcare costs for cancer alone. Additionally, NCI acknowledges that the burdens of cancer—physical, emotional, and financial—are "unfairly shouldered by the poor, the elderly, and minority populations."[2] The number of cancer diagnoses will only continue to climb as our population ages, with an estimated 18.2 million cancer survivors (those undergoing treatment, as well as those who have completed treatment) alive in 2020.[3] By comparison, an estimated 11.9 million survivors were living in the United States in 2007.[2]

[1] *Cancer Facts and Figures 2008*. American Cancer Society; 2008.
[2] *The Nation's Investment in Cancer Research: An Annual Plan and Budget Proposal for FY2009*. National Cancer Institute, 2008.
[3] Future Supply and Demand for Oncologists. *Journal of Oncology Practice* 2007; 3(2): 79–86.

Cancer Research: Benefiting all Americans

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 across the United States.

Though over a half-million Americans will die this year from the many diseases defined as cancer, progress *is* being made. Because of continued progress made by the nation's researchers, cancer death rates have continued to decline; between 1991 and 2004, the death rates for cancer in men and women declined 18.4 percent and 10.5 percent, respectively.[4]

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. Another initiative, the Childhood Cancer Therapeutically Applicable Research to Generate Effective Treatments Initiative, is identifying targets that can lead to better treatments for young people with cancer.

These projects—along with the work being performed by dedicated physicians and researchers 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.

A Generation of Science at Risk

The nation's investment in cancer research is in jeopardy. Since 2004, the budget of the NCI has—through actual cuts and the effects of biomedical inflation—lost 12 percent of its spending power.[2] The current success rate for R01 applications—the R01 is the cornerstone grant of medical research—submitted to NIH is 25 percent; only one in four applications submitted to NIH are funded. These funds are often approved only after the researcher has resubmitted the application several times. In 1999, the success rate for a first R01 submission was 29 percent; in 2007, that rate was 12 percent. The low approval rate and lengthy delays in receiving funds have combined to raise the average age of receiving a first R01 grant from age 39 in 1990 to age 43 in 2007.[5]

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[4] Cancer Statistics, 2008. *CA: Cancer Journal for Clinicians* 2008; 58(2): 71–96.

[5] *A Broken Pipeline? Flat Funding of the NIH Puts a Generation of Science at Risk.* A Follow-up Statement by a Group of Concerned Universities and Research Institutions, 2008.

Because of this, young researchers—the next generation of scientists whose novel ideas will build upon those of their seasoned mentors—may be lost. As NIH itself states, "New investigators are the innovators of the future—they bring fresh ideas and technologies to existing biomedical research problems, and they pioneer new areas of investigation. Entry of new investigators into the ranks of independent, NIH-funded researchers is essential to the health of this country's biomedical research enterprise."[6]

Research projects that are funded are often more conservative in scope than those of a few years ago. Scientists who perform the invaluable task of evaluating R01 proposals are electing to fund conventional projects that will lead to incremental progress; these reviewers are also less likely to fund truly "out-of-the-box" ideas that may not bear fruit—but if they were successful, these ideas could move the pace of research exponentially.[5] In years past, funding has been available to support both of these types of projects, a mix that led to the rapid progress to which we have become accustomed—and that has contributed to lengthening and improving the lives of cancer patients around the world.

The Nation's Cancer Centers

The nexus of cancer research in the United States is the nation's network of cancer centers that are 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 $3.17 billion[7] from NCI to conduct cancer research; this represents 66 percent of NCI's total budget. In fact, 85 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 is dependent on federal dollars, via training grants and other funding from NCI. Decreasing federal support will significantly undermine 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.

Stagnant funding prevents expansion at existing centers but also prevents new centers from achieving NCI designation. While most major metropolitan areas in the United States have easy access to an NCI-designated cancer center, several states and many underserved areas do not. Without enhanced funding to establish and nurture cancer centers in these areas, far too many Americans face the burden of cancer without the benefit of the cutting-edge care available only at a dedicated cancer center.

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[6] NIH Office of Extramural Research Website: http://grants.nih.gov/grants/new_investigators/. Retrieved 3/28/08.
[7] *National Cancer Institute 2007 Fact Book*. U.S. Department of Health and Human Services, U.S. National Institutes of Health, 2007.

Ensuring the Future of Cancer Care and Research

Because of an aging population, an increasing number of cancer survivors require ongoing monitoring and care from oncologists, and new therapies that tend to be complex and often extend life. As a result, demand for oncology services is projected to increase 48 percent by 2020. However, the supply of oncologists expected to increase by only 20 percent and 54 percent of currently practicing oncologists will be of retirement age within that timeframe. Also, alarmingly, there has been essentially no growth over the past decade in the number of medical residents electing to train on a path toward oncology as a specialty.[8]

Cancer physicians—while essential—are only one part of the oncology workforce that is in danger of being stretched to the breaking point. The Health Resources and Services Administration predicted that by 2020, over 1 million nursing positions will go unfilled, and a 2002 survey by the Southern Regional Board of Education projected a 12percent shortage of nurse educators by last year.[9]

Without immediate action, these predicted shortages will prove disastrous for the state of cancer care in the United States. The discrepancy between supply and demand for oncologists will amount to a shortage of 9.4 to 15.1 million visits, or a shortage of 2,550 to 4,080 oncologists.[8] The Department of Health and Human Services projects that today's 10-percent vacancy rate in registered nursing positions will grow to 36 percent, representing more than 1 million unfilled jobs by 2020.[10]

Greater federal support for training oncology physicians, nurses, and other professionals who treat cancer must be enacted to prevent a disaster within our healthcare system when demand for oncology services far outstrips the system's ability to provide adequate care for all.

Americans Support Federal Funding for Research

The research community has long understood the obstacles that are facing cancer research. Though the nuances of R01 grants and oncology workforce training may not be well understood by the average American, the people of the United States believe in supporting the disparate activities that make up America's biomedical research infrastructure.

In a 2007 Research!America poll, 91 percent of those surveyed believed it was somewhat or very important for policymakers to create more incentives to encourage individuals to pursue careers as nurses, while 89 percent believed the same for encouraging careers as physicians. Forty-seven percent of those surveyed agreed that he U.S. must increase investment in NIH to ensure our future health and economic security, and 54 percent favored annual 6.7-percent increases in funding for NIH in 2008, 2009, and 2010. An overwhelming majority—70 percent—agreed that the U.S. is losing its global competitive edge in science, technology, and innovation.[11]

We encourage our Representatives in Congress to respond to the concerns of the American people by enhancing support for biomedical research that will lead to improved health for everyone in the United States and around the world.

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[8] *Forecasting the Supply of and Demond for Oncologists: A Report to the American Society of Clinical Oncology (ASCO) from the AAMC Center for Workforce Studies.* American Society of Clinical Oncology, 2007.

[9] ONS: Ready to Collaborate with Other Policymakers to Ensure Future of Quality Cancer Care *Oncology Times*, August 25, 2007; (29): 8–9.

[10] Oncology Nursing Society Website: http://www.ons.org/lac/pdf/correspondence/110/082807.pdf. Retrieved 3/28/08.

[11] *Your Congress–Your Health Survey, 2007.* Charlton Research Company for Research!America, 2007.

Conclusion

These are exciting times in science and, particularly, in cancer research. Discoveries made today can translate to prevention methods, treatments and even cures in the future. Research funding through the NIH and NCI make these discoveries possible.

AACI urges the members of the House Committee on Appropriations, Subcommittee on Labor, Health & Human Services, Education, and Related Agencies to dedicate an appropriation of $31.1 billion for the NIH in FY 2009 (a $1.9 billion increase over FY 2008 levels). We ask for your support in increasing this critical funding that will help set the pace for cancer research for years to come.

American Chemical Society
Public Testimony
on the
U.S. Department of Education

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

March 27, 2008

The American Chemical Society (ACS) appreciates the opportunity to submit public testimony to the Labor, Health and Human Services, Education, and Related Agencies Subcommittee on the fiscal year 2009 budget for the U.S. Department of Education (DoEd).

The ACS is a nonprofit scientific and educational organization, chartered by Congress in 1937, with more than 160,000 chemical scientists and engineers as members. The world's largest scientific society, ACS advances the chemical enterprise, increases public understanding of chemistry and science, and brings its expertise to bear on state and national matters.

A hardworking and entrepreneurial American workforce, coupled with aggressive federal and private investment in scientific and technological research, sent a man to the moon, harnessed the atom, sequenced the human genome, and built a dynamic, robust, and growing economy that is the envy of the world. As the 21st Century blossoms, we must revitalize our commitment to strengthen the pillars of American innovation and competitiveness – education, basic research, and a business environment to drive innovation.

Last year, Congress showed strong bipartisan support for increased investment to strengthen the U.S. science, technology, engineering, and mathematics (STEM) education pipeline and basic research in the physical sciences by enacting the *America COMPETES Act*. This groundbreaking legislation authorizes a dramatic expansion of federal investments in many aspects of STEM education from teacher training and recruitment, to educational research, to support for students studying in science and technology fields. As other nations around the globe are quickly advancing scientifically and technologically, it is imperative that the Congress – and especially your Subcommittee – appropriate the funding necessary to fully implement the *America COMPETES Act*.

American Competitiveness Initiative

The ACS supports the $175 million proposed for FY 2009 by the Administration's American Competitiveness Initiative for math and science education programs at the Department of Education.

We support the proposed funding level of $70 million for the Advanced Placement/International Baccalaureate as well as $95 million for the new Math Now program. Both of these new

initiatives were authorized by the America COMPETES Act and are broadly supported by the scientific, education, and business communities.

Our Society continues to strongly support the Administration's Adjunct Teacher Corps initiative, proposed at $10 million in FY2009, which would encourage up to 30,000 experienced professionals with subject-matter knowledge to enter the classroom to teach part- or full-time in areas of high need, including science and math. We recommend that sufficient funding be provided to ensure adequate teacher development and certification for these professionals.

K–12 Education

We profoundly disagree with Administration's decision to flat fund the DoEd Math and Science Partnership program and strongly support a budget increase in FY 2009 toward the fully authorized level of $450 million. One of the most critical issues facing STEM education today is the supply of qualified K–12 science and mathematics teachers. The Math and Science Partnerships program, authorized in the *No Child Left Behind Act* at an increasing annual level to reach a sustainable level of $450 million by FY 2007, is the sole source of dedicated K–12 math and science funding at the Department of Education. It supports valuable long-term, content-based, continuing education for math and science teachers—the type of training that research shows is most effective in improving student achievement.

Vocational and Technical Education

We are highly disappointed by the Administration's decision to eliminate the Perkins Career and Technical Education program, which was reauthorized by Congress with overwhelming support in 2006. We urge that Congress appropriate full funding for this broadly supported program to aid students in acquiring rigorous academic and technical skills to prepare them for careers in science and technology that will help maintain U.S. competitiveness in the global economy.

Higher Education

We support the Administration's proposal to expand the Graduate Assistance in Areas of National Need (GAANN) program by 10 percent in FY 2009 to $32.5 million. The budget request for GAANN, which provides graduate students in science and other high-need fields with enhanced fellowship assistance, would support 747 fellowships in 2009, including 529 new fellows. ACS supports expansion of this program to at least 1,200 fellowships. Our Society also believes that the Minority Science and Engineering Improvement program is an effective mechanism to increase the participation of underrepresented minorities in scientific and technological careers.

In closing, we thank you for the opportunity to express our views on the funding priorities of your Subcommittee. We strongly urge you to make the sustained and robust investments in STEM education that will be critical to the success of U.S. global competitiveness and continued economic growth.

NAEVR
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Serving as Friends of the National Eye Institute

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[About NAEVR and List of Members on Last Page]

NAEVR WRITTEN TESTIMONY IN SUPPORT OF INCREASED FUNDING FOR THE NATIONAL INSTITUTES OF HEALTH (NIH) AND THE NATIONAL EYE INSTITUTE (NEI) LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES SUBCOMMITTEE OF THE U.S. HOUSE OF REPRESENTATIVES COMMITTEE ON APPROPRIATIONS

March 26, 2008

EXECUTIVE SUMMARY

NAEVR requests Fiscal Year (FY) 2009 NIH funding at $31 billion, or a 6.6 percent increase over FY2008, to balance the biomedical inflation rate of 3.6 percent and to begin to restore NIH's purchasing power. Although NAEVR commends the Congressional leadership's actions to significantly increase NIH funding above the Administration's budget request in FY2008 appropriations, the net 0.46 percent increase meant a net loss in NIH purchasing power. For five consecutive years, NIH funding has failed to keep pace with the biomedical inflation rate and NIH has lost more than 10 percent of its purchasing power. The Administration's FY2009 budget, which proposes to freeze the NIH budget at the FY2008 level, threatens to further hinder the momentum of discovery leading to treatments that are saving lives—as well as restoring the quality of life—and maintaining the nation's competitive edge in medical research. Secure and consistent funding for health and scientific research must be part of the nation's long-term strategies for sustained economic growth. NIH is a world-leading institution and must be adequately funded so that its research can reduce healthcare costs, increase productivity, improve quality of life, and ensure our nation's global competitiveness.

NAEVR requests that Congress make vision health a top priority by funding the NEI at $711 million in FY2009, or a 6.6 percent increase over FY2008. The NEI was flat funded in FY2008, meaning that over the past five funding cycles it has lost 18 percent of its purchasing power, reducing the number of grants by 160, which threatens its impressive record of breakthroughs in basic and clinical research that have resulted in treatments and therapies to save and restore vision, as well as to prevent eye disease. Vision impairment/eye disease is a growing, major public health problem that disproportionately affects the aging and minority populations, costing the United States $68 billion annually in direct and societal costs, let alone reduced independence and quality of life. Adequately funding the NEI is a cost-effective investment in our nation's health, as it can delay, save, and prevent expenditures, especially to the Medicare and Medicaid programs.

FY2009 NEI FUNDING AT $711 MILLION ENABLES IT TO LEAD COLLABORATIVE RESEARCH REFLECTING THE NEW PARADIGM OF 21st CENTURY HEALTHCARE THAT IS PREDICTIVE, PREEMPTIVE, PERSONAZLIED, AND PARTICIPATORY

NEI research addresses the NIH's overall major health challenges as set forth by NIH Director Elias Zerhouni, M.D.: an aging population; health disparities; the shift from acute to chronic diseases; and the co-morbid conditions associated with chronic diseases (e.g., diabetic retinopathy as a result of the epidemic of diabetes). NEI research responds to Dr. Zerhouni's vision for NIH research that is collaborative and cost-effective and meets the 21st century "P4Medicine" paradigm of predictive, preemptive, personalized, and participatory research and clinical practice. For example:

- One-quarter of all genes identified to date through NEI's collaboration with the Human Gene Project is associated with eye diseases, such as age-related macular degeneration (AMD), retinitis pigmentosa (RP), and glaucoma. NEI-funded researchers have discovered gene variants strongly associated with an individual's risk of developing AMD, the leading cause of blindness in older Americans. These variants, which are responsible for about 60 percent of the cases of AMD, are associated with the body's inflammatory response and may relate to other inflammation-associated diseases, such as Alzheimer's and Parkinson's disease. As NEI Director Dr. Paul Sieving has stated, "One of the important stories during the next decade will be how Alzheimer's disease and macular degeneration fit together."

- NEI is currently conducting the second phase of its Age-Related Eye Disease Study (AREDS), which follows up on initial findings that high levels of dietary zinc and antioxidant vitamins (Vitamins C, E and beta-carotene) are effective in reducing vision loss in people at high risk for developing advanced AMD—by a magnitude of 25 percent. The cost-effectiveness and public health consequences of this research are significant: 1.3 million Americans would develop advanced AMD if no treatment was given, and if all individuals at risk availed themselves of the AREDS supplement regimen, more than 300,000 of them would avoid advanced AMD and any associated vision loss during the next five years.

- NEI's collaborative research into factors that promote or inhibit new blood vessel growth has resulted in the first generation of ophthalmic drugs approved by the Food and Drug Administration (FDA) to inhibit abnormal blood vessel growth in "wet" AMD, thereby stabilizing and restoring vision, and NEI's Diabetic Retinopathy Clinical Research (DRCR) Network is further evaluating these drugs for treatment of macular edema associated with diabetic retinopathy (DR). In March 2008, NEI-funded researchers announced that damage from both AMD and DR was prevented and even reversed when the protein Robo4 was activated in mouse models that simulate the two diseases. Robo4 treated and prevented the diseases by inhibiting abnormal blood vessel growth and by stabilizing blood vessels to prevent leakage. Since this research into the "Robo4 Pathway" used animal models associated with these diseases that are already used in drug

development, the time required to test this approach in humans could be shortened, expediting approvals for new therapies.

These examples primarily reflect NEI's trans-Institute research within NIH. The NEI has also collaborated with other Department of Health and Human Services (DHHS) agencies, specifically to share the results of its basic and clinical research which may impact the product approval and reimbursement processes. For example:

- In a March 2008 meeting, NEI collaborated with FDA's Center for Drug Evaluation and Research (CDER) and Center for Devices and Radiological Health (CDRH) to consider the appropriateness of new clinical endpoints in glaucoma clinical trials. Advances in visual imaging technologies—many of which emerged from collaborative research between the NEI and the National Institute of Biomedical Imaging and Bioengineering (NIBIB)—have enabled researchers to better detect structural changes in the nerve fiber layer of the retina and contours of the optic nerve head. These structural changes could potentially be used as a direct endpoint in a clinical trial, rather than a surrogate endpoint such as elevated intra-ocular pressure, when appropriately correlated to functional changes in vision to assure clinical significance of a new therapy. This meeting, which followed a November 2006 joint NEI-FDA/CDER meeting on clinical endpoints in AMD and DR clinical trials, represents the cost–effectiveness of NEI funding, as its research results may ultimately shorten the time and cost associated with clinical trials, as well as facilitate the approval of new diagnostics and therapies for patients.

- In collaboration with the Centers for Medicare and Medicaid Services (CMS), the NEI has launched the *Comparison of AMD Treatments Trial* (CATT), which is a comparative effectiveness study of the two drugs that are used to block growth of the abnormal blood vessels in patients with the "wet" form of AMD. NEI's collaboration with CMS could guide clinical practice and reduce costs to the Medicare program.

THE NEI'S DIMINISHED PURCHASING POWER JEOPARDIZES ITS ABILITY TO FOLLOW UP ON RESEARCH BREAKTHROUGHS FROM PAST INVESTMENT

The NEI must be adequately funded to initiate promising new research, to pursue results that have emerged from previous breakthroughs, and to offer up its "fair share" of funding in its extensive collaborations. The number of NEI grants has declined by 160 over the past five years, from 1,214 in FY2004 to 1,054 in FY2008, representing myriad "lost opportunities"—any one of which could have been the key to curing eye disease or restoring vision. Examples of such lost opportunities include:

- Ocular gene therapy holds great promise, especially for retinal degenerative diseases in which nearly 200 gene defects have been implicated. Investigators supported by the NEI and private-funding organization Foundation Fighting Blindness (FFB) have begun human clinical trials of a gene therapy to treat Leber

Congenital Amaurosis (LCA), a rapid retinal degeneration that blinds infant in the first year of life. Previous research has restored vision in dogs with LCA, and the results of the human clinical trials are forthcoming. Although the NEI could expand this program to target more diseases, current budget realities limit further research.

- Promising protocols proposed within the Diabetic Retinopathy Clinical Research Network will not be funded. The DRCR Network is a large, multi-center study that engages ophthalmologists and optometrists, many in community health centers, in basic and clinical research into diabetic eye disease. Past NEI diabetes networks developed laser treatments for DR that save $1.6 billion annually in federal disability payments.

- NEI funding for new epidemiology studies has already become limited, which jeopardizes future research into identifying the basis and progression of eye disease in additional ethnic populations, such as Asian and Native Americans. Past NEI studies have identified a three-fold greater risk of glaucoma in African Americans, as well as glaucoma being the leading cause of irreversible vision loss in African Americans and Hispanics.

- NEI will not be able to fund proposed new Clinical Research Networks for AMD and for neuro-ophthalmic disorders. The latter could assist in understanding visual disorders associated with Traumatic Brain Injuries (TBI), especially those currently occurring in record numbers by soldiers in Iraq and Afghanistan.

In addition, NEI research into other significant eye disease programs such as cataract will be threatened, along with quality of life research programs into low vision and chronic dry eye. This occurs at a time when the US Census cites significant demographic trends that will increase the public health problem of vision impairment and eye disease, such as the first wave of 78 million Baby Boomers celebrating their 65th birthday in 2010, with about 10,000 Americans turning 65 each day for 18 years afterward.

VISION IMPAIRMENT/EYE DISEASE IS A MAJOR PUBLIC HEALTH PROBLEM THAT IS INCREASING HEALTHCARE COSTS, REDUCING PRODUCTIVITY, AND DIMINISHING QUALITY OF LIFE

The 2000 US Census reported that more than 119 million people in the United States were age 40 or older, which is the population most at risk for an age-related eye disease. The NEI estimates that, currently, more than 38 million Americans age 40 and older experience blindness, low vision or an age-related eye disease such as AMD, glaucoma, diabetic retinopathy, or cataracts. This is expected to grow to more than 50 million Americans by year 2020. The economic and societal impact of eye disease is increasing not only due to the aging population, but to its disproportionate incidence in minority populations and as a co-morbid condition of chronic disease, such as diabetes.

Although the NEI estimates that the current annual cost of vision impairment and eye disease to the US is $68 billion, this number does not fully quantify the impact of direct healthcare costs, lost productivity, reduced independence, diminished quality of life, increased depression, and accelerated mortality. The continuum of vision loss presents a major public health problem and financial challenge to the public and private sectors.

In public opinion polls over the past 40 years, Americans have consistently identified fear of vision loss as second only to fear of cancer. As recently as March 2008, the NEI's *Survey of Public Knowledge, Attitudes, and Practices Related to Eye Health and Disease* reported that 71 percent of respondents indicated that a loss of their eyesight would rate as a "10" on a scale of 1 to 10, meaning that it would have the greatest impact on their day-to-day life. As a result, federal funding for the NEI is a vital investment in the health, and vision health, of our nation as the treatments and therapies emerging from research can preserve and restore vision. Adequately funding the NEI can delay, save, and prevent expenditures, especially those associated with the Medicare and Medicaid programs, and is, therefore, a cost-effective investment.

NAEVR urges FY2009 NIH and NEI funding at $31 billion and $711 million, respectively.

ABOUT NAEVR

Founded in 1997, NAEVR is a non-profit advocacy organization comprised of a coalition of more than 50 professional, consumer, and industry organizations (see list below) involved in eye and vision research. NAEVR's goal is to achieve the best vision for all Americans through advocacy and public education about the value and cost-effectiveness of eye and vision research sponsored by the NIH, NEI, and other federal research entities.

Advanced Medical Optics
Alcon Laboratories, Inc.
Allergan, Inc.
AMD Alliance International
American Academy of Ophthalmology
American Academy of Optometry
American Association for Pediatric Ophthalmology and Strabismus
American Association of Ophthalmic Pathologists
American Glaucoma Society
American Ophthalmological Society
American Optometric Association
American Society of Cataract and Refractive Surgery
American Society of Retina Specialists
American Uveitis Society
Association for Research in Vision and Ophthalmology
Association of Schools and Colleges of Optometry
Association of University Professors of Ophthalmology
Association of Vision Science Librarians
Bausch & Lomb
Blinded Veterans Association
Discovery Eye Foundation
Eye Bank Association of America
EyeSight Foundation of Alabama
Fight for Sight
Foundation Fighting Blindness
Genentech, Inc.
Glaucoma Research Foundation
Inspire Pharmaceuticals, Inc
ISTA Pharmaceuticals, Inc
Juvenile Diabetes Research Foundation Intl
Lighthouse International
Lions Clubs Intl. Foundation
Macular Degeneration Partnership
Novartis
Ocular Microbiology and Immunology Group
Pfizer Inc
Prevent Blindness America
Prevention of Blindness Society of of Metropolitan Washington
Research to Prevent Blindness
Santen, Inc.
Second Sight
Sjogren's Syndrome Foundation
Tear Film and Ocular Surface Society
The Cornea Society
The Glaucoma Foundation
The Macula Society
The Retina Society
Vision Council of America
Vision Share, The Consortium of Eye Banks
Vistakon, Johnson & Johnson Vision Care, Inc.
Women in Ophthalmology
Women's Eye Health Task Force

Statement of Ron Pollack, Executive Director, Families USA
Concerning
Funding for the National Institutes of Health and the
Centers for Disease Control and Prevention in FY 2009

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

March 28, 2008

Families USA wishes to thank the Subcommittee for the opportunity to submit this written testimony concerning federal funding for the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC). This statement highlights the importance of the medical research that is conducted and supported by NIH and the CDC in addressing global health problems, especially infectious disease pandemics.

Since 1982, Families USA has advocated for U.S. policies that increase access to affordable health care for all Americans. Recognizing that international health affects domestic health, and that research conducted by the U.S. can provide tremendous help to people around the world, Families USA launched its Global Health Initiative two years ago. The Global Health Initiative advocates for increased U.S. investment in research and development of medical interventions for infectious diseases that disproportionately affect low-income countries.

The drug industry has little interest in investing in diseases that predominantly affect low-income countries because there is little potential for profit. It is in our nation's self-interest to fill the current funding gap and provide the needed resources so that our agencies and institutes can continue to conduct necessary global health research.

Research: A Crucial Tool for Improving Global Health

Turning the tide against complicated, deadly infectious disease pandemics such as HIV/AIDS, tuberculosis (TB), and malaria requires a comprehensive, multifaceted strategy. Research needs to be the cornerstone of any such strategy. Research is the *only* way to identify and develop new medical interventions to diagnose, prevent, and treat disease. To make progress in U.S. and global health, research is absolutely crucial.

Research that yields new and improved medical interventions will also increase the effectiveness of U.S. global aid programs that are already in place, such as the President's Emergency Plan for AIDS Relief (PEPFAR), the President's Malaria Initiative (PMI), and the Global Fund to Fight AIDS, TB, and Malaria.

The National Institute of Allergy and Infectious Diseases (NIAID) has taken a leadership role in conducting the bulk of the global health research and development activities that

are undertaken at NIH. Robust funding for NIAID is essential for addressing infectious disease crises around the globe and in the U.S.

The Fogarty International Center ("Fogarty"), which is also part of NIH, plays a crucial role in addressing global health challenges by facilitating collaboration between U.S. and international researchers through its international training and global health research capacity building programs. Fogarty's programs facilitate the development of medical discoveries worldwide.

The CDC's global health programs are also vitally important to protecting Americans and people around the world from disease. Cuts to the CDC's budget undermine both the U.S. and the global public health infrastructures that are crucial to rapidly responding to new disease outbreaks and combating existing global pandemics. Yet, some of the CDC's global health programs have been flat-funded for years, and other global health programs can no longer carry out their critical mission due to limited funds.

Global Health Research Matters to Our National Interests

Economic Interests: Many universities across the U.S. receive global health research funding from NIH and the CDC. This influx of cash spurs local economies. Moreover, in regions around the globe where disease prevalence is greatest, workforces suffer from substantially reduced productivity, and economic growth is hindered. In today's globalized economy, our economic health is intertwined with the economies of other nations.

Health Interests: The SARS outbreak that happened in Canada a few years ago, and the 2007 incident involving an American traveling internationally with multi-drug resistant TB, make it all too clear that infectious diseases abroad pose a substantial threat to the U.S. We desperately need new tools to combat these and other deadly diseases.

National Security and Political Interests: In areas of the world where the infectious disease burden is greatest, the social structure of entire countries has been unraveling, paving the way for political unrest and undermining democracy in many regions of the world. To reverse this trend, we must give NIH and the CDC the resources they need to make progress in global health.

Diplomatic Interests: We have a national diplomatic interest in funding global health research: As the wealthiest country on earth, we have the means to advance health and alleviate human suffering. Using our wealth to improve global health improves America's image and is an effective foreign policy tool.

Humanitarian Interests: As a nation of plenty and the leader of the free world, it is unconscionable for us to turn a blind eye to the plight of the vast majority of humankind. The number of people impacted by infectious diseases is staggering:

- One *billion* people are affected by, and many millions are left permanently disabled by, neglected tropical diseases that you may never have heard of—infectious diseases that are found mainly in low-income tropical and subtropical regions. Examples include Chagas disease and leishmaniasis.
- There are about 350 to 500 million cases of malaria each year, and malaria kills 18 percent of children under age five in sub-Saharan Africa.
- Currently, 33 million people around the world have HIV/AIDS.
- Tuberculosis (TB) infects people worldwide: One-third of the planet has latent TB and is at risk of developing active TB. The risk of developing active TB is heightened in those with HIV/AIDS and those suffering from malnutrition.

How Much Funding Is Needed?

NIH—Total Budget

NIH needs a 6.7 percent increase above its FY 2008 funding level across all institutes, centers, and offices, for a total budget of $31.1 billion in FY 2009.

Families USA's Global Health Initiative recommends a 6.7 percent increase in funding for FY 2009 across all of NIH. This includes a 3.7 percent increase to keep pace with the projected rise in inflation from 2008 to 2009, plus an additional 3.0 percent to begin correcting for the historic underfunding of NIH (in recent years, the NIH budget has not kept pace with inflation).

NIH—Global Health Programs

NIAID needs an increase of $83.1 million above its FY 2008 funding level, on top of the overall NIH increase of 6.7 percent, for a total budget of $5 billion in FY 2009.

We determined the necessary funding level for NIAID by examining worldwide research needs for HIV/AIDS vaccines and microbicides, malaria, TB, and neglected tropical diseases. These research needs are based on the assessments of numerous organizations, for example, the Global Network for NTD Control, AVAC, IAVI, UNAIDS, the Alliance for Microbicide Development, Roll Back Malaria, WHO, and the Stop TB Partnership.

To fully address research needs in these areas (while maintaining the agency's current share of the world's public-sector spending), NIAID would need $582 million more than it is currently budgeted (on top of the overall NIH adjustment of 6.7 percent). To implement this increase in a fiscally responsible time frame, our calculations spread the $582 million increase over seven years, yielding $83.1 million per year.

The Fogarty International Center needs an increase of $2.4 million above its FY 2008 funding level, on top of the overall

NIH increase of 6.7 percent, for a total budget of $74 million in FY 2009.

To make progress in combating diseases such as HIV/AIDS, TB, and malaria, Fogarty would need a 25 percent increase above its 2008 funding level. As with the recommended adjustment for NIAID, the adjustment for Fogarty would also be spread over seven years. In 2009, this would amount to an additional $2.4 million for Fogarty (on top of the overall NIH adjustment of 6.7 percent), or $74.6 million in total funding.

The CDC's Global Health Programs

The CDC's global health programs need a $35.5 million increase above their FY 2008 funding levels, for a total budget of $405.5 million in FY 2009.

As with NIH, CDC funding has been shortchanged for many years, especially funding for its global health programs. This places the nation's and the world's health at risk.

Our assessment of gaps in the CDC's current funding and our evaluation of its prior funding indicate that $512 million is needed right now for the CDC's global health programs. However, we understand that the realities of the current fiscal environment will likely necessitate implementation of any funding increases over multiple years. Therefore, we recommend that funding for the CDC's global health programs be increased over four years to a total of $512 million, updated annually thereafter for inflation. This amounts to $405.5 million in FY 2009, which is a $35.5 million increase above FY 2008 funding.

Call for Action

People across the U.S. and throughout the world are looking to NIH and the CDC for new medical advances that will lead to a healthier tomorrow. Shortchanging NIH and the CDC places everyone's health at risk. We urge the Subcommittee to fund NIH and the CDC at the levels specified above.

For additional information, please contact Janet Goldberg at 202-628-3030 or jgoldberg@familiesusa.org.

SIECUS Sexuality Information and Education Council of the United States

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Statement of the Sexuality Information and Education Council of the United States (SIECUS) on Eliminating Funding for Abstinence-Only-Until-Marriage Programs and Providing Adequate Funding for Evidence-Based HIV Prevention Programs and Family Planning Services

Fiscal Year 2009 House Committee on Appropriations
Subcommittee on Labor, Health and Human Services and Education
Submitted for the Record
March 31, 2008

SIECUS, the Sexuality Information and Education Council of the United States, has served as a strong national voice for sexuality education, sexual health, and sexual rights for over 40 years. SIECUS affirms that sexuality is a fundamental part of being human, one that is worthy of dignity and respect. We advocate for the right of all people to accurate information, comprehensive education about sexuality, and sexual health services. SIECUS works to create a world that ensures social justice and sexual rights.

As an organization concerned about the health and education of our nation's young people, we urge you to oppose any funding for abstinence-only-until-marriage programs and to provide funding for evidence-based programs, such as HIV prevention programs and family planning services. We are committed to sound science and the health and welfare of our nation's youth and we wish to express our profound concern with the continuation of any funding for abstinence-only-until-marriage programs in the Fiscal Year (FY) 2009 Labor, Health and Human Services, and Education (Labor-HHS) appropriations bill. This bill includes two discretionary abstinence-only-until-marriage programs: the Community-Based Abstinence Education (CBAE) grant program and the Adolescent Family Life Act (AFLA). The President's FY 2009 budget request proposed increasing funding for abstinence-only-until-marriage programs to $204 million—the entire $27.7 million increase slated for the CBAE account. We encourage the Congress to show its support for evidence-based sexuality education or HIV prevention programs by eliminating funding for the CBAE program. All such funds should be re-directed to evidence-based prevention and educational programs.

Scientific evidence does not support abstinence-only-until-marriage programs. These programs have been funded by the federal government for over 25 years and yet, no study in a professional peer-reviewed journal has found them to be broadly effective. Most recently, a federally funded study of abstinence-only-until-marriage programs was conducted by Mathematica Policy Research Inc. on behalf of the U.S. Department of Health and Human Services. Released in April 2007, the study found no evidence that abstinence-only-until-marriage programs have achieved their goal to increase rates of sexual abstinence—the entire supposed purpose of the programs. Students in the abstinence-only-until-marriage programs had a similar age of first sex and similar numbers of sexual partners as their peers who were not in the programs. In addition, the average age of sexual debut was the same for the abstinence-only-until-marriage participants and control groups (14 years, 9 months).[1]

This report followed on the findings from 13 states that have evaluated their own Title V abstinence-only-until-marriage programs with results ranging from finding the programs ineffective to finding them to be harmful. For example, the 2004 evaluation completed in President Bush's home-state of Texas included five self-selected "abstinence education" contractors who participated in a study conducted by researchers at Texas A&M University. Analysis found that there were "*no significant changes*" in the percentages of students who "pledg[ed] not to have sex until marriage."[ii] In addition, the analysis revealed that the percentage of students reporting having ever engaged in sexual intercourse increased for nearly all ages between 13 and 17. One of the study's investigators said, "we didn't see any strong indications these programs were having an impact in the direction desired...these programs seem to be much more concerned about politics than kids, and we need to get over that."[iii]

Furthermore, in early November 2007, the National Campaign to Prevent Teen and Unplanned Pregnancy released *Emerging Answers 2007*, a report authored by Dr. Douglas Kirby, a leading sexual health researcher, discussing what programs work in preventing teen pregnancy and sexually transmitted diseases, including HIV. The report found strong evidence that abstinence-only-until-marriage programs do not have any impact on teen sexual behavior.[iv]

- The study found that no evidence to support the continued investment of public funds.
  "In sum, studies of abstinence programs have not produced sufficient evidence to justify their widespread dissemination...Only when strong evidence demonstrates that particular programs are effective should they be disseminated more widely."

- The study also found that, to date, no abstinence-only-until-marriage program that is of the type to be eligible for funding by the federal government has been found in methodologically rigorous study to positively impact teen sexual behavior.
  "At present, there does not exist any strong evidence that any abstinence program delays the initiation of sex, hastens the return to abstinence, or reduces the number of sexual partners. In addition, there is strong evidence from multiple randomized trials demonstrating that some abstinence programs chosen for evaluation because they were believed to be promising actually had no impact on teen sexual behavior."

In addition, a report released by the non-partisan Government Accountability Office (GAO) in November 2006 adds additional evidence to the already significant body of knowledge that abstinence-only-until-marriage programs are providing very little oversight and have few mechanisms in place to measure the effectiveness of the programs. The report documents the actions of the U.S. Department of Health and Human Services (HHS) and finds, in part, that:

- The Administration for Children and Families (ACF), the division of HHS responsible for the vast majority of the programs, including Community-Based Abstinence Education grantees, does not review its grantees' materials for scientific accuracy and does not require grantees to review their own materials for scientific accuracy.
- ACF has a total lack of appropriate and customary measurements to determine if funded programs are actually working. ACF took over the administration of these programs in 2001 and promptly gutted evidence-based measures such as determining whether programs reduced teen pregnancy rates. In their place, ACF now only requires grantees to provide non-health based measures, such as how many young people were in the program and the number of hours the program operated.

Furthermore, these programs are not supported by any of the leading public health and medical organization in this country or abroad. Every major medical and public health organization supports a comprehensive approach to sexuality education. These include the American Academy of Pediatrics, the American Medical Association, the American Nurses Association, the American Public Health Association, the Institute of Medicine, the National Institutes of Health, and the Society for Adolescent Medicine, among others. Several, including the American Public Health Association, the Institute of Medicine, and the Society for Adolescent Medicine, have gone so far as to call for the repeal of current abstinence-only-until-marriage programs and funding.

In addition, on November 21, 2007, ten public health researchers sent a letter to House Speaker Nancy Pelosi and Senate Majority Leader Harry Reid urging Congress to reduce or eliminate federal support for abstinence-only-until-marriage programs, in part because the programs have "multiple scientific and ethical errors." The researchers declared that abstinence-only-until-marriage programs withhold "potentially life-saving information" about birth control and ignore the health needs of lesbian, gay, bisexual, and transgender (LGBT) youth. The letter focused on the large body of evidence showing that abstinence-only-until-marriage programs are ineffective in getting young people to delay sexual initiation, noting that, "Recent reports in professional publications by the authors of this letter have highlighted multiple deficiencies in federal abstinence-only programs." The researchers noted at the time that, "...we are surprised and dismayed that the Congress is proposing to extend and even increase funding for these programs." They continued by concluding that "We strongly urge the U.S. Congress to reconsider federal support for abstinence-only education programs and policies."

It is noteworthy that 17 states have declined participation in the federal Title V abstinence-only-until-marriage program. Acting on principle and in the best interest of their youth, these governors have rebuffed a source of much needed revenue because they concluded that these unduly restrictive and ideologically driven programs were, at a minimum, ineffective and, at worst, harmful.

Finally, from a political perspective, it is puzzling that Congress would increase funding for these programs when more than 90% of parents support comprehensive sexuality education and more than 6 in 10 voters say they are more likely to vote for a candidate who supports comprehensive sexuality education.

In light of its lack of support from voters as well as medical and public health institutions, and its proven failure, we respectfully ask that you eliminate funding for abstinence-only-until-marriage programs and redirect funds to evidence-based HIV prevention programs and education.

The budget requests from the Bush administration for domestic HIV prevention have been woefully out of step with community needs and reality. Data from the Centers for Disease Control and Prevention (CDC) indicate that over one million individuals are living with HIV in the United States and the annual incidence rate is rising. At the same time, HIV prevention funding has faced significant budget cuts over the past six years. Sadly, in those same six years over 240,000 people have become infected with HIV. For the past several years, it has been estimated that there are approximately 40,000 new HIV infections each year. However, sometime this year, the CDC will release new incidence estimates showing that there may actually be approximately 50,000 to 60,000 people are newly infected each year. State and local health departments and community based organizations need increased resources to strengthen and expand outreach, HIV testing efforts and

prevention programs targeting high-risk populations including racial and ethnic minority communities, young gay men of color, substance users, women and youth. The CDC's HIV/AIDS prevention activities help to support outreach and education efforts in local communities, and is essential in reducing the number of new infections. In FY2008 CDC's HIV Prevention budget was cut by $3.5 million. According to the Kaiser Family Foundation, overall spending for domestic HIV prevention *decreased* by over $70 million dollars between Fiscal Years 2003 and 2007.

It is difficult to surpass holding ground at 40,000—or possibly now 60,000—new infections each year when the fiscal resources are not made available to invest in prevention. With a shifting epidemic that we are still trying to understand, AIDS-service organizations and other community-based groups are left to meet new and rising demands with fewer resources. The larger HIV/AIDS community is requesting an increase of $608 million for a total of $1.3 billion for CDC prevention activities in FY 2009 and we mirror that request here.

We also ask that $400 million in funding be appropriated to the Title X family planning program for FY 2009, as a minimal investment in basic health care for low-income women and men. The current funding level is $300 million. A 2005 government review of Title X family planning services confirms that the program serves a unique and valuable purpose, is cost-effective, and is effectively managed. Nevertheless, funding continues to fall well short of what is needed to meet the current demand for services, much less keep up with inflation, medical advances, and a growing population of uninsured Americans. Had Title X funding kept up with inflation it would now be funded at more than $759 million.

America's families need real solutions that will help delay the onset of sexual activity and prevent unintended pregnancy and sexually transmitted diseases, including HIV/AIDS. Abstinence-only programs are not the answer. America's youth deserve more and we ask Congress to act in the best interest of young people by supporting public health and education policies that are comprehensive, rooted in the best science, and reflect mainstream values.

In the Fiscal Year 2003 *Budget Message of the President*, President Bush said, "Where government programs are succeeding, their efforts should be reinforced...and when objective measures reveal that government programs are not succeeding, those programs should be reinvented, redirected, or retired." We could not agree more with this sentiment. This means ending funding for abstinence-only-until-marriage programs and increasing funding for proven programs, such as HIV-prevention programs and basic family planning services.

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[i] Christopher Trenholm, et. al., "Impacts of Four Title V, Section 510 Abstinence Education Programs: Final Report," (Trenton, NJ: Mathematica Policy Research, Inc., April 2007), accessed 6 September 2007, <www.mathematica-mpr.com/publications/pdfs/impactabstinence.pdf>.

[ii] Patricia Goodson, et al., *Abstinence Education Evaluation Phase 5: Technical Report* (College Station, TX: Department of Health & Kinesiology–Texas A&M University, 2004), 170-172. Emphasis included in original document.

[iii] "Texas Teens Increased Sex After Abstinence Program," *Reuters*, 2 February 2005, accessed 17 February 2005, <http://news.yahoo.com/news?tmpl=story&u=/nm/20050131/hl_nm/health_abstinence_texas_dc>.

[iv] Douglas Kirby, *Emerging Answers 2007: Research Findings on Programs to Reduce Teen Pregnancy and Sexually Transmitted Diseases*, (Washington, DC: The National Campaign to Prevent Teen and Unplanned Pregnancy, 2007), p. 15, accessed 5 February 2007, <http://www.thenationalcampaign.org/EA2007/EA2007_full.pdf>.

American College of Cardiology

Public Witness Testimony for the Record to the

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

March 31, 2008

The American College of Cardiology (ACC) appreciates the opportunity to provide the subcommittee with recommendations for Fiscal Year 2009 (F Y 09) funding for life-saving cardiovascular research and prevention. The ACC is a more than 34,000 member, non-profit professional medical society and teaching institution whose mission is to advocate for quality cardiovascular care—through education, research promotion, development and application of standards and guidelines—and to influence health care policy.

The Need for a Federal Investment in Cardiovascular Disease Research

Cardiovascular disease continues to be the leading cause of death for both women and men in the United States. While the number of deaths due to cardiovascular disease is on the decline, one in three Americans suffer from heart disease. The economic impact of cardiovascular disease on the U.S. health care system continues to grow as the population ages and as the prevalence of it increases, costing the nation an estimated $449 billion this year due to medical expenses and lost productivity.[1]

In order to continue the progress made in the fight against heart disease, the ACC urges Congress to reject the flat-funding and cuts to many critical health agencies included in the Administration's FY 09 budget proposal. The combination of inflation and stagnant federal funding for NIH and other key health agencies in recent years has threatened the laboratories and continuing research of established investigators. The ACC encourages Congress to provide a strong federal investment in research and prevention programs that address cardiovascular disease. Federal research is providing for breakthrough advances that fundamentally change our understanding of the prevention and treatment of cardiovascular disease, leading to better outcomes, decreased costs, and increased quality of life for patients.

Cardiovascular Disease Research Needs

As the U.S. healthcare system continues its move toward the use of performance measurement to foster the delivery of the highest quality of care to patients, the need for meaningful clinical practice guidelines, from which performance measures are developed, becomes even more critical.

The performance measures that will be used to determine whether patients are receiving the most effective, efficient, and highest quality cardiovascular care are derived from clinical guidelines developed by the ACC and the American Heart Association (AHA). The ACC strives to produce the preeminent medical specialty practice guidelines, with more than 16 guidelines on a range of

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[1] American Heart Association. *Heart Disease and Stroke Statistics - 2008 Update.* Dallas, Texas: American Heart Association; 2008.

cardiovascular topics. They are developed through a rigorous, evidence-based methodology employing multiple layers of review and expert interpretation of the evidence on an ongoing, regular basis. Many clinical research questions remain unanswered or understudied, however. The guideline recommendations based on expert opinion rather than clinical data vary by cardiovascular topic from only 20 percent for coronary bypass surgery to more than 70 percent for valvular heart disease.

Through its clinical policy development process, the ACC has identified knowledge gaps for cardiovascular disease. If addressed, these currently unresolved issues have potential to positively impact patient outcomes, costs, and the efficiency of care delivery. Medicine includes a degree of uncertainty about the ability of a particular procedure, device, or therapy to benefit a patient. Yet, an investment in answering the following scientific questions through the NIH, and in particular the NHLBI, as well as through the Agency for Healthcare Research and Quality (AHRQ), will help to better narrow the target population who can benefit from treatment and therefore increase the efficacy and efficiency of patient-centered care delivery.

1. What is the effect of common cardiovascular therapies on elderly populations whose metabolism and kidney function is lower and may not respond to medications in the same way as the younger patients typically included in clinical trials?
2. What is the effect of common cardiovascular therapies on patients with multiple other diseases/conditions?
3. What are the best approaches to increasing patient compliance with existing therapies?
4. What screening and risk models (existing or new) could further define who will benefit from various therapies?
5. What are the optimal management strategies for anticoagulation and antiplatelet agents in heart attack patients, patients with stents, and atrial fibrillation patients to maximize benefit and reduce bleeding risks?
6. What are the best approaches to managing complex but understudied cardiovascular topics such as congenital heart disease and valvular heart disease? Both congenital heart disease and valvular heart disease have become areas of higher research interest as techniques have developed to extend the lives of these patients.
7. What are the risks and benefits of common off-label uses of widely used therapies and procedures, such as drug eluting stents?
8. What are the best catheter-based techniques to increase treatment success and reduce complications for both coronary and cardiac rhythm procedures?

The above list of topics is not exhaustive but gives an overview of some of the themes of the evidence gaps that exist across the ACC's guidelines. In addition to specific clinical research topics, the ACC recommends funding to help address structural issues that could help identify, prioritize, and interpret research findings over the long term.

1. The NIH should fund more trials of direct comparison between pharmacological and other therapies. Without these important trials, the current emphasis on promoting comparative effectiveness will be founded upon efficacy trials and not effectiveness.
2. The NHLBI should work with the clinical cardiology community to proactively design clinical trials to address unanswered clinical questions and identify methods that allow

for greater comparability among studies. NHLBI should work with ACC and the AHA to develop an evidence model that would drive future research initiatives based on current evidence gaps in the guidelines; and

3. NIH should fund the development of a robust informatics infrastructure across Institutes to process research evidence. Studies should be designed such that their results could be "fed" into a computer model that would provide additional insights for developers of clinical recommendations.

Collaborating to Improve Cardiovascular Care

Facilitating the transfer of new knowledge to health care professionals, patients and the public is an important part of federal research efforts. For example, the NHLBI continues to collaborate with the ACC to raise awareness of Peripheral Arterial Disease (P.A.D.) through the "Stay in Circulation: Take Steps to Learn about P.A.D." campaign. The ACC is promoting the campaign through its membership and has formed a P.A.D. Guidelines Implementation Task Force, of which NHLBI is a member, which has developed tools based on the PAD Guidelines to help physicians diagnose and treat the more than eight million Americans affected by the disease. New slides sets on renal artery stenosis and a quality improvement program are under development this year.

In addition, the NHLBI and AHRQ continue to be supporters of the "D2B: An Alliance for Quality" program, which saves time and lives by reducing the door-to-balloon times in U.S. hospitals performing primary percutaneous coronary intervention (PCI) by providing hospitals with key evidence-based strategies and supporting tools needed to begin reducing their D2B times.

Finally, through its Centers for Education and Research on Therapeutics (CERT), AHRQ has been crucial in helping fund research by ACC on its clinical policy development process. The CERT grant provided resources to help ACC better understand and adapt how its guidelines and performance measures are developed and disseminated. It also provided resources to support the development of a framework for ACC to address appropriateness of medical technology. This evaluation of ACC processes for the development of clinical policy has been an essential part of translating research from bench to bedside. Lastly, the grant has provided funding to expand the use of quality improvement as a part of ACC educational programs.

The Role of Comparative Effectiveness Research

As the federal government increases its comparative effectiveness research efforts, the ACC offers its thoughts for Congress' consideration. The ACC believes that comparative effectiveness research should reflect the principle that physicians and patients should have the best available evidence upon which to make choices in health care items and services. While a potentially valuable tool--if conducted correctly--for improving both the quality and cost of health care, the ACC cautions that physicians, patients, policymakers and payers must use the research findings wisely once obtained, as the potential for misuse and abuse of such research is substantial—and can have significantly negative impacts on access to care for not only our most vulnerable populations, but potentially all stakeholders.

The ACC strongly believes that keeping cost analyses independent of comparative clinical effectiveness research ensures that the clinical research achieves a high degree of credibility among all stakeholders. Further, the entity responsible for supervising/conducting this research must not also make coverage and benefit decisions; such decisions should be independently made, based on the best available scientific evidence, and should take into consideration the need for flexibility based on the individual needs and complexities of the patient. Lastly, the ACC urges the concurrent development and implementation of strategies for the widespread dissemination and use of the results of comparative research by health care providers, through systematic programs of physician education and support from specialty societies such as the ACC, which has its own practice guidelines and other quality improvement tools.

ACC Funding Recommendations for FY09

As the subcommittee considers its appropriations for programs within the Department of Health and Human Services, the ACC urges support of the following FY 09 funding recommendations.

National Institutes of Health

The ACC supports an FY 09 NIH budget of $31.128 billion, a 6.5 percent increase. Research conducted through the NIH has resulted in better diagnosis and treatment of cardiovascular disease, thereby improving the quality of life for those living with the disease and lowering the number of deaths attributable to it. Adequate funding through the NIH is necessary for basic, clinical, and translational research that facilitates the delivery of new discoveries to the bedside.

National Heart Lung and Blood Institute

The ACC recommends $3.112 billion, a 6.5 percent increase, for the NHLBI in FY 09 for continuing its critical research into the causes, diagnosis, and treatment of heart, blood vessel, lung and blood diseases. This investment will allow NHLBI to fulfill the goals laid out in its recently released strategic plan, "Shaping the Future of Research: A Strategic Plan for the National Heart, Lung, and Blood Institute."

Agency for Healthcare Research and Quality

The ACC supports $360 million for the AHRQ. With the continuing emphasis on the need for comparative effectiveness research, increasing the federal investment in AHRQ health services research is critical.

Centers for Disease Control and Prevention's (CDC) Division for Heart Disease and Stroke Prevention

The ACC recommends $70 million for the CDC Division for Heart Disease and Stroke Prevention, whose public education efforts are making strides in the prevention of and early intervention in treating cardiovascular disease – thereby potentially reducing future care costs significantly.

Health Resources and Services Administration (HRSA) Rural and Community Access to Emergency Defibrillation (AED) Program

The ACC supports $8.9 million in FY 09 for the HRSA Rural and Community AED program, an important initiative that saves lives by placing external defibrillators in public facilities.

Testimony
Before the United States House of Representatives
Committee on Appropriations
Subcommittee on Labor, Health and Human Services,
Education and Related Agencies
February 28, 2008

The Disability Backlog at the Social Security Administration

Support Staff is a Vital Component to Addressing the Backlog at the Social Security Administration

Statement Submitted for the Record by
The Federal Managers Association

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Chairman Obey, Ranking Member Walsh and Members of the House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies:

On behalf of the Federal Managers Association (FMA) and the nearly 1,000 managers in the Social Security Administration's Office of Disability Adjudication and Review (ODAR), please allow us to take a moment and thank you for this opportunity to present our views before the Subcommittee. As federal managers, we are committed to carrying out the mission of our agency in the most efficient and cost effective manner while providing those necessary services to millions of Americans.

Established in 1913, the Federal Managers Association is the largest and oldest association of managers and supervisors in the federal government. FMA was originally organized to represent the interests of civil service managers and supervisors in the Department of Defense and has since branched out to include some 35 different federal departments and agencies including many managers and supervisors within the Social Security Administration (SSA). We are a nonprofit professional membership-based organization dedicated to advocating excellence in public service and committed to ensuring an efficient and effective federal government. FMA members and their colleagues in the SSA Office of Disability Adjudication and Review are responsible for ensuring the success of the administration of Social Security's disability determination process and in providing needed services to American customers.

As you are keenly aware, the Social Security Administration plays a vital role in serving over 160 million American workers and their families. Each month, SSA pays out benefits to 48 million beneficiaries. Over 7 million low-income Americans depend on the agency's Supplemental Security Income (SSI) program to stay afloat in a cost-inflating world, and nearly 7.2 million disabled Americans receive benefit payments through Social Security Disability Insurance (SSDI). At the February 28, 2008 hearing, Commissioner Astrue testified that SSA's productivity has increased over 15% since fiscal year 2001. Considering the magnitude of its mission, the Social Security Administration does a remarkable job administering critical programs.

In the Office of Disability Adjudication and Review, however, there currently exists a backlog of over 757,000 requests for a hearing. It already takes over 500 days to process a typical request for hearing and these delays tarnish SSA's otherwise strong record of service to the American public. At the beginning of 2002, SSA had 468,262 pending hearing requests. In six years, that number increased to over 750,000, despite the fact that dispositions are at record levels. Although clericals in hearing offices prepared 472,168 cases in FY07, claimants submitted almost 557,970 new requests during the same period. As such, the backlog of files simply awaiting preparation for review by an Administrative Law Judge (ALJ) at the close of January 2008 totaled 442,399 cases; an increase of 3,116 cases since the beginning of fiscal year 2007. Unless something is done to reverse this trend, the backlog could realistically reach one million by 2013 with the aging Baby Boom generation.

As managers and supervisors within ODAR, we are acutely aware of the impact these backlogs are having on our ability to deliver the level of service the American public deserves.

We are here to confirm what you've heard several times before - that the ongoing lack of adequate staffing levels and resources have contributed to these backlogs. If these inadequacies continue, clearing the backlogs will be impossible and service delivery will continue to deteriorate.

We at FMA appreciate the attention the Subcommittee is placing on examining the reasons for the backlog and addressing remedies to the problem. ODAR began fiscal year 2008 with 419,752 pending cases awaiting preparation for a hearing. In all likelihood, those cases will realistically wait at least one year before any action is even initiated to prepare the case for review and hearing in front of an Administrative Law Judge. In January, processing times across the nation ranged from a low of 343 days in the Boston region to a high of 649 days in the Chicago region. The American public deserves better service.

Within ODAR, production is measured by the number of dispositions completed per day by an Administrative Law Judge. In FY05 and FY06, this record-level figure was 2.2 dispositions per day per ALJ. A work year is approximately 250 work days, yielding a reasonable expectation that an ALJ can produce an estimated average of 550 dispositions a year given the current staffing limitations. At the end of January 2007, SSA employed 1,088 ALJs, resulting in a best case scenario of 557,150 dispositions for FY07, which is about the same number of new cases filed in a given year.

Earlier this year, hiring letters went out to 144 of the 175 administrative law judges SSA plans to employ this fiscal year. Already 136 judges have accepted. A total of 175 ALJs could translate into an additional 82,500 dispositions, but only if adequate staff is available to prepare the cases for review. While this is certainly a step in the right direction, Administrative Law Judges alone will not solve the problem. Without additional staffing, the current level of prepared work would be distributed among more judges, essentially resulting in the same dispositional outcome. Without adequate support staff to prepare cases for the judges, both existing and new, we will not achieve an increase in hearing dispositions – the only solution to reducing the backlog.

Undoubtedly, adequate clerical support is necessary to prepare cases for hearing. As it stands, hearing offices do not even have the staff to accommodate the current judges, let alone enough staff to process the nearly new 47,000 cases the Office of Disability Adjudication and Review receives each month. If receipts remained flat, the backlog will remain at over 700,000 cases, almost one-third of which are over 365 days old. At the beginning of FY07, ODAR had over 63,000 cases which were over 1,000 days old; a number which is both unacceptable to the agency as well as the American people it serves. Commissioner Astrue identified these cases as ODAR's number one priority and this backlog has since been eliminated. FMA applauds the Commissioner for his efforts; however, the 900 day old cases are now approaching this milestone. Currently, just fewer than 54,000 cases will be over 900 days old by the close of FY08. We are committed to working with the Commissioner as he tackles this challenge.

With the aging Baby Boom population, it is reasonable to assume that receipts will continue to out-pace dispositions. As the requests for hearings continue to rise, more is

demanded from ODAR staff on all levels. The *bottom line* is that the hearing offices lack sufficient staff to process the work on hand much less even begin to work on new cases. It should be evident that under the best case scenario, the current staffing levels in ODAR barely maintain the status quo. That means that the backlog stays the same and processing times continue at an estimated 500 days.

The existing staff must make room for the new cases as they attempt to address the backlog. In recent years, however, budgetary constraints have forced the agency to hire additional Administrative Law Judges without providing adequate support staff to prepare the cases for hearing. We recognize that the Commissioner is trying to address the backlog by adding these judges; however, additional ALJs without the supporting clerical staff to prepare cases in a timely manner will not solve the problem. By following in his predecessor's footsteps, Commissioner Astrue will encounter the same problems – no matter how many new judges come on board, without clerical staff to prepare cases for them, the backlog cannot be addressed.

As previously stated, there is currently insufficient support staff to ensure optimal ALJ productivity and to handle the backlog. The accepted staff to ALJ ratio has been four and one half production staff per ALJ. However, this only ensures productivity necessary to handle *incoming* work, not the backlog. For offices with heavy backlogs, the four and one half to one standard is inadequate. Management and administrative employees should not be included in these figures, as they are not the employees performing the production work on hearing requests. And, of course, staffing shortfalls cannot be remedied without adequate funding.

The solutions to the backlog problem are simply adequate staffing levels and timely budgets which will allow us to address the pending cases. As of last month, the backlog was at 757,221 requests for a hearing. However, it is worth noting that the agency can reasonably process 400,000 cases at any given time. As such, the actual "backlog" is around 350,000 cases. As noted earlier, a trained, productive ALJ, with adequate support staff, should be able to produce about 550 dispositions in a given year. Approximately 1,000 additional ALJs and 5,000 additional support staff would allow ODAR to work down the backlog in one year while providing timely processing of new cases as they arrive. We at FMA recognize that these numbers present a large funding challenge for Congress.

To enable SSA to meet the goals set forth in Commissioner Astrue's testimony before your Subcommittee on February 28, 2008, Congress must approve a sufficient level of funding for the agency. The Continuing Resolution (CR) which was signed into law in March 2007 was severely inadequate to address both the staffing and backlog problem at SSA for fiscal year 2007, despite the meager increase SSA received above the fiscal year 2006 appropriation. Since 2001, Congress has appropriated, on average, $180 million less than the President has requested each year. The dollar value of this differential is equivalent to processing an additional 177,000 initial claims and 454,000 hearings. Over the last ten years (FY98 – FY07), Congress has appropriated nearly $1.3 billion less than the President's request. Without a doubt, this has had a devastating effect on the services provided to the American public, as evidenced by the situation we are in today.

Recognizing the needs of SSA, Congress appropriated $150 million above the President's request for FY08 in an effort to bring down the backlog. Congress should be applauded for their commitment to serving the American people in this capacity. In fact, it is this increase which is allowing the agency to hire the additional 175 ALJs.

The President requested $10.327 billion for SSA's administrative expenses in FY09, only $100 million below Commissioner Astrue's request and six percent more than Congress appropriated this fiscal year. Furthermore, the House Budget Resolution (H.Con.Res. 312) provided for an additional $240 million for SSA's administrative expenses.

To remedy the unprecedented backlog situation, Congress should *at a minimum* pass the President's 2009 budget request of $10.327 billion for SSA's Limitation on Administrative Expenses account. Under his budget, the agency would be able to process 85,000 more hearings in FY09 than in FY08. In FY06 and FY07, SSA replaced one worker for every three that retired. The President's budget will allow for a 1 to 1 replacement ratio.

In addition to having an immediate impact on the current backlog, underfunding the Social Security Administration will negatively impact every service area of the agency. Staffing at SSA will soon reach its lowest level since 1972; however, SSA today has nearly twice the number of beneficiaries it had in 1972. SSA officials estimate that more than 40% of its 65,000 employees will retire by 2014. Reversing this trend is a necessary step to reducing the backlog.

While the President's budget request for FY09 is a start, it is certainly not a cure all solution. Throwing money at the problem will not fully solve it without a well-trained, dedicated staff of federal employees willing to avert a crisis in the coming years. We believe this is the workforce we have now, strengthened under the leadership of former-Commissioner Barnhart and Commissioner Astrue. By fully funding the President's request, we can continue this tradition.

In this era of shrinking budgets, SSA has attempted to maximize its use of scarce resources to provide the best possible service to the American public. The challenges faced by the managers and supervisors are not short term; they are a demographic reality. The same citizens putting stress on the Social Security trust fund because they are approaching retirement are also entering their most disability-prone years. ODAR is struggling to handle the current workload and will be hard pressed to manage the anticipated increase in hearing requests without additional staff.

We are the men and women who work with disabled Americans everyday. We see people of all ages come in and out of our offices seeking the services they depend on for survival from the Social Security Administration. We are committed to serving a community of Americans in need, but we need you to provide us with the necessary resources to help them. Thank you for your time and consideration of our views.

Written Testimony of
Jill Kagan
Chair, National Respite Coalition
Policy Division of the ARCH National Respite Network
Washington, DC
For the House Subcommittee on Labor, HHS and Education Appropriations
Public Witness Testimony for the Record
March 30, 2008

Mr. Chairman, I am Jill Kagan, Chair of the ARCH National Respite Coalition, a network of respite providers, family caregivers, state and local agencies and organizations across the United States who support respite. Twenty-five state respite coalitions, including the Wisconsin Respite Care Association and the New York Respite Coalition, are also affiliated with the NRC. This statement is presented on behalf of the these organizations, as well as the members of the Lifespan Respite Task Force, a coalition of over 80 national and more than 100 state and local groups who supported the passage of the Lifespan Respite Care Act (P.L. 109-442). Together, we are requesting that the Subcommittee include funding for the newly enacted Lifespan Respite Care Act in the FY 09 Labor, HHS and Education Appropriations bill at its modest authorized level of $53.3 million for FY 09.

Many Members of Congress already support funding for Lifespan Respite. We join the 26 Members of Congress who, along with Rep. Langevin (D-RI) and Rep. Ferguson (R-NJ), recently sent a letter to the Subcommittee making this same request. The Senate Budget Resolution also reserves $53 million in the Dept. of Health and Human Services Account for Lifespan Respite.

Who Needs Respite?

A national survey found that 44 million family caregivers are providing care to individuals over age 18 with disabilities or chronic conditions (National Alliance for Caregiving (NAC) and AARP, 2004). In 2001, the last year federal data were collected, 9.4 million children under age 18 were identified with chronic or disabling conditions (National Survey of Children with Special Health Care Needs, U.S. Health Resources and Services Administration, 2001). These surveys suggest that a conservative estimate of the nation's family caregivers probably exceeds 50 million.

Compound this picture with the growing number of caregivers known as the "sandwich generation" caring for young children as well as an aging family member. It is estimated that between 20 and 40 percent of caregivers have children under the age of 18 to care for in addition to a parent or other relative with a disability. And in the US, 6.7 million children, with and without disabilities, are in the primary custody of an aging grandparent or other relative other than their parents.

These family caregivers are providing about 80% of all long-term care in the U.S. It has been estimated that in the U.S., these family caregivers provide $350 billion in uncompensated care, an amount comparable to Medicare spending ($342 billion in 2005) and more than total spending for Medicaid, including both federal and state contributions and both medical and long-term care ($300 billion in 2005). (AARP, 2007).

What is Respite Need?

State and local surveys have shown respite to be the most frequently requested service of the nation's family caregivers, including a recent study, "Evercare Study of Caregivers in Decline" (Evercare and NAC, 2006). Yet respite is unused, in short supply, inaccessible, or unaffordable to a majority of the nation's family caregivers. The 2004 NAC/AARP survey of caregivers found that despite the fact that the most frequently reported unmet needs were "finding time for myself," (35%), "managing emotional and physical stress" (29%), and "balancing work and family responsibilities" (29%), only 5% of family caregivers were receiving respite (NAC and AARP, 2004). It was recently found that in rural areas, the percentage of family caregivers able to make use of respite dropped to 4% (Easter Seals and NAC, 2006)

Barriers to accessing respite include reluctance to ask for help, fragmented and narrowly targeted services, cost, and the lack of information about how to find or choose a provider. Even when respite is an allowable funded service, a critically short supply of well trained respite providers may prohibit a family from making use of a service they so desperately need.

Twenty of 35 state-sponsored respite programs surveyed in 1991 reported that they were unable to meet the demand for respite services. In the last 15 years, we suspect that not too much has changed. A recent study conducted by the Family Caregiver Alliance identified 150 family caregiver support programs in all 50 states and Washington, DC funded with state-only or state/federal dollars. Most of the funding comes through the federal National Family Caregiver Support Program. As a result, programs are administered by local area agencies on aging and primarily serve the elderly. And again, some programs provide only limited respite, if at all. Only about one-third of these 150 identified programs serve caregivers who provide care to adults age 18-60 who must meet stringent eligibility criteria. As the report concluded, "State program administrators see the lack of resources to meet caregiver needs in general and limited respite care options as the top unmet needs of family caregivers in the states."

The 25 state coalitions and other National Respite Network members confirm that long waiting lists or turning away of clients because of lack of resources is still the norm.

While most families take great joy in helping their family members to live at home, it has been well documented that family caregivers experience physical and emotional problems directly related to their caregiving responsibilities. Three-fifths of family caregivers age 19-64 surveyed recently by the Commonwealth Fund reported fair or poor health, one or more chronic conditions, or a disability, compared with only one-third of non-caregivers (Ho, Collins, Davis and Doty, 2005). A study of elderly spousal caregivers (aged 66-96) found that caregivers who experience caregiving-related stress have a 63% higher mortality rate than noncaregivers of the same age (Schulz and Beach, December 1999).

Supports that would ease their burden, most importantly respite care, are too often out of reach or completely unavailable. Even the simple things we take for granted, like getting enough rest or going shopping, become rare and precious events. One Massachusetts mother of a seriously ill child spoke to the demands of constant caregiving: "I recall begging for some type

of in-home support...It was during this period when I fell asleep twice while driving on the Massachusetts Turnpike on the way to appointments at Children's Hospital. The lack of respite...put our lives and the lives of everyone driving near me at risk."

Restrictive eligibility criteria also preclude many families from receiving services or continuing to receive services they once were eligible for. A mother of a 12-year-old with autism was denied additional respite by her state DD (Developmental Disability) agency because she was not a single mother, was not at poverty level, wasn't exhibiting any emotional or physical conditions herself, and had only one child with a disability. As she told us, "Do I have to endure a failed marriage or serious health consequences for myself or my family before I can qualify for respite? Respite is supposed to be a preventive service."

For the millions of families of children with disabilities, respite has been an actual lifesaver. However, for many of these families, their children will age out of the system when they turn 21 and they will lose many of the services, such as respite, that they currently receive. In fact, 46% of U.S. state units on aging identified respite as the greatest unmet need of older families caring for adults with lifelong disabilities. An Alabama mom of a 19-year-old-daughter with multiple disabilities who requires constant care recently told us about her fears at a respite summit in Alabama, "My daughter Casey has cerebral palsy, she does not communicate, she is incontinent she eats a pureed diet, she utilizes a wheelchair, she is unable to bathe or dress herself. At 5'5" and 87 pounds I carry her from her bedroom to the bathroom to bathe her, and back again to dress her.... Without respite services, I do not think I could continue to provide the necessary long-term care that is required for my daughter...As I age, I do wonder how much longer I will be able to maintain my daily ritual as my daughter's primary caregiver."

Disparate and inadequate funding streams exist for respite in many states. But even under the Medicaid program, respite is allowable only through state waivers for home and community-based care. Under these waivers, respite services are capped and limited to narrow eligibility categories. Long waiting lists are the norm.

Respite may not exist at all in some states for adult children with disabilities still living at home, or individuals under age 60 with conditions such as ALS, MS, spinal cord or traumatic brain injuries, or children with serious emotional conditions. In Tennessee, a young woman in her twenties gave up school, career and a relationship to move in and take care of her 53 year-old mom with MS when her dad left because of the strain of caregiving. She went for years providing constant care to her mom with almost no support. Now 31, she wrote, "And I was young – I still am – and I have the energy, but – it starts to weigh. Because we've been able to have respite care, we've developed a small pool of people and friends that will also come and stand in. And it has made all the difference."

Respite Benefits Families and is Cost Saving

Respite has been shown to be a most effective way to improve the health and well-being of family caregivers that in turn helps avoid or delay out-of-home placements, such as nursing homes or foster care, minimizes the precursors that can lead to abuse and neglect, and strengthens marriages and family stability. A recent report from the US Dept of Health and Human Services prepared by the Urban Institute found that higher caregiver stress among those caring for the aging increases the likelihood of nursing home entry. Reducing key stresses on caregivers, such as

physical strain and financial hardship, through services such as respite would reduce nursing home entry (Spillman and Long, USDHHS, 2007)

The budgetary benefits that accrue because of respite are just as compelling, especially in the policy arena. Delaying a nursing home placement for just one individual with Alzheimer's or other chronic condition for several months can save government long-term care programs thousands of dollars. In an Iowa survey of parents of children with disabilities, a significant relationship was demonstrated between the severity of a child's disability and their parents missing more work hours than other employees. They also found that the lack of available respite care appeared to interfere with parents accepting job opportunities. (Abelson, A.G., 1999)

Moreover, data from an ongoing research project of the Oklahoma State University on the effects of respite care found that the number of hospitalizations, as well as the number of medical care claims decreased as the number of respite care days increased (FY 1998 Oklahoma Maternal and Child Health Block Grant Annual Report, July 1999). A Massachusetts social services program designed to provide cost-effective family-centered respite care for children with complex medical needs found that for families participating for more than one year, the number of hospitalizations decreased by 75%, physician visits decreased by 64%, and antibiotics use decreased by 71% (Mausner, S., 1995).

In the private sector, the most recent study by Metropolitan Life Insurance Company and the National Alliance for Caregivers found that U.S. businesses lose from $17.1 billion to $33.6 billion per year in lost productivity of family caregivers. Offering respite to working family caregivers could help improve job performance and employers could potentially save billions (MetLife and National Alliance for Caregiving, 2006).

Lifespan Respite Care Program Will Help

The Lifespan Respite Care Act is based on the success of statewide Lifespan Respite programs in four states: Oregon, Nebraska, Wisconsin and Oklahoma. A new Arizona State Lifespan Respite program will soon be up and running. Michigan passed state Lifespan Respite legislation in 2004 but has not provided the funding to implement the program, and new state Lifespan Respite legislation is currently pending in Kansas in preparation for the federal funds.

Lifespan Respite, which is a coordinated system of community-based respite services, helps states use limited resources across age and disability groups more effectively, instead of each separate state agency or community-based organization being forced to constantly reinvent the wheel or beg for small pots of money. Pools of providers can be recruited, trained and shared, administrative burdens can be reduced by coordinating resources, and the savings used to fund new respite services for families who may not currently qualify for any existing federal or state program.

The state Lifespan Respite programs provide best practices on which to build a national respite policy. The programs have been recognized by prominent policy organizations, including the National Conference of State Legislatures, which recommended the Nebraska program as a model for state solutions to community-based long-term care. The National Governors Association and the President's Committee for People with Intellectual Disabilities also have

highlighted lifespan respite systems as viable solutions. And most recently, the White House Conference on Aging recommended enactment of the Lifespan Respite Care Act to Congress.

The Lifespan Respite Task Force, a coalition of over 80 diverse national organizations, representing family caregivers, individual disabilities or chronic conditions, faith-based organizations, and social, health care and mental health services, aging and children' groups, diligently worked alongside its bipartisan congressional champions to see the legislation through to enactment in December 2006.

The purpose of the new law is to expand and enhance respite services, improve coordination, and improve respite access and quality. Under a competitive grant program, states would be required to establish state and local coordinated Lifespan Respite care systems to serve families regardless of age or special need, provide new planned and emergency respite services, train and recruit respite workers and volunteers and assist caregivers in gaining access to services.

Those eligible would include family members, foster parents or other adults providing unpaid care to adults who require care to meet basic needs or prevent injury and to children who require care beyond that required by children generally to meet basic needs.

The federal Lifespan Respite program would be administered by the U.S. Department of Health and Human Services (HHS), which would provide competitive grants to statewide agencies through Aging and Disability Resource Centers working in collaboration with state respite coalitions or other state respite organizations. The program is authorized at $53.3 million in FY 09 rising to $95 million in FY 2011. The program has received no Congressional funding to date.

No other federal program mandates respite as its sole focus. No other federal program would help ensure respite quality or choice, and no current federal program allows funds for respite start-up, training or coordination or to address basic accessibility and affordability issues for families. We urge you to include $53.3 million in the FY 09 Labor, HHS, Education appropriations bill so that Lifespan Respite Programs can be replicated in the states and more families, with access to respite, will be able to continue to play the significant role in long-term care that they are fulfilling today.

Complete references available upon request.

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American Society for Pharmacology & Experimental Therapeutics

Written testimony of the American Society for Pharmacology and Experimental Therapeutics to the Senate Appropriations Subcommittee on Labor, Health and Human Services, Education & Related Agencies
Fiscal Year 2009
Appropriations for the National Institutes of Health

The American Society for Pharmacology and Experimental Therapeutics (ASPET) is pleased to submit written testimony in support of the National Institutes of Health FY 2009 budget. ASPET is a 4,500 member scientific society whose members conduct basic and clinical pharmacological research within the academic, industrial and government sectors. Our members discover and develop new medicines and therapeutic agents that fight existing and emerging diseases as well as increasing our knowledge regarding how therapeutics work.

ASPET members are well aware of Congress' historic support of the NIH. However, appropriations over the past five years have failed to adequately fund the NIH to meet the scientific opportunities and challenges to our public health. The NIH research portfolio can barely keep pace with the inflation rate and the country's leadership in biomedical research will be threatened without renewed Congressional support. Five years after the completion of a bipartisan plan to double the NIH budget that ended in 2003, the NIH budget in now going backwards. The Administration's recommended FY 2009 budget, if enacted would mean that the NIH's ability to conduct biomedical research would be reduced by about 14% in inflation adjusted dollars since FY 2003.

To prevent this erosion and sustain the biomedical research enterprise, ASPET recommends that the NIH receive $31.1 billion in FY 2009, a 6.5% increase above the FY 2008 approved budget. A 6.5% increase will help to regain the momentum of discovery and pre-eminent research and recover the losses caused by biomedical research inflation.

NIH Improves Human Health and is an Economic Engine

Recent budget levels for the NIH constitute a retraction in the budget, sending the wrong signal to the best and brightest of our students who will not be able to or have chosen not to pursue a career in biomedical research. A diminished NIH research enterprise will mean a continued reduction in research grants and the resulting phasing-out of research programs and declining morale, an increasing loss of scientific opportunities such as the discovery of new therapeutic targets to develop, fewer discoveries that produce spin-off companies that employ individuals in districts around the country. In contrast, a 6.5% increase would provide the institutes with an opportunity to fund more high quality and innovative research, and provide the resources and incentives that will drive more young scientists to commit to careers supporting continuing improvements in public health.

Many important drugs have been developed as a direct result of the basic knowledge gained from federally funded research, such as new therapies for breast cancer, the prevention of kidney transplant rejection, improved treatments for glaucoma, new drugs for depression, and the cholesterol lowering drugs known as statins that prevent 125,000 deaths from heart attack each year. AIDS related deaths have fallen by 73% since 1995 and the five-year survival rate for childhood cancers rose to almost 80% in 2000 from under 60% in the 1970s. And for the first time in 70 years, the number of deaths from cancer has fallen. The link between basic research, drug discovery and clinical applications was vividly illustrated when three pharmacologists were awarded the 1998 Nobel Prize in Physiology or Medicine for their research on nitric oxide. More recently, NIH funded research for the 2005 Nobel Prize winners in chemistry. These scientists developed metal-containing molecules that are now being used by the pharmaceutical industry to aid in the drug discovery process. Historically, our past investment in basic biological research has led to innovative medicines that have virtually eliminated diphtheria, whooping cough, measles and polio in the U.S. Eight out of ten children now survive leukemia. Death rates from heart disease and stroke have been reduced by half in the past 30 years. Molecularly targeted drugs such as Gleevec™ to treat adult leukemia do not harm normal tissue and dramatically improve survival rates. NIH research has developed a class of drugs that slow the progression of symptoms of Alzheimer's disease. The robust past investment in the NIH has provided major gains in our knowledge of the human genome, resulting in the promise of pharmacogenetics and a reduction in adverse drug reactions that currently represent a major, worldwide health concern. But unless more robust funding is restored, scientific opportunities will be delayed, lost, or forfeited to biomedical research opportunities in other countries and the human and economic cost will continue to impact all of us.

Scientific inquiry leads to better medicine but there remain challenges and opportunities that need to be addressed, including:

- The need to increase support for training and research in integrative/whole organ science to see how drugs act not just at the molecular level - but also in whole animals, including human beings.

- The need to meet public health concerns over growing consumer use of botanical therapies and dietary supplements. These products have unsubstantiated scientific efficacy and may adversely impact the treatment of chronic diseases, create dangerous interactions with prescription drugs, and may cause serious side effects including death among some users.

Support for Integrative Organ System Science

ASPET supports efforts to increase funding for training and research in integrative organ system science (IOSS). IOSS is the study of responses in organs and organisms, including intact animals. Identification of isolated cellular and molecular components of drugs *in vitro* are important for identifying mechanisms of actions but are inadequate in determining all the complex interactions that happen *in vivo* in the actual organs of species. Because of the great advances in cellular and molecular biology over the past two decades, there has been much less emphasis in whole organ biology such that academic infrastructure in this area has eroded and there remain few faculty and institutions that can provide the appropriate scientific training in this important area of research.

Too few individuals have opportunities to be trained beyond cellular and molecular techniques. As a consequence, the pool of talent with expertise in whole organs has greatly diminished and the biotechnology and pharmaceutical industry are having great difficulty finding well-trained whole organ scientists to fill critical positions in their drug discovery departments. As a result of this training and research deficit, a more thorough and comprehensive examination of new therapeutic approaches may be compromised before clinical trials begin.

The lack of training and research opportunities to develop scientists well rounded in cellular, molecular and in vivo whole organ biology impacts progress in medicine and the training of future physicians. Development of preventive approaches and effective therapeutic strategies for many disorders with devastating health consequences and increasing incidence in an aging population will require intensive study at all levels from molecular to whole organ. For instance, obesity is not just a metabolic disorder. Obesity impacts many organ functions, including the heart, circulatory system, and brain. Similarly, clinical depression should not be viewed as just a neurological disorder because depression affects multiple organs in a variety of ways. And the discovery of new drugs to treat neurodegenerative diseases such as Alzheimer's and Parkinson's will ultimately need to look at complex whole animal systems. For these reasons, scientists must be trained to look broadly at complex medical problems afflicting humans. Medical progress in the post-genomic era needs scientists or teams of scientists who can integrate the results of studies in gene function at the molecular, cellular, organ system, whole animal and behavioral levels to fully understand the actions of current drugs and to facilitate the development of safe new drugs and treatment strategies.

To reverse the decline and adequately support training and research in integrative organ systems, integrative biology, program project grants, and pre and post-doctoral training programs should be implemented that support integrative training and research activities. Multi-disciplinary institutional and individual training and research grants on whole systems and integrative biology should be funded to investigate disease processes. ASPET is pleased that the National Institute of General Medical Sciences has recognized this training and research deficit and has funded four summer workshops to train students in integrative whole organ sciences. ASPET encourages other institutes to explore available mechanisms to begin developing a pool of talented scientists with the appropriate skills in integrative, whole organ systems biology. While many industrial concerns provide limited support for training and research at the post-doctoral level, their efforts remain necessarily focused on drug discovery and development. It is the role of the NIH and academic institutions to provide adequate training opportunities to develop the next generation of integrative scientists.

Support for training and research in integrative whole organ sciences has been affirmed in the FY 2002 U.S. Senate Labor/Health and Human Services & Related Agencies Appropriations Report (107-84). The Senate report supports ASPET recommendation that "Increased support for research and training in whole systems pharmacology, physiology, toxicology, and other integrative biological systems that help to define the effects of therapy on disease and the overall function of the human body." These principles and recommendations are also affirmed in the FASEB Annual Consensus Conference Report on Federal Funding for Biomedical and Related Life Sciences Research for FY 2002.

Support for Research on Botanicals and Herbal Therapies to Meet Public Health Needs

ASPET has for years supported peer-reviewed pharmacological examination of the mechanisms of actions of medicinal plants and is pleased that the NIH's National Center for Complementary and Alternative Medicine (NCCAM) continues rigorous investigations into the basic biology of various botanical agents. ASPET continues to recommend increased support to study the interaction of botanical remedies and dietary supplements with prescription medications. This support is critical to the promotion and funding of the highest quality research in botanical medicine, will help meet urgent needs of this neglected area of biological research, and will address a growing public health problem. Support for highly innovative research on botanicals should be encouraged among all institutes and centers.

The increased use of botanical and dietary supplements by consumers to treat various ailments and diseases is a major public health concern. One national survey reported that in 1997 an estimated 15 million adults (18.4% of all prescription users) took herbal remedies concurrently with prescription medicines. Between 1990 and 1997, the use of herbal products grew by 380%. Although there is little solid scientific evidence to support the therapeutic efficacy of many botanical and dietary supplement products, the industry records over $19 billion in annual sales. Botanical products were once regulated as drugs and the FDA had authority to prevent the sale of unproven herbal ingredients. However, legislative reforms in 1994 eliminated the FDA's authority to test or approve herbal products prior to marketing. Thus, at a time when many more consumers are using more herbal products, there is little research on either their clinical efficacy or basic mechanisms of action. The growing use of herbal products by consumers, their interactions with prescription drugs - and mechanisms of such interactions - represent a serious and growing public health problem that demands scientific attention and redress by regulatory and legislative action.

Through the NIH, research into the safety and efficacy of botanical products can be conducted in a rigorous and high quality manner. Sound pharmacological studies will help determine the value of botanical preparations and the potential for their interactions with prescription drugs as well as chronic disease processes. This research will allow the FDA to review the available pharmacology and review valid evidence-based reviews to form a valid scientific foundation for regulating these products.

Conclusion

The biomedical research enterprise is facing a critical moment as funding stagnates. Reversing this trend and helping to sustain the extraordinary scientific progress that has been made at the NIH and at the academic institutions funded by the NIH over the past years is a major challenge facing this Subcommittee. A 6.5% increase for the NIH in FY'09 will allow the NIH to make greater strides to prevent, diagnose and treat disease, improving the health of our nation and restoring the NIH to its role as a national treasure that attracts and retains the best and brightest scientists to biomedical research.

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ARVO WRITTEN TESTIMONY IN SUPPORT OF INCREASED FISCAL YEAR 2009 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

March 28, 2008

ABOUT ARVO

ARVO, the world's largest association of physicians and scientists who study diseases and disorders affecting vision and the eye, has more than 12,300 members from the United States and 73 countries. As some 80 percent of the 7,000 United States members have or are affiliated with NIH grants, ARVO submits these comments supporting increased FY2009 NIH and NEI funding.

ARVO REQUESTS FY2009 NIH FUNDING AT $31 BILLION, OR A 6.6 PERCENT INCREASE OVER FY2008, TO MATCH INFLATION/RESTORE PURCHASING POWER AND FUND YOUNG INVESTIGATORS/CLINICIAN SCIENTISTS

NIH is a world-leading institution and must be adequately funded so that its research can reduce healthcare costs, increase productivity, improve quality of life, and ensure our nation's global competitiveness. Although ARVO commends the Congressional leadership's actions to significantly increase NIH funding above the Administration's budget request in FY2008 appropriations, the net 0.46 percent increase meant a net loss in NIH purchasing power. For five consecutive years, NIH funding has failed to keep pace with the biomedical inflation rate and NIH has lost more than 10 percent of its purchasing power. The Administration's FY2009 budget, which proposes to freeze the NIH budget at the FY2008 level, threatens to further hinder the momentum of discovery leading to treatments that are saving lives—as well as restoring the quality of life—and maintaining the nation's competitive edge in medical research. Secure and consistent funding for health and scientific research must be part of the nation's long-term strategies for sustained economic growth.

Adequate NIH funding is also essential to a strong and vibrant research community, which risks losing established investigators and failing to attract young scientists. The NIH funding situation threatens to affect an entire generation of young researchers. As noted in the March 2008 report entitled *A Broken Pipeline? Flat Funding of the NIH Puts a Generation of Science at Risk* and in March 13, 2008, House LHHS Appropriations Subcommittee Citizen Witness hearing testimony presented by the Federation of

American Societies for Experimental Biology (FASEB), the 60,000 postdoctoral researchers who represent America's scientific future and are on the path to a lifelong career in research are being negatively affected by the decline in NIH's budget. This impact includes:

- Fewer hires, lower salaries, and increased layoffs in the research community
- Young scientists seeing their mentors struggle to maintain grant funding
- Students seeking job opportunities outside of research or in other countries
- An appreciable drop in applications in 2007 from 2006—by nearly 600—of R01 grant applications by previously unfunded researchers ("new investigators")
- An increase in the average age from 34.2 to 41.7 years for investigators who receive their first research project grant award

These concerns are especially acute for the eye and vision research community, especially for its clinician scientists, who have been so instrumental to the NEI's impressive track record of the translation of basic research into clinical applications that directly benefit patient care.

ARVO REQUESTS FY2009 NEI FUNDING AT $711 MILLION, OR A 6.6 PERCENT INCREASE OVER FY2008, TO ENSURE THE VISION HEALTH OF ALL AMERCIANS

The NEI was flat funded in FY2008, meaning that over the past five funding cycles it has lost 18 percent of its purchasing power, reducing the number of grants by 160, which threatens its impressive record of breakthroughs in basic and clinical research that have resulted in treatments and therapies to save and restore vision, as well as to prevent eye disease. Vision impairment/eye disease is a growing, major public health problem that disproportionately affects the aging and minority populations, costing the United States $68 billion annually in direct and societal costs, let alone reduced independence and quality of life. Adequately funding the NEI is a cost-effective investment in our nation's health, as it can delay, save, and prevent expenditures, especially to the Medicare and Medicaid programs.

FY2009 NEI FUNDING AT $711 MILLION ENABLES IT TO LEAD COLLABORATIVE RESEARCH REFLECTING THE NEW PARADIGM OF 21st CENTURY HEALTHCARE THAT IS PREDICTIVE, PREEMPTIVE, PERSONAZLIED, AND PARTICIPATORY

NEI research addresses the NIH's overall major health challenges as set forth by NIH Director Elias Zerhouni, M.D.: an aging population; health disparities; the shift from acute to chronic diseases; and the co-morbid conditions associated with chronic diseases (e.g., diabetic retinopathy as a result of the epidemic of diabetes). NEI research responds to Dr. Zerhouni's vision for NIH research that is collaborative and cost-effective and meets the 21st century "P4Medicine" paradigm of predictive, preemptive, personalized, and participatory research and clinical practice. For example:

- One quarter of all genes identified to date through NEI's collaboration with the Human Genome Project is associated with eye diseases, such as age-related

macular degeneration (AMD), retinitis pigmentosa (RP), and glaucoma. NEI-funded researchers have discovered gene variants strongly associated with an individual's risk of developing AMD, the leading cause of blindness in older Americans. These variants, which are responsible for about 60 percent of the cases of AMD, are associated with the body's inflammatory response and may relate to other inflammation-associated diseases, such as Alzheimer's and Parkinson's disease. As NEI Director Dr. Paul Sieving has stated, "One of the important stories during the next decade will be how Alzheimer's disease and macular degeneration fit together."

- NEI is currently conducting the second phase of its Age-Related Eye Disease Study (AREDS), which follows up on initial findings that high levels of dietary zinc and antioxidant vitamins (Vitamins C, E and beta-carotene) are effective in reducing vision loss in people at high risk for developing advanced AMD—by a magnitude of 25 percent. The cost-effectiveness and public health consequences of this research are significant: 1.3 million Americans would develop advanced AMD if no treatment was given, and if all individuals at risk availed themselves of the AREDS supplement regimen, more than 300,000 of them would avoid advanced AMD and any associated vision loss during the next five years.

- NEI's collaborative research into factors that promote or inhibit new blood vessel growth has resulted in the first generation of ophthalmic drugs approved by the Food and Drug Administration (FDA) to inhibit abnormal blood vessel growth in "wet" AMD, thereby stabilizing and restoring vision, and NEI's Diabetic Retinopathy Clinical Research (DRCR) Network is further evaluating these drugs for treatment of macular edema associated with diabetic retinopathy (DR). In March 2008, NEI-funded researchers announced that damage from both AMD and DR was prevented and even reversed when the protein Robo4 was activated in mouse models that simulate the two diseases. Robo4 treated and prevented the diseases by inhibiting abnormal blood vessel growth and by stabilizing blood vessels to prevent leakage. Since this research into the "Robo4 Pathway" used animal models associated with these diseases that are already used in drug development, the time required to test this approach in humans could be shortened, expediting approvals for new therapies.

These examples primarily reflect NEI's trans-Institute research within NIH. The NEI has also collaborated with other Department of Health and Human Services (DHHS) agencies, specifically to share the results of its basic and clinical research which may impact the product approval and reimbursement processes. For example:

- In a March 2008 meeting, NEI collaborated with FDA's Center for Drug Evaluation and Research (CDER) and Center for Devices and Radiological Health (CDRH) to consider the appropriateness of new clinical endpoints in glaucoma clinical trials. Advances in visual imaging technologies—many of which emerged from collaborative research between the NEI and the National Institute of Biomedical Imaging and Bioengineering (NIBIB)—have enabled researchers to

better detect structural changes in the nerve fiber layer of the retina and contours of the optic nerve head. These structural changes could potentially be used as a direct endpoint in a clinical trial, rather than a surrogate endpoint such as elevated intra-ocular pressure, when appropriately correlated to functional changes in vision to assure clinical significance of a new therapy. This meeting, which followed a November 2006 joint NEI-FDA/CDER meeting on clinical endpoints in AMD and DR clinical trials, represents the cost –effectiveness of NEI funding, as its research results may ultimately shorten the time and cost associated with clinical trials, as well as facilitate the approval of new diagnostics and therapies for patients.

- In collaboration with the Centers for Medicare and Medicaid Services (CMS), the NEI has launched the *Comparison of AMD Treatments Trial* (CATT), which is a comparative effectiveness study of the two drugs that are used to block growth of the abnormal blood vessels in patients with the "wet" form of AMD. NEI's collaboration with CMS could guide clinical practice and reduce Medicare costs.

THE NEI'S DIMINISHED PURCHASING POWER JEOPARDIZES ITS ABILITY TO FOLLOW UP ON RESEARCH BREAKTHROUGHS FROM PAST INVESTMENT

The NEI must be adequately funded to initiate promising new research, to pursue results that have emerged from previous breakthroughs, and to offer up its "fair share" of funding in its extensive collaborations. The number of NEI grants has declined by 160 over the past five years, from 1,214 in FY2004 to 1,054 in FY2008, representing myriad "lost opportunities"—any one of which could have been the key to curing eye disease or restoring vision. Examples of such lost opportunities include:

- Ocular gene therapy holds great promise, especially for retinal degenerative diseases in which nearly 200 gene defects have been implicated. Investigators supported by the NEI and private-funding organization Foundation Fighting Blindness (FFB) have begun human clinical trials of a gene therapy to treat Leber Congenital Amaurosis (LCA), a rapid retinal degeneration that blinds infants in the first year of life. Previous research has restored vision in dogs with LCA, and the results of the human clinical trials are forthcoming. Current budget realities limit NEI's expansion of this program to target more diseases.

- Promising protocols proposed within the Diabetic Retinopathy Clinical Research Network will not be funded. The DRCR Network is a large, multi-center study that engages ophthalmologists and optometrists, many in community health centers, in basic and clinical research into diabetic eye disease. Past NEI diabetes networks developed laser treatments for DR that save $1.6 billion annually in federal disability payments.

- NEI funding for new epidemiology studies has already become limited, which jeopardizes future research into identifying the basis/progression of eye disease in additional ethnic populations, such as Asian and Native Americans. Past NEI

studies have identified a three-fold greater risk of glaucoma in African Americans, as well as glaucoma being the leading cause of irreversible vision loss in African Americans and Hispanics.

- NEI will not be able to fund proposed new Clinical Research Networks for AMD and for neuro-ophthalmic disorders. The latter could assist in understanding visual disorders associated with Traumatic Brain Injuries (TBI), especially those currently occurring in record numbers by soldiers in Iraq and Afghanistan.

NEI research into other significant eye disease programs such as cataract will be threatened, along with quality of life research programs into low vision and chronic dry eye. This occurs at a time when the US Census cites significant demographic trends that will increase the public health problem of vision impairment and eye disease, such as the first wave of 78 million Baby Boomers celebrating their 65th birthday in 2010, with about 10,000 Americans turning 65 each day for 18 years afterward.

VISION IMPAIRMENT/EYE DISEASE IS A MAJOR PUBLIC HEALTH PROBLEM THAT IS INCREASING HEALTHCARE COSTS, REDUCING PRODUCTIVITY, AND DIMINISHING QUALITY OF LIFE

The 2000 US Census reported that more than 119 million people in the United States were age 40 or older, which is the population most at risk for an age-related eye disease. The NEI estimates that, currently, more than 38 million Americans age 40 and older experience blindness, low vision or an age-related eye disease such as AMD, glaucoma, diabetic retinopathy, or cataracts. This is expected to grow to more than 50 million Americans by year 2020. The economic and societal impact of eye disease is increasing not only due to the aging population, but to its disproportionate incidence in minority populations and as a co-morbid condition of chronic disease, such as diabetes.

Although the NEI estimates that the current annual cost of vision impairment and eye disease to the US is $68 billion, this number does not fully quantify the impact of direct healthcare costs, lost productivity, reduced independence, diminished quality of life, increased depression, and accelerated mortality. The continuum of vision loss presents a major public health problem and financial challenge to the public and private sectors.

In public opinion polls over the past 40 years, Americans have consistently identified fear of vision loss as second only to fear of cancer. As recently as March 2008, the NEI's *Survey of Public Knowledge, Attitudes, and Practices Related to Eye Health and Disease* reported that 71 percent of respondents indicated that a loss of their eyesight would rate as a "10" on a scale of 1 to 10, meaning that it would have the greatest impact on their day-to-day life. As a result, federal funding for the NEI is a vital investment in the health, and vision health, of our nation as the treatments and therapies emerging from research can preserve and restore vision.

ARVO urges FY2009 NIH and NEI funding at $31 billion and $711 million, respectively.

Written Public Testimony of Marsha Seltzer, Ph.D., Chair of the Intellectual and Developmental Disabilities Research Centers Association (IDDRCA)

House Committee on Appropriations Subcommittee on Labor, Health & Human Services, Education, and Related Agencies
March 31, 2008

Mr. Chairman, on behalf of the Intellectual and Developmental Disabilities Research Centers Association (IDDRCA), I thank you for this opportunity to share with you and your Committee some of the exciting recent achievements in the world of intellectual and developmental disabilities research. I am Marsha Seltzer, Director of the Waisman Center at the University of Wisconsin and Chair of the IDDRCA. Unfortunately, as I share with you exciting research developments occurring within our network of research centers, I also must share the impact of NIH budgets on our research efforts and the challenges that recent budgets put on the work of the Centers.

During the last few fiscal years critical research being conducted at Intellectual and Developmental Disabilities Research Centers (IDDRCs) has slowed due to cuts in the NIH budget. Since the doubling of NIH funding ended in 2003, funding for NIH has failed to keep pace with biomedical inflation and as a result, NIH has lost more than 13% of its purchasing power. Recently funded DDRCs experienced approximately an 11% cut, even though they received outstanding scientific evaluations. To address our concerns, we respectfully ask the Committee to increase NIH funding by approximately 6.6%, $1.9 billion, to $31.1 billion for FY 2009. This would restore funding lost to NIH since 2003. In addition, we ask that you increase funding by approximately 6.6% to $1.34 billion for the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) and restore cuts in IDDRC funding.

NICHD was established in 1963 with Congressional action to establish "centers of excellence" in intellectual and developmental disabilities research. The IDDRC program was the nation's first sustained and integrated effort to prevent and treat disabilities through biomedical and behavioral research. To commemorate this year's 45th Anniversary, NICHD and the IDDRC program were officially renamed in honor Eunice Kennedy Shiver who worked tirelessly to establish them. Currently, 14 members of our association are supported by core funds from NICHD. In addition, seven other research centers are affiliate members of our association because of their common interest to share research and participate in the activities of this esteemed network. The disabilities and disorders the members of the IDDRCA study include autism, Down syndrome, fragile X syndrome, cerebral palsy, and literally hundreds of other causes of intellectual disabilities in children and adults. Today, the IDDRCA is the world's largest concentration of scientific expertise in the fields of intellectual and developmental disabilities. Our Centers, and the network they form, substantially foster communication, innovation, and excellence in research. We work collaboratively on a wide range of research projects, and together with the Society for Developmental Pediatrics, produce the highly regarded quarterly journal, "Intellectual and Developmental Disabilities Research Reviews." Each edition highlights important new research on a specific developmental disability or a critical prevention or treatment breakthrough.

Our research Centers are located within premier research intensive universities and often are affiliated with major medical centers that provide academic, scientific and clinical expertise as well as institutional support. Collectively, our work represents a multidisciplinary, vigorous, and innovative research program directed at understanding, treating and reducing the incidence of developmental disabilities. Additionally, our investigators are engaged in a very important mission - training the next generation of scientific investigators and clinicians in this area of great importance to America's children and families.

Although a significant portion of the research portfolios at the Centers consists of fundamental studies that are directed at understanding the biological and behavioral processes in animal models and human subjects, each Center also directs considerable attention toward seeking solutions to practical issues and problems. Our connection to the University Centers for Excellence in Developmental Disabilities (UCEDDs) is critical in translating our research to practice. The scope of the research conducted at the Centers encompasses every known major dimension of intellectual and developmental disabilities.

Over the last four decades there has been a huge payoff in the federal investment in the Intellectual and Developmental Disabilities Research Centers. Numerous disorders that cause intellectual disabilities can now be prevented or treated to improve developmental outcomes. The Centers' scientific achievements have helped improve quality of life for individuals and families affected by disabilities. Among the most exciting aspects of this work are the fundamental biological and environmental triggers for many of these disabilities that are being revealed and especially breakthrough research on prevention and intervention strategies. I am pleased to share some examples with you.

Recent Breakthroughs in the Causes of Intellectual and Developmental Disabilities

As I noted, there are literally hundreds of causes of intellectual and developmental disabilities. Over the past four decades the investment made in the Developmental Disability Research Centers has led to the discovery of a substantial number of these. Here are some recent examples:

- Researchers at the Vanderbilt University IDDRC discovered genetic mutations that disrupt a key protein that is critical for brain development and controlling mood and emotion in children and adults. These mutations are highest among individuals with **autism** who exhibit symptoms of obsessive-compulsive disorder. This finding should help us finally pin down some of the causes of autism, and eventually aid with early diagnosis and intervention.
- Researchers at the Children's Hospital of Philadelphia IDDRC discovered the cause of **Cornelia de Lange Syndrome**. This inherited disorder causes mental retardation, growth retardation, abnormal limb development, cardiac dysfunction and other developmental problems. This discovery may open new paths to prevention and treatment.
- Researchers at the University of Alabama Medical Center IDDRC utilized molecular biological and genetic engineering approaches to determine how **cytomegalovirus infection** in pregnant women disrupts and damages fetal brain development. This discovery may lead to the development of an effective method to prevent these effects.
- Researchers at the University of North Carolina IDDRC used brain imaging techniques to identify generalized enlargements of brain matter in **very young children with autism**.

These abnormal increases appear to begin in the latter part of the first year of life, suggesting that this may be a critical period for the onset of autism. This finding may lead to both earlier diagnosis and earlier intervention for this disorder.

- Researchers at the University of Wisconsin IDDRC demonstrated for the first time a **critical role of early social deprivation in the development of brain systems** underlying the formation of human social bonds. This research grew from numerous observations that children who were reared in foreign orphanages and then adopted between 1 and 5 years of age into families in the United States often suffer from long term problems in forming normal emotional and social relationships with their adoptive families and peers. This discovery has immediate and broad implications for the development of treatments targeted on the disrupted brain region.
- **Rett syndrome** is a genetically caused progressive neurological disorder that leads to severe mental retardation and autism in females. Researchers at the Baylor College of Medicine IDDRC in Houston have discovered that a specific protein known as MeCP2 plays a causal role in the brain pathology of this disorder. Researchers at Children's Hospital in Boston IDDRC and other centers are building on this discovery in an effort to determine additional effects of this gene mutation that may give rise to defects in human cognition. This landmark discovery may eventually pave the way for effective preventive treatments.
- Researchers at the Baylor College of Medicine recently demonstrated that multiple mechanisms of inherited **childhood epilepsy** appear to originate from a prenatal impairment of a neurotransmitter released at thalamic synapses in the brain. They have developed a new brain imaging technique that is now allowing them to pinpoint the genes that cause temporal lobe epilepsy in children with this disorder. This discovery may lead to methods for preventing these effects.
- Other researchers at Baylor recently discovered that a molecule known as Math1 is essential for the normal development of the entire neural system in terms of our ability to coordinate auditory, vestibular, and proprioceptive systems so as to be able to sense our position in space. This same molecule has already been shown to impact several other specific neural systems. The disruption of this molecule for any reason **may lead to serious neural developmental problems**. The discovery of its central role opens the door to investigate its potential impact on a wide range of disorders.
- **Fragile X syndrome** is the most common inherited cause of mental retardation and the most common single-gene neuropsychiatric disease known. The biology underlying Fragile X syndrome, is rapidly revealing itself in research being conducted at several IDDRCs. Research with animal models of this disorder has suggested that several potential intervention approaches that may correct for the abnormal protein expression that impacts neural development and appears to result from the disorder. Initial tests of novel intervention approaches in animal models are underway.
- Researchers at the University of Wisconsin IDDRC have been examining a key symptom of **autism** – an inability to respond appropriately in social interaction with others. They have found that when children with autism look at faces that are expressing emotion, they show accentuated activation in brain circuits associated with emotional arousal and threat. When they avert their gaze from these faces, brain activation in these regions is reduced. This information may contribute to the development of effective therapeutic interventions for this

core trait of the disorder.

Recent Breakthroughs in Prevention and Therapeutic Intervention – Translational Research
Although the IDDRCs have a long history of research on prevention and intervention approaches, these efforts have been accelerating in recent years with the NIH's increased emphasis on translational research. Well over one hundred clinical trials are currently underway at all IDDRCs with some centers reporting more than 30 such trials underway or recently completed. The potential impact of new interventions that are presently under investigation for individuals with intellectual and developmental disabilities is truly astounding. For example:

- More and more **very low birth weight premature babies** are surviving, but many will have significant intellectual and developmental problems. Researchers at the University of Kansas IDDRC have developed a small high tech device that measures the oromotor functioning of very young premature infants to determine their ability to effectively suck and then quickly trains them to suck normally. This intervention can prevent these developmental problems associated with inadequate early nutrition and will likely be standard equipment in NICU's throughout the world within a few years.
- **Learning disabilities** affect 10-20% of the world's population. A common genetic cause of these disorders is neurofibromatosis Type 1. Researchers at the UCLA IDDRC have discovered that a commonly prescribed type of drug known as Statins can reverse the neurological effects of this disorder in a mouse model. Efforts are now underway to test the effects of this drug on humans who have this common disorder.
- **X-linked adrenoleukodystrophy** (X-ALD) causes progressive paraparesis and severe disabilities in children, and was the focus of the movie "Lorenzo's Oil." Researchers at the Kennedy Krieger IDDRC in Baltimore are presently conducting a large clinical trial to determine if administration of Lorenzo's Oil affects the rate of progression in pre-symptomatic patients and significantly reduces the risks associated with the disease.
- Research at Kennedy Krieger has also revealed that almost 20% of individuals with **autism** spectrum disorder have total cholesterol levels well below the 5th percentile suggesting that hypocholesterolemia may be a factor contributing to this disorder. These researchers are now testing whether the drug Semivastatin, which is known to increase cholesterol production, will have a positive effect on children with **Smith-Lemli-Opitz syndrome**, a disorder associated with decreased cholesterol production that also carries a high risk of autism.
- Children of mothers who drink alcohol during pregnancy are at-risk for **Fetal Alcohol Syndrome** disorder, which is associated with significant life-long cognitive and social impairments. A study being conducted at the University of Washington IDDRC has demonstrated that a brief intervention targeted on pregnant women who report drinking alcohol was highly successful in achieving abstinence in these women with substantial positive effects on their children's development as compared to women who did not receive this brief intervention.
- **Communication and language development** are severely impacted by mental retardation as well as autism. Researchers at several Centers are investigating innovative early intervention techniques intended to enhance development in these children. Promising results have been recently reported by investigators at the UCLA, Vanderbilt, and University of Kansas

IDDRCs.

Many of these clinical intervention trials that are presently underway across the IDDRC network are only possible due to the unique concentration of scientific talent and specialized resources associated with these Centers. The potential of these studies to enhance the development and functioning of children and families in their country and around the world faced with the challenges due to hundreds of different causes that lead to intellectual and developmental disorders has never been greater. The range of disorders under investigation include Autism Spectrum Disorders, Down syndrome, Fragile X Syndrome, Fetal Alcohol Syndrome, Specific Language Impairment, Muscular Dystrophy, a wide range of Learning Disabilities, and dozens of rare, complex disorders that we are just now coming to understand.

While we have made extraordinary progress over the past four decades, we still have far to go. With knowledge generated by the IDDRCs, we will be able to:

- Use brain imaging and genetic methods to **better understand the causes** of specific disabilities and design strategies for treatment.
- **Develop new therapies to prevent or reverse** some of the symptoms of specific disabilities.
- Better understand the process of **brain cell development** and enrichment through studying the interplay of the brain's own chemistry with a child's experiences.
- **Prevent many types of developmental disabilities** by treating maternal infections and viruses transmitted to their infants.
- Capitalize on the brain's natural "plasticity" to optimize brain development in children born with developmental disabilities through **early intervention** or by extending the period of brain development.
- **Design learning environments** so all children have improved academic outcomes, including those with learning and intellectual disabilities.
- **Determine which child with a disability will respond best** to which speech or communication learning approach.
- **Develop culturally competent** psychological and medical assessment and treatment procedures for children born into minority families.
- **Prevent and treat behavior problems among children and adults** with disabilities that are especially prone to such difficulties, such as children with autism, fragile X syndrome, or Rett's syndrome.
- **Assist families in preparing their adult sons and daughters** with disabilities for successful lives of their own and prepare older people with developmental disabilities for coping with the normal process of aging.

Recommendation to Subcommittee

In order to continue and build upon the capacity of IDDRCs, we again respectfully ask the Committee to increase NIH funding by approximately 6.6% to $31.1 billion for FY 2009. This would restore funding lost to NIH since 2003. In addition, we ask that you increase funding by approximately 6.6% for NICHD to the level of $1.34 billion for NICHD in FY 2009 and restore cuts in IDDRC funding. I thank you Mr. Chairman for taking time to learn about the IDDRC network and the scope of work being conducted at these Centers across the nation.

Contact: John Sciamanna, Co-Director of Government Affairs, Child Welfare League of America

The Child Welfare League of America (CWLA) submits the following testimony on behalf of public and private child-serving agencies nationwide. We urge the Appropriations Committee to restore funding for the Prompting Safe and Stable Families program to no less than $100 million in discretionary funding, the amount provided in FY 2003. This level of funding is still well below the $200 million level authorized and previously committed to by the Administration.

We request that the Committee fund the Child Abuse Prevention Treatment Act (CAPTA) state grants at $84 million for strengthening states' child protection systems and the CAPTA Title II community-based prevention grants funding at $80 million.

Many argue that as a nation, we are only willing to spend on families and children in the child welfare system once a child has been removed and then only if they meet stringent eligibility requirements through the limited Title IV-E foster care and adoption assistance programs. They further argue that we should invest more to prevent abuse. CWLA agrees. This, however, takes a commitment to funding these prevention services in a meaningful way.

An analysis of thirteen discretionary programs that are targeted to address child welfare services, including the promotion of adoption and services to prevent child removal, shows that of the total 2007 discretionary funding of $629 million, a total of $24 million was cut in 2008, a reduction of nearly four percent.

Of the thirteen programs, eleven were cut: Child Welfare Services, Promoting Safe and Stable Families (PSSF), Mentoring for Children of Prisoners, Child Welfare Training, Child Abuse Prevention Treatment Act (CAPTA) State Grants, CAPTA Community Based Grants, Adoption Awareness, Adoption Opportunities, Adoption Incentives, Abandoned Infants, and Education and Training Vouchers for youth leaving care. There was a slight increase of $1.4 million in CAPTA Discretionary grants and a new administration earmark of $10 million was created for home visiting programs. The home visiting program is funded through CAPTA.

The PSSF program received the biggest funding cut. For FY 2008 PSSF was cut drastically, with discretionary funding reduced from the 2007 level of $89 million to $63 million. As we indicated states are required to spend at least twenty percent of their funds on each of four services, families in need of adoption services, families in need of reunification services, families being targeted for intense preservation services, and services targeted to support families. While there was a $40 million increase in mandatory funding as part of the 2006 PSSF reauthorization, this funding was earmarked for other services by the authorizers.

We ask the Subcommittee to once again reject the Administration's proposal to cut the Social Services Block Grant (SSBG) by 30 percent or $500 million. We appreciate the fact that members of Congress have rejected this in the last two budgets.

Background On the Need For Funding

Child Protective Services

In 2005, an estimated 3.3 million children were reported as abused or neglected. Approximately 899,000 children were substantiated as abused or neglected. More than sixty-two percent of child victims were victims of neglect, sixteen percent were physically abused and more than nine percent were sexually abused. Thirty percent of victims were age 3 or younger. In 2005, 1,371 children died from child abuse. Of the children who have been substantiated as abused or neglected, nearly 40 percent do not receive follow up services.[i]

The first goal of any CPS response is keeping children safe from child abuse and neglect. The CPS response begins with the assessment of reports of child abuse and neglect. If the child is at risk or has been abused or neglected, CPS should ensure the child and his or her family receive services and supports from the agency and the community.

CWLA believes the best ways to ensure children are safe from all forms of maltreatment are comprehensive, community-based approaches to protecting children, and supporting and strengthening families. Public and private agencies, in collaboration with citizens and community entities, can prevent and remedy child maltreatment, achieve safety, and promote child and family well-being.

CPS systems in the fifty states are funded by a variety of sources. The Social Services Block Grant (SSBG) serves as a major source of funding with forty-one states spending $257 million in SSBG funds in 2005 for child protection. SSBG is once again threatened with a potential reduction of $500 million in the President's proposed FY 2009 budget, a reduction that would be devastating to CPS and many child welfare services. CPS systems also draw from the CAPTA, despite funding under the grants part of that program being limited to $27 million, which is well below the full authorized level.

CPS is one part of the child welfare system. If the efforts at reunification of a family fail, or the adoption fails, or services are not available to families and children who come into contact with the system, these very same children may enter the system again. Children with a history of maltreatment are more likely to experience a recurrence of maltreatment than those who were not prior victims.[ii]

An optimal child welfare system encompasses a continuum of services ranging from prevention of abuse and neglect to permanency and stability for children who experience foster care. Key parts of this system are a family-centered approach, a stable and highly professional workforce, the availability of targeted services to prevent child abuse and neglect, maintaining families when maltreatment has occurred and child safety can be assured, and achieving permanency and stability for children who experience foster care.

Family Centered Approach
Research in child maltreatment, juvenile justice, children's mental health, and parent education supports the effectiveness of interventions that involve the entire family over those targeting the individual parent or child.[iii] A family-centered approach engages families in addressing problems that affect the care of their children. Such engagement has been linked positively to compliance with and completion of case plans. [iv]

Prevention of Abuse and Neglect
Studies have demonstrated the effectiveness or promise of several approaches to prevention of child maltreatment. Models such as some of the home visiting programs have produced evidence that they positively impact a variety of outcomes for children and families, including prevention of abuse and neglect. High quality pre-kindergarten programs like the Chicago Child Parent Centers and Head Start that include parental involvement and supports have also demonstrated effectiveness.[v] Independent studies have found that the financial savings achieved by the most effective of these approaches far exceeds their costs.[vi] Rigorous cost-benefit analyses conducted by the Washington State Institute for Public Policy showed cost savings for several pre-kindergarten and home visitation programs as well as for Parent-Child Interaction Therapy, a center-based intervention that provides direct coaching to parents as they interact with their young children.[vii] Family-based therapeutic models such as Functional Family Therapy and Multi-Systemic Therapy have been tested in sites across the country and there is substantial evidence of their benefits to youths and their families.[viii]

Maintaining Families
Many children can be safely maintained in their families through the timely application of interventions that correctly target the underlying causes of maltreatment. Studies support the benefits of interventions that have a behavioral, skill-building focus and that address family functioning in multiple domains including home, school, and community. Cognitive behavioral models have been demonstrated to reduce physical punishment and parental aggression in less time than alternative approaches. [ix] The most effective treatment involves all members of the family and addresses not only parenting skills, but also parent-child interaction and a range of parental life competencies such as communication, problem solving, and anger control. Attention to immediate, concrete needs has also been identified as a key factor in supporting family engagement and positive outcomes.[x]

Aftercare and Transitional Services
Data indicate that about 25 percent of all children who exit out-of-home care will return at some point, often within one year. The likelihood of re-entry is especially great when children or parents have numerous or complex needs or when they are exposed to extreme environmental stressors.[xi] Although the level of maltreatment recurrence and/or subsequent re-entry into foster care is undoubtedly related to decision-making and services offered prior to reunification, it strongly suggests a need for aftercare services.

Research in family reunification aftercare, indicates that it is most successful when it is initially intensive and includes the availability of concrete services[xii] and ongoing

assessment of risk. The association of social isolation with failed reunification also suggests the importance of linking with extended family, extra-familial social networks, and informal resources. Tapering off of services should be based on the family's needs rather than on an arbitrary time frame.[xiii]

Services during and after the adoption process are also an important part of the service continuum. Although the rate of adoption dissolution is quite low overall, research indicates that some placements may have greater needs for follow-up services and supports. Most families adopting through a public agency used some type of counseling. As in other types of child welfare intervention, family-focused approaches appear to be the most helpful in supporting adoption stability. Research suggests that adoptive parents may also value participation in support groups, access to literature and seminars, and concrete services like respite care, subsidies, and health benefits.[xiv]

Promoting Safe and Stable Families

The Promoting Safe and Stable Families program (PSSF) supports four services that address four types of families in need: those in need of basic support services to strengthen the family and keep them whole, families being reunified, families we are trying to preserve, and adoptive families in need of support.

In funding this program we urge appropriators to focus on these families to understand the value of these four services:

Family Support Services (FSS) were developed to respond to the concerns, interests, and needs of families within a community. Family Support Services are targeted to families with difficulties and concerns related to the proper functioning of the family and care of the children. The focus of the program is on prevention. Services address the need to improve the well-being of a child, family functioning, and the parent's ability to provide for the family, before they are in crisis. Family support programs work with outside community organizations such as schools and child welfare agencies. The aim is to provide temporary relief to families and to teach them how to better nurture their children. Services include parent education, child care relief, and self-help groups.

Reunification is the first permanency option states consider for children entering care. Yet, in many ways, it is the most challenging option to achieve in a plan-based, permanent way. We know that fifty-one percent, or 262,706, of children in care on September 30, 2005 had a case plan goal of reunification with their parents or other principal caretaker. At the same time fifty-four percent, or 151,770, of those children who left care in 2005, were returned to their parent's or caretaker's home.[xv]

Successful permanency through reunification requires many things, including skilled workers, readily available supportive and treatment resources, clear expectations and service plans, and excellent collaboration across involved agencies. Reunification also requires culturally appropriate support and treatment services for families and the critical need for after care or post-permanency services to ensure that safety and permanency are maintained following reunification.

Family Preservation Services (FPS) are comprehensive, short-term, intensive services for families. These services are delivered primarily in the home and designed to prevent the unnecessary out-of-home placement of children. The services are intended to protect a child in a home where allegations of child abuse or neglect have occurred, prevent subsequent abuse or neglect, prevent placement of a child, or reduce the stay for a child in out-of-home care. Families in need of family preservation services are usually referred by public welfare agencies. Services are provided within 24 hours of referral and the family's involvement is voluntary. These services respond to families on a 24-hour basis, including services such as family therapy, budgeting, nutrition, and parenting skills.

Adoption support is an important need as the number of adoptions has increased. There is still more work to be done. Services may include information and referral, case management services, support groups and a range of other services. Of the 506,483 children in foster care in 2005, approximately 122,195 were waiting to be adopted. Of the children waiting, 36% were black non-Hispanic, 40% were white non-Hispanic, 15% were Hispanic, 2% were Native American or Alaskan Native and 3% were of undetermined ethnicity. In 2005, the median age of children waiting to be adopted was 8.4 years; 4% of the children waiting to be adopted were younger than 1 year; 33% were ages 1 to 5; 25% were ages 6 to 10; 29% were 11 to 15; and 8% were 16 to 18.[xv]

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Statement of the Association of Maternal and Child Health Programs (AMCHP)

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Submitted to the:

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

Submitted for the Record by:
Nan Streeter
President
Association of Maternal & Child Health Programs

March 28, 2008

The Association of Maternal and Child Health Programs (AMCHP) is pleased to submit this testimony in support of **fully funding the Maternal and Child Health (MCH) Services Block Grant at $850 million in FY 2009**. When our children are healthy, they are more likely to succeed. MCH programs help promote our children's success by identifying emerging and urgent health needs, while continuing to assure services like prenatal care, immunizations and access to health services. The MCH Block Grant provides funding to state MCH agencies, which directly serve almost 35 million women and children in the U.S. State MCH programs reach millions more through support of population-wide programs that reach all women and children, such as newborn screening for genetic disorders, lead poisoning prevention, injury prevention, and public education.

AMCHP supports full funding of the MCH Block Grant to enable states to:

- **Provide and enable access to comprehensive preconception, prenatal and postnatal health care and public health services** that reduce infant mortality and improve the overall health of mothers and children
- **Ensure access to quality health care** through enabling services such as transportation and translation
- **Increase the number of children** receiving health assessments and follow-up diagnostic and treatment services
- **Provide and ensure access to preventive and rehabilitative services for children**, including immunizations, screenings, nutrition and dental education and mental health services
- **Implement family-centered and community-based systems of coordinated health care** for children and youth with special health care needs
- **Partner with schools, youth service groups, and other agencies and organizations** to prevent behaviors that place youth at risk.

In 2002, funding for the MCH Block Grant peaked at $731 million and has been level funded or reduced ever since. The FY 2008 omnibus appropriations bill cut funding to $666 million. This alarming reduction threatens the progress states have made in improving the health of mothers, children, and families. When Title V of the Social Security Act was passed in 1935, the Federal Government pledged its support of State efforts to extend and improve health and welfare services for mothers and children. The MCH Block Grant today remains the only Federal program that focuses solely on improving the health of all mothers and children. The reduction of federal support for this vital program in recent years represents an alarming gap in the Federal-State partnership needed to assure the health of all women, children, and families in the America.

AMCHP members report that reductions to the MCH Block Grant require cutbacks in needed services at the state and local level. Reductions to the MCH Block Grant erode the remarkable successes that have been made in improving the health of mothers and

children over the past half century. For example, today the infant mortality rate is 77% lower than in 1950, immunization rates have reached historic highs, childhood deaths from injuries are down dramatically, and most children report having a usual source of health care. Despite this substantial progress, consider the following troubling trends in the health of our nation's mothers and children:

- Over the past decade, **improvements in reducing maternal and infant mortality have stalled** and preterm and low birth weight births have increased. Today the United States ranks 29th in infant mortality rates in international comparisons.
- **Racial and ethnic disparities persist across several health status indicators**, and the black infant mortality rate is double the rate for whites.
- **Teen pregnancy rates rose in 2007** for the first time in 14 years.
- **Childhood obesity** is a national epidemic requiring urgent public health intervention, with some age groups experiencing a threefold obesity rate increase over the past two decades.

Considering these and many other urgent health needs, we ask for your leadership in supporting full funding for the MCH Block Grant at $850 million in FY 2009.

The MCH Block Grant improves the health of America's women and children by:

- **Supporting programs that work.** The MCH Block Grant earned the second highest program rating by the Office of Management and Budget (OMB)'s Program Assessment Rating Tool (PART). OMB found that MCH 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. The program has performance measures and evaluations that document the effective impact of this modest investment in innovative approaches. Reduction to the MCH Block Grant threatens the ability of these programs to carry on this work.
- **Addressing the growing needs of women, children and families.** As states face economic hardships and face limits on their Medicaid and SCHIP programs, more women and children seek care and services through MCH-funded programs. Resources are needed to reduce infant mortality, provide mental health care 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 health systems and leveraging federal funding** for other health programs such as community health centers, Healthy Start, WIC, Combating Autism, SCHIP and Medicaid. The MCH Block Grant invests in state needs assessments, planning and policy development, quality assurance and standards development, training, collection of health care data and analysis, and development of information systems that complement health care services and promote prevention for all populations. Close coordination with other health programs assures that funding is maximized and services are not duplicated.

Over the years, the achievements of MCH Block Grant-supported projects have been integrated into the ongoing care system for children and families. Landmark projects have produced guidelines for child health supervision from infancy through adolescence; influenced the nature of nutrition care during pregnancy and spread the message about the benefits of breastfeeding; recommended standards for prenatal care; identified successful strategies for the prevention of childhood injuries; and developed health safety standards for out-of-home child care facilities.

During the Senate's debate on the FY2009 budget resolution, Senator Chris Dodd introduced a bi-partisan amendment co-sponsored by Senator Orin Hatch that called for full funding of the MCH Block Grant. Upon introducing the amendment, Senator Dodd stated:

> *The MCH program is critical to the health and well-being of millions of families across this country, including some of the most vulnerable members of our society. Years of funding cuts and level funding have stretched maternal and child health programs to their limits...The MCH block grant is a proven success for helping ensure a healthy future for our Nation's children [and] I urge my colleagues to support my amendment to increase MCH block grant funding to $850 million in this year's budget resolution.*

This amendment passed the Senate by unanimous consent, and over 30 national organizations have joined in support of full funding (see attached letter).

AMCHP urges the House of Representatives to recognize the need for additional resources for states and their partners to continue this vital work. **We request your support and leadership to fully fund the Title V Maternal and Child Health Services Block Grant at $850 million for FY 2009.** Full funding for the MCH Block Grant is an effective and efficient investment in our nation's women, children, and families.

Submitted by: Jovita A. Tolbert, Director of Program Services,
National Association for State Community Services Programs

Public Testimony for the Record by the
NATIONAL ASSOCIATION FOR STATE COMMUNITY SERVICES PROGRAMS
Related to Appropriations by the
HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH & HUMAN SERVICES, EDUCATION AND RELATED AGENCIES
Concerning the
COMMUNITY SERVICES BLOCK GRANT
March 30, 2007

Over the past several years and once again this year, the President has zeroed out the Community Services Block Grant (CSBG) program in his budget. However, recognizing the importance of the numerous self-sufficiency services provided by the CSBG Network, Congress has continued to support the program in word and in action by providing the CSBG program with funding. The National Association for State Community Services Programs (NASCSP), the national association representing state administrators of the Department of Health and Human Services' Community Services Block Grant (CSBG) and state directors of the Department of Energy's Low-Income Weatherization Assistance Program, would like to thank Congress for its continued support of the Community Services Block Grant (CSBG) and requests an appropriation of $700 million for the state grant portion of the CSBG. We are requesting $700 million in CSBG funding this year in order for the CSBG Network to continue addressing the long-term needs of those families affected by Hurricanes Katrina and Rita and those families transitioning from welfare to work, and to assist low-income workers in remaining at work through supportive services such as transportation and child care. It is essential that the CSBG funding be increased for FY 2009. The across the board cuts to the CSBG funding over the past several years have decreased the ability of the CSBG Network to provide essential services to low-income Americans.

BACKGROUND

The states believe the CSBG is a unique block grant that has successfully transferred decision-making to the local level. Federally funded with oversight at the state level, the CSBG has maintained a local network of nearly 1,100 agencies which operate in 99% of counties in the nation. This network serves nearly **15 million low-income individuals, members of more than 7 million low-income families**, CSBG eligible entities, largely local Community Action Agencies (CAAs), provide states with a stable and guaranteed network of designated entities which are mandated to change the conditions that perpetuate poverty for individuals, families, and communities. There is no other program in the U.S. mandated by federal statute to respond to poverty. To fulfill that mandate, CAAs provide services based on the characteristics of poverty in their communities. For one community, this might mean providing job placement and retention services; for another, developing affordable housing. In rural areas, it might mean providing access to health services or developing a rural transportation system.

Since its inception, the CSBG has shown how partnerships between states and local agencies benefit citizens in each state. We believe it should be viewed as a model of how the federal government can best promote self-sufficiency for low-income persons in a flexible, decentralized, non-bureaucratic and accountable way.

Long before the creation of the Temporary Assistance for Needy Families (TANF) block grant, the CSBG set the standard for private-public partnerships that work to revitalize local communities and address the needs of low-income residents. Family oriented, while promoting economic development and individual self-sufficiency, the CSBG relies on an existing and experienced community-based service delivery system of CAAs and other non-profit organizations to produce results for its clients.

WHAT DO LOCAL CSBG AGENCIES DO?

Since CAAs operate in rural areas as well as in urban areas, it is difficult to describe a typical Community Action Agency. However, one thing that is common to all is the goal of self-sufficiency for all of their clients. Reaching this goal may mean providing day care for a struggling single mother as she completes her General Equivalency Diploma (GED) certificate, moves through a community college course and finally is on her own supporting her family without federal assistance. Many CAAs administer the Head Start Program which helps meet the educational needs of low-income families. It may mean assisting a recovering substance abuser as he seeks employment. Many of the Community Action Agencies' clients are persons who are experiencing a one-time emergency. Others have lives of chaos brought about by many overlapping forces - a divorce, sudden death of a wage earner, illness, lack of a high school education, closing of a local factory or the loss of family farms.

CAAs provide access to a variety of opportunities for their clients. Although they are not identical, most will provide some, if not all, of the services listed below:

- a variety of crisis and emergency safety net services
- employment and training programs
- transportation and child care for low-income workers
- individual development accounts
- micro business development help for low-income entrepreneurs
- local community and economic development projects
- housing, transitional housing, and weatherization services
- Head Start
- energy assistance programs
- nutrition programs
- family development programs
- senior services

CSBG is the core funding which holds together a local delivery system able to respond effectively and efficiently, without a lot of red tape, to the needs of individual low-income households as well as to broader community needs. In addition, CSBG funds many of these services directly. Without the CSBG, local agencies would not have the capacity to work in their communities developing local funding, private donations and volunteer services and running programs of far greater size and value than the actual CSBG dollars they receive.

CAAs manage a host of other federal, state and local programs which makes it possible to provide a one-stop location for persons whose problems are usually multi-faceted. Over half (52%) of the CAAs manage the Head Start program in their community. Using their unique position in the community, CAAs recruit additional volunteers, bring in local school district personnel, tap into faith-based organizations for additional help, coordinate child care and bring

needed health care services to Head Start centers. In many states they also manage the Low Income Home Energy Assistance Program (LIHEAP), raising additional funds from utilities for this vital program. CAAs may also administer the Weatherization Assistance Program and are able to mobilize funds for additional work on residences not directly related to energy savings that, for example, may keep a low-income elderly couple in their home. CAAs also coordinate their programs with the Community Development Block Grant program to stretch federal dollars and provide a greater return for tax dollars invested. They also administer the Women, Infants and Children (WIC) nutrition program, as well as job training programs, substance abuse programs, transportation programs, domestic violence and homeless shelters, and food pantries.

For every CSBG dollar they receive, CAAs leverage $5.47 in non-federal resources (state, local, and private) to coordinate efforts that improve the self-sufficiency of low-income persons and lead to the development of thriving communities.

WHO DOES THE CSBG SERVE?

National data compiled by NASCSP show that the CSBG serves a broad spectrum of low-income persons, particularly those who are not being reached by other programs and are not being served by welfare programs. Based on the most recently reported data, from fiscal year 2005 CSBG serves:

- More than 3 million families with incomes at or below the poverty level; of these customer families, 31% are severely poor as they have incomes at or below 50% of the poverty guideline.
- More than 1.3 million families headed by single mothers.
- More than 1.6 million "working poor" families with wages or unemployment benefits as income; collectively, they make up 45% of all program participants.
- More than 404,000 TANF participant families, 23% of all TANF families nationwide.
- About 4 million children.
- Almost 2.8 million people without health insurance.
- Almost 1.8 million adults who had not completed high school.

MAJOR CHARACTERISTICS OF THE CSBG NETWORK

Due to the unique structure of the CSBG, the CSBG Network has earned a reputation for its:

EMERGENCY RESPONSE: CAAs are utilized by federal and state emergency personnel as a frontline resource to deal with emergency situations such as floods, hurricanes and economic downturns. They are also relied on by citizens in their community to deal with individual family hardships, such as house fires or other emergencies.

In fact, during and after Hurricanes Katrina and Rita, the state CSBG offices and local CAAs quickly mobilized to provide immediate and long-term assistance to over 355,000 evacuees. This immediate assistance included, but was not limited to, transportation, food, medical check-ups, housing, utility deposits, job placement, and clothing. State CSBG offices and CAAs across the

country coordinated their relief efforts with other agencies providing disaster relief assistance such as FEMA, Red Cross, and other faith-based and community-based organizations.

State CSBG offices, through their local network of CAAs, continue to provide the long-term assistance evacuees will need as they re-establish themselves through self-sufficiency and family development programs. These programs offer comprehensive approaches to selecting and offering supportive services that promote, empower and nurture the individuals and families seeking economic self-sufficiency. At a minimum, these approaches include:

- A comprehensive assessment of the issues facing the family or family members and of the resources the family brings to address these issues;
- A written plan for becoming more financially independent and self-supporting;
- A comprehensive mix of services that are selected to help the participant implement the plan;
- Professional staff members who are flexible and can establish trusting, long-term relationships with program participants; and
- A formal methodology used to track and evaluate progress as well as to adjust the plan as needed.

LEVERAGING CAPACITY: In FY 2006, every CSBG dollar leveraged $18.73 from all other sources. Of those leveraged funds, $5.47 came from non-federal resources (state, local, and private) to coordinate efforts that improve the self-sufficiency of low-income persons and lead to the development of thriving communities.

VOLUNTEER MOBILIZATION: CAAs mobilize volunteers in large numbers. In FY 2006, the most recent year for which data are available, the CAAs elicited more than 44 million hours of volunteer efforts, the equivalent of almost 21,187 full-time employees. Using just the minimum wage, these volunteer hours are valued at nearly $227 million.

ADAPTABILITY: CAAs provide a flexible local presence that governors have mobilized to deal with emerging poverty issues.

Moreover, the CSBG Network has also earned a reputation for its:

ACCOUNTABILITY: The federal Office of Community Services, state CSBG offices, and CAAs have worked closely to develop a results-oriented management and accountability (ROMA) system. Through this system, individual agencies determine local priorities within six common national goals for CSBG and report on the outcomes that they achieved in their communities.

LOCAL DIRECTION AND OVERSIGHT: Tri-partite boards of directors guide CAAs. These boards consist of one-third elected officials, one-third representatives from the private sector, and not less than one-third of the members are representative of the low-income persons in the neighborhoods served by the CAA. The boards are responsible for establishing policy and approving business plans of the local agencies. Since these boards represent a cross-section of the local community, they guarantee that CAAs will be responsive to the needs of their community.

The statutory goal of the CSBG is to ameliorate the effects of poverty. The primary goal of every CAA is self-sufficiency for its clients. Helping families become self-sufficient is a long-

term process that requires multiple resources. This is why the partnership of federal, state, local and private enterprise has been so vital to the successes of the CAAs.

EXAMPLES OF CSBG AT WORK

Since 1994, CSBG has implemented a Results-Oriented Management and Accountability (ROMA) system. Through ROMA, the effectiveness of programs is captured through the use of goals and outcomes measures. Below you will find the network's nationally aggregated outcomes achieved by individuals, families and communities as a result of their participation in innovative CSBG programs during FY 2006:

- **104,792** participants gained employment with the help of community action
- **34,115** participants obtained "living wage" employment with benefits
- **82,981** low-income participants obtained safe and affordable housing in support of employment stability
- **715,870** low-income households achieved an increase in non-employment financial assets, including tax credits, child support payments, and utility savings, as a result of community action ($288 million in aggregated savings)
- **1,301** families achieved home ownership as a result of accumulated savings from IDA savings accounts
- **157,061** low-income people obtained pre-employment skills and received training program certificates or diplomas, completed Adult Basic Education or GED coursework and received certificates or diplomas, and/or completed post-secondary education and obtained a certificate or diploma
- **4,498,366** new community opportunities and resources were created for low-income families as a result of community action work or advocacy, including "living wage" jobs, affordable and expanded public and private transportation, medical care, child care and development, new community centers, youth programs, increased business opportunity, food, and retail shopping in low-income neighborhoods

At the end of the day, the CSBG Network represents our abiding national commitment to care for the less fortunate and in recognition that we are stronger when we do so. The CSBG and CSBG Network, in addition to other non-profit faith-based and community-based organizations, are a critical complement to the public sector's efforts towards helping to lift low-income Americans and their communities out of poverty and into self-sufficiency.

In fiscal year 2006, **the CSBG Network assisted approximately 22% of the persons in poverty that year and almost 15 million low-income individuals who are members of more than 7 million low-income families.** Renewed funding for the CSBG Network is one of the best ways to ensure that America has an experienced, guaranteed and trusted network to assist its most vulnerable families in achieving and maintaining self-sufficiency. As such, **NASCSP requests $700 million in CSBG funding for fiscal year 2009.**

National Coalition for Osteoporosis and Related Bone Diseases

National Osteoporosis Foundation
American Society for Bone and Mineral Research
The Paget Foundation
Osteogenesis Imperfecta Foundation

Written Statement of the
National Coalition for Osteoporosis and Related Bone Diseases
to the
House Subcommittee on Labor, Health and Human Services and Education
March 31, 2008

Mr. Chairman and Members of the Committee --

The National Coalition for Osteoporosis and Related Bone Diseases (the Coalition) appreciates the opportunity to address the need for increased and sustained funding in fiscal year 2009 for the National Institutes of Health (NIH) overall and, in particular for research on bone diseases and disorders which cuts across numerous NIH institutes.

The Coalition is committed to reducing the impact of bone diseases and disorders through expanded biomedical, clinical, epidemiological and behavioral research. The participants of the Coalition are the American Society for Bone and Mineral Research, the National Osteoporosis Foundation, the Paget Foundation for Paget's Disease of Bone and Related Disorders and the Osteogenesis Imperfecta Foundation.

Bones have a tremendous impact on how we live, function, and perform; but, we sometimes forget that bones are composed of active cells and are subject to metabolic and genetic processes, trauma, and the gradual wear and tear caused by aging. For example:

Osteoporosis, the most prevalent bone disease, is characterized by low bone mass and structural deterioration of bone tissue, leading to bone fragility and an increased susceptibility to fractures, especially of the hip, spine and wrist, although any bone can be affected. In the U.S. today, 10 million individuals are estimated to already have the disease and almost 34 million more are estimated to have low bone mass, placing them at increased risk for osteoporosis. In 2005, osteoporosis-related fractures were responsible for an estimated $19 billion in costs.

Paget's disease of bone is a chronic skeletal disorder which may result in enlarged or deformed bones in one or more regions of the skeleton. Excessive bone breakdown and formation can result in bone which is dense, but fragile. Pain is the most common symptom. Complications may include arthritis, fractures, bowing of limbs and hearing loss if Paget's disease affects the skull. The cause of Paget's disease is unknown.

Osteogenesis Imperfecta (OI)—commonly known as the "brittle bone" disorder—is a genetic disorder characterized by bone that break easily, often from little or no apparent cause. A person with OI may break a rib while coughing, or a leg by rolling over in their sleep. OI has been documented in all ethnic groups, and affects a person throughout their lifetime.

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Cancer Metastasis to Bone. A frequent complication of cancer is its spread to bone (bone metastasis) that occurs in up to 80 percent of patients with myeloma and 70 percent of patients with either breast or prostate cancer—causing severe bone pain and pathologic fractures. Only 20 percent of breast cancer patients and 5 percent of lung cancer patients survive more than 5 years after discovery of bone metastasis.

The bone diseases represented by the Coalition affect people of all ages, races and ethnic groups and lead to permanent deformity and lifelong disability. These are devastating diseases and disorders with significant physical, psychosocial and financial consequences. For example:

Hip Fracture. A bone disorder that is growing, but is preventable, is hip fracture. It is a common and costly disorder affecting the elderly. Without effective prevention, treatment and education strategies, the number of hip fractures will spiral to epidemic proportion by 2025.

Currently in the United States, a hip fracture occurs every two minutes, mostly among persons over 60 years of age and requires hospitalization and surgery. Among those who suffer a hip fracture, 20 percent will die within one year, and among those who survive 50 percent will be unable to walk independently and 25 percent will require long-term care.

A woman's lifetime risk of hip fracture is 1 in 6, compared with a 1 in 9 risk of breast cancer diagnosis. In men, the lifetime risk of experiencing an osteoporotic fracture is 30 percent, similar to the risk of developing prostate cancer.

In 1991, hip fractures accounted for an estimated $2.9 billion in Medicare costs. By 2025 the incidence of hip fractures and their associated costs are projected to grow two-three fold and will surpass 3 million and $25 billion, respectively.

In recent years, as a result of research, progress has been made in several areas. For example:

- Drugs have been developed that slow bone loss and replace lost bone. Some of these drugs reduce hip fracture risk by 20 to 40 percent.
- Recent research has identified new targets for effective therapy to reduce fracture incidence.
- There is increased awareness of the impact of exercise and good nutrition on bone health.

However, the recent cutbacks in research funding support have seriously threatened to undermine the progress that has been achieved, as well as future potential treatments.

What is Needed?

- Additional research at the National Institutes of Health that focuses on better bone building therapies and improves the treatment for those who experience a first hip fracture.
- Additional research focused on increasing the rate of healing of bone fracture.

- Prevention programs – for example, improved screening programs and awareness programs.

In addition, research needs be directed into the following critical areas of bone diseases and disorders:

- Research is needed into the pathophysiology of bone loss in diverse populations in order to develop targeted therapies to improve bone density, bone quality and bone strength. Research is also needed to identify the parameters that lead to the better prediction, prevention and treatment of bone diseases; to identify racial differences in bone and the origin of racial differences in fracture patterns; and to identify patients at risk for fracture who do not meet current criteria for osteoporosis, as well as study the effects of current and developing osteoporosis treatments on these patients.

- The National Cancer Institute research program in osteosarcoma biology must be enhanced through exploratory and other grant mechanisms emphasizing: development of suitable genetic and orthotopic models, studies on the role the tumor microenvironment plays in tumor progression, the identification of tumor progenitor cells and the biology of tumor invasion.

- Research on the development of clinically-relevant experimental models of tumor dormancy, studies on dormant tumor cells and their interaction with the microenvironment, and identification of factors that trigger dormancy of invasive tumor cells or activation of dormant cells.

- Expansion of genetics research on diseases such as osteogenesis imperfecta, fibrous dysplasia, osteopetrosis, and Paget's disease. The National Institute of Arthritis and Musculoskeletal and Skin Diseases, the National Institute on Aging and other institutes are urged to issue Program Announcements on the interaction of environmental and genetic factors in Paget's disease and for a study of the current prevalence of Paget's disease. Furthermore, expansion of research on skeletal stem cell biology and the genetics and pathophysiology of rare bone disorders such as fibrous dysplasia, melhoreostosis, XLinked hypophosphatemic rickets and fibrodysplasia ossificans progressive is needed.

- Research is needed in the new, emerging field of metabolic diseases and bone. The burgeoning increase in childhood obesity and its negative consequences on bone represents a significant health threat that needs full understanding. New research indicates connections between diabetes and neurological diseases and bone that were previously not suspected and these need further research. Therapies are required for secondary osteoporosis in children such as calcium supplementation and physical activity. Also, data are almost non-existent on the beneficial and/or adverse effects of bone therapies such as bisphosphonates in children and adults with many chronic diseases.

Mr. Chairman and Members of the Committee, there is an enormous amount of work to be done, treatments to be developed and cures to be found. Researchers are on the brink of great discoveries that can revolutionize health care and the treatment of bone diseases and disorders. However, because of inadequate funding of the NIH, research progress is being immeasurably

slowed. We need a commitment from you to provide the National Institutes of Health with sufficient money to at least keep up with biomedical inflation.

RECOMMENDATION

The National Coalition for Osteoporosis and Related Bone Diseases joins with the Ad Hoc Group for Medical Research, the Campaign for Medical Research, the Federation of American Societies for Experimental Biology, the National Health Council, Research!America and others urging no less than a **6.5% increase in NIH funding for Fiscal Year 2009.**

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Written Statement of the
Society for Maternal-Fetal Medicine
to the
House Subcommittee on Labor, Health and Human Services and Education
March 31, 2008

Mr. Chairman and Members of the Committee –

The Society for Maternal-Fetal Medicine is pleased to have the opportunity to submit testimony on behalf of the FY 2009 budget for the National Institute of Child Health and Human Development (NICHD). We urge the Committee, as you move forward with your deliberations on the fiscal year 2009 budget for the National Institutes of Health (NIH), to keep in mind the enormous lost opportunities that the NIH, and in particular the NICHD, will experience if the level of funding is not sufficiently increased.

Established in 1977, the Society for Maternal-Fetal Medicine (SMFM) is dedicated to expanding research opportunities in maternal-fetal medicine to identify new approaches to the diagnosis and treatment of pregnancy complications.

A maternal-fetal medicine subspecialist is an individual who has completed two to three years of Maternal-Fetal Medicine fellowship after completing four years of Obstetrics and Gynecology residency. Fellowship training provides additional education and practical experience to gain special competence in various obstetrical, medical, and surgical complications of pregnancy. By virtue of this training and technical proficiency, the maternal-fetal medicine specialist provides care or consultation for both mother and fetus (unborn baby) in a complicated pregnancy.

Most women seek consultation from or care by a maternal-fetal medicine doctor because they are at risk and are considering becoming pregnant or because they are pregnant and are at high risk, such as:

- women with medical or surgical disorders such as heart disease, high blood pressure, preeclampsia (toxemia), diabetes, kidney or gastrointestinal disease or infectious diseases; or

- healthy women whose pregnancy is at markedly increased risk for adverse outcome, such as twins, triplets or more, recurrent pre-term labor and delivery, premature rupture of membranes; recurrent pregnancy loss.

The special problems faced by these mothers may lead to death, short-term or in some cases life-long problems for their babies. For example:

- Pre-term birth (birth before the fetus is at 37 weeks' gestation). – Over half a million children are born preterm each year. Preterm infants are at high risk

for a variety of disorders, including mental retardation, cerebral palsy, and vision impairment. These infants are also at risk for long-term health issues, including cardiovascular disease (heart attack, stroke, and high blood pressure) and diabetes.

NICHD has been a leader in the field of maternal-fetal medicine research. SMFM applauds NICHD for planning and conducting the Surgeon General's Conference on Preterm Birth, which is scheduled to occur in June 2008. NICHD's commitment to basic, clinical and translational research has lead to new ways to treat and improve the health of pregnant women and infants.

- The Maternal Fetal Medicine Units Network addresses issues pertaining to preterm births, fetal growth abnormalities, neurologic sequelae of the newborn, and maternal complications of pregnancy.

- The Genomics and Proteomics Network for Premature Birth focuses on the hereditary information in DNA and the structure and function of proteins to understand the underlying processes that lead to preterm birth.

- Stillbirth Collaborative Research Network focuses on understanding the causes of stillbirth, as well as the extent of the problem.

Research conducted and supported by the NICHD, has given preterm infants and their families hope for the future.

Recent Accomplishments

NICHD-supported research in maternal-fetal medicine has been dramatic. Great strides are being made in the understanding of pregnancy and its complications.

- Researchers studying preeclampsia found that women who, in mid-pregnancy, have a lower level of a substance known as placental growth factor were more likely to develop preeclampsia. Preeclampsia is a sudden, dangerously high increase in high blood pressure that threatens the health of a pregnant woman and her fetus. Pre-eclampsia strikes without warning and can result in maternal seizures and even death. This advance may lead to a screening test for preeclampsia and a treatment to help women avoid the condition.

- Research on preterm birth led to the discovery that giving a form of progesterone to women with a history of preterm birth can reduce their risk of delivering a subsequent baby prematurely. In addition scientists have identified that it is not beneficial for other at risk women, such as those with a twin gestation; thus refining the use of this intervention to only those who will benefit and decreasing exposure of a medication that is not beneficial to another group of women.

- Another NICHD study found that women with a condition known as trichomoniasis are also at increased risk for preterm delivery. The study found that giving antibiotics does not reduce the risk of preterm birth associated with infection; moreover this treatment actually increased the preterm birth rate.

NICHD is at the forefront of several novel and important research areas, but there are still many areas about maternal health, pregnancy, fetal well-being, labor and delivery and the developing child that are not close to being understood. For example:

- ***Pregnancy complications*** affect the life of both the mother and child. In some cases, these are life long, such as the sequelae of preterm birth for the baby and permanent losses of function after maternal stroke due to ecclampsia or preeclampsia in pregnancy. Although history is a powerful predictor of subsequent outcome, nearly half of all pregnant women have no pregnancy history to guide the practitioner and there is minimal to no information to predict and hence offer preventative interventions. In addition, this group of women are at very high risk of adverse outcomes, their rate of preterm birth increased 50% in the last decade, they are at highest risk for developing preeclampsia, which puts them at risk for multiple devastating maternal complications, fetal death, and preterm delivery. Were predictors known, not only would the outcome for the first pregnancy improve, but the impact would have broad public health ramifications as the subsequent pregnancies would be a lower risk.

- ***Late Pre-term Birth.*** – Despite research efforts, preterm birth rates continue to rise, reaching 12%. The largest component of preterm birth is in the late preterm category—those deliveries between 34 and 37 weeks of gestation. Unfortunately, although mortality is low the morbidity is significant for these babies—including respiratory complications, difficulty transitioning after delivery, and feeding issues. Although many late preterm deliveries are due to maternal or fetal indications, many have no reason listed in vital records to what triggered the delivery. Research is needed to address the causes of these late preterm births and to identify interventions for their prevention.

Without a substantial increase and sustained investment in the critical medical research being conducted by the National Institutes of Health, and the National Institute of Child Health and Human Development in particular, the health of pregnant women and their babies will continue to be at risk and NICHD's mission of promoting healthy development throughout the lifespan will be hindered.

Thank you for the opportunity to submit our concerns to the Committee.

Commissioned Officers Association
of the U.S. Public Health Service

Gerard M. Farrell
Captain U.S. Navy (Ret)
Executive Director

31 March 2008

Committee on Appropriations,
Subcommittee on Labor, Health & Human Services, Education, and Related Agencies
U.S. House of Representatives
Washington, D.C.

Dear Subcommittee Members:

On behalf of the Commissioned Officers Association (COA), I urge you to approve $50 million to support the DHHS Secretary's transformation of the USPHS Commissioned Corps, including a new emergency preparedness activity within the Commissioned Corps.

The Secretary's proposed development of Health and Medical Response (HAMR) Teams is a new initiative resulting from recommendations to improve public health preparedness and response following the devastating hurricanes of 2005. The requested funds would be used to organize, train, equip and roster medical and public health professionals in pre-configured and deployable teams.

All HAMR Team members would be USPHS officers and full-time employees of the Office of the Surgeon General. All HAMR Team members would receive advanced training in areas such as advanced trauma life support and the emergency medical management of casualties due to chemical or biological agents or ionizing radiation.

The HAMR teams would provide relief and greater flexibility for overtaxed National Disaster Medical Response Teams and other part-time and volunteer organizations. They would address not only clinical tasks but the full range of public health concerns in a major crisis.

Creation of this new emergency response capability was among the top priorities of Michael Leavitt, Secretary of Health and Human Services, for Fiscal Year 2008. The Administration's budget request contained $38 million for this purpose. Ultimately the HAMR teams were not funded, for reasons that remain unclear. They are once again among the Secretary's top priorities for Fiscal Year 2009.

The HAMR teams would be the Secretary's first asset in addressing deployment needs in the event of a terrorist attack, natural disaster, or international humanitarian mission. They would provide relief for USPHS officers and civilian federal health employees who have taken on significant emergency preparedness and crisis response tasks since 2001. This has taken them away from equally important day-to-day responsibilities in public health practice, health sciences research, drug and medical device regulation, and preventive health education.

While the vast majority of the 6,000 active-duty USPHS officers are assigned to duty stations in the

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Indian Health Service and many other agencies of the federal government, the USPHS officers comprising the HAMR teams would be full-time employees in the Office of the Surgeon General. This would guarantee a dedicated, immediately deployable force. HAMR team members would maintain a state of readiness through continuous training or actual deployment, including disaster response assistance to state and local health departments.

The HAMR team proposal grows out of recommendations contained in the White House report on "lessons learned" from the federal response to the 2005 hurricanes. The performance of the 2,500 PHS officers in that crisis was one of the few aspects of the federal response to draw widespread praise.

Our nation remains at risk of terrorist attack. At the federal level, the U.S. Department of Health and Human Services is responsible for detecting and preventing attacks and for responding to mass casualty events. Because the training of medical emergency teams is absolutely essential to that mission, sufficient funding to support the effort should be approved.

On behalf of the Commissioned Officers Association, I thank you for your consideration of this request.

Sincerely,

Gerard M. Farrell
Captain, U.S. Navy (Ret.)
Executive Director

STATEMENT SUBMITTED BY

CHRISTIAN LOUCQ, MD
DIRECTOR
THE PATH MALARIA VACCINE INITIATIVE

TO THE
HOUSE SUBCOMMITTEE ON
LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION, AND RELATED AGENCIES

U.S. HOUSE OF REPRESENTATIVES

MARCH 25, 2008

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www.malariavaccine.org www.path.org

Mr. Chairman and other distinguished members of the subcommittee, I sincerely appreciate the opportunity to submit this testimony in support of additional funding for malaria programs through increased funding for the National Institutes of Health (NIH) and the Global Fund to Fight AIDS, Tuberculosis and Malaria.

I am Christian Loucq, director of the PATH Malaria Vaccine Initiative (MVI). MVI works to accelerate the development of malaria vaccines and to ensure their availability and accessibility in the developing world. Our vision is a world free from malaria.

The National Institute of Allergy and Infectious Diseases (NIAID) at NIH is responsible for much of the U.S. government's malaria research. NIAID performs and oversees a wide range of work, including basic research that is critical to ensuring that new tools will be available tomorrow to fight both existing and new diseases. Without sufficient resources at its disposal, NIAID's ability to fulfill this important role will be diminished.

The Global Fund is now the leading source worldwide for financial resources to implement in-country programs against AIDS, TB, and malaria. As such, it is plays a critical role in bringing the interventions available today to the people and communities in malaria-endemic countries.

Malaria is a Leading Killer of Children and Pregnant Women

In the brief minute that it took to read aloud this introduction, two children died from malaria. That's one child every 30 seconds.

In Africa, malaria is responsible for 9 percent of all deaths. While young children die most often, pregnant women are also affected: as many as 10,000 women die from malaria in pregnancy annually, and associated infant deaths are 10 to 20 times that figure. In the worst-affected countries, malaria kills as many as one child in five. In all, at least one million people die annually from this disease, almost all of them young African children; 500 million people worldwide suffer from acute malaria each year.

Progress in using the tools of today and in developing the tools for tomorrow

With the establishment of the Global Fund in 2002, an innovative public-private partnership was launched to help ensure access to medicines, bednets, and other interventions in a way that is responsive to the needs of affected countries. By the end of 2007, the Global Fund had supported the distribution of 46 million insecticide-treated bed nets and 5.3 million treatments of artemisinin combination therapy drugs.

The Global Fund is a partner to the U.S. government in its bilateral efforts, but with an important distinction: its reach is broader, to 136 countries worldwide. In this regard, it is similar to a multilateral institution and enables the U.S. government to leverage its contributions to reach those who would not be reached with U.S. funds acting alone. At PATH, the organization of which MVI is a program, we are doubly aware of the impact of

the Global Fund, in light of the work we are doing in Zambia through PATH's Malaria Control and Evaluation Partnership in Africa.

With regard to the tools of tomorrow, proof of concept for a malaria vaccine has existed for almost 40 years. The challenge, however, has been acquiring the knowledge required to translate this proof into a safe and effective product. The malaria parasite has co-existed with humans for thousands of years and has developed immune-evasive strategies and multiple pathways for pathogenesis. With 5,600 genes—almost two-thirds of them seemingly unique to this organism—*P. falciparum* has thousands of potential targets for a vaccine. Until only a few years ago we were severely hindered in our efforts to develop and test new vaccines by the fact that only a handful of these potential vaccine targets had been successfully identified.

Today, armed with a fully sequenced *P. falciparum* genome, as well as powerful tools that enable us to better define the immunological interaction between the parasite and its host, we are better positioned than ever before to effectively identify, validate and test new vaccine targets. We are therefore at a critical juncture: investment in malaria needs to increase to enable us to cross the finish line in our quest to beat this devastating disease.

The NIAID has long played a leading role in seeking solutions to the malaria puzzle by performing everything from basic malaria research to vaccine and drug research and development (R&D). It is a kind of national laboratory that undertakes its own research, funds the research of others, and partners with diverse institutions to tackle diseases—such as malaria—that up until very recently were rightly called "neglected."

Most critically, NIAID is an engine that generates the discoveries that programs like MVI depend on. The pipeline for malaria vaccines is thirsty for new ideas and NIAID is key to keeping the faucet turned on. Vaccine developers can generally point to a success rate of one in ten. For a malaria vaccine that rate may be even smaller; we don't know because a vaccine has yet to make it to market. But a vaccine is needed if we are to eradicate—in the long term—this killer disease.

Increased Funding is Needed

PATH and the MVI program applaud the recent wave of global support for programs to control and, ultimately, to eradicate malaria. The U.S. government has been a part of that wave and its continued support is vital to future progress. We also applaud the government for its investments in research, an area of U.S. leadership.

But it simply is not enough. Funding for NIH, including NIAID and other institutions such as the Fogarty International Center, is not keeping pace with inflation. Simply to maintain existing programs, nearly $3 billion would be needed to match what was appropriated four years ago. And while less neglected than before, global health research remains underfunded. NIH spends just 0.3 percent of its budget on malaria research. At the very least, funding for NIH should keep up with inflation in fiscal 2009, that is, increase by at least 3.6 percent. To

make up for past underfunding of global health research would require at least another $130 million in annual increases for the next five years.

The Global Fund received $841 million from all U.S. government sources in fiscal 2008, the largest amount to date. This amount cannot be allowed to decrease, as it helps to set the bar for other donor contributions and is a way to further leverage U.S. taxpayer funds.

My message to you is that the NIH could do even more good with increased resources. So could the Global Fund. In these complicated financial times, the challenge will be even greater to ensure that both institutions receive the support that they deserve and, at a minimum, no less than in previous years.

We have never been closer to developing a safe and effective malaria vaccine for use among children in Africa tomorrow; and there has never been as much hope about what we can achieve today.

I urge the committee to stand in support of increased malaria funding for NIH and the Global Fund. Money invested in this area is yielding results that matter.

I thank you for your consideration.

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Statement by

Kathy Spahn

President & Chief Executive Officer

Helen Keller International

Subcommittee on Labor, Health and Human Services,

Education and Related Agencies

Committee on Appropriations

U.S. House of Representatives

March 31, 2008

Mr. Chairman, thank you for this opportunity to submit testimony to the Committee on behalf of Helen Keller International's ChildSight® program. My name is Kathy Spahn, and I am a President and Chief Executive Officer of Helen Keller International. I am requesting that you recommend that $2 million of funding through the Department of Education be used in support of the ChildSight® program in fiscal year 2009. It is our hope that in ten years, ChildSight® can reach low-income populations all across the nation.

CHILDREN WITH VISUAL NEEDS

The mission of ChildSight® is to improve the vision and academic potential of school children living in urban and rural poverty. Vision and learning are inextricably linked. Most learning platforms – books, computer screens, blackboards and classroom presentations – require clear vision in order for a child to interact, assimilate information, and respond. Uncorrected refractive error (more commonly known as near-sightedness, far-sightedness and astigmatism) can significantly affect a child's academic performance and overall development.

The inability to learn due to poor vision is a widespread, and largely unaddressed, problem affecting poor, predominantly minority public school students throughout our nation. Each year millions of disadvantaged children do not have access to healthcare, let alone basic eye health services needed to properly assess and address their vision needs.

ChildSight® tackles this challenge by going directly into the schools to conduct vision screenings, to identify children with refractive error, and to provide them with the prescription eyeglasses they need, free of charge. By supplying students with an essential learning tool, eyeglasses, ChildSight® helps to ensure these children can take advantage of all the educational opportunities available to them.

THE CHILDSIGHT® PROGRAM

The hallmark of the ChildSight® program is the provision of prescription eyeglasses at the school site. As a service, it is immediate and convenient, and it seeks to overcome the economic, social and transportation barriers to care by bringing these essential services directly to students at school. ChildSight® provides direct access to vision screening and refraction by a licensed doctor of optometry or ophthalmology, who then prescribes the necessary lenses for each child.

With support from this Committee, the Department of Education and private donations, the ChildSight® program has screened over one million impoverished school children in over 500 schools nationwide and has delivered free prescription eyeglasses to more than 124,000 students with poor vision since the program's inception in 1994.

The children served by ChildSight® come from families who live at or below 200% of the poverty level and have little or no access to vision care programs. All of our services are provided at no expense to the child's family. ChildSight® in partnership with funds from the Department of Education has helped meet the needs of these young students.

We have seen the positive results of the ChildSight® program. Teachers we have surveyed throughout the country reported that a majority of students who had their vision corrected with ChildSight® eyeglasses exhibited:

- significant improvement in the completion of schoolwork and homework;
- increased class participation and a reduction in disruptive behavior; and
- a dramatic improvement in grades, self-confidence and self-perception.

AREAS SERVED BY CHILDSIGHT®

What started as a pilot program in New York City in 1994 has since grown to serve children in seven states: California (Los Angeles), Connecticut (Bridgeport, Hartford, New Haven and New London), New Jersey (Irvington, Jersey City, Newark, Passaic and Plainfield), New Mexico (Gallup), New York (New York City), Ohio (Cleveland) and Texas (El Paso). ChildSight®'s services are supported through the provision of funding from the United States Department of Education's Fund for the Improvement of Education, along with private sector support from corporations and foundations.

Support from the U.S. Department of Education was particularly instrumental in the establishment of ChildSight®'s rural programs serving isolated communities surrounding El Paso Texas and Gallup, New Mexico. Recognizing the enormous burden of rural poverty, the severe lack of health resources and the barriers to accessing care, Helen Keller International established ChildSight® rural program in Gallup, New Mexico. Since its launch in 2004, ChildSight® New Mexico has now screened nearly 14,000 children throughout 12 Gallup-McKinley County Schools and 11 Eastern Navajo Bureau of Indian Affairs Schools, and has provided close to 3,300 children with the prescription eyeglasses they needed.

PUBLIC/PRIVATE UNDERTAKING

ChildSight® is truly a public/private endeavor. The program's success is due in large part to the dedication and commitment of the many physicians, educators, community activists and business people at each of our local sites. Along with their support and the generous contributions of foundations and corporations, we continue to seek the institutionalization and long-term sustainability of our programs. Previous endorsement by the U.S. Department of Education has played an important role in our ability to leverage committed support from the private sector. We have received significant long-term funding from several foundations including The Starr Foundation, the Lavelle Fund for the Blind, the Reader's Digest Partners for Sight Foundation and the Annenberg Foundation.

Local health care professionals at each of our sites join us as members of the ChildSight® team. More than 30 optometrists and pediatric ophthalmologists continue to meet the vision care needs of the students we serve. ChildSight® contracts with 18 ophthalmic clinics and seven optical shops nationwide, all selected for their strong professional credentials. Services among all these community professionals are either donated or provided at a reduced, reasonable rate.

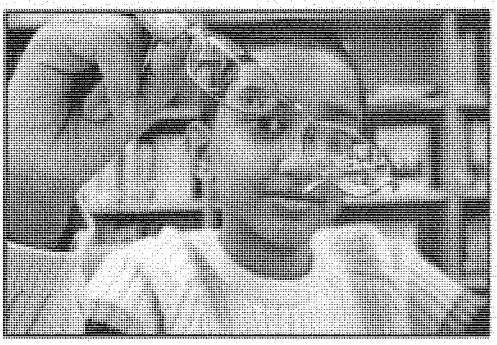
SOLVING THE PROBLEM

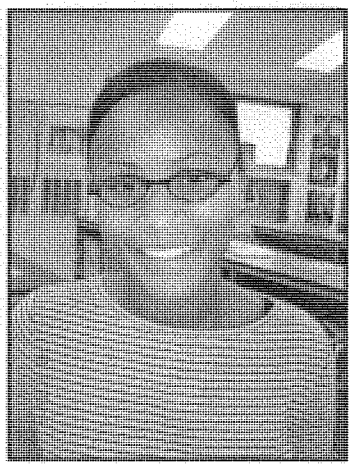
Our data, collected over 14 years of service, confirms that one in every four children between the ages of 10 and 15 fail standard vision screenings as a result of refractive error.

I ask that the Committee recognize our concern that so much more needs to be done. Children who need eyeglasses must receive them while they are still in school, so that they can make full use of the opportunity to gain a valuable education. I also ask you to consider the reality that children in many areas of urban and rural poverty are missing the chance to be helped because we cannot yet reach them. If students must struggle with the blurred, imprecise images they see on textbook pages and in classroom demonstrations, then the opportunity for more children to gain an adequate education in our public schools is being wasted. This is especially tragic since this is a result of an easily fixable but neglected visual handicap.

In closing, I ask the committee to recommend at least $2 million dollars in fiscal year 2009 to support ChildSight® in its current locations, to expand the current rural sites, and to launch this important program in other regions of the country.

Thank you, Mr. Chairman. Your attention and consideration are greatly appreciated, and I close with the wise words of our founding board member, Helen Keller: "If we look at difficulties bravely, they will present themselves to us as opportunities."





The National Center for Learning Disabilities
James Wendorf, Executive Director

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

Mr. Chairman, my name is James Wendorf and I am the Executive Director of the National Center for Learning Disabilities (NCLD). NCLD is a not-for-profit organization founded in 1977, which seeks to ensure that all individuals with learning disabilities (LD) gain access to research-based knowledge and opportunities to fully achieve their potential. NCLD protects the rights of individuals with LD and promotes the widespread implementation of effective research-based instructional methods.

I am pleased to testify today to encourage the committee's endorsement of the Maryland Committee for Children's request for funding in the FY2009 appropriation bill because of their plan to demonstrate the effectiveness of their new training modules in early childhood settings that have the potential to change the way early childhood professionals are trained in the future. This training will underline the importance of systematic approaches for recognizing and responding to early signs of learning difficulties in young children in order to mitigate or prevent later learning problems.

The training modules are based on the Recognition and Response (R&R) system, a pre-k early intervening system that integrates universal screening and progress monitoring with research-based interventions to improve academic instruction for all children. NCLD has been a lead partner within a network of organizations in the development of this program, supplemental resources and web site. NCLD is also invested in supporting this request because of the usage of the *Get Ready to Read*! screening tool as one of the screening measures. This tool, developed by NCLD, is for parents of young children and early childhood professionals to promote reading and school success. The tool seeks to ensure that parents, early child care providers and teachers have information on whether a child has the early literacy skills they need before they enter kindergarten.

Background

NCLD believes that effective and developmentally appropriate literacy instruction depends on a reliable understanding of where a child is in making progress toward being ready to read. Parents of young children and early childhood professionals need a better understanding of the prerequisite skills for reading and other aspects of literacy. They must be able to assess children's skills against standard criteria. They also need to be able to recognize behaviors that place children at risk for reading and other forms of literacy failure. In addition, they need information and resources to take effective steps to ensure early success in learning to read, write, listen, and otherwise communicate effectively.

Recognition and Response and the Screening Tool

Adapted from Response to Intervention (RTI), Recognition and Response (R&R) is a pre-k early intervening system that integrates universal screening and progress monitoring with research-based interventions to improve academic instruction for all children. Using empirical evidence on RTI as a guide, the R&R system was designed to maximize the potential benefits of providing early intervening approaches in pre-k in order to minimize the need for intervening services upon entering kindergarten. R&R, like RTI, was designed with an emphasis on improving the quality of the general education curriculum as a potential means to improve school readiness for all children, especially for those who show signs of struggle to learn. The system teaches pre-k educators to recognize early warning signs of learning difficulties and respond in ways that positively affect a child's early school success. NCLD recently hosted a briefing to House and Senate staff members on the research behind R&R and the potential for this system to improve student outcomes in the future.

The Get Ready to Read! 20-item screening tool, developed in 2000, focuses on the building blocks of literacy: linguistic awareness, letter knowledge, book knowledge, and emergent writing. The tool is derived from the most current research- and practice-based knowledge about reliable early predictors of reading and other literacy skill success, and early identification of literacy problems in the preschool and early elementary grades. It is designed for both print and Web dissemination and is prepared in English and Spanish. The tool allows for the collection of process and outcome evaluative data. It is easily usable by a wide audience of parents, childcare providers, teachers, and related professionals including those who work with children of various cultural and socioeconomic backgrounds. Additionally, the screening tool has been widely disseminated through a network of national and state organizations, as well as through NCLD and a commercial publisher.

Federal Support

With federal appropriation dollars, NCLD and our partner, the Maryland Committee for Children, seek to conduct early childhood professional development and literacy training statewide in Maryland using their newly developed set of seven training modules. This training program in conjunction with in-depth technical assistance on how to use the *Get Ready to Read!* screening tool and support resources will greatly influence the type of early childhood professional development and support that is available in the field. Providing the opportunity to use this pilot training program statewide will allow the training to be refined in order to disseminate the training regional and nationally as the use of R&R grows.

The cornerstone of the project is providing professional development to educators and providers using the *"At Risk yet Full of Potential: Responding to the Learning Needs of Low Income and English Language Learners"*. The modules focus on the three tiered model of recognizing and responding to the learning styles and needs of all children so that every child has an opportunity to experience success in the early learning environment. Tier I provides teachers with the means of determining whether instruction for the whole class may need to be modified and helps them identify children who require additional supports. Tier II provides teachers with specific instructional practices that have been shown to be effective in addressing a particular

learning problem using strategies that require minimal adjustments to classroom routines (e.g., working with small groups). Tier III provides teachers with more intensive, individualized approaches. A collaborative problem-solving process that includes parents and specialists assists teachers in selecting appropriate interventions linked to assessment data at each level of the intervention hierarchy. The modules: *What is Learning Difference?*, *Observing and Documenting for Informed Instruction*, *Assessments and Screening Tools*, *Effective Communication with Parents, Making the Curriculum Work for All Children*, *Transitioning Children and Families into Kindergarten* and *The Referral Process*. As suggested in the list of training modules, the workshops will also include the use of screening tools and school readiness assessments such as the *Get Ready to Read!* screening tool and Work Sampling and provide strategies for how to interpret results and use the results to affect program implementation and practice.

This funding program will allow early education and child care professionals to learn how to recognize and respond to early warning signs in children who show signs of struggling to learn. The professionals also will be trained in the selection and implementation of appropriate learning activities to foster the development of needed skills. Support of this project is essential for continuing the intensive on-the-ground work that needs to be completed in order to ensure early childhood educators and parents receive the information they need to support children in the years before kindergarten. The training provide with this funding will serve to support children from year to year once the adults in the setting have received the training and support outlined in this request.

Mr. Chairman, by supporting this project, you have the chance to bring our collective investment in research, early education and literacy to the next level. It's an exciting challenge and opportunity. Together, we can help educators and others vested in our children's success to have direct access to in-depth professional development and support (regardless of their education level and training) and an easy-to-use tool that can determine whether to seek early intervention to prevent reading failure. By spending a limited amount of time and money early in a child's life, we can help prevent spending many times that amount later. Let's take action with the reliable science available to us and give young children an early chance at success in school and in their lives. Thank you for your consideration and support.

UNITED TRIBES TECHNICAL COLLEGE
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Statement on
FY 2009 Department of Education Carl Perkins Act Budget (Section 117) and HEA Title III

Submitted to
House and Senate Appropriations Subcommittees on
Labor-HHS-Education and Related Agencies

David M. Gipp, President, United Tribes Technical College (UTTC)
Myra Pearson, UTTC Board Chairman and Chairman of the Spirit Lake Tribe

March 5, 2008

For 39 years, United Tribes Technical College (UTTC) has provided postsecondary career and technical education, job training and family services to some of the most impoverished Indian students from throughout the nation. We are governed by the five tribes located wholly or in part in North Dakota. We have consistently had excellent results, placing Indian people in good jobs and reducing welfare rolls. The Perkins funds constitute about half of our operating budget and provide for our core instructional programs. We do not have a tax base or state-appropriated funds on which to rely. Our program is entirely consistent with one of the stated goals of the U.S. Department of Education's Strategic Plan: access to postsecondary education.

The request of the United Tribes Technical College Board is:

- **$8.5 million or $1 million above the FY 2008 enacted level** under Section 117 of the Carl Perkins Act. These funds are shared by United Tribes Technical College and Navajo Community College.
- **$1 million from Title III of the Higher Education Act (HEA) to continue the infrastructure development of our south campus.**

Authorization. Section 117 of the Carl Perkins Career and Technical Education Act (20 U.S.C. Section 2327) is the source of authorization of Perkins funding for UTTC. Funding under this Act has in recent years been distributed on a formula basis to UTTC and to Navajo Technical College, neither of which receive funding under the Tribally Controlled Colleges or Universities Act. Funds have been authorized and appropriated by Congress for the program since FY 1991.

Administration Request. Despite the explicit Congressional authorization for Carl Perkins funding for Section 117, and despite the Administration's requests for funding for Section 117 in all previous years, the Administration has requested nothing for this program for FY 2009. This crass, outrageous and irresponsible cut, if carried out, would irreparably harm Indian students who often have no other chance for improving their lives but through UTTC and Navajo Technical College. It represents a failure to understand our educational mission, the nature of the populations we serve

and contradicts the Department of Education stated goal of access to postsecondary education mentioned above.

Our students are disadvantaged in many ways. They often come from impoverished backgrounds or broken families. They may be overcoming extremely difficult personal circumstances as single parents. They often lack the resources, both culturally and financially, to go to other mainstream institutions. UTTC provides a set of family and culturally-based campus services, including: an elementary school for the children of students, housing, day care, a health clinic, a wellness center, several on-campus job programs, student government, counseling, services relating to drug and alcohol abuse and job placement programs that enable our students to start on the road to realizing their potential.

The Administration states that UTTC has other sources of funding to carry out its mission. This is not correct. Our present Perkins and Bureau of Indian Education funds (also cut entirely from the President's FY 2009 budget) provide for nearly all of our core postsecondary educational programs. Almost none of the other funds we receive can be used for core career and technical educational programs; they are supplemental and help us provide the services our students need to be successful. Moreover, these other programs are competitive, which means we have no guarantee that such funds will be available to us in the future. We cannot continue operating without Perkins funds.

Core Perkins Funding. Below are some important facts about United Tribes Technical College which supports our request for $8.5 million under the Perkins Act.

UTTC Performance Indicators. UTTC has:

- An 81 percent retention rate
- A placement rate of 94 percent (job placement and going on to four-year institutions)
- A projected return on federal investment of 20-to-1 (2005 study comparing the projected earnings generated over a 28-year period of UTTC Associate of Applied Science and Bachelor degree graduates of June 2005 with the cost of educating them.)
- The highest level of accreditation. The North Central Association of Colleges and Schools has accredited UTTC again in 2001 for the longest period of time allowable – ten years or until 2011- and with no stipulations. We are also the only tribal college accredited to offer accredited on-line (Internet based) associate degrees.
- More than 20 percent of our students now go on to four-year or advanced degree institutions.

The demand for our services is growing and we are serving more students. For the 2007-2008 year we enrolled 1122 students (an unduplicated count), nearly four times the number served just six years ago. Most of our students are from the Great Plains, where the Indian reservations have a jobless rate of 76 percent (Source: 2003 BIA Labor Force Report), along with increasing populations. The need for our services will continue to increase at least for the next five to ten years.

In addition, we are serving 248 students during school year 2007-2008 in our Theodore Jamerson Elementary school and 252 children, birth to five, are being served in our child development centers.

UTTC course offerings and partnerships with other educational institutions. We offer 15 vocational/technical programs and award a total of 15 two-year degrees (Associate of Applied Science (AAS)) and six (6) one-year certificates, as well as a four year degree in elementary education in cooperation with Sinte Gleska University in South Dakota. We are accredited by the North Central Association of Colleges and Schools for the longest accrediting period provided of ten years.

Licensed Practical Nursing. This program has one of the highest enrollments at UTTC and results in the greatest demand for our graduates. Our students have the ability to transfer their UTTC credits to the North Dakota higher educational system to pursue a four-year nursing degree.

Medical Transcription and Coding Certificate Program. This program provides training in transcribing medical records into properly coded digital documents. It is offered through the college's Exact Med Training program and is supported by Department of Labor funds.

Tribal Environmental Science. Our Tribal Environmental Science program is supported by a National Science Foundation Tribal College and Universities Program grant. This five-year project allows students to obtain a two-year AAS degree in Tribal Environmental Science.

Community Health/Injury Prevention. Through our Community Health/Injury Prevention Program we are addressing the injury death rate among Indians, which is 2.8 times that of the U.S. population, the leading cause of death among Native Americans ages 1-44, and the third leading cause of death overall. This program has in the past been supported by the Indian Health Service, and is the only degree-granting Injury Prevention program in the nation.

Online Education. We are continuing to create increased opportunities for education by providing web-based and Interactive Video Network courses from our North Dakota campus to American Indians residing at other remote sites as well as to students on our campus. Online courses provide the scheduling flexibility students need, especially those students with young children.

We offer online fully accredited degree programs in the areas of Early Childhood Education, Community Health/Injury Prevention, Health Information Technology, Nutrition and Food Service and Elementary Education. Over 50 courses are currently offered online, including those in the Medical Transcription and Coding program. We presently have 59 online students.

Another significant online course is suicidology – the study of suicide: its causes, prevention and the behavior of those who threaten or attempt suicide. Suicide in Indian country dramatically affects our communities, particularly our youth. According to the IHS, suicide rates in Indian Country are 6-8 times the national rate.

We also provide an online Indian Country Environmental Hazard Assessment program, offered through the Environmental Protection Agency. This is a training course designed to help mitigate environmental hazards in reservation communities.

Computer Information Technology. This program is at maximum student capacity because of limitations on resources for computer instruction. In order to keep up with student demand and the latest technology, we need more classrooms, equipment and instructors. We provide all of the Microsoft Systems certifications that translate into higher income earning potential for graduates.

Nutrition and Food Services. UTTC helps meet the challenge of fighting diabetes in Indian Country through education. Indians and Alaska Natives have a disproportionately high rate of type 2 diabetes, and have a diabetes mortality rate that is three times higher than the general U.S. population. The increase in diabetes among Indians and Alaska Natives is most prevalent among young adults aged 25-34, with a 160 percent increase from 1990-2004. (Source: FY 2009 Indian Health Service Budget Justification).

As a 1994 Tribal Land Grant institution, we offer a Nutrition and Food Services AAS degree in order to increase the number of Indians with expertise in nutrition and dietetics. Currently, there are very few Indian professionals in the country with training in these areas. Our degree places a strong emphasis on diabetes education, traditional food preparation, and food safety.

We have also established the United Tribes Diabetes Education Center that assists local tribal communities, our students and staff to decrease the prevalence of diabetes by providing educational programs, training and materials. We publish and make available tribal food guides to our on-campus community and to tribes.

Business Management/Tribal Management. Another critical program for Indian country is business and tribal management. This program is designed to help tribal leaders be more effective administrators and entrepreneurs. As with all our programs, curriculum is constantly being updated.

Job Training and Economic Development. UTTC continues to provide economic development opportunities for many tribes. We are a designated Minority Business Development Center serving South and North Dakota. We administer a Workforce Investment Act program and an internship program with private employers in the region.

South Campus Infrastructure Development. The bulk of our current educational training and student housing is provided in 100 year old buildings, part of a former military base used by UTTC since its founding in 1969 and donated to us by the U.S. in 1973. They are very expensive to maintain, do not meet modern construction and electrical code requirements, are not generally ADA compliant, and cannot be retrofitted to be energy efficient.

As a result, UTTC has developed plans for serving more students in new facilities that will provide training and services to meet future needs. These plans include the development of infrastructure on adjacent land purchased with a donation that will become our south campus. We have received some funds for this project and have the plans in place. *We are asking for an additional $1 million in FY 2009 from Title III of the HEA to be able to continue this work.*

Our vision for the south campus is to serve up to 5,000 students. We expect that funding for the entire project will come from federal, state, tribal and private sources. Aside from student housing, the first building will be a combined science and administration building.

We cannot survive without the core career and technical education funds that come through the Department of Education. These funds are essential to the operation of our campus. Our programs at UTTC continue to be critical and relevant to the welfare of Indian people throughout the Great Plains region and beyond. Thank you for your consideration of our request.

Testimony submitted by:

Max McConkey, Chair
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to:
Subcommittee on Labor, Health and Human Services,
Education, and Related Agencies, Committee on Appropriations
U.S. House of Representatives
March 14, 2008

Good morning. I am Max McConkey, the 2008 Chair of the Board of Directors for Knowledge Alliance and the Chief Policy and Communications Officer at WestEd, a non-profit research, development and service agency that has been enhancing and increasing education and human development within schools, families and communities for over 40 years. My testimony represents the views of Knowledge Alliance's leadership and Board of Directors, and we thank you for the opportunity to provide to the Subcommittee our appropriations proposal for FY 2009.

Knowledge Alliance is a non-profit, non-partisan trade association dedicated to expanding the use of research-based knowledge in policy and practice in K-12 education. We are a strong and dynamic community of highly successful education organizations and agencies, all of which are constantly looking for new and better ways to support high-quality education research, development, dissemination, technical assistance and evaluation at the federal, regional, state, tribal and local levels.

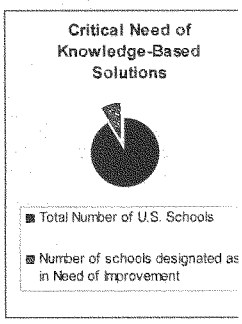
Much of our collective work is focused on advancing the effective use of research-based knowledge as a central organizing concept for school improvement and education reform. We firmly believe that the effective creation, translation and application of research-based knowledge can significantly enhance and accelerate the nationwide efforts to improve academic performance and close achievement gaps in K-12 education. Effective

knowledge use also helps advance the national initiatives to transform education into an evidence-based field and enhance the proper implementation of No Child Left Behind (NCLB) and the Education Sciences Reform Act (ESRA).

Critical Challenges

At Knowledge Alliance, we believe it is now time to intensify the focus on creating, translating, and applying research-based knowledge into useful tools that will improve classroom policies and practices in low-performing schools, for the following critical reasons:

Escalating demand for knowledge-based solutions -- As the US Department of Education indicated in its recent budget justifications, the accountability schedules in the No Child Left Behind Act will significantly increase the number of schools in need of improvement and place even more pressure on the limited resources currently available for school improvement:



> *"The most recently available State-reported assessment results suggest that while most States are making progress in improving student achievement in the two core subjects, accelerating that rate of improvement will be a key challenge in meeting the 100% proficiency goal by 2014...between the 2004-05 and 2007-08 school years, the total number of schools identified for improvement increased by more than 1,800 or 18%, while the number of schools identified for restructuring more than tripled, rising from 1,180 in 2004-05 to 3,923 in 2007-08."*

Many more schools are on the cusp and in need of additional support. To fulfill the promise of NCLB, much greater attention needs to be directed to delivering research-based solutions to these schools in need.

Inadequate federal investments in education R&D -- The NCLB requires educators to use instructional practices and innovations supported by research, but the Department of Education spends less than one percent of its budget on research, development and statistics, the smallest of any cabinet level agency.

Federal department/agency	FY 2009 research and development request
Defense	$80.7 billion
Health and Human Services	$29.9 billion
NASA	$10.7 billion
Energy	$10.6 billion
National Science Foundation	$5.2 billion
Agriculture	$2 billion
Commerce	$1.2 billion
Homeland Security	$1.1 billion
Transportation	$901 million

Veterans Affairs	$884 million
Interior	$617 million
Environmental Protection Agency	$550 million
Education	$324 million

Source: American Association for the Advancement of Science.

This low level of investment means that not only will schools and districts continue to find it difficult to fulfill NCLB's mandate for using such practices, but that they will not be able to build the evidence base needed by educators to achieve the improvements envisioned by NCLB. The bottom line is that schools and students will suffer without an increased investment in developing and testing research-based practices.

Expanding capacity crisis -- A 2006 report by the Center on Education Policy (CEP) found that there is a growing capacity crisis at the state and local levels to support schools in need of improvement. We agree with CEP's assessment that "...the Department and the Congress should (provide) more funding and ... other types of support to help strengthen states' and districts' capacity to assist schools identified for improvement. Many states and districts lack sufficient funds, staff, or expertise to help improve all identified schools..." A national study by the Center for Research on Education Outcomes also found that this crisis is further exacerbated by state education agencies' very low capacity to evaluate the education programs that are carried out at the state and district levels.

Weak policy link between the federal research enterprise and federal school improvement efforts -- NCLB stimulates and shapes greater demand for research-based knowledge solutions through its accountability and sanctioning provisions, and ESRA aims to increase the supply of research-based knowledge through its investments in research and development. There are numerous provisions in NCLB regarding scientifically-based research and in ESRA for addressing school improvement, but the links between supply and demand have not been fully developed and remain functionally weak. We attribute part of the problem to federal policy that fails to create a strong systematic link between ESRA and NCLB focusing on the critical areas of knowledge development, transfer, application and use in school improvement.

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

Recommendations

Our appropriations proposal for FY 2009 calls for greater federal investments in research-based programs to help states and districts respond to the rapidly increasing needs of low performing schools. More specifically, we strongly support funding for federal education programs that explicitly support knowledge use in school improvement, or have a strong potential to do so. We urge a stronger and more comprehensive federal effort to respond both to the greater demand for knowledge-based solutions and to the under-funded supply of well-tested practices and programs. Specifically, we propose the following:

Top priority: A Research-Based School Improvement Package -- We believe the growing capacity crisis in school improvement warrants a mobilization of the federally supported research enterprise and the school improvement community to create a powerful and focused immediate impact. To do this, we recommend that you consider five essential interrelated programs as a research-based school improvement package and increase their overall investments in tandem. The five programs and our recommendations are as follows:

Comprehensive Centers
Recommendation: $67.1 million ($10 million increase over FY 2008)
The 16 regional centers and five content centers work directly with State Education Agencies in building state capacity to turning around low performing schools. The Centers apply and provide in-depth, research-based knowledge in key improvement areas such as assessment and accountability, instruction, teacher quality, innovation and school improvement provisions in NCLB. We propose an increase that would enable the content centers to intensify their research-based services and increase the regional centers' ability to help states respond directly to the increasing number of schools in need of improvement and corrective action.

Regional Educational Laboratories
Recommendation: $77.6 million ($12 million increase over FY 2008)
The Regional Educational Laboratory Program is composed of a network of 10 laboratories that serve the education reform and school improvement needs of designated regions. The laboratories address regionally identified education problems through rigorous research studies, rapid response studies and related technical assistance activities. The proposed increase would create a special triage "urgent response" system to address the most pressing, immediate educational reform issues in each region as well as fund a mandated evaluation of the network.

Research, Development and Dissemination
Recommendation: $187 million ($27 million increase over FY 2008)
This fund supports a diverse portfolio of programs, projects and studies that create, translate, disseminate and/or apply research-based knowledge relevant to school improvement and the implementation of NCLB. Ongoing initiatives cover

key issue areas such as academic subjects, teacher quality, cognition and learning, reading and math. The recommended boost would increase the number of rigorous research studies focusing on pressing school improvement issues by at least 20 and support the President's proposal for a new research initiative to identify and evaluate models for turning around schools.

National Research and Development Centers
Recommendation: $26 million (same as FY 2008; within the RD&D fund above)
These Centers address enduring education issues of national significance through sustained, focused, interdisciplinary research. The Centers' funding is provided under the Research, Development and Dissemination Program. The $26 million would be used to provide supplemental grants to Centers so they could expand the size or number of rigorous research studies on their designated topics, and for increasing the overall number of Centers.

Title I School Improvement Grants
Recommendation: $491 million (same as FY 2008)
These grants support local efforts to turn around low performing schools and school districts and to ensure that high poverty schools have the extra resources they need to help their students reach proficiency in math and reading, as required by NCLB. We strongly support the Administration's request of $491 million and efforts to effectively deliver scientifically based research solutions schools with the greatest needs.

Important Support: Programs Contributing to School Improvement -- We recommend continued support for the following programs which will play an increasingly significant role in state and local efforts to respond to the escalating demand for school improvement and solutions.

Comprehensive School Reform
Recommendation: $1.6 million (same as FY 2008)
We urge the continuation of the national activities for this successful and highly rated program to coordinate, collect, assess and disseminate successful interventions for school reform. We do not support the President's proposal for elimination.

Math Science Partnerships
Recommendation: $200 million ($21 million increase over FY 2008)
This program's focus on developing rigorous mathematics and science curricula and supporting teacher recruitment efforts will play a vital role in improving student achievement in STEM subjects and ultimately enhance our national competitiveness. We support an increase of $21 million over the President's request.

ANSR AMERICANS FOR NURSING SHORTAGE RELIEF

Testimony of the Americans for Nursing Shortage Relief (ANSR) Alliance Regarding Fiscal Year 2009 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

March 31, 2008

The undersigned organizations of the ANSR Alliance greatly appreciate the opportunity to submit written testimony regarding fiscal year (FY) 2009 appropriations for Title VIII – Nursing Workforce Development Programs. The ANSR Alliance is comprised of fifty-one national nursing organizations that united in 2001 to identify and promote creative strategies for addressing the nursing and nurse faculty shortages, including passage of the ***Nurse Reinvestment Act of 2002***.

The ANSR Alliance stands ready to work with lawmakers to advance programs and policy that will sustain and strengthen our nation's nursing workforce. To ensure that our nation has a sufficient and adequately prepared nursing workforce to provide quality care to all well into the 21st century, ANSR urges Congress to:

- **Appropriate at least $200 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 2009.**
- **Restore the Advanced Education Nursing program (Sec. 811) and fund it at a level on par with the proposed FY 2009 increase for the other Title VIII programs.**

The Nursing Shortage

Nursing is one of the largest health care professions with an estimated 2.9 million licensed RNs in the United States.[1] Nurses work in a variety of settings, including public health, long-term care, and hospitals. Advanced practice nurses (nurse practitioners, nurse midwives, clinical nurse specialists, and certified registered nurse anesthetists) practice in numerous settings, including primary care, hospitals, and surgical care facilities. Approximately three out of five jobs are in hospitals.[2] A federal report published in 2004 estimates that by 2020 the national nurse shortage will increase to more than 1 million full-time nurse positions. According to these projections, which are based on the current rate of nurses entering the profession, only 64 percent of projected demand will be met.[3] A

[1] Steiger, D.M., Bausch, S., Johnson, B., Peterson, A. (2006) ***The Registered Nurse Population: Findings from the March 2004 National Sample Survey of Registered Nurses***. Health Resources and Services Administration, U.S. Department of Health and Human Services.

[2] Bureau of Labor Statistics, U.S. Department of Labor. ***Occupational Outlook Handbook, 2006-2007 Edition***, Registered Nurses.

[3] Health Resources and Services Administration. (2004) ***What is Behind HRSA's Projected Supply, Demand, and Shortage of Registered Nurses?***

2007 study that uses different assumptions published in ***Health Affairs*** has adjusted the demand projection to 340,000 nurses by 2020.[4] In either scenario, the shortage presents an extremely serious challenge to health care access and quality patient care. Even considering only the smaller projection of vacancies, this shortage still results in a frightening 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 2005, the American Hospital Association reported that hospitals needed 118,000 more RNs to fill immediate vacancies, and that this 8.5 percent vacancy rate is hampering the hospitals' ability to provide emergency care.[5] Government estimates indicate that this situation only promises to worsen due to an insufficient supply of individuals matriculating in nursing schools, an aging existing workforce, and the inadequate availability of nursing faculty to educate and train the next generation of nurses. At the exact same time that the nursing shortage is expected to worsen, the baby boom generation is aging and the number of individuals with serious, life-threatening, and chronic conditions requiring nursing care will increase. Consequently, more must be done today by the government to help ensure an adequate nursing workforce for the patients of today and tomorrow.

A particular focus on securing and retaining adequate numbers of faculty is essential to ensure that all individuals interested in – and qualified for – nursing school can matriculate in the year they are accepted. In the 2005-2006 academic year, research reported by the National League for Nursing found that schools of nursing rejected more than 88,000 qualified applications because of shortages of faculty, classroom space, and clinical placement for students.[6] Aside from having a limited number of faculty, nursing programs struggle to provide space for clinical laboratories and to secure a sufficient number of clinical training sites at health care facilities.

The current and deepening nurse faculty shortfall is a critical reason that the Advanced Education Nursing line item in the Title VIII programs must be fully funded. This program supported 13,877 graduate nursing students in FY 2006. The students that are supported by this funding are the pool of future faculty for the nursing profession. Whether supporting students in clinical education or as faculty in schools of nursing, it is essential that advanced education nursing funding be restored.

The Nursing Supply Impacts America's Emergency Preparedness

The National Center for Health Workforce Analysis at HRSA's Bureau of Health Professions reports that the nursing shortage makes it challenging for the health care sector to meet current service needs. Nursing shortfalls exacerbating capacity insufficiencies throughout the health care system have ripple effects, for example, seen in the problems encountered by most communities' day-to-day emergency care services. Facing a pandemic flu or other natural or man-made disaster of significant

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[4] Auerbach, D.I, Buerhaus, P.I., & Staiger, D.O. (2007). Better late than never: Workforce supply implications of later entry into nursing. ***Health Affairs***. 26(1): 178-185

[5] American Hospital Association. (2005). Prepared to Care: The 24/7 Role of America's Full-service Hospitals.

[6] National League for Nursing. (2008). ***Nursing Data Review Academic Year 2005-06***, Executive Summary.

proportions makes the nursing shortage an even greater national concern, as well as an essential part of national preparedness and response planning

Nurses play a critical role as front-line, first-responders. When word of the devastation caused by Hurricanes Katrina and Rita reached nurses across the country, they immediately volunteered in American Red Cross shelters, medical clinics, and hospitals throughout that widespread region. Nurses and advanced practice registered nurses (e.g., nurse midwives, nurse practitioners, clinical nurse specialists, and certified registered nurse anesthetists) are particularly critical national resources in an emergency, able to provide clinical nursing care as well as primary care. During Katrina and Rita, nurse midwives delivered babies in airplane hangars, and nurses trained in geriatric care assisted in caring for those traumatized by their evacuation from the comforts of their homes, assisted living facilities, or nursing homes. Nurse practitioners diligently staffed temporary and permanent health care clinics to provide needed primary care to hurricane victims. Many nurses contributed not just through their clinical expertise, but also by offering psychological support as they listened to survivors recount their stories of pain and tragedy.

These stories seem particularly relevant in demonstrating the essential assistance nurses provide during tragedies, and reinforce the need to ensure an adequate supply of all types of nurses. Unless steps are taken now, the nation's ability to respond to disasters will be further hindered by the growing nursing shortage. An investment in the nursing workforce is a reasonable and cost-effective investment toward rebuilding the public health infrastructure and increasing our nation's health care readiness and emergency response capabilities.

The Funding Reality

Enacted in 2002, the ***Nurse Reinvestment Act*** (P.L. 107-205) addressed new and expanded initiatives, including loan forgiveness, scholarships, career ladder opportunities, and public service announcements to advance nursing as a career. Despite the enactment of this critical measure, HRSA fails to have the resources necessary to meet the current and growing demands for our nation's nursing workforce. The President's proposed budget for FY 2009 reduces overall funding of Title VIII by $46.1 million dollars, a 30% decrease compared to FY 2008. This cut is achieved by zeroing out funding for "Advanced Education Nursing." This funding cut, if implemented, will further diminish training and potentially jeopardizes the delivery of health care. Funding of all of the Title VIII programs make a difference. For example:

- **FY 2006 Nursing Education Loan Repayment Program:** Of the 4,222 applicants, 615 awards were made. This translates to 14.6 percent of applicants receiving awards.
- **FY 2007 Nursing Education Loan Repayment Program:** Whereas last fiscal year, only 12 percent of the 4,845 nursing student applications reviewed were awarded loans in this program (i.e., 586 applicant awards).

The ANSR Alliance requests that the Subcommittee provide a minimum of $200 million in FY 2009 to fund the Title VIII – Nursing Workforce Development Programs. We also urge the restoration of the Advanced Education Nursing program (Sec. 811) funded at a level on par with the proposed FY 2009 increase for the other Title VIII programs.

This funding can be used to restore the Advanced Education Nursing program and fund a higher rate of Nurse Education Loan Repayment and Nursing Scholarship applications, as well as implement other essential endeavors to sustain and boost our nation's nursing workforce. We thank you for considering our request.

Summary

Programmatic Area	Final FY 2008	President's Budget FY 2009	ANSR Alliance FY 2009 Request
Title VIII - Nursing Workforce Development Programs at HRSA	**$156,046,000**	**$109,853,000**	**$200,000,000**

Academy of Medical-Surgical Nurses
American Academy of Ambulatory Care Nursing
American Academy of Nurse Practitioners
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, Inc.
American College of Nurse Practitioners
American Society of Plastic Surgical Nurses
Association of periOperative Registered Nurses
Association of Rehabilitation Nurses
Association of Women's Health, Obstetric and Neonatal Nurses
Emergency Nurses Association
Infusion Nurses Society
International Society of Nurses in Genetics
National Association of Clinical Nurse Specialists
National Association of Neonatal Nurses
National Association of Nurse Massage Therapists
National Association of Nurse Practitioners in Women's Health
National Association of Orthopaedic Nurses
National Association of Pediatric Nurse Practitioners
National Association of Registered Nurse First Assistants
National Black Nurses Association
National Council of State Boards of Nursing
National League for Nursing
National Organization for Associate Degree Nursing
National Student Nurses' Association
Oncology Nursing Society
RN First Assistants Policy & Advocacy Coalition
Society of Urologic Nurses and Associates

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National League
for **Nursing**

Testimony Regarding Fiscal Year 2009 Appropriations for
Title VIII Nursing Workforce Development Programs
March 28, 2009

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 sole organization representing leaders in nursing education and nurse faculty across **all** the types of nursing programs in the United States. With more than 1,200 nursing schools and health care agencies, some 25,000 individual members comprising nurses, educators, administrators, public members, and 18 constituent leagues, the National League for Nursing is the premier organization – established 115 years ago – dedicated to excellence in nursing education that prepares the nursing workforce to meet the needs of our diverse populations in an ever-changing health care environment. The NLN appreciates the opportunity to discuss the status of nursing education and the damage that could ensue to patients and our nation's health care by the ill-considered cuts aimed at the Nursing Workforce Development Programs, authorized under Title VIII of the Public Health Service Act.

The NLN endorses the Subcommittee's past policy strategies for health care capacity-building via nursing education. We likewise respect your recognition of the requisite role nurses play in the delivery of cost-efficient health care services and the generation of quality health outcomes.

The National League for Nursing is disturbed, however, that the tenth-year and counting nursing shortage is outpacing the level of federal resources and investments that have been expended to help alleviate the nationwide nursing scarcity. The NLN is gravely concerned that the Administration's proposed FY 2009 appropriations for nursing education are inconsistent with the health care reality facing our nation. The President's budget proposes a funding decrease of $46.193 million (or 29.6 percent) for the Health Resources and Services Administration's (HRSA) Nursing Workforce Development Programs. This budget cut will diminish education and development, a shortsighted and hazardous course of action that potentially further jeopardizes the delivery of health care for the people in the United States. Thirty-five years ago in 1973, during another less serious nursing shortage, Congress appropriated nearly $161 million for nurse education programs. In today's dollars, that amount would be worth more than $742.8 million – 4.76 times the amount the federal government currently is spending on Title VIII programs.

The NLN contends that the federal strategy should be to broaden, not curtail, Title VIII initiatives by increasing investments to be consistent with national demand. We urge the Subcommittee to ***fund the Title VIII programs at a minimum level of $200 million for FY 2009.*** The NLN also advocates that Sec. 811 of Title VIII – ***Advanced Education Nursing Program – be restored and funded at an augmented level equal to the other Title VIII programs.***

NURSE SHORTAGE AFFECTED BY FACULTY SHORTAGE

The Subcommittee is well aware that today's nursing shortage is real and unique from any experienced in the past with an aging workforce and too few people entering the profession at the rate necessary to meet growing health care requirements. In its biennial 10-year employment projections for 2006-2016, the U.S. Department of Labor's Bureau of Labor Statistics (BLS) reported that during that 10-year period, the system is projected to generate 587,000 new registered nurses (RN) jobs, with hundreds of thousands of job openings resulting from the need to replace experienced nurses who will leave the occupation. BLS's model-based findings estimate that employment of RNs is expected to grow 23 percent from 2006 to 2016, a much faster rate than the average for all occupations. The NLN research provides evidence of a strong correlation between the inability of nursing programs to keep pace with the demand for new RNs and the shortage of nurse faculty. Without faculty to educate our future nurses, the shortage cannot be resolved.

The NLN's ***Nursing Data Review 2005-2006: Baccalaureate, Associate Degree, and Diploma Program*** revealed that applications to RN programs fell a notable 8.7 percent during 2005-06, down from a peak in applications a year earlier. The drop is suspected to be the result of "applicant discouragement" defined by the NLN as widespread awareness of the difficulty of gaining entry to nursing school, fueled by the continuing crippling shortage of nurse educators.

Despite the reduced number of applications, many factors indicate that opportunities to obtain a nursing education are still in short supply. Eighty-eight thousand (88,000) qualified applications – or one out of every three qualified applications submitted to nursing education programs this year – were denied due to lack of capacity. Baccalaureate degree programs turned away 20 percent of their applications, while associate degree programs turned away 32.7 percent.

On a positive front, the NLN's data show a marked increase in the percentage of graduating prelicensure students who are members of racial or ethnic minority groups, with the increase distributed across all racial and ethnic categories: Asians, African Americans, Hispanics, and American Indians. After three consecutive years in which the proportion of minorities entering the RN workforce stagnated at approximately 20 percent, the fraction of minority graduates jumped to 24.5 percent in 2006. Research increasingly links minority health disparities to a lack of cultural competence on the part of health care providers, who often differ from their patients with respect to racial-ethnic background. This concern has been particularly acute within the RN workforce where the percentage of minorities has been slow to increase, and only exceeded 10 percent in the last decade. Additionally, the percentage of men graduating from basic RN programs has exhibited a small but steady growth trend over the past three years, with men reaching just over 12.1 percent of graduates in 2006.

TRENDS STRESSING FACULTY SHORTAGE

The NLN's research, reported in its ***Nurse Educators 2006: A Report of the Faculty Census Survey of RN and Graduate Programs***, indicated that the nurse faculty vacancies in the United States continued to grow even as the numbers of full- and part-time educators increased. The estimated number of budgeted, unfilled, full-time positions countrywide in 2006 was 1,390. This number represents a 7.9 percent vacancy rate in baccalaureate and higher degree programs, which is an increase of 32 percent since 2002; and a 5.6 percent vacancy rate in associate degree programs, which translates to a 10 percent rise in the same period. It is not surprising that the problem of

nurse faculty vacancies often is described as acute and as exacerbating the national nurse-workforce shortfall.

The present nurse faculty staffing deficit is expected to intensify as the existing nurse educator workforce reaches retirement age. A ***2006 NLN/Carnegie Foundation Preparation for the Professions Program*** national survey of nurse educators found that fully one half of today's nurse faculty say they expect to retire within the next 10 years, while just over one in five (21 percent) expect to retire within the next five years. The NLN/Carnegie data also distinguished the nurse faculty cohort from the rest of the academic workforce by age: Where 48 percent of nurse educators are age 55 and over, only 35 percent of U.S. academics and only 29 percent of health science faculty are over the age of 54.

Salaries are a significant issue for recruitment and retention of nurse educators. The NLN/Carnegie study found that nurse faculty earn only 76 percent of the salary that faculty in other academic disciplines earn. Colleges and universities also are reporting that the nurse educator's compensation is not competitive with that of nurses in clinical settings. The NLN notes that although few data are available on salaries of nurses with doctorates, the U.S. Department of Health and Human Services ***Preliminary Findings: 2004 National Sample Survey of Registered Nurses (NSS-RN)*** data on salaries of master's-prepared nurses can be used to compare the competiveness of nurse faculty salaries. The NLN/Carnegie study reports "nurse faculty salaries (annualized to a 12-month calendar) rank only eighth among the 11 positions evaluated by the NSS-RN study. Not only are master's-prepared nurse faculty paid 33 percent less than nurse anesthetists, but they are also paid 17 percent less than head nurses and nurse midwives, and approximately 12 percent less than nurse practitioners and clinical nurse specialists with the same educational credentials."

Workload is another factor distinguishing nurse faculty from their peers. According to the NLN/Carnegie research, 90 percent of the nurse educators, responding to the survey, work full-time, many adding administrative duties to teaching responsibilities, resulting in a 56-hour average work week. In addition to their work inside their primary academic institutions (PAI), more than 62 percent of nurse faculty picked up work outside their PAI, averaging an additional day each week (7-10 hours). With 45 percent of nurse faculty reporting dissatisfaction with their current workload, "over one in four nurse educators who said they were likely to leave their current job cited the desire for reduced workload as a motivating factor."

Data also indicate that in large part the nurse faculty workforce is not reflective of the nation's population or of the nursing student population. The NLN/Carnegie study affirmed that 96 percent of the nurse faculty are female, contrasting with the three-fifths of the U.S. postsecondary faculty who are males. The 2006 NLN/Carnegie study reports that nursing also lags significantly behind the remainder of academia with respect to diversity. Seven percent of nurse educators are minorities while 16 percent of U.S. faculty belong to a racial minority group.

The homogeneity of the nurse faculty plays out as a unique capacity constraint, limiting nursing schools' ability to provide culturally appropriate health care education toward developing a health care system that understands and addresses the needs of the nation's rapidly diversifying population. Factors such as biases and stereotyping, communication barriers, cultural sensitivity/competence, and system and organizational determinants contribute to health care disparities, generating a compelling need for workforce diversity.

THE FEDERAL FUNDING REALITY

Today's undersized supply of appropriately prepared nurses and nursing faculty does not bode well for our nation, where the shortages are deepening health disparities, inflated costs, and poor quality health care outcomes. Congress moved in the right policy direction in passing the ***Nurse Reinvestment Act*** in 2002. That act helped develop Title VIII programs into a more comprehensive system of capacity-building strategies to develop nurses by providing schools of nursing with grants to strengthen activities, such as 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. Yet, as the HRSA Title VIII data show, it is abundantly clear that Congress must step up in providing critical attention and significantly more funding to this ongoing systemic problem.

Nursing Education Loan Repayment Program – In FY 2007, with 4,845 applicants to the Title VIII Nursing Education Loan Repayment Program, 586 awards were made, or 12 percent of applicants received awards. Whereas in FY 2006, of the 4,222 applicants to this program, 615 awards were made – translating to 14.6 percent of applicants receiving awards.

Nursing Scholarship Program – In FY 2007, only 173 students were awarded scholarships due to the program's funding capacity; versus a total of 218 awards in FY 2006.

Advanced Education Nursing (AEN) Program – This program supports the graduate education that is the foundation to professional development of advanced practice nurses, whether with clinical specialties or with a specialty in teaching. In FY 2007, AEN supported 16,092 graduate nursing students across the various specialties. The President's proposed FY 2009 budget eliminates this program, which is fundamental to appropriately preparing future nursing faculty, the engine of the workforce pipeline. AEN must be restored and fully funded in order to prevent the nation from losing ground in the effort to remedy the nurse and nurse faculty shortages.

As the only organization that collects data across all levels of the nursing education infrastructure, the NLN can state with authority that the nursing shortage in this country will not be reversed until the concurrent shortage of qualified nurse educators is addressed. Without adequate faculty, there are simply too few spots in nursing education programs to train all the qualified applicants out there. This challenge requires millions of dollars of increased funding for the professional development of nurses. The NLN urges Congress to ***strengthen existing Title VIII nurse education programs by funding them at a minimum level of $200 million for FY 2009; and to restore the Advanced Education Nursing program (Sec. 811) and fund it at an increased level equivalent to the other Title VIII Nursing Workforce Development Programs' proposed increase for FY 2009.***

Your support will help ensure that nurses exist in the future who are prepared and qualified to take care of you, your family, and all those in this country who will need our care.

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Presented by:

Gilda Ventresca-Ecroyd
Vice President of Government Affairs
New York University (NYU)
Medical Center

Subcommittee on Labor, Health and Human Services
Of the House Appropriations Committee

Regarding the NYU Medical Center' Emergency Preparedness Project and

The Fiscal Year (FY) 2009
Appropriations

March 27, 2008

Mr. Chairman and Members of the Subcommittee, thank you for providing this opportunity to submit testimony on the Labor, HHS Appropriations bill for FY 2009. I am Gilda Ventresca-Ecroyd, Vice President for Government Affairs at the NYU Medical Center.

The NYU Medical Center strongly supports substantial increases in funding for biomedical research under the National Institutes of Health (NIH). The NIH has experienced almost flat funding over the past several years and this has negatively impacted biomedical research in this country. Many scientists, especially young scientists, are going unfunded or underfunded. If the situation is not rectified soon, many of these scientists will have to leave the laboratory entirely. New, innovative research that could save lives will suffer and so will the patients who might have benefitted from new discoveries. The NIH must have a substantial cost of living increase over the next four years in order to provide a stable environment for research.

We also encourage the Subcommittee to restore Title VII Health Professions funding to its FY 2005 levels in order to support key federal programs for minority medical education and programs such as NYU's Primary Care Resident initiative that may soon no longer be funded because of lack of funding to renew programs.

In addition, the NYU Medical Center respectfully requests $2 million for information technology, security and equipment needs for the Emergency Department and other emergency preparedness needs to be included in the Labor, HHS Appropriation Bill, Health Resources Services Administration account for FY 2009. The total project cost is estimated to be approximately $55 million.

The Emergency Department provides compassionate, dignified, state-of-the-art emergency care, regardless of insurance coverage, socioeconomic status, native language, literacy or disability. Each of our faculty physicians is board-certified or board eligible in the clinical specialty of emergency medicine. Many are also board certified in clinical toxicology. In addition, our coordinated multi-hospital disaster preparedness efforts form a critical part of the safety net for New York City. The NYU Medical Center has one of the highest case mix indices (acuity) in the State of New York. The Geriatric cardiovascular, neurological, hematological, pediatric and transplantation-related emergencies are common.

This project is designed to improve the emergency preparedness needs across the NYU Medical Center, particularly in the Emergency Department. These facility improvements are necessary in order to be prepared for a national disaster, local emergency or public health situation involving Lower Manhattan. This project includes a major construction initiative that will enhance the space capacity of the Emergency Department. As a part of the program, there is an extraordinary need for equipment to be used in the diagnostic and treatment of our patients. This project also includes information and communication technology that will allow us to be more responsive to the needs of our patients, physicians and staff. Ancillary services and technology needs in related departments must also be addressed. Some of these departments include:

Radiology, Laboratory, Pathology, and Operating Rooms. Mechanical systems will need to be upgraded, including sprinklers, fire alarms, nurse calls, lighting, information technology cabling for medical gasses (oxygen) suction and medical air. A new trauma room with all the necessary equipment is also planned.

Thank you for your interest in support for biomedical research, the NIH, Title VII Health Professions and Emergency Preparedness at the NYU Medical Center.

Testimony Submitted on behalf of the Friends of CDC

Kent "Oz" Nelson, Retired Chair and CEO of United Parcel Service and the Co-Chair of the Friends of CDC

March 31, 2008

Chairman Obey, Representative Walsh, and members of the Subcommittee, thank you for the opportunity to submit testimony on behalf of the Friends of CDC to discuss infrastructure funding for the Centers for Disease Control and Prevention (CDC) in the FY2009 budget. My name is Oz Nelson, and I am the Retired Chair and CEO of United Parcel Service and the Co-Chair of the Friends of CDC.

I would like to begin my testimony by offering sincere thanks on behalf of the Friends of CDC for the efforts of the Subcommittee in securing funding for CDC Buildings and Facilities in the FY2009 Labor, Health and Human Services Appropriations Bill. We are extremely grateful for your commitment to this important effort.

Before I tell you more about the condition of the CDC and the need for continued Congressional action, I would like to tell you why I am involved in this effort and about the Friends of CDC. Following a 1999 CEO tour of several of CDC's totally inadequate labs and office facilities, the Corporate Friends of CDC was organized for the sole purpose of highlighting the need for infrastructure funding for the Centers for Disease Control at its two Atlanta-based campuses. This group currently includes AT&T, United Parcel Service, GE Power Systems, The Home Depot, Inc., Cox Enterprises, Inc, Southern Company, Theragenics Corporation, and HCA. It is a voluntary, civic minded group deeply concerned that the facilities at the nation's premier public health institution could be allowed to deteriorate to the point they were when this endeavor began.

Since their formation in 1999, the Friends have advocated with officials at CDC, HHS, OMB and Congress for full and timely funding of the CDC Buildings and Facilities Master Plan. During the last eight years Congress has appropriated $1.4 billion towards the Master Plan, resulting in an historic and far-reaching construction project that has changed the face of CDC. But the job is not yet complete. The total cost of the Master Plan is $1.7 billion and to that end we are requesting $250 million in the FY2009 budget for improving CDC buildings and facilities.

As you know, the range of CDC's assignments has grown tremendously over the past decade. The CDC is on the front lines of defense protecting the health of every American because of its ability to identify, classify, and recommend courses of action in dealing with a potential biological, radiological, or chemical attack in the United States or around the world. This being said, several of the CDC facilities still do not offer a sufficient level of security or an adequate support structure to CDC's scientists.

Since CDC began executing the Master Plan, a series of threats to the nation's health and security have emerged, ranging from terrorist attacks, to the rapid spread of the West Nile Virus, to the emergence of SARS, Avian Flu, Marburg Virus, and monkeypox. These threats continue

to challenge CDC's capacity and plainly illustrate the need for additional funding to accelerate the CDC=s Master Plan and enable the CDC to be better prepared and capable of responding to the range of public emergencies which the United States is likely to face in the coming years.

In addition to infectious diseases, CDC works on preventing chronic diseases such as cardiovascular disease, cancer, and diabetes. Other areas of CDC's activities include maximizing the immunization rates of children and adults; preventing a wide range of environmental diseases by preventing exposure to toxic chemicals; conducting examinations and surveys to produce data on the health of Americans; preventing and controlling injuries; protecting employees from workplace injuries and diseases; and the training of public health and other health care workers throughout the country.

Thanks to your support, CDC is making substantial progress in implementing the Ten-Year Master Plan for buildings and facilities for the Atlanta-based portion of the Centers for Disease Control and Prevention. In addition, progress has been made on both the Edward R. Roybal Campus near Emory University and the Chamblee Campus in construction of new labs and support buildings, upgrades to physical security, and upgrades to vital campus infrastructure such as electrical power and water.

The remaining funds needed by CDC to complete the Master Plan would be devoted to the following projects. CDC has entered into the planning phase for the construction of Buildings 24, 107, and 108. These Research Support Facilities will play an important role in allowing the CDC to accomplish its goal of providing adequate facilities for its workforce. As a result of these capital improvements, the agency will be better equipped to achieve its overarching goal of protecting the nation's public health.

Building 24, which will be located on the CDC's Roybal Campus, will be occupied by non-laboratory staff from the CDC's Coordinating Center for Infectious Diseases (CCID). With a cost of approximately $134 million, of which $63 million has been appropriated to date, this facility will primarily consist of office space for 1,100 occupants. Additionally, this facility will replace existing non-laboratory space currently being utilized by CCID staff on the Roybal Campus.

Buildings 107 and 108, which will be one project, will be located on the CDC's Chamblee Campus and be occupied by staff from the Coordinating Center for Health Promotion (CoCHP), which includes the National Center for Birth Defects and Developmental Disabilities (NCBDDD), the National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP), and the Office of Genomics and Disease Prevention. With a similar design to the Environmental Health Facility (Building 106), these research support facilities will be one joint project with a total cost of approximately $254 million to complete. No money has been appropriated to date for these buildings. When completed, the buildings will also house approximately 2,200 occupants, all of which are currently located in leased office space. This is critically important in allowing the agency to successfully consolidate many of its staff members from leased space into secure, CDC-owned facilities.

The investment in these facilities is critical to assuring that CDC scientists are physically and logistically equipped to protect our businesses and our families from the growing threats of terrorism and emerging diseases over the coming decades. **The Friends of CDC respectfully request $250 million in fiscal year 2009** to insure that the CDC is better prepared to face its current and prospective public health challenges.

Thank you for the opportunity to submit testimony on behalf of the Friends of CDC.

Testimony Submitted on behalf of the Association of University Programs in Occupational Health and Safety (AUPOHS)

Kent Oestenstad, Ph.D.
Associate Professor and Director, Deep South Center for Occupational Health and Safety
President, Association of University Programs in Occupational Health and Safety

March 31, 2008

Thank you for the opportunity to submit testimony to the Subcommittee in support of funding for the National Institute for Occupational Safety and Health (NIOSH) and for the NIOSH-funded Education and Research Centers (ERCs). My name is Dr. Kent Oestenstad. I am the director of the Deep South Center for Occupational Health and Safety located at the University of Alabama at Birmingham.

I am testifying on behalf of the Association of University Programs in Occupational Health and Safety (AUPOHS), an organization that represents 17 multi-disciplinary, university-based Education and Research Centers (ERCs) which are funded by NIOSH, the federal agency responsible for providing education and training for the prevention of work-related injuries and illnesses. The ERCs are regional resources for all parties involved with occupational health and safety – industry, labor, government, academia, and the general public. ERCs play the following roles in helping the nation reduce losses associated with work-related illnesses and injuries:

- Prevention Research: Developing the basic knowledge and associated technologies to prevent work-related illnesses and injuries.
- Professional Training: Graduate degree programs in Occupational Medicine, Occupational Health Nursing, Safety Engineering, Industrial Hygiene, and other related fields to provide qualified professionals in essential disciplines.
- Research Training: Preparing doctoral-trained scientists who will respond to future research challenges and who will prepare the next generation of occupational health and safety professionals.
- Continuing Education: Short courses designed to enhance professional skills and maintain professional certification for those who are currently practicing in occupational health and safety disciplines. These courses are delivered throughout the regions of the 17 ERCs as well as through distance learning technologies.
- Regional Outreach: Responding to specific requests from local employers and workers on issues related to occupational health and safety.

The Scope of the Problem of Occupational Injury and Illnesses

The many causes of occupational injury and illness represent a striking burden on America's health and well-being. Yet, despite significant improvements in workplace safety and health over the last several decades:

- Each day, an average of 9,000 U.S. workers sustain disabling injuries on the job, 16

workers die from an injury suffered at work, and 137 workers die from work-related diseases.

- In 2005, more than 4.2 million workers sustained work-related injuries and illnesses in the private sector alone.

- The Liberty Mutual 2005 Workplace Safety Index estimates that employers spent $50.8 billion in 2003 on wage payments and medical care for workers hurt on the job; the indirect costs exceeded $200 billion.

This is an especially tragic situation because **most work-related fatalities, injuries and illnesses are preventable** with effective, professionally directed, health and safety programs.

Here are some of the important issues that NIOSH deals with:

- When the Senate office buildings were attacked with anthrax, NIOSH and ERC professionals responded.

- NIOSH, helped by ERCs, took a lead role in protecting the safety of 9/11 emergency responders in New York City and Virginia.

- We are now seeing serious health problems in the workers who were at Ground Zero. NIOSH and the New York - New Jersey ERC are playing the major lead in their medical follow-up.

- NIOSH is the leading federal agency conducting research and providing guidance on the worker health implications in the emerging field of nanotechnology.

We need manpower to address the sorts of issues mentioned above and it is the NIOSH ERCs that produce the graduates who fill key positions in health and safety programs, regionally and around the nation. And because ERCs provide training that is multi-disciplinary, ERC graduates protect workers in virtually every walk of life. Despite the recognized success of the ERCs in training such qualified professionals, the country continues to have ongoing shortages.

Furthermore, we do not live in a static environment. The rapidly changing workplace continues to present new health risks to American workers that need to be addressed through occupational safety and health research. For example, between 2000 and 2015, the number of workers 55 years and older will increase 72 percent to over 31 million. Work related injury and fatality rates begin increasing at age 45, with rates for workers 65 years and older nearly three times as high as the average for all workers.

In addition to factors that increasingly affect the vulnerability of our workers, we constantly face new threats to worker health. As an example, one of the greatest concerns regarding a potential outbreak of avian influenza is the drastic effect it may have on our workforce. The protection of health care workers in particular will become a major priority if we are to protect our population.

Despite being the primary federal agency for occupational disease and injury prevention in the nation, NIOSH receives only about one dollar per worker per year for its mission of research, professional education, and outreach.

Homeland Security

The heightened awareness of terrorist threats, and the increased responsibilities of first responders and other homeland security professionals, illustrates the need for strengthened workplace health and safety in the ongoing war on terror. The NIOSH ERCs play a crucial role in preparing occupational safety and health professionals to identify and ameliorate vulnerabilities to terrorist attacks and other workplace hazards and increase readiness to respond to biological, chemical, or radiological attacks.

Thanks to the Subcommittee's support for occupational health and safety research, NIOSH developed more effective methods to test for anthrax contamination in congressional offices. These procedures were quickly adopted by the Coast Guard, the FBI, and government building contractors. More recently, in response to ongoing safety concerns regarding the tunnels under the U.S. Capitol Complex, NIOSH was asked to evaluate health hazards in the tunnels for workers who maintain the plumbing that provides steam and chilled water to Congress, the Library of Congress, the Supreme Court and other federal buildings.

In addition, occupational health and safety professionals have worked for several years with emergency response teams to minimize losses in the event of a disaster. NIOSH took a lead role in protecting the safety of 9/11 emergency responders in New York City and Virginia, with ERC-trained professionals applying their technical expertise to meet immediate protective needs and conducting ongoing activities to safeguard the health of clean-up workers. Additionally, NIOSH is now administering $81 million in grants to provide health screening of World Trade Center responders. Included in the grantees is the New York - New Jersey ERC.

In the face of the growing concerns surrounding homeland security, ERCs have rapidly upgraded research coordination and expanded training opportunities, including sponsoring national and regional forums on response to bioterrorism and other disasters.

The Need for Occupational Safety and Health Manpower

The NIOSH ERCs were reviewed by the DHHS Office of the Inspector General in 1995. The resulting report affirmed the efficacy of the ERCs in producing graduates who pursue careers in occupational safety and health. Since the ERCs are regional, they are ready to respond to various trends in industries throughout the country. In the southeast, for example, automobile manufacturing has been the major growth industry since 2000. Alabama now has major facilities for Mercedes, Honda and Hyundai that employ thousands of workers. Graduates from the Deep South Education and Research Center (University of Alabama at Birmingham and Auburn University) fill key positions in the safety, health and environmental programs at all of these facilities. And because they provide training that is multi-disciplinary, ERCs graduate professionals can protect workers in virtually every walk of life. Despite the recognized success of the ERCs in training qualified occupational health and safety professionals, the country

continues to have ongoing shortages. The manpower needs are especially acute for doctoral-level trained professionals who can conduct research and help in implementing the National Occupational Research Agenda (NORA).

In May 2000, the Institute of Medicine issued its final report on the education and training needs for occupational safety and health professionals in the United States. This report concluded that "the continuing burden of largely preventable occupational diseases and injuries and the lack of adequate occupational safety and health services in most small and many larger workplaces indicate a clear need for more occupational safety and health professionals at all levels." Specific needs identified by the IOM report include:

- An insufficient number of doctoral-level graduates in occupational safety, thus limiting the nation's capacity to perform essential research and training in traumatic injury prevention.

- An inability to attract physicians and nurses into formal occupational safety and health academic training programs, thus limiting the resources needed to deliver occupational health services.

ERCs are accomplishing the critical mission of filling these gaps by preparing expert researchers and practitioners in occupational safety and health.

Recommendation for Fiscal Year 2009
In fiscal year 2009 AUPOHS requests a $50 million increase for NIOSH over the fiscal year 2008 appropriated level, and within that increase, not less than a $5 million increase for Education and Research Centers (ERCs).

A $50 million increase would enable NIOSH to keep pace with the changing nature of work and ensure that research and education to prevent work-related disease and injuries remain a high priority. Given that much of NIOSH's extramural research program is carried out by the Education and Research Centers (ERCs), sustaining the academic infrastructure provided by the ERCs is essential. Our recommendation would ensure that our nation's universities have the capacity and manpower to implement these initiatives and expand training programs to improve the health and productivity of American workers.

The ERCs play an essential role in preventive health research and the training of occupational safety and health professionals, many of which are in short supply. The 17 ERCs are distributed throughout the U.S. and have a critical community outreach function, as well as serve as local resources of occupational safety and health expertise. A $5 million increase will bring the total budget for the 17 ERCs to $26.4 million and promote achievement of the NIOSH strategic goal to increase the technical proficiency of the occupational safety and health professionals who lead occupational safety and health practice in both the private and public sectors.

Thank you for the opportunity to report the great need for research and training in occupational safety and health.

NIOSH-supported Education and Research Centers (ERCs)

Deep South Education and Research Center (Univ. Alabama at Birmingham/Auburn University)
Colorado Education and Research Center (University of Colorado at Denver)
Northern California Education and Research Center (UC Berkeley, UCSF)
Southern California Education and Research Center (UCLA and UC Irvine)
University of Cincinnati Education and Research Center
Harvard Education and Research Center
Johns Hopkins Education and Research Center
New York /New Jersey Education and Research Center
Southwest Center for Occupational and Environmental Health (University of Texas)
Illinois Education and Research Center (University of Illinois at Chicago)
Heartland Center for Occupational Health and Safety (University of Iowa)
Michigan Education and Research Center (University of Michigan)
Midwest Center for Occupational Health and Safety (University of Minnesota)
North Carolina Occupational Safety and Health ERC
Sunshine ERC (University of South Florida)
Rocky Mountain Center for Occupational and Environmental Health (University of Utah)
Northwest Center for Occupational Health and Safety (University of Washington)

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

Karen Peluso, Executive Director, Neurofibromatosis, Inc., Northeast
Susan Johnson, President, Texas Neurofibromatosis Foundation

March 31, 2008

Thank you for the opportunity to present testimony to the Subcommittee on the importance of continued funding at the National Institutes of Health (NIH) for Neurofibromatosis (NF), a terrible genetic disorder closely linked to cancer, learning disabilities, heart disease, memory loss, brain tumors, and other disorders affecting up to 175 million Americans in this generation alone. Thanks in large measure to this Subcommittee's strong and enduring support, scientists have made enormous progress since the discovery of the NF1 gene in 1990 resulting in clinical trials now being undertaken at NIH with broad implications for the general population.

On behalf of Neurofibromatosis, Inc., Northeast and the Texas Neurofibromatosis Foundation, both participants in a national coalition of NF advocacy groups, we speak on behalf of the 100,000 Americans who suffer from NF as well as approximately 175 million Americans who suffer from diseases linked to NF such as cancer, brain tumors, heart disease, memory loss and learning disabilities.

What is Neurofibromatosis (NF)?
NF is a genetic disorder involving the uncontrolled growth of tumors along the nervous system which can result in terrible disfigurement, deformity, deafness, blindness, brain tumors, cancer, and/or death. NF can also cause other abnormalities such as unsightly benign tumors across the entire body and bone deformities. In addition, approximately one-half of children with NF suffer from learning disabilities. While not all NF patients suffer from the most severe symptoms, all NF patients and their families live with the uncertainty of not knowing whether they will be seriously affected because NF is a highly variable and progressive disease.

NF is not rare. It is three times more common than Multiple Sclerosis (MS) and Cystic Fibrosis combined, but is not widely known because it has been poorly diagnosed for many years. Approximately 100,000 Americans have NF, and it appears in approximately one in every 3,000 births. It strikes worldwide, without regard to gender, race or ethnicity. Approximately 50 percent of new NF cases result from a spontaneous mutation in an individual's genes, and 50 percent are inherited. There are two types of NF: NF1, which is more common, and NF2, which primarily involves tumors causing deafness and balance problems. In addition, advances in NF research stand to benefit over 175 million Americans in this generation alone because NF, the most common neurological disorder caused by a single gene, is directly linked to many of the most common diseases affecting the general population.

If a child was diagnosed with NF it would mean tumors could grow anytime, anywhere on his/her nervous system, from the day he/she was born until the day he/she died with no way to predict when or how severely the tumors would affect his/her body - and no viable way to treat the disease outside of surgery - which often results in more tumors that grow twice as fast. That

same child would then have a 50% chance to pass the gene to his/her children. That's an overwhelming diagnosis and it bears repeating: NF is one of the most common genetic disorders in our country and has no cure and no viable treatment. But that is changing. The immediate future holds real promise.

Link to Other Illnesses
Researchers have determined that NF is closely linked to cancer, heart disease, learning disabilities, memory loss, brain tumors, and other disorders including deafness, blindness and orthopedic disorders.

Cancer – Research has demonstrated that NF's tumor suppressor protein, neurofibromin, inhibits RAS, one of the major malignancy causing growth proteins involved in 30 percent of all cancer. Accordingly, advances in NF research may well lead to treatments and cures not only for NF patients but for all those who suffer from cancer and tumor-related disorders. Similar studies have also linked epidermal growth factor receptor (EGF-R) to malignant peripheral nerve sheath tumors (MPNSTs), a form of cancer which disproportionately strikes NF patients.

Heart disease – Researchers have demonstrated that mice completely lacking in NF1 have congenital heart disease that involves the endocardial cushions which form in the valves of the heart. This is because the same *ras* involved in cancer also causes heart valves to close. Neurofibromin, the protein produced by a normal NF1 gene, suppresses *ras*, thus opening up the heart valve. Promising new research has also connected NF1 to cells lining the blood vessels of the heart, with implications for other vascular disorders including hypertension, which affects approximately 50 million Americans. Researchers believe that further understanding of how an NF1 deficiency leads to heart disease may help to unravel molecular pathways affected in genetic and environmental causes of heart disease.

Learning disabilities – Learning disabilities are the most common neurological complication in children with NF1. Research aimed at rescuing learning deficits in children with NF could open the door to treatments affecting 35 million Americans and 5 percent of the world's population who also suffer from learning disabilities. Leading researchers have already rescued learning deficits in both mice and fruit flies with NF1 with a number of drugs, and clinical trials have now been approved by the FDA. This NF research could potentially save federal, state, and local governments, as well as school districts billions of dollars annually in special education costs resulting from a treatment for learning disabilities.

Memory Loss – Researchers have also determined that NF is closely linked to memory loss and are now investigating conducting clinical trials with drugs that may not only cure NF's cognitive disorders but also result in treating memory loss as well with enormous implications for patients who suffer from Alzheimer's disease and other dementias.

Deafness – NF2 accounts for approximately 5 percent of genetic forms of deafness. It is also related to other types of tumors, including schwannomas and meningiomas, as well as being a major cause of balance problems.

Autism – While there is no firm scientific evidence at this point, some published studies have

shown, and leading researchers have stated, that there is reason to believe there is an implication between NF and Autism.

Scientific Advances
Thanks in large measure to this Subcommittee's support; scientists have made enormous progress since the discovery of the NF1 gene in 1990. Major advances in just the past few years have ushered in an exciting era of clinical and translational research in NF with broad implications for the general population.

These recent advances have included:

- Phase II and Phase III clinical trials involving new drug therapies;
- Creation of a National Clinical Trials Consortia and NF Centers;
- Successfully eliminating tumors in NF1 and NF2 mice with the same drug;
- Developing advanced mouse models showing human symptoms;
- Rescuing learning deficits and eliminating tumors in mice with the same drug;
- Linking NF to vascular disorders such as congenital heart disease and hypertension, affecting more than 50 million Americans; and
- Conducting natural history studies to analyze the progression of the disease.

Future Directions
NF research has now advanced to the translational and clinical stages which hold incredible promise for NF patients, as well as for patients who suffer from many of the diseases linked to NF. This research is costly and will require an increased commitment on the federal level. Specifically, future investment in the following areas would continue to advance research on NF:

- Clinical trials;
- Funding of a clinical trials network to connect patients with experimental therapies;
- DNA Analysis of NF tissues;
- Development of NF Centers, tissue banks, and patient registries;
- Development of new drug and genetic therapies;
- Further development of advanced animal models;
- Expansion of biochemical research on the functions of the NF gene and discovery of new targets for drug therapy; and
- Natural history studies and identification of modifier genes – studies are already underway to provide a baseline for testing potential therapies and differentiate among different phenotypes of NF.

Congressional support for NF research
The enormous promise of NF research – and its potential to benefit over 175 million Americans in this generation alone – has gained increased recognition from Congress and the NIH. This is evidenced by the fact that six institutes at NIH are currently supporting NF research (NCI, NHLBI, NINDS, NIDCD, NHGRI, AND NCRR), and NIH's total research portfolio has increased from $3 million in FY1990 to $15 million in FY 2008. However, we are concerned that the NF research portfolio at NIH has declined by several million dollars in recent years

(FY05 $17.5 million, FY06 $16 million, FY07 $15.8 million, FY08 $15.4 million), despite appropriations report language recommending a greater investment. Given the potential offered by NF research for progress against a range of diseases, we are hopeful that NIH will substantially increase NF research funding.

We appreciate the Subcommittee's strong support for NF research and will continue to work with you to ensure that opportunities for major advances in NF research are aggressively pursued.

Thank you again for the opportunity to tell you of the progress and potential of NF research.

Testimony of William E. Kiernan, Ph.D., President
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Testimony Regarding FY 2009 Appropriations
Labor, Health and Human Services, Education Subcommittee
March 31, 2008

Mr. Chairman, on behalf of the Association of University Centers on Disabilities (AUCD), I am pleased to submit this written testimony for the record both as a means to thank you for the Committee's support of our Centers over the past several years, and as a way of alerting you to the exciting developments happening now across the national network of University Centers for Excellence in Developmental Disabilities, Education, Research and Service (UCEDDs) and Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Programs. The network of UCEDDs and LENDs is a showcase for unique and effective models for gathering new knowledge in the field of developmental disabilities and applying this knowledge both nationally and internationally, as well as in our own states, to improve the lives of people with developmental and other disabilities. I am William Kiernan, PhD, Director of the Institute for Community Inclusion, the University Centers for Excellence in Developmental Disabilities at the University of Massachusetts. I am submitting this testimony in my role as President of the AUCD Board of Directors.

First, let me describe the UCEDDs, one of the member networks of AUCD. The mission of the UCEDDs is to work with people with disabilities, members of their families, state and local government agencies, and community providers to provide training, technical assistance, service, research, and information sharing, with a focus on building the capacity of communities to sustain all their citizens to fully participate in the social and economic life of their communities.

Since the early 1960s, when Congress established a small number of research centers to study mental retardation, UCEDDs have grown into a national network of 67 Centers where each has developed its own area(s) of expertise based on the needs of the local community, state, and the evolving expectations of people with disabilities nationwide to be more included in community life. Authorized by the Developmental Disabilities Assistance and Bill of Rights Act (P.L. 106-402) UCEDDs currently focus on serving as a national education, service, research, and information dissemination resource for our nation. The DD Act mandates that UCEDDs promote opportunities for individuals with developmental disabilities to exercise self-determination, and be independent, productive, integrated and included in all facets of community life. The UCEDDs meet these objectives by conducting research, providing training and technical assistance, and providing exemplary evidence-based direct services and supports to people with developmental disabilities, their families, and communities. This includes state-of-the-art diagnosis and evaluation as well as support services for children and adults in a wide range of areas including health, cognitive and behavioral development, education, daily living, and employment.

Congress's investment in this valuable and effective network has been instrumental to the inclusion of people with disabilities in American communities. AUCD urges the Congress to provide sufficient funds to continue to take advantage of this highly efficient and productive national network to address emerging critical national needs, such as the alarming numbers of individuals diagnosed with Autism Spectrum Disorders. Nearly every UCEDD program is currently providing autism-related services to some degree, including direct services, research and evaluation, information, technical assistance, and/or interdisciplinary training of professionals. However, the potential of the UCEDD network to provide additional autism-related supports has only begun to be tapped.

We also need to address our nation's racial and ethnic health and mental health disparities as well as inequities in access to services and supports related to minority populations. It is well-documented that children and adults with developmental disabilities experience poorer health and more difficulty finding and paying for health care compared with other populations. Therefore, our network proposes to partner with Minority Serving Institutions which would increase our focus on research, education and services for African Americans, Hispanic Americans, Native Americans, Pacific Islander and Asian Americans. Each of these populations has unique cultural issues including language, customs, and traditions that must be considered as well as different levels of incidence and prevalence of diseases and disabilities that must be studied in order to better serve these populations. With assistance from existing UCEDDs, institutions of higher education that serve minority populations would be well positioned to train future leaders, conduct the necessary research and disseminate pertinent and culturally relevant information targeted to these populations.

We are respectfully seeking an appropriation of $41,000,000 under the ACF/DD program for University Centers for Excellence in Developmental Disabilities (a $4 million increase) which would allow up to four capacity-building grants of $250,000 to enable up to four UCEDDs to work in partnership with collaborating Minority Serving Institutions (as defined in the Higher Education Act) to focus on research, health, education, and services for African Americans, Hispanic Americans, Native Americans, Pacific Islanders, Asian Americans, and other ethnically and culturally diverse populations. The increase would also help UCEDDs address critical, emerging national needs, such as the growing number of individuals with Autism Spectrum Disorders and related neurodevelopmental disorders; allow the Administration on Developmental Disabilities to expand National Training Initiative grants; and provide for a cost-of-living increase to the Centers.

Now I will address the Leadership Education in Neurodevelopmental and Related Disabilities programs. LEND programs are improving the health status of infants, children and adolescents with or at risk for neurodevelopmental and related disabilities and their families. This is accomplished through the interdisciplinary training of professionals for leadership roles in the provision of health and related care, continuing education, technical assistance, research, and consultation. The LEND program focuses on the special health care needs of children with a wide range of neurodevelopmental, metabolic, and genetic disorders, including autism spectrum disorder. Currently, there are 34 LENDs in 27 states and D.C. All LEND programs operate within a university system and most have collaborative arrangements with local university hospitals, children's hospitals, and/or health care centers. Each LEND receives core funding

from the Maternal and Child Health Bureau of the Health Resources and Services Administration of the U.S. Department of Health and Human Services.

In 2006, Congress passed and the President signed the Combating Autism Act (PL 109-416) authorizing the Secretary to expand existing and develop new LENDs in states that do not have such a program. The intent of Congress was to provide autism spectrum disorder-related training in each of the existing 34 programs directed to developmental pediatricians, clinical psychologists, and other diagnosticians and interventionists. In states that do not have a LEND program, Congress intended to provide funding to establish such programs. The $5.4 million appropriated for FY 2008 as part of the Autism and Other Developmental Disorders within HRSA begins this expansion by providing funds to expand up to one-half of the existing LEND programs for this purpose and adding up to four new LEND programs in states that do not currently have one.

Therefore, we are respectfully seeking an increase in funding that is specifically set aside for LEND programs to $26,200,000 (a $2 million increase) for the LEND program within the HRSA Autism and Other Developmental Disorders program. This additional funding will enhance the capacity of up to five more of the existing LEND programs to expand their training of professionals in the interdisciplinary care and treatment of children with autism spectrum disorder and related neurodevelopmental disabilities as well as provide funds to develop up to two new LEND programs in states that do not have one. This $2 million would be part of the $42 million authorized for HRSA activities in FY 2009 under the Combating Autism Act.

As I have stated, the UCEDD and LEND networks engage in education and training at the university and community level, conduct translational and applied research, and offer services to individuals and families. Please allow me this opportunity to provide you with some examples.

Education – Quality of life in the community for individuals with disabilities depends upon well-trained professionals. Positioned within the university, LEND and UCEDD programs provided interdisciplinary education to professionals-in-training and provide continuing education for professionals practicing in multiple fields relating to disabilities. Whether the focus is on leadership, direct service, family centered care, advocacy, cultural competence, clinical or administrative personnel training, these pre-service and continuing education programs are geared to the needs of students, fellows, practicing professionals, and families and have been essential in raising and defining the educational standards of service across health, education, employment, and social service systems. Each year, UCEDDs and LENDs collectively provide education and training to approximately 500,000 health, education, mental health, and policy-making professionals, as well as people with disabilities and their families. UCEDDs and LENDs in communities nationwide provide this essential education and training.

One UCEDD in Oregon houses the Center on Positive Behavioral Intervention and Support. The Center assists local schools in identifying, adapting, and sustaining effective behavioral practices, including school-wide discipline programs. Results from their replication efforts in over 400 schools nationwide indicate that their technical assistance and research has enhanced

schools' capacity to address behavioral challenges, diminish disruptions, reclaim instructional time, and enhance quality and effectiveness of instruction.

Research – UCEDDs engage in cutting edge research on a wide variety of issues related to individuals with developmental disabilities and their families. By studying areas such as brain development, autism spectrum disorders, and early literacy, UCEDD researchers are learning how children and adults learn and how best to teach them. UCEDDs lead in developing and evaluating new ideas and promising practices that improve the lives of children and adults with disabilities and their families and increase their access to quality services. Many participate in federally established research projects on the causes and prevention of disabilities and chronic conditions. UCEDDs and LENDs also translate research into practice through the development and dissemination of informative products. The network operated 1,064 projects with a research component and produced 6,020 products in 2007.

The University Center for Excellence in Wisconsin is working to develop research to practice in the area of autism spectrum disorders. The Early Autism and Communication Research Clinic (EACRC), provides developmental, communication, and diagnostic evaluation services to children between ages 2 and 3 years old who have been diagnosed or are suspected to be on the autism spectrum and who participate in the Toddler Talk Project. The Wisconsin Center also has a project to develop a National Medical Home Initiative on Autism. The Initiative will serve as a model that demonstrates and promotes how the principles of the medical home can be applied to achieve early identification and intervention for children with ASD, with an additional benefit to show how the approach can assist in the developmental surveillance of all children, and thereby increasing the identification of children with other developmental delays.

Training – LEND programs train interdisciplinary professionals for leadership roles in the provision of health and related care, continuing education, technical assistance, research and consultation.

The UCEDD at University of Southern California (USC) at Children's Hospital Los Angeles is developing a model training program for medical providers when counseling families of children with Down Syndrome. The UCEDD at USC has also recently developed a Planning Guide for Dental Professionals Serving Children with Special Health Care Needs. The Planning guide is available online and includes the following five sections: preparations for dental visits; oral assessment and prevention; specialized treatments techniques; indicators of quality dental care; and linking with community resources.

UCEDDS have extensive and reciprocal collaborative relationships with state agencies that work with individuals with developmental disabilities. In a 2007 survey, a substantial percentage of Centers reported having working arrangements with their state MR/DD agency to provide training and technical assistance to state employees, Part C early intervention providers, and providers of adult services in the areas of person-centered planning, positive behavioral supports, employment supports, family support, communication, and abuse/neglect. The Institute for Community Inclusion, the Massachusetts UCEDD, is supporting the State Employment Leadership Network with now 18 state MR/DD agencies belonging and working on increasing employment options for consumer that are served by those agencies in their respective states.

Service – UCEDDs and LENDs provide direct services and supports to people with developmental and other disabilities, their families, and communities. This includes state-of-the-art diagnosis and evaluation as well as support services for children and adults in a wide range of areas including health, cognitive and behavioral development, education, daily living, and employment. Moreover, through technical assistance to other providers, they magnify the impact of their programs, reducing disparities among individuals and communities. In FY 2007, the AUCD network of centers and programs provided clinical services to 11,294 individuals and made 144,697 consults.

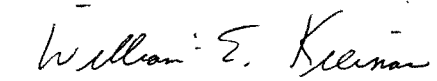
In Ohio, the UCEDD and LEND work in partnership with families living in rural counties of Ohio who encounter many barriers to accessing quality care for their children. Because most services for children with disabilities are in urban areas, families in Appalachia were traveling 100 miles to the city for multiple evaluations by individual disciplines. This resulted in a great expense in time and money for the family. The Center now sends teams of providers to rural areas to provide interdisciplinary care to families. They provide evaluation of children, training for local healthcare providers, and support for the families through a system of rural clinics. These clinics are improving access of needed services to families and providers and help local providers to better diagnose developmental disabilities such as cerebral palsy, fetal alcohol syndrome, autism and other genetic disorders.

Responding to National Needs – UCEDDs and LENDs are equipped to respond quickly to emerging national needs. They are currently expanding their work in the areas of aging and disability, and supports for veterans returning with disabilities. They continue to work with the federal government on policies and initiatives on emergency preparedness for people with developmental and other disabilities. Other national issues that have been addressed by UCEDDs and LENDs have included positive behavioral interventions and supports, reading disorders in children, design and dissemination of training programs for direct support personnel in developmental disabilities, and provision of training in methods to support employment for individuals with disabilities.

I again ask that you consider our request for funding of $41 million for the network of UCEDDs and $26,200,000 for the LENDs so that we may expand our network to more adequately serve our nation's growing population of Americans with developmental and other lifelong disabilities and to address our nation's health disparities.

Thank you for the opportunity to share this information about the UCEDDs and LEND programs. Your careful consideration of our appropriation requests is appreciated and we are happy to share more detailed information with you at your request.

Sincerely,



William E. Kiernan
President, AUCD

Association of
American Cancer Institutes

**Written Testimony to the United States House of Representatives
Appropriations Committee, Subcommittee for
Labor, Health and Human Services, Education and Related Agencies
Regarding FY 2009 Cancer-Related Funding
Submitted March 31, 2008**

Testimony submitted by:
Barbara Duffy Stewart, MPH
Executive Director
Association of American Cancer Institutes

The Association of American Cancer Institutes (AACI), representing 91 of the nation's premier academic and free-standing cancer centers, appreciates the opportunity to submit this statement for consideration as the Labor, Health and Human Services Appropriations Subcommittee plans the fiscal year (FY) 2009 appropriations for the National Institutes of Health (NIH) and the National Cancer Institute (NCI).

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. Years of flat funding for the NIH and NCI have eroded these institutions' ability to maintain their robust research programs. For FY 2009, the AACI joins its colleagues in the biomedical research community in recommending an appropriation of $31.1 billion for NIH (an increase of $1.9 billion over FY 2008 levels). Further, AACI respects the professional judgment of the NCI in requesting an appropriation of $5.26 billion (an increase of $455 over FY 2008 levels). AACI will work to ensure that Congress approves the maximum possible appropriations for NIH and NCI.

The Growing Cancer Burden

In 2008, there will be approximately 1.44 million new cases of cancer in the United States and approximately 565,650 deaths due to the disease.[1] The human toll of cancer is staggering, as is its financial toll; the NCI reports that in 2006, $206.3 billion was spent on healthcare costs for cancer alone. Additionally, NCI acknowledges that the burdens of cancer—physical, emotional, and financial—are "unfairly shouldered by the poor, the elderly, and minority populations."[2] The number of cancer diagnoses will only continue to climb as our population ages, with an estimated 18.2 million cancer survivors (those undergoing treatment, as well as those who have

[1] *Cancer Facts and Figures 2008*. American Cancer Society; 2008.
[2] *The Nation's Investment in Concer Research: An Annual Plan and Budget Proposal for FY2009*. National Cancer Institute, 2008.

completed treatment) alive in 2020.[3] By comparison, an estimated 11.9 million survivors were living in the United States in 2007.[2]

Cancer Research: Benefiting all Americans

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 across the United States.

Though over a half-million Americans will die this year from the many diseases defined as cancer, progress *is* being made. Because of continued progress made by the nation's researchers, cancer death rates have continued to decline; between 1991 and 2004, the death rates for cancer in men and women declined 18.4 percent and 10.5 percent, respectively.[4]

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. Another initiative, the Childhood Cancer Therapeutically Applicable Research to Generate Effective Treatments Initiative, is identifying targets that can lead to better treatments for young people with cancer.

These projects—along with the work being performed by dedicated physicians and researchers 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.

A Generation of Science at Risk

The nation's investment in cancer research is in jeopardy. Since 2004, the budget of the NCI has—through actual cuts and the effects of biomedical inflation—lost 12 percent of its spending power.[2] The current success rate for R01 applications—the R01 is the cornerstone grant of medical research—submitted to NIH is 25 percent; only one in four applications submitted to NIH are funded. These funds are often approved only after the researcher has resubmitted the

[3] Future Supply and Demand for Oncologists. *Journal of Oncology Practice* 2007; 3(2): 79–86.
[4] Cancer Statistics, 2008. *CA: Cancer Journal for Clinicians* 2008; 58(2): 71–96.

application several times. In 1999, the success rate for a first R01 submission was 29 percent; in 2007, that rate was 12 percent. The low approval rate and lengthy delays in receiving funds have combined to raise the average age of receiving a first R01 grant from age 39 in 1990 to age 43 in 2007.[5]

Because of this, young researchers—the next generation of scientists whose novel ideas will build upon those of their seasoned mentors—may be lost. As NIH itself states, "New investigators are the innovators of the future—they bring fresh ideas and technologies to existing biomedical research problems, and they pioneer new areas of investigation. Entry of new investigators into the ranks of independent, NIH-funded researchers is essential to the health of this country's biomedical research enterprise."[6]

Research projects that are funded are often more conservative in scope than those of a few years ago. Scientists who perform the invaluable task of evaluating R01 proposals are electing to fund conventional projects that will lead to incremental progress; these reviewers are also less likely to fund truly "out-of-the-box" ideas that may not bear fruit—but if they were successful, these ideas could move the pace of research exponentially.[5] In years past, funding has been available to support both of these types of projects, a mix that led to the rapid progress to which we have become accustomed—and that has contributed to lengthening and improving the lives of cancer patients around the world.

The Nation's Cancer Centers

The nexus of cancer research in the United States is the nation's network of cancer centers that are 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 $3.17 billion[7] from NCI to conduct cancer research; this represents 66 percent of NCI's total budget. In fact, 85 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 is dependent on federal dollars, via training grants and other funding from NCI. Decreasing federal support will significantly undermine 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

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[5] *A Broken Pipeline? Flat Funding of the NIH Puts a Generation of Science at Risk.* A Follow-up Statement by a Group of Concerned Universities and Research Institutions, 2008.

[6] NIH Office of Extramural Research Website: http://grants.nih.gov/grants/new_investigators/. Retrieved 3/28/08.

[7] *National Cancer Institute 2007 Fact Book.* U.S. Department of Health and Human Services, U.S. National Institutes of Health, 2007.

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.

Stagnant funding prevents expansion at existing centers but also prevents new centers from achieving NCI designation. While most major metropolitan areas in the United States have easy access to an NCI-designated cancer center, several states and many underserved areas do not. Without enhanced funding to establish and nurture cancer centers in these areas, far too many Americans face the burden of cancer without the benefit of the cutting-edge care available only at a dedicated cancer center.

Ensuring the Future of Cancer Care and Research

Because of an aging population, an increasing number of cancer survivors require ongoing monitoring and care from oncologists, and new therapies that tend to be complex and often extend life. As a result, demand for oncology services is projected to increase 48 percent by 2020. However, the supply of oncologists expected to increase by only 20 percent and 54 percent of currently practicing oncologists will be of retirement age within that timeframe. Also, alarmingly, there has been essentially no growth over the past decade in the number of medical residents electing to train on a path toward oncology as a specialty.[8]

Cancer physicians—while essential—are only one part of the oncology workforce that is in danger of being stretched to the breaking point. The Health Resources and Services Administration predicted that by 2020, over 1 million nursing positions will go unfilled, and a 2002 survey by the Southern Regional Board of Education projected a 12percent shortage of nurse educators by last year.[9]

Without immediate action, these predicted shortages will prove disastrous for the state of cancer care in the United States. The discrepancy between supply and demand for oncologists will amount to a shortage of 9.4 to 15.1 million visits, or a shortage of 2,550 to 4,080 oncologists.[8] The Department of Health and Human Services projects that today's 10-percent vacancy rate in registered nursing positions will grow to 36 percent, representing more than 1 million unfilled jobs by 2020.[10]

Greater federal support for training oncology physicians, nurses, and other professionals who treat cancer must be enacted to prevent a disaster within our healthcare system when demand for oncology services far outstrips the system's ability to provide adequate care for all.

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[8] *Forecasting the Supply of and Demand for Oncologists: A Report to the American Society of Clinical Oncology (ASCO) from the AAMC Center for Workforce Studies.* American Society of Clinical Oncology, 2007.

[9] ONS: Ready to Collaborate with Other Policymakers to Ensure Future of Quality Cancer Care *Oncology Times*, August 25, 2007; (29): 8–9.

[10] Oncology Nursing Society Website: http://www.ons.org/lac/pdf/correspondence/110/082807.pdf. Retrieved 3/28/08.

Americans Support Federal Funding for Research
The research community has long understood the obstacles that are facing cancer research. Though the nuances of R01 grants and oncology workforce training may not be well understood by the average American, the people of the United States believe in supporting the disparate activities that make up America's biomedical research infrastructure.

In a 2007 Research!America poll, 91 percent of those surveyed believed it was somewhat or very important for policymakers to create more incentives to encourage individuals to pursue careers as nurses, while 89 percent believed the same for encouraging careers as physicians. Forty-seven percent of those surveyed agreed that he U.S. must increase investment in NIH to ensure our future health and economic security, and 54 percent favored annual 6.7-percent increases in funding for NIH in 2008, 2009, and 2010. An overwhelming majority—70 percent—agreed that the U.S. is losing its global competitive edge in science, technology, and innovation.[11]

We encourage our Representatives in Congress to respond to the concerns of the American people by enhancing support for biomedical research that will lead to improved health for everyone in the United States and around the world.

Conclusion
These are exciting times in science and, particularly, in cancer research. Discoveries made today can translate to prevention methods, treatments and even cures in the future. Research funding through the NIH and NCI make these discoveries possible.

AACI urges the members of the House Committee on Appropriations, Subcommittee on Labor, Health & Human Services, Education, and Related Agencies to dedicate an appropriation of $31.1 billion for the NIH in FY 2009 (a $1.9 billion increase over FY 2008 levels). We ask for your support in increasing this critical funding that will help set the pace for cancer research for years to come.

[11] *Your Congress–Your Health Survey, 2007.* Charlton Research Company for Research!America, 2007.

Written Testimony of James Lacy, Past President, on behalf of Rotary International– 27 March, 2008
House Appropriations Subcommittee on Labor, Health and Human Services, and Education

Chairman Obey, Representative Walsh, members of the Subcommittee, Rotary International appreciates this opportunity to submit testimony in support of the polio eradication activities of the U. S. Centers for Disease Control and Prevention (CDC). The effort to eradicate polio stands as an unprecedented model of cooperation among national governments, civil society and UN agencies which have worked together over many years to achieve a global public good. Longstanding collaboration has enabled us to overcome tremendous challenges: war, natural disasters, and lack of infrastructure among them, so that we are currently within reach of shared victory over polio. What have we learned? Polio eradication strategies work even in the most challenging environments and under the most trying circumstances.

PROGRESS IN THE GLOBAL PROGRAM TO ERADICATE POLIO

I would like to take this opportunity to thank you, Chairman Obey, Representative Walsh, and members of the Subcommittee for your tremendous commitment to this effort. Thanks to your leadership in appropriating funds, progress toward a polio-free world continues.

- Only 4 countries are still polio-endemic – the lowest number in history: Nigeria, India, Pakistan and Afghanistan. And in these countries, polio circulates in very limited geographic areas.
- The number of polio cases has fallen from an estimated 350,000 in 1988 to less than 1,400 in 2007 – a more than 99% decline in reported cases.
- Cases due to type 1 polio, the most virulent and paralytic of the two remaining types of polio, fell by 84% in 2007. The absence of type 1 polio from the western part of Uttar Pradesh state, India, is a particularly striking development as this is the only area in India which had never interrupted indigenous polio transmission.
- Polio was cut by 76% in northern Nigeria in 2007.
- Twenty-five of the twenty-seven countries that were reinfected between 2003 and 2007 have stopped transmission of imported poliovirus.
- Among the reinfected countries, Somalia has just demonstrated that polio eradication can be achieved even in countries where a functioning government does not exist, and where longstanding civil strife and insecurity prevail. March 25, 2008 marks the 1-year anniversary since the last case of polio was reported in Somalia.
- The tools to eradicate polio are better than ever – the program now has vaccines which are twice as effective and diagnostic tools that detect and track poliovirus twice as fast as before.
- Policies to minimize the risks and consequences of the international spread of wild poliovirus are now in place.

Prospects for polio eradication are bright, but significant challenges remain. For example, operational challenges in reaching every child in the four endemic countries range from issues related to campaign quality, security, and funding. In addition, the need to deal with outbreak response activities in countries such as the Democratic Republic of Congo, Angola, Chad and Sudan are tragic and costly reminders that no child is safe until polio has been eradicated everywhere.

Continued political commitment is essential in all polio-affected countries. It is noteworthy that India, Nigeria and Pakistan have not relied solely upon international support, but have invested significant human and financial resources in their own polio eradication activities. In Afghanistan, President Karzai has appointed a special Polio Action Group to ensure effective

ministerial coordination of all polio eradication activities. Such high level commitment is vital to achieving polio eradication in the remaining polio-endemic countries.

The strong support received from the Department of Health and Human Services and the U.S. State Department in promoting global polio eradication efforts at various international forums, in engaging with other donor countries to secure additional resources, and in helping deal with challenges in polio-affected countries is greatly appreciated. The continued engagement of the US State Department will also be necessary to help secure "Days of Tranquility" in zones of conflict in southern Afghanistan to provide safe access to vaccinators to reach and vaccinate children during polio eradication campaigns.

The ongoing support of donor countries is essential to assure the necessary human and financial resources are made available to polio-endemic countries to take advantage of the window of opportunity to forever rid the world of polio. Access to children is needed, particularly in conflict-affected areas such as Afghanistan and its shared border with Pakistan. Polio-free countries must maintain high levels of routine polio immunization and surveillance. The continued leadership of the United States is essential to ensure we meet these challenges.

THE ROLE OF ROTARY INTERNATIONAL

Since 1985, Rotary International, a global association of more than 30,000 Rotary clubs, with a membership of over 1.2 million business and professional leaders in more than 200 countries, has been committed to battling this crippling disease. In the United States today there are more than 7,700 Rotary clubs with over 375,000 members. All of our clubs work to promote humanitarian service, high ethical standards in all vocations, and international understanding. Rotary International stands hand-in-hand with the United States Government and governments around the world to fight polio through local volunteer support of National Immunization Days, raising awareness about polio eradication, and providing financial support for the initiative.

Rotary International's financial commitment will reach US$850 million by the time the world is certified polio free – representing the largest contribution by an international service organization to a public health initiative ever. These funds have been allocated for polio vaccine, operational costs, laboratory surveillance, cold chain, training and social mobilization in 122 countries. More importantly, tens of thousands of Rotarians have been mobilized to work together with their national ministries of health, UNICEF and WHO, and with health providers at the grassroots level in thousands of communities. In the United States, hundreds of Rotarians have been inspired to travel at their own expense to assist their fellow Rotarians in polio-affected countries in Africa and Asia during National Immunization Days.

Rotary also leads the United States Coalition for the Eradication of Polio, a group of committed child health advocates that includes the March of Dimes Birth Defects Foundation, the American Academy of Pediatrics, the Task Force for Child Survival and Development, the United Nations Foundation, and the U.S. Fund for UNICEF. These organizations join us in expressing appreciation to you for your staunch support of the Global Polio Eradication Initiative.

THE ROLE OF THE U.S. CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)
Rotary commends CDC for its leadership in the global polio eradication effort, and greatly appreciates the Subcommittee's support of CDC's polio eradication activities. For Fiscal Year 2009, we would expect that CDC will spend $101.254 million for their polio eradication efforts, equal to the Fiscal Year 2006 level. This investment has helped to make the United States the leader among donor nations in the drive to eradicate this crippling disease. Due to Congress's unwavering support, in 2008 CDC is able to:

- Support the international assignment of more than 350 long- and short-term epidemiologists, virologists, and technical officers to assist the World Health Organization and polio-endemic countries to implement polio eradication strategies, and 15 technical staff on direct assignment to WHO and UNICEF to assist polio-endemic countries.
- Provide $40 million to UNICEF for approximately 240 million doses of polio vaccine and $9 million for operational costs for NIDs in all polio-endemic countries and other high-risk countries in Asia, the Middle East and Africa. Most of these NIDs would not take place without the assurance of CDC's support.
- Provide more than $25 million to WHO for surveillance, technical staff and NIDs' operational costs, primarily in Africa. As successful NIDs take place, surveillance is critical to determine where polio cases continue to occur. Effective surveillance can save resources by eliminating the need for extensive immunization campaigns if it is determined that polio circulation is limited to a specific locale.
- Train virologists from all over the world in advanced poliovirus research and public health laboratory support. CDC's Atlanta laboratories serve as a global reference center and training facility.
- Provide the largest volume of both operational (poliovirus isolation) and technologically sophisticated (genetic sequencing of polio viruses) lab support to the 145 laboratories of the global polio laboratory network. CDC has the leading specialized polio reference lab in the world.
- Serve as the primary technical support agency to WHO on scientific and programmatic research regarding: (1) laboratory containment of wild poliovirus stocks following polio eradication, and (2) when and how to stop or modify polio vaccination worldwide following global certification of polio eradication.

BENEFITS OF POLIO ERADICATION
Since 1988, over 5 million people who would otherwise have been paralyzed will be walking because they have been immunized against polio. Tens of thousands of public health workers have been trained to investigate cases of acute flaccid paralysis and manage massive immunization programs. Cold chain, transport and communications systems for immunization have been strengthened.

Increased political and financial support for childhood immunization has many documented long-term benefits. Polio eradication is helping countries to develop public health and disease surveillance systems useful in the control of other vaccine-preventable infectious diseases. Already all 47 countries of the Americas are free of indigenous measles, due in part to improvements in the public health infrastructure implemented during the war on polio. The

disease surveillance system--the network of 145 laboratories and trained personnel established during the Polio Eradication Initiative--is now being used to track measles, rubella, yellow fever, meningitis, and other deadly infectious diseases. Most recently, polio health workers have been trained to recognize symptoms of Avian Influenza in order to support surveillance and potential outbreak response activities for this emerging public health threat. The AFP surveillance system and global laboratory network that supports it will continue to support the surveillance of other diseases long after polio has been eradicated.

NIDs for polio have been used as an opportunity to give children essential vitamin A, which, like polio, is administered orally, saving the lives of at least 1.25 million children since 1998. The campaign to eliminate polio from communities has led to an increased public awareness of the benefits of immunization, creating a "culture of immunization" and resulting in increased usage of primary health care and higher immunization rates for other vaccines. It has improved public health communications and taught nations important lessons about vaccine storage and distribution, and the logistics of organizing nation-wide health programs. Additionally, the unprecedented cooperation between the public and private sectors serves as a model for other public health initiatives.

Polio eradication is a cost-effective public health investment, as its benefits accrue forever. On the other hand, more than 10 million children will be paralyzed in the next 40 years if the world fails to capitalize on the more than $5 billion already invested in polio eradication.

FISCAL YEAR 2009 BUDGET REQUEST

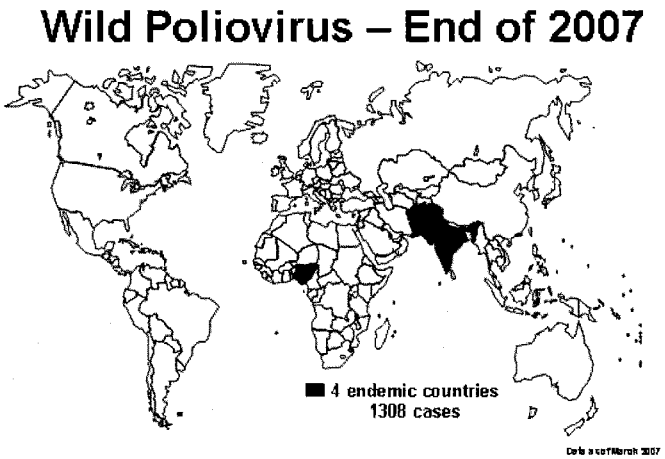
The World Health Organization estimates that $1.8 billion is needed from donors for the period 2008-2012. For Fiscal Year 2009, we respectfully request that you maintain the level of funding that has been provided in the past ($101.254 million) for the targeted polio eradication efforts of the Centers for Disease Control and Prevention. The funds we are seeking will allow CDC to continue intense supplementary immunization activities in Asia and to improve the quality of immunization campaigns in Africa to interrupt transmission of polio in these regions as quickly as possible. These funds will also help maintain certification standard surveillance. This will ensure that we protect the substantial investment we have made to protect the children of the world from this crippling disease by supporting the necessary eradication activities to eliminate polio in its final strongholds—in South Asia and sub-Saharan Africa.

The United States' commitment to polio eradication has stimulated other countries to increase their support. Other countries that have followed America's lead and made special grants for the global Polio Eradication Initiative include the United Kingdom ($621 million), Japan ($333 million), Germany ($223 million), and Canada ($205 million). Since 2002, the members of the G8 have committed to provide sufficient resources to eradicate polio. G8 member states, many of which were already leading donors to the Polio Eradication Initiative, have encouraged other donors to provide support, and have emphasized the importance of polio eradication when meeting with leaders of polio-endemic countries. As a result, the base of donor nations that have contributed to the Global Polio Eradication Initiative has expanded to include Spain, Sweden, Saudi Arabia, and even contributions from United Arab Emirates, Kuwait, Hungary, and Turkey.

Intense political commitment on the part of endemic nations is also essential to ensuring polio eradication is achieved. It is noteworthy that India recently committed to provide US$260 million in funding for polio eradication activities there and Nigeria has committed to provide approximately US$30 million, and Pakistan has committed to fund its vaccine needs for 2008-2010. In Afghanistan, President Karzai has appointed a Polio Action Group that reports directly to him. Such strong leadership will demonstrates the high level of priority these countries place on polio eradication.

The strong resolve of the remaining polio affected countries combined with the continued leadership of the United States and other global donors will ensure that we seize the opportunity to banish the crippling polio virus to the history books. The lessons learned from the shared victory of governments, UN agencies, and civil society entities like Rotary International will leave a lasting legacy for future public health and development initiatives.

Exhibt A



American Academy of Physician Assistants
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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 2009 APPROPRIATIONS
March 31, 2008

On behalf of the more than 68,000 clinically practicing physician assistants in the United States, the American Academy of Physician Assistants is pleased to submit comments on FY 2009 appropriations for Physician Assistant (PA) educational programs that are authorized through Title VII of the Public Health Service Act.

A member of the Health Professions and Nursing Education Coalition (HPNEC), the Academy supports the HPNEC recommendation to provide at least $300 million for Title VII programs in FY 2009, including a minimum of $7 million to support PA educational programs. This would fund the programs at the 2005 funding level, not accounting for inflation.

The Academy believes that the recommended restoration in funding for Title VII health professions programs is well justified.

A review of PA graduates from 1990 – 2006 demonstrates that PAs who have graduated from PA educational programs supported by Title VII are 59% more likely to be from underrepresented minority populations and 46% more likely to work in a rural health clinic than graduates of programs that were not supported by Title VII.

Title VII safety net programs are essential to the development and training of primary health care professionals and, in turn, provide increased access to care by promoting health care delivery in medically underserved communities. Title VII funding is especially important for PA programs as it is the only federal funding available on a competitive application basis to these programs.

The Academy is extremely concerned with the Administration's proposal to eliminate funding for most Title VII programs, including training programs in primary care medicine and dentistry.

As Members of the Subcommittee are aware, these programs are designed to help meet the health care delivery needs of the nation's Health Professional Shortage Areas (HPSAs). By definition, the nation's more than 5,500 HPSAs experience shortages in the primary care workforce that the market alone can't address. In addition, the Health Resources and Services Administration (HRSA) predicts that there will be a need for over 11,000 health care professionals to implement the President's Community Health Center (CHC) Initiative. The increased funding for these CHCs will provide medical care to approximately 6 million people in the U.S. However, these centers must have an adequate supply of primary care clinicians to serve these facilities and communities. And across the country today, Title VII is fulfilling that role by providing funding for the pipeline of health professionals that serve CHCs now and in the future.

We wish to thank the members of this subcommittee for your historical role in supporting funding for the health professions programs, and we hope that we can count on your support to restore funding to these important programs in FY 2009 to the FY 2005 funding level.

Overview of Physician Assistant Education

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

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

The second year of PA education consists of clinical rotations. On average, students devote more than 2,000 hours, or 50-55 weeks, to clinical education, divided between primary care medicine – family medicine, internal medicine, pediatrics, and obstetrics and gynecology – and various specialties, including surgery and surgical specialties, internal medicine subspecialties, emergency medicine, and psychiatry. During clinical rotations, PA students work directly under the supervision of physician preceptors, participating in the full range of patient care activities, including patient assessment and diagnosis, development of treatment plans, patient education, and counseling.

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

Physician Assistant Practice

Physician assistants are licensed health care professionals educated to practice medicine as delegated by and with the supervision of a physician. In all states, physicians may delegate to PAs those medical duties that are allowed by law and are within the physician's scope of practice and the PA's training and experience. All states, the District of Columbia, and Guam authorize physicians to delegate prescriptive privileges to the PAs they supervise. PAs are located in almost all health care settings and medical and surgical specialties. Fifteen percent of all PAs practice in non-metropolitan areas where they may be the only full-time providers of care (state laws stipulate the conditions for remote supervision by a physician). Approximately 37 percent of PAs are in primary care. In 2007, an estimated 245 million patient visits were made to PAs and approximately 303 million medications were prescribed or recommended by PAs.

Critical Role of Title VII Public Health Service Act Programs

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

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

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

Title VII Support of PA Educational Programs

Targeted federal support for PA educational programs is authorized through section 747 of the Public Health Service Act. The program was reauthorized in the 105th Congress through the Health Professions Education Partnerships Act of 1998, P.L. 105-392, which streamlined and consolidated the federal health professions education programs. Support for PA education is now considered within the broader context of training in primary care medicine and dentistry.

P.L. 105-392 reauthorized awards and grants to schools of medicine and osteopathic medicine, as well as colleges and universities, to plan, develop, and operate accredited programs for the education of physician assistants, with priority given to training individuals from disadvantaged communities. The funds ensure that PA students from all backgrounds have continued access to

an affordable education and encourage PAs, upon graduation, to practice in underserved communities. **These goals are accomplished by funding PA educational programs that have a demonstrated track record of: 1) placing PA students in health professional shortage areas; 2) exposing PA students to medically underserved communities during the clinical rotation portion of their training; and 3) recruiting and retaining students who are indigenous to communities with unmet health care needs.**

The PA programs' success in recruiting and retaining underrepresented minority and disadvantaged students is linked to their ability to creatively use Title VII funds to enhance existing educational programs. For example, PA programs in Texas use Title VII funds to create new clinical rotation sites in rural and underserved areas, including new sites in border communities, and to establish non-clinical rural rotations to help students understand the challenges faced by rural communities. One Texas program uses Title VII funds for the development of Web based and distant learning technology and methodologies so students can remain at clinical practice sites. In New York, a PA program with a 90% ethnic minority student population uses Title VII funding to focus on primary care training for underserved urban populations by linking with community health centers, which expands the pool of qualified minority role models that engage in clinical teaching, mentoring, and preceptorship for PA students. Several other PA programs have been able to use Title VII grants to leverage additional resources to assist students with the added costs of housing and travel that occur during relocation to rural areas for clinical training.

Without Title VII funding, many of these special PA training initiatives would not be possible. Institutional budgets and student tuition fees simply do not provide sufficient funding to meet the needs of medically underserved areas or disadvantaged students. The need is very real, and Title VII is critical in meeting that need.

Need for Increased Title VII Support for PA Educational Programs

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

Changes in the health care marketplace reflect a growing reliance on PAs as part of the health care team. Currently, the supply of physician assistants is inadequate to meet the needs of society, and the demand for PAs is expected to increase. A 2006 article in the *Journal of the American Medical Association* (*JAMA*) concluded that the federal government should augment the use of physician assistants as physician substitutes, particularly in urban CHCs where the proportional use of physicians is higher. The article suggested that this could be accomplished by adequately funding Title VII programs. Additionally, the Bureau of Labor Statistics projects that the number of available PA jobs will increase 49 percent between 2004 and 2014. Title VII

funding has provided a crucial pipeline of trained PAs to underserved areas. One way to assure an adequate supply of physician assistants practicing in underserved areas is to continue offering financial incentives to PA programs that emphasize recruitment and placement of PAs interested in primary care in medically underserved communities.

Despite the increased demand for PAs, funding has not proportionately increased for Title VII programs that educate and place physician assistants in underserved communities. Nor has Title VII support for PA education kept pace with increases in the cost of educating PAs. A review of PA program budgets from 1984 through 2004 indicates an average annual increase of seven percent, a total increase of 256 percent over the past 20 years, as federal support has decreased.

Recommendations on FY 2009 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 2009. For instance, while it is important to fund clinical research at the National Institutes of Health (NIH) and to have an infrastructure at the Centers for Disease Control and Prevention (CDC) that ensures a prompt response to an infectious disease outbreak or bioterrorist attack, the good work of both of these agencies will go unrealized if the Health Resources and Services Administration is inadequately funded. HRSA administers the "people" programs, such as Title VII, that bring the results of cutting edge research at NIH to patients through providers such as PAs who have been educated in Title VII-funded programs. Likewise, CDC is heavily dependent upon an adequate supply of health care providers to be sure that disease outbreaks are reported, tracked, and contained.

The Academy respectfully requests that Title VII health professions programs receive $300 million in funding for FY 2009, including a minimum of $7 million to support PA educational programs. Thank you for the opportunity to present the American Academy of Physician Assistants' views on FY 2009 appropriations.

Testimony Submitted by the
American College of Obstetricians and Gynecologists

US House Committee on Appropriations
Subcommittee on Labor, Health and Human Services and Education

Contact Person: Krysta Jones
Government Affairs Representative
202-314-2322
March 31, 2008

The American College of Obstetricians and Gynecologists (ACOG), representing 51,000 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 Obey, Ranking Member Walsh, and the entire Subcommittee for their leadership to continually address women's health.

The Nation has made important strides to improve women and children's health over the past several years, and ACOG is grateful to this Committee for its commitment to ensure that public health agencies work together to translate vital research into valuable public health policy solutions for women of all ages.

We urge the Committee to support a 6.6 percent increase for the National Institutes of Health (NIH), and a 6.6 percent increase for the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) at the NIH in fiscal year 2009. We also continue to support efforts to secure adequate funds for important public health programs at the Health Resources and Services Administration (HRSA), $7.9 billion, and the Centers for Disease Control and Prevention (CDC), $7.4 billion, (including funding for the Agency for Toxic Substances and Disease Registry) for CDC's core programs, excluding the mandatory funding provided for the Vaccines for Children Program (VFC), for which we are requesting $2.88 billion, a 6.6 percent increase over FY08.

I. Ensuring Medically Accurate Education and Preventing Teen Pregnancies

Comprehensive Sexuality Education and Teen Pregnancy Prevention

Young people need education that encourages them to delay sexual activity while providing them with accurate information about how to protect themselves against unintended pregnancies and sexually transmitted infections (STIs). The National Center for Health Statistics (NCHS) found that the teen birth rate in the United States increased three percent

between 2005 and 2006-the first such increase in 15 years; more than 750,000 teenagers become pregnant each year, and 80% of these pregnancies are unintended. A March 2008 CDC report found that 25% of girls and young women ages 14 to 19 have at least one of four common STIs. We must decrease these alarming rates.

Since 1996, Congress has committed over half a billion dollars in federal and state funding for abstinence-only education programs. In order to qualify for federal funding, some of these programs are prohibited from discussing medically accurate information about contraceptives and STIs. While it is valuable to promote abstinence from sexual intercourse as the preferred responsible behavior for adolescents, reputable studies show that comprehensive programs that provide scientifically accurate information about sexuality, STIs, contraception, preventive health care, and abstinence, are the most effective in combating teen pregnancy and STIs.

ACOG opposes additional funding for abstinence-only education, and supports increased funding for comprehensive sexuality education and teen pregnancy prevention programs.

II. Improving Contraceptive Research and Access to Family Planning

Contraceptive Research
Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)

The United States has one of the highest unintended pregnancy rates of the industrialized nations. Of the approximately 6 million pregnancies each year, an estimated one half are unintended. Contraceptive use saves as much as $19 billion in health care costs annually. It is critical that Congress continue to invest in contraceptive research, ensuring that women have access to safe and effective contraceptives, to help them time and space their pregnancies. The NICHD's research on male and female contraceptives can help reduce the number of unintended pregnancies and abortions, and improve women's health.

Title X Family Planning Program
Health Resources and Services Administration (HRSA)

Since 1970, the Title X Family Planning program at HRSA has provided low-income women with timely screenings, education, and contraception, services that can help prevent breast and cervical cancer, sexually transmitted infections (STIs), and unintended pregnancies.

Title X clinics serve more than five million low-income women at 4,500 clinics nationwide, helping women plan the number and timing of their pregnancies and stay healthy. One in seven women get their Pap tests, and one in three women get tested or treated for STIs at family planning clinics. Title X clinics are serving increasing numbers of patients without commensurate increases in funding. We urge you to increase funding for this vital program to $400 million for FY09.

III. Ensuring All Women Have Safe and Healthy Pregnancies

Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)

Drug Safety During Pregnancy

In 2004, the NICHD created the Obstetric and Pediatric Pharmacology Branch to centralize research on the effect of prescription drugs on children and pregnant women.

Obstetricians and their pregnant patients need much more information on the fetal and maternal risks and benefits of medications. ACOG urges Congress to support the Branch's research on the interactions between therapeutics, pregnancy and development, and training in reproductive, perinatal, and pediatric epidemiology.

Reducing High-Risk Pregnancies

NICHD's Maternal Fetal Medicine Unit Network, working at 14 sites across the US will help reduce the risks of cerebral palsy, caesarean deliveries, and gestational diabetes. ACOG urges Congress to increase funding for this Network and its important research.

NICHD's MFM Unit Network sites include: University of Alabama, University of Texas-Houston, University of Texas-Southwestern, Wake Forest University, University of North Carolina, Brown University-Women and Infant's Hospital, Columbia University, Drexel University, University of Pittsburgh-Magee Women's Hospital, University of Utah, Northwestern University, Wayne State University, Case Western University, and Ohio State University,

Reducing the Prevalence of Premature Births

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. ACOG is grateful for Congressional support of the Surgeon General's Conference on Preterm Birth to be held in June 2008, which will further our understanding and ability to treat the causes of and risk factors for preterm labor and delivery.

IV. Improving Maternal and Infant Health

Healthy Start Program
Health Resources and Services Administration (HRSA)

After decades of decline, the U.S. infant mortality rate is again on the rise and is particularly severe among minority and low-income women. The infant mortality rate among African American women has been increasing since 2001 and reached 14.2 deaths per 1,000 births in 2004, more than twice the national rate. There also has been a startling

rise in infant mortality in the South. Mississippi, for example, had an infant mortality rate of 11.4 in 2005 compared to 9.6 the previous year.

The Healthy Start program at HRSA builds on community resources to help ensure that women in high infant mortality communities have access to early prenatal and infant care. The Fetal and Infant Mortality Review (FIMR) is a Healthy Start program 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 you to fund the Healthy Start program at $120 million in FY09 to help lower the high infant mortality rate, and address issues related to disparities.

Pregnancy Risk Assessment Monitoring System
Centers for Disease Control and Prevention (CDC)

The Pregnancy Risk Assessment Monitoring System (PRAMS), a joint project of the CDC and state health departments, collects state-specific data on maternal attitudes and experiences before, during, and shortly after pregnancy. PRAMS data helps identify women and infants at high risk for health problems and monitor changes in health status. Despite its success, federal funding limits mean the CDC can only operate PRAMS programs in 38 states. ACOG urges Congress to fund PRAMS in all 50 states.

National Center on Birth Defects and Developmental Disabilities (NCBDDD)
Centers for Disease Control and Prevention (CDC)

Birth defects affect about one in every 33 babies born in the United States each year. Babies born with birth defects have a greater chance of illness and long term disability than babies without birth defects. Preventing birth defects should be a national priority.

The NCBDDD and ACOG have worked together to on a number of proven prevention efforts, including increasing understanding of genetic screening and diagnostic tests, technical guidance on preconception care and prenatal genetic screening, better information on and ways to reduce maternal alcohol use, better care for women with gestational diabetes mellitus and improved access to care for women with disabilities. ACOG urges Congress to increase funding for the NCBDDD.

V. Issues Throughout A Woman's Lifespan: Breast and Cervical Cancer

Vaccines for Children (VFC) and the Section 317 Program
Centers for Disease Control and Prevention (CDC)

A new vaccine can protect girls and women from cervical cancer. In 2006, the Food and Drug Administration (FDA) approved the vaccine Gardasil for girls and women ages 9-26 to prevent certain types of human papilloma virus (HPV) which can lead to cervical cancer.

The VFC and the Section 317 programs at the CDC provide vaccines for children and low-income adults, but at $350 for the three dose regimen, many families cannot afford the vaccine and federal funding leaves these programs badly underfunded. Congress should increase funding for the VFC and the Section 317 programs in FY09 to ensure the availability of the HPV vaccine to these important populations.

The vaccine is an important tool to combat cervical cancer, but it is not a substitute for routine screening. Regular pap tests are necessary to diagnose HPV before it develops into cervical cancer.

National Breast and Cervical Cancer Early Detection Program
Centers for Disease Control and Prevention (CDC)

The National Breast and Cervical Cancer Early Detection Program (NBCCEDP) provides critical breast and cervical cancer screening to low-income, uninsured and underserved women who do not otherwise have access to these lifesaving interventions. Since 1991, the NBCCEDP has conducted over 5.8 million breast and cervical screenings. Yet the program only serves 15% of the eligible population. In April 2007, Congress reauthorized this important program, and Congress should ensure the program is funded at its authorized level of $225 million in FY09 so that it can serve more women in need of the program.

Medicaid Breast and Cervical Cancer Prevention and Treatment Act (BCCPT)
Center for Medicare and Medicaid Services (CMS)

Low-income, uninsured and underinsured women who are found to have breast or cervical cancer after being screened through the NBCCEDP need serious medical care. In 2000, Congress created the Medicaid Breast and Cervical Cancer Prevention and Treatment program to provide this care to 34,535 women to date. This program too is historically underfunded, leaving many women without access to needed care. Congress should fully fund this program, providing states with enough funds to treat women with breast and cervical cancers.

Again, we would like to thank the Committee for its continued support of programs to improve women's health.

tourette syndrome association, inc.

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February 15, 2008

The Honorable David Obey, Chairman
House Appropriations Subcommittee on
Labor Health, Human Services,
And Education United States House
of Representatives B-300 Rayburn
House Office Building
Washington, DC 20515

The Honorable Jim Walsh, Ranking
House Appropriations Subcommittee on Labor,
Health, Human Services, and Education
United States House of Representatives
1001 Longworth House Office Building
Washington, D.C. 20515

Dear Chairman Obey and Ranking Member Walsh:

As the only national voluntary non-profit membership organization in this field, advocating on behalf of all individuals with Tourette Syndrome, the national Tourette Syndrome Association (TSA) respectfully requests your support for $2 million for the continued funding of the Tourette Syndrome Public Health, Education, and Research Program at the Centers for Disease Control and Prevention (CDC).

Tourette Syndrome (TS) is an inherited neurobiological disorder that effects children in all racial and ethnics groups. The symptoms of this disorder are rapid, repeated, and involuntary movements and sounds called tics. It is estimated that 200,000 Americans are diagnosed with TS and endure the stigma, isolation and psychological impact of this disorder. There is no cure for TS although some individuals benefit from medication and other clinical treatment.

In 2000, Congress passed the Children's Health Act, of which TS received Title 23. This Act authorizes the TS Public Health, Education, and Research Outreach Program to increase recognition and diagnosis of TS, decrease stigma attached to the disorder, and increase the provision of appropriate, effective treatment to those with TS.

In its first three years, the TS Program has provided authoritative education on Tourette Syndrome recognition, diagnosis and treatment, to over 15,847 professionals, in 201 live programs in all fifty states. In year four of the program, Congress passed the Consolidated Appropriations Act of 2008 (H.R. 2764/P.L. 110-161), which included $1.7 million for the TS program, within the National Center on Birth Defects and Developmental Disabilities at the CDC. The program continues to address the education and training of physicians, allied healthcare workers, and education professionals to ensure proper and timely diagnosis and treatment of children with TS.

Another critical requirement for improving the lives of children and adults with TS is a comprehensive epidemiological study of the disorder. The research component of the program will focus on collecting scientific knowledge regarding this condition. The program will seek to determine the prevalence of the disorder in the general population and the frequency of co-occurring disorders such as Attention Deficit Hyperactivity Disorder and Obsessive-Compulsive Disorder.

We thank you and commend you for your leadership in ensuring an ongoing federal commitment to the improvement of health and the expansion of research, treatment, education, and prevention of diseases and disorders.

Sincerely,

Judit Ungar
President

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WRITTEN STATEMENT OF DR. GENE COPELLO, EXECUTIVE DIRECTOR, THE AIDS INSTITUTE, TO THE SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES
HOUSE COMMITTEE ON APPROPRIATIONS

Dear Chairman Obey and Members of the Subcommittee:

The AIDS Institute, a national public policy research, advocacy, and education organization, is pleased to comment in support of critical HIV/AIDS and Hepatitis programs as part of the FY2009 Labor, Health and Human Services, Education and Related Agencies appropriation measure. We thank you for your consistent support of these programs over the years, and trust you will do your best to adequately fund them in the future in order to provide for, and protect the health of many Americans.

HIV/AIDS

HIV/AIDS remains one of the world's worst health pandemics in history. Worldwide, some 33.2 million people are infected with this incurable infectious disease, and more than 6,800 new infections occur each day. Tragically, AIDS has already claimed the lives of over 25 million. Here in the U.S., according to the CDC, 984,155 people have been diagnosed with AIDS, and 550,394 people have died. It is estimated there are more than 40,000 new infections in the U.S. each year, although this number may soon be revised to as high as 55,000 to 60,000. At the end of 2005, an estimated 1.2 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 12% of the US population, account for half of the HIV/AIDS cases. HIV/AIDS also disproportionately affects the poor, and about 70 percent of those infected rely on public health care financing.

The U.S. government has played a leading role in fighting AIDS, both here and abroad. The vast majority of the discretionary programs supporting HIV/AIDS efforts domestically and a portion of our Nation's contribution to the global AIDS effort 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 and global AIDS programs. The AIDS Institute asks that you do your best to adequately fund these programs at the requested level.

We are keenly aware of budget constraints and competing interests for limited dollars. Unfortunately, despite the growing need, several domestic HIV/AIDS programs have experienced cuts in recent years including HIV prevention funding at the CDC and some parts of the Ryan White HIV/AIDS Program.

This year, the President has proposed to cut CDC HIV Prevention even more, and increase Ryan White programs by a mere .004 percent, while cutting some parts of the program. The AIDS Institute asks you to reject these cuts and increase the entire program at the community requested level. Below are the program requests and supporting explanation by The AIDS Institute:

Centers for Disease Control and Prevention-HIV Prevention and Surveillance

FY 2008:	$692 million
FY 2009 President's Request:	$691 million
FY 2009 Community Request:	$1,300 million

While the CDC has reported for many years the number of new HIV infections in the U.S. is estimated to be 40,000 each year, they have announced they will release new incidence numbers in the near future in which, according to press reports, indicate the number is more like 55,000 to 60,000. While the current numbers are enough to cause alarm, the new estimates will hopefully convince Congress there is a heightened immediate need for increased funding, rather than additional cuts.

The increase in new infections is particularly occurring in certain populations, such as the poor, African- Americans, men who have sex with men, Latinos, substance users and the incarcerated. In order to address the specific needs of these populations, CDC is going to need additional funding.

Investing in prevention today will save money tomorrow. Every case of HIV that is prevented saves, on average, $1 million of lifetime treatment costs for HIV. One recent study concluded the cost of new HIV infections in the US in 2002 was estimated at $36.4 billion, including $6.7 billion in direct medical costs and $29.7 billion in productivity losses. Another study concluded preventing the estimated 40,000 new HIV infections in the U.S. each year would avoid obligating $12.1 billion annually in future medical costs.

Despite the savings of lives and costs that prevention provides, the Congress cut the program by $3.5 million in FY08 and the Administration is proposing to cut it in FY09 by another $1 million. Cuts of greater magnitude have been occurring for actual direct prevention programming while increases have gone for HIV testing. Since one quarter of the over one million people living with HIV in the U.S. are unaware of their HIV status, The AIDS Institute supports increased testing programs. However, we do not support funding these efforts at the expense of prevention intervention programs.

The Administration is also proposing $30 million to implement the Early Diagnosis Grant Program. The AIDS Institute does not support this request and urges that the money should be directed instead to CDC HIV/AIDS prevention programs.

Ryan White HIV/AIDS Programs

FY 2008:	$2,167 million
FY 2009 President's Request:	$2,168 million
FY 2009 Community Request:	$2,782 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 reaches over 531,000 low-income, uninsured, and underinsured people each year.

In FY08, the program overall received an increase of $29 million, although some parts of it experienced cuts, including an unprecedented $19 million cut for Part B, which provides money to the states. The President has proposed a .004 percent increase for Ryan White in FY09, or only $1.1 million. Within this request, some parts of the program would receive minor increases, while others would receive decreases. The AIDS Institute urges you to reject this budget proposal and instead provide substantial funding increases to all parts of the Ryan White Program. Consider the following:

1) Caseload levels are increasing. People are living longer due to lifesaving medications; there are at least 40,000 new infections each year; and increased testing programs, according to the CDC, will identify 12,000 to 20,000 new people infected with HIV each year. All of this will necessitate the need for more Ryan White services and medications.

2) The price of healthcare, including medications, is increasing and state and local budgets are experiencing cutbacks due to the economic downturn.

3) There are significant numbers of people in the U.S. who are not receiving life-saving AIDS medications. An IOM report concluded that 233,069 people in the U.S. who know their HIV status do not have continuous access to Highly Active Antiretroviral Therapy. A CDC study concluded 212,000 or 44% of eligible people living with HIV/AIDS, aged 15–49 in the US, are not receiving antiretroviral therapy.

Given these factors, cuts in funding or flat or minor increases are unacceptable. 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 urge you to reject the President's proposed cut of $7.7 million and instead request an increase of $213 million, for a total of $840 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 $95 million increase, for a total of $482 million.

The **AIDS Drug Assistance Program (ADAP)** provides life-saving HIV drug treatment to over 100,000 people; the majority of whom are people of color (60%) and very poor (80% are at or below 200% of the federal poverty level). Due to a lack of funding, states have not been able to include all necessary drugs on their formularies, have limited eligibility and capped enrollment. In order to address the 386 new ADAP clients each month and drug cost increases, we are requesting an increase of $134.6 million for a total of $943.5 million.

Part C provides early medical intervention and other supportive services to over 225,000 people at over 360 directly funded clinics. We are requesting a $100.5 million increase, for a total of $299 million.

Part D provides care to over 53,000 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 $48.8 million increase, for a total of $122.5 million.

Part F includes the AIDS Education and Training Centers (AETCs) program and the Dental Reimbursement program. We are requesting a $15.9 million increase for the AETC program, for a total of $50 million, and a $6 million increase for the Dental Reimbursement program, for a total of $19 million.

The AIDS Institute supports increased funding for the **Minority AIDS Initiative** (MAI). MAI funds services nationwide that address the disproportionate impact that HIV has on communities of color.

National Institutes of Health-AIDS Research

FY 2008:	$2.9 billion
FY 2009 President's Request:	$2.9 billion
FY 2009 Community Request:	$3.35 billion

Through the NIH, research is conducted to understand the AIDS virus and its complicated mutations; discover new drug treatments; develop a vaccine and other prevention programs such as microbicides; and ultimately, a cure. Much of this work at the NIH is done in cooperation with private funding. 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 best HIV can be prevented in various affected communities. We ask the Committee to fund critical AIDS research at the community requested level of $3.35 billion.

Administration for Children & Families: Community Based Abstinence Education

Efforts to improve prevention methods and weed out non-effective programs should be a constant undertaking and be guided by science and fact based decision-making. It is for these reasons The AIDS Institute opposes abstinence-only-until-marriage programs, for which the President requested a $28 million increase. While we support abstinence-based prevention programs as part of a comprehensive prevention message, there is no scientific proof that abstinence-only programs are effective. On the contrary, they reject proven prevention tools, such as condoms, and fail to address the needs of homosexuals, who can not marry, and who remain greatly impacted by HIV/AIDS.

Substance Abuse and Mental Health Services Administration

Many persons infected with HIV also experience drug abuse and/or mental health problems, and require the programs funded by SAMHSA. Given the growing need for services, we are disappointed by proposed funding cuts at SAMHSA, including $63 million for the Center for Substance Abuse Treatment, $36 million for the Center for Substance Abuse Prevention, and $126 million for the Center for Mental Health Services. We ask the Committee to reject these cuts, and adequately fund these programs.

Viral Hepatitis

Viral Hepatitis, whether A, B, or C, is an infectious disease that also deserves increased attention by the federal government. According to the CDC, there are an estimated 1.25 million Americans chronically infected with Hepatitis B, and 60,000 new infections each year. Although there is no cure, a vaccine is available, and a few treatment options are available. An estimated 4.1 million (1.6%) Americans have been infected with Hepatitis C, of whom 3.2 million are chronically infected. Currently, there is no vaccine and very few treatment options. It is believed that one-third of those infected with HIV are co-infected with Hepatitis C.

Given these numbers, we are disappointed the Administration is calling for a decrease in funding for Viral Hepatitis at the CDC. The program is currently being funded at a level that is substantially less than what it was funded in FY03 and falls short of the $50 million that is needed. These funds are needed to establish a program to lower the incidence of Hepatitis through education, outreach, and surveillance, and to support such initiatives as the CDC National Hepatitis C Prevention Strategy and the 2002 NIH Consensus Statement on the Management of Hepatitis C and accompanying recommendations.

The AIDS Institute asks that you give great weight to our testimony and remember it as you deliberate over the FY2009 appropriation bill. Should you have any questions or comments, feel free to contact Carl Schmid, Director of Federal Affairs, The AIDS Institute (202) 462-3042 or cschmid@theaidsinstitute.org. Thank you very much.

FY 2009 HOUSE APPROPRIATIONS COMMITTEE PUBLIC TESTIMONY

SUBMITTED BY THE ENDOCRINE SOCIETY

FOR THE SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND REALTED AGENCIES

DIRECTED AT THE DEPARTMENT OF HEALTH AND HUMAN SERVICES/NATIONAL INSTITUTES OF HEALTH

The Endocrine Society would like to submit the following testimony regarding Fiscal Year 2009 federal appropriations for biomedical research, with emphasis on appropriations for the National Institutes of Health. The Endocrine Society is the world's largest and most active professional organization of endocrinologists representing over 14,000 members worldwide. Our organization is dedicated to promoting excellence in research, education, and clinical practice in the field of endocrinology. The Society is comprised of thousands of researchers who depend on federal support for their careers and their scientific 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 National Institutes of Health (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.

Unfortunately, the gains experienced by the NIH during the doubling period have not kept pace with inflation. In FY 2008, the NIH received only a $300 million dollar increase and it may receive no increase in FY 2009 unless Congress alters the President's budget request. These funding levels are significantly below the 3.5 percent increase needed simply to maintain NIH's existing purchasing power. In order to fully understand the importance of maintaining the growth experienced during the doubling period, policymakers must first understand the impact that research programs have on patients and scientists.

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. In addition to improving quality and length of life, these advances in treatment also reduce the health care costs of our nation. Diabetes is a devastating condition that affects an increasingly large number of Americans and requires a large proportion of the nation's healthcare spending. More than 20 million Americans are affected by either type 1 or type 2 diabetes, and 11 percent of the nation's health care expenditures go to diabetes care. However, only about 3.5 percent of the National Institutes of Health (NIH) budget went to diabetes research in 2006. Congressional funding for diabetes research has been generous, but increasing incidence requires increased funding in order to stave off rising health care costs.

No new diabetes medications would have ever 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.

However, it is clear that there are many more pathways that remain to be discovered. These newly discovered pathways require continued research to bridge the gap from the basic lab bench and translate these discoveries for patients to use. The primary goals of medicine are to prevent and treat disease and to reduce suffering. Continued federal support for basic science and clinical research in diabetes will go a long way toward attaining those goals.

These advances in diabetes treatment would not have been possible without the efforts of the scientists who have chosen to dedicate their lives' work to identifying the next treatment or cure. As the amount of real dollars allocated to federal research funding declines, so too do the opportunities for researchers. As a result, scientists are often forced to find other careers or move to other countries to continue their research, depleting the pool of talent that government agencies and pharmaceutical companies have to draw from. Fewer scientists and less research would result in this country losing its place as a leader in medical progress. The U.S. government must acknowledge this potentially bleak future and place more value and emphasis on research and development efforts. Without these scientists in our workforce, many medical breakthroughs will either never happen or will happen as a result of overseas research.

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. For FY 2009, The Endocrine Society recommends that the NIH receive $31.1 billion in order to recoup the losses caused by biomedical inflation over the last few years, fund necessary new research programs, and build on the discoveries made during the doubling period.

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

March 30, 2008

The Honorable Dave Obey
Chairman
House Appropriations Subcommittee on Labor,
Health and Human Services, Education and Related Agencies
2358 Rayburn House Office Building
Washington, DC 20515

The Honorable James T. Walsh
Ranking Member
House Appropriations Subcommittee on Labor,
Health and Human Services, Education and Related Agencies
1016 Longworth House Office Building
Washington, DC 20515

Dear Mr. Chairman and Ranking Member Walsh:

Thank you for the opportunity to submit this written testimony with regard to the FY 2009 Labor-HHS-Education appropriations bill. My testimony is on behalf of the Brain Injury Association of America (BIAA), our national network of state affiliates, and hundreds of local chapters and support groups from across the country.

A traumatic brain injury (TBI) is a blow or a jolt to the head that temporarily or permanently disrupts brain function – i.e. who we are and how we think, act, and feel. In the civilian population alone very year, more than 1.5 million people sustain brain injuries from falls, car crashes, assaults and contact sports. Males are more likely than females to sustain brain injuries. Children, teens and seniors are at greatest risk.

And now we are seeing an increasing number of servicemembers returning from the conflicts in Iraq and Afghanistan with TBI, which has been termed one of the signature injuries of the War. The Army's Traumatic Brain Injury Task Force, released this past January, reported estimates that up to 20 percent of Marines and soldiers returning from Afghanistan and Iraq might have experienced brain injuries. This means that possibly upwards of 150,000 American troops have been, or will be, impacted by TBI as a result of ongoing combat operations. Many of these returning servicemembers 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 11 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 was gravely disappointed that last year, even as Congress had the good judgment to add hundreds of millions dollars to the budgets of the Department of Defense and the Department of Veterans Affairs to help address the problem of TBI among returning servicemembers, funding for the HRSA Federal TBI Program was reduced from $8.91 million to $8.754 million.

If I may, I would like to provide you with an example of the disconnect which results as a consequence of these appropriations decisions. Last year's reduction in funding for the HRSA Federal TBI Program means that one of our state affiliates - the Brain Injury Association of New York (BIANYS) – whose work has been supported through the HRSA Federal TBI Program, now may face reduced funding to support its current efforts to develop relationships with the New York State Division of Veterans Affairs in order to assist returning servicemembers with TBI and their families through the provision of training, education, collaboration, and outreach services.

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:

- **$9 million** for the Centers for Disease Control and Prevention TBI Registries and Surveillance, Prevention and National Public Education/Awareness;
- **$15 million** for the Health Resources and Services Administration (HRSA) Federal TBI State Grant Program; and
- **$6 million** for the HRSA Federal TBI Protection & Advocacy (P&A) Systems Grant Program.

In addition, BIAA urges you to provide sufficient funding in FY 2009 to enable the National Institute on Disability and Rehabilitation Research (NIDRR) within the Department of Education to sustain and increase its medical rehabilitation research portfolio and to continue its annual allocation of at least $8.3 million to fund 16 TBI Model Systems research centers. The FY2008 Defense Authorization bill, which was recently signed into law, includes specific language directing new TBI research efforts within the Department of Veterans Affairs to collaborate with NIDRR TBI research programs, such as the TBI Model Systems of Care. The TBI Model Systems of Care program has established a vital national network of expertise and research in the

field of TBI, and weakening this program would have deleterious effects on both military and civilian populations.

Last year, Congress provided $900,000 in additional stopgap funding for the TBI Model Systems of Care program in order to maintain 16 valuable TBI research centers around the country, and to prevent the nation's valuable TBI research capacity from being diminished. It is essential that Congress maintain this investment.

Furthermore, BIAA urges increased support for medical rehabilitation research at NIDRR, which is the country's lead federal agency on rehabilitation and disability research. In addition to the challenges of flat funding for NIDRR for at least the past five fiscal years, the agency has recently signaled an intent to narrow its focus to emphasize research of interest to its parent agency, the Office of Special Education and Rehabilitative Services (i.e., employment and vocational rehabilitation research) at the expense of research related to health and function, particularly medical rehabilitation research. NIDRR appears to be making a conscious effort to move away from a long-term, key aspect of the NIDRR research portfolio; improving the health and functioning of people with disabilities. Given the multi-dimensional character of the disability experience, NIDRR's scope needs to transcend the specific federal department and agency in which it is currently located.

In the recent past, NIDRR has eliminated funding for:

- A rehabilitation research and training center (RTC) on neuromuscular disease, the only federal source for rehabilitation research funding for persons with conditions such as ALS, muscular dystrophy, and peripheral nerve diseases;
- An RTC on arthritis and related musculoskeletal conditions;
- An RTC on health and wellness of people with spinal cord injuries; and
- An RTC on community integration of individuals with traumatic brain injury, one of the key aspects of functioning with a TBI over the long term.

Each of these grants were funded at $800,000 per year for a five-year period. Each of these centers developed valuable insight and disseminated meaningful information that improved the lives of these disability groups during the course of these grants.

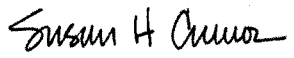
To make matters worse, NIDRR recently announced that grant announcements for four additional RTCs would be delayed and reformulated to focus attention on employment and vocational rehabilitation. These announcements may or may not be released over the remainder of this fiscal year. The four RTCs that have been delayed address the areas of Multiple Sclerosis, stroke, aging with a disability, and the psychiatric aspects of disability.

In order to preserve the valuable health and functioning research capacity developed by NIDRR over three decades, BIAA recommends that Congress increase the President's FY 2009 request by $3.2 million in new federal dollars in order to reinstate the four RTCs that were eliminated over the course of the past six months, and explicitly direct that these funds be used for the purposes of continuing these RTCs through a competitive grant process.

As for the four delayed RTCs addressing Multiple Sclerosis, stroke, aging with a disability, and the psychiatric aspects of disability, BIAA requests that Congress impress upon NIDRR in FY 2008 the importance of preserving the traditional focus of these research centers and direct NIDRR to expeditiously reissue competitive grant announcements for these critical research centers.

Thank you for this opportunity to testify. BIAA appreciates your leadership and looks forward to working with you in the months and years ahead to not only maintain, but enhance funding for federal TBI programs.

Sincerely,



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

The Nation's Voice on Mental Illness

3/25/08

STATEMENT OF ANAND PANDYA, MD,
PRESIDENT, NATIONAL ALLIANCE ON MENTAL ILLNESS
TO THE LABOR-HHS-EDUCATION SUBCOMMITTEE
COMMITTEE ON APPROPRIATIONS
U.S. HOUSE OF REPRESENTATIVES
REGARDING FY 2009 FUNDING FOR THE NATIONAL INSTITUTE OF MENTAL HEALTH (NIMH) AND THE SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION (SAMHSA)

MARCH 28, 2008

Chairman Obey and members of the Subcommittee, I am Anand Pandya, MD, President of the National Alliance on Mental Illness (NAMI). I am pleased today to offer NAMI's views on the Subcommittee's upcoming FY 2009 bill. With 210,000 members, NAMI is the nation's largest grassroots advocacy organization representing persons with serious brain disorders and their families. Through our 1,200 affiliates in all 50 states, we support education, outreach, advocacy and research on behalf of persons with serious brain disorders such as schizophrenia, manic depressive illness, major depression, severe anxiety disorders and major mental illnesses affecting children.

The cost of mental illness to our nation is enormous. It is estimated that the direct and indirect cost of untreated mental illness to our nation exceeds $82 billion annually. However, these direct and indirect costs do not measure the substantial and growing burden that is imposed on "default" systems that are too often responsible for serving children and adults with mental illness who lack access to treatment. These costs fall most heavily on the criminal justice and corrections systems, emergency rooms, schools, families and homeless shelters. Moreover, these costs are not only financial, but also human in terms of lost productivity, lives lost to suicide, and broken families. Investment in mental illness research and services are – in NAMI's view – the highest priority for our nation and this Subcommittee.

National Institute of Mental Health (NIMH) Research Funding
The National Institute of Mental Health (NIMH) is the only federal agency whose main objective is to fund biomedical research on serious mental illnesses. Through research, NIMH and the scientists it supports seek to gain an understanding of the fundamental mechanisms underlying illnesses that obstruct thought, emotion, and behavior and an understanding of what goes wrong in the brain in mental illness. NIMH strives, at the same time, to hasten the translation of this basic knowledge into clinical research that will

lead to better treatments and ultimately be effective in our complex world with its diverse populations and evolving health care systems.

For FY 2009, the President is proposing $1.407 billion for scientific and clinical research at the National Institute of Mental Health (NIMH). This is only a $2 million increase above the FY 2008 level, far below the level needed to keep pace with medical research inflation. Since 2003, the end of the 5-year effort by this Subcommittee to double biomedical research finding, the NIH has lost nearly 15% of its purchasing power as a result of flat budgets. If this trend is not reversed, the consequences for advancing mental illness research will be devastating. If NIMH funding continues to lag, we will lose the chance to define the individualized strategies and future medication options that this vital research heralds. A third generation of antipsychotic medication for schizophrenia, stronger antidepressant medication for depression and treatment strategies for bipolar disorder that improve long-term outcomes, are crucially important to those who suffer and will not be realized without further support from the federal government.

Further, we will be unable to fund in the United States whole genome studies for serious mental illness which could transform the understanding of the causes and risk factors for these devastating illnesses and open new avenues for effective treatment. Likewise, we will be unable to advance schizophrenia and bipolar research progress, for example, understanding if early intervention with medication, therapy and rehabilitation will prevent disability or morbidity in persons with new onset schizophrenia. Finally, continued flat funding for NIMH will prevent us from addressing the epidemic of suicide in this country, including a substantial number of our young people who die or are disabled before their lives have truly started and the elderly who are cheated from their retirement years.

For FY 2009, NAMI supports the recommendations of the Ad Hoc Group on Medical Research and the Mental Health Liaison Group for a 6.5% increase for the overall NIH budget and a similar increase for the NIMH. This would boost NIMH funding to $1.499 billion and allow the agency to regain lost purchasing power and keep pace with the Biomedical Research and Development Price Index.

Redefining NIMH to Its Mission

NAMI applauds NIMH's efforts to re-align the Institute along 3 core principles: relevance, traction, and innovation.

- **Relevance** refers to relevance to the mission. NIMH should continue its strong support of basic science, but as the NAMHC workgroup recommends in its report (http://www.nimh.nih.gov/council/brainBehavioralScience.cfm) some research areas are more relevant than others.
- **Traction** refers to the capacity for rapid progress in research areas where new tools, such as 2-photon imaging, yield definitive answers to long-standing questions.
- **Innovation** is often endangered during periods of limited budget growth. This work is highly relevant and NIMH is gaining traction, but unless a priority is placed on such "discovery" science, this unprecedented opportunity for innovation may not

receive the support it deserves.

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

Funding for Programs at SAMHSA's Center for Mental Health Services (CMHS)
The Center for Mental Health Services (CMHS) – part of the Substance Abuse and Mental Health Services Administration (SAMHSA) – is the principal federal agency engaged in support for state and local public mental health systems. Through its programs CMHS provides flexible funding for the states and conducts service demonstrations to help states move toward adoption of evidence-based practice.

Overall, the President is proposing a $209 reduction for the SAMHSA – dropping funding down to $3.025 billion for FY 2009. Within CMHS, funding would be reduced by $144 million, largely through reductions and terminations of a number of demonstration and technical assistance programs.

The President's request for major activities at CMHS for FY 2009 is as follows:

- The Mental Health Block Grant – Proposed for a current freeze at $421 million,
- The PATH Homeless Formula Grant - $60 million, a $7 million increase above current levels,
- Children's Mental Health - $114 million, a $12 million increase above current levels, and
- PAIMI Protection & Advocacy - $34 million, a $1 million reduction.

Beyond seeking to impose level funding for these SAMHSA programs, the President's budget seeks $144 million in overall reductions to Programs of Regional and National Significance (PRNS) at CMHS, dropping the FY 2008 appropriation from $299.3 million, down to $155.3 million. PRNS are largely demonstration, targeted capacity expansion and other discretionary activities at the agency. Most of these reductions would come through terminating research demonstration programs and technical assistance programs.

Among the activities within the PRNS account that are targeted for reductions are:

- Mental Health Transformation State Incentive Grants (SIGs) – The budget proposes no future SIG grants, a $26 million reduction,
- Mental Health System Transformation – A $20.8 million program proposed for elimination,
- Garrett Lee Smith Suicide Prevention State Grants – The budget proposes an $11.7 million reduction, from $29.5 million, down to $17.8 million,
- Homelessness Prevention and Service Demonstrations – Proposed for a an $10.6 million cut, from $13.6 million down to $2.8 million,
- Seclusion and Restrain Technical Assistance -- $2.4 million proposed for elimination,
- Criminal Justice and Juvenile Justice Grants – A $6.68 million activity for FY 2008, proposed for a $2.8 million reduction, and
- Older Adults – A $4.8 million program proposed for elimination.

NAMI urges the Subcommittee to restore these cuts to the CMHS PRNS program for FY 2009. These targeted capacity expansion and service demonstration initiatives are critical for the agency to continue its role as a leader in promoting replication of effective services that reach children and adults with serious mental illness.

Suicide Prevention Activities at SAMHSA

NAMI is especially troubled by the President's proposal to cut funding for suicide prevention activities under the Garrett Lee Smith Act. Each year, over 31,000 Americans die by suicide and over 1.4 million make a suicide attempt. Suicide deaths consistently outnumber homicide deaths by a margin of three to two. The statistics are troubling for our nation:

- In 2003, twice as many Americans died from suicide than from HIV/AIDS,
- Suicide is the third leading cause of death for those between the ages of 10 and 24 and the second leading cause of death for American college students,
- While the elderly comprise only 12% of the population, they account for about 18% of our nation's suicides,
- Research has shown that more than 90 percent of people who die by suicide have a mental illness and/or substance abuse disorder.

Congress must continue to invest in effective suicide prevention strategies. NAMI urges this Subcommittee to provide full funding for suicide prevention activities under the Garrett Lee Smith Act for FY 2009 -- $40 million.

Chronic Homelessness and Mental Illness

Together, Congress and the President have set a goal of ending chronic homelessness by 2012. Ninety states and local governments have responded to this challenge by creating plans to end homelessness, and 130 more states and local governments are in the process of developing similar plans. To address chronic homelessness, completed plans call for developing 80,000 new permanent supportive housing units. This will require creating 16,000 units of new permanent supportive housing for chronically homeless people in each of the next 5 years. Federal funding at the level of $5,000 per unit will leverage other resources to provide the comprehensive services needed to help chronically

homeless people achieve housing stability and pursue recovery from mental illness and substance abuse problems.

Over the course of a year, between 200,000 and 250,000 people experience long term or chronic homelessness. They are homeless for long periods of time or repeatedly, have one or more disabilities, and often cycle between homeless shelters, the streets, mental health facilities, emergency rooms, hospitals, and jails. The public cost for their care is extremely high, and their outcomes are very poor.

The current funding level of SAMHSA homeless programs is $56 million. The President's FY 2009 proposed budget recommended a $20 million funding cut to this total. NAMI urges an increase of $44 million for the Grants for the Benefit of Homeless Individuals (GBHI) and Treatment Systems for Homeless programs at SAMHSA, boosting funding to $100 million for FY 2009.

The Social Security Disability Claims and Appeals Backlog Crisis Must Be Addressed
Mr. Chairman, people with mental illness and other severe disabilities have been bearing the brunt of the backlog crisis for disability claims and appeals at Social Security. Behind the numbers are individuals with disabilities whose lives have unraveled while waiting for decisions – families are torn apart; homes are lost; medical conditions deteriorate; once stable financial security crumbles; and many individuals die. NAMI congratulates this Subcommittee on the progress made for FY 2008 with the appropriation for SSA's Limitation on Administrative Expenses (LAE), boosting it to $9.747 billion. This amount was $148 million above the President's request and was the first time in years that the agency has received at least the President's request. While the FY 2008 appropriation will allow the agency to hire some new staff and to reduce processing times, it will not be adequate to fully restore the agency's ability to carry out its mandated services.

The President's request for the SSA FY 2009 LAE is encouraging, but does not go far enough to put the agency on a clear path to provide its mandated services at a level expected by the American public. In order for SSA to meet its responsibilities, it is projected that the agency needs a minimum of $11.0 billion for its FY 2009 administrative budget. This amount will allow the agency to not only significantly reduce the backlog, but also keep local offices open, provide adequate telephone services to the public, and maintain the integrity of its programs by performing more continuing disability reviews and SSI redeterminations.

Conclusion
Chairman Obey, thank you for the opportunity to share NAMI's views on the Labor-HHS-Education Subcommittee's FY 2009 bill. NAMI's consumer and family membership thanks you for your leadership on these important national priorities.

Fiscal Year 2009 Testimony

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

Submitted by: Joseph C. Isaacs • Executive Director • Association of Women's Health, Obstetric and Neonatal Nurses • March 31, 2008

The Association of Women's Health, Obstetric and Neonatal Nurses (AWHONN) appreciates this opportunity to provide testimony on the fiscal year (FY) 2009 appropriations for the Department of Health and Human Services (HHS).

AWHONN is a specialty nursing organizations with nearly 23,000 nurses dedicated to the mission of advancing the health and well-being of women and newborns. AWHONN members are registered nurses, nurse practitioners, and certified nurse-midwives, who are clinicians, executives, managers and educators serving in hospitals and health systems, independent practices, universities, and community clinics throughout the United States.

Nurses are typically the first and most consistent point of contact in the health care setting. Evidence suggests that they spend more time with patients — up to four times on average — than any other health care provider. As such, nurses have a unique perspective on the health care system and the public health programs and agencies funded under HHS.

We appreciate the leadership of the Subcommittee in providing generous funding in past years to the important public health and biomedical research programs within its jurisdiction. We recognize the challenges the Subcommittee will face in FY 2009 in reconciling various expenditures in the face of overall budget deficits, but have faith that you will not sacrifice the nation's health needs in making these determinations.

AWHONN members know first hand the significant health returns our nations has achieved based on the investments made in the various programs discussed below. We urge your continuing support of them at levels that serve the nation adequately. We emphasize the term "adequately," as we and the large coalition of organizations that stand behind these recommendations believe the proposed funding levels are truly necessary just to maintain current progress in FY 2009 and do not represent "stretch" spending at this time of necessary trade-offs.

Health Resources and Services Administration (HRSA)

AWHONN recommends $7.9 billion for HRSA in FY 2009.

HRSA is responsible for a variety of programs ranging from support for health professions education to the care of underserved populations to the special needs of mothers and children. The funding for these programs has not kept pace with need and we cannot afford to lose further ground if the nation's safety net. Our health system's infrastructure is to be preserved in ways that ensure quality care in the United States.

- ***Title VIII - Nursing Workforce Development Programs***

AWHONN recommends $200 million for Title VIII programs in FY 2009. Title VIII programs help to address the nation's continuing nursing and nurse faculty shortage via scholarships, grants and loan repayments to nursing students, recent nursing graduates and nursing school faculty. Title VIII also provides grants to schools of nursing and health centers to foster greater diversity and improved retention rates in the nursing workforce.

The Nursing Shortage
Nursing is the nation's largest health care profession with nearly 2.5 million jobs. However, the U.S. is experiencing a shortage of nurses, which is expected to intensify as the baby-boomer population ages and the need for healthcare services and providers grows. Today, less than 9% of all nurses are under the age of 30. With the average age of nurses standing at 46.8 years old, a wave of retirements is expected in the near future.

According to projections from the U.S. Bureau of Labor Statistics, more than 1.2 million new and replacement nurses will be needed by 2014. Unless we act now, this shortage may jeopardize access to quality patient care.

The Nurse Faculty Shortage
In addition to a shortage of nurses at the bedside, the U.S. is also facing a shortage of nursing school faculty members. From 2002 to 2006 almost 129,000 *qualified* candidates were turned away from entry-level baccalaureate nursing programs. Almost 75% of nursing schools cited faculty shortages as a primary reason for not accepting all qualified applicants into nursing programs.

The average age of nurse faculty is 55 years old. Much like nurses at the bedside, a wave of retirements is expected in the coming years. However, according to an April 2006 report, HRSA projects that nursing schools must increase the number of graduates by 90% in order to adequately address the nursing shortage.

Without an adequate number of faculty members to prepare the next generation of nurses, the shortage is expected to intensify even further.

Title VIII Programs are Effective in Addressing the Shortages
Ongoing attrition among practicing nurses and faculty nurses due to retirement and the growing demand for health services have left the nation with a severe shortage of nurses.

Significant near- and long-term gains can be made in addressing the nursing shortage if Title VIII Nursing Workforce Development Programs are adequately funded. **AWHONN joins the larger nursing community and 155 members of the House of Representatives in requesting a funding level of $200 million for FY 2009.** This figure was determined based on an a serious calculation of what will be required to sustain current progress toward reversing the nursing shortages and averting a reversal of the positive momentum that has been achieved toward achieving needed workforce levels.

- ***Title V - Maternal and Child Health Block Grant (MCHB)***

AWHONN recommends $850 million for Title V in FY 2009. MCHB programs provide prenatal health services to two million women, and primary and preventive health care to more than 17 million children, including almost one million children with special health needs. Title V special projects target underserved urban and rural areas with efforts at the community level to promote collaboration between public and private sector leaders, and health care providers. Title V programs also underwrite public education campaigns addressing critical issues such as immunizations, prenatal care and healthy weight. In addition to targeting primary care to the underserved, Title V programs are essential to helping people to help themselves and avert costly health care services.

- ***National Health Service Corps (NHSC)***

AWHONN recommends 200 million for NHSC in FY 2009. The National Health Service Corps (NHSC) provides health care services to communities in serious need of qualified health professionals. The program enables clinicians, including nurses, to acquire scholarships or loan repayments for practicing in a designated Health Professional Shortage Area (HPSA) for a minimum of two years. Since 1972, more than 28,000 physicians, nurses, dentists, and mental health professionals have provided critical primary care services to the underserved through NHSC.

Currently, NHSC supports the important work of approximately 4,000 providers nationally, with a significant backlog of eligible candidates to meet needs estimated to require nearly 30,000 health care professionals nationwide. NHSC providers are a critically important element in our nation's health safety net and a means of supporting the education and practice of providers who are in categories of health professionals in undersupply across the country. The Administration's proposed FY 2009 cuts to this program would prove devastating to the Corps' ability to recruit and provide awards. We urge your leadership in averting this catastrophe at the reasonable funding level of 200 million that would be applied to both NHSC lines: the recruitment line, which provides the scholarship and loan repayments, and the field line which includes Ready Responders, SEARCH, and the Ambassador Programs.

National Institutes of Health (NIH)

AWHONN recommends a $1.9 billion increase for NIH funding, totaling $31.1 billion for FY 2009.

NIH is the world's leading medical research enterprise. Thanks to a doubling of the NIH budget in the 1990s, the U.S. has amassed a wealth of knowledge that continues to provide the science behind new discoveries and possible treatments for life's most devastating diseases. Research done at the NIH is leading to better patient care. Further, its outcomes are returning financially to the government via novel licensing agreements and patents; and to the overall U.S. economy through job creation in university labs , as well as private pharmaceutical and device companies.

The proposed increase in NIH funding for FY09 accounts for general inflation, as well as biomedical inflation, so that NIH can maintain its current purchasing power and continue to pursue groundbreaking research and life saving discoveries. While AWHONN supports the NIH in its entirety, several institutes are especially important to the advancement of nursing and the health and well-being of women and newborns.

- ***National Institute of Nursing Research (NINR)***

  AWHONN recommends $150 million for NINR in FY 2009. NINR supports nurse-led research that contributes to advancing high quality, evidence based care across the lifespan. Research at NINR has targeted, among other topics, health disparities, risk reduction, chronic illnesses and care for rural and underserved populations. NINR promotes a uniquely important nursing perspective, as there is no caregiver that interacts with patients more or is more trusted by patients than nursing professionals. There is no other body that funds important nursing research similarly in this country, and NINR research has contributed measurably to more efficient and effective health care as our nation struggles to fill continuing staffing shortages and gaps in health care services.

- ***National Institute of Child Health and Human Development (NICHD)***

  AWHONN recommends $1.34 billion for NICHD in FY 2009. NICHD is tasked with understanding human development, from pre-conception to adulthood. The Institute has many opportunities to research and correct some of the nation's leading health problems among our most vulnerable populations. Its legacy of contributions to the scientific literature and to diagnostics and treatments now in use is a testament to the value of past Congressional investment. There is no other Institute that devotes itself more to ensuring the quality of life and health care for women of childbearing age, and the potential for successful beginnings of life for their offspring.

- ***National Institute of Mental Health (NIMH)***

  AWHONN recommends $ 1.5 billion in for NIMH in FY 2009. NIMH aims to reduce the burden of mental illness and behavioral disorders through research on mind, brain and behavior. Tasked with researching some of our nation's most devastating mental and behavioral disorders, such as autism, bipolar disorder, and, in the instance of women of childbearing age, perinatal mood and anxiety disorders such as postpartum depression, NIMH has the potential by some estimates to improve the lives of one-third of all Americans who suffer some level of mental impairment.

- ***National Institute of Environmental Health Sciences (NIEHS)***

  AWHONN recommends $684 million for NIEHS in FY 2009. Research conducted by NIEHS plays a critical role in our understanding of environmental exposures and the health of Americans. Through their research, various types of cancer, birth defects, infertility and other chronic illnesses have been shown to be attributable in many instances to gene disruptions caused by exposure to environmental contaminants. These findings have tremendous potential to lead to means of averting or reversing the impacts of such disease triggers.

AWHONN thanks the committee for your consideration and greatly appreciates this opportunity to submit testimony on these critical funding areas.

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HOUSE COMMITTEE ON APPROPRIATIONS
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,
EDUCATION AND RELATED AGENCIES

TESTIMONY BY NANCY PERRY, VICE PRESIDENT OF GOVERNMENT AFFAIRS FOR
THE HUMANE SOCIETY OF THE UNITED STATES,
ON THE FY 2009 BUDGET
March 31, 2008

On behalf of The Humane Society of the United States (HSUS) and our more than 10 million supporters nationwide, we appreciate the opportunity to provide testimony on our top funding priority for the Labor, Health and Human Services, Education and Related Agencies Subcommittee in Fiscal Year 2008. We are also submitting our testimony on behalf of The Humane Society Legislative Fund (HSLF) and the Doris Day Animal League. Thank you for the opportunity to present testimony relevant for the Fiscal Year 2009 budget request.

The HSUS requests that no federal funding be appropriated for breeding of chimpanzees for research or for the transfer of government-owned chimpanzees to private hands (including endowments for their maintenance) unless for retirement to appropriate sanctuary. The basis of our request can be found below.

Breeding of Chimpanzees for Research

- The National Center for Research Resources has announced a permanent end to funding the breeding of federally owned and supported chimpanzees (including the funding of NIH for projects that require chimpanzee breeding) primarily due to the excessive costs of lifetime care of chimpanzees in laboratory settings. We seek to ensure that no other federal agency provides funding for breeding of government-owned chimpanzees due to the future financial implications to the government and taxpayers of doing so.

- The cost of maintaining chimpanzees in laboratories is exorbitant, totaling up to $8.5 million each year for the current population of approximately 600 federally owned or supported chimpanzees (up to $39 per day per chimpanzee; up to $854,000 per chimpanzee's 60-year lifetime). Breeding of additional chimpanzees into laboratories will only perpetuate a number of burdens on the government.
- The U.S. currently has a surplus of chimpanzees available for use in research due to overzealous breeding for HIV research and subsequent findings that they are a poor HIV model.[1]
- Expansion of the chimpanzee population in laboratories only creates more concerns than presently exist about their quality of care.
- Use of chimpanzees in research raises strong public concerns.

Transfer of ownership of government-owned chimpanzees

- If the government-owned and supported chimpanzees leave the federal system and are transferred into private hands with an accompanying federally-funded endowment, their lifetime support will not be guaranteed as required now by the CHIMP Act and their transfer to a suitable sanctuary will be highly unlikely. These chimpanzees will instead of warehoused and/or used for research for their entire lifetime—with the backing of the government through an endowment. This will surely lead to a public outcry.
- If private industry breeds and uses chimpanzees in invasive research with federal endowment money, the private sector would be unfairly, and perhaps illegally, benefiting from federally owned "resources" meant for the betterment of the American public, not for the profit of private industry.

- To date, the private sector has been less than fiscally responsible for the life time care of chimpanzees who they have used for private profit. Even in the situations where they eventually retire their chimpanzees, private users rarely offer financial compensation for their chimpanzees' lifetime care and on the few occasions that they have offered some financial compensation, it falls far short of what is actually needed.

We instead urge the government to transfer all 600 government-owned chimpanzees to the national sanctuary system and appropriate a portion of the funding currently being given to chimpanzee laboratories to the sanctuary system. A transfer of the chimpanzees to sanctuary would: (1) consolidate and lessen chimpanzee maintenance costs, (2) provide the chimpanzees with better care, and (3) offer the public the humane solution they are asking for.

Background and history

Beginning in 1995, the National Research Council (NRC) confirmed a chimpanzee surplus and recommended a moratorium on breeding of federally owned or supported chimpanzees[1], who now number approximately 600 of the 1200 total chimpanzees available for research in the U.S. On May 22, 2007 the National Center for Research Resources (NCRR) of NIH announced a permanent end to the funding of chimpanzee breeding, which applies to all federally-owned and supported chimpanzees. Further, it has also been noted that "a huge number" of chimpanzees are not being used in active research protocols and are therefore "just sitting there."[2] If no breeding is allowed, it is projected that the government will have almost no financial responsibility for the chimpanzees it owns within 30 years due to the age of the population—any breeding today will extend this financial burden to 90 years. There is no justification for breeding of additional chimpanzees for research; therefore lack of federal

funding for breeding will ensure that no breeding of federally owned or supported chimpanzees for research will occur in FY 2009.

Concerns regarding chimpanzee care in laboratories

Inspections conducted by the U.S. Department of Agriculture demonstrate that basic chimpanzee housing requirements are often not being met. Inspection reports for three federally funded chimpanzee facilities reported housing of chimpanzees in less than minimal space requirements, inadequate environmental enhancement, and/or general disrepair of facilities. These problems add further argument against the breeding of even more chimpanzees.

Chimpanzees have often been a poor model for human health research

The scientific community recognizes that chimpanzees are poor models for HIV because chimpanzees do not develop AIDS. Similarly, chimpanzees do not model the course of the human hepatitis C virus yet they continue to be used for this research, adding to the millions of dollars already spent without a sign of a promising vaccine. According to the chimpanzee genome, some of the greatest differences between chimpanzees and humans relate to the immune system[3], calling into question the validity of infectious disease research using chimpanzees.

Ethical and public concerns about chimpanzee research

Chimpanzee research raises serious ethical issues, particularly because of their extremely close similarities to humans in terms of intelligence and emotions. Americans are clearly concerned about these issues: 90% believe it is unacceptable to confine chimpanzees individually in government-approved cages; 71% believe that chimpanzees who have been in the laboratory for over 10 years should be sent to sanctuary for retirement[4]; and 54% believe that it is unacceptable for chimpanzees to "undergo research which causes them to suffer for human benefit."[5]

House Committee on Appropriations
Subcommittee on Labor HHS
The Humane Society of the United States
on the FY 2009 Budget
March 31, 2008

We respectfully request the following committee report language:

"The Committee directs that no funds provided in this Act be used to support the breeding of chimpanzees for research, to support research that requires breeding of chimpanzees, or to support the transfer of ownership of federally owned chimpanzees to private entities (including endowments for their maintenance). Exemption: transfer of the federally-owned chimpanzees to an appropriate sanctuary that meets the national chimpanzee sanctuary system standards."

We appreciate the opportunity to share our views for the Labor, Health and Human Services, Education and Related Agencies Appropriations Act for Fiscal Year 2009. We hope the Committee will be able to accommodate this modest request that will save the government a substantial sum of money, benefit chimpanzees, and allay some concerns of the public at large. Thank you for your consideration.

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1. NRC (National Research Council) (1997) *Chimpanzees in research: strategies for their ethical care, management and use*. National Academies Press: Washington, D.C.
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3. The Chimpanzee Sequencing and Analysis Consortium/Mikkelsen, TS, *et al.*,(1 September 2005) Initial sequence of the chimpanzee genome and comparison with the human genome, *Nature* 437, 69-87.
4. 2006 poll conducted by the Humane Research Council for Project Release & Restitution for Chimpanzees in laboratories
5. 2001 poll conducted by Zogby International for the Chimpanzee Collaboratory

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Statement of the American Society for Microbiology
Submitted to the House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies
on Fiscal Year 2009 Funding for the Centers for Disease Control and Prevention

The American Society for Microbiology (ASM) wishes to submit the following statement in support of increased funding for the Centers for Disease Control and Prevention (CDC). The ASM strongly believes that the CDC must receive sustained and sufficient funding to support its mission as the nation's principal public health agency. The Administration's proposed FY 2009 budget for CDC falls 7.5 percent below the FY 2008 level and clearly is inadequate to support CDC's science based programs which are so critical to preserving public health.

The recently released World Health Organization's (WHO) report of higher than expected incidences of extensively drug-resistant tuberculosis (XDR-TB), illustrates the consequences of underestimating the global threat from infectious diseases. In the United States, recent recalls of contaminated ground beef, peanut butter and produce, along with other events like the spread of drug-resistant staph infections in medical facilities and communities, also warn us against under funding of CDC programs in infectious disease surveillance and prevention.

The ASM believes that the Administration's FY 2009 proposed budget for CDC would undermine essential CDC capabilities. We recommend instead that Congress appropriate $7.4 billion for the FY 2009 CDC budget. With annual US healthcare costs projected by federal economists to exceed $4 trillion by 2017, it seems prudent to invest now in preventing diseases, present and future. We need to make increased investments in the CDC to slow or stop disease outbreaks through education, prevention, preparedness and research.

CDC Infectious Disease Programs Safeguard US and Global Public Health

The Administration's proposed funding cuts for the FY 2009 CDC budget will weaken the Agency's key infectious disease programs. The $1.87 billion allocated for infectious diseases is a decrease of $30 million, or 5.1 percent below the FY 2008 level. CDC's diverse programs include research and surveillance activities that must be sustained, long term, not suddenly created in response to some unexpected disease outbreak. CDC initiatives that focus on preparing against emerging infectious diseases or slowing the spread of antimicrobial resistant (AR) pathogens are wisely investing federal resources in cost effective prevention. All these programs rely on adequate Congressional appropriations that recognize infectious disease control as central to the CDC's overall mission of protecting the public. Unfortunately, the proposed individual program levels for FY 2009 would constrict these CDC activities, which is shortsighted given the ever changing nature of pathogens and patient populations.

Antimicrobial Resistance: Across the CDC, any program related to infectious disease must now consider potential pathogens that have evolved sufficiently to resist traditional

drug therapies. Last year's media reports of highly virulent staph infections among sports teams and international travelers infected with XDR-TB were snapshots of the reality that AR infections are steadily increasing in incidence and severity. A CDC study released in October determined that in the United States during 2005, methicillin-resistant *Staphylococcus aureus* (MRSA) caused more than 94,000 life threatening infections and nearly 19,000 deaths, the first national baseline of MRSA's impact on public health. Earlier CDC studies had determined that more than 70 percent of bacterial hospital-acquired infections are resistant to at least one of the antimicrobial drugs most commonly used to treat them. In 2007, the CDC made new treatment recommendations for gonorrhea after finding that rising numbers of cases are resistant to commonly used and previously highly effective antimicrobials. Surveillance data had shown that between 2001 and 2006, fluoroquinolone-resistant cases rose from less than 1 percent of reported infections to over 13 percent. Gonorrhea, the nation's second most commonly reported infectious disease, causes an estimated 700,000 new infections annually. Additionally, oseltamivir-resistant H1N1 was recognized in Europe and the US this year. Continued emergence of this strain could be a potential threat in the context of pandemic flu preparedness and the stockpiling of Tamiflu.

Another year of shrinking support for the CDC will undercut the nationwide strategy begun in 1999 with creation of the interagency Antimicrobial Resistance Task Force, co-chaired by the CDC. In 2001, the Task Force launched its Public Health Action Plan to Combat Antimicrobial Resistance, outlining an ambitious agenda to improve surveillance, prevention and control, and research and product development. Last fall, ASM commented on the Strategies to Address Antimicrobial Resistance Act (STAAR Act; HR 3697, S. 2313), which encourages greater federal efforts against AR infections, and recommended that the CDC be appointed the lead agency for the Task Force and the Action Plan. The Agency's infectious disease programs integrate proven CDC expertise that ranges from case reporting networks to research on faster diagnostic tests for field use. Monitoring outbreaks like those caused by MRSA, pathogenic E. coli, or XDR-TB, is optimized through CDC surveillance systems that include the National Healthcare Safety Network. However, as more and more hospitals are required via state mandates to report nosocomial infections including MRSA, they will have to register with the National Healthcare Safety Network database, causing a strain on this network. Additional resources will be necessary to for the database to support this growth.

ASM recommends that Congress appropriate additional resources for CDC antimicrobial resistance programs of $65 million in FY 2009. The Administration's FY 2009 CDC budget would instead cut allocations for AR activities to $16.5 million, 2.5 percent below last year. This is an unfortunate backward approach to a public health problem that is growing nationally and internationally.

Emerging Infectious Diseases: Funding for emerging infectious diseases (EID) would be cut under the proposed FY 2009 budget which decreases funding to "All Other Infectious Diseases" by $26.6 million, or 20 percent under last year's appropriation. ASM recommends that at a minimum, funding for this group of diseases should be restored to the FY 2007 or FY 2008 level of $130-132 million, with an adjustment for

inflation. Failure to do so could impinge on the CDC's capacity to quickly respond to EID outbreaks in the United States and abroad. Rapid responses rely upon a well funded infrastructure of special pathogens expertise and laboratories, training programs for state and local laboratory personnel, and domestic or global case reporting computer networks. Weak fiscal support of EID-related programs could slow what has been to date, very rapid CDC reaction, typified by the SARS, West Nile virus and foodborne outbreaks that mobilized CDC resources in recent years.

Unpredictable emerging and re-emerging infectious diseases are a constant in public health and must not be ignored. The viruses causing HIV infection and Ebola fever were once unknown pathogens eventually linked by scientists to newly emergent diseases. Long familiar diseases like dengue fever and cholera are today spreading to new geographic regions or reappearing in areas once thought freed of the diseases. CDC assisted studies reported in 2007 included discovery of a new, potentially deadly bacterial species isolated from a US traveler to Peru and related to trench fever. Researchers using a new molecular typing test developed by CDC reported that a viral strain typically tied to common colds and stomach flu, adenovirus 21, is becoming more virulent and more common in the United States, with half of the patients requiring hospitalization. The agency prepares for the unexpected through its time tested blend of ongoing surveillance, education and training programs, prevention protocols, and basic research on best methods. CDC uses these science based tools in an impressive range of activities that could be curtailed by the Administration's inopportune budget cuts for FY 2009.

If Congress does not reverse the downturn in CDC funding, another specific budget category to be reduced is the National Center for Zoonotic, Vector-Borne and Enteric Diseases (NCZVED), which addresses a broad range of relatively rare emerging pathogens and diseases like SARS, hantavirus, Ebola, and "mad cow" disease. The program also includes activities on far more prevalent disease like Lyme disease and foodborne diseases such as salmonellosis and E. coli 0157, as well as the growing threat of drug-resistant malaria, the reemergence of yellow fever in South America, and the increasing threat of dengue and dengue hemorrhagic fever throughout much of Asia and the Americas. The CDC 2009 request includes $60.6 million for NCZVED, a decrease of $7.2 million below FY 2008, despite the continual call for CDC expertise in special pathogens and food safety. For example, CDC recently confirmed test results from the national lab in Uganda that identified a new virus subtype causing an outbreak of Ebola fever. CDC also responded last year to outbreaks of Marburg hemorrhagic fever in Uganda and Rift Valley fever in Kenya, where it led efforts to establish a Rift Valley fever veterinary diagnostic laboratory. The agency also updated traveler advisories based on rising reports of mosquito-borne dengue fever in Latin America and the Caribbean. Disease patterns in this category can be altered by diverse elements like farming practices, human or vector migration, and climate patterns. Public health responses undoubtedly benefit from CDC's skillful collaboration among scientific disciplines and across national borders.

Additionally, Federal investment in the WNV program over the years has created a strong infrastructure assisting states in the prevention, detection and response to WNV and other

vector-borne diseases. Since FY 2007, however, program funding has dwindled causing concern that the infrastructure will not be able to support the core capacity of activities, including lab capacity and national, state and local expertise in all vector-borne diseases. Appropriate support for this program in FY 2009 and beyond is critical as WNV becomes more endemic in this country.

Finally, as foodborne disease outbreaks continue to rise, CDC needs additional resources to support databases such as PulseNet and FoodNet. Last year's investigation of over 700 cases of *Salmonella* infection in 48 states which were linked to contaminated peanut butter, is an example of CDC's real time surveillance and control efforts. Large multiple state investigations, however, are a strain on CDC's limited databases. Additional resources will help to improve and enhance these data collection networks.

HIV/AIDS, Viral Hepatitis, STDs and TB Prevention: The CDC budget category covering HIV/AIDS, hepatitis, sexually transmitted diseases (STDs), and tuberculosis characterizes the breadth of CDC responsibilities in protecting public health. Unfortunately, funding on these programs would stagnate under the FY 2009 budget, losing $2 million, or 0.2 percent of its FY 2008 level. The recent report of hepatitis C infections traced by public health officials to outpatient procedures at a Las Vegas clinic is a timely reminder that the various types of viral hepatitis, which kill more than 5,000 Americans annually, are not a minor health problem. New infections with sexually transmitted pathogens are rising in the United States. In 2006, more than 1 million cases of chlamydia broke the unenviable US record for annual reports of a sexually transmitted disease, but officials believe that actual case numbers are closer to 2.8 million. CDC surveillance networks also reveal that cases of syphilis and gonorrhea are increasing, complicated by drug resistant forms.

At the end of 2007, there were about 33.2 million persons worldwide living with HIV infection, including over 1 million in the United States. Co-infection with TB is becoming more prevalent (an estimated one third of persons living with HIV), and TB is the cause of death in up to half of AIDS cases. The concurrent spread of drug resistant forms of tuberculosis, especially in areas hard hit by HIV/AIDS, deeply worries public health experts. CDC should work towards assuring necessary laboratory support for tuberculosis diagnosis and sensitivity testing in areas where antiretroviral therapy and anti-tuberculosis therapy are being distributed in HIV endemic areas that are co-endemic with TB. Without such laboratory support, we are at risk of contributing to the MDR and XDR-TB epidemic through the use of ineffective drugs. Any advances made in diagnosis and controlling tuberculosis and HIV/AIDS must be preserved with sufficient federal funding. The Administration's proposed CDC FY 2009 budget does correctly recognize the opportunity offered by estimates that up to 25 percent of US cases are unaware of their infection, providing increased funds to expand domestic HIV testing and early diagnosis in high risk US locations and populations.

ASM Asks Congress to Reverse Erosion of CDC Funding

ASM recommends that Congress approve $7.4 billion for CDC funding in FY 2009. This request to significantly increase the CDC budget acknowledges the major contributions made by the agency to disease prevention in the United States and elsewhere. Whether focusing on influenza, bioterrorism, quarantine stations, or other priorities, ongoing CDC programs bring together agency and other scientists, along with health care officials and governments, to find science based solutions to complex situations. The CDC surveillance networks and field research teams can detect and help contain disease outbreaks anywhere in the world. The strength of CDC's many infectious disease programs lies in steady sources of talented personnel and sufficient funding. Eroding federal support with flat or declining appropriations is not the best advised approach to preserving the nation's public health.

WRITTEN TESTIMONY OF BARBARA HAYES, Ph.D.
CHAIRWOMAN

ASSOCIATION OF MINORITY HEALTH PROFESSIONS SCHOOLS

PRESENTED TO THE

APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES

COMMITTEE ON APPROPRIATIONS

U.S. HOUSE OF REPRESENTATIVES

SUMMARY OF FISCAL YEAR 2009 RECOMMENDATIONS:

1)$300 MILLION FOR THE TITLE VII HEALTH PROFESSIONS TRAINING PROGRAMS, INCLUDING:

- **$33.6 MILLION FOR THE MINORITY CENTERS OF EXCELLENCE.**

- **$35.6 MILLION FOR THE HEALTH CAREERS OPPORTUNITY PROGRAM.**

2)$250 MILLION FOR THE NATIONAL INSTITUTES OF HEALTH'S NATIONAL CENTER ON MINORITY HEALTH AND HEALTH DISPARITIES.

3)SUPPORT FOR THE NATIONAL CENTER FOR RESEARCH RESOURCES EXTRAMURAL FACILITIES CONSTRUCTION PROGRAM.

- **$ 6.7% INCREASE FOR RESEARCH CENTERS FOR MINORITY INSTITUTIONS.**
- **$ 119 MILLION FOR EXTRAMURAL FACILITIES CONSTRUCTION.**

4)$65 MILLION FOR THE DEPARTMENT OF HEALTH AND HUMAN SERVICES' OFFICE OF MINORITY HEALTH.

5)$65 MILLION FOR THE DEPARTMENT OF EDUCATION'S STRENGTHENING HISTORICALLY BLACK GRADUATE INSTITUTIONS PROGRAM.

Mr. Chairman and members of the subcommittee, thank you for the opportunity to present my views before you today. I am Dr. Barbara Hayes, Chairwoman of the Association of Minority Health Professions Schools (AMHPS) and the dean of the school of pharmacy at Texas Southern University. 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, time and time again, you have encouraged your colleagues and the rest of us to take a look at our nation and evaluate our needs over the next ten years. I want to say that minority health professional institutions and the Title VII Health Professionals Training programs address a critical national need. Persistent and 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. 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.

An October 2006 study by the Health Resources and Services Administration (HRSA), entitled "The Rationale for Diversity in the Health Professions: A Review of the Evidence" found that minority health professionals serve minority and other medically underserved populations at higher rates than non-minority professionals. The report also showed that; minority populations tend to receive better care from practitioners who represent their own race or ethnicity, and non-English speaking patients experience better care, greater comprehension, and greater likelihood of keeping follow-up appointments when they see a practitioner who speaks their language. **Studies have also demonstrated that when minorities are trained in minority health profession institutions, they are significantly more likely to: 1) serve in rural and urban medically underserved areas, 2) provide care for minorities and 3) treat low-income patients.**

As you are aware, Title VII Health Professions Training programs are focused on improving the quality, geographic distribution and diversity of the healthcare workforce in order to continue eliminating disparities in our nation's healthcare system. These programs provide training for students to practice in underserved areas, cultivate interactions with faculty role models who serve in underserved areas, and provide placement and recruitment services to encourage students to work in these areas. Health professionals who spend part of their training providing care for the underserved are up to 10 times more likely to practice in underserved areas after graduation or program completion.

Institutions that cultivate minority health professionals, like the AMHPS members, have been particularly hard-hit as a result of the cuts to the Title VII Health Profession Training programs in fiscal year 2006 (FY06), FY07, and FY08. Given their historic mission to provide academic opportunities for minority and financially disadvantaged students, and healthcare to minority and financially disadvantaged patients,

minority health professions institutions operate on narrow margins. The cuts to the Title VII Health Professions Training programs amount to a loss of core funding at these institutions and have been financially devastating.

In FY09, funding for the Title VII Health Professions Training programs must be restored to the FY05 level of $300 million, with two programs - the Minority Centers of Excellence (COEs) and Health Careers Opportunity Program (HCOPs) - in particular need of a funding restoration. In addition, the National Institutes of Health (NIH)'s National Center on Minority Health and Health Disparities (NCMHD), as well as the Department of Health and Human Services (HHS)'s Office of Minority Health (OMH), are both in need of a funding increase.

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.

Presently the statute is configured in such a way that the "original four" institutions compete for the first $12 million in funding, "Hispanic and Native American" institutions compete for the next $12 million, and "Other" institutions can compete for grants when the overall funding is above $24 million. For funding above $30 million all eligible institutions can compete for funding.

However, as a consequence of limited funding for COEs in FY06, FY07, and FY08, "Hispanic and Native American" and "Other" COEs have lost their support. Out of 34 total COEs in FY05, only 4 now remain due to the cuts in funding. Many AMHPS institutions lost its COE funding as well, which was a devastating blow to our institutions.

For FY09, I recommend a funding level of $33.6 million for COEs.

Health Careers Opportunity Program (HCOP)

HCOPs provide grants for minority and non-minority health profession institutions to support pipeline, preparatory and recruiting activities that encourage minority and economically disadvantaged students to pursue careers in the health professions. Many HCOPs partner with colleges, high schools, and even elementary schools in order to identify and nurture promising students who demonstrate that they have the talent and potential to become a health professional.

Collectively, the absence of HCOPs will substantially erode the number of minority students who enter the health professions. Over the last three decades, HCOPs have trained approximately 30,000 health professionals including 20,000 doctors, 5,000 dentists and 3,000 public health workers. If HCOPs continue to lose federal support, then these numbers will drastically decrease. It is estimated that the number of minority students admitted to health professional schools will drop by 25-50% without HCOPs. **A reduction of just 25% in the number of minority students admitted to medical school will produce approximately 600 fewer minority medical students nationwide.**

As a result of cuts in the FY06, FY07, and FY08 Labor-HHS Appropriations process, only 4 out of 74 total HCOPs currently receive federal funding.

For FY09, I recommend a funding level of $35.6 million for HCOPs.

NATIONAL INSTITUTES OF HEALTH (NIH): EXTRAMURAL FACILITIES CONSTRUCTION

Mr. Chairman, if we are to take full advantage of the recent funding increases for biomedical research that Congress has provided to NIH over the past decade, it is critical that our nation's research infrastructure remain strong. The current authorization level for the Extramural Facility Construction program at the National Center for Research Resources is $250 million. The law also includes a 25% set-aside for "Institutions of Emerging Excellence" (many of which are minority institutions) for funding up to $50 million. Finally, the law allows the NCRR Director to waive the matching requirement for institutions participating in the program. We strongly support all of these provisions of the authorizing legislation because they are necessary for our minority health professions training schools.

Unfortunately, funding for NCRR's Extramural Facility Construction program was completely eliminated in the FY06 Labor-HHS bill, and no funding was restored in the funding resolution for FY08. ***In FY09, please restore funding for this program to its FY04 level of $119 million, or at a minimum, provide funding equal to the FY05 appropriation of $40 million.***

RESEARCH CENTERS IN MINORITY INSTITUTIONS

The Research Centers at Minority Institutions program (RCMI) at the National Center for Research Resources has a long and distinguished record of helping our institutions develop the research infrastructure necessary to be leaders in the area of health disparities research. Although NIH has received unprecedented budget increases in recent years, funding for the RCMI program has not increased by the same rate. ***Therefore, the funding for this important program grow at the same rate as NIH overall in FY09.***

STRENGTHENING HISTORICALLY BLACK GRADUATE INSTITUTIONS - DEPARTMENT OF EDUCATION

The Department of Education's Strengthening Historically Black Graduate Institutions program (Title III, Part B, Section 326) is extremely important to 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 FY09, an appropriation of $65 million (an increase of $5.4 million over FY09) is suggested to continue the vital support that this program provides to historically black graduate institutions.

National Center on Minority Health and Health Disparities

The National Center on Minority Health and Health Disparities (NCMHD) is charged with addressing the longstanding health status gap between minority and nonminority populations. The NCMHD 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 NCMHD also supports biomedical research focused on eliminating health disparities and develops a comprehensive plan for research on minority health at the NIH. Furthermore, the NCMHD 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 FY09, I recommend a funding level of $250 million for the NCMHD.

Department of Health and Human Services' Office of Minority Health

Specific programs at OMH include:

1) Assisting medically underserved communities with the greatest need in solving health disparities and attracting and retaining health professionals,
2) Assisting minority institutions in acquiring real property to expand their campuses and increase their capacity to train minorities for medical careers,
3) Supporting conferences for high school and undergraduate students to interest them in health careers, and
4) Supporting cooperative agreements with minority institutions for the purpose of strengthening their capacity to train more minorities in the health professions.

The OMH has the potential to play a critical role in addressing health disparities. Unfortunately, the OMH does not yet have the authority or resources necessary to support activities that will truly make a difference in closing the health gap between minority and majority populations.

For FY09, I recommend a funding level of $65 million for the OMH.

Mr. Chairman, please allow me to express my appreciation to you and the members of this subcommittee. With your continued help and support, AMHPS's member institutions and the Title VII Health Professions Training programs can help this country to overcome health and healthcare disparities. Congress must be careful not to eliminate, paralyze or stifle the institutions and programs that have been **proven to work**. 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 SUSAN KELLY, Ph.D., F.A.P.S.
PRESIDENT
AND
CHIEF EXECUTIVE OFFICER

CHARLES R. DREW UNIVERSITY OF MEDICINE AND SCIENCE
1731 EAST 120TH STREET
LOS ANGELES, CA 90059

PRESENTED BEFORE THE

HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES

SUMMARY OF FISCAL YEAR 2009 RECOMMENDATIONS:

1) $300 MILLION FOR THE HEALTH RESOURCES AND SERVICES ADMINISTRATION TITLE VII HEALTH PROFESSISONS TRAINING PROGRAMS, INCLUDING:

   - $33.6 MILLION FOR THE MINORITY CENTERS OF EXCELLENCE AND

   - $35.6 MILLION FOR THE HEALTH CAREERS OPPORTUNITY PROGRAM.

2) PROVIDE A 6.7% INCREASE FOR FY2008 TO THE NATIONAL INSTITUTES OF HEALTH (NIH), SPECIFICALLY

   - A PROPORTIONAL INCREASE TO THE NATIONAL CANCER INSTITUTE (NCI),

   - $250 MILLION FOR THE NATIONAL CENTER ON MINORITY HEALTH AND HEALTH DISPARITIES (NCMHD),

   - SUPPORT THE NATIONAL CENTER FOR RESEARCH RESOURCES:

     - PROPORTIONAL INCREASE FOR RESEARCH CENTERS FOR MINORITY INSTITUTIONS AND INSTITUTIONAL DEVELOPMENT AWARD (IDeA) PROGRAM INSTITUTIONS AND

     - $119 MILLION FOR EXTRAMURAL FACILITIES CONSTRUCTION.

3) CONTINUE TO URGE NCI TO SUPPORT THE ESTABLISHMENT OF A COLLABORATIVE MINORITY HEALTH COMPREHENSIVE RESEARCH CENTER AT A HISTORICALLY MINORITY INSTITUTION IN COLLABORATION WITH THE EXISTING NCI CANCER CENTERS. CONTINUE TO URGE NCRR

AND NCMHD TO COLLABORATE ON THE ESTABLISHMENT OF A MINORITY HEALTH COMPREHENSIVE RESEARCH CENTER.

4) $65 MILLION FOR THE DEPARTMENT OF HEALTH AND HUMAN SERVICES' OFFICE OF MINORITY HEALTH, AND

- URGE SUPPORT FOR THE HEALTH PROFESSIONS LEADERSHIP DEVELOPMENT AND SUPPORT PROGRAM AT THE CHARLES DREW UNIVERSITY

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 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 and your predecessors, Mr. Chairman, for the support that this subcommittee has given to the National Institutes of Health (NIH) and its various institutes and centers over the years, NIH has been and continues to be invaluable to our university and especially our community.

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. In our over 35 years of enrolling students, the university has become a significant source of Latino and African American doctors and health professionals. We have made a measurable contribution to improving health care in this nation by graduating over 400 physicians, 2000 physician assistants, 2500 physician specialists, and numerous other health professionals - almost all from diverse communities. Even more importantly, our graduates go on to serve underserved communities and ten years later, over 70% of them are still working with people who are in most need and who have the poorest access to decent health care.

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. As you can see, we are a unique institution, and we serve a very important constituency, which regrettably, represents a growing segment of the overall US population.

Currently, The Charles Drew University is experiencing a period of positive, dynamic growth. Though our former affiliate hospital, Martin Luther King-Harbor, is experiencing difficulties, our institution is transforming and continues to make an expanding contribution to the health work force, by graduating the highest caliber of health professionals – particularly, significant number of Latinos and African Americans, who are highly sought after for employment and further training positions. Many serve in our community where recent circumstances and public health budget cuts have reduced

the number of beds and physicians back to the low level that existed in 1965, when the voiceless community of South Los Angeles was forced to rebel in order to get the health and social resources it deserves.

Our university continues to flourish and garner respect and support from our colleagues, community partners and those we serve. After thirty years, in partnership with the University of California, we are establishing our own four-year medical school and a new School of Nursing to prepare nurses as well as nursing faculty – particularly from minority populations. The Charles Drew University remains a beacon of hope for our students and our community as we have been since we began when we rose out of the ashes of the 1965 Watts civil unrest.

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.

HRSA's Minority Centers of Excellence (COE) and Health Careers Opportunity Program (HCOP) support health professions institutions with a historic mission and commitment to increasing the number of minorities in the health professions.

Mr. Chairman, in FY06 these programs were cut by over 50%. Unfortunately, those cuts were sustained in the funding resolution passed earlier in this Congress. Looking ahead a decade, as you have encouraged your colleagues and us to do, the cuts of recent years to these programs will seriously hamper our ability to provide the desperately needed healthcare advances for our citizens. Those cuts will widen the health disparities gap that is already far too wide, and they will exacerbate the already present national physician shortage, particularly in urban areas.

Minority Centers of Excellence: The purpose of the Minority Centers of Excellence (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 FY09, the funding level for Minority Centers of Excellence should be $33.6 million (an increase of $21.8 million over FY08).

Health Careers Opportunity Program: Grants made to health professions schools and educational entities under Health Careers Opportunity Program (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 FY09, the HCOP funding level of $35.6 million is suggested (an increase of $25.8 million).

NATIONAL INSTITUTES OF HEALTH'S CONTRIBUTION TO FIGHTING HEALTH DISPARITIES

Racial and ethnic disparities in health outcomes for a multitude of major diseases in minority and underserved communities continue to plague a nation that was built on the premise of equality. As articulated in the Institute of Medicine report entitled "Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care," this problem is not getting better on its own. For example, African American males develop cancer fifteen percent more frequently than their white counterparts. While African American women are not as likely as white women to develop breast cancer, they are much more likely to die from breast cancer once it is detected. In fact, according to the American Cancer Society, those who are poor, lack health insurance, or otherwise have inadequate access to high-quality cancer care, typically experience high cancer incidence and mortality rates. Similarly to African American populations, Latino communities suffer much higher incidences of heart disease, diabetes, obesity and some cancers than white populations. These devastating statistics beg for more research dollars and better access to quality clinical resources to address the deep-seated problems.

In response to these and similar findings in our own community and across the nation, The Charles Drew University has been working to build a new Life Sciences Research Facility on its campus. The Center will specialize in providing not only cutting-edge research but associated medical treatments for the community that focus on prevention and the development of new strategies in the fight against cancer. These strategies will be disseminated locally and nationally to communities at risk, as well as to others engaged in comprehensive cancer prevention programs everywhere.

Mr. Chairman, as I mentioned earlier, the support that the subcommittee has given to the National Institutes of Health (NIH) and its various institutes and centers has been and continues to be critical to the effectiveness of our university and our community. The dream of a state of the art research facility to aid in the fight against cancer and other

diseases in our underserved community would be infeasible in our disadvantaged location without the resources of NIH.

To help establish the Life Sciences Research Building and expand our innovative translational research activities that focus on improving the health of underserved communities, The Charles Drew University is requesting increased congressional support for the National Center for Research Resources (NCRR), the National Center for Minority Health and Health Disparities (NCMHD), the National Cancer Institute (NCI), Health Resources and Services Administration (HRSA) and the Department of Health and Human Services' Office of Minority Health.

National Center for Minority Health and Health Disparities: The National Center on Minority Health and Health Disparities (NCMHD) is charged with addressing the longstanding health status gap between under-represented minority and non minority populations. The NCMHD 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 NCMHD also supports biomedical research focused on eliminating health disparities and developed a comprehensive plan for research on minority health at NIH. Furthermore, the NCMHD 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 FY09, $250 million is recommended for NCMHD to support these critical activities.

Research Centers At Minority Institutions: The Research Centers at Minority Institutions program (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. The new Clinical and Translational Research Applications (CTSA) essentially preclude smaller institutions such as RCMI and IDeA schools to compete and link to the CTSA roadmap. We request an additional $40 million to support a CTSA-like roadmap mechanism for RCMI and IDeA schools, and $9.5 million to support the RCMI Translational Research Network, and also small grant mechanisms to fund pilot studies linked to the NIH Roadmap, the newly developed Global Alliance for HIV/AIDS, and community centers of health research and education excellence. This is a total of an additional $49.5 million in FY09.

Extramural Facilities Construction: Mr. Chairman, one issue that sets The Charles Drew University and many minority-dedicated institutions apart from the major universities of this country is the facilities where research takes place. The need for research infrastructure at our nation's minority serving institutions must also remain strong to maximize efforts to reduce health disparities. The current authorization level for the Extramural Facility Construction program at the National Center for Research Resources (NCRR) is $250 million.

TESTIMONY OF WAYNE J. RILEY, M.D., M.P.H., MBA, FACP
PRESIDENT
AND
CHIEF EXECUTIVE OFFICER

MEHARRY MEDICAL COLLEGE

PRESENTED BEFORE THE

HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES

SUMMARY OF FISCAL YEAR 2009 RECOMMENDATIONS:

1) **$300 MILLION FOR THE TITLE VII HEALTH PROFESSIONS TRAINING PROGRAMS, INCLUDING:**

   - **$33.6 MILLION FOR THE MINORITY CENTERS OF EXCELLENCE.**

   - **$35.6 MILLION FOR THE HEALTH CAREERS OPPORTUNITY PROGRAM.**

2) **$250 MILLION FOR THE NATIONAL INSTITUTES OF HEALTH'S NATIONAL CENTER ON MINORITY HEALTH AND HEALTH DISPARITIES.**

3) **$169 MILLION FOR THE NATIONAL CENTER FOR RESEARCH RESOURCES EXTRAMURAL FACILITIES CONSTRUCTION PROGRAM.**

   a. **$ 6.7% INCREASE FOR RESEARCH CENTERS FOR MINORITY INSTITUTIONS.**
   b. **$ 119 MILLION FOR EXTRAMURAL FACILITIES CONSTRUCTION.**

4) **$65 MILLION FOR THE DEPARTMENT OF HEALTH AND HUMAN SERVICES' OFFICE OF MINORITY HEALTH.**

5) **$65 MILLION FOR THE DEPARTMENT OF EDUCATION'S STRENGTHENING HISTORICALLY BLACK GRADUATE INSTITUTIONS PROGRAM.**

Mr. Chairman and members of the subcommittee, thank you for the opportunity to present my views before you today. I am Dr. Wayne J. Riley, President and CEO of Meharry Medical College in Nashville, Tennessee. I have previously served as vice-president and vice dean for health affairs and governmental relations and associate professor of medicine at Baylor College of Medicine in Houston, Texas and as assistant chief of medicine and a practicing general internist at Houston's Ben Taub General Hospital. In all of these roles, I have seen firsthand the importance of minority health professions institutions and the Title VII Health Professions Training programs.

Mr. Chairman, time and time again, you have encouraged your colleagues and the rest of us to take a look at our nation and evaluate our needs over the next ten years. I took you seriously and came here prepared to offer my best judgments. First, I want to say that it is clear that healthcare 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.

In FY08, funding for the Title VII Health Professions Training programs must be restored to the FY05 level of $300 million, with two programs - the Minority Centers of Excellence (COEs) and Health Careers Opportunity Program (HCOPs) - in particular need of a funding restoration. In addition, the National Institutes of Health (NIH)'s National Center on Minority Health and Health Disparities (NCMHD), as well as the Department of Health and Human Services (HHS)'s Office of Minority Health (OMH), are both in need of a funding increase.

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.

Presently the statute is configured in such a way that the "original four" institutions compete for the first $12 million in funding, "Hispanic and Native American" institutions compete for the next $12 million, and "Other" institutions can compete for grants when the overall funding is above $24 million. For funding above $30 million all eligible institutions can compete for funding.

However, as a consequence of limited funding for COEs in FY06, FY07, and FY08, "Hispanic and Native American" and "Other" COEs have lost their support. Out of 34 total COEs in FY05, only 4 now remain due to the cuts in funding.

For FY09, I recommend a funding level of $33.6 million for COEs.

Health Careers Opportunity Program (HCOP)

HCOPs provide grants for minority and non-minority health profession institutions to support pipeline, preparatory and recruiting activities that encourage minority and economically disadvantaged students to pursue careers in the health professions. Many HCOPs partner with colleges, high schools, and even elementary schools in order to identify and nurture promising students who demonstrate that they have the talent and potential to become a health professional.

Collectively, the absence of HCOPs will substantially erode the number of minority students who enter the health professions. Over the last three decades, HCOPs have trained approximately 30,000 health professionals including 20,000 doctors, 5,000 dentists and 3,000 public health workers. If HCOPs continue to lose federal support, then these numbers will drastically decrease. It is estimated that the

number of minority students admitted to health professional schools will drop by 25-50% without HCOPs. **A reduction of just 25% in the number of minority students admitted to medical school will produce approximately 600 fewer minority medical students nationwide.**

As a result of cuts in the FY06, FY07, and FY08 Labor-HHS Appropriations process, only 4 out of 74 total HCOPs currently receive federal funding. As President of Meharry, I feel this loss as we were one of the 70 institutions who lost their HCOP grants.

For FY09, I recommend a funding level of $35.6 million for HCOPs.

NATIONAL INSTITUTES OF HEALTH (NIH): EXTRAMURAL FACILITIES CONSTRUCTION

Mr. Chairman, if we are to take full advantage of the recent funding increases for biomedical research that Congress has provided to NIH over the past decade, it is critical that our nation's research infrastructure remain strong. The current authorization level for the Extramural Facility Construction program at the National Center for Research Resources is $250 million. The law also includes a 25% set-aside for "Institutions of Emerging Excellence" (many of which are minority institutions) for funding up to $50 million. Finally, the law allows the NCRR Director to waive the matching requirement for institutions participating in the program. We strongly support all of these provisions of the authorizing legislation because they are necessary for our minority health professions training schools.

Unfortunately, funding for NCRR's Extramural Facility Construction program was completely eliminated in the FY06 Labor-HHS bill, and no funding was restored in the funding resolutions for FY07 or FY08. ***In FY09, please restore funding for this program to its FY04 level of $119 million, or at a minimum, provide funding equal to the FY05 appropriation of $40 million.***

RESEARCH CENTERS IN MINORITY INSTITUTIONS

The Research Centers at Minority Institutions program (RCMI) at the National Center for Research Resources has a long and distinguished record of helping our institutions develop the research infrastructure necessary to be leaders in the area of health disparities research. Although NIH has received unprecedented budget increases in recent years, funding for the RCMI program has not increased by the same rate. *Therefore, the funding for this important program grow at the same rate as NIH overall in FY09.*

STRENGTHENING HISTORICALLY BLACK GRADUATE INSTITUTIONS - DEPARTMENT OF EDUCATION

The Department of Education's Strengthening Historically Black Graduate Institutions program (Title III, Part B, Section 326) is extremely important to MMC and other minority serving health professions institutions. The funding from this program is used to enhance educational capabilities, establish and strengthen program development offices, initiate endowment campaigns, and support numerous other institutional development activities. In FY09, an appropriation of $65 million (an increase of $5.4 million over FY08) is suggested to continue the vital support that this program provides to historically black graduate institutions.

National Center on Minority Health and Health Disparities

The National Center on Minority Health and Health Disparities (NCMHD) is charged with addressing the longstanding health status gap between minority and nonminority populations. The NCMHD 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 NCMHD also supports biomedical research focused on eliminating health disparities and develops a comprehensive plan for research on minority health at the NIH. Furthermore, the NCMHD 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 FY09, I recommend a funding level of $250 million for the NCMHD.

Department of Health and Human Services' Office of Minority Health

Specific programs at OMH include:

1) Assisting medically underserved communities with the greatest need in solving health disparities and attracting and retaining health professionals,
2) Assisting minority institutions in acquiring real property to expand their campuses and increase their capacity to train minorities for medical careers,
3) Supporting conferences for high school and undergraduate students to interest them in health careers, and
4) Supporting cooperative agreements with minority institutions for the purpose of strengthening their capacity to train more minorities in the health professions.

The OMH has the potential to play a critical role in addressing health disparities. Unfortunately, the OMH does not yet have the authority or resources necessary to support activities that will truly make a difference in closing the health gap between minority and majority populations.

For FY09, I recommend a funding level of $65 million for the OMH.

Mr. Chairman, please allow me to express my appreciation to you and the members of this subcommittee. With your continued help and support, Meharry Medical College along with other minority health professions institutions and the Title VII Health Professions Training programs can help this country to overcome health and healthcare disparities. Congress must be careful not to eliminate, paralyze or stifle the institutions and programs that have been **proven to work**. Meharry and other minority health professions schools seek to close the ever widening health disparity gap. If this subcommittee will give us the tools, we will continue to work towards the goal of eliminating that disparity as we have done for 1876.

Thank you, Mr. Chairman, for this opportunity.

Testimony of
Israel Mendoza, Chair
National Council of State Directors of Adult Education

Mr. Chairman, I want to thank you for the opportunity to share with you and the other Members of the Subcommittee information on the importance of increased funding for adult education programs.

My name is Israel David Mendoza and I am the Chairman of the National Council of State Directors of Adult Education as well as the current Director of the Adult Basic Education state office in Washington State.

I want to emphasize that the Council is not requesting increased funding at the expense of funding for K-12 and other key education programs. We see adult education as part of a continuum of lifelong education services. We recognize there is a great need, across programs, for increased funding.

It is my goal today to demonstrate why you should consider a substantial funding increase for adult education.

As you may be aware, adult education plays an instrumental role in the success of a variety of other federal programs, including job training, welfare, citizenship, health care, aging, and the education of our nation's children.

To clarify, many individuals seeking job training services, our unemployed and underemployed individuals, as well as welfare recipients, need to improve their academic and literacy skills before they can benefit from job training programs. Adult education fills that need.

Adult education also provides parents with the educational skills they need if they are to help their children succeed in school. Parents want to help their children with schooling but are challenged to do so if they themselves lack an adequate education. Adult education helps empower parents to become more involved in their child's education, such as attendance at school functions and parent/teacher conferences.

To immigrant populations, adult education provides a pathway to citizenship and the key English language and academic skills they need to assimilate and become part of the fabric of our great nation and local communities.

Adult education plays an important role in keeping our nation competitive. Only two percent of the annual workforce is recent graduates. Eighty percent of individuals who will make up the 2018 workforce are in the workforce now. Investing in the future workforce is important, but investing in the current workforce is critical.

As the demands of the workforce change, we must have a way to train and retrain our current workforce. Today's workers face more and more challenges as technology is constantly changing job requirements. We must ensure a well-educated workforce today at the same time as we prepare our children to be part of tomorrow's workforce. For those lacking a high school diploma or adequate literacy skills, the challenge of keeping current can be extremely difficult. We face the real prospect that jobs will be sent overseas merely because we do not invest in upgrading our workers' skills to meet current and future occupational demands.

We also have begun to recognize the unique connection between adult education and health care. According to the American Medical Association, forty six percent of adults cannot read and follow medical instructions. In addition, according to the National Assessment of Adult Literacy (NAAL), many of our nation's seniors have low levels of health literacy. Among adults who received Medicare or Medicaid, 27 percent and 30 percent, respectively, had ***below basic*** health literacy. Imagine you are a Medicare recipient trying to understand health care or prescription instructions or Medicare forms and you have low literacy skills. The same is true for Hispanic adults, who had lower average health literacy than adults in any other racial/ethnic group. For any of these individuals, not being able to understand health care instructions could have devastating results. Adult education programs are already working with health care organizations and senior groups forging relationships to create services to benefit seniors and other adults with low literacy skills.

A more recent target population for adult education is coming from adults who need to further their education but who are not yet college ready. Too often these individuals are placed in low level developmental or remedial education classes in colleges where they use Pell grants to pay for these classes. If the students succeed in making it through these courses, they often find that their Pell grant resources have been depleted. Adult education could provide much of the instruction offered in developmental education that covers the secondary level academic skills. By utilizing adult education, the student would retain access to Pell funds that could actually be used for college level coursework.

The need for adult education services nationwide was set forth in the National Assessment of Adult Literacy, conducted by the National Center for Education Statistics and released in December, 2005. According to the NAAL, approximately 93 million individuals (43% of the adult population) could benefit from adult education services. Thirty million of these individuals are at the lowest levels of literacy and have few of the skills they need to provide for the basic needs of their family. We know at this time there are more than 100,000 of these individuals waiting for services in programs throughout the United States. In a recent survey, forty of the forty-three states reporting had adult education programs with waiting lists. For example, 22 of 42 programs in Wisconsin reported waiting lists. Similar reports came from California, Connecticut, Idaho, Illinois, Maryland, Minnesota, New Mexico, New York, Ohio, Pennsylvania, and Rhode Island. An increase of $100 million would enable us to greatly reduce our waiting lists.

Mr. Chairman, we know the federal adult education program works. According to the Office of Management and Budget, Performance Assessment Rating Tool (PART), adult education is currently one of only four programs deemed to be "Effective"—OMB's highest rating. By OMB standards, adult education and literacy is a good investment of federal dollars. Although adult education has a proven track record, at the present time the system is able to serve only 3 million individuals in need a year, combining federal, state and local funds. The need is great.

We encourage you to increase funding for adult education state grants to a total of $750 million for FY 2009. With additional funds we can eliminate the waiting list and modestly expand our services and help many more high school dropouts, unemployed and underemployed individuals, parents, and new immigrants gain the skills they need to lead productive lives and contribute fully to their families and their communities.

We would also like to suggest a funding level of $99 million for Even Start. This unique program combines adult education with early childhood education to break the cycles of illiteracy that currently exist in many families throughout the United States.

Thank you again for allowing me to present our request for funding for adult education programs.

TESTIMONY OF SHERRY BLACK
SUBMITTED TO THE
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES APPROPRIATIONS

UNITED STATES HOUSE OF REPRESENTATIVES

SUBJECT: FISCAL YEAR 2009 APPROPRIATIONS FOR

THE FOSTER GRANDPARENT PROGRAM
A Program of the Corporation for National and Community Service

March 31, 2008

Mr. Chairman and Members of the Subcommittee, thank you for the opportunity to submit this testimony in support of FY 2009 funding for the Foster Grandparent Program (FGP), the oldest and largest of the three programs known collectively as the National Senior Volunteer Corps, which are authorized by Title II of the Domestic Volunteer Service Act (DVSA) of 1973, as amended and administered by the Corporation for National and Community Service (CNS). The National Association of Foster Grandparent Program Directors (NAFGPD) is a membership-supported professional organization whose roster includes the majority of more than 350 directors, who administer Foster Grandparent Programs nationwide, as well as local sponsoring agencies and others who value and support the work of FGP.

Mr. Chairman, I would like to begin by thanking you and the distinguished members of the Subcommittee for your steadfast support of the Foster Grandparent Program. No matter what the circumstances, this Subcommittee has always been there to protect the integrity and mission of our programs. Our volunteers and the children they serve across the country are the beneficiaries of your commitment to FGP, and for that we thank you. I also want to acknowledge your outstanding staff for their tireless work and very difficult job they have to "make the numbers fit." – an increasingly difficult task in this budget environment.

ADMINISTRATION'S REQUEST FOR FGP

Although the number of older people in America eligible to serve as Foster Grandparent volunteers is increasing by leaps and bounds as the "Baby Boomer" cohort ages, we were extremely disappointed to learn that – instead of seeking an increase for FGP to enable FGP to engage more low-income seniors in service – **the Administration has proposed slashing funding for FGP by $40.825 million – a more than 37% cut.**

IMPACT OF THE ADMINSTRATION'S PROPOSED FUNDING CUT

FGP is the **only** program in existence today that actively seeks out, trains, enables, places and supports the elderly poor in contributing to their communities by changing the lives of children who desperately need one-on-one attention and assistance. This cut will take FGP **back 12 years**, to a funding level that is only slightly **more than what was appropriated for the program in 1995.**

If enacted, this request will have a devastating effect on FGP programs nationwide:

- Funding for FGP would be slashed $40.825 million dollars.
- 10,200 Foster Grandparent volunteers will be cut permanently, slashing the total number of Foster Grandparent volunteers from 30,550 to 20,350.
- Local communities will lose more than 10 million hours of volunteer service every year.
- FGP will permanently lose almost 10,200 Volunteer Service Years (VSY's, or volunteer "slots") if this budget is implemented. For each VSY that is cut from a Foster Grandparent Program, that program will lose approximately $4,500 from its federal grant.
- 117,000 disadvantaged children/youth will lose their foster grandparent, an older adult they can count on!

- Low-income Baby Boomers will be excluded from serving as Foster Grandparents, because there will be no funds available to recruit and place new volunteers as they reach the age of 60. There are currently 6,000,000 low-income seniors eligible for FGP; in 20 years, there will be 13,000,000.

NAFGPD respectfully requests that the subcommittee:

1) **provide $115.937 million for the Foster Grandparent Program in FY 2009**, an increase of $5.000 million over the FY 2006 and FY 2007 levels of funding (and the amount FGP would have received in FY 2008 had there not been an across-the-board cut of 1.747%) for the program and an $47.763 million increase over the Administration's FY 2009 Bud get Request for FGP. This critical funding will ensure the continued viability of the Foster Grandparent Program, and allow for important expansion of this unique program. Specifically, this proposal would fund a 3% cost of living increase for every Foster Grandparent Program as well as expansion grants to existing programs that would add 370 new low-income senior volunteers to serve 3000 additional children;
2) **maintain current appropriations statutory language that prohibits CNCS from using funds in the bill to pay non-taxable stipends to volunteers whose incomes exceed 125% of the national poverty level.** Congress has repeatedly over the last seven years re-affirmed that the non-taxable stipend must be reserved for low-income volunteers. We ask that you again protect the mission of the Foster Grandparent Program to enable low-income older people to serve their communities – by maintaining this important statutory language.

FGP: AN OVERVIEW

Established in 1965, the Foster Grandparent Program was the first federally funded, organized program to engage older volunteers in significant service to others. It remains today the only volunteer program in existence that enables seniors living on very low incomes to serve as community volunteers by providing a small non-taxable stipend that allows volunteers to serve at little or no cost to themselves. From the 20 original programs based totally in institutions for children with severe mental and physical disabilities, FGP now comprises nearly 350 programs in every state and the District of Columbia, Puerto Rico, and the Virgin Islands. These programs are now primarily in community-based child caring agencies or organizations -- where most special needs children can be found today -- and are administered locally through a non-profit organization or agency and Advisory Council comprised of community citizens dedicated to FGP and its mission. FGP represents the best in federal partnerships with local communities, with federal dollars flowing directly to local sponsoring agencies, which in turn determine how the funds are used. Through this partnership and the flexibility of the program, FGP is able to meet the immediate needs of the local communities. This was demonstrated by Foster Grandparent Programs in communities that were impacted by the influx of Hurricane Katrina evacuees. Foster Grandparents rallied to provide services to children in shelters, child care centers, and schools.

FGP: THE VOLUNTEERS

There are currently 30,500 Foster Grandparent volunteers who give 31 million hours annually to more than 280,000 children, including almost 6,000 children of prisoners through 10,200 local agencies. FGP is a versatile, dynamic, and uniquely multi-purpose program. The program gives Americans 60 years of age or older, who are living on incomes at or less than 125% of the poverty level, the opportunity to serve 15 to 40 hours every week and use the talents, skills and wisdom they have accumulated over a lifetime to give back to the communities which nurtured them throughout their lives. FGP provides intensive pre-service orientation and at least 48 hours of ongoing training every year to keep volunteers current and informed on how to work with children who have special needs.

FGP engages older people who are not usually asked to serve, those usually considered as needing services rather than being able to serve: 50% are between the ages of 61 and 74, 47% are 75+, and 50% are from various ethnic groups. FGP actively seeks out these low-income seniors. We dare to ask them to serve, and we help them to develop the additional skills they may need to function effectively in settings unfamiliar to them, like public schools, hospitals, childcare centers, and juvenile detention facilities. Through their service, our older volunteers say they feel and stay healthier, that they feel needed and productive. Most importantly, they leave to the next generation a legacy of skills, perspective and knowledge that has been learned the hard way—through experience.

FGP: THE CHILDREN

Through our volunteers, FGP also provides person-to-person service to children and youth under the age of 21 who have special or exceptional needs, many of whom face serious, often life-threatening challenges. With the changing dynamics in family life today, many children with disabilities and special needs lack a consistent, stable adult role model in their lives. The Foster Grandparent is very often the only person in a child's life who is there every day, who accepts the child, encourages him/her no matter how many mistakes the child makes, and focuses on the child's successes.

Special needs of children served by Foster Grandparents include AIDS or addiction to crack or other drugs; abuse or neglect; physical, mental, or learning disabilities; speech, or other sensory disabilities; incarceration and terminal illness. Of the children served, 7% are abused or neglected, 25% have learning disabilities, and 10% have developmental delays. FGP focuses its resources in areas where they will have the most impact: early intervention services and literacy activities. Nationally, 90% of the children served by Foster Grandparents are under the age of 12, with 39% of these children age 5 or under. Foster Grandparents work intensively with these very young children to address their problems at as early an age as possible, before they enter school. Nearly one-half of FGP volunteers serve nearly 12 million hours annually addressing literacy and emergent-literacy problems with special needs children.

Activities of the FGP volunteers with their assigned children include teaching parenting skills to teen parents; providing physical and emotional support to babies and toddlers at-risk; helping children with developmental delays, speech, or physical disabilities develop social and self-help skills; reinforcing reading and mathematic skills; and giving guidance and serving as mentors to incarcerated or other youth.

FGP: THE VOLUNTEER SITES

The Foster Grandparent Program provides child-caring agencies and organizations offering services to special-needs children with a consistent, reliable, invaluable extra pair of hands **15 to 40 hours every week** to assist in providing these services. Seventy-one percent of FGP volunteers serve in public and private schools as well as sites that provide early childhood pre-literacy services to very young children, including Head Start.

FGP: COST-EFFECTIVE SERVICE

The Foster Grandparent Program serves local communities in a high quality, efficient and cost-effective manner, saving local communities money by helping our older volunteers stay independent and healthy and out of expensive in-home or institutional care. Using the Independent Sector's 2006 valuation for one hour of volunteer service ($18.77/hour), the value of the service given by Foster Grandparents annually is **over $503 million**, and represents a 4-fold return on the federal dollars invested in FGP.

The value local communities place on FGP and its multifaceted services is evidenced by the large amount of cash and in-kind donations contributed by communities to support FGP. For example, FGP's FY 2007 federal allocation was matched with $36.1 million in non-federal donations from states and local communities in which Foster Grandparents volunteer. **This represents a non-federal match of 26% - well over the 10% local match required by law.**

CONCLUSION: The message is clear: 1) the population of low-income seniors available to volunteer 15 to 40 hours every week is increasing; 2) communities need and want more Foster Grandparent volunteers and more Foster Grandparent Programs. The Subcommittee's continued investment in FGP now will pay off in savings realized later, as more seniors stay healthy and independent through volunteer service, as communities save tax dollars, and as children with special needs are helped to become contributing members of society.

Mr. Chairman, in closing I would like to again thank you for the subcommittee's support and leadership for Foster Grandparent Programs over the years. The National Association of Foster Grandparent Program Directors believes that you and your colleagues in Congress appreciate what our low-income senior volunteers accomplish every day in communities across the country.

Statement of the American Society for Nutrition (ASN)
Submitted to the House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies on Fiscal Year 2009 Funding for the National Institutes of Health and the National Center for Health Statistics

The American Society for Nutrition (ASN) appreciates this opportunity to submit testimony regarding fiscal year (FY) 2009 appropriations for the National Institutes of Health (NIH) and the National Center for Health Statistics (NCHS). ASN is the professional scientific society dedicated to bringing together the world's top researchers, clinical nutritionists and industry to advance our knowledge and application of nutrition to promote human and animal health. Our focus ranges from the most critical details of research to very broad societal applications. **ASN respectfully requests $31.2 billion for NIH, and we urge you to adopt the President's request of $125 million for NCHS in fiscal year (FY) 2009.**

Basic and applied research on nutrition, nutrient composition, the relationship between nutrition and chronic disease and nutrition monitoring are critical to the health of all Americans and the U.S. economy. Awareness of the growing epidemic of obesity and the contribution of chronic illness to burgeoning health care costs has highlighted the need for improved information on dietary components, dietary intake, strategies for dietary change and nutritional therapies. Preventable chronic diseases related to diet and physical activity cost the economy over $117 billion annually, and this cost is predicted to rise to $1.7 trillion in the next ten years. It is for this reason that we urge you to consider these recommended funding levels for two agencies under the Department of Health and Human Services that have profound effects on nutrition research, nutrition monitoring, and the health of all Americans—the National Institutes of Health and the National Center for Health Statistics.

National Institutes of Health
The National Institutes of Health (NIH) is the nation's premier sponsor of biomedical research and is the agency responsible for conducting and supporting 90 percent (nearly $1 billion) of federally-funded basic and clinical nutrition research. Nutrition research, which makes up about four percent of the NIH budget, is truly a trans-NIH endeavor, being conducted and funded across multiple Institutes and Centers. Some of the most promising nutrition-related research discoveries have been made possible by NIH support.

In order to fulfill the extraordinary promise of biomedical research, including nutrition research, **ASN recommends an FY 2009 funding level of $31.2 billion for the agency, which is a $1.9 billion increase over FY 2008.**

Over the past 50 years, NIH and its grantees have played a major role in the explosion of knowledge that has transformed our understanding of human health, and how to prevent and treat human disease. Because of the unprecedented number of breakthroughs and discoveries made possible by NIH funding, scientists are helping Americans to live longer, healthier and more productive lives. Many of these discoveries are nutrition-related and have impacted the way clinicians prevent and treat heart disease, cancer, diabetes and age-related macular degeneration.

During the next 25 years, the number of Americans with chronic disease is expected to reach 46 million, and the number of Americans over age 65 is expected to be the largest in our nation's history. Sustained support for basic and clinical research is required if we are to confront successfully the health care challenges associated with an older, and potentially sicker, population.

Unfortunately, over the last five years the NIH budget has failed to keep up with inflation and subsequently, the percentage of dollars funding nutrition-focused projects has declined. Flat budgets have reduced the purchasing power of the agency by 13 percent, and the success rate for research proposals to NIH likely will be reduced by half from that of six years ago. New opportunities for ground-breaking research are going unfunded, and there is a chance that the number of new therapies under development will begin to decrease. It is imperative that we renew our commitment to biomedical research and to fulfill the hope of the American people by making the NIH a national priority. Otherwise, we risk losing our nation's dominance in biomedical research.

CDC National Center for Health Statistics

The National Center for Health Statistics (NCHS), housed within the Centers for Disease Control and Prevention (CDC), is the nation's principal health statistics agency. The NCHS provides critical data on all aspects of our health care system, and it is responsible for monitoring the nation's health and nutrition status. Nutrition and health data, largely collected through the National Health and Nutrition Examination Survey (NHANES), is essential for tracking the health and well being of the American population, and it is especially important for observing health trends in our nation's children. Knowing both what Americans eat and how their diets directly affect their health provides valuable information to guide policies on food safety, food labeling, food assistance, military rations and dietary guidance.

Over the past few years, flat and decreased funding levels have threatened the collection of this important information, most notably vital statistics and the NHANES. To address this problem, **ASN recommends an FY 2009 funding level of $125 million for the agency, which is an $11 million increase over FY 2008.** This recommendation is consistent with the funding level recommended by President Bush in his FY 2009 budget proposal.

Current funding levels for NCHS are precarious. Before the modest increase Congress provided last year, NCHS had lost $13 million in purchasing power since FY 2005 due to years of flat funding, coupled with inflation and the increased costs of technology and information security. These shortfalls forced the elimination of data collection and quality control efforts, threatened the collection of vital statistics, stymied the adoption of electronic systems and limited the agency's ability to modernize surveys to reflect changes in demography, geography, and health delivery.

Moreover, nearly 30 percent of the funding for NHANES comes from other federal agencies such as the NIH and the Environmental Protection Agency. When these agencies face flat budgets or cuts, they withdraw much-needed support for NHANES, placing this national treasure in even greater jeopardy.

The obesity epidemic is a case in point that demonstrates the value of the work done by NCHS. It is because of NHANES that our nation became aware of this growing public health problem, and as obesity rates have increased to 31 percent of American adults (which we know because of continued monitoring), so too have rates of heart disease, diabetes and certain cancers. It is only through continued support of this program that the public health community will be able to stem the tide against obesity. Continuous collection of this data will allow us to determine not only if we have made progress against this public health threat, but also if public health dollars have been targeted appropriately. A recent report from the Institute of Medicine recognized the importance of NHANES and called for the enhancement of current surveillance systems to monitor relevant outcomes and trends with respect to childhood obesity.[1]

In addition to our FY 2009 request, we urge the Committee to consider a path to boost funding for the NCHS to $175 million by 2013. Reaching this level over five years, through annual increases of $11 million, would allow the agency to reach what its supporters call "blue sky." Such an increase would ensure uninterrupted collection of vital statistics and sustain over-sampling of vulnerable populations.

ASN thanks your Committee for its support of the NIH and NCHS in previous years. If we can provide any additional information, please contact Mary Lee Watts, ASN Director of Public Affairs, at (301) 634-7112 or mwatts@nutrition.org.

Sincerely,

Joanne R. Lupton

Joanne R. Lupton, PhD
President, American Society for Nutrition

[1] Institute of Medicine. *Progress in Preventing Childhood Obesity* Washington, DC: National Academies Press, 2006.

Testimony of

Sharon P. Robinson
President and CEO
American Association of Colleges for Teacher Education

Representing the American Association of Colleges for Teacher Education

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

This testimony addresses the need for the federal government to invest more substantially in the preparation of PK-12 school personnel.

Serving Learners

March 18, 2008

The Honorable David Obey
Chairman
Subcommittee on Labor, HHS, and Education
House Committee on Appropriations
2314 Rayburn House Offices Building
Washington, D.C. 20515

The Honorable James T. Walsh
Ranking Member
Subcommittee on Labor, HHS, and Education
House Committee on Appropriations
2369 Rayburn House Office Building
Washington, D.C. 20515

Dear Chairman Obey and Ranking Member Walsh:

I want to extend my appreciation to you and your colleagues in Congress for your support of federal education programs. Your commitment makes a significant difference for the education of our millions of PK-12 and post-secondary students.

As you and your colleagues begin the FY 2009 appropriations process, **the American Association of Colleges for Teacher Education (AACTE) urges you to increase the federal government's investment in the preparation of school personnel**. While there are significant funds behind Title II of the No Child Left Behind Act in the Improving Teacher Quality State Grants, the vast majority of these funds, and other funds in Title II, go towards class size room reduction and the professional development of practicing teachers. Equally important, though, is the preparation of teachers and other school personnel. And, in this respect, the federal government's investment has declined over the years. As this nation is in the midst of teacher retention and shortage crises, it is critical that the government responds with a plan that provides for systemic change.

There are several programs within the Department of Education intended to strengthen and improve school personnel recruitment and preparation efforts. We are working with program authorizers in Congress and staff within the agencies to ensure that these programs work in concert with each other. However, one of the key factors that prevents these programs from becoming agents of systemic change is the consistent under-funding of these programs. The cost of preparing school personnel is significant. With the TEACH Grant program (authorized in the College Cost Reduction and Access Act) slated to begin soon, we anticipate that the scholarship money for prospective teachers will be a significant recruitment tool. However, the programs that prepare these candidates need to be strengthened and expanded so that they have the capacity to prepare more and higher quality teachers.

Below you will find AACTE's recommendations for FY 2009.

1. **Fund the Teacher Quality Enhancement Grant program at the $60 million level**– 90% of all school personnel are prepared or receive professional development through higher education institutions. Yet, the TQE program and the Teachers for a Competitive Tomorrow program (see next bullet) are the only federal programs targeted directly to higher-education based educator preparation programs. The TQE program is authorized at the $300 million level but is currently funded at only $33.6 million. By increasing funding to $60 million this would bring it back to the FY 2007 funding level. Included within both the House and Senate Higher Education Act reauthorization proposals is a significantly revised and strengthened authorization for the Teacher Quality Enhancement Grant program. The grants will be given to partnerships that include higher education institutions and K-12 schools and that have, at a minimum, a one year clinical component required of the candidates that go through these programs. Grants under both proposals can be used to develop one-year teacher residency programs for which the teacher candidate would be given a living stipend during the program. These are all good improvements to the program, but there needs to be increased funds to support the changes. The clinical component teacher preparation is often the most expensive component. Additionally, the living stipend required of the residency programs is a significant financial commitment for the institution.

2. **Fund Teachers for a Competitive Tomorrow at the $60 million level** – This is a new program authorized in the America Competes Act, and it is currently funded at $1.96 million. AACTE recommends funding the program at the $60 million level so that it is on par with our proposed funding for the TQE program. With the teacher shortage and retention crisis acutely felt in the math and science teaching fields, this program is a crucial piece of the response to ameliorate the teacher shortage challenges. This competitive grant program helps higher education institutions build baccalaureate and master's degree programs that allow students to major in STEM fields while working toward teacher certification.

3. **Fund the Transition to Teaching program at the $60 million level** – This program, authorized in Title II of NCLB at the $150 million level and currently funded at $43.7 million, supports the development of teacher preparation programs suited for career-changers and others who enter teaching through non-traditional routes. Higher education institutions and other entities have used funds from this program to develop innovative preparation programs that accommodate the needs of a diverse educator candidate pool while ensuring that candidates are prepared to teach in today's K-12 classrooms.

4. **Fund the Troops-to-Teachers program at the $25 million level** – Like Transition to Teaching, this program aims to attract teachers from another profession into the classroom. With the significant number of active duty troops throughout the world, there is also an increasing number of troops who are leaving the military after completing their service. Troops-to-Teachers has been very successful at recruiting retired military into the teaching profession. By funding the program at $25 million, this would almost double the government's investment in the program (currently at $14.4 million) during a time in which there is higher military interest in entering the K-12 teaching ranks.

5. **Fund the IDEA Personnel Preparation program at the $120 million level** – Currently funded at $88.15 million, this program provides essential funds to prepare and develop special educators. Special education teachers, much like math and science teachers, are in high demand in the K-12 schools with the shortage being significant. With the wide breadth and increasing number of special need students there needs to be an adequate supply of teachers who can work with them to ensure student learning. The concomitant shortage of special education faculty continues to persist.

6. **Fund the Elementary and Secondary School Counseling program at the $61.5 million level** – AACTE is pleased that this program received a boost in FY 2008 appropriations and urges you to continue to increase the investment. $61.5 million is what the House put forward in its FY 2008 appropriations bill, and AACTE along with the American School Counselors Association, recommends that Congress adopt this number for FY 2009. School counselors play a vital role in the school community by providing not only psychological services to K-12 students but also college and employment advising.

7. **Fund the School Leadership Grant program at the $16 million level** - Current funding for the program is at $14.7 million. AACTE supports the National Association of Elementary School Principals' and the National Association of Secondary School Principals recommendation to fund this program at $16 million. A key factor in turning around a low-performing school and maintaining a successful school is the principal and other school leaders. Principals need significant preparation in school management, curriculum development, and pedagogical instruction in order to work effectively with their teachers and students.

8. **Fund the Math and Science Partnership program at the $450 million level**– AACTE supports the STEM Education Coalition's recommendation to fully fund this program at its authorization level of $450 million. With current funding at $178.9 million, this program needs a significant boost to have a systemic impact on the preparation of STEM teachers. The MSP helps build the capacity of higher education institutions to prepare and provide professional development for K-12 STEM teachers.

The American Association of Colleges for Teacher Education (AACTE) is a national voluntary association of higher education institutions and other organizations and is dedicated to ensuring the highest quality preparation and continuing professional development for teachers and school leaders. Our overarching mission is to enhance PK-12 student learning. Collectively, the AACTE membership prepares more than two-thirds of the new teachers entering schools each year in the United States.

If you or your staff have any questions, please do not hesitate to contact Jane West at (202) 293-2450 or jwest@aacte.org. Thank you for your consideration of the perspective of AACTE and its membership of close to 800 private, state, and municipal colleges and universities--large and small--located in every state, the District of Columbia, the Virgin Islands, Puerto Rico, and Guam.

Sincerely,

Sharon P. Robinson

Sharon P. Robinson, Ed.D.
President and CEO

Testimony of John H. Klippel, M.D., President and CEO, Arthritis Foundation
Submitted to the House Committee on Appropriations
Subcommittee on Labor, Health & Human Services, Education, and Related Agencies
March 31, 2008

The Arthritis Foundation greatly appreciates the opportunity to submit testimony in support of the continued federal commitment to arthritis research at the National Institutes of Health and arthritis public health initiatives at the Centers for Disease Control and Prevention, which are aimed at improving the lives of 46 million adults and 294,000 children living with arthritis in the United States.

The medical and societal impact of arthritis in the United States is staggering. Arthritis costs the economy **$128 billion**, which was equivalent to 1.2% of the U.S. gross domestic product in 2003. These costs include $81 billion in direct costs for expenses like physician visits and surgical interventions, and $47 billion in indirect costs for missed work days. Arthritis is the most common cause of disability in the United States, and nearly one-third of adults with arthritis experience work limitations.

The Arthritis Foundation strongly believes that in order to prevent or delay arthritis from impacting people and to mitigate the effects of arthritis that an investment both from the private and public sector must be made today. Research shows that the pain and disability of arthritis *can* be decreased through early diagnosis and appropriate management, including evidence based self-management activities such as weight control and physical activity. The Arthritis Foundation's Self-Help Program, a group education program has been proven to reduce arthritis pain by 20% and physician visits by 40%. These interventions are recognized by the Centers for Disease Control and Prevention to reduce health care expenditures. The Arthritis Foundation offers and partners with other organizations to offer the Self-Help Program, and an Aquatic Program, and an Exercise Program as part of our Life Improvement Series. Each of these programs is proven to reduce pain and physician visits, decrease stiffness and increase function.

The public sector investment at the federal government level entails the Centers for Disease Control and Prevention's arthritis program. In early 1998, the Arthritis Foundation joined forces with the CDC to develop the National Arthritis Action Plan – an innovative public health strategy. Among the goals are improving the scientific information base on arthritis, increasing awareness that arthritis is a national health problem, and encouraging more individuals with arthritis to seek early intervention and treatment to reduce pain and disability. Due to the Subcommittee's support and leadership, the CDC was provided with $10 million in Fiscal Year 1999 to begin to make this vision a reality. Ten years later, the CDC's arthritis program has not kept pace and in fact, has seen a decline in funding from just a few years ago. In Fiscal Year 2008, the arthritis program was funded at $13 million.

Approximately half of the CDC's arthritis program funding is distributed through a competitive grant process, to 36 state health departments. Over the past five years, these 36 state health departments in partnership with other state organizations have successfully used

CDC funding to increase public awareness of the burden of arthritis and increase the availability of interventions that have been proven to improve the quality of life and health care of people with arthritis. In 2007, a CDC convened expert panel recommended that individual state health departments receive larger financial grants in order to maximize the impact of the state program. The CDC is currently reviewing grant submissions from the states and will announce later this summer which 10-18 states will receive CDC funding this year. From the previous number of 36 states funded, this will result in between 18-26 states losing CDC support for their arthritis program. While more efficient and effective programs are desired in *all* states, the loss of programs in a significant number of states comes at a time when the prevalence of arthritis continues to climb. The CDC estimates 67 million or 25% of the adult population will have arthritis by 2030. More than 57% of adults with heart disease and more than 52% of adults with diabetes also have arthritis. Arthritis limits the ability of people to effectively manage other chronic diseases. It is not the time to withdraw support, but rather a significant investment must be made now to sustain and improve the reach of these interventions.

The Arthritis Foundation strongly recommends Congress appropriate $23 million in Fiscal Year 2009 for CDC's arthritis program, which is equivalent to 50 cents per person with arthritis. This is a $10 million increase from Fiscal Year 2008, which will ensure that qualified, participating states can continue the vital work of lessening the burden of arthritis on Americans and the American work force.

As the Arthritis Foundation celebrates our 60th anniversary of working to prevent, control, and cure arthritis, we have reached several critical milestones, which have included new treatment options and the aforementioned proven strategies in preventing the onset and progression of the disease. However, as we take stock of these accomplishments, it is important to remember the challenges still faced in helping to improve the quality of life for Americans living with arthritis, and ultimately finding a cure.

Research funded by the National Institutes of Health and the Arthritis Foundation has produced a revolutionary class of biological therapies that alleviate painful inflammation and prevent disability. While these advances have changed the lives of Americans living with arthritis significantly, there is still no cure for the disease and its prevalence and impact continues to grow.

The Arthritis Foundation firmly believes research holds the key to tomorrow's advances and provides hope for a future free from arthritis pain. From its inception in 1948, a core mission of the Arthritis Foundation is to raise funds each year to support peer-reviewed research. Last year in 2007, the Arthritis Foundation invested $13 million in research through 179 grants, including 69 new and 110 continuing grants to researchers in over 100 academic institutions.

As the largest non-profit contributor to arthritis research, the Arthritis Foundation fills a vital role in the big picture of arthritis research. Our research program complements government and industry-based arthritis research by focusing on training new investigators and pursuing innovative strategies for preventing, controlling and curing arthritis. To date, the Arthritis

Foundation has funded more than 2,200 researchers with more than $380 million in grants. By supporting researchers in the early stages of their careers, the Arthritis Foundation makes important initial discoveries possible that lead to ultimate breakthrough results. However, even with this commitment every year grants that rate "stellar" in our peer review process go unfunded. These are potential cures without the funding to be realized.

An increased public investment in biomedical research holds the real promise of improving the lives of millions of Americans with arthritis. This investment will reduce the burden of arthritis on the U.S. economy with less missed work days, disability payments, and expensive surgical interventions. To illustrate this point, less than 50% of working age adults with rheumatoid arthritis are still employed 10 years after disease onset. Nearly 2/3 of people diagnosed with arthritis are *under* the age of 65. 750,000 hospitalizations and 36 million outpatient visits annually are due to arthritis.

Promising research in the broad field of arthritis includes the following examples:

Osteoarthritis currently impacts 23 million Americans and is the leading cause of hip and knee replacement. The Osteoarthritis Initiative at NIH is a comprehensive effort to use multiple imaging modalities, biomarkers, and genetic data to characterize osteoarthritis incidence and progression. Importantly, it represents a successful partnership between industry and the National Institute of Arthritis and Musculoskeletal and Skin Diseases, which will lead to the identification of novel biomarkers of diagnostic and prognostic significance and to the development of new therapies.

Last year a former Arthritis Foundation grant recipient, Peter K. Gregersen, M.D., of the Feinstein Institute for Medical Research in Manhasset, New York, who has spent years of his professional life analyzing the human genome, and a huge international team of investigators, which included scientists from NIAMS, announced two genes that impart an increased risk of developing rheumatoid arthritis.

Researchers supported in part by the Arthritis Foundation uncovered a pathway that regulates joint destruction associated with inflammatory arthritis. Researchers David M. Lee, M.D., Ph.D., and Michael Brenner, M.D., of Brigham and Women's Hospital, Harvard Medical School in Boston, along with an international team of scientists, found that blocking the action of a protein called cadherin-11 prevents the joint destruction that characterizes inflammatory arthritis in laboratory mice. They are hopeful that their success in mice will lead to a new treatment option for people with rheumatoid arthritis and other inflammatory joint diseases.

Although cartilage is a relatively simple tissue, scientists still face challenges in engineering and growing replacement material that behaves like natural tissue. Arthritis Foundation-funded researcher Farshid Guilak, Ph.D., of Duke University Medical Center, and colleagues at Duke and at the Massachusetts Institute of Technology have taken an important step toward surmounting these obstacles. The team created a new framework structure upon which cartilage tissue can be grown by developing a microscopic technology that weaves fibers in three directions. This three-dimensional scaffold is porous so the fabric can be

seeded with cells that have been suspended in a gel. The cell-infused fabric can then be transplanted into a damaged joint. The plan is that the gel and fabric will eventually degrade and be absorbed by the body, leaving only healthy, strong cartilage. If everything progresses according to plan, a new form of engineered cartilage will be available to treat joints damaged by osteoarthritis or other cartilage injuries.

The mission of the National Institute of Arthritis and Musculoskeletal and Skin Diseases is to support research into the causes, treatment, and prevention of arthritis and musculoskeletal and skin diseases, the training of basic and clinical scientists to carry out this research, and the dissemination of information on research progress in these diseases. Research opportunities at NIAMS are being curtailed due to the stagnating and in some cases declining numbers of new grants being awarded for specific diseases. The training of new investigators has unnecessarily slowed down and contributed to a crisis in the research community where new investigators have begun to leave biomedical research careers in pursuit of other more successful endeavors.

Sustaining the field of pediatric rheumatology is essential to the care of 294,000 children under the age of 17 living with a form of juvenile arthritis. Children who are diagnosed with juvenile arthritis will live with this chronic and potentially disabling disease for their entire life. Therefore, it is imperative that children are diagnosed quickly and treated with the most effective treatment protocols known for their particular disease. The establishment of a national data collection system to ensure that the safety and effectiveness of these treatments is essential and that they are applied in the most beneficial manner, especially for children.

A 2007 Health Resources and Services Administration report to Congress found that there are fewer than 200 practicing pediatric rheumatologists in the United States, and 10 states have no specialists at all who are qualified to diagnose and treat children with arthritis. With this critical 75% shortage, it is even more important for the existing pediatric rheumatologists to be supported and to share their expert knowledge across the country through a national network of cooperating clinical centers for the care and study of children with arthritis. The Arthritis Foundation has given substantial financial support to the development of the Childhood Arthritis and Rheumatology Research Alliance (CARRA). **However, in addition, NIAMS has a unique opportunity to leverage its public research funds through CARRA's capabilities, and the Arthritis Foundation urges Congress to express support for a national network of cooperating clinical centers for the care and study of children with arthritis.**

The Arthritis Foundation is dedicated to finding a cure for arthritis. However, the investment in NIH research is absolutely crucial to realize this dream. With continued and increased investment in research, the Arthritis Foundation believes a cure is on the horizon. **The Arthritis Foundation urges Congress to expand funding and provide a $1.9 billion increase in Fiscal Year 2009 for NIH to continue to fuel innovation and discoveries that could put an end to the pain of arthritis.**

The Arthritis Foundation has labored under many myths surrounding arthritis.

- Arthritis is an inevitable part of the aging process.
- It cannot be prevented.
- There are no effective treatment options apart from taking a few aspirin.
- Exercise is harmful for individuals with arthritis.
- Children do not get arthritis.

Today, the Arthritis Foundation is prepared with the necessary tools, expertise, and energy to shatter these myths and capitalize on the fruits of our collective research to help improve the lives of Americans living with arthritis. On behalf of the 46 million adults and nearly 300,000 children with arthritis, I urge the members of the Subcommittee and Congress to help us win the war against arthritis by increasing critical funding for the National Institutes of Health and the Centers for Disease Control and Prevention.

STATEMENT OF THE AMERICAN INDIAN HIGHER EDUCATION CONSORTIUM
SUBMITTED TO THE U.S. HOUSE OF REPRESENTATIVES - COMMITTEE ON APPROPRIATIONS
SUBCOMMITTEE ON LABOR, HHS, EDUCATION, AND RELATED AGENCIES

March 31, 2008

Summary of Requests: Summarized below are the Fiscal Year 2009 (FY09) recommendations for the nation's 36 Tribal Colleges and Universities (TCUs), covering three areas within the Department of Education and one in the Department of Health and Human Services, Administration for Children and Families' Head Start Program.

DEPARTMENT OF EDUCATION PROGRAMS:

A. Higher Education Act Programs:

- **Strengthening Developing Institutions:** Section 316 of Title III-A, specifically supports TCUs through two separate competitive grant programs: a) basic development grants and b) facilities/construction grants designed to address the critical facilities needs at TCUs. The TCUs *urge the Subcommittee to reject the President's FY09 budget recommendation to eliminate discretionary funding for this vital program and instead appropriate $32.0 million and include report language restating that funds not needed to support continuation grants or new planning or implementation grants shall be used for facilities, renovation, and construction grants.*

- **Pell Grants**: TCUs urge the Subcommittee to fund the Pell Grants Program at the highest possible level.

B. Perkins Career and Technical Education Programs: The TCUs urge the Subcommittee to reject the funding cut proposed in the President's budget and appropriate $8.5 million for Sec. 117 of the Carl D. Perkins Career and Technical Education Improvement Act, which funds our two Tribally Controlled Postsecondary Vocational Institutions: United Tribes Technical College and Navajo Technical College. Additionally, TCUs strongly support the Native American Career and Technical Education Program (NACTEP) authorized under Sec. 116 of the Act.

C. Relevant Title IX Elementary and Secondary Education Act (ESEA) Programs:

- **Adult and Basic Education:** Although federal funding for tribal adult education was eliminated in fiscal year 1996, TCUs continue to offer much needed adult education, GED, remediation and literacy services for American Indians, yet their efforts cannot meet the demand. *The TCUs request that the Subcommittee direct $5.0 million of the Adult Education State Grants appropriated funds to make awards to TCUs to support their ongoing and essential adult and basic education programs.*

- **American Indian Teacher and Administrator Corps:** The American Indian Teacher Corps and the American Indian Administrator Corps offer professional development grants designed to increase the number of American Indian teachers and administrators serving their reservation communities. *The TCUs request that the Subcommittee support these programs at $10.0 and $5.0 million, respectively.*

DEPARTMENT OF HEALTH & HUMAN SERVICES PROGRAM:

D. Tribal Colleges and Universities Head Start Partnership Program (DHHS-ACF): Tribal Colleges and Universities are ideal partners to help achieve the goals of Head Start in Indian Country. The TCUs are working to meet the mandate that Head Start teachers earn degrees in Early Childhood Development or a related discipline. *The TCUs request that $5.0 million be designated for the TCU-Head Start partnership program, to ensure the continuation of current programs and the resources needed to support additional TCU-Head Start partnership programs.*

STATEMENT OF THE AMERICAN INDIAN HIGHER EDUCATION CONSORTIUM
SUBMITTED TO THE U.S. HOUSE OF REPRESENTATIVES - COMMITTEE ON APPROPRIATIONS
SUBCOMMITTEE ON LABOR, HHS, EDUCATION, AND RELATED AGENCIES

March 31, 2008

Mr. Chairman and Members of the Subcommittee, on behalf of this nation's 36 Tribal Colleges and Universities (TCUs), which comprise the American Indian Higher Education Consortium (AIHEC), thank you for the opportunity to share our Fiscal Year 2009 (FY09) funding recommendations for programs within the U.S. Department of Education and the U.S. Department of Health and Human Services - Head Start program.

This statement will cover two areas: a) background on the Tribal Colleges and Universities (TCUs), and b) justifications for our funding recommendations.

I. Background on Tribal Colleges and Universities

The Tribal College Movement began in 1968 with the establishment of Navajo Community College, now Diné College, in Tsaile, Arizona. Rapid growth of tribal colleges soon followed, primarily in the Northern Plains region. In 1972, the six original tribally controlled colleges established AIHEC to provide a support network for member institutions. Today, AIHEC represents 36 Tribal Colleges and Universities located in 14 states, which were begun specifically to serve the higher education needs of American Indians. Annually, these institutions serve students from more than 250 federally recognized tribes, more than 80 percent of whom are eligible to receive federal financial aid.

Tribal Colleges and Universities are accredited by independent, regional accreditation agencies and like all institutions of higher education, must undergo stringent performance reviews on a periodic basis to retain their accreditation status. In addition to college level programming, TCUs provide essential high school completion (GED), basic remediation, job training, college preparatory courses, and adult education programs. TCUs fulfill additional roles within their respective reservation communities functioning as community centers, libraries, tribal archives, career and business centers, economic development centers, public meeting places, and child and elder care centers. Each TCU is committed to improving the lives of its students through higher education and to moving American Indians toward self-sufficiency.

Tribal Colleges and Universities provide access to higher education for American Indians and others living in some of the nation's most rural and economically depressed areas. The average family income for a student first entering a TCU is approximately $14,000, which is 33 percent below the federal poverty threshold for a family of four ($21,200). In addition to serving their student populations TCUs offer a variety of community outreach programs.

These institutions, chartered by their respective tribal governments, were established in response to the recognition by tribal leaders that local, culturally based institutions are best suited to help American Indians succeed in higher education. TCUs effectively blend traditional teachings with conventional postsecondary curricula. They have developed innovative ways to address the needs of tribal populations and are overcoming long-standing barriers to success in higher education for American Indians. Since the first TCU was established on the Navajo Nation 40 years ago, these vital institutions have come to represent the most significant development in the history of American Indian higher education, providing access to, and promoting achievement among, students who may otherwise never have known postsecondary education success.

Despite their remarkable accomplishments, TCUs remain the most poorly funded institutions of higher education in the country. Chronic lack of adequate funds remains the most significant barrier to their expanded success. Funding for the institutional operating budgets of 25 reservation-based TCUs is provided through Title I of the Tribally Controlled College or University Assistance Act (P.L. 95-471). Currently, the institutional operating budgets of these colleges are funded at $5,304 per Indian student -- only enrolled members of a federally recognized tribe may be counted as Indian students for the purpose of determining an institution's operations funding level. Because TCUs are located on federal trust land, states have no obligation to fund them -- not even for the non-Indian state-resident students who account for approximately 20 percent of TCU enrollments. Yet, if these same students attend any other public institution in the state, the state would provide basic operating funds to the institution. While mainstream public institutions have had a foundation of stable state tax-based support, TCUs must rely on annual federal appropriations for their day-to-day institutional operating budgets. In the almost three decades since the Tribal College Act was initially funded, these reservation-based colleges have never received the authorized funding level for the institutional operations. In fact, they have lost ground. When you consider inflation over that time period, TCUs would need to be funded at $6,574 per Indian student to simply receive a level of funding with the same buying power they received in their initial appropriation in FY 1981, which was $2,831 per Indian student. This is not simply a matter of appropriations falling short of an authorization. It effectively impedes the TCUs from having the resources necessary to provide educational services afforded students at state- funded institutions of higher education.

Inadequate funding has left many TCUs with no choice but to continue to operate under severely distressed conditions. The need remains urgent for construction, renovation, improvement, and maintenance of key TCU facilities, such as basic and advanced science laboratories, computer labs, and increasingly important student housing, day care centers, and community service facilities. Although the situation has improved dramatically at many TCUs in the past several years, some TCUs still operate -- at least partially -- in donated and temporary buildings. Few have dormitories, even fewer have student health centers and only one TCU has a science research laboratory.

As a result of more than 200 years of federal Indian policy -- including policies of termination, assimilation and relocation -- many reservation residents live in conditions of poverty comparable to that found in Third World nations. Through the efforts of TCUs, American Indian communities are availing themselves of resources needed to foster responsible, productive, and self-reliant citizens.

II. Justifications

A. Higher Education Act

The Higher Education Act Amendments of 1998 created a separate section (§316) within Title III-A specifically for the nation's Tribal Colleges and Universities. Programs under Titles III and V of the Act support institutions that enroll large proportions of financially disadvantaged students and that have low per-student expenditures. Although TCUs, which are truly developing institutions, are providing access to quality higher education opportunities to some of the most rural and impoverished areas of the country, the President's FY 2009 budget proposes eliminating all discretionary funding for the TCU Title III grants program. TCUs recognize and are grateful for the positive step that Congress took by including in the FY2008 Reconciliation Act much needed supplemental funding for Title III and Title V programs, including the TCU program. The FY09 budget recommendation effectively negates this progress by eliminating discretionary funding needed to fund multi-year development grants. We believe it was the intent of Congress to supplement the Title III program funds, NOT to supplant

discretionary funding for the very institutions that disproportionally educate low-income chronically underserved populations. A clear goal of the Higher Education Act Title III programs is "to improve the academic quality, institutional management and fiscal stability of eligible institutions, in order to increase their self-sufficiency and strengthen their capacity to make a substantial contribution to the higher education resources of the Nation." The TCU Title III program is specifically designed to address the critical, unmet needs of their American Indian students and communities, in order to effectively prepare them for the workforce of the 21st Century. *The TCUs urge the Subcommittee to reject the President's budget recommendation to eliminate discretionary funding and appropriate $32.0 million in FY 2009 for Title III-A section 316, an increase of $8.8 million over FY08 and $32.0 million over the President's request. These funds will afford these developing institutions the resources necessary to continue their ongoing grant programs and address the needs of their historically underserved students and communities. Additionally, we request that report language be restated clarifying that funds not necessary to support continuation grants or new planning or implementation grants shall be used for facilities, renovation, and construction grants to ensure TCUs will be able to operate in adequate and safe facilities.*

The importance of Pell grants to TCU students cannot be overstated. U.S. Department of Education figures show that the majority of TCU students receive Pell grants, primarily because student income levels are so low and our students have far less access to other sources of financial aid than students at state-funded and other mainstream institutions. Within the tribal college system, Pell grants are doing exactly what they were intended to do -- they are serving the needs of the lowest income students by helping them gain access to quality higher education, an essential step toward becoming active, productive members of the workforce. *The TCUs urge the Subcommittee to fund this critical grants program at the highest possible level.*

B. Carl D. Perkins Career & Technical Education Act

Tribally-Controlled Postsecondary Vocational Institutions: Section 117 of the Perkins Act provides basic operating funds for two of our member institutions: United Tribes Technical College in Bismarck, North Dakota, and Navajo Technical College in Crownpoint, New Mexico. *The TCUs urge the Subcommittee to reject the President's budget proposal to eliminate funding for this program and to appropriate $8.5 million.*

Native American Career and Technical Education Program: The Native American Career and Technical Education Program (NACTEP) under Sec. 116 of the Act reserves 1.25% of appropriated funding to support Indian vocational programs. *The TCUs strongly urge the Subcommittee to continue to support NACTEP, which is vital to the survival of vocational education programs being offered at Tribal Colleges and Universities.*

C. Greater Support of Indian Education Programs

American Indian Adult and Basic Education (Office of Vocational and Adult Education): This program supports adult basic education programs for American Indians offered by TCUs, state and local education agencies, Indian tribes, institutions, and agencies. Despite a lack of funding, TCUs must find a way to continue to provide basic adult education classes for those American Indians that the present K-12 Indian education system has failed. Before many individuals can even begin the course work needed to learn a productive skill, they first must earn a GED or, in some cases, even learn to read. The number of students in need of remedial education before embarking on

their degree programs is considerable at TCUs. There is a broad need for basic adult educational programs and TCUs need adequate funding to support these essential activities. *TCUs respectfully request that the Subcommittee direct $5.0 million of the Adult Education State Grants appropriated funds to make awards to TCUs to help meet the ever increasing demand for basic adult education and remediation program services.*

American Indian Teacher/Administrator Corps (Special Programs for Indian Children): American Indians are severely under represented in the teaching and school administrator ranks nationally. These competitive programs are designed to produce new American Indian teachers and school administrators for schools serving American Indian students. These grants support recruitment, training, and in-service professional development programs for Indians to become effective teachers and school administrators and in doing so become excellent role models for Indian children. We believe that the TCUs are the ideal catalysts for these two initiatives because of their current work in this area and the existing articulation agreements they hold with 4-year degree awarding institutions. *The TCUs request that the Subcommittee support these two programs at $10.0 million and $5.0 million, respectively, to increase the number of qualified American Indian teachers and school administrators in Indian Country.*

DEPARTMENT OF HEALTH AND HUMAN SERVICES/ADMINISTRATION FOR CHILDREN & FAMILIES/HEAD START

Tribal Colleges and Universities (TCU) Head Start Partnership Program: The TCU-Head Start Partnership has made a lasting investment in our Indian communities by creating and enhancing associate degree programs in Early Childhood Development and related fields. Graduates of these programs help meet the degree mandate for all Head Start program teachers. More importantly, this program has afforded American Indian children Head Start programs of the highest quality. A clear impediment to the ongoing success of this partnership program is the erratic availability of discretionary funds made available for the TCU-Head Start Partnership. In FY 1999, the first year of the program, some colleges were awarded 3-year grants, others 5-year grants. In FY 2002, no new grants were awarded. In FY 2003, funding for eight new TCU grants was made available, but in FY 2004, only two new awards could be made because of the lack of adequate funds. The President's FY09 budget includes a total request of *$7,026,571,000* for Head Start Programs. *The TCUs request that the Subcommittee direct the Head Start Bureau to designate a minimum of $5.0 million, of the over $7.0 billion recommended in the budget, for the TCU-Head Start Partnership program, to ensure that this critical program can continue and expand so that all TCUs have the opportunity to participate in the TCU- Head Start partnership program.*

Conclusion

Tribal Colleges and Universities are providing access to higher education opportunities to many thousands of American Indians and essential community services and programs to many more. The modest Federal investment in TCUs has already paid great dividends in terms of employment, education, and economic development, and continuation of this investment makes sound moral and fiscal sense. TCUs need your help if they are to sustain and grow their programs and achieve their missions to serve their students and communities.

Thank you again for this opportunity to present our funding recommendations. We respectfully ask the Members of the Subcommittee for their continued support of the nation's Tribal Colleges and Universities and full consideration of our FY 2009 appropriations needs and recommendations.

Testimony of the TriCouncil for Nursing
Regarding Fiscal Year 2009 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

March 31, 2008

The Tri-Council is a long-standing nursing alliance focused on leadership and excellence in the nursing profession. It brings together the four professional organizations of the American Association of Colleges of Nursing (AACN), the American Nurses Association (ANA), the American Organization of Nurse Executives (AONE), and the National League for Nursing (NLN) whose collaborative leadership affects the breadth of nursing practice, including nurse executives, nurse educators, nurse researchers, and most importantly, those nurses providing direct patient care.

The Nursing Workforce Development Programs under Title VIII of the ***Public Health Service Act*** strive to meet the health needs of the nation by assuring an adequate supply and distribution of qualified Registered Nurses (RNs). These Programs increase access to quality care through improved composition, diversity, and retention of the nursing workforce; improved quality of nursing education and practice; and the identification of and use of data, program performance measures, and outcomes to make informed decisions on nursing workforce issues. **The TriCouncil for Nursing urges Congress to ensure that adequate funding is available to address the critical nursing and nurse faculty shortages through the Nursing Workforce Development Programs authorized by Title VIII of the *Public Health Service Act.***

This testimony highlights the fundamental importance of the Nursing Workforce Development Programs as they relate to an adequately prepared nursing workforce. To ensure that our nation has a sufficient national supply of RNs who will provide quality and safe patient care to every individual requiring health services, the Tri-Council respectfully requests the following:

- **$200 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 2009.**
- **The Advanced Education Nursing training program (Sec. 811) should be restored and funded at an increased level.**

The Nursing Shortage

We are now in the tenth year of a critical nursing shortage that has had an impact on all aspects of healthcare delivery and has made access to care a difficult challenge for our neediest and most fragile populations. The nursing shortage has been fueled by the inability of our nursing programs to produce enough nurses to meet the projected demand for RNs over the next 13 years. Despite the growing interest for nursing education, an inadequate number of nursing faculty are available to educate new nurses. Additionally, a rapidly aging population with a growing demand for healthcare services is expected to overburden a health system that is currently under stress.

With an estimated 2.9 million RNs and advanced practice registered nurses (APRNs), the profession represents the largest health profession of the healthcare workforce. Nurses provide care in virtually all locations in which health care is delivered. Because of the healthcare system's dependence upon nursing, the worsening shortage points to serious challenges on several fronts.

The Health Resources and Services Administration (HRSA) projects that, absent aggressive intervention, the supply of nurses in America will fall 36 %(more than 1 million nurses) below requirements by the year 2020. This report, *What is Behind HRSA's Projected Supply, Demand, and Shortages of Registered Nurses?* is available online at: See: http//hrsa.gov/bhpr/workforce/behindshortage.pdf

The lack of young people entering the nursing profession has pushed up the average age of the working nurse. Today, the average age of the RN population is estimated to be 47. See: http://bhpr.hrsa.gov/healthworkforce/reports/rnpopulation/preliminaryfindings.htm

HRSA also projects that, if recent trends continue, the number of RNs leaving the workforce will outpace those entering the profession by 2016. See: http://www.kaisernetwork.org/health_cast/uploaded_files/Nursing_Shortage_Presentation_nesseler_2.pdf

The American Hospital Association reports that hospitals needed 118,000 more RNs to fill immediate vacancies in December, 2005. Hospitals report that this 8.5% vacancy rate is hampering the ability to provide emergency care. See: http://www.aha.org/aha/content/2006/pdf/PreparedToCareFinal.pdf

The National Commission on Nursing Workforce for Long-Term Care released a report in May, 2005 stating that there are nearly 100,000 vacant nursing positions in long-term care facilities on any given day, and the nurse turnover rate exceeds 50%. The shortage is costing long-term care facilities an estimated $4 billion a year in recruitment and training expenses. See: http://www.ahca.org/research/workforce_rpt_050519.pdf

As cited in the Journal of the American Medical Association in March of 2006, an average vacancy rate of 10.4% for registered nurses and 9.2% for nurse practitioners exists at our

nation's 5,000 community health centers. Vacancy rates are even higher in urban areas and small, isolated rural areas.

According to a May 2001 report, *Who Will Care for Each of Us?: America's Coming Health Care Crisis*, released by the Nursing Institute at the University of Illinois, the ratio of potential caregivers to the people most likely to need care (the older adult) will decrease by 40% between 2010 and 2030. Demographic changes may limit access to health care unless the number of nurses and other caregivers grows in proportion to the rising older adult population.

The nursing shortage is stressing military health care delivery. The Army, Navy, and Air Force are offering new lucrative RN recruitment packages that include large sign-on bonuses, generous scholarships, and loan forgiveness packages. Yet, neither the Army nor the Air Force has met their active service nurse recruitment goals since the 1990s. On May 10, 2005, Army leaders warned the Senate Appropriations Committee that they were experiencing a 30% shortage of certified registered nurse anesthetists. In 2004, the Navy Nurse Corps recruitment fell 32% below target. This ongoing nurse shortage is creating real concerns about the ability to deliver needed health care to today's military. See:
http://appropriations.senate.gov/subcommittees/record.cfm?id=237756 and See:
http://appropriations.senate.gov/subcommittees/record.cfm?id=237762

In testimony on March 7, 2007, Army leaders stated that they were experiencing shortfalls of more than 30% in certain key combat specialties such as anesthesia and critical care. Recruitment and retention within the Navy Nurse reserve component continues to be a matter of great concern as is the 15% shortage of nurses within the Air Force Nurse Corps.
http://appropriations.senate.gov/Hearings/2007_03_07

Impact of the Nursing Shortage on Patient Care:

According to American Hospital Association's 2005 Workforce Survey, staffing shortages are contributing to emergency department overcrowding, emergency department diversions, decreased patient satisfaction, delayed discharges, increased wait times for surgery, and cancelled surgeries.
http://www.ahapolicyforum.org/ahapolicyforum/resources/content/TakingthePulse2005.pdf

A study based on a review of more than 6 million patients was published in the *New England Journal of Medicine* in May, 2002. The researchers found that hospitalized patients had better outcomes when a greater proportion of their nursing care was provided by RNs, and when the number of hours of RN care per day increased. Specifically, nursing shortages were found to correlate with longer lengths of stay, increased incidence of urinary tract infections and upper gastrointestinal bleeding, higher rates of pneumonia, shock and cardiac arrest. Increased hours of RN care resulted in fewer "failure-to-rescue" deaths from pneumonia, shock or cardiac arrest, upper gastrointestinal bleeding, sepsis and deep venous thrombosis. See:
http://content.nejm.org/cgi/content/abstract/346/22/1715

A study published in the January/February 2006 journal *Health Affairs* shows that if hospitals increased RN staffing, more than 6,700 patient deaths and four million inpatient days could be avoided each year. See http://www.nursingworld.org/pressrel/2006/pr0110.htm.

Research published in the October 23, 2002 *Journal of the American Medical Association* demonstrated that more nurses at the bedside could save thousands of patient lives each year. In reviewing the experiences of more than 232,000 surgical patients at 168 hospitals, researchers from the University of Pennsylvania concluded that a patient's overall risk of death rose roughly 7 % for each additional patient above four on a nurse's workload. Having too few nurses may actually cost more money given the high costs of replacing burnt-out nurses and caring for patients with poor outcomes. See:
http://www.nursing.upenn.edu/news/pdf/PennNursing_JAMA_10-22-02.pdf

In *Health Care at the Crossroads: Strategies for Addressing the Evolving Nursing Crisis*, a report released in August 2002 by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO), the authors found that a shortage of nurses in America's hospitals is putting patient lives in danger. JCAHO reported in that the shortage of nurses contributes to nearly a quarter of all unexpected incidents that kill or injure hospitalized patients.
http://www.jcaho.org/PublicPolicy/nurse_staffing.htm

Nurse Faculty Shortage and Nursing Education:

According to the American Association of Colleges of Nursing's 2007-2008 annual survey, enrollment in entry-level baccalaureate nursing programs increased by 5.4% from 2006 to 2007. These data, based on an 86% response rate from 751 schools, illustrates that enrollments are not increasing to meet the demand. Between academic years, 2005 and 2006, enrollments in baccalaureate programs had increased by 7.6%. Further adding to the educational crisis, AACN found that schools of nursing turned away 40,285 qualified applicants to baccalaureate and graduate programs in academic year 2007. The number one reason cited by schools of nursing for not accepting all applicants into entry-level baccalaureate programs was insufficient faculty (71.4%). See: www.aacn.nche.edu

The National League for Nursing's (NLN) wide-lens study of 2005-2006 on all types of pre-licensure nursing programs (e.g., baccalaureate, associate, and diploma degree) revealed that applications to these RN programs fell a notable 8.7% during that year, down from a peak in applications a year earlier. The drop is suspected to be the result of "applicant discouragement", i.e., widespread awareness of the difficulty in gaining entry to nursing school, fueled by the continuing crippling shortage of nurse educators. Despite a reduced number of applications, unmet demand for placement persists, with 88,000 qualified applications – or one out of every three qualified applications submitted to these diverse RN education programs – were denied due to lack of capacity. See: www.nln.org/research/datareview/executive_summary.pdf.

Current Funding Levels Are Not Meeting the Need:

In FY 2007, HRSA was forced to turn away 93% of the applicants for the Nurse Education Loan Repayment Program (NELRP) due to lack of funding. HRSA statistics show that from a pool of

4,710 eligible applications of RNs interested in working in facilities deemed to have a critical shortage only 315 awards were made. The remaining 4,395 nurses were not funded. See: Freedom of Information Act Case Number HRSA 08-078.

Similarly, in FY 2007, HRSA turned away 96% of the applicants for the Nursing Scholarship Program due to lack of adequate funding. This means that from an applicant pool of 4,894 students interested in nursing, awards were made to 172 nursing students. See: Freedom of Information Act Case Number HRSA 08-078.

The Funding Reality:

The authorities granted under Title VIII are capable of providing flexible and effective support to assist students, schools of nursing, and health systems in their efforts to recruit, educate, and retain registered nurses. The TriCouncil fully understands the competing priorities faced by this Congress, but we also maintain that Title VIII Nursing Workforce Development Programs must be funded at an adequate level to begin to impact the shortage.

The Tri-Council for Nursing urges you to support the request of $200 million for these critical programs and restore funding to the Advanced Education Nursing program.

Jeanette Lancaster, PhD, RN, FAAN
President
Geraldine Bednash, PhD, RN, FAAN
Executive Director
American Association of Colleges of Nursing

Rebecca M. Patton, MSN, RN, CNOR
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Written Testimony of Shelley Fuld Nasso
Director, Public Policy,
Susan G. Komen for the Cure Advocacy Alliance

Submitted to the House Appropriations Subcommittee
on Labor, Health and Human Services, Education, and Related Agencies
March 31, 2008

Chairman Obey, Ranking Member Walsh, and members of the subcommittee:

On behalf of the Susan G. Komen for the Cure Advocacy Alliance, I would like to thank you for the opportunity to submit written testimony regarding federal funding to fight breast cancer. Specifically, I would like to take this time to stress the importance of increased funding for the National Institutes of Health (NIH), including the National Cancer Institute (NCI), and the Centers for Disease Control and Prevention (CDC), both of which play a critical role in finding and delivering the cures for breast cancer. In addition, Komen for the Cure supports full funding for the Patient Navigator Outreach and Chronic Disease Prevention Act of 2005 administered by the Health Resources and Services Administration. As the appropriations subcommittee with jurisdiction over these agencies, we hope you will consider our request.

Background on Susan G. Komen for the Cure

Susan G. Komen for the Cure is the world's largest grassroots network of breast cancer survivors and activists fighting to save lives, empower people, ensure quality care for all and energize science to find the cures. Thanks to events like the Komen Race for the Cure, in its first 25 years, Komen for the Cure invested $1 billion to fulfill its promise, becoming the largest source of nonprofit funds dedicated to the fight against breast cancer in the world. To continue this progress, Komen for the Cure has pledged to invest another $2 billion in the next ten years. In 2007 alone, Komen for the Cure awarded almost $70 million in community health grants for education, screening and treatment, and more than $75 million in grants for cancer research. And Komen is on track to award more than $100 million in research grants this year. But while Komen has had a significant impact on breakthrough research in breast cancer, we can't do it alone. Federal funding for research must keep pace with biomedical inflation and the ever-changing world of science.

In addition to grant-making, Komen has advocated tirelessly for improved access to high quality care for breast cancer patients. We have long been a champion of the National Breast and Cervical Cancer Early Detection Program (NBCCEDP), and we successfully advocated for the program's reauthorization last year. But again, we can't do it alone. Successful programs such as the NBCCEDP must be fully funded to allow all women access to the screening and treatment services they deserve.

The Importance of NIH and NCI Funding

Komen for the Cure supports the One Voice Against Cancer (OVAC) request of **$30.81 billion for the NIH in fiscal year 2009 (FY09).** This represents a 6.5% increase over the FY08

budget. In addition, Komen supports OVAC's request for a **9.5% increase in funding for FY09 for the NCI** ($5.26 billion). The NCI funding increase is based on the professional judgment budget (also known as the "by-pass" budget) issued by the NCI and would provide sufficient funding for continuing current services. It should be noted that the appropriation given to the NCI by Congress has traditionally met or exceeded the amount requested in the by-pass budget. Fiscal Year 2006 marked the first year that the appropriation dipped below the by-pass budget—we must reverse this trend. In addition, a 9.5% increase provides the NCI only with enough resources to continue current services. The Institute has stated that a 25% increase would be needed to implement new initiatives. In this context, we believe 9.5% is a reasonable request.

Previous investments in research have allowed us to make significant progress toward discovering and delivering the cures for breast cancer. During the "doubling" of the NIH budget from 1998-2003, incredible advances were made in our understanding of the genetic causes of cancer, how to disrupt the growth and spread of cancerous cells without destroying healthy cells, and in the development of diagnostic tools and treatments that can be tailored to an individual or specific type of cancer based on genetic traits. Today, research opportunities abound in both basic and translational settings, including:

- *Adult stem cell research.* Some researchers believe that stem cells (cells that give rise to all cells in the body) are the source of at least some, and perhaps all, cancers. Breakthroughs in adult stem cell research may allow us to develop more effective treatments;

- *RNA interference.* A technology with the potential to turn off the genes that make cancer grow;

- *Nanotechnology.* Tiny particles can be coated with a special material, and when introduced into the body, these particles may be able to target and kill cancer cells from the inside out;

- *Gene therapy.* In gene therapy, a specific gene can be transferred into a patient's cancer cells to make them more responsive to treatment. A gene can also be transferred into a patient's immune system cells to make them better able to fight the cancer;

- *Anti-angiogenesis drugs.* Anti-angiogenesis drugs work by preventing tumors from developing new blood vessels, thereby preventing growth of the tumor; and

- *Targeted therapies and personalized medicine.* An ever-expanding list of targeted therapies is making breast cancer treatment more specific and possibly less toxic.

However, many of these promising areas of research will not receive funding if the NIH and the NCI continue to be under-funded. A recent report by a group of concerned universities, "*A Broken Pipeline?: Flat Funding of the NIH Puts a Generation of Science at Risk*" paints a grim picture for the future of science. Only 24% of NIH R01 grants (or equivalents) were funded in 2007, down from 32% in 1999. Even worse, only 12% of grants were funded on the first

submission in 2007, compared to 29% in 1999. Scientists spend more time writing than researching. For young investigators, the success rate is particularly difficulty – 1 in 4 NIH grants is awarded to a first-time grantee. Persistent under-funding at the NIH is costing us a generation of promising young scientists and untold missed opportunities to find a cure for breast cancer. Opportunities we can't recoup if we do not act now to reverse the downward trend in the NIH budget.

One in eight women will be diagnosed with breast cancer in the course of her lifetime. In 2008, more than 182,000 women will be diagnosed with breast cancer and more than 40,000 women will die from the disease. The burden of breast cancer, and of all cancers, remains enormous. Cancer deaths account for one out of every four deaths in the United States and cost our economy over $200 billion annually, and yet we spend only $5 billion at NCI on oncology research. We owe it to all of those affected by this disease, and to their families, friends and loved ones, to adequately fund the NIH and the NCI so that we can find a cure for cancer. We owe it to young investigators who have dedicated their professional lives to cancer research to provide adequate federal funding through the NIH and NCI so they can continue to make innovative breakthroughs in science. And finally, we owe it to the U.S., as the global leader of biomedical research to continue to provide increases in funding to the NIH.

The CDC National Breast and Cervical Cancer Early Detection Program

In addition to an increase in funding for NIH and NCI, Komen for the Cure also requests that Congress appropriate **$250 million for CDC's National Breast and Cervical Cancer Early Detection Program** (NBCCEDP).

The NBCCEDP is designed to reach underserved women to provide screening services for breast and cervical cancer as well as appropriate referrals for treatment and support services as necessary. In addition to clinical services, NBCCEDP programs develop and disseminate public information about the importance of screening, improve the education, training and skills of health professionals in the detection of breast and cervical cancer, engage in outreach efforts to serve as many eligible women as possible, monitor and evaluate the program, including the quality of screening services, and report certain data to CDC. The heart of the program is to provide screening services to low-income, uninsured, and underinsured women aged 18 to 64 with incomes under 250 percent of the federal poverty level. The women served are often in at-risk populations and those least likely to be screened. According to the CDC, since 1991, the NBCCEDP has served more than 3 million women by providing more than 7.2 million screening examinations, and diagnosing 30,963 breast cancers, 1,934 invasive cervical cancers, and 101,624 precursor cervical lesions.

The NBCCEDP is an invaluable service to women who are served by the program. There is no cure for breast cancer. Without a cure, early detection is key to survival. Timely mammography screening of women over age 40 could prevent 15 to 30 percent of all deaths from breast cancer—when breast cancer is detected early, while still confined to the breast, the five-year survival rate is more than 98 percent. However, many low income women are uninsured or underinsured and would never receive a mammogram without access to NBCCEDP services.

From a high of $210 million in FY2004, funding for the NBCCEDP has either declined or remained essentially flat for the subsequent years. In FY2008, the program received only approximately $200 million, despite an authorization level of $225 million. Programs are severely strained by the lack of adequate resources—only 14.7 percent of eligible women were screened for breast cancer and only 6.7 percent of eligible women were screened for cervical cancer in 2006. We urge Congress to fully fund NBCCEDP to allow these programs to reach as many women as possible and save as many lives as possible.

Patient Navigators

Finally, Komen for the Cure would like to offer support for **full funding ($6.5 million) for FY09 for the Patient Navigator Outreach and Chronic Disease Prevention Act of 2005** administered by the Health Resources and Services Administration. The Act authorizes appropriations of $2 million for FY06, $5 million for FY07, $8 million for FY08, $6.5 million for FY09, and $3.5 million for FY10, however no money has been appropriated to date.

Patient navigation services are critical to address barriers to quality cancer care, particularly for minority and underserved patients who often do not speak English, have low literacy skills, are uninsured, and/or live long distances from treatment centers. These patients have difficulty accessing quality care and have trouble coordinating their cancer care, leading to disjointed treatment, inadequate patient-doctor communication, difficulty with follow-up appointments, and poor adherence to treatment regimens. Patient navigators help patients "navigate" the maze of doctors, insurers and patient support groups. For breast cancer patients, a patient navigator can provide personalized education on breast surgery options, chemotherapy, and radiation therapy, as well as facilitating communication with physicians and other health professionals.

Komen for the Cure is committed to ensuring all breast cancer patients have access to a patient navigator if they so desire. To this end, we urge Congress to fully fund the Patient Navigator Outreach and Chronic Disease Prevention Act at $6.5 million for FY09.

Funding Requests

Thank you for the opportunity to submit this written testimony. To reiterate, our FY09 funding requests are as follows:

- **NIH: $30.81 billion (6.5% increase over FY08);**
- **NCI: $5.26 billion (9.5% increase in over FY08);**
- **CDC's National Breast and Cervical Cancer Program: $250 million.**
- **Patient Navigator Outreach and Chronic Disease Prevention Act: $6.5 million.**

Dr. Marina L. Weiss, Senior Vice President Public Policy and Government Affairs
Testimony on Behalf of **March of Dimes Foundation**
Committee on Appropriations
Subcommittee on Labor, Health and Human Services and Education
FY09 Funding -- Department of Health and Human Services

The 3 million volunteers and 1,400 staff members of the March of Dimes Foundation appreciate the opportunity to submit the Foundation's federal funding recommendations for Fiscal Year 2009 (FY09). The March of Dimes is a national voluntary health agency founded in 1938 by President Franklin D. Roosevelt to prevent polio. Today, the Foundation works to improve the health of mothers, infants and children by preventing birth defects, premature birth and infant mortality through research, community services, education, and advocacy. The March of Dimes is a unique partnership of scientists, clinicians, parents, members of the business community, and other volunteers affiliated with 51 chapters in every state and Puerto Rico.

The volunteers and staff of the March of Dimes are deeply concerned that the funding recommendations proposed in the Administration's Budget are not sufficient to meet the challenge of improving the health of families in every state. In particular, proposals for continued under-funding of critical research and public health programs central to the health of mothers and children should be rejected in favor of the funding increases recommended below which we believe to be essential investments in the future of our nation.

National Institutes of Health (NIH)

The March of Dimes joins the larger research community in recommending a $1.9 billion increase in funding for the NIH bringing total federal support to over $30 billion. Since the doubling of NIH's budget was completed in 2003, the agency has lost 15% of its purchasing power due to biomedical inflation. With the threats to children's health, and the economic and societal costs associated with long-term disabilities and care, it is imperative to increase the overall investment in medical research.

Office of the Director

The March of Dimes strongly supported congressional approval of $110.9 million for the National Children's Study (NCS) in FY08 Consolidated Appropriations Act, allowing for implementation of the next phase of the study. **The Foundation urges the Subcommittee to include within the Office of the Director $192.3 million ($81.4 million increase) for the NCS in FY09.** While the amount may seem substantial, it is dwarfed by the cost of treating the diseases and conditions the study is designed to address. In 2009, the National Children's Study will be enrolling women from across the country in a study that will make vital contributions to better understand numerous illnesses affecting children beginning with pregnancy-related outcomes, a targeted area of the study. In particular, the NCS holds the potential to provide data on the causes of birth defects and premature birth, including, but not limited to, the role that diabetes and pre-diabetic conditions may play in birth defects, and the impact of infection and inflammation in stimulating pre-term delivery.

National Institute of Child Health and Human Development (NICHD)

The March of Dimes recommends $1.34 billion for NICHD in FY09. In recent years, the NICHD has made a major commitment to enhance our understanding of the factors that result in premature birth and to develop strategies to prolong pregnancy so that infants are born

at full term. Since 1981, the preterm birth rate in the United States has increased 30% resulting in 543,000 premature births in 2006 – or 1 in 8 newborns. Any woman can have a preterm baby and in about a third of the cases, the causes remain unknown.

This growing problem of preterm births was brought into sharp focus by the 2006 Institute of Medicine (IOM) report entitled, "Preterm Birth: Causes, Consequences and Prevention." The IOM found that the annual economic burden associated with preterm birth in the United States was at least $26.2 billion, or $51,600 per infant born preterm. In 2003, the national hospital bill alone for the care of these babies exceeded $18 billion, half of which was borne by Medicaid and other public programs with the remainder being charged to employers and families. Additionally, according to the IOM, there are persistent disparities in preterm birth rates among different racial and ethnic groups: In 2004, the rate of preterm birth in the United States was highest for black infants (17.9%), followed by Native Americans (13.7%) Hispanics (12%), whites (11.5%) and Asians (10.5%).

The NICHD supported research including work done through the Maternal-Fetal Medicine Units (MFMU), Neonatal Research (NR) and the Genomics and Proteomics Networks must continue. Specifically, over the past year NICHD funded clinical trials to investigate the impact of administering a derivative of progesterone to reduce preterm labor and delivery in women with a short cervix and women with multiple gestations. The findings from these clinical trials will further enhance our understanding of the causes of preterm labor and delivery.

Centers for Disease Control and Prevention (CDC)

National Center on Birth Defects and Developmental Disabilities (NCBDDD)

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. Of particular interest to the March of Dimes is NCBDDD's birth defects program that includes surveillance, research and prevention activities. For FY09, the March of Dimes requests an **increase of $3 million to support the National Birth Defects Prevention Study and an additional $2 million for folic acid education.** In the March of Dimes professional judgment, these modest increases are sorely needed to continue progress in reducing the incidence of birth defects.

As the causes of nearly 70% of birth defects are unknown, it is important to continue to fund the National Birth Defects Prevention study—the largest case controlled study of birth defects ever conducted—to unveil the causes and to prevent birth defects. The nine centers located in Massachusetts, New York, North Carolina, Georgia, Texas, Arkansas, Iowa, Utah and California participating in the study identify infants with major birth defects; interview mothers about medical history, environmental exposures and lifestyle before and during pregnancy; and collect DNA samples to study gene-environment interactions. With nearly 11 years worth of data and samples collected and $85 million invested, this study is a rich source of information on possible causes of birth defects.

Several years of erosion in funding make it critical to provide a $3 million increase for the National Birth Defects Prevention Study in FY09. Without this increase CDC will be unable to maintain operation of all nine Centers of Excellence and will lose the capacity to conduct important analyses of genetic samples.

NCBDDD also provides funding to assist states with community-based birth defects tracking systems, programs to prevent birth defects and improve access to health services for children with birth defects. Surveillance forms the backbone of a vital, functional and responsive public health network. Additional resources are sorely needed to help states seeking

assistance.

Finally, NCBDDD is conducting a national public and health professions education campaign designed to increase the number of women taking folic acid. CDC estimates that up to 70% of neural tube defects (NTDs), serious birth defects of the brain and spinal cord including anencephaly and spina bifida could be prevented if all women of childbearing age consume 400 micrograms of folic acid daily before becoming pregnant. Since 1996, the rate of NTDs in the United States has decreased by 26%. Although progress is being made, according to a recent CDC analysis, 60% of women of childbearing age are still not consuming the daily recommended amount of folic acid making it more important than ever that CDC be provided the resources it needs to expand its educational campaign.

Safe Motherhood/Infant Health

The National Center for Chronic Disease Prevention and Health Promotion, Division of Reproductive Health works to promote optimal reproductive and infant health. **The March of Dimes recommends a $5 million increase, as authorized in the PREEMIE Act (P.L. 109-450), for CDC to expand epidemiological studies to evaluate the social, biological, and medical factors associated with preterm birth, in an effort to identify ways to prevent preterm birth and racial disparities.**

The Safe Motherhood/Infant Health program is designed to promote infant and reproductive health. Finding the causes and preventing preterm birth is complex and requires research that examines medical, social, infection related, genetic, environmental and behavioral factors. Currently, CDC is partnering with a number of universities and organizations to support research into the causes of preterm birth and the reasons for disparities between racial and ethnic groups. It is essential that this work continue.

National Immunization Program

According to the CDC, every day in the U.S. approximately 11,000 babies are born who will need as many as 28 vaccinations before they are two years of age to be protected against 14 vaccine-preventable diseases. Nearly one million two-year-olds in the U.S. have not received one or more of the recommended vaccines. CDC's National Immunization Program provides grants to state, local, and territorial public health agencies to reduce the incidence of disability and death resulting from vaccine preventable diseases. The March of Dimes urges the Subcommittee to continue its longstanding policy of ensuring that federal vaccine programs are well funded. **For FY09, the March of Dimes recommends $802.4 million. In the Foundation's professional judgment these funds are needed so that the National Immunization Program has the resources it requires to account for vaccine price increases and introduction of new vaccines.**

Polio Eradication

Since its creation as an organization dedicated to research and services related to polio, **the March of Dimes has been committed to the eradication of this disabling disease. For FY09 the Foundation recommends a funding level of $101.254 million for CDC's FY09 global polio eradication program.** Level with FY08, this funding would allow CDC to continue its supplementary immunization activities in the remaining endemic and high-risk countries in Africa and Asia and to move quickly to interrupt polio transmission in these regions. The U.S. government must maintain its commitment to the worldwide polio eradication initiative that promises to save lives and reduce unnecessary health-related costs globally.

National Center for Health Statistics

The National Center for Health Statistics (NCHS) provides data essential for both public and private research and programmatic initiatives. The National Vital Statistics System and the National Survey on Family Growth, for example, are the principal sources of information on the utilization of prenatal care and on birth outcomes, including preterm delivery, low birthweight and infant mortality. Despite the $4.6 million increase Congress provided last year for the National Vital Statistics system, the program remains under funded and an additional $3 million is needed to support collection of vital statistics from states for the remainder of the calendar year. Without this investment, the United States will become the first industrialized nation unable to collect birth, death and other vital statistics. **The March of Dimes supports a funding level of $125 million, an increase of $11 million over FY08, to ensure the continuation of NCHS' central role in monitoring the nation's health.**

Health Resources and Services Administration (HRSA)

Newborn Screening

Newborn screening is a vital public health activity used to identify and treat genetic, metabolic, hormonal and functional conditions in newborns. Screening detects disorders in newborns that, if left untreated, can cause disability, mental retardation, serious illnesses or even death. Parents are often unaware that while nearly all babies born in the United States undergo newborn screening for genetic birth defects, the number and quality of these tests vary from state to state. The March of Dimes, the American Academy of Pediatrics and the American College of Medical Genetics recommend that at a minimum, every baby born in the United States be screened for a core group of 29 *treatable* conditions regardless of the state in which the infant is born. As of March 2008, only 19 states and the District of Columbia currently screen for all 29 conditions.

Current federal support for state newborn screening activities is provided through the Maternal and Child Health Block Grant, Special Projects of Regional and National Significance (SPRANS). **The Foundation urges that $4.9 million of SPRANS funding be set-aside for newborn screening activities (an increase of $3 million over FY08).** In the Foundation's view, this funding is needed to support state efforts to improve programs, acquire innovative testing technologies and increase capacity to reach and educate health professionals and parents with accurate information on newborn screening programs and follow up services.

Healthy Start

The Healthy Start Initiative is a collection of community-based projects focused on reducing infant mortality, low birthweight and racial disparities in perinatal outcomes. The **March of Dimes strongly supports Healthy Start and recommends a funding level of $110 million in FY09** for this important program which is designed to decrease the nation's unacceptably high rate of infant mortality.

Maternal and Child Health Block Grant

Title V of the Social Security Act, the Maternal and Child Health (MCH) Block Grant, provides assistance for a growing number of community-based programs (i.e.: home visiting, respite care for children with special health care needs and supplementary services for pregnant women and children enrolled in Medicaid and SCHIP), but federal support has not kept pace with increased enrollment and demand for services. **The March of Dimes therefore**

recommends full funding of the MCH Block Grant at the authorized level of $850 million.

Thank you for the opportunity to testify on the federally supported programs of highest priority to the March of Dimes. The Foundation's volunteers and staff in every state, the District of Columbia and Puerto Rico look forward to working with Members of the Subcommittee to secure the resources needed to improve the health of the nation's mothers, infants and children.

FY2009 FEDERAL FUNDING RECOMMENDATIONS
(Dollars in Millions)

PROGRAM	FY2008 FUNDING	MARCH OF DIMES FY 2009 RECOMMENDATION
National Institutes of Health (Total)	29,230	31,130
National Children's Study	110.9	192.3
National Institute of Child Health & Human Development	1,255	1,340
National Human Genome Research Institute	487	519
National Center on Minority Health and Disparities	200	213
Centers for Disease Control and Prevention (CDC)	6,375	7,400
Save Motherhood/Infant Health (NCCDPHP)	42.3	47.3
Birth Defects Research & Surveillance	13.7	16.7
Folic Acid Education Campaign	2	4
Immunization	523	802
Polio Eradication	98	101
National Center for Health Statistics	114	125
Health Resources and Services Administration (Total)	6,948	7,948
Maternal and Child Health Block Grant	666	850
Newborn Screening	1.9	4.9
Newborn Hearing Screening	12	12
Consolidated (Community) Health Centers	2,065	2,313
Healthy Start	100	110
Agency for Healthcare Research and Quality	335	360

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OFFICE OF THE
EXECUTIVE DIRECTOR

Official Written Testimony for Fiscal Year 2009
Submitted to the Subcommittee on Labor, Health and Human Services,
Education and Related Agencies
Committee on Appropriations
United States House of Representatives
Washington, DC

Submitted by Dr. Julia M. Watkins
Executive Director, Council on Social Work Education
March 31, 2008

On behalf of the Council on Social Work Education, I am pleased to offer this written testimony to the House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies for the official committee record. I will focus my testimony on issues pertaining to fostering a diverse social work workforce through training and accessibility to higher education. In particular, this statement will touch on the importance of funding the Substance Abuse and Mental Health Services Administration's (SAMHSA) Minority Fellowship Program at $6 million for Fiscal Year 2009; the need to protect the National Institute of Mental Health (NIMH) minority training program which is also in jeopardy of cancellation; and the importance of sustaining funding for programs within the Department of Education that expand accessibility in higher education.

EDUCATING SOCIAL WORKERS TO HELP VULNERABLE POPULATIONS

The Council on Social Work Education (CSWE) is a nonprofit national association representing more than 3,000 individual members as well as over 650 graduate and undergraduate programs of professional social work education. The Council on Higher Education Accreditation (CHEA) authorizes CSWE to establish national educational standards while evaluating individual academic programs to determine if these standards are met for professional accreditation. The central components of these accreditation requirements include critical-thinking, evidence based practice, communication skills, human behavior theory and supervised experiential learning. Social work education focuses students on leadership and direct practice roles helping individuals, families, groups, and communities by creating new opportunities that empower people to be productive, contributing members of their communities.

In particular, social work education prepares students at the graduate and undergraduate levels for professional practice in the leadership and staffing of our nation's most vital social service programs. Social workers help vulnerable populations in society—such as children and adults with physical or mental disabilities, trauma victims, individuals under stress or facing coping challenges both temporary and permanent, and segments of society needing assistance to adjust to changing circumstances or overcome injustices—be as healthy and productive as possible.

Social work educational programs provide rigorous academic experiences in both classroom and field agency or organizational internship settings and professional social work graduates are employed in a wide array of settings such as public schools, veterans' hospitals and general as well as other special service health care facilities, substance abuse prevention and treatment programs, child protective services, family service settings, and gerontological long-term care facilities. CSWE recognizes that fostering a diverse workforce is key to providing the best possible service to populations in need.

FOSTERING A DIVERSE SOCIAL WORK WORKFORCE THROUGH TRAINING AND ACCESSIBILITY

Minority Fellowship & Training Programs, Department of Health and Human Services
In 1974, amidst concerns about the limited number of minority scholars able to do indigenous research to improve services to minority communities, the National Institute of Mental Health (NIMH) within the National Institutes of Health (NIH) initiated a training program with the goal of increasing the number of minority doctoral students focusing their research in mental health. A few years later the Substance Abuse and Mental Health Services Administration (SAMHSA) created its own program that strived to achieve greater numbers of minority doctoral students preparing for leadership roles in the mental health and substance abuse field. These two programs provide grants to professional organizations which in turn administer fellowship grants to pre- and post-doctoral students. CSWE is one of the administering organizations. Together these programs make up CSWE's Minority Fellowship Program (MFP).

The MFP has been instrumental in the recruitment and training of underrepresented groups (African-American, Asian-American, Latinos, American Indians), in the field of substance abuse and mental health. Through effective recruitment and selection, the MFP has facilitated minority students' retention and success in doctoral programs in mental health and substance abuse. The MFP fellows receive a unified program of assistance to include mentoring, research training, access to professional networks, and on-going guidance in cooperation with their department advisors, which supports success in all facets. CSWE has supported over 500 minority fellows since the program's inception and two-thirds of those students have gone on to receive their doctoral degrees. They are employed at universities and agencies throughout the United States.

The Administration's FY 2009 budget request proposes to eliminate funding for the SAMHSA program, which received $3.8 million in FY 2008 and $4.2 million in FY 2007. The Minority Fellowship Program directly contributes to reversing disparities in mental health services and the quality of those services to minority populations. For this reason, ***CSWE urges the Subcommittee to restore this vital SAMHSA program for FY 2009 and in addition provide much needed additional resources in the sum of $6 million so that the program can continue to turnout minority mental health professionals equipped to provide culturally competent, accessible mental health and substance abuse services to diverse populations.***

In addition to the SAMHSA MFP, the minority education program in NIH's mental health institute is also in jeopardy. The NIMH minority education program focuses on increasing the number of minority doctoral students conducting mental health research; it is the "research" side of mental health training while the SAMHSA program represents the "clinical" side.

NIMH Director Thomas Insel has expressed his intent to eliminate funding for this program upon the expiration of the sole remaining institutional training grant in 2010. As the Subcommittee knows, new and young investigators continue to face an up-hill climb in terms of breaking into the NIH grant pool for the first time. NIH Director Elias Zerhouni has testified before your Subcommittee several times about the need for "new talent" at NIH, stating as recently as last year that "One of NIH's highest priorities will be to preserve the ability of new and junior scientists with fresh ideas to enter the competitive world of NIH funding."

While we applaud NIH's efforts to diversify the NIH grant pool through the development of such programs as the "Pathway to Independence" program and others, at a time when NIH has pledged a commitment to growing "fresh talent," NIMH is essentially abandoning a proven program that has educated and prepared hundreds of minority scholars for research and leadership in the mental health sciences.

While we understand that this issue cannot be fixed via the annual appropriations process, ***we urge the Subcommittee to put pressure on NIH to reconsider its intent to cut off funding for this crucial training program beginning in 2010.***

Aid for Institutional Development, Department of Education

Fostering a diverse workforce is central to ensuring that we are able to provide culturally competent services to minority populations. Social workers must be able to relate to the communities they serve. However, getting minority students into the workforce pipeline is often difficult due to the many barriers to higher education facing minority and lower-income populations.

The Department of Education supports several programs whose goal is to expand the accessibility of higher education to lower-income and minority populations. These programs provide financial assistance to minority-serving institutions to address needs in academic quality, student services, educational equipment acquisition, facility construction, and faculty and staff development. In turn, funds for these programs make these institutions more accessible while at the same time culturally relevant.

For FY 2009, the Administration has proposed to substantially cut funding for these very important programs. Specifically, cuts are proposed for programs geared toward strengthening Tribally Controlled Colleges and Universities; Alaska Native and Native Hawaiian-serving Institutions; Historically Black Colleges and Universities; Historically Black Graduate Institutions; Predominantly Black Institutions; Asian American and Native American Pacific Islander-serving, and Native American-serving nontribal institutions.

CSWE asks the Subcommittee to reject the President's proposed cuts for FY 2009 and provide these programs with at least the amount enacted for FY 2008. Minority-serving institutions like these play a vital role in educating the diverse workforce that is the backbone of the social work profession, and since they do not have access to the same resources (large endowments, high tuition) as other institutions, they depend heavily on this modest federal support to function. While the Administration's rationale for these cuts is that the College Cost Reduction Act of last

year provides additional mandatory funding for these institutions, we presume that Congress provided those funds so that minority-serving institutions could move forward, not remain stagnant.

Thank you for the opportunity to express these views on behalf of the Council on Social Work Education. We hope the Subcommittee will take these points into consideration as you move forward in the FY 2009 appropriations process. Please do not hesitate to contact me with any questions.

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HOUSE COMMITTEE ON APPROPRIATIONS
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,
EDUCATION AND RELATED AGENCIES
FOR FY 2009 BUDGET

TESTIMONY OF
THEODORA CAPALDO, ED.D. PRESIDENT

THE NEW ENGLAND ANTI-VIVISECTION SOCIETY
PROJECT R&R: RELEASE AND RESTITUTION FOR CHIMPANZEES IN U.S. LABORATORIES

March 31, 2008

Founded in 1895, the New England Anti-Vivisection Society is one of the oldest and longest standing animal protection organizations in the United States. On behalf of our more than 25,000 supporters and supporters of our program, Project R&R, we submit testimony on our funding priorities for the Labor, Health and Human Services, Education and Related Agencies Subcommittee in Fiscal Year 2009. Dedicated to human health and well being as well as laboratory animal well being, we appreciate the opportunity to present testimony relevant for the FY 2009 budget request. We believe these priorities will serve both humans and animals.

We appreciate the opportunity to submit testimony to the Labor, Health and Human Services, Education and Related Agencies Appropriations Act for Fiscal Year 2009. Thank you.

NEAVS/Project R&R requests that no federal funding be appropriated for:

- breeding of chimpanzees or other great apes for research
- transfer of federally-owned chimpanzees to private ownership
- housing/maintenance/endowments for federally-owned chimpanzees in private facilities
- maintenance of surplus chimpanzees except in retirement in sanctuary
- research involving the use of chimpanzees

NEAVS/Project R&R requests that federal funding be appropriated for:

- transfer of federally-owned chimpanzees into sanctuary
- housing/maintenance grants for federally-owned chimpanzees in sanctuary
- retirement of all "surplus" chimpanzees now held in laboratories
- reallocation of funding for chimpanzee research into funding non-animal research methods

Substantiating Information

1. The National Center for Research Resources (NCRR) announced a permanent end to funding for the breeding of federally-owned and supported chimpanzees (including funding NIH projects requiring chimpanzee breeding). This NCRR decision recognizes the exorbitant costs of lifetime care of chimpanzees in laboratory settings and its consequent drain to limited and precious research dollars. No other federal agency should threaten this fiscally, ethically, and scientifically sound NCRR decision by providing funding for breeding of federally-owned chimpanzees. To do so would perpetuate an animal model that has been of limited or no value, especially in relation to the costs they require for their care and maintenance. Chimpanzees live for decades and 71 % of the American public, according to an independent public opinion survey, believe those in labs for 10 or more years should be retired. A current estimate of the U.S. population puts that figure at approximately 93 % of the chimpanzees now held in labs.

2. The government is currently spending close to $10 million dollars each year to care for approximately 600 federally-owned or supported chimpanzees (nearly $1.0 million per chimpanzee's lifetime). Breeding perpetuates this fiscal burden on the government. Further, grants to private companies, like Charles River Laboratory's (CRL) federal $43 million 10 year grant could have gone further, covered more chimpanzees, and provided superior care had it been appropriated for sanctuary care and not the laboratory care provided by CRL at Alamogordo. This funding is an example of federal subsidizing of private profits, not an example of sound research dollar priorities.

3. The U.S. is still managing the "surplus of chimpanzees" previously bred to be available to HIV research. Today their use in HIV/AIDS research has diminished to the point of hardly existent. They proved to be a poor, even dangerous model in not only AIDS research but in every area of major "killer diseases" for humans, including cancer, heart disease, stroke, etc. (*An Assessment of the Role of Chimpanzees in AIDS Vaccine Research,* Jarrod Bailey, Ph.D., 2008)

4. Studies have indicated that the majority of chimpanzee research published (in addition to research not accepted for publication) is never later cited in studies to do with human prophylactic, diagnostic, or therapeutic methods. This indicates that in general, the chimpanzee model has made limited contributions to human health and in many cases has actually led to dangerously erroneous applications to humans. (*Chimpanzee Research: An Examination of Its Contribution to Biomedical Knowledge and Efficacy in Combating Human Diseases*, Jarrod Bailey, Ph.D. and Jonathan Balcombe, Ph.D., 2007)

5. The transfer of government-owned and supported chimpanzees into private facilities with accompanying federal endowments would perpetuate their financial burden on taxpayers, and only private facilities would profit from such an arrangement. The lifetime support of federally-owned chimpanzees is required by the CHIMP Act. The government can provide this care more efficiently and effectively through maintaining ownership and transferring all government-owned chimpanzees into the federally supported sanctuary system or private sanctuary that meets those standards. The government can share the cost of their lifetime care with private donations from the public, who would be assured that the chimpanzees are no longer available for research. Private laboratories interested in "maintaining" a chimpanzee population are a fiscally inefficient solution for the government. Such facilities do not provide the quality care that sanctuaries can provide. The private warehousing and/or lifetime use of chimpanzees in private research – supported with government taxpayer dollars -- will lead to public outcry.

6. If private industry receives federal support for breeding and using government owned, once owned or government endowed chimpanzees for their own private research, then private industry would be unfairly, and perhaps illegally, benefiting from federally-owned "resources" meant for the betterment of the American public, not for the profit of private industry.

7. To date, the private sector has not been fiscally responsible for the lifetime care of chimpanzees once their use to them for private profit is over. When their chimpanzees are retired, the private sector has not, to date, offered financial compensation for their chimpanzees' lifetime care. Instead, on the few occasions where the chimpanzees were sent to sanctuary with some funding, the financial compensation falls far short of what is actually needed, leaving the burden of responsibility on the private facilities and their public donors.

8. If the government: transfers all approximately 600 federally-owned chimpanzees to the national sanctuary system or to private sanctuary that meets or exceeds these standards; appropriates to those sanctuaries the funding currently being given to chimpanzee laboratories; and, prohibits breeding, there is an end to the financial burden that this misused and underproductive animal model has caused the government. The government needs a solution, and the funding priority suggestions set forth herein would offer a major step toward such a solution.

9. Transferring all federally-owned chimpanzees to sanctuary will: (a) consolidate and decrease costs; (b) provide better care; and, (c) offer the public the humane solution they are asking for.

10. Scientific justification for maintaining the exorbitant costs associated with such a physically strong, intellectual curious, socially and emotionally complex species as a chimpanzee does not exists. A 2007 article, "The Endangered Lab Chimp" in *Science*, noted that "a huge number" of chimpanzees are not being used in active research protocols and are therefore "just sitting there." If breeding ends and current mortality rates continue (as they are expected given the aging population of chimpanzees in U.S. labs), the government will have no – or a bare minimal -- financial responsibility for the chimpanzees it owns within 20 -30 years. No federal funding for breeding will ensure that no breeding of federally-owned or supported chimpanzees for research will occur in FY 2009 and be a major step to ending the government's non-productive, high cost involvement in chimpanzee research. As years of a voluntary breeding moratorium showed,

private industry is not willing to breed without government support. It understands the costs and refuses to adequately provide for the lifetime care of chimpanzees it already owns. If the use of chimpanzees was lucrative or necessary, then the private industry's dollars and practices would reflect that. However, it is not. The federal government needs to follow suit in such "wise business" decisions.

11. The American and world (great ape research is banned or severely limited in eight scientifically advanced nations and a European Union wide ban is expected to pass soon) public are deeply concerned about the use of chimpanzees in research. Their close emotional, cognitive, and social similarities to humans have put them in a unique category of interspecies ethics. This moral reality has been acknowledged by the government (requirements for their care in the CHIMP Act that apply to no other animal species used in research) and scientists (several private laboratories that used chimpanzees have closed or stop using them), and the American public are clearly concerned about these issues. As the voice of the American public, our administrative offices should consider that: 90% of Americans believe it is unacceptable to confine chimpanzees individually in government-approved cages; 71% believe that chimpanzees who have been in the laboratory for over 10 years should be retired to sanctuary; 54% believe that it is unacceptable for chimpanzees to "undergo research which causes them to suffer for human benefit"; and, twice as many American's support an outright ban on chimpanzee research as do those who oppose such a ban.

12. Therefore, we respectfully request the following committee report language:

"The Committee directs that funds provided in this Act not be used:

to support the breeding of chimpanzees or other great apes for research; to support research that requires breeding of chimpanzees; to support the transfer of ownership of federally-owned chimpanzees to private entities (including endowments for their maintenance); to maintain surplus chimpanzees except in retirement in sanctuary; or to fund new research involving the use of chimpanzees.

The Committee directs that funds provided in this Act be used:

to transfer federally-owned chimpanzees into sanctuary; to house and maintain federally-owned chimpanzees in sanctuary; to retire all "surplus" chimpanzees now held in laboratories; and to reallocate funding from chimpanzee research into non-animal research methods."

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Statement of the Friends of the Health Resources and Services Administration
On the Health Resources and Services Administration Budget for Fiscal Year 2009
House Committee on Appropriations
Subcommittee on Labor, Health and Human Services and Education
Submitted for the Record
March 31, 2008

The Friends of the Health Resources and Services Administration (HRSA) is a non-profit and non-partisan alliance of more than 120 national organizations, collectively representing millions of public health and healthcare professionals, academicians and consumers. Our member-organizations strongly support the programs at HRSA designed to ensure Americans' access to health services, and the elimination of health disparities.

Through its programs in thousands of communities across the country, HRSA provides a health safety net for medically underserved individuals and families, including 47 million Americans who lack health insurance, 50 million Americans who live in neighborhoods where primary health care services are scarce, and more than one million people living with HIV/AIDS. HRSA funding goes where the need exists, in communities all over America and especially among populations experiencing racial/ethnic and rural/urban disparities in health status. We support a growing trend in HRSA programs to increase flexibility of service delivery at the local level, necessary to tailor programs to the unique needs of America's many varied communities, as well as HRSA long-time commitment to enhancing the health resources that lay the foundation for health care delivery across the country. The agency's overriding goal is to achieve 100 percent access to health care, with zero disparities. **In the best professional judgment of the members of the Friends of HRSA, to respond to this challenge, the agency will require an overall funding level of at least $7.9 billion for fiscal year (FY) 2009.**

The Friends of HRSA are gravely concerned about the President's budget recommendation of $992 million in cuts for FY 2009, including over 20 program eliminations. These proposed cuts would considerably undermine the agency's ability to achieve its goals of improving access and eliminating disparities. A significantly greater investment is necessary to adequately fund HRSA's many programs and new initiatives that help millions of Americans live healthier, more productive lives. In the 21st century, rapid advances in research and technology promise unparalleled advances in the nation's health care delivery system. HRSA could be well positioned to meet these new challenges in providing needed health care to the nation's most vulnerable citizens.

In the President's budget, the Bureau of Primary Care received a $27 million increase over the FY 2008 funding level, all of which is designated for the Health Centers Program. This will continue to support the over 1,000 grantees that provide primary healthcare services to an estimated 17.1 million medically underserved and low-income patients. It will also fund up to 40 new access point grants and 25 planning grants. HRSA primary care centers include community health centers, migrant health centers, health care for the homeless programs, public housing primary care programs, and school-based health centers. Health centers provide access to high-quality, family-oriented, culturally and linguistically competent primary care and preventive services, including mental and behavioral health, vision, and dental services. Forty percent of health center patients are uninsured, 64 percent are from racial and ethnic minority groups, and over 92 percent live below 200 percent of the Federal poverty level. While recent growth in the health centers program has been substantial, a significant need remains in underserved communities

across the country. We strongly encourage the Committee to continue its support of existing health centers and efforts to expand the reach and scope of the Health Centers Program into new communities.

In the President's budget, the National Health Service Corps received a $3 million cut. Approximately 50 million Americans live in communities with a shortage of health professionals, lacking adequate access to primary care. The Corps supports the recruitment and retention of primary care clinicians to practice in underserved communities in exchange for scholarships and loan repayment. The Corps supports over 3,400 clinicians, with over half working in community health centers. Growth in the Health Centers Program must be complemented with growth in the recruitment and retention of primary care clinicians to ensure adequate staffing. This cannot be accomplished with the proposed funding cut.

The Bureau of Health Professions received the largest cut - $542 million - in the President's budget. This cut includes the proposed elimination of most Health Professions Programs authorized under Titles VII and VIII of the Public Health Service Act and the Children's Hospital Graduate Medical Education Program. The budget eliminates all Title VII health professions programs and provides only $110 million for the Title VIII nursing workforce development programs. These programs are an essential component of America's healthcare safety net, bringing healthcare providers to underserved communities and filling the gaps in the health professions supply not met by traditional market forces. The Title VII and VIII programs work in concert with the Health Centers Program and the National Health Service Corps to strengthen the healthcare safety net by enhancing the supply, distribution and diversity of the health professions workforce. They are the only federal programs designed to train providers in interdisciplinary settings to meet the needs of underserved populations and increase minority representation in the health professions workforce. Through loans, scholarships, and grants to academic institutions and non-profit organizations, these programs provide support for the training of primary care physicians, nurses, dentists, physician assistants, advanced practice nurses, public health personnel, psychologists, pharmacists, healthcare educators, and other allied health providers. In addition, the Patient Navigator program places navigators in health facilities to help underserved populations take advantage of prevention tools and get the quality care they need. We are concerned that eliminating most of the health professions programs will exacerbate existing provider shortages in rural, medically underserved, and federally designated health professions shortage areas. Cuts to the Health Professions Programs threaten to disrupt the pipeline of new providers that Health Centers and other safety-net health facilities need to meet the long-term needs of underserved communities. Cuts also will impede the recruitment of underrepresented minorities and students of disadvantaged backgrounds into the health professions, which will intensify health disparities. Furthermore, we are concerned about the impact health professions cuts will have on children's care, through the elimination of the Children's Hospital Graduate Medical Education Program, and our aging Baby Boomer generation, though the elimination of Title VII geriatric education programs. We strongly encourage the Subcommittee to restore funding to these vital programs.

The President's budget would cut the Maternal and Child Health (MCH) Programs by $39 million. Among these programs, the budget recommends level funding for the MCH Title V Block Grant at $666 million for FY 2009, an appropriation slightly higher than that received in FY 1993 without adjusting for inflation. For over 70 years, the MCH Block Grant has provided a source of flexible funding for states and territories to address their unique needs related to improving the health of mothers, infants and children, including reducing the infant mortality rate of 6.9 deaths per 1,000 live births nationwide. Today, this program provides prenatal services to over two million mothers—almost half of all mothers who give birth annually—and primary and preventive care to over 17 million children, including almost one million children with special needs. This funding level present a daunting challenge to state maternal and child health programs trying to cope with greater need and ever increasing medical costs. Furthermore, the

President's budget eliminates the Traumatic Brain Injury (TBI), Universal Newborn Hearing Screening and Emergency Medical Services for Children programs. Without these programs, the services and associated costs will be borne by the MCH Block Grant.

Nationally, at least 5.3 million Americans suffer from the effects of TBI and have a long-term or lifelong need for help to perform activities of daily living. This results in an estimated societal cost of over $60 billion per year in direct medical costs and indirect costs like lost productivity. The TBI Program provides grants to states to coordinate, expand and enhance service delivery systems in order to improve access to services and support for persons with TBI and their families. The TBI program also provides funds to state protection and advocacy programs which work to ensure that people with TBI get access to the supports and services they need. TBI can strike anyone at any time—from falls, vehicle crashes, sports injuries, violence, and other causes. Despite the increasing numbers of soldiers returning from war with head injuries, increasing numbers of children being identified as disabled due to head injuries, and the release of an Institute of Medicine Report stating the importance of the program to brain injury survivors and their families, the President's FY 2009 budget eliminates the TBI Program. We encourage the Subcommittee to restore funding for this critical program.

Every day, 33 babies are born with hearing loss in the U.S. making it the most common birth defect (three out of every 1,000 infants). Newborn hearing screening is cost-efficient and lowers the age at which children with congenital permanent hearing loss are identified. Research shows that children who are identified early and enrolled in an intervention program by six months of age adapt better socially and perform better academically. More than 90 percent of newborns are screened for hearing loss prior to hospital discharge and this practice is now the standard of care in the United States. The Universal Newborn Hearing Screening Program provides 53 grants to states and territories supporting statewide systems of newborn hearing screening, audiologic diagnostic testing before three months of age, and enrollment in early intervention programs before the age of six months, with ties to a medical home and family-to-family support services. We are dismayed that the President's FY 2009 budget eliminates this program and we encourage the Subcommittee to restore its funding.

The proposed elimination of the Emergency Medical Services for Children (EMSC) program is also of great concern, especially in light of the recent Institute of Medicine report that highlights significant shortcomings in pediatric emergency care. The EMSC program is a national initiative designed to reduce child and youth disability and death due to severe illness and injury. EMSC grants provide funding for states and territories to improve existing emergency medical services systems and develop and evaluate better procedures and protocols for treating children. Children are not merely small adults; they have unique and specific needs that this programs works to address. We request that the EMSC program be restored and fully funded to ensure children receive optimal medical care.

The MCH Block Grant also supports state newborn screening activities through the Special Projects of Regional and National Significance (SPRANS). We encourage that $4.9 million of SPRANS funding be set-aside for newborn screening activities, an increase of $3 million over FY 2008. Newborn screening is a vital public health activity used to identify and treat genetic, metabolic, hormonal, and functional conditions in newborns. Screening detects disorders in newborns that, if left untreated, can cause disability, mental retardation, serious illnesses, or even death. Parents are often unaware that while nearly all babies born in the U.S. undergo newborn screening for genetic birth defects, the number and quality of these tests vary from state to state. The March of Dimes, the American Academy of Pediatrics and the American College of Medical Genetics recommend that at a minimum, every baby born in the United

States be screened for a core group of 29 treatable conditions regardless of the state in which the infant is born. As of March 2008, only 19 states and the District of Columbia currently screen for all 29 conditions.

The Office of Rural Health Policy received a $150 million cut in the President's FY 2009 budget, an 86 percent reduction over FY 2008. This Office promotes better healthcare services for the almost one quarter of our population that lives in rural communities. These communities suffer from inadequate access to quality healthcare and experience the higher rates of illness associated with a lower socioeconomic status. The proposed cuts include the elimination of the Rural Access to Emergency Devices, the Rural Hospital Flexibility Program, Rural Outreach grants, the Denali Commission, and the Delta Health Initiative. The Rural Access to Emergency Devices grant program helps rural communities purchase automated external defibrillators (AEDs) and provides first responders training in their use and maintenance. Sudden cardiac arrest strikes over 160,000 Americans each year and these devices can more than double a victim's chance of survival. The Rural Hospital Flexibility Program provides grants to State governments for a variety of purposes such as to develop and implement Rural Health Plans, stabilize rural hospitals and help them obtain designation as "Critical Access Hospitals", improve and integrate emergency medical services, and improve the quality of care in rural communities. Rural Outreach grants support the development of new and innovative healthcare delivery systems in rural communities that lack essential healthcare service. These grants fund a variety of programs that provide care to at least two million rural citizens across the country that would not otherwise have access to these services, including hospice, pediatric dental care and prenatal care. The Denali Project supports health infrastructure development in Alaska by providing resources for the planning, design and construction of primary healthcare facilities. Finally, the Delta Health Initiative funds rural organizations to address local healthcare needs in the rural Delta region. Programs funded through the Initiative have provided services to over 300,000 people including chronic disease management, access to pharmacy services, practice management services, oral health, school-based health services, mental health/substance abuse services, and teenage pregnancy prevention. We encourage the Subcommittee to restore funding to these important programs that address the many unique healthcare needs of rural communities.

The HIV/AIDS Bureau, which administers the Ryan White HIV/AIDS Program, received a meager $1 million increase in the FY 2009 proposed budget. Over one million Americans are living with HIV. This program provides the largest single source of federal discretionary funding for HIV/AIDS health care for more than half a million low-income, uninsured and underinsured Americans. The proposed funding level is insufficient to meet a growing demand of people seeking care and stagnant funding is diminishing the availability of services to persons living with HIV/AIDS. These cuts have forced state, local and public health clinics' HIV/AIDS programs to stretch already thin budgets to treat existing clients while trying to provide care and treatment to those newly diagnosed as HIV-positive. We strongly encourage the Committee to increase its commitment to the HIV/AIDS Bureau and efforts to expand the reach and scope of the Ryan White HIV/AIDS Program to more people living with HIV/AIDS.

The AIDS Drug Assistance Programs (ADAP) received a $6 million increase in the President's FY 2009 proposed budget. Unfortunately, this program, which provides life-sustaining treatment to 159,000 people living with HIV/AIDS, cannot be sustained on such an increase. ADAP grow by 386 new clients per month. Without significant increases, States are expected to have to institute additional cost-containment measures such as waiting lists, reduced formularies, increased cost-sharing for ADAP clients, and lowered eligibility requirements for enrollment.

The Title X Family Planning programs, level funded in the President's budget, provide comprehensive, voluntary and affordable family planning services to nearly five million low-income women and men —

many of whom are uninsured — at more than 4,400 clinics nationwide. Title X funded clinics help improve access to contraceptives, which help women plan the number and timing of their pregnancies, improves maternal and infant health, and helps to prevent approximately 1.3 million unplanned pregnancies each year, nearly half of which would end in abortion. In fact, for every public dollar invested in family planning, $3.80 is saved in Medicaid costs for pregnancy and newborn care. In addition, they provide a broad package of preventive health services, including breast and cervical cancer screening, blood pressure checks, anemia testing, and STD/HIV screening. Today, almost 17 million women need publicly supported contraceptive care – a number which continues to grow. These programs require a substantial increase in investment to meet the growing demand and medical inflation.

The C.W. Bill Young Cell Transplantation Program received a $1 million cut in the FY 2009 proposed budget. This program helps patients who need a potentially life-saving bone marrow or cord blood transplant, including patients with diseases like leukemia, lymphoma, sickle cell anemia, or other inherited metabolic or immune system disorders. Today, only 72 percent of Americans can find an adult match on the National Registry and for minority populations that number is significantly lower. The proposed funding reduction would compromise the program's ability to provide greater access to transplants for patients with these disorders and expand research with the aim of improving patient outcomes.

The President's budget cut funding for the Poison Control Centers by a devastating 63 percent, $17 million under the FY 2008 level. These centers are a critical resource for people, health professionals and organizations. Poisoning can happen to anyone, at anytime in any place and can lead to serious illness or even death. Each year, more than two million possible poisonings are reported to the nation's poison centers. On average, poison centers handle one possible poisoning every 13 seconds. These critical centers cannot afford to lose any resources and we encourage the subcommittee to fully fund this program.

A major source of HRSA's strength is its many linkages and partnerships with other federal agencies, state, national and local organizations. For example, HRSA and the Centers for Medicare and Medicaid Services (CMS) jointly implementing outreach on the State Children's Health Insurance Program in addition to working together to improve data sharing and coordination, particularly on Medicaid. Work also is ongoing with the Substance Abuse and Mental Health Services Administration (SAMHSA) to integrate behavioral health and substance abuse screening, early intervention, referral and follow-up into primary health care settings funded through HRSA grants. HRSA and the Centers for Disease Control and Prevention (CDC) cooperate on a variety of disease prevention and health promotion activities.

Cross-cutting HRSA programs continually respond to new public health challenges. For instance, tooth decay remains the single most chronic childhood disease in the nation. However, about 125 million Americans have no dental insurance. Lack of access to dental care is especially severe among children of poor, rural and minority families, as well as children with developmental disabilities. A quarter of the nation's school-age children have 80 percent of all dental disease, putting them at risk for a host of related illnesses. And as new drugs help people with HIV/AIDS live longer, healthier lives, their need for regular oral health care will continue to increase. HRSA can help both groups by increasing the number of dentists in community and school-based centers and by providing greater reimbursements to hospital dental clinics and dental schools for the growing costs of treating people living with HIV/AIDS.

We urge the members of the Subcommittee to restore the allocations that were cut and fund the agency at a level that allows HRSA to effectively implement these important programs. The members of the Friends of HRSA are grateful for this opportunity to present our views to the Subcommittee.

AIRI *Association of Independent Research Institutes*	**Written Statement for the Record by Michael "Chip" Morgan, President, Association of Independent Research Institutes** ***Prepared for*** **Subcommittee on Labor/HHS/Education and Related Agencies** **Committee on Appropriations** **United States House of Representatives** **March 31, 2008**

The Association of Independent Research Institutes (AIRI) respectfully submits this written statement for the FY 2009 Public Record to the U.S. House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies.

AIRI is a national organization of roughly 90 independent, non-profit research institutes that perform basic and clinical research in the biological and behavioral sciences. Our member institutes are private, stand-alone research centers that set their sights on the vast frontiers of medical science. 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 be structurally nimble and capable of adjusting their research programs to emerging areas of inquiry. While the primary function of AIRI institutes is research, most are strongly involved in training the next generation of biomedical researchers. In a testament to the quality of research and innovative ideas that AIRI institutes bring to the national biomedical enterprise, our institutions consistently exceed the success rates of the overall National Institutes of Health (NIH) grantee pool, and receive about 11 percent of NIH's peer reviewed, competitively awarded extramural grants. On average, AIRI member institutes receive a total of $1.6 billion in extramural grants from NIH in any given year.

The doubling of the NIH budget over 1998 – 2003 allowed the biomedical research community to accelerate solutions to human disease and disability. We have blazed new trails for medical research, delving into the intricacies of how the human body musters its defenses and of how those responses can be evaluated, enhanced, and modified. In addition, increased funding at NIH has helped us to realize new scientific management strategies such as fostering interdisciplinary research and creating new robust teams of scientists that, before the doubling, did not have scientific common ground. These research teams navigate the fast progressing research environment where there is an increasing need to integrate and aggregate basic research, computational capabilities, and clinical evidence into new therapies and cures more quickly. Further, federal investment in NIH has helped us to redefine health and healthcare goals based on scientific discoveries that were out of reach prior to the doubling. We now discuss disease and healthcare in terms of developing new predictive, preventative and pre-emptive tactics.

Last year, AIRI endorsed the FY 2008 Ad Hoc Group for Medical Research proposal to increase the NIH budget by 6.7 percent over each of the next three fiscal years, FY 2008 –

FY 2010. At the time, we recognized that competing budget priorities put pressure on Congress to face difficult funding trade-offs yet we asked the Subcommittee to adopt a long-term commitment to NIH. As you are aware, the final FY 2008 appropriation for NIH was a disappointment to your Subcommittee and the rest biomedical research community. For the fifth straight year, NIH funding failed to match even the pace of biomedical inflation.

Unfortunately, the President's FY 2009 budget request for NIH continues this flat funding trend for the agency for the sixth straight year. If the President's FY 2009 request is enacted, the agency will have lost over 13.4 percent of its purchasing power during this time period when taking into account the anticipated 3.5 percent biomedical inflation rate for this year. *As such, AIRI joins its colleagues in the biomedical community in calling for a $1.9 billion (6.6 percent) increase in NIH's total discretionary budget for FY 2009.*

The NIH-funded research conducted at independent research institutes and other institutions across the nation is important for curbing projected dramatic increases in U.S. healthcare costs over the long term. Sustained, multi-year federal funding commitments will be critical to forestalling the onset of diseases such as heart disease and stroke, Alzheimer's disease, mental health disorders, and cancer as 80 million baby boomers begin to retire and face the diseases of aging. NIH-funded research has had an enormous impact and remains a cornerstone in the nation's battle against existing and emerging diseases. Flat funding for the agency reduces NIH's ability to meet the research demands of the nation and slows the medical advances that can be made by the entire research community.

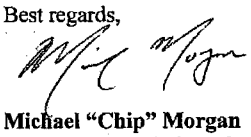
In addition to funding for NIH biomedical research overall, AIRI hopes that the Subcommittee will continue to support programs and policies championed by NIH Director Dr. Zerhouni that foster a sustainable, biomedical research workforce. The biomedical research community is dependent upon a knowledgeable and skilled workforce to address current and future critical health research challenges. The cultivation and preservation of this workforce is dependent upon several factors, including the ability to: recruit scientists and students globally; train researchers both in basic and clinical biomedical research; develop and retain researchers at critical stages during their early careers; support new and young investigators; and maintain the NIH extramural investigator salary cap at Executive Level I. As we work to enhance biomedical research capabilities, we should not impose barriers that would discourage talented people from committing to careers in research. The recruitment and development of these scientists will be a key to sustaining our national competitiveness.

Additionally, AIRI urges Congress to support NIH extramural shared instrumentation and equipment grant programs. As the investment in medical research and the national biomedical research agenda have expanded, the need for acquisition and modernization of laboratory equipment and infrastructure has become critical. NIH equipment grants meet the specific infrastructure needs of research institutions to maximize productivity of their research grants. These grants aid in the attainment of state of the art research tools that allow U.S. laboratories to investigate biomedical questions on the cutting edge of science.

Medical research is a long-term process and, in order to meet the challenges of improving human health, curbing rising healthcare expenditures, and securing a global leadership role in the life sciences, we must increase our federal commitment and investment in NIH. It is essential to sustain the momentum of NIH-funded research so that it continues to meet the goal of improving the health of all Americans.

AIRI would like to thank the Subcommittee for its important work to ensure the health of the nation, and we appreciate this opportunity to present recommendations concerning the FY 2009 Appropriations bill in the FY 2009 Public Record.

Best regards,



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NPRCs *National Primate Research Centers*	**Written Statement for the Record Provided by the Eight National Primate Research Center Directors** ***Prepared for*** **Subcommittee on Labor/HHS/Education and Related Agencies** **Committee on Appropriations** **United States House of Representatives** **March 26, 2008**

The Directors of the eight National Primate Research Centers (NPRCs) respectfully submit this written testimony for the record to the U.S. House of Representatives 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 strong support for the National Institutes of Health (NIH).

The NPRCs are a national network of eight primate research centers supported by the NIH National Center for Research Resources (NCRR). The centers comprise the National Primate Research Program (NPRP), which was created by Congress in 1960. The program seeks to address human health problems through scientific research using the animal models that most closely resemble humans in their genetics, physiology, and disease processes – nonhuman primates. NPRC investigators and resources support research projects sponsored by nearly every institute at NIH. For example, NPRCs conduct research to help understand and treat conditions such as heart disease, hypertension, cancer, diabetes, hepatitis, AIDS, kidney disease, Alzheimer's disease, and Parkinson's disease. We also conduct research on emerging infectious diseases and support many aspects of biodefense. Each NPRC makes its facilities and resources available to over 2,000 external NIH-funded investigators from around the country. Our centers create collaborative research environments that allow scientists to combine their individual expertise beyond the scope of established disciplinary research projects.

Also, NPRCs are integral partners in new science partnerships that will transform America's health and healthcare in the 21st century. NIH has responded to the rapidly changing world by strategically framing the next generation of biomedical research through cross-cutting, interdisciplinary initiatives such as those supported in the NIH Roadmap, the NIH Neuroscience Blueprint, the Clinical and Translational Science Award program and the Genes, Environment and Health Initiative. NPRCs are poised to continue research and resource partnerships that will nurture the collaborative environment necessary to successfully and efficiently conduct research within these evolving NIH frameworks.

In 2007, NPRCs endorsed the FY 2008 Ad Hoc Group for Medical Research proposal to increase the NIH budget by 6.7 percent over each of the next three fiscal years, FY 2008 – FY 2010. At the time, we recognized that competing budget priorities put pressure on Congress to face difficult funding trade-offs yet we asked the Subcommittee to adopt long-term commitment to NIH. As you are aware, the final FY 2008 appropriation for NIH was a disappointment to your Subcommittee and the rest of the biomedical research community. For the fifth straight year, NIH funding failed to match even the pace of biomedical inflation.

NATIONAL PRIMATE RESEARCH CENTERS

Unfortunately, the President's FY 2009 budget request for NIH continues this flat funding trend for the agency for the sixth straight year. If the President's FY 2009 request is enacted, the agency will have lost over 13.4 percent of its purchasing power during this time period when taking into account the anticipated 3.5 percent biomedical inflation rate for this year. *As such, NPRCs joins its colleagues in the biomedical community in calling for a $1.9 billion (6.6 percent) increase in NIH's total discretionary budget for FY 2009.*

The NIH-funded research being conducted at NPRCs and other institutions across the nation is important for curbing projected dramatic increases in U.S. healthcare costs over the long term. NPRCs' research and resources are critical to the translational phase of biomedical research (i.e. the stage prior to applying research findings to clinical trials using human subjects). To accommodate the increased focus of NIH on translational science and other research demands placed on NPRCs, NCRR should increase NPRCs P51 base grant (the mechanism that funds each NPRC) so that all appropriate areas of research can benefit from primate resources without delay. It is unacceptable that while the NIH budget doubled and demand for primate resources increased, NPRCs budgets were held relatively flat by NCRR.

Sustained, multi-year federal funding commitments by Congress for NIH and by NCRR for NPRCs will be critical to forestalling the onset of diseases such as heart disease and stroke, Alzheimer's disease, mental health disorders, and cancer as 80 million baby boomers begin to retire and face the diseases of aging. Some of the research projects accomplished with the help of nonhuman primate research include:

Heart Disease and Stroke – To date, advances against heart disease have cut deaths due to heart attack and stroke by more than 50 percent and save our economy more than half a trillion dollars annually in healthcare expenses and worker productivity. Nonhuman primates are used to investigate how genes interact with dietary factors to influence an individual's risk of developing atherosclerosis or hypertension. It is not possible to conduct this research with human subjects because it requires long-term feeding of defined diets, specialized pedigrees and the ability to frequently monitor multiple aspects of physiology. Establishment of the pedigreed baboon as model in which to study risk factors for atherosclerosis has led to improvements in methods used to search the genome for genes regulating these risk factors. Increased funding for NIH and support for NPRCs will allow investigators to build on this research and apply significant findings to human health.

Alzheimer's Disease – A new report from the Alzheimer's Association shows that there are more than 5 million people in the US living with Alzheimer's disease today –10 percent more than the previous estimate of 4.5 million from five years ago. The report puts Medicare's expenditures for beneficiaries with Alzheimer's and other dementias at $91 billion for 2005 – that figure is projected to increase to $160 billion by 2010 and $189 billion by 2015. NPRCs are using rhesus monkeys to establish better models for studying the basic mechanisms of Alzheimer's disease, and for testing new diagnostic and therapeutic methods. Two distinct and cutting edge approaches are being developed to express in rhesus monkeys the human mutant genes that cause Alzheimer's disease. Further NIH-funded investigation and NPRCs support could lead us to early interventions for

Alzheimer's that would decrease the healthcare cost burden and safeguard the health of millions of Americans.

Mental Health Disorders – The National Institute of Mental Health points out that the annual economic cost of mental illness in the U.S. is estimated at well over $150 million, including direct and indirect costs. Further, according to statistics from the Centers for Medicare and Medicaid Services, the direct costs of mental health care represent 6.2 percent of overall healthcare costs which totaled 14.5 percent of the gross domestic product in 2001. Just one example of NPRCs contribution to this category of diseases and disorders is a project in which research conducted with non-human primates produced a strong link between significant stress early in life and the increased incidence of mental health problems during adolescence. The research strengthens the case for proactive treatment or counseling of children who undergo a significant early-life stress. Non-human primates provide unique insight into a variety of mental health disorders in ways that cannot be achieved in controlled studies in humans. Increased NIH funding and NPRCs support will allow researchers across the nation and at NPRCs to continue work toward developing reliable diagnostic tools and therapies so that the quality of life will be enhanced for the millions of Americans burdened by mental health disorders.

Cancer – According to NIH data, thirty years ago, for the five most common cancers, the five-year survival rates were: breast, 75 percent; prostate 68 percent; colon, 50 percent; rectum, 49 percent; and lung, 13 percent. However, due in large part to NIH-funded research advances, data as of 2001 (the latest year for which NIH has statistics) shows the five-year survival rates for the most common cancers have increased to: prostate, 100 percent; breast, 90 percent; colon, 65 percent; rectum, 65 percent; and lung, 16 percent. It is known that approximately 20 percent of cancers have a viral etiology. As such, a project taken on by NPRCs uses non-human primate models of viral-induced cancer to help scientists to understand fundamental mechanisms through which normal cells are transformed into cancerous cells. Increased and steady NIH funding and NPRC support will allow researchers to build on past progress in treating, curing and reducing the burden of cancer – this will lead to both a decline in the projected rise of U.S. healthcare expenditures and result in an American workforce with more healthy, productive years.

As a result of years of expanded investment and advancement in NIH biomedical research, the demand for NPRC resources has increased. The ability of NIH-funded researchers to conduct future projects with primate models will depend on the enhancement of three key areas: 1) the nationwide availability of primates; 2) the quality and capacity of primate housing and breeding facilities, as well as the availability of related state-of-the-art diagnostic and clinical support equipment at NPRCs; and 3) the number of personnel trained in primate care and management at NPRCs. These areas can be enhanced by an NIH/NCRR commitment to increase the NPRCs P51 base grants. Increases to the P51 base grants would allow NPRCs: to reprioritize and expand existing breeding colonies of species for which the need exceeds the supply; to invest in repairs, renovation, and construction of research facilities, as well as to purchase modern laboratory equipment; and to ensure that adequate

numbers of experts are trained in laboratory animal medicine and research, because NPRCs must maintain primate management teams comprised of behavioral specialists, veterinarians, and primate research experts to ensure excellent primate care, health, and research success.

Increases from NIH/NCRR to the NPRC P51 base grants are necessary to meet the needs discussed above and are critical to the ability of NPRCs to supply adequate primate resources for scientists across the nation to carry out important research projects. As mentioned previously, these research projects span the disease foci at NIH institutes and centers, and also play important roles in the NIH Roadmap, the NCRR Strategic Plan, the NIH Neuroscience Blueprint, the Clinical and Translational Science Award program, the Genes, Environment and Health Initiative and grand challenges facing the scientific community. In the 1950's, primate research produced the first vaccine for one of the world's worst childhood killers, the Polio virus, reducing the number of cases in the United States from 58,000 to one or two per year. More recently, primate research enabled the development of a safe and effective vaccine for hepatitis B. Every school child in the country is now vaccinated against hepatitis B. Primates have also served as the best model for various types of HIV research, and their availability for use has resulted in at least 14 licensed anti-viral drugs for treatment of HIV infection. Primate models will continue to be necessary to defend the world against possible future epidemics such as SARS, West Nile Virus, and avian flu. In addition to deadly viral epidemics, primate research has enabled the discovery of better treatments and therapies for diseases and occurrences such as stroke, cataracts, depression and other psychiatric illnesses. Significant advances in prenatal and postnatal care have also resulted from primate research.

Not only do primates have the potential to provide answers for long-standing research questions, primate research provides an unparalleled opportunity to address more recently defined research priorities, such as those relating to genomics and bioterrorism. The specific availability of information in the primate genome, which is quite similar to the human genome, makes primates essential in studies that require an integrated understanding of a whole biological system. Recent reports suggest that extensive analysis of genome structure and function in nonhuman primates could make immediate and significant contributions to the overall mission of NIH by accelerating progress in understanding many human diseases. Also, primates serve as critical animal models in biodefense research projects for which, in some cases, it would be inappropriate to conduct early clinical trials in humans. Primates are recognized as vital research resources within federal strategic plans regarding biodefense research, including: the National Institute of Allergy and Infectious Diseases (NIAID) Strategic Plan for Biodefense Research; the NIAID Research Agenda for Category A Agents; and the NIAID Research Agenda for Category B and C Priority Pathogens. Also, NPRCs are partners in NIAID-funded Regional Centers of Excellence for Biodefense and Emerging Infectious Diseases as well as with NIAID-funded National and Regional Biocontainment Laboratories.

As NIH and the national biomedical research agenda evolve, NPRCs adjust to meet the resource needs of the research community and also to maintain research programs that are on the cutting-edge of science. The reservoirs of knowledge residing within the NPRCs create new opportunities for research partnerships with investigators at host academic institutions and in the biomedical research community at large. Never have the research

questions been so profound, or the implications for human health so critical. NPRCs are poised to bridge the gap between knowledge already gleaned from simple cellular and animal models and knowledge that is needed to promote human health, and to translate that knowledge into vaccines, therapeutic drugs, and other strategies to prevent or treat human diseases. Past accomplishments demonstrate, and current and future research directions will rely on, the roles of robust primate research programs in addressing critical research questions. The breadth and success of primate research programs confirm the vital role that the eight NPRCs play in biomedical research nationwide.

Thank you for the opportunity to submit this written testimony and for your attention to the critical need for primate research and enhancement of the NPRCs P51 base grant, as well as our recommendations concerning funding for NIH in the FY 2009 Appropriations bill.

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STATEMENT OF
THE AMERICAN THORACIC SOCIETY

submitted to

THE HOUSE LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION APPROPRIATIONS SUBCOMMITTEE

on the

FISCAL YEAR 2009 LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION APPROPRIATIONS BILL

March 31, 2008

SUMMARY: FUNDING RECOMMENDATIONS (in millions $)

National Institutes of Health	$30,537
National Heart, Lung & Blood Institute	$3,112
National Institute of Allergy & Infectious Disease	$4,675
National Institute of Environmental Health Sciences	$683
Fogarty International Center	$70
National Institute of Nursing Research	$146
Centers for Disease Control and Prevention	$10, 700
National Institute for Occupational Safety & Health	$253
Environmental Health: Asthma Activities	$70
Div. of Tuberculosis Elimination	$300
Chronic Disease Prev. & Health Promotion: COPD	$6

The American Thoracic Society (ATS) is pleased to submit our recommendations for programs in the Labor Health and Human Services and Education Appropriations Subcommittee purview.

The American Thoracic Society, founded in 1905, is an independently incorporated, international education and scientific society that focuses on respiratory and critical care medicine. For 100 years, the ATS has continued to play a leadership role in scientific and clinical expertise in diagnosis, treatment, cure and prevention of respiratory diseases. With approximately 18,000 members who help prevent and fight respiratory disease around the globe, through research, education, patient care and advocacy, the Society's long-range goal is to decrease morbidity and mortality from respiratory disorders and life-threatening acute illnesses.

LUNG DISEASE IN AMERICA

Lung disease is a serious health problem in the U.S. Each year, close to 400,000 Americans die of lung disease. One in seven deaths is caused by lung disease, making it America's number three cause of death. More than 35 million Americans suffer from a chronic lung disease. In 2005, lung diseases cost the U.S. economy an estimated $157.8 billion in direct and indirect costs.

Lung diseases represent a spectrum of chronic and acute conditions that interfere with the lung's ability to extract oxygen from the atmosphere, protect against environmental or biological challenges and regulate a number of metabolic processes. Lung diseases include chronic obstructive pulmonary disease, lung cancer, tuberculosis, influenza, sleep disordered breathing, pediatric lung disorders, occupational lung disease, sarcoidosis, asthma and severe acute respiratory syndrome (SARS).

The ATS is extremely concerned that the President's FY09 budget proposes to freeze NIH spending at the FY08 level and would impose a significant funding cut for the Centers for Disease Control and Prevention (CDC). We ask that this subcommittee recommend a 6.5 percent increase for NIH so that the institute can respond to biomedical research opportunities and public health needs. In order to stem the devastating effects of lung disease, research funding must continue to grow to sustain the medical breakthroughs made in recent years. We also ask that the CDC budget be adjusted to reflect increased needs in chronic disease prevention, infectious disease control, including strengthened TB control to prevent the spread of drug-resistant TB, and occupational safety and health research and training. There are three lung diseases that illustrate the need for further investment in research and public health programs: Chronic Obstructive Pulmonary Disease, pediatric lung disease, asthma and tuberculosis.

COPD

Chronic Obstructive Pulmonary Disease (COPD) is the fourth leading cause of death in the United States and the third leading cause of death worldwide. Yet, COPD remains relatively unknown to most Americans. COPD is the term used to describe the airflow obstruction associated mainly with emphysema and chronic bronchitis and is a growing health problem.

While the exact prevalence of COPD is not well defined, it affects tens of millions of Americans and can be an extremely debilitating condition. It is estimated that 11.2 million patients have COPD while an additional 12 million Americans are unaware that they have this life threatening disease.

According to the National Heart, Lung and Blood Institute (NHLBI), COPD cost the U.S. economy an estimated $37 billion per year. We recommend the Subcommittee encourage NHLBI to devote additional resources to finding improved treatments and a cure for COPD.

Medical treatments exist to relieve symptoms and slow the progression of the disease. Today, COPD is treatable but not curable. Fortunately, promising research is on the horizon for COPD patients. Despite these leads, the ATS feels that research resources committed to COPD are not commensurate with the impact the disease has on the United States and that more needs to be done to make Americans aware of COPD, its causes and symptoms. The ATS commends the NHLBI for its leadership on educating the public about COPD through the National COPD Education and Prevention Program. As this initiative continues, we encourage the NHLBI to maintain its partnership with the patient and physician community.

While additional resources are needed at NIH to conduct COPD research, CDC has a role to play as well. To address the increasing public health burden of COPD, the ATS encourages the CDC to create a COPD program the Center for Chronic Disease Prevention and Health Promotion with a recommended funding level of $6 million for FY09. We are hopeful that the program will include development of a national COPD response plan, expansion of data collection efforts and creation of other public health interventions for COPD. The ATS also encourages the CDC to add COPD-based questions to future CDC health surveys, including the National Health and Nutrition Evaluation Survey (NHANES), the National Health Information Survey (NHIS) and the Behavioral Risk Factor Surveillance Survey (BRFSS). By collecting information on the prevalence of COPD, researchers and public health professionals will be better able to understand and control the disease.

PEDIATRIC LUNG DISEASE

Lung disease affects people of all ages. The ATS is pleased to report that infant death rates for various lung diseases have declined for the past ten years. However, of the seven leading causes of infant mortality, four are lung diseases or have a lung disease component. In 2003, lung diseases accounted for 18 percent of all deaths under one year of age. It is also widely believed that many of the precursors of adult respiratory disease start in childhood. The ATS encourages the NHLBI to continue with its research efforts to study lung development and pediatric lung diseases.

The pediatric origins of chronic lung disease extend back to early childhood factors. For example, many children with respiratory illness are growing into adults with COPD. In addition, it is estimated that close to 20.5 million people suffer from asthma, including an estimated 6.8 million children. While some children appear to outgrow their asthma when they reach adulthood, 75 percent will require life-long treatment and monitoring of their condition. Asthma is the third leading cause of hospitalization among children under the age of 15 and is the leading cause of chronic illness among children.

ASTHMA

The ATS believes that the NIH and the CDC must play a leadership role in assisting individuals with asthma. National statistical estimates show that asthma is a growing problem in the United States. Approximately 22.2 million Americans currently have asthma, of which 12.2 million had an asthma attack in 2005. African Americans have the highest asthma prevalence of any racial/ethnic group. The age-adjusted death rate for asthma in the African-American population is three times the rate in whites.

ASTHMA SURVEILLANCE

There is a need for more data on regional and local asthma prevalence. In order to develop a targeted public health strategy to respond intelligently to asthma, we need locality-specific data. CDC should take the lead in collecting and analyzing this data and Congress should provide increased funding to build this these tracking systems.

In FY08, Congress provided approximately $30.7 million for CDC's National Asthma Control Program. The goals of this program are to reduce the number of deaths, hospitalizations, emergency department visits, school or work days missed, and limitations on activity due to asthma. We recommend that CDC be provided with $70

million in FY09 to expand the program and establish grants to community organizations for screening, treatment, education and prevention of childhood asthma.

SLEEP

Sleep is an essential element of life, but we are only now beginning to understand its impact on human health. Several research studies demonstrate that sleep illnesses and sleep disordered breathing affect an estimated 50-70 million Americans. A recent study conduced by CDC found that roughly 10% of Americans had not gotten enough rest at any point in the previous 30 days. The public health impact of sleep illnesses and sleep disordered breathing is still being determined, but is known to include traffic accidents, lost work and school productivity, cardiovascular disease, obesity, mental health disorders, and other sleep-related comorbidities. We cannot appropriately address these problems if we do not consider how chronic sleep loss contributes to them. Despite the increased need for study in this area, research on sleep and sleep-related disorders has been underfunded. The ATS recommends funding level of $2 million in FY09 to support activities related to sleep and sleep disorders at the CDC, including for the National Sleep Awareness Roundtable (NSART), surveillance activities, and public educational activities. The ATS also recommends an increase of funding for research on sleep disorders at the Nation Center for Sleep Disordered Research (NCSDR) at the NHLBI.

TUBERCULOSIS

Tuberculosis (TB) is a global public health crisis that remains a concern for the U. S. Tuberculosis is an airborne infection caused by a bacterium, ***Mycobacterium tuberculosis***. Tuberculosis primarily affects the lungs but can also affect other parts of the body, such as the brain, kidneys or spine. The statistics for TB are alarming. Globally, one-third of the world's population is infected with the TB germ, 9.2 million active cases develop each year and 1.7 million people die of tuberculosis annually. It is estimated that 9-14 million Americans have latent tuberculosis. Tuberculosis is the leading cause of death for people with HIV/AIDS.

According to the CDC, although the overall rate of new TB cases is declining in the U.S., the annual rate of decrease in TB cases has slowed significantly, from about 7.3 percent (1993 to 1999) to 3.8 percent currently (2000 – 2007). This rate represents one of the smallest declines since 1992, when over $1 billion was spent in New York City alone to regain control of TB. The ATS is concerned that TB rates in African Americans remain high and that TB rates in foreign-born Americans are growing.

The rapid spread of drug resistant TB and the emergence of extensively drug-resistant (XDR) TB has created a global health emergency. According to a February 2008 World Health Organization (WHO) report on drug resistant TB, about 5% of all new TB cases are drug resistant. The highest rates of drug resistance can be found in former Soviet bloc countries such as Azerbaijan and Ukraine and areas where HIV/AIDS is endemic, such as South Africa. Because it is resistant to most of the drugs used to treat TB, XDR-TB is virtually untreatable and has an extremely high fatality rate. In a South African outbreak in 2005-2006, XDR-TB killed 52 out of 53 infected patients. Because of the ease with which TB can spread, drug resistant TB will continue to pose a serious risk to the U.S. as long as it exists anywhere else in the world.

While we urge immediate action in response to the drug resistant TB global health crisis, we also recognize the best way to prevent the future development of other resistant strains of tuberculosis is through supporting effective tuberculosis control programs in the U.S. and throughout the globe. We ask the subcommittee to take the first steps to eliminating TB in the U.S. and prevent further outbreaks of drug resistant forms of TB. The ATS, in collaboration with Stop TB USA, recommends a funding level of $300 million in FY 2009 for CDC's Division of TB Elimination.

The NIH has a prominent role to play in the elimination of tuberculosis through the development of new tools to fight the disease, however the ATS is concerned that the NIH has cut funding for TB research from $158 million in 2005 to $150 million in 2006 - 2008. We encourage the NIH to expand efforts to develop new tools to reduce the rising global TB burden, including faster diagnostics that effectively identify TB in all populations, new drugs to shorten the treatment regimen for TB and combat drug resistance, and an effective vaccine.

Fogarty International Center TB Training Programs

The Fogarty International Center (FIC) at NIH provides training grants to U.S. universities to teach AIDS treatment and research techniques to international physicians and researchers. Because of the link between AIDS and TB infection, FIC has created supplemental TB training grants for these institutions to train international health care professionals in the area of TB treatment and research. These training grants should be expanded and offered to all institutions. The ATS recommends Congress provide $70 million for FIC, which would allow the expansion the TB training grant program from a supplemental grant to an open competition grant.

RESEARCHING AND PREVENTING OCCUPATIONAL LUNG DISEASE

The National Institute of Occupational Safety and Health (NIOSH) is the sole federal agency responsible for conducting research and making recommendations for the prevention of work-related diseases and injury. In addition to conducting research, NIOSH investigates potentially hazardous working conditions, makes recommendations and disseminates information on preventing workplace disease, injury, and disability; and provides training to occupational safety and health professionals. The ATS recommends that Congress provide $253 million in FY09 for NIOSH to expand or establish the following activities: the National Occupational Research Agenda (NORA); tracking systems for identifying and responding to hazardous exposures and risks in the workplace; emergency preparedness and response activities; and *training* medical professionals in the diagnosis and treatment of occupational illness and injury.

CONCLUSION

Lung disease is a growing problem in the U.S. It is this country's third leading cause of death. The lung disease death rate continues to climb. Overall, lung disease and breathing problems constitute the number one killer of babies under the age of one year. Worldwide, tuberculosis is one of the leading infectious disease killers. The level of support this subcommittee approves for lung disease programs should reflect the urgency illustrated by these numbers. The ATS appreciates the opportunity to submit this statement to the subcommittee.

Infectious Diseases Society of America's (IDSA) Statement Concerning FY 2009 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

March 31, 2008

The Infectious Diseases Society of America (IDSA) appreciates this opportunity to bring attention to the disastrous cuts proposed for leading infectious disease programs in President Bush's fiscal year (FY) 2009 budget. Should these cuts go into effect, the nation's and world's ability to control and contain an ever-increasing number of infectious diseases threats will be severely diminished. As many recent news stories have shown, existing and emerging infections continue to challenge Americans in U.S. hospitals and communities as well as people around the globe. These infections include HIV/AIDS, methicillin-resistant *Staphylococcus aureus* (MRSA), Tuberculosis (TB) including extensively drug-resistant (XDR) TB, malaria and other resistant and susceptible organisms, such as *Escherichia coli*, *Pseudomonas aeruginosa*, *Neisseria gonorrhoeae*, *Acinetobacter baumannii*, and *Klebsiella species*.

IDSA represents more than 8,000 infectious diseases physicians and scientists devoted to patient care, education, research, prevention, and public health. Our members care for patients of all ages with serious infections, including meningitis, pneumonia, TB, antibiotic-resistant bacterial infections such as MRSA, and those with cancer or transplants who have life-threatening infections caused by unusual microorganisms, food poisoning, and HIV/AIDS, as well as emerging infections like severe acute respiratory syndrome (SARS).

Especially hard-hit in this year's budget is the Centers for Disease Control and Prevention (CDC), the primary Federal agency responsible for conducting and supporting public health protection through health promotion, prevention, preparedness, and research. CDC would see a cut of nearly half a billion dollars in its total budget, to $5.9 billion. IDSA instead recommends increasing funding for CDC to $7.4 billion, roughly a 15 percent increase over current funding. This corresponds well with the Professional Judgment delivered last year by CDC Director Julie Gerberding, which said that $7.2 billion would be needed in FY2008 to properly fund CDC.

Within the CDC budget, IDSA is especially concerned about the slashing of the Infectious Diseases program budget, which would be reduced by more than $34 million, to $1.9 billion. Last year, Dr. Gerberding told Congress the program needed an increase of nearly $315 million in FY2008, but CDC received less than one-fifth of that amount. IDSA recommends an FY2009 funding level of $2.1 billion for CDC's Infectious Diseases programs.

Within the Infectious Disease programs' proposed budget, the agency's already severely strapped Antimicrobial Resistance budget would be further cut to $16.5 million. This vital program is necessary to help combat the rising crisis of drug resistance, a critical medical

problem marked most publicly by the upsurge in MRSA infections. A CDC-supported report published last October in the *Journal of the American Medical Association* indicated that invasive MRSA infections kill more than 19,000 Americans annually -- more than emphysema, HIV/AIDS, or Parkinson's disease. In response to the acute MRSA problem and the growing antimicrobial resistance epidemic, IDSA recommends increasing FY2009 funding for resistance programs at CDC by $16 million, to a total of $33 million. Such funding increases will enable CDC to strengthen the National Healthcare Safety Network, which supports surveillance of drug-resistant healthcare associated infections, gather morbidity and mortality data related to resistance, track the development of dangerous resistant bugs as they develop, educate physicians and parents about the need to protect the long-term effectiveness of antibiotics, and strengthen infection control activities across the United States.

In addition, a proposed $26 million cut (which represents a more than 20 percent reduction, to $103.6 million) to CDC's "Other Emerging Infectious Diseases" line item would hobble the agency's core infrastructure and ability to respond to new threats as they emerge. Past and existing threats have included rabies, rotavirus, food-borne diseases, Ebola, SARS, and others. Congress replaced a similar proposed cut in its FY08 enacted budget. The proposed cut would severely affect CDC laboratory capacity, research grants to academic partners, and support for state public health departments and public health laboratories. The cuts specifically may affect the testing and surveillance of antimicrobial resistant gonorrhea, domestic and global tuberculosis and invasive bacterial pathogens, and also threaten the continued development or improvement of laboratory tests for several new and existing viruses. IDSA recommends that the Other Emerging Infectious Diseases line item be increased to at least $145 million for FY2009.

The Section 317 Program at CDC has been one of our country's greatest public health achievements. In part through the Section 317 Program that provides funding for immunization to states and other jurisdictions, the United States has made significant progress toward eliminating vaccine-preventable diseases among children. At a time when new CDC-recommended vaccines are available and a greater commitment to immunizations for both children and adults is necessary, the proposed cuts to this program will undermine access to a critical intervention that saves lives and millions of dollars in unnecessary medical spending. Therefore, IDSA is recommending a funding level for the Section 317 Program of $802 million.

IDSA also supports changes which will significantly strengthen the Section 317 Program's support for adult and adolescent immunization. Each year, more than 46,000 adults die of vaccine-preventable diseases (VPDs). Costs related to illnesses from adult VPDs are approximately $10 billion. Distinct funding floors for adult vaccine purchase and infrastructure are needed in amounts sufficient to cover immunization of the majority of under-insured and uninsured adults with all CDC-recommended vaccines.

Recent cuts have eroded national TB control programs, which is especially concerning as threats from XDR and multi-drug resistant TB grow. As news reports on incidences of TB have shown, CDC is stretched extremely thin in their ability to respond and control TB outbreaks. A total of $300 million is needed across CDC for efforts to prevent, control and eliminate TB.

The budget request for HIV prevention and surveillance activities at CDC also is woefully inadequate. These programs are critical to reducing the number of new HIV cases occurring annually in the United States. Sufficient resources must be devoted to HIV prevention to support CDC's portfolio of prevention programs, including the initiative to identify people with HIV/AIDS earlier through routine HIV screening. This program will lead to lifesaving care sooner and will help to prevent further transmissions. IDSA supports funding of $1.3 billion for these programs in FY2009. We also support funding of $2.78 billion for the Ryan White CARE Act programs within the Health Resources and Services Administration, including $299.3 million for Part C programs. Ryan White programs are vital to our health care safety net and are struggling to meet the need for HIV services in communities across the country.

The President also proposes to flat-fund the National Institutes of Health (NIH) in FY2009, which represents a continued setback for this important agency. NIH is the single-largest funding source for infectious diseases research in the United States and the life-source for many academic research centers. The NIH-funded work conducted at these centers lays the ground work for advancements in treatments, cures, and medical technologies. However, since 2003, NIH has lost 13 percent of its purchasing power due to the rate of biomedical research inflation and stagnating annual budgets. Because of the flat budget, three out of four research proposals submitted to NIH are not funded. Peer reviewers are forced to become more risk averse, leading to a narrowing of scientific vision. Without higher-risk research, the pace of scientific discovery and the rate of medical advancement diminish. Without medical advancements, thousands of Americans will have to wait longer for the cures they need. Not only are we experiencing a rusting of innovative biomedical research, we are also losing a generation of physician scientists.

The President's budget proposal does not come close to reaching the authorized funding level of $32.8 billion set for FY2008 contained in the NIH Reform Act, which passed in 2006. Therefore, IDSA is recommending an increase of at least $1.9 billion in FY2009 for NIH, to a total of $31.1 billion. This increase would return the budget to historical growth (equaling the rate of biomedical research inflation plus approximately 3 percent).

NIH's Fogarty International Center is at the forefront of global health and is a leader in extending the U.S. federal biomedical enterprise abroad. It taps innovative thinking from all parts of the world and fosters important scientific partnerships. Through Fogarty, the U.S has supported research and research training programs conducted by both U.S. and foreign investigators across a wide range of infectious diseases and needs, including HIV/AIDS, malaria, and tuberculosis. The Center's efforts have led to improved local health outcomes -- but so much more can be done. For this reason, IDSA strongly supports increasing Fogarty's funding level in FY2009 to $100 million -- an increase of $33 million. These additional resources will enable Fogarty to increase research training initiatives, forge new partnerships between U.S. and foreign research institutions, and conduct much-needed implementation research to increase the effectiveness of international programs.

IDSA also proposes an increase in antimicrobial resistance research funding at NIH of $100 million in FY2009, bringing it to a total of $321 million. This funding level would allow NIH to strengthen clinical research and establish a clinical trials network to study resistant infections as

well as antibacterial use and development. Well-designed, multi-center randomized controlled trials would create an excellent basis of evidence from which coherent and defensible recommendations could be developed.

Additionally, in the Agriculture appropriations bill, IDSA would propose that antimicrobial resistance programs at the Food and Drug Administration receive at least a $10 million increase in new funding in FY2009, bringing its resistance funding to $34 million. This would allow FDA to establish and periodically update antibiotic susceptibility breakpoints based on testing and data collection, including through the purchase of vendor data; fund Critical Path initiatives for antibiotics; more aggressively review the safety of antibiotic use in food animals; and quicken its pace in developing critical guidance for industry on antibiotic clinical trial designs.

The Department of Health and Human Services' Biomedical Advanced Research and Development Authority (BARDA) holds great potential to encourage and facilitate the development of new medical countermeasures and technologies. Congress authorized $1.07 billion for this mission; however, since BARDA's creation in December 2006, only $201 million has been provided. We are disappointed that Congress' and the Administration's intent in creating BARDA have not been actualized. The current funding level has not allowed HHS to establish an active, robust advanced research and development portfolio for biomedical products. An analysis conducted by the Center for Biosecurity indicates that $817 million in FY 2009 would be required to support one year of advanced development for just the 32 candidate medical countermeasures against biological threats currently in development. IDSA recommends that $850 million of multi-year appropriations be allocated to BARDA in FY 2009 to fund biological therapeutics, diagnostics, and technologies. Such funding would help ensure the availability of resources throughout the advanced stages of development and the flexibility for BARDA to partner effectively with developers.

IDSA commends the BARDA Influenza and Emerging Disease Program for taking great strides to advance our knowledge and ability to produce a safe and efficacious pre-pandemic vaccine. However, many challenges remain, including complexities of vaccine manufacturing and surge capacity as well as the timely production of a more closely-matched pandemic strain vaccine. For this critical program to continue to move forward, IDSA strongly encourages the Congress to fund the Influenza and Emerging Disease Program at $1.29 billion, to be available over multiple years. This $790 million increase over the budget proposal would include $308 million for advanced vaccine development, $234 million for vaccine stockpiling, and $248 million for antiviral stockpiling.

Funding for pandemic influenza preparedness at other agencies within HHS has also been proposed in FY2009. We were greatly disappointed last year when the final omnibus appropriations bill included only $74 million for pandemic flu, rather than the $948 million requested. This year's budget request would fund ongoing pandemic flu activities at the federal agencies at $313 million. IDSA strongly supports this funding.

Today's investment in infectious disease research, prevention, and treatments will pay significant dividends in the future by dramatically reducing health care costs and improving the quality of

life for millions of Americans. In addition, U.S. leadership in infectious diseases research and prevention 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.

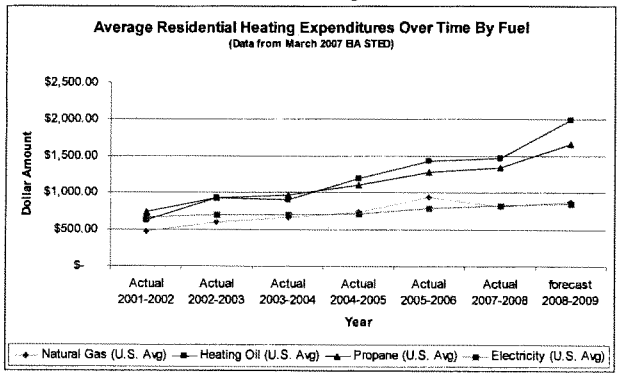
Testimony of the National Consumer Law Center on Behalf of Our Low-Income Clients[1]
Before the House Committee on Appropriations
Subcommittee on Labor, Health & Human Services, Education, and Related Agencies

FY 2009 Appropriations for the Low Income Home Energy Assistance Program
Prepared by Olivia Wein, Staff Attorney, National Consumer Law Center

The federal Low Income Home Energy Assistance Program (LIHEAP)[2] is the cornerstone of government efforts to help needy seniors and families avoid hypothermia in the winter and heat stress (even death) in the summer. We are in a sustained period of much higher household energy prices and expenditures and the demand for this program is growing as increases in energy prices far outstrip the ability of low-income households to pay. In light of the crucial safety net function of this program in protecting the health and well-being of low-income seniors, the disabled and families with very young children, we respectfully request that LIHEAP be fully funded at its authorized level of $5.1 billion for FY 2009 and that advance funding of $5.1 billion be provided for the program in FY 2010.

The Cost of Home Energy Remains at Record High Levels

Residential heating expenditures remain at record high levels. The average residential heating expenditures are projected to be 95% higher for heating oil, 28% higher for natural gas, 66% higher for propane, and 18.5% higher for electricity than the averaged expenditures for 2001-2006. The current U.S. Department of Energy short-term forecast of residential heating expenditures predicts that, on average, residential bills are still among the highest on record. The cost of electricity, used for both heating and cooling, has been increasing rapidly due, in part, to increases in the price of natural gas used to generate electricity in many power plants and the lifting of price caps in states that restructured their electric markets. In a brief span of time, energy bills have walloped low-income households. The effect of these continually rising prices on low-income households is devastating.

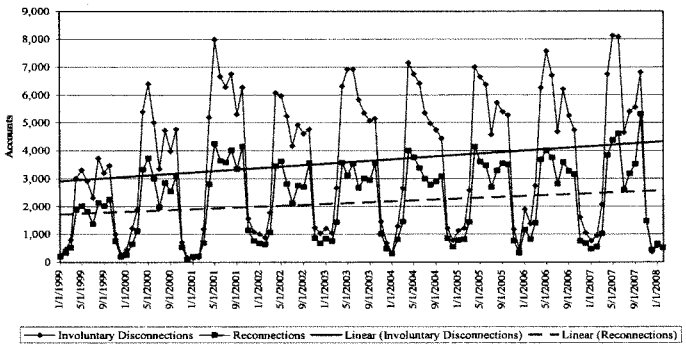


[1] Pennsylvania Utility Law Project (PULP) on behalf of its low-income clients, Esparanza Community Housing Corporation (CA), Community Housing Development Corporation of North Richmond (CA).
[2] 42 U.S.C. §§ 8621 et seq.

States' Data On Electric And Natural Gas Disconnections And Arrearages Show That More Households Are Falling Behind

The steady and dramatic rise in residential energy costs has resulted in increases in electric and natural gas arrearages and disconnections. For example, in **Rhode Island** there were over 30,000 residential service disconnections in 2007, over 5,000 more than in any previous year. Of those 30,000 shutoffs, over 5,200 were not restored. Similarly, the gap between service disconnections and reconnections has been increasing over time, suggesting increased durations of service loss and greater numbers of households that do not regain access to service under their own accounts as demonstrated by data from **Iowa.**[3]

Iowa Electric and Natural Gas Utilities:
Residential Service Disconnections and Reconnections



Although there are winter utility shut-off moratoria in place in many states, not every home is protected against energy shut-offs in the middle of winter. As we approach the lifting of winter shut-off moratoria, we expect to see a wave of disconnections as households are unable to afford the cost of the energy bills. The chart illustrating Iowa's shut-off and reconnection data shows the typical sharp increase in disconnections in the spring once the winter moratorium ends in a state. Low-income families are falling further behind as we endure year after year of rising home energy prices. We expect the disconnection peaks to grow and the gap between disconnections and reconnections to also grow.

Iowa: While the basic LIHEAP block grant for Iowa is at last year's levels, this winter has been colder than in the past several years and natural gas prices remain high and propane prices are around a third higher this year than the same point last year. In February 2008, the number of low-income households with past due energy accounts and the total amount of the low-income arrears were the second highest on record for this time of year since these data have been

[3] Chart provided by the Iowa Bureau of Energy Assistance.

tracked. As an indication of the effect of long term effect of rising home energy prices, the total number of LIHEAP households in arrears in February 2008 was 67% higher than five years ago at this point in time and 159% higher than in February 1999. The total amount of arrearages of LIHEAP households has also grown sharply due to the increase in prices. By February 2008, the total amount of LIHEAP household arrears had increased 58% from the same period five years ago and 176% compared to arrears in February 1999. The total number of LIHEAP households served in FY 2009 is expected to exceed the number of households served last year.[4]

Ohio: Ohio has experienced a steady and dramatic demand for low-income energy assistance. The number of households entering into the state's low-income energy affordability program, the Percentage of Income Payment Program (PIPP), increased 7% from January 2007 to January 2008. The increase is an even more dramatic 75% between January 2002 and January 2008. The total dollar amount owed (arrearage) by low-income PIPP customers increased 14% from January 2007 to January 2008 and 84% when comparing PIPP customer arrears from January 2002 to January 2008. The growing demand is also apparent from the frontlines. One community action agency in Ohio reports that: "We have been busy with HEAP this winter...as always.. but this year even busier than last. There are still many people in the lobby every day seeking this assistance, and many we have never seen before. It is an indication of how serious the struggle is for Ohioans this year." Ohio has experienced an increase in enrollment for the regular LIHEAP block grant program (HEAP) from 2005 to 2007 with 262,561 total households in 2005; 354,371 in 2006; 360,656 in 2007 and expects to see an increase in enrollment by the end of this program year as well."[5]

Pennsylvania: Utilities in Pennsylvania that are regulated by the Pennsylvania Public Utility Commission (PA PUC) have established universal service programs that assist utility customers in paying bills and reducing energy usage. Even with these programs, electric and natural gas utility customers find it difficult to keep pace with their energy burdens. The PA PUC estimates that more than 16,857 households entered the current heating season without heat-related utility service – this number includes about 3,095 households who are heating with potentially unsafe heating sources such as kerosene or electric space heaters and kitchen ovens. In mid-December 2007, an additional 11,468 residences where electric service was previously terminated were vacant and over 5,826 residences where natural gas service was terminated were vacant. In 2007, the number of terminations increased 44% compared with terminations in 2004. As of December 2007, 19.2% of residential electric customers and 16.9% of natural gas customers were overdue on their energy bills.[6]

LIHEAP Is a Critical Safety Net Program for the Elderly, the Disabled and Households With Young Children

Preliminary estimates by the National Energy Assistance Directors' Association are that FY 2008 participation rates will remain near the same levels as in FY 2007, reaching an estimated

[4] Conversations with the Director of the Iowa Bureau of Energy Assistance (March 19, 2008).
[5] Public Utilities Commission of Ohio and correspondence with staff at the Ohio Community Development Division (March 11, 2008).
[6] Pennsylvania Public Utility Commission Bureau of Consumer Services.

5.5 million households.[7] Yet, energy prices have been on a continued upward climb. The high residential energy prices have eroded LIHEAP's purchasing power and the ability of the LIHEAP program to help protect our most vulnerable citizens from extreme weather conditions that cause illness, physical harm and even death.

LIHEAP Is Vital To Poor Seniors: Poor seniors are cutting back on energy usage because it is not affordable. In general, elder households use less total household energy than non-elderly households, which is attributable primarily to the smaller dwelling units. However, poor elderly households use markedly less energy than non-poor elderly households. The disparity in usage between the poor elderly and the non-poor elderly is present in each of the Census regions: with the poor elderly using 37% less in the Northeast Census Region, 40% less in the Midwest Census Region, 20% less in the South Census Region and 54% less in the West Census region. Even worse, poor elderly households, on average, consume 12% more energy per square foot of living space (this measurement is also referred to as energy intensity) than non-poor elderly households. This disparity is attributable to the poorly weatherized living spaces and the use of old, inefficient heating equipment and appliances.[8] In the summer, the inability to keep the home cool can be lethal, especially to seniors. According to the CDC, in 2001 300 deaths were caused by excessive heat exposure, and seniors and young children are particularly vulnerable to heat stress.[9] The CDC also notes that air-conditioning is the number one protective factor against heat-related illness and death.[10] LIHEAP assistance helps these vulnerable seniors keep their homes at safe temperatures during the winter and summer and also funds low-income weatherization work to make homes more energy efficient.

Dire Choices and Dire Consequences: Recent national studies have documented the dire choices low-income households are faced with when energy bills are unaffordable. Because adequate heating and cooling are tied to the habitability of the home, low-income families will go to great lengths to pay their energy bills. Low-income households faced with unaffordable energy bills cut back on necessities such as food, medicine and medical care.[11] The U.S. Department of Agriculture recently released a study that shows the connection between low-income households, especially those with elderly persons, experiencing very low food security and heating and cooling seasons when energy bills are high.[12] The US Conference of Mayor's December 2007 *Status Report on Hunger and Homelessness in America's Cities* cites utility assistance programs as one of the most common ways to reduce hunger.[13] A pediatric study in Boston documented

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[7] National Energy Assistance Directors' Association, *Testimony of the National Energy Assistance Directors' Association on the Low Income Home Energy Assistance Program Before the Subcommittee on Health, Education, Labor and Pensions, US Senate (March 5, 2008).*

[8] NCLC analysis of U.S. Energy Information Administration, 2001 Residential Energy Consumption Survey data on elderly energy consumption and expenditures.

[9] CDC, "Extreme Heat: A Prevention Guide to Promote Your Personal Health and Safety" available at www.bt.cdc.gov/disasters/extremeheat/heat_guide.asp.

[10] *Id.*

[11] *See e.g.*, National Energy Assistance Directors' Association, *2005 National Energy Assistance Survey*, Tables in section IV,G (September 2005)(To pay their energy bills, 20% of LIHEAP recipients went without food, 35% went without medical or dental care, 32% did not fill or took less than the full dose of a prescribed medicine). Available at http://www.neada.org/comm/surveys/NEADA_2005_National_Energy_Assistance_Survey.pdf.

[12] Mark Nord and Linda S. Kantor, *Seasonal Variation in Food Insecurity Is Associated with Heating and Cooling Costs Among Low-Income Elderly Americans*, The Journal of Nutrition, 136 (Nov. 2006) 2939-2944.

[13] Exhibit 1.4 shows 60% of cities in the study cited utility assistance programs as a way to reduce hunger.

an increase in the number of extremely low weight children, age 6 to 24 months, in the three months following the coldest months, when compared to the rest of the year.[14] Clearly, families are going without food during the winter to pay their heating bills, and their children fail to thrive and grow.

When people are unable to afford paying their home energy bills, dangerous and even fatal results occur. Families resort to using unsafe heating sources, such as space heaters, ovens and burners, all of which are fire hazards.[15] In the summer, the inability to afford cooling bills can result in heat-related deaths and illness. The loss of essential utility services can be devastating, especially for poor families that can find themselves facing hypothermia in the winter, hyperthermia in the summer, eviction, property damage from frozen pipes and the use of dangerous alternative sources of heat.

LIHEAP is an administratively efficient and effective targeted health and safety program that works to bring fuel costs within a manageable range for vulnerable low-income seniors, the disabled and families with young children. **LIHEAP must be fully funded at its authorized level of $5.1 billion in FY 2009 in light of the steady increase in home energy costs and the increased need for assistance to protect the health and safety of low-income families by making their energy bills more affordable. In addition, FY 2010 advance funding would facilitate the efficient administration of the state LIHEAP programs.** Advanced funding provided certainty of funding levels to states to set income guidelines and benefit levels before the start of the heating season. States can also plan the components of their program year (e.g., amounts set aside for heating, cooling and emergency assistance, weatherization, self-sufficiency and leveraging activities).

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[14] Deborah A. Frank, MD *et al.*, *Heat or Eat: The Low Income Home Energy Assistance Program and Nutritional and Health Risks Among Children Less Than 3 years of Age,* AAP Pediatrics v.118, no.5 (Nov. 2006) e1293-e1302. *See also*, Child Health Impact Working Group, *Unhealthy Consequences: Energy Costs and Child Health: A Child Health Impact Assessment Of Energy Costs And The Low Income Home Energy Assistance Program* (Boston: Nov. 2006) and the *Testimony of Dr. Frank Before the Senate Committee on Health, Education, Labor and Pensions Subcommittee on Children and Families* (March 5, 2008).

[15] John R. Hall, Jr., *Home Fires Involving Heating Equipment: Space Heaters* (In 2005 there were an estimated 19,700 home fires involving space heaters resulting in 490 deaths, 980 injuries and $518 million in property damage) National Fire Protection Association (Nov. 2007).

Testimony on behalf of the
Population Association of America/Association of Population Centers
Regarding the Fiscal Year 2009 Appropriation for the
National Institutes of Health, National Center for Health Statistics, and Bureau of Labor Statistics
Submitted to the
House Committee on Appropriations
Subcommittee on Labor, Health and Human Services and Education
The Honorable David Obey, Chair
The Honorable James Walsh, Ranking Member
Submitted by

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Introduction

Thank you, Mr. Chairman Obey, Mr. Ranking Member Walsh, and other distinguished members of the Subcommittee, for this opportunity to express support for the National Institutes of Health (NIH), the National Center for Health Statistics (NCHS), and Bureau of Labor Statistics (BLS).

Background on the PAA/APC and Demographic Research

The Population Association of America (PAA) is a scientific organization comprised of over 3,000 population research professionals, including demographers, sociologists, statisticians, and economists. The Association of Population Centers (APC) is a similar organization comprised of over 30 universities and research groups that foster collaborative demographic research and data sharing, translate basic population research for policy makers, and provide educational and training opportunities in population studies. Over 30 population research centers are located nationwide, including the University of Wisconsin-Madison, State University New York Albany, Brown University, Ohio State University, University of California at Los Angeles, University of North Carolina-Chapel Hill, and Pennsylvania State University.

Demography is the study of populations and how or why they change. Demographers, as well as other population researchers, collect and analyze data on trends in births, deaths, and disabilities as well as racial, ethnic, and socioeconomic changes in populations. Major policy issues population researchers are studying include the demographic causes and consequences of population aging, trends in fertility, marriage, and divorce and their effects on the health and well being of children, and immigration and migration and how changes in these patterns affect the ethnic and cultural diversity of our population and the nation's health and environment.

The NIH mission is to support research that will improve the health of our population. The health of our population is fundamentally intertwined with the demography of our population. Recognizing the connection between health and demography, the NIH supports extramural population research programs primarily through the National Institute on Aging (NIA) and the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD).

National Institute on Aging

According to the Census Bureau, by 2029, all of the baby boomers (those born between 1946 and 1964) will be age 65 years and over. As a result, the population age 65–74 years will increase from 6% to 10% of the total population between 2005 and 2030. This substantial growth in the older population is driving policymakers to consider dramatic changes in federal entitlement programs, such as Medicare and Social Security, and other budgetary changes that could affect programs serving the elderly. To inform this debate, policymakers need objective, reliable data about the antecedents and impact of changing social, demographic, economic, and health characteristics of the older population. The NIA Behavioral and Social Research (BSR) program is the primary source of federal support for research on these topics.

In addition to supporting an impressive research portfolio, that includes the prestigious Centers of Demography of Aging Program, the NIA BSR program also supports several large, accessible data surveys. One of these surveys, the Health and Retirement Study (HRS), has become one of the seminal sources of information to assess the health and socioeconomic status of older people in the United States. The HRS, now entering its 16th year, has tracked 27,000 people, and has provided data on a number of issues, including the role families play in the provision of resources to needy elderly and the economic and health consequences of a spouse's death. The Social Security Administration recognizes and funds the HRS as one of its "Research Partners" and posts the study on its home page to improve its availability to the public and policymakers. HRS is particularly valuable because its longitudinal design allows researchers: 1) the ability to immediately study the impact of important policy changes such as Medicare Part D; and 2) the opportunity to gain insight into future health-related policy issues that may be on the horizon, such as recent HRS data indicating an increase in pre-retirees self-reported rates of disability. Next year, the HRS will begin collecting DNA, enhancing the value of this survey as an important source of biosocial data.

With additional support in FY 2009, the NIA BSR program could fully fund its existing centers and support its ongoing surveys without enacting draconian cost cutting measures, such as cutting sample size. Additional support would allow NIA to expand the centers' role in understanding the domestic macroeconomic as well as the global competitiveness impact of population aging. NIA could also use additional resources to support individual investigator awards by precluding an 18% cut in competing awards, improving its funding payline, and sustaining training and research opportunities for new investigators.

National Institute on Child Health and Human Development

Since its establishment in 1968, the NICHD Center for Population Research has supported research on population processes and change. Today, this research is housed in the Center's Demographic and Behavioral Sciences Branch (DBSB). The Branch encompasses

research in four broad areas: family and fertility, mortality and health, migration and population distribution, and population composition. In addition to funding research projects in these areas, DBSB also supports a highly regarded population research infrastructure program and a number of large database studies, including the Fragile Families and Child Well Being Study and National Longitudinal Study of Adolescent Health.

NIH-funded demographic research has consistently provided critical scientific knowledge on issues of greatest consequence for American families: work-family conflicts; marriage and childbearing; childcare; and family and household behavior. However, in the realm of public health, demographic research is having an even larger impact, particularly on issues regarding adolescent and minority health. Understanding the role of marriage and stable families in the health and development of children is another major focus of the NICHD DBSB. Consistently, research has shown children raised in stable family environments have positive health and development outcomes. Policymakers and community programs can use these findings to support unstable families and improve the health and well being of children.

In 2007, the DBSB issued a revised five-year strategic plan, *Future Directions for the DBSB*. With the help of its expert panel and with input from others inside and outside of the agency, the Branch identified three important research areas-- family formation; causes and consequences for population health; and the effects of migration-- for focus during the 2007 through 2011 period. In addition to these areas of emphasis, the Branch will continue to develop and support other
areas within its portfolio, including research on HIV/AIDS; unintended pregnancy and infertility; race and ethnicity; and population and environment. Although the field is enthusiastic about the opportunities the revised strategic research plan presents, we recognize the Institute needs consistent, sufficient funding to realize its potential.

With additional support in FY 2009, NICHD could restore full funding to its large-scale surveys, which serve as a resource for researchers nationwide. Furthermore, the Institute could apply additional resources toward improving its funding payline. Additional support could be used to preclude cuts of 17% to 22% in applications approved for funding and to support and stabilize essential training and career development programs necessary to prepare the next generation of researchers.

National Center for Health Statistics

Located within the Centers for Disease Control (CDC), the National Center for Health Statistics (NCHS) is the nation's principal health statistics agency, providing data on the health of the U.S. population and backing essential data collection activities. Most notably, NCHS funds and manages the National Vital Statistics System, which contracts with the states to collect birth and death certificate information. NCHS also funds a number of complex large surveys to help policy makers, public health officials, and researchers understand the population's health, influences on health, and health outcomes. These surveys include the National Health and Nutrition Examination Survey, National Health Interview Survey, and National Survey of Family Growth. Together, NCHS programs provide credible data necessary to answer basic questions about the state of our nation's health.

The President's FY 2009 budget requests $125 million in program funds for NCHS. This recommendation represents an increase of $11 million over FY 2008. Although it may sound generous, this increase is absolutely essential for stabilizing the agency and its key operations. Before Congress increased the agency's budget last year by approximately $4 million, NCHS had lost $13 million in purchasing power since FY 2005 due to years of flat funding and inflation. These shortfalls forced the elimination of some data collection and quality control efforts, threatened the collection of vital statistics, stymied the adoption of electronic systems, and limited the agency's ability to modernize surveys to reflect changes in demography, geography, and changes in health delivery.

If Congress fails to, at a minimum, provide the Administration's FY 2009 request, NCHS will be forced to eliminate over-sampling of minority populations in its National Health and Nutrition Examination Survey, which will compromise our understanding of health disparities at a time when our society is becoming increasingly diverse. The agency also needs this funding increase to collect vital statistics from states for the remainder of the calendar year. Without an additional $3 million, which is included in the President's request, the United States is at risk of becoming the first industrialized nation unable to continuously collect birth, death, and other vital health information.

Bureau of Labor Statistics

The Bureau of Labor Statistics (BLS) produces and disseminates valuable economic data used by our members to analyze trends in areas such as unemployment, income, health insurance coverage, and spending. In its Fiscal Year 2009 submission, the Administration proposed the elimination of an important survey BLS began in 2003, the American Time Use Survey (ATUS).

The ATUS provides the *only* available information on how Americans use their time. ATUS provides essential information on time use activities, including time spent caring for children, cleaning the house, working for pay, and caring for sick adults. Understanding how the population spends its time, outside of traditional work, is necessary for anyone who wants to understand the changing lives of American families, to monitor the well-being of the American population, to measure national output, productivity and other outcomes that are essential to forming sound economic policies and to making informed social policy decisions.

Although the ATUS is a relatively new survey, it has already proven to be an invaluable component of the statistical infrastructure, giving us unique insights into American society. Moreover, the power of the ATUS has grown as more years of data have accumulated. Every other advanced nation in the world collects time use data. If the ATUS is eliminated, American businesses, families, policymakers and researchers will lose out on critical information that can improve the quality of our lives.

The BLS needs an additional $6 million in Fiscal Year 2009 budget to collect ATUS data from the full sample originally planned for the survey and to preserve its other ongoing survey operations with a full sample—most notably, the Current Population Survey.

Summary of Fiscal Year 2009 Recommendations

NIH is facing the prospect of another decrease in FY 2009 and another year of funding below the level of inflation. PAA and APC join the Ad Hoc Group for Medical Research in supporting an FY 2009 appropriation of $31.1 billion, an increase of 6.6% over the FY 2008 appropriation, for the NIH. For population research, this increased support is necessary to ensure the best research projects, including new and innovative projects, are being awarded, surveys and databases are supported, and training programs are stabilized. In addition, we urge the Subcommittee to include language in the FY 2009 bill allowing NIH to continue the National Children's Study (NCS) and to appropriate $192 million for NCS in FY 2009 through the NIH Office of the Director.

PAA and APC, as members of the Friends of NCHS, support a FY 2009 appropriation of $125 million, an $11 million increase over the FY 2008 appropriation, for the NCHS. This funding is needed to maintain the nation's vital statistics system and to sustain and update the agency's major health survey operations.

We also respectively ask the Subcommittee to restore funding for the American Time Use Survey by allocating an additional $6 million for the Bureau of Labor Statistics and by reversing the Administration's proposal to end this essential data collection effort.

Thank you for considering our requests and for supporting federal programs that benefit the field of demographic research.

The National Violent Death Reporting System (NVDRS): Linking Data. Saving Lives

Thank you for this opportunity to submit testimony in support of increased funding for the National Violent Death Reporting System (NVDRS), which is administered by the National Center for Injury Prevention and Control of the Centers for Disease Control and Prevention (CDC). The National Violence Prevention Network, a broad and diverse alliance of health and welfare, suicide and violence prevention, and law enforcement advocates (names attached on last page) is requesting a $4 million increase in funding for Fiscal Year 2009 to allow the CDC to expand NVDRS beyond the 17 states that currently participate in the program.

Each year, 50,000 Americans die violent deaths. Homicide and suicide are, respectively, the third and fourth leading causes of death for people aged 1–39 years. An average of 80 people take their own lives every day.

Before NVDRS was created, federal and state public health and law enforcement officials collected valuable information about violent deaths, but didn't combine it into one comprehensive reporting system. Instead, data was held in a variety of different systems, and policymakers lacked the clear picture necessary to develop effective violence prevention policies.

When it was created in 2002, NVDRS promised to capture data that is critical to identifying patterns and developing strategies to save lives. With a clearer picture of why violent deaths occurs, law enforcement and public health officials can work together more effectively to identify those at risk and provide effective preventive services.

Currently, NVDRS funding levels only allow the program to operate in 17 states, including Alaska, California, Colorado, Georgia, Kentucky, Maryland, Massachusetts, New Jersey, New Mexico, North Carolina, Oklahoma, Oregon, Rhode Island, South Carolina, Utah, Virginia, and Wisconsin. Eight additional states, plus the District of Columbia, were previously approved for participation in the NVDRS, but were unable to join due to funding shortfalls: Connecticut, Illinois, Maine, Michigan, Minnesota, New York, Ohio, and Texas. Several other states have expressed an interest in joining once new funding becomes available.

While NVDRS is beginning to strengthen violence and suicide prevention efforts in the 17 participating states, many other states will lack this benefit until additional funding is allocated.

NVDRS Provides Critical Data for Suicide Prevention

Although it is preventable, more than 30,000 Americans die by suicide each year, and another 1.8 million Americans attempt it, costing more than $3.8 billion in hospital expenses and $13 billion in lost earnings.

In the United States today, there is no comprehensive national system to track suicides. However, because NVDRS includes information on all violent deaths – including deaths by suicide – information from the system can be used to develop effective suicide prevention plans at the community, state, and national level.

For instance, NVDRS data from 13 states uncovered significant racially and ethnically-based differences in mental illness diagnoses and treatment among those who died by suicide. Specifically, whites were more likely to have been diagnosed with depression or bipolar disorder, while blacks were more likely than other groups to have been diagnosed with schizophrenia. Hispanics were less likely to have been diagnosed with a mental illness or to have received treatment at all, although the family reports of depression were comparable to other racial groups.

Of particular note, CDC determined from national NVDRS data for 2005 that the suicide of veterans comprised 20% of all suicides. The types of data collected by NVDRS on these suicides, including gender, blood alcohol content, mental health diagnosis, and intimate partner violence or physical health problems, will guide our military communities and veterans' services in formulating effective programs to identify and treat at-risk individuals.

With such information available for the first time, officials in participating states are using NVDRS data in a myriad of ways. For example,

- With the sixth-highest rate of elder suicide in the nation, Oregon tailored its NVDRS data to develop an epidemiological profile of victims and establish an elder suicide prevention plan. NVDRS data indicated that most victims of elder suicide in Oregon had been suffering from physical illness, and that 37 percent had visited a doctor in the 30 days prior to their death. As a result of this NVDRS data, the state developed an elder suicide prevention plan that calls for better integration of primary care and mental health services, so that potential suicide victims can be better identified and treated. The plan also calls for training primary health care providers, integrating mental health care into primary care, and educating family members about the risks of suicide and warning signs of depression.

- NVDRS data found that one in four of Virginia's suicide victims had served in the military. Among male victims over 65, more than 60 percent were veterans. These findings indicate that the state's suicide prevention and education efforts must extend to veterans' hospitals and service providers.

- NVDRS data provides state health officials in South Carolina with vital information that indicates behavior patterns, enables health officials to identify individuals at risk, and to intervene early with appropriate preventive measures. After NVDRS data showed that more than 40 percent of suicide victims were currently or formerly receiving mental health treatment or tested positive for psychiatric medication, the state established its first ever suicide prevention plan, which also included the formation of a Suicide Prevention Task Force.

- In New Jersey, state officials using NVDRS information discovered that far more homicides were related to gang violence than they had previously been aware of, and they were able to inform police departments of a broader gang violence profile. Now that

they track the gang violence problem more accurately, they are adapting violence reduction efforts based on these findings.

NVDRS Provides Critical Data to Protect Children and Adolescents

Child abuse and other violence involving children and adolescents remains a problem in America, and it is only through a comprehensive understanding of its root causes that many needless deaths can be prevented. Studies suggest that between 3.3 and 10 million children witness some form of domestic violence annually. Additionally, 1,387 children died as a result of abuse or neglect in 2004, according to the federal Administration on Children, Youth, and Families, part of the Department of Health and Human Services.

Children are most vulnerable and most dependent on their caregivers during infancy and early childhood. Sadly, NVDRS data has shown that young children are at the greatest risk of homicide in their primary care environments. Combined NVDRS data from Alaska, Maryland, Massachusetts, New Jersey, Oregon, South Carolina, and Virginia determined that African American children four years old and under are more than four times more likely to be victims of homicide than Caucasian children, and that homicides of children four and under are most often committed by a parent or caregiver in the home. The data also shows that household items, or "weapons of opportunity," were most commonly used, suggesting that poor stress responses may be factors in these deaths. Knowing the demographics and methods of abusers can lead to more effective, targeted prevention programs.

Other examples of how NVDRS data is informing programs to protect children and adolescents from violence include the following:

- Data from NVDRS pilot sites in Connecticut, Maine, Utah, Wisconsin, Pennsylvania, and California found that almost 30 percent of suicide victims age 17 and under told someone they felt suicidal. Many teen suicides also appear to be linked to recent events in their lives, with nearly one-third of suicides taking place on the same day as a crisis and almost half within the same week. This data underscores the importance of developing community-based programs to rapidly respond to the warning signs of suicide.

- With data generated by NVDRS, state health officials in Massachusetts have been able to monitor suicides and homicides more accurately among specific populations, such as foster children and youths in custody. The NVDRS data has been used to secure grants for violence prevention programs for these special populations, about whom data had previously been impossible to obtain.

NVDRS Provides Critical Data to Prevent Intimate Partner Violence

While intimate partner violence (IPV) has declined along with other trends in crime over the past decade, thousands of Americans still fall victim to it every year. Women are much more likely than men to be killed by an intimate partner. Intimate partner homicides accounted for 33.5

percent of the murders of women and less than four percent of the murders of men in 2000, according to the Bureau of Justice Statistics.

Although the program is still in its early stages, NVDRS is providing critical information that is helping law enforcement and health and human service officials allocate resources and develop programs in ways that target those most at risk for intimate partner violence, thereby preventing needless deaths. For example, NVDRS data shows that while occurrences are rare, most murder-suicide victims are current or former intimate partners of the suspect, and a substantial number of victims were the suspect's children. In addition, NVDRS indicates that women are about seven times more likely than men to be killed by a spouse, ex-spouse, lover, or former lover, and the majority of these incidents occurred in the women's homes.

Examples of how state officials are using NVDRS data to better understand and prevent intimate partner violence include:

- Based on an analysis of NVDRS data, the Kentucky Injury Prevention Research Center concluded that among women killed by an intimate partner, only 39% had had filed for a restraining order or been seen by or reported to Adult Protective Services. This finding underscored a perceived need in the community to improve outreach linking potential victims to local protective services.

- Working with the state's NVDRS program, the Alaska Department of Law and Public Safety found there is a high risk for intimate partner violence, both homicide and suicide, when one partner is attempting to leave the relationship. Findings such as this one are molding the state's strategy for domestic violence prevention.

Strengthening and Expanding NVDRS in FY 2009

At an estimated annual cost of $20 million for full implementation, NVDRS is a relatively low-cost program that yields high-quality results. While state-specific information provides enormous value to local public health and law enforcement officials, national data from all 50 states, the U.S. territories and the District of Columbia, must be obtained to complete the picture and establish effective national violence prevention policies and programs.

That is why the National Violence Prevention Network, a coalition of national organizations who advocate for national violence prevention programs, is calling on Congress to provide no less than $7.5 million for NVDRS for FY 2009 – an increase of $4 million. The cost of *not* implementing the program is much greater: without national participation in the program, thousands of American lives remain at risk.

We thank you for the opportunity to submit this statement for the record and applaud your past commitment to NVDRS. The investment in NVDRS has already begun to pay off, as the 17 participating states are adopting effective violence prevention programs. We believe that increased funding that will lead to national implementation of NVDRS is a wise public health investment, and our nation will reap enormous benefits in reducing deaths from domestic

violence, veteran suicide, teen suicide, gang violence and other violence that affects our citizens so tragically each year. We look forward to working with you secure an appropriation of at least $7.5 million in FY 2009.

For additional information please contact, Paul Bonta, Associate Executive Director for Policy and Government Affairs at the American College of Preventive Medicine, at pbont@acpm.org or 202-466-2044.

The following organizations — representing a diverse alliance of health and welfare, suicide and violence prevention, and law enforcement advocates — urge Congress to provide at least $7.5 million to strengthen and expand the National Violent Death Reporting System in FY 2009:

Ambulatory Pediatric Association
American Academy of Pediatrics
American Association of Suicidology
American College of Emergency Physicians
American College of Physicians
American College of Preventive Medicine
American Pediatric Society
American Psychiatric Association
American Psychological Association
American Public Health Association
Association of Medical School Pediatric Department Chairs
Child Welfare League of America
Children's Healthcare Is a Legal Duty (CHILD)
Coalition for American Trauma Care
Council of State and Territorial Epidemiologists
Emergency Nurses Association
Family Violence Prevention Fund
National Association of County & City Health Officials
National Association of Medical Examiners
National Association of Pediatric Nurse Practitioners
National Black Police Association
National Organization of People of Color Against Suicide
National School Safety Center
New York Academy of Medicine
The Police Foundation
Society for Adolescent Medicine
Society for Pediatric Research
Society for Public Health Education
State and Territorial Injury Prevention Directors Association
Suicide Awareness/Voices of Education (SAVE)
Suicide Prevention Action Network USA (SPAN USA)
Voices for America's Children

Testimony to the House Appropriations Subcommittee on Labor, Health and Human Services, and Education Concerning Programs in the United States Departments of Labor, Health and Human Services, and Education
By
The National Alliance to End Homelessness
Nan Roman, President
March 31, 2008

The National Alliance to End Homelessness (the Alliance) is a nonpartisan, nonprofit organization that has several thousand partner agencies and organizations across the country. These partners are local faith-based and community-based nonprofit organizations and public sector agencies that provide homeless people with housing and services such as substance abuse treatment, job training, and physical health and mental health care. In addition, we have supported over 180 state and local entities who have completed ten year plans to end homelessness. The Alliance represents a united effort to address the root causes of homelessness and challenge society's acceptance of homelessness as an inevitable by-product of American life.

Summary of Appropriations Goals
Moving Forward to End Homelessness – Communities across America are working toward ending homelessness. Communities are using federal, state, and local funds to help homeless persons maintain housing. It is important that this progress not be undermined. To this end, the Alliance recommends the following:

- Allocate an additional $44 million for services for homeless people within SAMHSA's PRNS accounts of the Center for Mental Health Services and Center for Substance Abuse Treatment.
- Increase funding to Projects for Assistance in Transition from Homelessness (PATH) to $75 million.
- Increase the Runaway and Homeless Youth Act Programs to $140 million.
- Provide a $248 million increase in the Community Health Center program within Health Resource Services Administration. This would result in a $21.5 million increase in the Health Care for the Homeless program.
- Fund Education for Homeless Children and Youth services at its full authorized level of $85 million.
- Increase funding for the Homeless Veterans Reintegration Program to $50 million.

Connecting Homeless Families, Individuals, and Youth to Mainstream Services – People experiencing homelessness also depend on mainstream programs such as the ones below to live day to day and once housed, remain housed. The Alliance recommends the following to meet this goal:

- Fund the Social Services Block Grant at $2.8 billion
- Reject cuts and fund the Community Services Block Grant at $700 million
- Appropriate $60 million in education and training vouchers for youth exiting foster care under the Safe and Stable Families Program.

- Fund the Community Mental Health Services Performance Partnership Block Grant at $482.9, a $61.9 million increase.
- Fund the Substance Abuse Prevention and Treatment Block Grant at $1.858 billion

Background
Our 2007 report, *Homelessness Counts*, estimates that 744,313 people are homeless on any given night. This includes **98,452** families with children and **23 percent** of homeless people are defined as chronically homeless; these are people with a disability and have been homeless repeatedly or continuously for twelve months. Successful interventions for all homeless populations couple housing with an appropriate level of services for the family or individual.

For chronically homeless populations, permanent supportive housing successfully and cost effectively ends homelessness. These programs couple a home with intensive supportive services such as access to health care, mental health services, addiction treatment, employment training and case management.

There are also successful housing programs linked with services which are proving to be effective for all homeless populations, as well as those at-risk of homelessness. The services, based on clients' need, are usually less intensive than in permanent supportive housing but still essential for these families, individuals and youth.

Therefore, not only does the Department of Housing and Urban Development play a role in ending homelessness, so do the Departments of Labor, Health and Human Services, and Education. **We call on Congress to adequately fund programs that assist states and local entities in developing permanent housing and the necessary social services to end homelessness for all Americans.**

Detailed Program Descriptions
Goal #1 - Moving Forward to End Homelessness
Support Services for Permanent Supportive Housing Projects
The Alliance recommends allocating an additional $44 million for services in permanent supportive housing within SAMHSA's Center for Mental Health Services and Center for Substance Abuse Treatment. Years of reliable data and research demonstrate that the most successful intervention to solve chronic homelessness is linking housing to appropriate support services. Current investments by SAMHSA in homeless programs are highly effective and cost efficient.

Last year, the Department of Health and Human Services updated its 2004 report entitled *Ending Chronic Homelessness: Strategies for Action.* The updated strategic plan, U.S Department of Health and Human Services: Strategic Action Plan on Homelessness, broadened HHS' focus to include all homeless populations and their need for services. While acknowledging some success since 2004, the strategic plan explained that personal and programmatic barriers to mainstream programs, such as Medicaid, welfare, Medicare

and general substance abuse and mental health services funds, still exist and must be overcome to have an adequate level of funds needed to end homelessness

Projects for Transition Assistance from Homelessness (PATH)
The Alliance recommends that Congress increase PATH funding to $75 million and adjust the funding formula to increase allocations for small states and territories. PATH provides outreach to eligible consumers and ensures that those consumers are connected with mainstream services, such as Supplemental Security Income (SSI), Medicaid and welfare programs. Under the PATH formula grant, approximately 30 states share in the program's annual appropriations increases. The remaining states and territories receive the minimum grant of $300,000 for states and $50,000 for territories. These amounts have not been raised since the program was authorized in 1991. To account for inflation, the minimum allocation should be raised to $600,000 for states and $100,000 for territories. Amending the minimum allocation requires a legislative change. If the authorizing committees do not address this issue, we hope that appropriators will explore ways to make the change through appropriations bill language.

Runaway and Homeless Youth Programs
The Alliance recommends funding the Runaway and Homeless Youth Act (RHYA) programs at $140 million. RHYA programs support cost-effective, community and faith-based organizations that protect youth from the harms of life on the streets. The RHYA programs can either reunify youth safely with family or find alternative living arrangements. RHYA programs end homelessness by: engaging youth living on the street with Street Outreach Programs, quickly providing emergency shelter and family crisis counseling through the Basic Centers, or providing supportive housing that helps young people develop lifelong independent living skills through Transitional Living Programs. Recently, the Congressional Research Service issued a report complimenting the good work of RHYA programs but detailing the gaps in services due to limited funding. For example, only one-tenth of the youth who connect with a RHYA program are able to receive services. It is essential that Congress increase this program.

Community Health Centers and Health Care for the Homeless (HCH) programs
The Alliance recommends a $248 million increase in the Community Health Center program within Health Resource Services Administration. This would resulting a $21.5 million increase in the Health Care for the Homeless program. Persons living on the street suffer from health problems resulting from or exacerbated by being homeless, such as hypothermia, frostbite, and heatstroke. In addition, they often have infections of the respiratory and gastrointestinal systems, tuberculosis, vascular diseases such as leg ulcers, and hypertension.[1] Health care for the homeless programs are vital to prevent these conditions from becoming fatal. Congress allocates 8.7% of the Consolidated Health Centers account for Health Care for the Homeless (HCH) projects.

Education for Homeless Children and Youth

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[1] Harris, Shirley N, Carol T. Mowbray and Andrea Solarz. *Physical Health, Mental Health and Substance Abuse Problems of Shelter Users.* Healt h and Social Work, Vol. 19, 1994

The Alliance recommends funding Education for Homeless Children and Youth (EHCY) at $85 million. The most important potential source of stability for homeless children is school. The mission of the Education for Homeless Children and Youth program is to ensure that these children can continue to attend school and thrive. The Education for Homeless Children and Youth program, within the Department of Education's Office of Elementary and Secondary Education, removes obstacles to enrollment and retention by establishing liaisons between schools and shelters and providing funding for transportation, tutoring, school supplies, and the coordination of statewide efforts to remove barriers.

Homeless Veterans Reintegration Program (HVRP)
The Alliance recommends that Congress increase HVRP funding to $50 million. HVRP, within the Department of Labor's Veterans Employment and Training Service (VETS), provides competitive grants to community-based, faith-based, and public organizations to offer outreach, job placement, and supportive services to homeless veterans. HVRP is the primary employment services program accessible by homeless veterans and the only targeted employment program for any homeless subpopulation. It is estimated that this program only reaches about two percent of the overall homeless veteran population. An appropriation at the authorized level of $50 million would enable HVRP grantees to reach approximately 19,866 homeless veterans.

Goal #2 – Connecting Homeless Families, Individuals and Youth to Mainstream Services
Social Services Block Grant (SSBG)
The Alliance recommends that Congress increase SSBG funding to $2.8 billion. SSBG funds are essential for programs dedicated to ending homelessness. In particular, youth housing programs and permanent supportive housing providers often receive state, county, and local funds which originate from the SSBG. As the U.S. Department of Housing and Urban Development has focused its funding on housing, programs that provide both housing and social services have struggled to fund the service component of their programs. This gap is often closed using federal programs such as SSBG.

Community Services Block Grant (CSBG)
The Alliance recommends that Congress rejects cuts and fund CSBG at $700 million. Funding cuts for CSBG will destabilize the progress communities have made toward ending homelessness by not only ending services directly provided by CSBG funds but limiting a community's ability to access other federal dollars such as those provided by HUD. Community Action Agencies (CAAs), which are the primary local recipients of CSBG funding, are directly involved in housing and homelessness services. In several communities, CAAs lead the Continuum of Care (CoC). CoCs coordinate local homeless service providers and the community's McKinney-Vento Homeless Assistance Grant application process with the Department of Housing and Urban Development.

In the fiscal year 2004 Community Services Block Grant Information Systems report published by the U.S. Department of Health and Human Services, CAAs reported administering $207.4 million in Section 8 vouchers, $30 million in Section 202 services[2]

[2] Section 202 is dedicated to housing from elderly and disabled individuals and families

and $271.1 million in other Department of Housing and Urban Development (HUD) programs which includes homeless program funding[3].

Foster Youth Education and Training Vouchers
The Alliance recommends that Congress appropriate $60 million in education and training vouchers for youth exiting foster care under the Safe and Stable Families Program. The Education and Training Voucher Program offers funds to foster youth and former foster youth to enable them to attend colleges, universities and vocational training institutions. Students may receive up to $5000 a year for college or vocational training education. The funds may be used for tuition, books, housing, or other qualified living expenses. Given the large number of people experiencing homelessness who have a foster care history, it is important to provide assistance such as these education and training vouchers to stabilize youth, prevent economic crisis, and prevent possible homelessness.

Community Mental Health Performance Partnership Block Grant
The Alliance recommends that Congress appropriate $482.9 million for the Community Mental Health Performance Partnership Block Grant. The Mental Health Block Grant provides flexible funding to states to provide mental health services. Ending homelessness requires federal, state and local partnerships. Additional mental health funds will give states the resources to improve their mental health system and serve all people with mental health disorders better, including homeless populations. For example, block grant funds can be used to pay for services linked to housing for homeless people, thereby meeting the match requirements for projects funded through Shelter Plus Care or the Supportive Housing Program.

Substance Abuse Prevention and Treatment Block Grant
The Alliance recommends that Congress appropriate $1.858 billion for the Substance Abuse Prevention and Treatment Block Grant. The Substance Abuse Prevention and Treatment (SAPT) Block Grant is the primary source of federal funding for substance abuse treatment and prevention for many low-income individuals, including those experiencing homelessness. Studies have shown that half of all people experiencing homelessness have a diagnosable substance use disorder. States need more resources to implement proven treatment strategies and work with housing providers to keep homeless, especially chronically homeless populations stably housed.

Conclusion
Homelessness is not inevitable. As communities implement plans to end homelessness, they are struggling to find funding for the services homeless and formerly homeless clients need to maintain housing. The federal investments in mental health services, substance abuse treatment, employment training, youth housing, and case management discussed above will help communities create stable housing programs and change social systems which will end homelessness for millions of Americans.

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[3] U.S. Department of Health and Human Services, Administration of Children and Families. The Community Services Block Grant FY 2004 Statistical Report. Prepared by the National Association for State Community Services Programs.

United States House of Representatives

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

Executive Summary

Richard S. Weisman, Pharm.D., DABAT, FAACT
American Association of Poison Control Centers

- In 2008, the Harvard Injury Control Research Center reported that poisonings from accidents and unknown circumstances more than tripled in rate since 1990. In 2005, the last year for which data is available, 26,858 people died from accidental or unknown poisonings. This represents an increase of 20,000 since 1990 and an increase of 2,400 between 2004 and 2005. Fatalities from poisoning are increasing in the United States in near epidemic proportions. The funding of programs to reverse this trend is needed now more than ever.

- Poisoning is the second most common form of unintentional death in the United States. In 2007, the 61 certified U.S. Poison Centers which serve all 50 states and territories and 100% of the U.S. population were notified regarding either treatment or prevention recommendations 4,132,505 times. Sixty percent of these exposures involved children under the age of 6 who were exposed to toxins in their homes.

- Poison Centers are our nation's primary defense against injury and deaths from poisoning and toxic exposures. Twenty-four hours a day, seven days a week, 365 days a year, the general public, as well as health care practitioners, including military health care facilities and personnel, domestically and internationally contact their local poison centers for help in diagnosing and treating victims of poisoning.

- In 2007, Vassilev and Marcus and in 2008, Bunn, Slavova and Spiller published separate studies in the *Journal of Toxicology and Environmental Health*, documenting that hospitalized poisoned patients in both New Jersey and Kentucky who received assistance from a poison control center had a statistically significant reduction in their duration of hospitalization and health care costs. Nationally, such savings from reduced hospital stays alone exceed $1 billion.

- The 2004 study of the HHS-funded Institute of Medicine of the National Academies ("IOM") report stated that for every $1 invested in America's Poison Center, $7 of health care costs are saved. The IOM study recommended that "Congress should amend the current Poison Control Center Enhancement and Awareness Act (P.L. 108-194) to provide sufficient funding to support the

proposed Poison Prevention and Control System with its national network of regional poison control centers. Federal support for the core poison center activities at the current level of service justifies annual federal funding of more than $100 million annually." (*Forging a Poison Prevention and Control System*, 2004)

- Despite their success, poison centers struggle to exist. Most centers are funded by a fragile patchwork of state, local and private moneys. Since centers do not generate revenue and are provided as a national public health service, they have become easy targets when sponsoring hospitals and state legislatures trim their budgets.

- Public Law 108-194, the "Poison Control Center Enhancement and Awareness Act Amendments of 2003," became law on December 19, 2003, to respond to this crisis and take advantage of network telecommunications and data technology improvements to develop a nationwide response system. It authorizes an annual appropriation of $30.1 million to stabilize poison centers and encourages the enhancement and improvement of poison education, prevention and treatment services, as well as the centers' core communication and information infrastructures.

- The United States Department of Health and Human Services Fiscal Year 2009 Justification of Estimates for Appropriations Committees issued on February 4, 2008 stated that in 2005 "72.5 percent of all human exposure calls (2.4 million) to poison centers were able to be managed on-site, avoiding unnecessary visits to health care facilities. With an average emergency room visit costing $560, poison center calls saved nearly $1 billion in annual medical expenses." Such savings represents an extraordinary return on the FY 2005 Congressional appropriation of $23 million.

- In the event of a terrorist event, poison centers will be relied upon as a primary source for accurate medical information regarding the treatment of patients who have been exposed to a chemical, radiological or biological agent. Real-time data collected from poison control centers can be an important source of information for the detection, monitoring and response for contamination of the air, water, pharmaceutical or food supply.

- Providing the full appropriation of $30.1 million as authorized in P.L. 108-194, the Poison Control Center Enhancement and Awareness Act, for Fiscal Year 2009, is a wise and extremely practical investment in the health of our nation with an immediate return in lives as well as precious United States health care dollars saved.

Testimony of:

Richard S. Weisman, Pharm.D., DABAT

Mr. Chairman and Members of the Subcommittee: My name is Dr. Richard S. Weisman. I am a member of the American Association of Poison Control Centers (AAPCC), as well as an Associate Professor of Pediatrics at the University of Miami, School of Medicine and the Director of the Florida Poison Information Center in Miami.

Poisoning is the second most common form of unintentional death in the United States. In any given year, there will be between two and four million poison exposures. Sixty percent of these exposures will involve children under the age of 6 who are exposed to toxins in their home. However, the fastest growing age group is America's senior citizens. Poison centers are now frequently called when confusion with medication schedules occur or when questions arise about medication interactions with food, drink or other medications.

In 2008, the Harvard Injury Control Research Center reported that poisonings from accidents and unknown circumstances more than tripled in rate since 1990. In 2005, the last year for which data are available, 26,858 people died from accidental or unknown poisonings. This represents an increase of 20,000 since 1990 and an increase of 2,400 between 2004 and 2005. Fatalities from poisoning are increasing in the United States in near epidemic proportions. The funding of programs to reverse this trend is needed now more than ever.

Poison control centers are our nation's primary defense against injury and deaths from poisoning. Twenty-four hours a day, the general public, as well as health care practitioners, contact their local poison centers for help in diagnosing and treating victims of poisoning. These poisonings involve everything from aspirin overdoses and food poisonings to snake bites. With correct diagnosis and treatment, medical outcomes are improved and fatalities drastically reduced. Rapid assessment and treatment translate into countless lives saved. In the world of poisoning emergencies and funding for poison control centers, it is proven that, from a cost and lives impacted point of view; an ounce of prevention is worth a pound of cure.

In 2004, The Institute of Medicine of the National Academies (IOM) recommended that the "Congress should amend the current Poison Control Center Enhancement and Awareness Act to provide sufficient funding to support the proposed Poison Prevention and Control System with its national network of regional poison control centers. Support for the core activities at the current level of service is estimated to require more than $100 million annually." (*Forging a Poison Prevention and Control System*, 2004)

In 2007, Vassilev and Marcus, and in 2008, Bunn, Slavova and Spiller, published studies in the *Journal of Toxicology and Environmental Health*, documenting that hospitalized poisoned patients in both New Jersey and Kentucky who received assistance from a poison control center had a statistically significant reduction in their duration of hospitalization and health care costs. When compared to the inpatient hospital reference group with no preexisting medical conditions and who did not consult the poison center (mean charges = $8748, mean length of stay = 3.2 days), poison control center consultation without a preexisting medical condition was significantly associated with decreased total hospitalization charges and decreased length of stay (mean charges = $4999, mean length of stay = 1.9 days). When the patient had a preexisting medical condition, PCC consultation was still associated with decreased total hospitalization charges and length of stay (mean charges = $8145, mean length of stay = 2.4 days) compared to those patients with a preexisting medical condition who did not consult the poison center (mean charges = $10,607, mean length of stay = 3.6 days). These results suggest that after accounting for a patient's age and gender, consultation with the poison center is significantly associated with reduced total hospitalization charges and reduced length of stay for inpatient hospitalization, and this association holds for patients with and without a preexisting medical condition.

In 2007 alone, our nation's poison centers were consulted by more than 4.1 million U.S. residents who were victims of poisoning exposure. Most often these calls were from a mom, a dad or another child-care provider. With poison center assistance, 70% of these cases were managed safely at home. Since a call to the poison center is much less expensive than a trip to the emergency department, this results in dramatic cost savings to health care systems and taxpayers. A 1995 study by the Department of Health and Human Services, published in the peer-reviewed journal *Annals of Emergency Medicine*, showed poison centers reduced such medical spending by up to $400 million annually. As a result of the federal investment starting in F.Y. 2000 in the nation's poison centers, federal direct health care costs nationally exceed $525 million annually. (See Attached 2008 Chart prepared by AAPCC and HRSA.) The 2004 IOM study determined that for every dollar spent on poison control centers at least $7 in medical costs are saved. But the cost savings from poison control centers could be even greater.

HHS

Poison control centers also provide two critical elements—toxic and chemical identification and technical information response—in this nation's developing bio-terrorism response network. In the event of a terrorist event, poison centers will be relied upon as a source of accurate medical information about the treatment of patients who have had an exposure to a chemical, radiological or biological agent. Real-time data collected from poison control centers can be an important source of information for the detection, monitoring and response for contamination of the air, water, pharmaceutical or food supply.

Despite their success, poison centers struggle to exist. Most centers are funded by a fragile patchwork of state, local and private moneys. Since centers do not generate revenue, they have become easy targets when sponsoring hospitals and state legislatures

trim their budgets. The result is more catastrophic than such well-intentioned administrators and lawmakers can imagine. The cost of poisoning emergencies increases up to five-fold and is shifted onto the public sector, as was graphically experienced in Louisiana in the early 1990s. Moreover, the medical community loses a training environment. Parent education programs, which help prevent unintentional poisonings in the first place, suffer. Budget cuts reduce poison center manpower, and the volume of calls exceeds the already overtaxed poison centers. A child's chance of surviving a poisoning is reduced. I would be willing to share with you specific examples of these very difficult situations.

Public Law 108-194, the "Poison Control Center Enhancement and Awareness Act," became law on December 19, 2003, to respond to this crisis and take advantage of network telecommunications and data technology improvements to develop a nationwide response system. It authorizes an annual appropriation of $30.1 million to stabilize poison centers and encourages the enhancement and improvement of poison education, prevention and treatment services, as well as the centers' core communication and information infrastructure.

All 50 states, U.S. territories and the District of Columbia received direct benefits from these stabilization grants to provide poison center services. This funding in part was used to create a single, nationwide "800" telephone number, 800-222-1222, that can be accessed from anywhere in the United States. The grants that have been offered have included:

(1) Financial Stabilization Grants: Grants ranging from $60,000 to $2, 000,000 were awarded in this category to enable certified poison control centers or poison control systems to achieve financial stability, strengthen and maintain poison prevention programs and services and strengthen the centers as sources of recommendations for poisonings.

(2) Incentive Grants: Competitive grants at $125,000 were awarded to encourage collaboration and systems development between centers to strengthen poison prevention and treatment alternatives. Applicants may be certified or uncertified poison control centers. Centers were able to apply for grants in this category in addition to applying for a Financial Stabilization or Certification grant. This category carries a matching requirement of one non-federal dollar for every two federal dollars contributed. Specific guidance regarding collaboration between poison control centers and the matching requirement is supplied in the application materials for this program.

In the FY 2008 budget, Congress appropriated $26,528,000.00 for our nation's poison centers. This funding will allow poison centers in many areas of the country to continue to provide quality care for poisoning victims and to continue preparation for bioterrorism as well as handling the increased number of emergency and information calls generated by the national toll free 800-222-1222 telephone number.

We have a remarkable opportunity to change history and provide for the health and safety of our children and families. As our country prepares for the possibilities of bioterrorist attacks, poison control centers and their established infrastructure of professional medical expertise and information serve as the foundation for local, state, regional and national emergency response involving toxic substances.

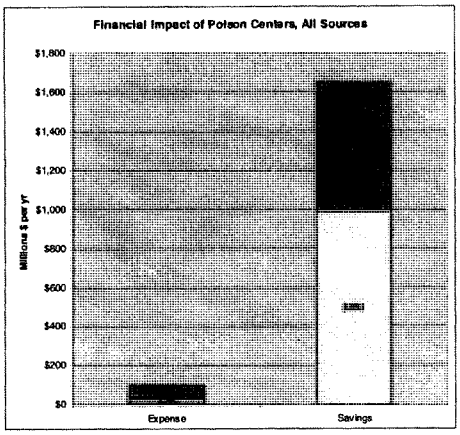
Therefore, we respectfully request that you approve the full appropriation as authorized by P.L. 108-194 for America's network of poison control centers. Supporting this appropriation for poison centers will continue to improve poison center access by further enhancing the single, nationally advertised, easy to remember toll-free telephone number 800-222-1222. The appropriations will allow every U.S. resident to immediately obtain quality poison center services and will save money by dramatically reducing the number of unnecessary ambulance transports and emergency department visits. For patients with significant poisonings, the appropriation will provide access for our emergency departments to the nation's most highly trained and skilled toxicologists. The result will be a reduction in injury, illness and death due to poisoning. When the diagnosis is made early, definitive therapy will be started promptly reducing the cost of hospitalizations.

Mr. Chairman, providing the full appropriation of $30.1 million for P.L. 108-194, the Poison Control Center Enhancement and Awareness Act, for Fiscal Year 2009 is an extraordinary investment in the health of our nation with an immediate return in lives as well as precious United States health care dollars saved. We have the opportunity to turn the tide against one of the most common forms of injury in the United States (now proven to be growing at epidemic proportions)—unintentional poisoning, as well as further prepare all Americans and our communities to properly identify, understand and timely respond to any unplanned toxic substance accident or terrorist attack upon our citizenry. We hope that you will carefully review this important request and provide the continued funding necessary for our nation's poison control centers to meet and, wherever possible, exceed these ambitious goals for public health awareness and safety established in P.L. 108-194.

The following is a partial list of national organizations which continue to support P.L. 108-194 and this Fiscal Year 2009 funding request.

American Academy of Clinical Toxicology
American Academy of Pediatrics
American Association of Poison Control Centers
American College of Emergency Physicians
American College of Medical Toxicology
American Medical Association
American Society of Health System Pharmacists
Association of Maternal and Child Programs
Association of State and Territorial Health Officials
Emergency Nurses Association
National Association of Children's Hospitals and Related Institutions
National Association of Emergency Medical Technicians

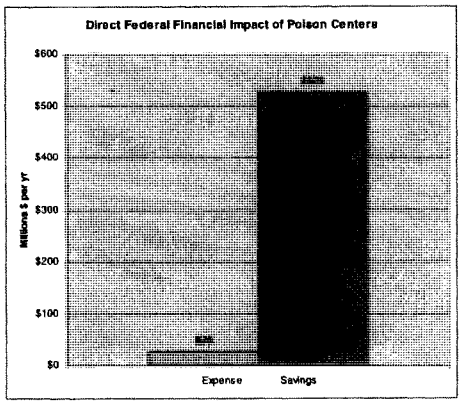
National Association of State Emergency Medical Services Directors
National Conference of State Legislatures
National Safe Kids Campaign
State and Territorial Injury Prevention Directors



Comparison of Financial Expenses and Savings Attributable to Poison Centers, US, 2005.

Expenses:
$26M – direct Federal contribution,
$74M – other sources (IOM)

Savings:
$993M – reduced length of stay for poisonings attributable to Poison Center assistance
$653M – cost avoidance from reduction of ED visits by prehospital management of poison exposures by Poison Centers



Comparison of Direct Federal Financial Expense and Savings Attributable to Poison Centers, US, 2005

Direct Federal Contribution: $26M

Direct Federal Savings from Federal Medicare (22% of healthcare spending) and Federal share of Medicaid (9.9% of healthcare spending): $525M

Submitted by:
Rebecca Osthus, Ph. D.
Science Policy Analyst
The American Physiological Society

This statement is submitted to the House Appropriations Subcommittee on Labor-HHS, and Education.

The American Physiological Society Statement on FY 2009 Funding for the National Institutes of Health

The American Physiological Society (APS) thanks the Subcommittee for its sustained support for the National Institutes of Health (NIH). The doubling of the agency's budget that took place between 1998 and 2003 allowed the NIH to explore new and innovative ways to address challenges in biomedical research. The increased funding has allowed researchers to investigate scientific opportunities on an unprecedented scale, creating significant momentum and excitement in the research community. To maximize and build upon that momentum, the NIH must be able to continue to provide support for scientists and researchers around the country. For the last five years, the NIH budget has failed to keep pace with inflation, resulting in a loss of purchasing power of more than 10%. The Administration's FY 2009 budget proposal would fund the NIH at $29.3 billion, the same as in FY 2008. **The APS urges you to make every effort to provide the NIH with $31.1 billion in FY 2009 so we can take advantage of scientific opportunities and strengthen the nation's scientific workforce to face future challenges.**

The APS is a professional society dedicated to fostering research and education as well as the dissemination of scientific knowledge concerning how the organs and systems of the body work. The Society was founded in 1887 and now has more than 10,000 member physiologists. Our members conduct NIH-supported research at colleges, universities, medical schools, and other public and private research institutions across the U.S. The APS offers these comments on the budget recognizing both the enormous financial challenges facing our nation and the enormous opportunities before us to make progress against disease.

Research challenges and solutions

Looking ahead, the scientific and medical communities see many challenges on the horizon including an aging population, the growing incidence of obesity, diabetes and heart disease, and new and emerging infectious diseases. The NIH has taken a forward-thinking approach to these challenges, and developed a vision for the future of health care that focuses on predicting who will develop diseases with the goal of developing personalized prevention and treatment strategies that will pre-empt disease onset before symptoms appear.[1] The goal of this approach is to minimize health care expenses by

keeping Americans healthier longer, instead of the current model of health care, which is based on intervention once symptoms occur. In order to make this vision a reality, extensive research is needed to increase our understanding of the basic mechanisms of disease and pursue the most effective intervention strategies.

An example of this proactive approach is beginning to take shape in Alzheimer's disease research. Alzheimer's is a devastating neurological disease that afflicts a growing number of older Americans. Researchers have used both basic and clinical research to begin to determine who is at risk for developing the disease, identify the underlying genetic variants, and understand the molecular pathology in the brains of those who are affected. This work has led to several new targets for drug development that will be explored in the coming years, hopefully leading to the development of new ways to prevent and treat Alzheimer's disease.

Another recent breakthrough that holds the promise of saving many lives through disease prevention is the development of a vaccine that protects against cervical cancer. Scientists have known for some time that human papilloma virus (HPV) infection can in some cases lead to the development of cervical cancer in women. While effective screening methods for early detection are available, the disease remains a significant cause of death in the United States and around the world, where health care systems are not able to provide routine screening for precancerous cells. The recently released cervical cancer vaccine is designed to prevent infection by several of the viruses that cause most of the cancers and by vaccinating young women it is hoped that the incidence of cervical cancer will decline.

The Scientific Workforce

In addition to supporting research, the NIH must also address workforce issues to be sure that our nation's researchers are ready to meet the challenges they will face in the future. Recent data from the NIH shows that the average age of NIH supported principal investigators (PI) is now 50.8 years, up from an average of 39.1 years in 1980.[2] In addition, the average age of the new NIH PI has increased to 42.4 years. As the scientific workforce ages and researchers retire, there is concern that there will not be an adequate number of young scientists who are trained to replace them. NIH has undertaken several programs to encourage and fund early-career investigators, but falling success rates may discourage trainees from pursuing careers in academic science. The FY 2009 budget request would result in an overall success rate for grant applications of just 18%, the lowest figure in decades. As funding falters, the best and brightest minds will turn away from careers in medical science. If NIH cannot fund new ideas, this will not only hamper efforts to find cures, it will also discourage up and coming researchers who could become the next generation of basic and clinical scientists.

Recommendations

The APS joins the Federation of American Societies for Experimental Biology (FASEB) and the Ad Hoc Group for Medical Research Funding in urging that NIH

be provided with $31.1 billion in FY 2009 to permit the agency to maintain its current wide-ranging and important research efforts. Because the majority of the NIH budget is distributed to scientists who carry out their research in all 50 states, the investment that Congress makes in biomedical research creates jobs and contributes to economic vitality in communities throughout the country. The continued health and prosperity of our nation's people depends on a robust and consistent investment in basic, translational and clinical research.

[1] http://www.nih.gov/strategicvision.htm (accessed March 19, 2008)
[2] http://grants.nih.gov/grants/new_investigators/resources.htm#data (accessed March 21, 2008)

National Association of State Alcohol and Drug Abuse Directors, Inc.

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Executive Director
Lewis E. Gallant, Ph.D.

Testimony on FY 2009 Federal Funding for Addiction Treatment, Prevention, Recovery Services and Research

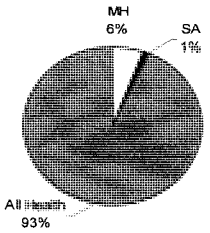
Submitted to the House Appropriations Subcommittee on Labor, Health and Human Services (HHS), Education and Related Agencies
The Hon. David Obey (WI), Chairman
The Hon. James T. Walsh (N.Y.), Ranking Member

Submitted by Lewis E. Gallant, Ph.D., Executive Director, National Association of State Alcohol and Drug Abuse Directors (NASADAD)

March 31, 2008

Chairman Obey, Ranking Member Walsh, and members of the Subcommittee, on behalf of the National Association of State Alcohol and Drug Abuse Directors (NASADAD), and our component organizations, the National Prevention Network (NPN), and the National Treatment Network (NTN), thank you for your leadership on issues related to addiction treatment, prevention, recovery services and research. We are pleased to offer recommendations on FY 2009 funding.

Substance Abuse Spending Represents Tiny Fraction of All Health Expenditures: It is estimated that substance abuse represented 1 percent of the expenditures for all healthcare ($1,614 billion) in 2003. With over 22.6 million Americans suffering from substance abuse or dependency problems in 2006, we believe an increase in federal investments for addiction services and research will save lives, families and money.



SA = substance abuse. MH = mental health.

National Expenditures for Mental Heath Services and Substance Abuse Treatment: 1993-2003, T. Mark. et al. Substance Abuse and Mental Health Services Administration (SAMHSA). 2007

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Substance Abuse Prevention and Treatment (SAPT) Block Grant: NASADAD recommends $1,858.7 million for the SAPT Block Grant in FY 2009 – an increase of $100 million over FY 2008 and $80 million over the President's request. NASADAD supports such an increase in the SAPT Block Grant to enable all States the ability to expand capacity for much needed prevention and treatment services.

The SAPT Block Grant, a program distributed by formula to all States and territories, represents the backbone of the nation's publicly funded addiction system and serves our nation's most vulnerable populations: those with HIV/AIDS, pregnant and parenting women, youth, veterans and their families, and others. This vital program helps States and communities address their own unique needs – whether the problem is alcohol, methamphetamine, prescription drug abuse or persons using multiples substances.

Important Prevention Funding: Twenty percent of the SAPT Block Grant is dedicated to funding much needed substance abuse prevention programming. The prevention set-aside has helped produce demonstrable results. The Monitoring the Future (MTF) Survey found a 23 percent decline in any illicit drug use in the past month by 8th, 10th and 12th graders combined between 2001 and 2006. As a result, there were 840,000 fewer teens using drugs in 2006 compared to 2001. A strong commitment to the SAPT Block Grant will ensure a strong commitment to much needed prevention services for our youth.

SAPT Block Grant Funded Services Achieve Results: We agree with the House Appropriations Committee, as noted last year in Committee Report 110-231, that "...the SAPT block grant is an effective and efficient program." The Committee also noted in the same report that "Data collected from States demonstrate that SAPT block grant funded programs help people remain abstinent from alcohol and other drug use; find or regain employment; find stable housing; stay away from criminal activity; reunite with their families; and live productively in communities across the country." Through the National Outcome Measures (NOMs) initiative, States report excellent results from programs funded by the SAPT Block Grant – including the following examples:

Wisconsin's Division of Disability, Elder Services, Substance Abuse and Mental Health reported 25,381 admissions to treatment in State Fiscal Year 2005. The Division reported the following outcomes in 2005 for those clients completing treatment: 77 percent were abstinent at discharge. For prevention, the Division reported that fewer students experimented with alcohol before the age of 13 (from 37 percent in 2003 to 24 percent in 2005/2006). In addition, past month marijuana use decreased (from 22 percent in 2003 to 16 percent in 2005).

New York's Office of Alcoholism and Substance Abuse Services (OASAS) reports over 84,000 annual new admissions to the OASAS funded treatment system and, in the 2007 SAPT Block Grant application, included patient outcomes comparing admission to treatment to discharge: 75.1 percent increase in the number of patients abstinent from drug use; 26.7 percent increase in the number patients employed; 32.5 percent decrease in the number of patients who were homeless; and 61.4 percent decrease in the number of patients arrested in the past month.

The California Department of Alcohol and Drug Programs (ADP) reported 216,840 admissions during State Fiscal Year 2006/2007 and noted the following outcomes comparing admission to treatment and discharge (these figures are the actual percentage changes rather than the absolute percentage changes): a 35 percent increase in abstinence from alcohol; an 28 percent increase in abstinence from other drug use; an 17 percent increase in social support of recovery; an 10 increase in employment; an 8 decrease in arrests; and a 2 percent decrease in homelessness.

Rhode Island's Division of Behavioral Healthcare Services reported 8,170 admissions to treatment in 2006 and reported the following client outcomes: an 84.3 percent increase in the number of patients abstinent from alcohol; a 74.8 percent increase in the number of patients abstinent from other drugs; an 81.3 percent decrease in the number of patients arrested; and a 23 percent decrease in homelessness.

Pennsylvania's Bureau of Drug and Alcohol Programs reported 92,224 admissions to treatment and provided prevention services to 111,145 individuals in State Fiscal Year 2005. In SFY 2005, the Bureau reported the following client outcomes comparing admission to discharge: 77 percent of clients addicted to alcohol were abstinent; 71 percent of clients addicted to cocaine/crack were abstinent; 75 percent of clients addicted to marijuana were abstinent; and 65 percent of clients addicted to heroin were abstinent.

Illinois' Division of Alcoholism & Substance Abuse reported 77,386 admissions to treatment and provided services to 165,289 persons in State Fiscal Year (SFY) 2006. In SFY 2006, the Division reported the following client outcomes: 62 percent increase in the number of patients abstinent from alcohol; a 73 percent increase in the number of patients abstinent from illicit drug use; a 33 percent increase in the number of patients employed; and a 24 percent decrease in homelessness.

NASADAD wishes to recognize Dr. Terry Cline, SAMHSA Administrator, for his leadership, outreach and collaboration with States to improve service delivery.

Center for Substance Abuse Treatment (CSAT): NASADAD recommends $420 million in FY 2009 – an increase of $20.2 million compared to FY 2008 and an increase of $80 million compared to the President's request.

NASADAD is extremely concerned with the FY 2009 proposed budget that would cut CSAT by $63 million compared to FY 2008. The proposed budget for CSAT would eliminate the following activities that are important to State substance abuse agencies:

- *Recovery Community Services Program*, a cut of $5.2 million.
- *State Service Improvement*, with no funding FY 2008 and $907,000 in FY 2007.
- *Pregnant and Postpartum Women*, a cut of $11,790,000.

- *Program Coordination and Evaluation*, a cut of $5,214,000. This initiative supports important initiatives such as Recovery Month.

- *Strengthening Treatment Access & Retention*, a cut of $3.6 million.

- *Children and Families*, a cut of $24,278,000.

The proposed budget for CSAT would significantly reduce funding for other programs that are important to State substance abuse agencies, including

- *Opioid Treatment Programs/Regulatory Activities*, a cut of $2,886,000 compared to the FY 2008 level of $8,903,000)

- *Targeted Capacity Expansion [TCE]*, a cut of $11,191,000 compared to the FY 2008 level of $28,989,000.

- *Services Accountability* (supports CSAT data collection activities), a cut of $13,617,000 compared to the FY 2008 level of $23,093,000.

- *Addiction Technology Transfer Centers [ATTCs]*, a cut of $478,000 compared to the FY 2008 level of $9,081,000.

- *Treatment Systems for the Homeless*, a cut of $9,906,000 compared to the FY 2008 level of $42,5000,000.

NASADAD wishes to acknowledge Dr. H. Westley Clark, Director of CSAT, for his leadership and excellent partnership with NASADAD and States.

Center for Substance Abuse Prevention (CSAP): NASADAD recommends $215 million – an increase of $20.9 million compared to FY 2008 and an increase of $56.9 million compared to the President's proposal.

NASADAD is very concerned with the proposal to cut funding for CSAP by $36 million compared to FY 2008. The proposed budget for CSAP would negatively impact a number of activities that are important to State substance abuse agencies.

For example, NASADAD is concerned with a proposal to fund the *Strategic Prevention Framework State Incentive Grant* at $95,389,000, representing a cut of $9,318,000 compared to the FY 2008 level of $104,707,000. Presently, the proposed FY 2009 budget does not identify whether SAMHSA would allocate future SPF-SIG awards at levels equal to previous years. NASADAD views resources for the SPF-SIG program as a top priority and recommends funding that would enable all States and jurisdictions to receive an award in an amount that is not less than the last cohort.

NASADAD is also concerned with the proposal to fund the *Centers for the Application of Prevention Technologies [CAPTs]* at $4,381,000, representing a cut of $7,656,000 compared to the FY 2008 level of $12,216,000. NASADAD remains concerned with any

action that could threaten the continuation of the CAPTs in their present form and structure. NASADAD recommends funding at FY 2008 levels for the CAPTs in order to enable these regional Centers to continue to improve the quality of each State's substance abuse prevention service system by translating the latest science and research into everyday practice. These resources will also support the infrastructure necessary to retain the Centers and allow for State-specific tailored services to continue uninterrupted.

Other concerns with the FY 2009 proposed budget center on the following proposals:

- *Sober Truth on Prevention Underage Drinking [STOP Act]*, which is proposed to be eliminated, representing a cut of $5,404,000.

- *Methamphetamine Prevention*, a cut of $2,386,000 compared to the FY 2008 level of $2,967,000.

- *Program Coordination/Data Coordination and Consolidation Center*, a cut of $5,186,000 compared to the FY 2008 level of $6,016,000.

- *Evidence Based Practices*, which is proposed to remain at zero funding as it was in FY 2008, while the program was funded at $1,443,000 in FY 2007.

NASADAD wishes to acknowledge the work of Dr. Anna Marsh, Acting Director of CSAP, for her work and dedication on prevention issues.

Safe and Drug Free Schools and Communities – State Grants: NASADAD recommends $346.5 million, representing a $51.8 million increase over FY 2008 and $246.5 million increase over the President's request.

The SDFSC State Grants program is an effective initiative that represents a core component of each State's substance abuse prevention system. We believe the program benefits from close collaboration with NASADAD members. In particular, certain Governors choose NASADAD members as the designee to manage these important funds. This designation allows for a more comprehensive and coordinated approach to planning and implementing an effective State-wide system of care.

National Institute on Drug Abuse (NIDA): NASADAD recommends $1,067.8 million, representing an increase of $67.1 million over FY 2008 and an increase of $66.2 million over the President's request. NASADAD wishes to thank Dr. Nora Volkow, Director of NIDA, for her collaboration with State substance abuse agencies through its "Blending Initiative." This work improves the translation of research into everyday practice.

National Institute on Alcohol Abuse and Alcoholism (NIAAA): NASADAD recommends $465.5 million, for an increase of $29.2 million over FY 2008 and an increase of $28.9 million over the President's request.

Thank you very much for your continued support of programs benefiting addiction treatment, prevention, research and recovery. We look forward to working with you.

TESTIMONY SUBMITTED FOR THE RECORD

HOUSE OF REPRESENTATIVES APPROPRIATIONS SUBCOMMITTEE ON LABOR-HHS-EDUCATION

By HOWARD BEDLIN
Vice-President, National Council on Aging

March 2008

Section I – Basic Programs in the Older Americans Act

The Older Americans (OAA) is the backbone of services to America's aging population. First enacted in 1965, the OAA helps seniors to stay independent and healthy through a wide range of services and programs, including: home-delivered meals, congregate meals, senior center services, transportation, support for family caregivers, home and community services, health promotion, disease prevention, nursing home ombudsmen, grants for Native Americans, community service employment for low-income older workers, and numerous program innovations. With strong support from the National Council on Aging (NCOA) and many other aging-related organizations, Congress reauthorized the OAA in the fall of 2006, strengthening it in many ways and adding important new initiatives.

These are the major components of the OAA, receiving more than 92 percent of the annual appropriations:

- *Supportive Services (Title III-B)* – services that enable older persons to remain in their own homes and age in place, rather than enter institutions. The most frequently provided services are home health, personal care and transportation.
- *Nutrition Services (Title III-C)* – congregate and home-delivered meals, increasing the health, functionality and quality-of-life for millions of seniors. Approximately 40 percent of home-delivered meal providers have waiting lists.
- *National Family Caregiver Support Program (Title III-E)* – services to help ease the burdens of caregivers, including respite care, counseling and supplemental services.
- *Senior Community Service Employment Program (Title V, known as SCSEP)* – part-time employment and training for low-income workers, helping to lift them out of poverty and restore a sense of self-worth. SCSEP strengthens communities through community service job placements.

All OAA programs are under the Administration on Aging of the Department of Health and Human Services, except for the SCSEP, which is under the Department of Labor (DoL). Total appropriations for all of OAA in FY08 come to $1.935 billion -- $1.413 billion to the Administration on Aging (AoA) and $522 million to DoL for SCSEP.

OAA funding was virtually frozen (with very small increases) from FY02 to FY05, and then cut in FY06. This frozen funding eroded many services because of rising prices, and simultaneously diminished the ability of OAA programs to reach the growing population of seniors in need. In FY07 Congress increased OAA funding by a small amount, adding $20

million in nutrition services and $51.3 million for SCSEP to cover the increase in the federal minimum wage. The FY08 increases were similar to FY07: a modest $30.4 million increase for nutrition and some other AoA programs, plus $38.0 million for SCSEP's minimum wage increase. Though the SCSEP increases of the past two cycles sound significant, they have not expanded the program nor helped it to keep up with inflation, but have only provided sufficient funds to pay the same number of enrollees at the higher minimum wage level.

Attached to this testimony is a graph showing the gap between actual appropriations and the amount needed to keep up with inflation and the senior population increase over the last six years. If funding since FY02 had simply kept pace with inflation and the growing number of seniors, it would be $380 million higher in FY08 than it actually is. The graph illustrates starkly why the nation's network of aging services providers has been forced to cut back on services.

Looked at another way, the total increase in appropriations from FY02 to FY08 for all OAA programs was less than 8 percent. However, the mandated minimum wage expansion for SCSEP enrollees consumed about two-thirds of the total funding increase; if the minimum wage dollars are not included in the calculation, all OAA programs combined received total increases of less than 3 percent in six years, far less than the rise in inflation in that period.

The OAA urgently needs a significant boost in funding, for the following reasons:

- OAA programs help to preserve the health and independence of our nation's seniors, enabling them to remain in their own homes longer.
- Spending money on OAA programs saves taxpayers' dollars in the long run, by reducing premature nursing home placements, averting malnutrition and controlling chronic health conditions.
- With flat funding, service providers are constantly faced with difficult choices about which services to cut. Rising food and gas prices hit nutrition programs hard.
- Strengthening the OAA was the top priority of the delegates to the once-per-decade 2005 White House Conference on Aging, and Congress responded with the 2006 reauthorization. Congress needs to take the next step and provide substantial increases in funding for the #1 priority of those bipartisan delegates.

In view of the above, the National Council on Aging urges Congress to **increase funding for all existing OAA programs by 9 percent in FY09.** An increase of 9 percent over FY08 would be $174 million -- $127 million for AoA and $47 million for the SCSEP in DoL.

Section II – Recently-added Programs in the Older Americans Act

The reauthorization of the OAA, signed into law in October of 2006, added valuable new initiatives that deserve significant start-up funding:

(1) The bill authorized a National Center on Senior Benefits Outreach and Enrollment that will marshal person-centered, cost effective techniques to enroll seniors in a broad range of benefits programs for which they are eligible. Currently millions of Medicare beneficiaries who are eligible for the Part D Low-income Subsidy have not yet signed up for it. Likewise, millions of

seniors who qualify for other federal, sate and private assistance – including food stamps, SSI and Medicare Savings Programs – do not participate. Enrolling in these programs for which they are eligible could help such seniors emerge from deep and chronic poverty. Upon receiving the initial $4 million that is needed to get started, the National Center will work with community based organizations, provide training and technical assistance, maintain decision enrollment tools, and develop a clearinghouse on best practices.

(2) The OAA amendments authorized expansion of evidence-based health promotion and disease prevention activities under AoA's *Choices for Independence* initiative, establishing a national technical assistance program and directing the aging network to develop evidence-based educational and behavioral change programs to reduce the risk of injury, disease, and disability. Evidence-based programs help older people better manage their chronic conditions, improve their physical and mental health, and reduce their risk of falls. The Stanford Chronic Disease Self-Management Program, has provided ample evidence that such initiatives produce significant Medicare and Medicaid savings for the federal government. NCOA believes that the *Choices for Independence* program should be fully funded for $28 million in FY09, including the evidence-based health promotion activities, and opposes the proposal to limit the program to five states.

(3) The OAA amendments authorized AoA to conduct demonstration projects that provide opportunities for older adults to participate in multigenerational and civic engagement activities designed to meet critical community needs, including support for grandparents raising children and for volunteers working with families who have a child with a disability or chronic illness. The law also authorized other demonstration projects that coordinate multigenerational and civic engagement activities, and promote volunteerism. NCOA strongly supported these initiatives when they were passed, because they will bring benefits to children, benefits to youth, benefits to older adults and benefits to communities. The demonstration projects should be funded at $9 million, with an additional $1 million for the creation of a national blueprint for civic engagement for older adults, as described in Section 202(c) of the OAA amendments.

Summarizing the three initiatives above, the National Council on Aging urges Congress to appropriate sufficient start-up funding in FY09 for these new programs in the 2006 reauthorization:

-- $4 million for the National Center on Senior Benefits Outreach and Enrollment;
-- $28 million for *Choices for Independence* and its evidence-based health programs; and
-- $10 million for civic engagement activities.

Section III – Falls Prevention and Reduction Among Older Americans

Each year, one in three Americans aged 65 and older falls; about 30% of those who fall require medical treatment. In 2005, approximately 1.8 million older adults were treated in emergency departments for nonfatal injuries from falls, more than 433,000 were hospitalized, and nearly 16,000 died. **Falls are the leading cause of both fatal and nonfatal injuries for those 65 and over.** According to the Centers for Disease Control and Prevention (CDC), the mortality rate from falls among older Americans increased 39% from 1999 to 2005.

The costs of these falls are enormous. CDC reports that $19 billion annually is spent on treating the elderly for the effects of falls: $12 billion for hospitalization, $4 billion for emergency department visits, and $3 billion for outpatient care. Most of these expenses are paid for through Medicare.

Many of the falls that seniors suffer are preventable, and the results of recent pilot programs offer some promising directions for cost-effective interventions, such as: comprehensive clinical assessments, exercise programs to improve balance and strength, management of medications, correction of vision, and reduction of home hazards.

CDC is the lead Federal agency for injury prevention and control through its National Center for Injury Prevention and Control (NCIPC). Currently the federal government allocates $1 million per year to NCIPC to address a problem that costs us more than $19 billion a year. Astonishingly, the President's FY09 budget reduces funding for NCIPC, and proposes raising the nation's goal for fatalities from falls among those 65 and over from an FY08 goal of 48 per 100,000 to an FY09 goal of 56 per 100,000.

The National Council on Aging urges Congress to move in the opposite direction from the President's proposal. We believe the federal government has a significant role to play in reducing senior falls – including fatalities from falls – and thus we urge you to **appropriate an additional $20.7 million** in the FY09 Labor-HHS-Education bill for CDC's NCIPC to carry out falls prevention and reduction activities.

TESTIMONY OF SARA AMUNDSON
EXECUTIVE DIRECTOR, THE HUMANE SOCIETY LEGISLATIVE FUND
FOR THE
HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES REGARDING THE NATIONAL INSTUTUTES OF HEALTH AND NATIONAL INSTITUTE OF ENVIRONMENTAL HEALTH SCIENCES
March 30, 2008

The Humane Society Legislative Fund (HSLF) supports a strong commitment by the federal government to research, development, standardization, validation and acceptance of non-animal and other alternative test methods. We are also submitting our testimony on behalf of The Humane Society of the United States and Doris Day Animal League, representing more than 11 million members and supporters. Thank you for the opportunity to present testimony relevant for the fiscal year 2009 budget request for the National Institutes of Health (NIH) and the National Institute of Environmental Health Sciences (NIEHS) for the fiscal year 2009 activities of the National Toxicology Program Center for the Evaluation of Alternative Toxicological Test Methods (NICEATM), the support center for the Interagency Coordinating Committee for the Validation of Alternative Test Methods (ICCVAM). The NIH request is relevant to the actual director's budget.

Function of the ICCVAM

The ICCVAM performs a valuable function for regulatory agencies, industry, public health and animal protection organizations by assessing the validation of new, revised and alternative toxicological test methods that have interagency application. After appropriate independent peer review of the test method, the ICCVAM recommends the test to the federal regulatory agencies that regulate the particular endpoint the test measures. In turn, the federal agencies maintain their authority to incorporate the validated test methods as appropriate for the agencies' regulatory mandates. This streamlined approach to assessment of validation of new, revised and alternative test methods has reduced the regulator burden of individual agencies, provided a "one-stop shop" for industry, animal protection, public health and environmental advocates for consideration of methods and set uniform criteria for what constitutes a validated test methods. In addition, from the perspective of animal protection advocates, ICCVAM can serve to appropriately assess test methods that can refine, reduce and replace the use of animals in toxicological testing. This function will provide credibility to the argument that scientifically validated alternative test methods, which refine, reduce or replace animals, should be expeditiously integrated into federal toxicological regulations, requirements and recommendations.

History of the ICCVAM

The ICCVAM is currently composed of representatives from the relevant federal regulatory and research agencies. It was created from an initial mandate in the NIH Revitalization Act of 1993 for NIEHS to "(a) establish criteria for the validation and regulatory acceptance of alternative testing methods, and (b) recommend a process through which scientifically validated alternative methods can be accepted for regulatory use." In 1994, NIEHS established the ad hoc ICCVAM to write a report that would recommend criteria and processes for validation and regulatory acceptance of toxicological testing methods that would be useful to federal agencies and the scientific community. Through a series of public meetings, interested stakeholders and agency representatives from all 14 regulatory and research agencies, developed the NIH Publication No. 97-3981, "Validation and Regulatory Acceptance of Toxicological Test Methods." This report, and subsequent revisions, has become the sound science guide for consideration of new, revised and alternative test methods by the federal agencies and interested stakeholders.

After publication of the report, the ad hoc ICCVAM moved to standing status under the NIEHS' NICEATM. Representatives from federal regulatory and research agencies and their programs have continued to meet, with advice from the NICEATM's Advisory Committee and independent peer review committees, to assess the validation of new, revised and alternative toxicological methods. Since then, several methods have undergone rigorous assessment and are deemed scientifically valid and acceptable. In addition, the ICCVAM is working to streamline assessment of methods from the European Union (EU) that have already been validated for use within the EU. The open public comment process, input by interested stakeholders and the continued commitment by the federal agencies has led to ICCVAM's success. It has resulted in a more coordinated review process for rigorous scientific assessment of the validation of new, revised and alternative test methods.

Request for Committee Report Language

In 2006, the NICEATM/ICCVAM at the request of the U.S. Congress began a process of developing a five-year roadmap for assertively setting goals to prioritize ending the use of antiquated animal tests for specific endpoints. The HSLF and other national animal protection organizations provided extensive comments on the process and priorities for the roadmap.

While the stream of methods forwarded to the ICCVAM for assessment has remained relatively steady, it is imperative that the ICCVAM take a more proactive role in isolating areas where new methods development is on the verge of replacing animal tests. These areas should form a collective call by the federal agencies that compose ICCVAM to fund any necessary additional research, development, validation and validation assessment that is required to eliminate the animal methods. We also strongly urge the NICEATM/ICCVAM to closely coordinate research, development and validation efforts with its European counterpart, the European Centre for the Validation of Alternative Methods (ECVAM) to ensure the best use of available funds and sound

science. This coordination should also reflect a willingness by the federal agencies comprising ICCVAM to more readily accept validated test methods proposed by the ECVAM to ensure industry has a uniform approach to worldwide chemical safety evaluation. Unfortunately, the plan was released in February 2008 and did not address a specific concern articulated by several stakeholders: what are the reason(s) and rationale for not accepting the recommendations of the ECVAM Scientific Advisory Committee regarding numerous methods deemed scientifically valid in Europe? We urge the Committee to consider addressing this consideration and we respectfully request the Subcommittee consider the following report language for the House Labor, Health and Human Services, Education and Related Agencies Appropriations bill to ensure that the ICCVAM and NICEATM respond to the specific lack of acceptance of European methods deemed scientifically valid:

"The Committee acknowledges the publication of the NICEATM/ICCVAM Five-Year Plan and encourages greater emphasis on key strategic actions. The Committee requests an analysis from the NICEATM/ICCVAM of possible scientific issues and regulatory testing requirements, regulations, policies or practices that may be barriers to assessment and acceptance by the US federal regulatory authorities of new, revised or alternative methods deemed scientifically valid by the European Centre for the Validation of Alternative Methods. The report shall be completed by December 2008."

National Institutes of Health Support For - *Toxicity Testing in the 21st Century: A Vision and a Strategy*

In February, the National Institutes of Health (NIH) launched an ambitious collaboration with the Environmental Protection Agency (EPA) to dramatically transform the way drugs, consumer products, pesticides, and other chemicals are assessed for safety. The new approach will use isolated cells, molecular targets, and lower organisms such as roundworms, instead of laboratory animals. According to the NIH, the research collaboration is expected "to generate data more relevant to humans; expand the number of chemicals that are tested; and reduce the time, money and number of animals involved in testing."

The new program, formalized by a memorandum of understanding (MOU), was unveiled at a February 14th press conference that featured Elias Zerhouni, director of the NIH, Francis Collins, head of the National Human Genome Research Institute (NHGRI), and other leading government scientists. The rationale behind the program was described in an article entitled "Transforming Environmental Health Protection" in the prestigious scientific journal *Science*.

The tripartite arrangement is designed to capitalize on the NIH Chemical Genomics Center's high-speed, automated screening robots to test compounds for toxicity; the experimental toxicology expertise of the National Toxicology Program, which is headquartered at the NIH's National Institute of Environmental Health Sciences; and the computational toxicology capabilities at the EPA's National Center for Computational Toxicology.

The government collaboration seeks to implement a June 2007 report by the National Research Council entitled *Toxicity Testing in the 21st Century: A Vision and a Strategy*, which calls for a sustained, well-funded effort across the toxicology community to shift the traditional toxicity-testing paradigm away from its heavy reliance on animal testing and towards high-throughput systems that monitor perturbations in toxicity pathways.

The government project could be seen as a successor, with equally visionary possibilities for biology, to Dr. Collins and NHGRI's highly successful Human Genome Project. In order for the new vision to be fully realized within a decade, what is needed is a well-funded government effort that would attract additional partners and resources from interested industries and overseas governments. According to the MOU, the collective budget for the project is yet to be determined.

Links:
NIH/NIEHS press release:
http://www.niehs.nih.gov/news/releases/2008/toxrelease.cfm
Memorandum of understanding:
http://www.niehs.nih.gov/news/releases/2008/docs/ntpnegcepamou.pdf
Science article:
http://www.niehs.nih.gov/news/releases/2008/docs/906.pdf
National Research Council report:
http://books.nap.edu/openbook.php?record_id=11970

We respectfully request the Subcommittee consider the following report language for the fiscal year 2009 House Labor, Health and Human Services, Education and Related Agencies Appropriations bill to ensure that the goal of the NRC's report and the commitment made by NIH through the Memorandum of Understanding be realized:

"The Committee directs the Director of NIH to provide funding for five-years to fully support NIH's elements of the Memorandum of Understanding between NIH and EPA entitled "High Throughput Screening, Toxicity Pathway Profiling, and Biological Interpretation of Findings." Priority shall be given to the use of the most relevant and reliable methods, and shall include specific focus on human cell systems and non-animal methods and on the building of a long-term research program, as described in the 2007 NRC Report "Toxicity Testing in the 21st Century, A Vision and a Strategy."

Fiscal Year 2009 Appropriations for the Nursing Workforce Development Programs
U.S. House Appropriations Subcommittee on Labor, Health and Human Services, and Education
March 31, 2008

Testimony submitted by:
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The American Association of Colleges of Nursing (AACN) respectfully submits this statement highlighting funding priorities for nursing education programs in FY 2009. AACN represents over 620 schools of nursing at public and private universities and senior colleges with baccalaureate and graduate nursing programs that include over 260,000 students and 13,000 faculty members. These institutions are responsible for educating almost half of our nation's nurses and all of the nurse faculty and researchers.

The Nationwide Nursing Shortage

The United States is in the midst of a decade-long shortage of Registered Nurses (RNs).[1] This shortage is expected to intensify as the baby-boomer population ages and the need for healthcare grows. According to the latest projections from the U.S. Bureau of Labor Statistics, more than 1.2 million new and replacement nurses will be needed by 2014.[2] Unless we act *now,* this shortage will further jeopardize access to quality patient care.

Healthcare delivery in the United States has experienced the negative effects of previous nursing shortages. During the 1940's, 1960's, and early 1970's[3], the nation's need for nurses greatly impacted patient care. While today's shortage shares some of the same contributing factors as those of the past, the aging nursing workforce, and fundamental changes in patient care such as length of stay and medical technology, further complicate the current demand for nurses.[3] Moreover, central to the present shortage, the nursing educational system is being threatened by a crippling shortage of nurse faculty, insufficient number of clinical placements and classroom space, and overall budget constraints.[4] According to AACN's 2007-2008 annual survey on baccalaureate and graduate programs, U.S. nursing schools turned away 40,285 qualified applicants. The number one reason cited in this survey was a lack of nurse faculty.[4]

Nursing and economic research clearly indicate that today's shortage is far worse than those of the past.[3] The current supply and demand for nurses demonstrates two distinct dilemmas. First, due to the present and looming demand for advanced health care by American consumers, the supply is not growing at a pace that will adequately meet long-term needs. This is further compounded by the number of nurses who will retire or leave the profession in the near future, ultimately reducing the supply of nurses. Second, the

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[1] Buerhaus, P.I., Donelan, K., Ulrich, B.T., Kirby, L., Norman, L., and Dittus, R. (2006). State of the Registered Nurse Workforce in the United States. *Nursing Economics.* 24(1), 6-12.
[2] Bureau of Labor and Statistics, (2005). *Occupational Projections to 2014.* Accessed March 10, 2008 from http://www.bls.gov/opub/mlr/2005/11/art5full.pdf
[3] Nevidjon, B. & Erickson, J.I. (2006). The nursing shortage: Solutions for the short and long term. As cited in: Andrist, L.C., Nicholas, P.K., & Wolf (2006). *A History of Nursing Ideas.* Boston: Jones and Bartlett Publishers.
[4] American Association of Colleges of Nursing. (2008). *2007-2008 Enrollment and Graduations in Baccalaureate and Graduate Programs in Nursing.* Washington, DC.

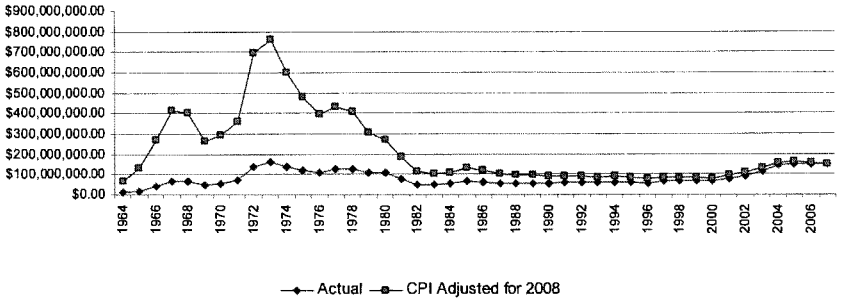
supply of nurses nationwide is stressed due to an ongoing shortage of nurse faculty. There is an enormous demand from individuals who wish to pursue a nursing education as evidenced by the thousands of qualified students turned away each year. However, the schools' ability to increase the nationwide supply of nurses is limited by the dwindling number of faculty. To address these related workforce issues, substantial efforts must be made to increase the number of faculty who will educate new nurses.

Nursing Workforce Development Programs: A Proven Solution

Congress has addressed past nursing shortages by creating the Title VIII authorities in 1964 and providing higher funding levels for the programs when the need for nurses was great. Unfortunately, due to a number of political and economic factors, funding for Title VIII over the last ten years has not increased to fully address the present nursing shortage.

In 1973, Congress appropriated $160.61 million to the Title VIII programs, the highest level of funding Title VIII has ever received. While this amount is close to the current funding level of $156.05 million, adjusting for inflation to address the 35-year difference, the current funding level would be $763.52 million (see Figure 1). More recently, stagnant funding levels for Title VIII between FY 2005 and FY 2007 have greatly impacted the purchasing power of these programs. In FY 2006 and 2007, $149.68 million was appropriated to Title VIII. The same allocation supported 91,198 nursing students and nurses in 2006 and only 71,729 in 2007.[5] This represents a loss of almost 20,000 nurses supported in one year.

Figure 1
Historical Funding for Title VIII Nursing Workforce Development Programs (in millions)



Source: Health Resources and Services Administration (HRSA), Division of Nursing, 2008 & U. S. Bureau of Labor Statistics, Inflation Calculator, 2008

Given the projections that the nursing shortage will continue to worsen over the next decade, more must be done to help alleviate the barriers that have significantly slowed the growth of the RN workforce. ***Therefore, AACN respectfully requests $200 million for Title VIII Nursing Workforce Development Programs in FY 2009***, an additional $43.95 million over the FY 2008 level. New monies would expand nursing education, recruitment, and retention efforts to help resolve all aspects contributing to the shortage.

An Overview of the Title VIII Programs: Effective Approaches to Address the Shortage

Over the last 44 years, the Nursing Workforce Development programs have addressed all aspects of nursing shortages – education, practice, retention, and recruitment. As the largest source of federal funding

[5] Electronic Mail Communications from the Health Resources and Services Administration, Division of Nursing, 2008.

for nursing education, these programs bolster RN education from entry-level preparation through graduate study. The Title VIII programs award grants to nursing education programs, as well as provide direct support to nurses and nursing students through loans, scholarships, traineeships, and programmatic grants. By supporting the supply and distribution of qualified nurses, these programs help to ensure that nurses are available to provide care to individuals in all healthcare settings. Additionally, the Title VIII programs also favor institutions that educate nurses for practice in rural and medically underserved communities.

The Nursing Workforce Programs are effective and meet their authorized mission. In a 2008 survey by AACN, 729 Title VIII student recipients reported that these programs played a critical role in funding their nursing education. The four major themes identified in this qualitative study indicate that the programs decreased the students' financial burden, allowed them to achieve their career goals, shortened the length of time to obtain their degree, and the funding was greatly appreciated.[6] Still, many students stated that this support did not completely erase their educational debt and urged Congress to continue the funding.[6] As mentioned, the Title VIII programs address all aspects of the nursing shortage. A description of each Nursing Workforce Development program is provided below along with an explanation to illustrate how they help supply the RN demand.

Advanced Education Nursing (AEN) Grants (Sec. 811) support programs that prepare graduate-level nurses to be primary care providers and nurse faculty. These grants help schools of nursing, academic health centers, and other nonprofit entities improve the education and practice of nurse practitioners, nurse-midwives, nurse anesthetists, nurse educators, nurse administrators, public health nurses, and clinical nurse specialists. In FY 2007, the AEN grants supported 5,978 nursing students through grant funding. The AEN program also offers traineeships to nursing students.[5]

- AEN Traineeships assist students during their graduate nursing education. These traineeships provide full or partial support for the costs of tuition, books, program fees, and reasonable living expenses. Ninety-nine percent of the eligible applications were approved in FY 2007, which supported 7,941 students.[5]
- Nurse Anesthetist Traineeships (NAT) support the education of students in nurse anesthetist programs. Much like the AEN Traineeships, the NATs provide full or partial support for the costs of tuition, books, program fees, and reasonable living expenses. One-hundred percent of the eligible applications were approved in FY 2007, which supported 2,173 students.[5]

According to AACN's 2008 Title VIII study, 79 percent of student respondents received funding from AEN grants or traineeships.[6] The students who responded expressed great appreciation for the funding and stated how it directly helped them to attain their academic and professional goals. The major themes identified were that the AEN grants and traineeships allowed students to go to school full time, which in turn helped them to graduate and practice sooner, and alleviated the high financial burden of graduate school.[6] Because the AEN grants support the education of future nurse faculty and nurse practitioners who provide primary care to thousands of Americans, it is imperative that funding for the AEN grants continues in FY 2009.

Workforce Diversity Grants (Sec. 821) prepare students from disadvantaged backgrounds to become nurses. This program awards grants and contract opportunities to nursing schools, nurse-managed health centers, academic health centers, state or local governments, and nonprofit entities looking to increase

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[6] American Association of Colleges of Nursing. (2008). The Effectiveness of Nursing Workforce Development Programs. Washington, DC.

access to nursing education for disadvantaged students, including racial and ethnic minorities under-represented among RNs. Through grant programs and individual awards, 32,847 minority nursing students were supported in FY 2007.[5]

Diversity within the nursing population does not parallel the cultural and ethnic background of American healthcare consumers. HRSA reports that only 10.7 percent of the nursing workforce identify themselves as an ethnic or racial minority.[7] According to the National Advisory Council on Nurse Education and Practice, diversifying the nursing profession is essential to meeting the healthcare needs of the nation and reducing health disparities that exist among many underserved populations.[8] In response to the need to enhance diversity, schools of nursing have substantially increased their minority enrollment. In fact, minority students currently account for 26 percent of enrollees in entry-level baccalaureate nursing programs.[4] While nursing has made great strides in recruiting and graduating nurses that mirror the patient population, more must be done to keep pace with the changing demographics of our country to ensure that culturally sensitive care is provided. The Nursing Workforce Diversity Grants help to achieve this goal.

Nurse Education, Practice, and Retention Grants (Sec. 831) help schools of nursing, academic health centers, nurse-managed health centers, state and local governments, and health care facilities strengthen nursing programs. This program focuses on nursing education, practice, and workforce retention by offering:

- Education Grants to: a) expand enrollments in baccalaureate nursing programs; b) develop internship and residency programs to enhance mentoring and specialty training; and c) provide for new technology, including distance learning.
- Practice Grants to: a) expand practice arrangements in non-institutional settings to improve primary health care in medically underserved communities; b) provide care for underserved populations such as the elderly, HIV/AIDS patients, substance abusers, and domestic abuse victims; c) provide skills to practice in existing and emerging health systems; and d) develop cultural competencies.
- Retention Grants to: a) maintain the Career Ladder program supporting nursing education efforts assisting individuals in obtaining the education necessary to either enter the profession or advance within it; and b) enhance patient care delivery systems by increasing collaboration and improving communication among nurses and other healthcare professionals. These grant programs supported 21,145 nurses and nursing students in FY 2007.[5]

As evidenced by the increase in enrollment and the rising interest in nursing careers, substantial efforts have been made to recruit new nurses, including individuals who are changing careers to nursing. However, the nursing profession is still struggling to educate and retain nurses to meet the demand in all healthcare settings. HRSA projects that nursing schools must increase the number of graduates by 90 percent in order to adequately address the nursing shortage.[7] Research shows that the stress of being a nurse often makes it difficult to retain both the new and experienced nurses in our healthcare system.[9] The Nurse Education, Practice, and Retention Grants help to ensure that the current nursing population is highly educated, prepared to practice nursing care in all healthcare areas, and remains in the profession.

Nurse Loan Repayment and Scholarship Programs (Sec. 846) support students and new graduates:

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[7] Health Resources and Services Administration (2004). *National Sample Survey of Registered Nurses.* Accessed February 19, 2008 from http://bhpr.hrsa.gov/healthworkforce/reports/rnpopulation/preliminaryfindings.htm

[8] National Advisory Council on Nurse Education and Practice (2003). *Third Report to the Secretary of Health and Human Services and the Congress.* Accessed February 20, 2008 from ftp://ftp.hrsa.gov/bhpr/nursing/nacreport.pdf

[9] PricewaterhouseCoopers' Health Research Institute *(2007) What Works: Healing the Health care Staffing Shortage.*

- Loan Repayment: Repays up to 85 percent of nursing student loans in return for at least three years of practice in a designated healthcare facility with a critical shortage of nurses. In FY 2007, 4,845 nursing student applications were reviewed, but only 586 (12 percent) were accepted due to the lack of funding.[5]
- Scholarship: Offers individuals who are enrolled or accepted for enrollment as a full-time nursing student the opportunity to apply for scholarship funds. Upon graduation, a nurse is required to work in a healthcare facility with a critical shortage of nurses for at least two years. Due to a lack of funding in FY 2007, only 32 percent of the applications accepted were approved, which funded only 173 student scholarships.[5]

According to the AACN Title VIII study, students reported that their education debt can range from $60,000 to $100,000 after graduation.[6] This substantial debt can often delay graduation as nurses need to work while attending school to offset what they will owe in the future. The Nurse Loan Repayment and Scholarship Program lessens the financial burden for nurses. However, the awards made through this program are limited. Therefore, increased funding is essential.

Nurse Faculty Loan Program Grants (Sec. 846a) increase the number of qualified nurse faculty by creating a student loan fund within individual schools of nursing. Students must agree to teach at a school of nursing in exchange for cancellation of up to 85 percent of their educational loans, plus interest, over a four-year period. The cancellation rate for the first three years is 20 percent per year and 25 percent in the final year. These grants assisted the education of 729 future nurse educators in FY 2007.

The shortage of nurse faculty is the most critical element of the current nursing shortage. Without additional faculty to teach incoming nursing students, the shortage will continue. Requiring years to graduate new nurse faculty, steps must be taken now to increase the population of nurse educators. The faculty shortage is a nationwide epidemic, with an 8.8 percent vacancy rate at nursing schools with baccalaureate and/or graduate programs. In 2007, AACN found that only 531 students graduated with research-focused doctorates.[4] This is a concern, as the majority of vacant faculty positions require a doctorate in nursing or a related field. The Nurse Faculty Loan Program is the only Title VIII program solely dedicated to educating the next generation of nurse faculty. Unfortunately, this program is sorely underfunded at $7.86 million.

Comprehensive Geriatric Education Grants (Sec. 855) are awarded to eligible entities such as schools of nursing or healthcare facilities to educate nursing staff to provide better healthcare services for the elderly. These grants may be used to educate RNs who will provide direct care to older Americans, develop and disseminate geriatric curriculum, prepare faculty members, and provide continuing education. In FY 2007, no new grants were approved. Therefore, only 19 continuing grants were funded, which supported 157 nursing students. This is down from 1,531 in FY 2006.[5]

As the baby-boomer population ages, the need for health care will increase dramatically. The Comprehensive Geriatric Education Grants allow nurses not only to become experts in the practice of geriatric nursing, but also to discover new methods to create cost-effective, high-quality services for this increasing population.

Conclusion

AACN acknowledges the fiscal challenges within which the Subcommittee and the entire Congress must work. However, the Title VIII authorities provide a dedicated, long-term vision for educating the new nursing workforce and the next cadre of nurse faculty. To be effective, they must receive additional funding. AACN respectfully requests **$200 million for Title VIII programs in FY 2009**. Additional funding for these programs will assist schools of nursing to expand their programs, educate more nurse faculty, increase the number of practicing RNs, and ultimately improve the patient care provided in our healthcare system.

Oncology Nursing Society
Written Testimony to the House Labor-Health and Human Services Appropriations Subcommittee
Regarding Fiscal Year 2009 Nursing and Cancer Related Funding
Submitted by: Paula Rieger, CEO Oncology Nursing Society
March 31, 2008

Overview

The Oncology Nursing Society (ONS) appreciates the opportunity to submit written comments for the record regarding fiscal year (FY) 2009 funding for cancer and nursing related programs. ONS, the largest professional oncology group in the United States, composed of more than 35,000 nurses and other health professionals, exists to promote excellence in oncology nursing and the provision of quality care to those individuals affected by cancer. As part of its mission, the Society honors and maintains nursing's historical and essential commitment to advocacy for the public good.

This year more than 1,437,180 million Americans will be diagnosed with cancer, and more than 565,650 will lose their battle with this terrible disease. Overall, age is the number one risk factor for developing cancer. Approximately 77 percent of all cancers are diagnosed at age 55 and older[1]. Despite these grim statistics, significant gains in the War Against Cancer have been made through our nation's investment in cancer research and its application. Research holds the key to improved cancer prevention, early detection, diagnosis, and treatment, but such breakthroughs are meaningless, unless we can deliver them to all Americans in need. Moreover, a recent survey of ONS members found that the nursing shortage is having an adverse impact in oncology physician offices and hospital outpatient departments. Some respondents indicated that when a nurse leaves their practice, they are unable to hire a replacement due to the shortage – leaving them short-staffed and posing scheduling challenges for the practice and the patients. These vacancies in all care settings create significant barriers to ensuring access to quality care.

To ensure that all people with cancer have access to the comprehensive, quality care they need and deserve, ONS advocates ongoing and significant federal funding for cancer research and application, as well as funding for programs that help ensure an adequate oncology nursing workforce to care for people with cancer. The Society stands ready to work with policymakers at the local, state, and federal levels to advance policies and programs that will reduce and prevent suffering from cancer and sustain and strengthen the nation's nursing workforce. We thank the Subcommittee for its consideration of our FY 2009 funding request detailed below.

Securing and Maintaining an Adequate Oncology Nursing Workforce

Oncology nurses are on the front lines in the provision of quality cancer care for individuals with cancer – administering chemotherapy, managing patient therapies and side-effects, working with insurance companies to ensure that patients receive the appropriate treatment, providing counseling to patients and family members, and engaging in myriad other activities on behalf of people with cancer and their families. Cancer is a complex, multifaceted chronic disease, and people with cancer require specialty-nursing interventions at every step of the cancer experience. People with cancer are best served by nurses specialized in oncology care, who are certified in that specialty.

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[1] American Cancer Society. *Cancer Facts and Figures 2008.* Atlanta: American Cancer Society: 2008.

Oncology Nursing Society
Written Testimony to the House Labor-Health and Human Services Appropriations Subcommittee
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Submitted by: Paula Rieger, CEO Oncology Nursing Society
March 31, 2008

As the overall number of nurses will drop precipitously in the coming years, we likely will experience a commensurate decrease in the number of nurses trained in the specialty of oncology. With an increasing number of people with cancer needing high-quality health care, coupled with an inadequate nursing workforce, our nation could quickly face a cancer care crisis of serious proportion, with limited access to quality cancer care, particularly in traditionally underserved areas. A study in the New England Journal of Medicine found that nursing shortages in hospitals are associated with a higher risk of complications – such as urinary tract infections and pneumonia, longer hospital stays, and even patient death[2]. Without an adequate supply of nurses, there will not be enough qualified oncology nurses to provide the quality cancer care to a growing population of people in need, and patient health and well-being could suffer.

Further, of additional concern is that our nation also will face a shortage of nurses available and able to conduct cancer research and clinical trials. With a shortage of cancer research nurses, progress against cancer will take longer because of scarce human resources coupled with the reality that some practices and cancer centers resources could be funneled away from cancer research to pay for the hiring and retention of oncology nurses to provide direct patient care. Without a sufficient supply of trained, educated, and experienced oncology nurses, we are concerned that our nation may falter in its delivery and application of the benefits from our federal investment in research.

ONS has joined with others in the nursing community in advocating $200 million as the FY 2009 funding level necessary to support implementation of the Nurse Reinvestment Act and the range of nursing workforce development programs housed at the U.S. Health Resources and Services Administration (HRSA). Enacted in 2002, the Nurse Reinvestment Act (P.L. 107-205) included new and expanded initiatives, including loan forgiveness, scholarships, career ladder opportunities, and public service announcements to advance nursing as a career. Despite the enactment of this critical measure, HRSA fails to have the resources necessary to meet the current and growing demands for our nation's nursing workforce. For example, in FY 2006 HRSA received 4,222 applications for the Nurse Education Loan Repayment Program, but only had the funds to award 615 of those applications[3]. Also, in FY 2007 HRSA received 6,611 applications for the Nursing Scholarship Program, but only had funding to support 220 awards[4].

While a number of years ago one of the biggest factors associated with the shortage was a lack of interested and qualified applicants, due to the efforts of the nursing community and other interested stakeholders, the number of applicants is growing. As such, now one of the greatest

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[2] Needleman J., Buerhaus P., Mattke S., Stewart M., Zelevinsky K. "Nurse-Staffing Levels and the Quality of Care in Hospitals." *New England Journal of Medicine* 346:, (May 30, 2002): 1715-1722.

[3] U.S. Health Resources and Services Administration: Nurse Education Loan Repayment Program:http://bhpr.hrsa.gov/nursing/loanrepay.htm

[4] U.S. Health Resources and Services Administration: Nursing Scholarship Program Statistics: http://bhpr.hrsa.gov/nursing/scholarship/

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factors contributing to the shortage is that nursing programs are turning away qualified applicants to entry-level baccalaureate programs, due to a shortage of nursing faculty. According to the American Association of Colleges of Nursing (AACN), U.S. nursing schools turned away 42,866 qualified applicants from baccalaureate and graduate nursing programs in 2006, due to insufficient number of faculty[5]. The nurse faculty shortage is only expected to worsen with time, as half of the RN workforce is expected to reach retirement age with in the next 10 to 15 years[6]. At the same time, significant numbers of faculty are expected to retire in the coming years, with insufficient numbers of candidates in the pipeline to take their places. If funded sufficiently, the components and programs of the Nurse Reinvestment Act will help address the multiple factors contributing to the nursing shortage.

The nursing community opposes the President's FY 2009 budget proposal that decreases nursing workforce funding by $46 million – a cut which eliminates all funding for advanced nursing education programs. With additional funding in FY 2009, these important programs will have much-needed resources to address the multiple factors contributing to the nationwide nursing shortage, including the shortage of faculty – a principal factor contributing to the current shortage. Advanced nursing education programs play an integral role in supporting registered nurses interested in advancing in their practice and becoming faculty. As such, these programs must be adequately funded in the coming year.

ONS strongly urges Congress to provide HRSA with a minimum of $200 million in FY 2009 to ensure that the agency has the resources necessary to fund a higher rate of nursing scholarships and loan repayment applications and support other essential endeavors to sustain and boost our nation's nursing workforce. Nurses – along with patients, family members, hospitals, and others – have joined together in calling upon Congress to provide this essential level of funding. The National Coalition for Cancer Research (NCCR), a non-profit organization comprised of 26 national organizations, is also advocating $200 million for the Nurse Reinvestment Act in FY 2009. ONS and its allies have serious concerns that without full funding, the Nurse Reinvestment Act will prove an empty promise, and the current and expected nursing shortage will worsen, and people will not have access to the quality care they need and deserve.

Sustain and Seize Cancer Research Opportunities

Our nation has benefited immensely from past federal investment in biomedical research at the National Institutes of Health (NIH). ONS has joined with the broader health community in advocating a 6.6% increase ($31.1 billion) for NIH in FY 2009. This will allow NIH to sustain and build on its research progress, resultin g from the recent doubling of its budget, while

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[5] American Association of Colleges of Nursing ,"2006-2007 Enrollment and Graduations in Baccalaureate and Graduate Programs in Nursing." http://www.aacn.nche.edu/IDS/datarep.htm, March 2007.
[6] Preliminary Results: "National Survey of Nurse Educators: Compensation, Workload, and Teaching Practices." *National League of Nursing/Carnetgie Foundation.* (February 7, 2007) http://www.nln.org/newsreleases/pres_budget2007.htm

avoiding the severe disruption to that progress that would result from a minimal increase. Cancer research is producing extraordinary breakthroughs – leading to new therapies that translate into longer survival and improved quality of life for cancer patients. We have seen extraordinary advances in cancer research, resulting from our national investment, which have produced effective prevention, early detection and treatment methods for many cancers. To that end, ONS calls upon Congress to allocate $5.26 billion to the National Cancer Institute (NCI) in FY 2009 to support the battle against cancer.

The National Institute of Nursing Research (NINR) supports basic and clinical research to establish a scientific basis for the care of individuals across the life span – from management of patients during illness and recovery, to the reduction of risks for disease and disability and the promotion of healthy lifestyles. These efforts are crucial in translating scientific advances into cost-effective health care that does not compromise quality of care for patients. Additionally, NINR fosters collaborations with many other disciplines in areas of mutual interest, such as long-term care for older people, the special needs of women across the life span, bioethical issues associated with genetic testing and counseling, and the impact of environmental influences on risk factors for chronic illnesses, such as cancer. ONS joins with others in the nursing community in advocating a FY 2009 allocation of $150 million for NINR.

Boost Our Nation's Investment in Cancer Prevention, Early Detection, and Awareness

Approximately two-thirds of cancer cases are preventable through lifestyle and behavioral factors and improved practice of cancer screening[7]. Although the potential for reducing the human, economic, and social costs of cancer by focusing on prevention and early detection efforts remains great, our nation does not invest sufficiently in these strategies. The nation must make significant and unprecedented federal investments today to address the burden of cancer and other chronic diseases, and to reduce the demand on the healthcare system and diminish suffering in our nation both for today and tomorrow.

As the nation's leading prevention agency, the Centers for Disease Control and Prevention (CDC) plays an important role in translating and delivering, at the community level, what is learned from research. Therefore, ONS joins with our partners in the cancer community in calling on Congress to provide additional resources for the CDC to support and expand much-needed and proven effective cancer prevention, early detection, and risk reduction efforts. Specifically, ONS advocates the following FY 2009 funding levels for the following CDC programs:

- $250 million for the National Breast and Cervical Cancer Early Detection Program;
- $65 million for the National Cancer Registries Program;
- $25 million for the Colorectal Cancer Prevention and Control Initiative;
- $50 million for the Comprehensive Cancer Control Initiative;

[7] American Cancer Society

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- $25 million for the Prostate Cancer Control Initiative;
- $5 million for the National Skin Cancer Prevention Education Program;
- $10 million for the Ovarian Cancer Control Initiative;
- $5.5 million for the Geraldine Ferraro Blood Cancer Program;
- $145 million for the National Tobacco Control Program; and
- $65 million for the Nutrition, Physical Activity, and Obesity Program.

Conclusion

ONS maintains a strong commitment to working with Members of Congress, other nursing societies, patient organizations, and other stakeholders to ensure that the oncology nurses of today continue to practice tomorrow, and that we recruit and retain new oncology nurses to meet the unfortunate growing demand that we will face in the coming years. By providing the FY 2009 funding levels detailed above, we believe the Subcommittee will be taking the steps necessary to ensure that our nation has a sufficient nursing workforce to care for the patients of today and tomorrow and that our nation continues to make gains in our fight against cancer.

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Spina Bifida Association
Written Testimony to the House Labor-Health and Human Services-Education Appropriations Subcommittee
Regarding Fiscal Year 2009 Funding For The National Spina Bifida Program
Submitted by: Scott T. Price, Esq., President, Spina Bifida Foundation
March 31, 2008

Summary

The Spina Bifida Association (SBA) respectfully requests that the Subcommittee provide the following allocations in FY 2009 to help improve quality-of-life for people with Spina Bifida:

- $7 million to the National Spina Bifida Program at the National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention (CDC) to support existing program initiatives and allow for the further development of the National Spina Bifida Patient Registry.

As you may know, these funding requests are supported by a broad bipartisan group of Members of Congress, including Congressional Spina Bifida Caucus leaders, Representatives Bart Stupak, Chris Smith, Ileana Ros-Lehtinen, and Dan Burton, among many others.

Background on Spina Bifida

On behalf of the more than 70,000 individuals and their families who are affected by Spina Bifida – the nation's most common, permanently disabling birth defect – the SBA appreciates the opportunity to submit written testimony for the record regarding FY 2009 funding for the National Spina Bifida Program and other related Spina Bifida initiatives. SBA is the national voluntary health agency working on behalf of people with Spina Bifida and their families through education, advocacy, research and service. The Association was founded in 1973 to address the needs of the Spina Bifida community and today serves as the representative of 45 chapters serving more than 125 communities nationwide. SBA stands ready to work with Members of Congress and other stakeholders to ensure our nation takes all the steps necessary to reduce and prevent suffering from Spina Bifida.

Spina Bifida, a neural tube defect (NTD), occurs when the spinal cord fails to close properly during the early stages of pregnancy, typically within the first few weeks of pregnancy and most often before the mother knows that she is pregnant. Over the course of the pregnancy – as the fetus grows – the spinal cord is exposed to the amniotic fluid which increasingly becomes toxic. It is believed that the exposure of the spinal cord to the toxic amniotic fluid erodes the spine and results in Spina Bifida. There are varying forms of Spina Bifida occurring from mild – with little or no noticeable disability – to severe – with limited movement and function. In addition, within each different form of Spina Bifida the effects can vary widely. Unfortunately, the most severe form of Spina Bifida occurs in 96 percent of children born with this birth defect.

The result of this neural tube defect is that most people with it suffer from a host of physical, psychological, and educational challenges – including paralysis, developmental delay, numerous surgeries, and living with a shunt in their skulls which seeks to ameliorate their condition by helping to relieve cranial pressure associated with spinal fluid that does not flow properly. As we have testified previously, the good news is that after decades of poor prognoses and short life

expectancy, children with Spina Bifida are now living long enough to become adults with Spina Bifida. These gains in longevity principally are due to breakthroughs in research, combined with improvements generally in health care and treatment. However, with this extended life expectancy, our nation and people with Spina Bifida now face new challenges – education, job training, independent living, health care for secondary conditions, aging concerns, among others. Despite these gains, individuals and families affected by Spina Bifida face many challenges – physical, emotional, and financial. Fortunately, with the advent of the National Spina Bifida Program four years ago, individuals and families affected by Spina Bifida now have a national resource to provide them with the support, information, and assistance they need and deserve.

While the consumption of 400 micrograms of folic acid daily prior to becoming pregnant and throughout the first trimester of pregnancy, can help reduce the incidence of Spina Bifida by up to 75 percent, 1,500 babies are born with Spina Bifida each year and our nation still must take steps to ensure that the tens of thousands of individuals living with Spina Bifida can live full, healthy, and productive lives.

Cost of Spina Bifida

It is important to note that the lifetime costs associated with a typical case of Spina Bifida – including medical care, special education, therapy services, and loss of earnings – are as much as $1 million. The total societal cost of Spina Bifida is estimated to exceed $750 million per year, with just the Social Security Administration payments to individuals with Spina Bifida exceeding $82 million per year. Moreover, tens of millions of dollars are spent on medical care paid for by the Medicaid and Medicare Programs. Our nation must do more to help reduce the emotional, financial, and physical toll of Spina Bifida on the individuals and families affected. Efforts to reduce and prevent suffering from Spina Bifida help to save money and save lives.

Improving Quality-of-Life through the National Spina Bifida Program

SBA has worked with Members of Congress to ensure that our nation is taking all the steps possible to prevent Spina Bifida and diminish suffering for those currently living with this condition. With appropriate, affordable, and high-quality medical, physical, and emotional care, most people born with Spina Bifida likely will have a normal or near normal life expectancy. The National Spina Bifida Program at the CDC works on two critical levels – to reduce and prevent Spina Bifida incidence and morbidity and to improve quality-of-life for those living with Spina Bifida. The program seeks to ensure that what is known by scientists is practiced and experienced by the 70,000 individuals and families affected by Spina Bifida. Moreover, the National Spina Bifida Program works to improve the outlook for a life challenged by this complicated birth defect – principally identifying valuable therapies from in-utero throughout the lifespan and making them available and accessible to those in need.

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The National Spina Bifida Program serves as a national center for information and support to help ensure that individuals, families, and other caregivers, such as health professionals, have the most up-to-date information about effective interventions for the myriad primary and secondary conditions associated with Spina Bifida. Among many other activities, the program helps individuals with Spina Bifida and their families learn how to treat and prevent secondary health problems, such as bladder and bowel control difficulties, learning disabilities, depression, latex allergy, obesity, skin breakdown and social and sexual issues. Children with Spina Bifida often have learning disabilities and may have difficulty with paying attention, expressing or understanding language, and grasping reading and math. All of these problems can be treated or prevented, but only if those affected by Spina Bifida – and their caregivers – are properly educated and taught what they need to know to maintain the highest level of health and well-being possible. The National Spina Bifida Program's secondary prevention activities represent a tangible quality-of-life difference to the 70,000 individuals living with Spina Bifida with the goal being living well with Spina Bifida.

One way to increase research in Spina Bifida, improve quality and save precious resources is to establish a patient registry for Spina Bifida. Plans are underway to create the National Spina Bifida Patient Registry intended to determine both the best practices clinically and the cost effectiveness of treatment of Spina Bifida and the support the creation of quality measures to improve care overall. It is only through research towards improved care that we can truly save lives while realizing a significant cost savings.

In FY 2008, SBA requested $7 million be allocated to the National Spina Bifida Program to support and expand the National Spina Bifida Program. While the House version of the FY 2008 LHHS appropriations bill provided $5.5 million request, the FY 2008 Continuing Appropriations Resolution provided just $5.198 million for this program. SBA understands and appreciates that the Congress and the nation face difficult budgetary challenges. However, the progress being made by the National Spina Bifida Program must be sustained and expanded to ensure that people with Spina Bifida – over the course of their lifespan – have the support and access to quality care they need and deserve. To that end, SBA advocates that Congress allocate $7 million in FY 2009 to the National Spina Bifida Program it can continue its current scope of the work and increase its folic acid awareness and Spina Bifida prevention efforts, further develop the National Spina Bifida Patient Registry, and sustain the National Spina Bifida Clearinghouse and Resource Center. Increasing funding for the National Spina Bifida Program will help ensure that our nation continues to mount a comprehensive effort to prevent and reduce suffering from Spina Bifida.

Preventing Spina Bifida

While the exact cause of Spina Bifida is unknown, over the last decade, medical research has confirmed a link between a woman's folate level before pregnancy and the occurrence of Spina Bifida. Sixty-five million women are at-risk of having a child born with Spina Bifida and each

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year approximately 3,000 pregnancies in this country are affected by Spina Bifida, resulting in 1,500 births. As mentioned above, the consumption of 400 micrograms of folic acid daily prior to becoming pregnant and throughout the first trimester of pregnancy can help reduce incidence of Spina Bifida up to 75 percent. There are few public health challenges that our nation can tackle and conquer by three-fourths in such a straightforward fashion. However, we must still be concerned with addressing the 25 percent of Spina Bifida cases that cannot be prevented by folic acid consumption, as well as ensuring that all women of childbearing age – particularly those most at-risk for a Spina Bifida pregnancy – consume adequate amounts of folic acid prior to becoming pregnant.

The good news is that progress has been made in convincing women of the importance of folic acid consumption and the need to maintain a diet rich in folic acid. Since 1968, the CDC has led the nation in monitoring birth defects and developmental disabilities, linking these health outcomes with maternal and/or environmental factors that increase risk, and identifying effective means of reducing such risks. This public health success should be celebrated, but it is only half of the equation as approximately 3,000 pregnancies still are affected by this devastating birth defect. The nation's public education campaign around folic acid consumption must be enhanced and broadened to reach segments of the population that have yet to heed this call – such an investment will help ensure that as many cases of Spina Bifida can be prevented as possible.

SBA is the managing agent for the National Council on Folic Acid, a multi-sector partnership reaching over 100 million people a year with the folic acid message. The goal is to increase awareness of the benefits of folic acid, particular for those at elevated risk of having a baby with neural tube defects (those who have Spina Bifida themselves or those who have already conceived a baby with Spina Bifida). With additional funding in FY 2009 these activities could be expanded to reach the broader population in need of these public health education, health promotion, and disease prevention messages. SBA advocates that Congress provide additional funding to CDC to allow for a particular public health education and awareness focus on at-risk populations (e.g. Hispanic-Latino communities) and health professionals who can help disseminate information about the importance of folic acid consumption among women of childbearing age.

In addition to a $7 million FY 2009 allocation for the National Spina Bifida Program, SBA urges the Subcommittee to provide increased funding for the NCBDDD so the agency can enhance its programs and initiatives to prevent birth defects and developmental disabilities and promote health and wellness among people with disabilities.

Improving Health Care for Individuals with Spina Bifida

The mission of the Agency for Healthcare Research and Quality (AHRQ) is to improve the outcomes and quality of health care; reduce its costs; improve patient safety; decrease medical

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errors; and broaden access to essential health services. The work conducted by the agency is vital to the evaluation of new treatments in order to ensure that individuals and their families living with Spina Bifida continue to receive the high quality health care that they need and deserve – SBA urges the Subcommittee to provide $360 million to AHRQ so the agency can continue to provide guidance to support the National Spina Bifida Patient Registry.

Sustain and Seize Spina Bifida Research Opportunities

Our nation has benefited immensely from our past federal investment in biomedical research at the National Institutes of Health (NIH). SBA joins with the rest of the public health and research community in advocating that NIH receive a 6.4% increase ($30.842 billion) in FY 2009. This funding will support applied and basic biomedical, psychosocial, educational, and rehabilitative research to improve the understanding of the etiology, prevention, cure and treatment of Spina Bifida and its related conditions. In addition, SBA requests that the Subcommittee include language in the report accompanying the FY 2009 LHHS measure to:

- Urge the National Institute of Child Health and Human Development (NICHD) – expansion of its role —and support of—a more comprehensive Spina Bifida research portfolio;
- Commend the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) for its interest in exploring issues related to the neurogenic bladder and to encourage the institute to forge ahead with its work in this important topic area; and
- Encourage the National Institute of Neurological Diseases and Stroke (NINDS) to continue and expand its research related to the treatment and management of hydrocephalus.

Conclusion

SBA stands ready to work with the Subcommittee and other Members of Congress to advance policies that will reduce and prevent suffering from Spina Bifida. Again, we thank you for the opportunity to present our views on funding for programs that will improve the quality-of-life for the 70,000 Americans and their families living with Spina Bifida and stand ready to answer any questions you may have.

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

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

I am Sharon Washington, the new executive director of the National Writing Project (NWP). NWP is authorized under Title II, Subchapter C, Subpart 2 of the Elementary and Secondary Education Act (ESEA) of 1965. It has been authorized as part of ESEA since 1991. The Department of Education's FY2009 budget request to Congress did not include funding for this program.

When teachers invest their time and energy in professional development, they expect a superior learning experience--a class or a program that serves as a model for their own classroom. They expect to learn about best practices and research that will improve their teaching and directly benefit their students. And they expect a professional development program to take into account their particular situation. For example, new teachers have different needs and concerns than veteran teachers. Teachers who teach special student populations expect professional development to be tailored to the specific needs of their students.

Teachers attend National Writing Project programs each year because these expectations are met and exceeded. With nearly 200 sites at colleges and universities in 50 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands, the NWP provides both a national network and local professional communities through which teachers from primary grades through university, in all subject areas, can join forces to make their classrooms and their schools more effective. At the heart of the NWP model is the idea that teachers can be leaders, and that they are pivotal to making positive changes in both teaching and student achievement. The good news is that NWP research shows that students do excel in the classrooms of writing project teachers. The federal investment in the NWP has played an essential role in its impact, as well as in its growth and in its research agenda.

Federal funds are an investment in a national infrastructure.

Independent evaluator Inverness Research calls the National Writing Project the "largest and longest-standing teacher development program in U.S. history." Local site performance data show the depth and breadth of the NWP:

- NWP sites conducted more than 7,000 local professional development programs in 2007, including 900 long-term partnerships with local schools.

- Over the period 2000–2006, NWP prepared more than 22,000 teachers to serve as leaders, who provide professional development to colleagues and make other contributions to their schools and school districts.
- Overwhelmingly (95%– 99%), these teacher-leaders rate their NWP professional development positively compared to other non-NWP professional development in which they participate.
- Over the period 2000–2006, the NWP network of sites delivered more than $150 million of professional development programming directly to teachers, an average of $25 million per year. This represents more than $2.70 for every $1 in federal investment in the NWP.

The depth and breadth of the NWP have important implications for teachers. New York City Writing Project teacher-leader Julie Conason explains what it means to be part of a professional community that has both local and national roots: "It is critical for me to be part of a national network as well as part of my local writing project community. I am able to exchange ideas and practices with other urban teachers through the NWP Urban Sites Network and, similarly, through the English Language Learners Network. And for teachers in rural areas, the writing project provides the opportunity to learn from each other through the Rural Sites Network. Together, when we look at how writing practices help our students, we strengthen each other."

Federal investment in the NWP infrastructure contributes to teacher retention. The NWP Legacy Study (2007), which documents the careers of 2,114 teachers who participated in summer institutes, provides good news in an era when many teachers leave the profession during their first five years. Seventy percent of NWP teachers remain in the classroom throughout their careers. Ninety-eight percent stay in education until they retire. The study found that summer institute participants serve an average of 22.7 years in education--more than 50 percent longer than teachers in general.

Once again, teacher Julie Conason is a telling case. "Who knows how long I would have stayed in this profession without the writing project community? At the time I encountered the New York City Writing Project, I was a dual-language teacher of kindergartners and first-graders in central Harlem. The year was 1992, and I had been teaching six years--and frankly, I was becoming discouraged, wondering how much of a difference I was actually able to make." For Julie, the summer institute was "an immersion experience.... I learned a great deal about how to structure a learning environment.... I learned about teaching writing at different grade levels, which made it possible for me to teach in middle and high school in subsequent years. I learned concrete strategies that changed both my teaching and my students' learning." Julie has been in public education in New York City for 22 years, over half of them teaching primary, middle, and high school students in monolingual and also in bilingual and English language learner classrooms.

Federal funds are an investment in growth and teacher access to NWP sites.

Each year between six and ten new NWP sites are established in areas of the country that previously had not been served. The NWP has also developed local satellite programs

through which existing sites provide services to teachers and schools at a distance from the host university. It's important to know that NWP's goal--to place a site within reach of every teacher in America--is valued by teachers themselves. Recently, Carol Mikoda, a teacher from a new site at the State University of New York, Cortland, wrote about her joy that the writing project had finally come to her area. "I have been waiting all of my professional life to feel this empowered, this energized," she said. "Because of this National Writing Project site and its summer institute in July, I no longer feel I am living a professional life of quiet desperation. Schools in upstate New York will start to feel the ripple effect from the energy of the teachers who will gather each summer to study and write, and then fan out into the surrounding school districts to demonstrate what they learn as writers and educators."

Federal funds are an investment in research and evaluation.

Independent National Research Study

Funding increases for the National Writing Project now support a five-year, $5 million independent national research study conducted by SRI International. The study uses a random assignment control group design in which researchers have assigned schools to one of two conditions: a partnership condition (the treatment group) or a delayed partnership condition (the control group). NWP local sites plan, develop, and deliver a sustained program of professional development designed to reach 35 to 100 percent of teachers in partnership schools over the course of the four-year data collection portion of the study. Delayed partnership schools agree to refrain from any substantial professional development related to writing for the duration of the study. At the end of the study, their local NWP site will form a partnership with them.

The initial sample for the study comprises 41 schools and 15 NWP sites. A wide range of geographic areas is represented: the sample includes sites from nine of the ten regions formally established by the U.S. Department of Education, and it includes schools from throughout the country. The treatment and control schools are comparable with respect to size, demographics, and student achievement levels. The sites reflect the diversity of sites in the NWP network with respect to experience and capacity. The study focuses on teachers and students in seventh and eighth grades, although the entire school may participate in partnership activities.

National Program of Local Site Research Studies

The NWP is carefully assembling a growing body of evidence derived from a national program of rigorous quasi-experimental studies. Between 2004 and 2007, in eight independent studies, researchers measured the extent to which students whose teachers received training by an NWP local site improved their writing skills. The studies were conducted in diverse settings representing all geographic regions of the country. Each study employed direct assessments of student writing, and included carefully matched comparison classes and/or students.

A team of external evaluators reviewed all of the research proposals for technical rigor. A panel of independent experts in writing assessment designed and oversaw the national scoring of student writing and refined the analytic framework for scoring writing. In this independent scoring of student writing, NWP students' improvement outpaced that of students in closely matched comparison groups in every one of the eight studies.

Federal funds are an investment in academic and workplace competitiveness.

The National Writing Project makes an invaluable contribution to the country by working with teachers to prepare students to succeed academically and in their chosen career paths. As the NWP executive director, I passionately support this effort, and I urge Congress to continue its investment in this program of national merit that has the potential to benefit all of America's school children.

A 2007 national public opinion survey revealed that writing is a priority for most of the American public. Three-quarters of those surveyed believe there is a greater need now to be able to write well than there was 20 years ago. Those of us who have children, grandchildren, or nieces and nephews do not need to be convinced on that score. We also know how essential it is for the new generation of students to be able to communicate effectively, and how important it will be to their future. The National Writing Project provides high-quality, large-scale, cost-effective professional development programs for teachers so that our nation's students will be accomplished writers and learners as well as engaged citizens in our democracy.

Statement of the American Society for Microbiology on FY 2009 Funding for the National Institutes of Health

The American Society for Microbiology (ASM) is seriously troubled by the continuing shrinkage of appropriations for the National Institutes of Health (NIH), with inflation-adjusted funding flat or declining since FY 2003. The President's proposed FY 2009 budget for NIH continues a disturbing trend that risks losing our scientific edge in biomedical research. With annual health spending in the United States likely to exceed $4 trillion by 2017, innovative medical research is critical to improvements in both public health and the national economy. Increasing biomedical research is key to finding new cures, treatments and preventions for infectious and chronic diseases that threaten our future. Increased biomedical research investment will also help ensure US competitiveness in medical breakthroughs and cutting edge technologies that will contribute to economic growth in the United States.

For five years the NIH budget has lost ground to biomedical research inflation, estimated at 3.5-3.7 percent. Since FY 2004 this situation has cost NIH and biomedical research approximately 11 percent in purchasing power. At the same time, annual funding has fallen far short of that needed to adequately support and build on opportunities in basic and clinical research. The FY 2008 NIH budget of $29 billion, minus the set-aside for the Global Fund for HIV/AIDS, Malaria and TB, is a meager 0.5 percent increase over FY 2007. The Administration's proposed $29 billion budget for FY 2009 regrettably flatlines NIH funding for the sixth year in a row. This budget request will clearly weaken fiscal support for NIH, which expends more than 80 percent of its budget on research at about 3,100 institutions and is the largest single funding source for research at US universities and colleges.

Because of flat budgets and expanding research opportunities, the success rates for NIH research grant applications continue to fall. The total number of grant recipients also will decline under the FY 2009 request. This is a sobering predictor of slower technical innovation and fewer medical advances. At the National Institute of Allergy and Infectious Diseases (NIAID), the number of research grant requests rose from 1,993 in 1997 to 4,900 in 2007, while success rates slipped from about 43 percent to 23 percent. The Institute's FY 2008 funding level was 2.3 percent below FY 2007. The FY 2009 NIAID request is only 0.2 percent above FY 2008 levels, before $300 million is transferred to the Global Fund. This downward trend will continue to undercut research that is the foundation of future biomedical successes and the fight against infectious diseases.

Shrinking support for biomedical research will also reduce the numbers of talented trainees and students who choose a career in biomedical research. At risk is the next generation of biomedical scientists who would otherwise be able to capitalize on recent advances in deciphering the human genome or translating basic research into tangible improvements in human health. These setbacks to biomedical research, training and public health will continue unless the NIH budget is increased. If the Administration and

Congress continue the pattern of neglect for NIH funding that has been going on for half a decade, it will be difficult for the nation's biomedical research enterprise to recover.

The ASM Recommends the NIH Budget be Increased by $1.9 Billion

The NIH Reform Act of 2006 authorized a funding level of $32.8 billion for the NIH's FY 2008 budget, which illustrates how far the NIH budget, currently at $29 billion in FY 2008, has fallen behind congressionally authorized levels of growth. Continuing fiscal shortfalls will weaken efforts of NIH to develop new therapies, vaccines, and diagnostics for a myriad of infectious and chronic diseases. To help reverse the ongoing erosion of biomedical research, the ASM recommends that the FY 2009 NIH budget be increased by $1.9 billion, an increase of 6.6 percent. This increase will help restore purchasing power that has been eroded by five years of flat funding and would provide some measure of growth for biomedical research.

Taking Advantage of Research Opportunities to Improve Public Health and Address Infectious Diseases

Federal investment in basic and applied research has had enormous payoff in medical advances against chronic and infectious diseases. NIAID supports research on a wide array of infectious diseases, from the more familiar killers like influenza to those less common—such as dengue fever, a flu-like illness spreading in its severe hemorrhagic form into new geographic areas, including the United States/Mexico border region. The following are just several examples of the changeable nature of both pathogens and their human hosts, evidence that strong biomedical research programs must be sustained:

- Seasonal influenza kills about 36,000 Americans each year and is an ever present concern. Even more worrisome is the potential for pandemic influenza if current bird flu viruses mutate into forms easily spread from human to human. Since the avian influenza virus H5N1 resurfaced in 2003, it has spread to more than 60 countries and infected more than 350 people, with over 60 percent mortality. NIAID scientists are collaborating with others worldwide to prevent a possible pandemic. Last year, for example, NIAID researchers identified genetic changes on the H5N1 surface that could permit easier entry into human cells, thereby suggesting potential approaches to improved surveillance and vaccines. The institute has initiated funding to establish six Centers of Excellence for influenza research and surveillance.

- Widespread, sometimes indiscriminate, use of antimicrobial drugs is a growing public health concern, as mutating pathogens become resistant to increasing classes of therapeutics. Antimicrobial resistance is a significant challenge to biomedical researchers trying to understand the mechanisms involved and to develop countermeasures. Recent surveillance studies report yet another newly emerging antimicrobial resistant pathogen, a multiple-drug resistant variant of the already problematic methicillin-resistant *Staphylococcus aureus* (MRSA). In 2005, MRSA was responsible for an estimated 94,000 life-threatening infections

in the United States and more than 18,000 deaths. The newly described variant of MRSA is resistant to even more drugs and causes more-virulent skin infections. NIAID-supported research is providing key information on resistant staph infections, like the just published studies identifying specific proteins secreted by MRSA that determine disease severity in humans. NIAID-funded scientists also have used comparative genome sequencing to reveal the origins of epidemic community-associated MRSA, a growing problem in this country. This February, an international team funded by NIH grants announced that a cholesterol-lowering drug could block staph infections in mice, an approach based on previous basic research on metabolic pathways in bacteria and in humans that might help circumvent drug-resistance in pathogens.

- NIAID's extensive research on global killers like malaria and tuberculosis recognizes that infectious diseases can easily cross time zones and national boundaries. Every 30 seconds, a child dies of malaria. One-third of the world's population carries the pathogen that causes tuberculosis, a disease that annually kills 1.6 million. In February, the WHO reported that multi-drug resistant tuberculosis (MDR-TB) has been recorded at the highest rates to dates, based on data from 81 countries. The WHO found that extensively drug resistant tuberculosis (XDR-TB), a virtually untreatable form of the disease, has been recorded in 45 countries, although few countries are currently equipped to diagnose it. Public health officials are finding drug-resistant strains of the TB pathogen in US populations. NIAID working groups have recently rewritten high-priority research agenda for these difficult-to-treat diseases, identifying critical areas where additional research is essential. In the past year, a promising new tuberculosis drug based on NIAID research was granted orphan drug status by US and European regulators. NIAID joined with stakeholders from industry, academia and government to announce a new partnership to focus on TB drug discovery and development. NIAID-supported TB research currently includes more than 300 projects worldwide.

- Infectious diseases, whether naturally occurring or deliberately spread, are among the greatest security challenges to the United States. Research to develop effective medical countermeasures to detect prevent and treat infectious diseases is a key responsibility of the NIAID. The NIAID has updated its Strategic Plan for Biodefense to address a broad spectrum strategy to prevent and respond to traditional and new types of threats that will require the capability to rapidly identify unknown and poorly defined agents, quickly evaluate the efficacy of available interventions and develop and deploy novel treatments. In recent years, the NIAID has expanded its basic and applied research portfolio and established a comprehensive infrastructure with extensive resources that support all levels of research. Examples of this infrastructure include the following:

    - Regional Centers of Excellence (RCEs) for Biodefense and Emerging Infectious Diseases, ten centers, located nationwide, provide resouces and communication systems that can be rapidly mobilized and coordinated

with regional and local systems in response to an urgent public health event.

- Cooperative Centers for Translational Research on Human Immunology and Biodefense further knowledge of human immune responses against infectious pathogens and elucidate molecular mechanisms responsible for both short-term immunity and long-term immune memory. The ultimate goal of these eight centers is to translate research on immunity to infection into clinical applications to protect against bioterrorist threats.
- National Biocontainment Laboratories (NBLs) and Regional Biocontainment Laboratories (RBLs), 2 NBLs and 13 RBLs are available or under construction for research requiring high levels of containment and are prepared to assist national, state and local public health efforts in the event of a bioterrorism or infectious disease emergency.
- Expanded Vaccine and Treatment Evaluation Units, multiple sites allow for more extensive clinical trials capacity and expertise.
- The Biodefense and Emerging Infections Research Resources Repository offers reagents and information essential for studying emerging infectious diseases and biological threats.
- Genomics and proteomics centers include the Microbial Sequencing Centers, the Pathogen Functional Genomics Resource Center, the Bioinformatics Resource Centers, and the Biodefense Proteomics Research Centers.
- The *In Vitro* and Animals Models for Emerging Infectious Diseases and Biodefense resource provides screening of potential therapeutics and the development of *in vitro* animal efficacy models for evaluating drugs and vaccines.
- The NIAID has supported a number of biodefense workshops and multiple training opportunities ranging from basic introductory courses to two-year fellowships to provide professional training in biosafety and biocontainment. These programs are available through the National Biosafety and Biocontainment Training Program, the RCEs, and NIAID Institutional Training Grants.

- The NIH routinely reevaluates its research priorities and adjusts programs to address changing disease threats, national priorities, or appropriated resources. An example is the agency-wide Roadmap for Medical Research, a strategy to leverage waning resources through interdisciplinary teams, state-of-the-art technologies, and harmonization of clinical research efforts. The NIH's singular ability to impact biomedical research broadly is epitomized by the recent launch of a new Roadmap initiative: the multi-center Human Microbiome Project to map the genomes of all microorganisms present in or on the human body, to better understand host-microbe interactions in both sickness and health. With next-generation DNA technologies, researchers will eventually sequence 1,000 microbial genomes, results to be deposited in public databases for use in designing new treatments and better methods to prevent disease.

Constant changes here and abroad, in populations, disease pathogens and vectors, climates, economies, cultures, and governments, all have potential to influence the global burden of human disease. Emerging threats like West Nile fever or Nipah virus coexist with global successes like polio or smallpox immunization campaigns. Persistent challenges like HIV/AIDS and foodborne illnesses continue to confound public health officials. It is imperative that the NIH maintain its science based agility to respond appropriately to both the anticipated and the unexpected health threat.

Biomedical Research is the Foundation of Research Competitiveness in a Global Economy

Past investments in biomedical research have returned exceptional benefits to the American people, but there are troubling indicators that our scientific edge is slipping. Globalization is now increasing worldwide competition in scientific discovery, technological innovation, and scientific talent. The US has declined to near parity with the EU-15 in recent years in biology publications. US federal support for academic R&D is falling for the first time in a quarter century. It is critical to note that the federal government supports the majority of basic research conducted by academic institutions. Basic research funded by the NIH fuels technological innovations and fosters the vitality of the US scientific enterprise. It helps create new industries and jobs, improves the quality of life of people and provides technology that contributes to national security.

The ASM strongly recommends that Congress end the past five years of fiscal neglect for NIH. It is absolutely essential that the United States increase support for biomedical research, which is an essential foundation for future US scientific competitiveness, knowledge based industries, and highly skilled jobs in this country. Biomedical innovation is key to economic competiveness and technological breakthroughs that improve our lives.

ASM Urges Congress to Increase FY 2009 Funding for NIH

The United States cannot afford to neglect greater investment in biomedical research. The continuing complacency that has led to the leveling off and erosion of support for biomedical research can diminish our defenses against both expected and unpredictable diseases. Also at risk are the nation's high quality scientific workforce, the tradition of technological innovation, and competitiveness in global markets, all nurtured by NIH supported research, laboratories and institutions. To assure continued public health benefits from biomedical research, the ASM strongly recommends that Congress increase the NIH budget by $1.9 billion for FY 2009.

GENE R. CARTER, EXECUTIVE DIRECTOR

Written Testimony of
Dr. Gene R. Carter
Executive Director/CEO
The Association for Supervision and Curriculum Development (ASCD)
Submitted to the
Committee on Appropriations Subcommittee on Labor, Health & Human Services, Education, and Related Agencies
March 31, 2008

Chairman Obey, Ranking Member Walsh, and Honorable Members of the Subcommittee:

Thank you for the opportunity to share ASCD's priorities for federal funding. My name is Dr. Gene Carter, and I am Executive Director and CEO of the Association for Supervision and Curriculum Development (ASCD).

ASCD is a nonprofit, nonpartisan organization representing 175,000 educators. ASCD members are found in schools throughout this country. They are superintendents, deputy superintendents, principals, teachers, professors of education, and school board members. With the exception of teacher unions, we represent more principals, superintendents, and educational leaders than any singular principal association or school administrator association. Formed in 1943, ASCD advocates for educational excellence and equity. As ASCD has grown in membership, our mission has evolved and expanded to address all aspects of effective teaching and learning—including professional development, educational leadership, capacity building, and effective pedagogy. ASCD membership is driven by best practices in the classroom to provide our children with the skills necessary to compete in the 21st century. We want the best policies to develop and educate the whole child.

ASCD believes that through effective program changes and increased flexibility education can thrive in this country. We also believe that accountability is as critical to education as textbooks. Although the proper accountability framework is a subject of debate, ASCD firmly believes in high standards and effective indicators that demonstrate progress towards those standards. Furthermore, ASCD is unique in that we have not previously submitted testimony to this committee asking for more resources. We have cautioned our membership against simply requesting more money when speaking with their members of Congress. We do not believe money alone will solve the problems facing education. However, we do believe that a lack of money exacerbates the difficulties schools face when preparing our children to succeed in this global economy. We offer the following recommendations for your consideration:

Funding Gaps: Authorization Versus Appropriations
Many in Congress believe legislative authorizations are a guardrail to restrain spending for federal programs. Given the tremendous gap between authorized amounts and the appropriated amounts, especially in Title I and IDEA, the need for such a "guardrail" is not readily apparent. ASCD appreciates that several members of this subcommittee and the full committee decried the

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inadequate funding and put forth tremendous efforts to provide significant education increases for both NCLB and IDEA. Unfortunately, the gap persists, and educators across this country—those charged with implementing and complying with the requirements of NCLB and IDEA—are finding their work seriously impacted by the lack of federal funds.

Looking at three significant and important programs—Title I, Title II, and IDEA—there is a federal funding difference of $19.6 billion between the authorized and appropriated amounts. This gap is exacerbated when combined with an inflation rate of 4.3 percent. In addition, student enrollment is expected to grow by almost 5 percent through 2014, the time frame included in the NCLB legislation. This gap requires schools to find crucial resources through state or local tax increases. Adding further pressure to this situation is the dismal fiscal outlook among the states for the next two years. Eighteen states are projecting budgetary shortfalls totaling $14 billion for FY 08, and 17 states are projecting shortfalls of $31 billion for FY 09—leading to either greater pressure on local taxpayers or drastic reductions in services to children.

We believe that the federal government has an obligation to support our schools and to pay for a larger share of the requirements associated with compliance of federal programs. Although we do not expect to see an increase of $19.6 billion, this funding gap illustrates a fundamental obstacle in the education of children. We urge the members of this committee to consider this situation when developing the funding legislation. We are hopeful this subcommittee will continue the promising support expressed by the House Budget Resolution, which contained a $7.1 billion increase over the President's FY09 discretionary funding request for education, training, and social services programs.

Looking ahead to FY 2009

ASCD urges you to provide the funding levels necessary to educate the whole child. Listed below are several programs we believe will make a substantial difference in helping schools, communities, educators, and policymakers to provide the necessary support and resources to ensure all children are healthy, safe, engaged, supported, and challenged.

Title I

Title I enables schools to better serve the neediest student populations. This program provides critical funds and learning resources to help compensate for the difficulties faced by disadvantaged children. Additional programs and learning materials help students, and schools continue to narrow the achievement gap. However, given increasing costs and growing student populations, funding for Title I has been inadequate. We know that schools are capable of doing much more, but we recognize that they are presently bound by their lack of resources. A significant increase in Title I funding will provide schools the flexibility to use the resources for assisting targeted student populations.

Title II

The correlation between teacher and school leader quality and student success is well documented. ASCD believes funding for Title II Teacher Quality Grants should be significantly higher than in previous years. It is time we begin to provide incentives, including salaries and professional development opportunities that better reflect the importance of teachers and educational leaders. We applaud past efforts by this committee to provide increased funds for

Title II. However, to ensure that our teachers are well prepared to meet growing demands, we must provide the programs and opportunities that enable more professional development opportunities. We also believe effective programs like the Teacher Incentive Fund and other grant programs—enabling schools to offer financial and professional incentives for high-quality educators to serve in high-need areas—is a critically important role that should receive increased funding.

High School Redesign

Our high schools are in crisis. We lose over one million students every year. One student drops out every 30 seconds. Beginning in the middle grades, the signs are clear as to which students are prone to dropping out. Students with low attendance, increasing academic difficulty or a failing grade, and decreasing or minimal engagement with educators all signify a danger of dropping out. Academic difficulty is not the only reason kids drop out; many students leave because they are not challenged or engaged by educators.

Yet, the answers exist. Pockets of successful schools graduate students and prepare them for high achievement in the real world or at advanced educational institutions. These solutions are not cheap. Effective high schools include personalized learning and mentoring to engage students. They have rich and relevant curricula that challenge students. The educators in these schools receive extensive professional development that is innovative and flexible. These high schools are also free to develop alternative scheduling options for fulfilling the Carnegie unit, including the length of the school day and school year. Yet additional resources are needed for many schools to develop and effectively implement these approaches.

Although there may be some hesitancy to invest significant resources now, given the difficult financial situation we face, consider numerous studies that demonstrate the hundreds of billions in dollars lost in productivity, taxes, and wages of high school dropouts. From a societal standpoint, dropouts are also associated with drastically higher medical and health care costs. High school dropouts also have higher incarceration rates. I am happy to share the extensive research on this topic. This committee faces a fundamental question: Do we spend this money now and invest in the future? Or does the country pay for our lack of funding in the future? Fortunately, a dedicated fund for secondary school improvement was unanimously approved as part of the Senate's 2009 Budget Resolution, signaling broad support for this investment. We are hopeful that this amendment remains as part of the final 2009 Budget Resolution. As such, it is our hope that this subcommittee will take the next step by including funding for high school redesign in the legislation.

Community Schools

One of the most cost-effective and innovative approaches to addressing not only educational needs but also the needs of local communities is full-service community schools. Full-service community schools facilitate collaboration among public schools, community-based organizations, and public and private partnerships, resulting in comprehensive educational, social, and health services provided to children and families. This approach does not saddle schools with the financial or service requirements of other agencies; instead these agencies use the school as the site or location to provide the relevant services. Full-service community schools create the school as the hub of the community and the centralized location to provide a

multitude of services by relevant professionals. These schools not only address the health and social needs of many students, but also they provide extensive resources for other community members that achieve broader societal goals, including job training, career counseling, medical assistance, and linkage with social service programs. We request the subcommittee do its part in providing more resources to support these schools and the related services provided.

Children's Heath and Learning

Among the many important choices facing the subcommittee, we encourage you to support those programs like Head Start that provide early childhood access to health services and pre-kindergarten education. Like high schools, the studies are numerous and overwhelming that children's health is an important factor in high academic achievement. The same is true of effective pre-kindergarten programs. If we truly want to close the achievement gap and prepare our children for success in the 21st century, we must provide these critical services.

Conclusion

We recognize that the nation's economy is currently under tremendous strain, and we fully comprehend the need to be fiscally responsible in a time of growing budget deficits and economic downturns. However, ASCD believes important domestic priorities like education are not an expense, but an investment. Our children's education, health, and our teachers' professional development are three of the most proven methods of maintaining our strength and competitiveness in a global economy. It is apparent now more than ever that our funding choices today will lay the foundation for our country's success tomorrow. To ensure that we educate our children and prepare them to be tomorrow's leaders; we need to make the investment in our children and students today.

Thank you again for the opportunity to share ASCD's positions. We look forward to working with you in the coming days to craft sound public policy for the good of our children and our future. Please contact me at 1-703-575-5494 with any questions or concerns. Thank you for your consideration.

NIAMS COALITION

Coalition of Voluntary and Professional Associations Concerned with the Programs of the National Institute of Arthritis and Musculoskeletal and Skin Diseases

Testimony of the NIAMS Coalition

Submitted to the House Committee on Appropriations

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

March 31, 2008

The NIAMS Coalition greatly appreciates the opportunity to submit testimony in support of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS). The NIAMS Coalition is comprised of more than 70 organizations (medical, patient advocacy and research based) dedicated to advancing the critical research funded at NIAMS. NIAMS funding has significantly affected the nation's ability to combat some of the most difficult chronic diseases such as arthritis, lupus, muscular dystrophy, osteoporosis, psoriasis, and scleroderma, which impact the lives of millions every day and cost the economy billions in health care costs. Chronic under-funding of NIAMS threatens the Institute's ability to achieve this important mission—at a time when health care costs are at an all time high, and Americans' basic health status lags behind that of others around the world. Investments in medical research can lead to delivery of the most effective and most clinically appropriate treatments for patients.

The mission of NIAMS is to support research into the causes, treatment, and prevention of arthritis and musculoskeletal and skin diseases, the training of basic and clinical scientists to carry out this research, and the dissemination of information on research progress in these diseases. Research opportunities at NIAMS are being curtailed due to the stagnating and in some cases declining numbers of new grants being awarded for specific diseases. The training of new investigators has unnecessarily slowed down and contributed to a crisis in the research community where new investigators have begun to leave biomedical research careers in pursuit of other more successful endeavors.

The NIAMS Coalition supports a 6.5% increase to the National Institutes of Health ($1.9 billion increase) and specifically a 6.5 % increase for the NIAMS budget bringing the NIAMS appropriation for FY09 to $542 million. Below are just a few examples of the research needs and opportunities that NIAMS addresses:

- More than 3,000 identified varieties of skin disease affect nearly 80 million Americans and can cause symptoms including itch, burning pain, chronic morbidity, severe emotional and mental distress, physical disfigurement, and/or death. The burden of skin disease extends beyond its financial toll, estimated at $38.6 billion per year in medical services and lost productivity, to include social and psychological costs to society.

NIAMS has funded fundamental and translational research that may one day provide better understanding of and cures for many skin diseases. NIAMS has explored skin microbiome research as part of NIH's "Human Microbiome Project" – a project examining the genomes of microorganisms and how they interact with their hosts.

- Osteoarthritis currently impacts 23 million Americans and is the leading cause of hip and knee replacement. The Osteoarthritis Initiative is a comprehensive effort to use multiple imaging modalities, biomarkers, and genetic data to characterize osteoarthritis incidence and progression. Importantly, it represents a successful partnership between industry and NIAMS, which will lead to the identification of novel biomarkers of diagnostic and prognostic significance and to the development of new therapies.
- As a chronic, life-altering and often debilitating genetic disease that affects 7.5 million in the United States, psoriasis brings with it serious co-morbidities such as increased risk of heart attack and diabetes and has serious physical and emotional impact on the people affected by the disease. It has taken nearly 30 years to understand that psoriasis is in fact not a disease of only the skin, but also of the immune system. We are finally identifying the immune cells involved in psoriasis; this knowledge will help scientists understand which cells or molecular processes should be targeted in psoriasis drug development, leading to more effective and potentially safer treatments and, eventually, a cure.
- Scleroderma is an autoimmune rheumatic disease affecting approximately 300,000 individuals in the U.S. Scleroderma (the name means "hard skin") can vary a great deal in terms of severity, ranging from mild to life threatening. Although there are medications to slow down disease progression and help with symptoms, there is as yet no cure for scleroderma; there is also no known cause. In localized scleroderma, the underlying problem is the overproduction of collagen (scar tissue). In systemic sclerosis, there are three processes at work: blood vessel abnormalities, fibrosis (overproduction of collagen) and immune system dysfunction, or autoimmunity. Research continues to assemble the pieces of the scleroderma puzzle to identify the susceptibility genes, to find the external trigger and cellular proteins driving fibrosis, and to interrupt the networks that perpetuate the disease.
- Osteoporosis is a major public health threat for 44 million Americans. Of the 10 million who have osteoporosis, 80 percent are women. The morbidity, mortality and disability associated with osteoporotic fracture places an enormous burden on our health care system. Research is needed to identify the parameters that lead to the better prediction, prevention and treatment of osteoporosis and related bone diseases. Additionally, research is needed to identify racial differences in bone and the origin of racial differences in fracture patterns; and to identify patients at risk for fracture who do not meet current criteria for osteoporosis, as well as study the effects of current and developing osteoporosis treatments on these patients. Additional research is needed on better bone building therapies that improve the treatment paradigms for those who experience a first hip fracture, on increasing the rate of healing of bone fractures, and on prevention programs that improve osteoporosis screening and awareness of hip fractures.
- Osteogenesis Imperfecta (OI) affects between 20,000 and 50,000 Americans. In severe cases fractures occur before and during birth. In some cases, an affected child can suffer repeated fractures before a diagnosis can be made. Undiagnosed OI may result in accusations of child abuse. Paget's disease of bone, is associated with bone pain, deformity, neurological complications, and arthritic conditions. Expanded genetics research is needed to better understand these inherited diseases of bone.
- Systemic lupus erythematosus (S.L.E.), commonly called lupus, is a chronic autoimmune disorder that can affect virtually any organ of the body. One of America's

least recognized major diseases, lupus affects more than 1.5 million Americans -- and recent studies show it is on the rise. There hasn't been a major new treatment approved for this devastating autoimmune disease in almost 50 years. Ninety percent of lupus victims are women, and it is more common among African American, Latino, Asian, and Native American women. The disease is a leading cause of kidney disease, stroke, and premature cardiovascular disease in women of childbearing age. NIAMS took the lead in developing the first ever lupus research agenda, "The Future Directions of Lupus," published in August 2007 and made publicly available via the NIH website. It identifies a wide range of research needs covering the full spectrum of lupus where research investment is desperately needed.

The NIAMS Coalition urges Congress to support the 6.5% increase for NIH and for NIAMS. NIH is facing the prospect of an unprecedented sixth straight year of flat funding, threatening the future of Americans' health and deterring talented researchers from staying in the field. The toll that this stagnant funding is taking on addressing America's needs in the health care areas represented by NIAMS is staggering. If NIAMS does not get consistent and robust funding, the nation risks losing the promising research that could cure disease for millions -- diseases for which no cure currently exists and has the potential of providing lower cost therapies and treatments.

For more information regarding this request of the NIAMS Coalition please contact Amy Melnick, Co-Chair, NIAMS Coalition at 202.887.2910, amelnick@arthritis.org or Sheila Rittenberg, Co-Chair NIAMS Coalition at 503-546-8365, srittenberg@psoriasis.org

Sincerely,

NIAMS COALITION MEMBERS

American Academy Of Dermatology
American Academy Of Orthopaedic Surgeons
American Academy Of Physical Medicine & Rehabilitation
American Association Of Colleges of Osteopathic Medicine
American Autoimmune Related Diseases Association Inc.
American Chronic Pain Association
American College Of Rheumatology
American Federation For Medical Research
American Nurses Association
American Orthopaedic Society For Sports Medicine
American Porphyria Foundation
American Skin Association Inc.
American Society For Bone And Mineral Research
APS Foundation of America, Inc
Arthritis Foundation
Arthritis Foundation -- Metro DC Chapter
Association Of Rheumatology Health Professionals
Basal Cell Carcinoma Nevus Syndrome Life Support Network
Biophysical Society
Cicatricial Alopecia Resarch Foundation
Cutaneous Lymphoma Foundation
Dermatology Foundation
Dermatology Nurses Association

Dystrophic Epidermolysis Bullosa Research Association
Ehlers-Danlos National Foundation
Epidermolysis Bullosa Action Network
Facioscapulohumeral Society, Inc. (Fsh)
Federation of American Societies For Experimental Biology
Foundation For Ichthyosis And Related Skin Types
Genetic Alliance
Gluten Intolerance Group Of North America
Health Partners
Hidradenitis Suppurativa Foundation, Inc
International Myeloma Foundation
International Pemphigus Foundation
Lupus Foundation Of America
Lupus Foundation Of Greater Washington
Lupus Foundation of Mid and Northern New York, Inc.
Lupus Research Institute
Lyme Disease Foundation
Muscular Dystrophy Association
Myositis Association Of America
National Alopecia Areata Foundation
National Association For Pseudoxanthoma Elasticum (Nape)
National Association Of Orthopaedic Nurses
National Atheletic Trainers' Association
National Eczema Association For Science And Education
National Eosinophilia Symdrome Network
National Fibromyalgia Association
National Foundation For Ectodermal Dysplasias
National Institute of Arthritis and Musculoskeletal and Skin Diseases, National Institutes of Health
National Marfan Foundation
National Organization For Rare Disorders
National Osteoporosis Foundation
National Psoriasis Foundation
National Vitiligo Foundation, Inc.
National Vulvodynia Association
Nevus Outreach, Inc.
Orthopaedic Research Society
Osteogenesis Imperfecta Foundation
Pachyonychia Congenita Project (PC Project)
Paget Foundation, The
Parent Project Muscular Dystrophy
PXE International
Reflex Sympathetic Dystrophy Syndrome Association Of America
Scleroderma Foundation
Scleroderma Foundation
Scleroderma Foundation of Greater Washington
Scleroderma Research Foundation
Scleroderma Support Foundation
Sjögren's Syndrome Foundation, Inc.
Society For Investigative Dermatology
Society for Women's Health Research
Spondylitis Association Of America
Sturge-Weber Foundation
Tuberous Sclerosis Alliance
Vitiligo Support International

Testimony of Robert Waters, JD

General Counsel

Advanced Initiatives in Medical Simulation

House Committee on Appropriations

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

Fiscal Year 2009

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Testimony of Robert Waters, JD
Advanced Initiatives in Medical Simulation

On behalf of Advanced Initiatives in Medical Simulation (AIMS), I appreciate this opportunity to submit testimony for the public record. AIMS is a coalition of individuals and organizations committed to promoting medical simulation technologies and techniques. Simulation-based training ensures better-trained health care providers, reduces medical errors, improves patient safety, decreases health costs and incidents of malpractice, improves clinical competencies, and improves the quality of patient care overall.

Summary Request

We urge the committee to further fund the Agency for Healthcare Research and Quality (AHRQ) to continue and expand its efforts to support research, convene workshops, and perform outreach to medical, nursing, and allied health schools to improve the utilization and development of simulation technologies in medical education and demonstrate the value of simulation-based medical training. We also request further collaboration between the Agency and the Department of Defense, the Telemedicine and Advanced Technology Research Center (TATRC), the Department of Veterans Affairs, and the National Institutes of Health in the further deployment of medical simulation research, tools, and training to improve patient care.

About Medical Simulation

Simulation is a training and feedback method in which learners practice tasks and processes in lifelike circumstances using models or virtual reality, with feedback from observers, peers, actor-patients, and video cameras to assist improvement in skills. Computer-based medical simulation provides a realistic and economical set of tools to improve and maintain the skills of health care providers adding a valuable dimension to medical training similar to professional training in aviation, defense, maritime, and nuclear energy.

Medical simulators allow individuals to review and practice procedures as often as required to reach proficiency without harming the patient. Simulation-based Medical Education (SBME) includes several tools and approaches:

- A full environment simulator is similar to flight simulators used to train pilots. The pilot is immersed in a complete replica of the cockpit environment. In medicine, sophisticated mannequins, known as patient simulators provides health care professionals with a computer-based patient that breathes, responds to drugs, talks, and drives all the clinical monitors in the operating room, e.g., blood pressure and pulse rate.

- Task trainers provide a simulated subset of functionality, such as how to give a smallpox inoculation or how to insert a chest tube.

- Computer-based training provides software programs that train and assess clinical knowledge and decision-making skills.

- Simulated/standardized patients allow students to interact with actors trained to act as patients providing students with valuable feedback on, among other things, bedside manner.

Medical simulation is a cross-disciplinary effort that brings together providers, including nurses, physicians, and allied health professionals across a variety of disciplines with computer scientists, researchers, educators, and human factors engineers.

Use of Medical Simulation

Currently, there are hundreds of schools in the United States providing "hands on" health care education to medical, nursing, and allied health students. These schools predominately use the apprenticeship model as its main teaching style, often referred to in medicine as "do one, see one, teach one."

Until recently, practicing on cadavers, laboratory animals, or real patients has been the only way to teach doctors, nurses, and other health professionals about anatomy and how to practice medicine. Of course, using anesthetized animals for medical training is challenging - the animals do not have the correct anatomy for realistic training, they are expensive, and they are not reusable. While cadavers have the correct anatomy, their use presents other challenges, including expense, difficulty in procuring the cadaver, and tissue degradation. In both instances, ethical issues are raised as well.

A health care provider's ability to react prudently in an unexpected situation is one of the most critical factors in creating a positive outcome in a medical emergency, regardless of whether it occurs on the battlefield, freeway, or hospital emergency room. This ability, however, is not a skill that one is born with, but rather it is learned and developed with time, training, practice, and repetition.

Today, advances in technology have created new and better, methods for teaching the practice of medicine and reinforcing best practices. One of the most exciting innovations in health care is in the field of medical simulation. Emplo ying medical simulation techniques can help move medicine from the old "see one, do one, teach one" method to a "see one, practice many, do one" model for success.

Medical simulation technologies have already begun to revolutionize medical education by ensuring clinical competency long after a clinician has finished his/her training, residency, fellowships, or internships. Just as airline pilot simulator training dramatically improved airline safety by reducing pilot error; the use of medical simulators can reduce unnecessary and costly medical errors, thereby, increasing patient safety and reducing health care costs.

Contact

If you have any questions, concerns, or would like further information, please contact AIMS General Counsel, Robert Waters, JD, at 202.230.5091 or robert.waters@dbr.com.

T L I

Testimony of Karen Edison, MD, Chair

Telehealth Leadership Initiative

House Committee on Appropriations

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

Fiscal Year 2009

Telehealth Leadership Initiative
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Testimony of Karen Edison, MD
Telehealth Leadership Initiative

On behalf of the Telehealth Leadership Initiative (TLI), I appreciate the opportunity to submit testimony for the public record. TLI is an organization dedicated to knocking down barriers to telehealth. Telehealth is a rapidly-growing field, entailing the use of electronic information and telecommunications technologies to enable health care providers and others dedicated to improving accessibility to support long-distance clinical health care, patient and professional health-related education, and public health and health administration requirements.

Request

Office for the Advancement of Telehealth (OAT) is the agency at the Department of Health and Human Services on the forefront of efforts to ensure minority communities, and rural and underserved Americans, such as those who are low-income and uninsured or enrolled in Medicare, can realize the benefits of telehealth technology. OAT can only operate to advance telehealth issues, improve patient safety, reduce medical errors, and increase patient access to primary and specialty care in both rural and urban settings if allocated adequate funding.

We respectfully request that the Committee support OAT and increase its funding for Fiscal Year (FY) 2009 to $13.8 million. This is the level supported by the Senate during consideration of the FY 2006 LHHS appropriations measure, although the amount was reduced during conference. Since FY 2006, there have been many groundbreaking advances in the field of telehealth. Additionally, during the consideration of the FY 08 LHHS bill, the full Senate approved an amendment appropriating $13.8 million to OAT, although the final amount was later dramatically reduced following conferencing with the House of Representatives.

These additional funds may be used for a variety ways to improve access to care in this country. OAT may expand existing and new telehealth resources centers, including at least one center to focus on telehomecare. Many Americans are unable to leave their homes to receive vital health services. Expanding resources to care for homebound patients will improve quality of life, as well as better equip said health care providers with the resources and knowledge to best care for these individuals. Additional funds will also allow OAT to provide grants to carry out programs under which health licensing boards or various states cooperate to develop and implement policies to reduce statutory and regulatory barriers to telehealth.

We firmly believe that supporting telehealth technology is cost-effective and will actually save money in the long run. Funding telehealth initiatives will help provide desperately needed services to underserved and rural communities. Lastly, supporting telehealth will ensure overall improvements in access to quality health care services nationwide.

Background

There are many benefits to the use of and increasing accessibility to telehealth. Telemedicine breaks down physical barriers that keep many from receiving adequate

health care, due to distance or inability to travel to access care and instantly connects health care providers through technology, to share medical expertise. Telehealth is a rapidly growing field and TLI is at the forefront of increasing accessibility to new developments and innovation. Technologies utilized by telehealth include, but are not limited to, videoconferencing, the internet, store-and-forward imaging, streaming media and wireless communications. While new means of connecting for the utilization of telehealth, there are considerable barriers remaining that keep these technologies from becoming an integral part of daily health care practice.

Contact

If you have any questions about this request, please contact Jayna Bonfini at 202.230.5158 or jayna.bonfini@dbr.com.

Thank you for your consideration.

Testimony of Robert Waters, JD, Executive Director

Home Care Technology Association of America

House Committee on Appropriations

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

Fiscal Year 2009

HCTAA
228 7th Street, SE, Washington, DC 20003
202-230-5152 | 202-230-5300 Fax

Testimony of Robert Waters, JD
Home Care Technology Association of America

On behalf of the Home Care Technology Association of America (HCTAA), I appreciate the opportunity to submit testimony for the public record. HCTAA is an organization dedicated to increasing the use of technology and telehealth home health care.

Request

Office for the Advancement of Telehealth (OAT) is the agency at the Department of Health and Human Services on the forefront of efforts to ensure minority communities, and rural and underserved Americans, such as those who are low-income and uninsured or enrolled in Medicare, can realize the benefits of telehealth technology. OAT can only operate to advance telehealth home care issues, improve patient safety, reduce medical errors, and increase patient access to primary and specialty care in both rural and urban settings if allocated adequate funding.

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Testimony of Robert Waters, JD
Home Care Technology Association of America

Background

There are many benefits to utilizing and increasing accessibility to home health care through telehealth. Telemedicine breaks down physical barriers that keep many from receiving adequate health care, due to distance or inability to travel to access care and instantly connects health care providers through technology, to share medical expertise. HCTAA's goal is to increase the use of this technology and telehealth in home health care to aid underserved and homebound patient populations nationwide.

In conjunction with the aging of America and increased awareness, home care technology is a rapidly growing field, of which HCTAA is at the forefront. The US is already feeling the strain of 77 million retiring baby boomers and their impact on the nation's health care system, requiring both short- and long-term health care solutions. To adequately accommodate this growth, reliance on access to efficient and affordable home care services is vital. Technologies utilized by telehealth include, but are not limited to, videoconferencing, the internet, store-and-forward imaging, streaming media and wireless communications. While new means of connecting for the utilization of telehealth, there are considerable barriers remaining that keep these technologies from becoming an integral part of daily home health care practices.

Contact

If you have any questions about this request, please contact me at Robert.waters@dbr.com or 202.230.5152 or Jayna Bonfini at 202.230.5158 or jayna.bonfini@dbr.com.

Thank you for your consideration.

Testimony on behalf of the
Friends of NICHD Coalition

Regarding the Fiscal Year 2009 Appropriation for the

Eunice Kennedy Shriver National Institute of Child Health and Human Development

before the
United States House of Representatives
Committee on Appropriations
Subcommittee on Labor, Health and Human Services and Education
The Honorable David Obey, Chair

March 31, 2008

Submitted by

Karen Studwell, Chair
Emil Wigode, Co-Chair
Friends of NICHD Coalition

Mr. Chairman and Members of the Subcommittee:

The Friends of the National Institute of Child Health and Human Development (NICHD) is a coalition of more than 100 organizations, representing scientists, physicians, health care providers, patients, and parents concerned with the health and welfare of women, children, families, and people with disabilities. We are pleased to submit testimony to support the extraordinary work of the NICHD. Pursuant to clause 2(g)4 of House Rule XI, the Coalition does not receive any federal funds.

The Coalition would like to thank Chairman Obey, Ranking Member Walsh, and the entire Subcommittee for its previous support of the federal investment in the National Institutes of Health (NIH). In recent years, however, NIH has been unable to keep pace with the biomedical rate of inflation, and its purchasing power has decreased by more than 13 percent since FY 2003. **To ensure that progress in basic, translational and clinical research is sustained, the Coalition joins the Ad Hoc Group for Medical Research in supporting an FY 2009 appropriation of $31.1 billion, an increase of approximately 6.6 percent.**

The Coalition also has particular interest in the important research conducted and supported by the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD). Since its establishment in 1963, the NICHD has made great strides in meeting the objectives of its broad biomedical and behavioral research mission. The NICHD research mission and portfolio includes a focus on women's health and human development, including

research on child development, before and after birth; maternal, child, and family health; reproductive biology and population issues; and medical rehabilitation.

Although the NICHD has made significant contributions to the well-being of our children, women, and families, much remains to be done. The Institute is already funding grant awards at dramatically reduced levels in the current fiscal year, and under the proposed budget, this situation will continue to worsen in FY 2009. With sufficient resources, the NICHD could build upon the promising initiatives described in this testimony and restore adequate funding to its research projects. **For FY 2009, the Friends of NICHD support an appropriation of $1.34 billion for NICHD, a 6.6 percent increase over FY 2008.**

New Discoveries

In the past year alone, NICHD has made great strides in pursuit of its research mission and has added impressive achievements to its incredible record of progress over the past 40 years. We are proud to be able to share with you some of the recent advances through which NICHD has contributed to the health and well-being of our nation and our world.

Tracking Brain and Behavioral Development: The NICHD is a one of the leading institutes in the NIH Magnetic Resonance Imaging (MRI) Study of Normal Brain Development, which seeks to track brain and behavioral development in 500 healthy children from diverse geographic, socioeconomic and ethnic backgrounds from birth to age 18. According the latest findings, children appear to have reached adult levels of performance on basic cognitive and motor skills by age 11 or 12. The long-term goal of the study team is to link these behavioral data to MRI scans of the children's brains. Together, the two data sets will allow researchers to view how the brain grows and reorganizes itself throughout childhood, and to explore the meaning of the structural changes they see. The database will also serve as a reference post for scientists to better understand what goes wrong in children with genetic disorders, prenatal exposure to alcohol or drugs or other brain injury.

New Pediatric Seizure Study: Last year, the NICHD announced plans for a new study into the safest and most effective treatment for pediatric seizures, or status epilepticus, which affects between 50,000 to 60,000 children in the United States each year. Status epilepticus may occur in patients with epilepsy or in patients without epilepsy who experience a seizure due to a high fever, low blood sugar, an infection of the central nervous system, or a head injury. Children who have no apparent risk factors may also develop status epilepticus. Currently, there are two drugs in use, diazepam and lorazepan, but there is no large-scale comparison study to show which one is preferable under which conditions. The study is the most comprehensive of its kind and 11 hospitals around the country will participate. The NICHD is funding the study in accordance with the **Best Pharmaceuticals for Children Act (BPCA),** under which NIH consults with the U.S. Food and Drug Administration to determine which approved drugs should be prioritized for further testing in children.

Unraveling Genetic Basis of Autism: NICHD is capitalizing on advances in genetics research by participating in the Autism Genome Project (AGP), a public-private collaboration involving more than 120 scientists and 50 institutions in 19 countries. The first study to emerge from AGP has implicated components of the brain's glutamate chemical messenger system and a previously overlooked site on chromosome 11. Based on 1,168 families with at least two affected members, the genome scan also adds to evidence that tiny, rare variations in genes may heighten risk for autism spectrum disorders. The spectrum of disorders collectively known as autism affects as

many as one in 150 Americans resulting in impaired thinking processes, emotional and social abilities, and motor control. With NIH support, the AGP is pursuing studies to identify specific genes and gene variants that contribute to vulnerability to autism. These include explorations of interactions of genes with other genes and with environmental factors, and laboratory research aimed at understanding how candidate susceptibility genes might work in the brain to produce the disorders.

Vaccine Shows Promise in Reducing Stillbirth: An estimated 40,000 children are born each year in the United States with the cytomegalovirus (CMV), a common virus that most Americans are exposed to at some point in their lives, but is linked to stillbirth and can also cause mental retardation, cerebral palsy and hearing loss in newborn children. NICHD researchers are working to develop a vaccine for women of childbearing age to reduce the risks of CMV in pregnancy. Scientists found in their prototype research that vaccinated guinea pigs had significantly less amounts of the virus in their blood than the control group and their offspring were more likely to survive as well as have higher birth weights. This basic animal research is the first step towards developing a vaccine for use in human populations.

Impact of Child Care: The NICHD Study of Early Child Care and Youth Development, the largest, longest running, and most comprehensive study of child care in the United States, continues to provide information about the long term impacts of child care on child development. The most recent analysis found that children who received higher quality child care before entering kindergarten had better vocabulary scores, and indication of language development, in the fifth grade than did children who received lower quality care. The researchers evaluated the children's academic achievement and cognitive functioning from kindergarten through fifth grade and social development through sixth grade as well as parenting quality and the quality of classroom instruction. Children who had been in center care in early childhood were more likely to score higher on teacher reports of aggression and disobedience, though the children's behavior was within the normal range of behavior.

Future Research Opportunities

Although this record of accomplishment has made significant contributions to the well-being of our children and families, much remains to be done. Progress in the following research areas can only be achieved with adequate federal investments.

Intellectual and Developmental Disabilities: The Mental Retardation and Developmental Disabilities Research Centers recently renamed Eunice Kennedy Shriver Intellectual and Developmental Disabilities Research Centers (IDDRC) are a national resource established by Congress in 1963 to serve as "centers of excellence" for research in mental retardation and developmental disabilities. They are the world's largest concentration of scientific expertise in the fields of intellectual and developmental disabilities. Many disorders are being studied by the IDDRC such as Down syndrome, Fragile X syndrome, Rett syndrome, and autism. Genetic and biomedical advances over the past few years hold the promise for understanding the threats to healthy and full development and ultimately to the prevention and amelioration of the impact of many disabilities. The pioneering work of this network of Centers is improving the lives of countless individuals and families.

Preterm Birth: Preterm birth is a serious and growing public health problem that affects over 500,000 babies each year. It is the leading cause of neonatal death and half of all premature

births have no known cause. The NICHD will be conducting a Surgeon General's Conference on Preterm Birth in June. This conference will produce a public-private agenda to find the answers to preventing preterm birth. It is imperative that NICHD has the funding to expand and coordinate research on the causes of preterm birth based on the public-private agenda that is produced at the Surgeon General's Conference.

SIDS: Though NICHD has made remarkable progress in reducing the rate of SIDS, it remains the leading cause of death in infants from one month of age to one year. More research and public education is needed to address the large number of babies dying of asphyxiation and suffocation in unsafe adult bed sharing situations. Additional support is also needed to expand the work of NICHD's Stillbirth Collaborative Research Network, where for the first time we are finding answers that may ultimately lead to prevention of many of these 26,000 devastating losses, many of which are late term and yet unexplained.

Contraceptive Research: Of the approximately 6 million pregnancies in the U.S. each year, an estimated one half are unintended. The NICHD conducts contraceptive research and development to provide safe and effective methods of preventing unintended pregnancies and helping women time and space the birth of their children.

Rehabilitation Research: The NICHD houses the National Center for Medical Rehabilitation Research (NCMRR). This Center fosters the development of scientific knowledge needed to enhance the health, productivity, independence, and quality-of-life of people with disabilities. A primary goal of Center-supported research is to bring the health related problems of people with disabilities to the attention of the best scientists in order to capitalize upon the myriad advances occurring in the biological, behavioral, and engineering sciences.

HIV/AIDS: NICHD research is focused on testing and refining effective interventions to slow HIV progression in women, treat infected infants, and reduce mother-to-child transmission. NICHD collaborative research efforts on interventions, such as drug therapy, have reduced maternal transmission of HIV from 25 percent to 1.2 percent worldwide. Until vaccines and cures for HIV are a reality, prevention of infection must rely upon individuals practicing protective behavior. NICHD research is needed to examine the psychological and social factors that influence an individual's decision-making and behaviors that reduce the risk of HIV infection or transmission, such as using condoms, avoiding sexual intercourse with infected individuals, and avoiding drug use that may lead to unsafe sexual practices or needle sharing.

Obesity: NICHD is integrally involved in research into the origins of obesity in childhood. Next to tobacco use, diet and exercise represent the areas in which prevention efforts will have the greatest impact in reducing the socioeconomic and societal burdens of disease through halting the obesity epidemic. More developmental research needs to be focused on understanding the interplay among behavioral, social and physical environment, and biological factors that lead to obesity so that effective and appropriate interventions can be developed earlier in the life cycle.

Hydrocephalus: More research needs to be done into the many complex issues surrounding hydrocephalus for the 200,000 children under 18 now living with this condition, ranging from obvious medical concerns due to repeated brain surgeries, to less well understood challenges involving learning disabilities of children with hydrocephalus, motor and sensory impairment,

and socialization challenges. NICHD has a significant role to play in working with other Institutes regarding the unique issues of hydrocephalus in children.

National Children's Study: The Children's Health Act of 2000 charged NICHD with leading the National Children's Study (NCS) - a national longitudinal study of environmental influences on the health and development of children and adolescents. This study will follow 100,000 children from before birth to early adulthood, providing one of the richest information resources available for answering questions related to children's health and development. The Friends of NICHD thanks the Committee for funding the NCS through the NIH Office of the Director in FY 2008, and urges the Committee to provide $192.3 million in new money for the Study in FY 2009.

Education and School Readiness Research: NICHD continues to build on its impressive portfolio of research on how children acquire the emotional, social and academics skills necessary to succeed in school and beyond. Having developed a substantial foundation of basic reading research, interventions are still needed for children with learning difficulties in reading and math, as children who do not overcome reading impairments carry these deficits into adulthood and the workforce. In recognition of the diverse student population in our nation's schools, NICHD research also includes a focus on children for whom English is a second language. More recent programs of math and science cognition as well as math learning disabilities will inform the nation's innovation agenda and ensure a competitive workforce. NICHD is also currently funding new initiatives to develop better measures of the social and emotional bases of school readiness, which will inform our early education programs.

Family Research: As the family is the primary context for child development, the NICHD has a played a significant role in examining the dramatic changes in family structure in the United States over the last 40 years. Scientists are currently focused on developing new study designs to better understand the family processes that transcend the traditional home environment, including the role of absent fathers, the contributions of grandparents and others outside the immediate family. Recognizing that so many parents are also in the workforce, NICHD is moving forward on its Work, Family, Health and Well-Being Initiative. The long-range goals of the initiative are to identify workplace interventions that can improve health by improving the ability of the worker to successfully meet both work and family demands.

Conclusion

The potential contributions of the Institute to the lives of countless individuals are limited only by the resources available for carrying out its vital mission. **This is why the Friends of NICHD ask you to provide an appropriation of $1.34 billion to the Institute.** Our nation and the world will continue to benefit from your promise to improving health and scientific advancement long after the doubling effort is over.

We thank you, Mr. Chairman, and the Committee, for your support of the Eunice Kennedy Shriver National Institute of Child Health and Human Development, and thank you for the opportunity to share these comments.

Testimony of the Health Professions and Nursing Education Coalition (HPNEC) Concerning Title VII & VIII Health Professions Programs

Submitted for the Record to the House Appropriations Subcommittee on Labor, Health and Human Services, and Education - March 31, 2008

The members of the Health Professions and Nursing Education Coalition (HPNEC) are pleased to submit this statement for the record in support of the health professions education programs authorized under Titles VII and VIII of the Public Health Service Act and administered by the Health Resources and Services Administration (HRSA).

HPNEC is an informal alliance of more than 60 national organizations representing a variety of schools, programs, health professionals, and others dedicated to ensuring that Title VII and VIII programs continue to help educate the nation's health care and public health personnel. HPNEC members are thankful for the support the Subcommittee has provided to the programs, which are essential to building a well-educated, diverse health care workforce.

The Title VII and VIII health professions and nursing programs are essential components of the nation's health care safety net, bringing health care services to our underserved communities. These programs support the training and education of health care providers with the aim of enhancing the supply, diversity, and distribution of the workforce, filling the gaps in the health professions' supply not met by traditional market forces. The Title VII and VIII health professions programs are the only federal programs designed to train providers in interdisciplinary settings to meet the needs of special and underserved populations, as well as increase minority representation in the health care workforce.

Since fiscal year (FY) 2006, the Title VII programs have struggled to recover from a 51.5 percent funding cut. Despite increases in FYs 2007 and 2008 for some programs, funding levels for all Title VII programs remain below the FY 2005 levels. Moreover, the President's FY 2009 budget proposes to eliminate funding for all Title VII programs and to cut Title VIII programs by $46 million (29.6 percent).

HPNEC members recommend that the Title VII and VIII health professions programs receive an appropriation of at least $550 million for FY 2009. This recommendation would ensure the programs have sufficient funds to continue fulfilling their mission of educating and training a health care workforce that meets the public's health care needs.

During their 40-year existence, the Title VII and VIII programs have created a network of initiatives across the country that supports the training of many disciplines of health providers. Together, the programs work in concert with other programs at the Department of Health and Human Services – including the National Health Service Corps and Community Health Centers (CHCs) – to strengthen the health safety net for rural and medically underserved communities.

According to annual performance measures developed by HRSA, in 2007, the Title VII & VIII programs exceeded expectations – by as much as 17 percent – in three key areas: the percentage of graduates and program completers that are underrepresented minorities and/or from disadvantaged backgrounds; the proportion of participants training in medically underserved communities; and the percentage of health professionals entering practice in underserved areas.[1]

[1] HRSA FY 2009 Justification of Estimates for Appropriations Committees

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HPNEC members urge the Subcommittee to consider the vital need for these health professions education programs as demonstrated by the passage of the Health Professions Education Partnerships Act of 1998 (P.L. 105-392), which reauthorized the programs. The reauthorization consolidated the programs into seven general categories:

- The purpose of the **Minority and Disadvantaged Health Professionals Training** programs is to improve health care access in underserved areas and the representation of minority and disadvantaged health care providers in the health professions. *Minority Centers of Excellence* support programs that seek to increase the number of minority health professionals through increased research on minority health issues, establishment of an educational pipeline, and the provision of clinical opportunities in community-based health facilities. The *Health Careers Opportunity Program* seeks to improve the development of a competitive applicant pool through partnerships with local educational and community organizations. The *Faculty Loan Repayment and Faculty Fellowship* programs provide incentives for schools to recruit underrepresented minority faculty. The *Scholarships for Disadvantaged Students (SDS)* make funds available to eligible students from disadvantaged backgrounds who are enrolled as full-time health professions students. Nurses received $15.1 million in FY 2007 from SDS grants, 32 percent of funds appropriated for SDS.

- The **Primary Care Training** category, including *General Pediatrics, General Internal Medicine, Family Medicine, General Dentistry, Pediatric Dentistry,* and *Physician Assistants*, provides for the education and training of primary care physicians, dentists, and physician assistants to improve access and quality of health care in underserved areas. Two-thirds of all Americans interact with a primary care provider every year. Approximately one half of primary care providers trained through these programs go on to work in underserved areas, compared to 10 percent of those not trained through these programs. The *General Pediatrics, General Internal Medicine,* and *Family Medicine* programs provide critical funding for primary care training in community-based settings and have been successful in directing more primary care physicians to work in underserved areas. They support a range of initiatives, including medical student training, residency training, faculty development and the development of academic administrative units. The *General Dentistry* and *Pediatric Dentistry* programs provide grants to dental schools and hospitals to create or expand primary care dental residency training programs. 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. Additionally, these programs 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.

- 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. *Health Education and Training Centers (HETCs)* were created to improve the supply of health professionals along the U.S.-Mexico border. They incorporate a strong emphasis on wellness through public health education activities for disadvantaged populations. *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 the elderly. The *Quentin N. Burdick Program for Rural Health Interdisciplinary Training* places an emphasis on long-term collaboration between academic institutions, rural health care agencies and providers to improve the recruitment and retention of health professionals in rural areas. The *Allied Health Project Grants* program represents the only federal effort aimed at supporting new and innovative education programs designed to reduce shortages of allied health professionals and create opportunities in medically underserved and minority areas. Health professions schools use this funding to help establish or expand allied health training programs. The need to address the critical shortage of certain allied health professionals has been acknowledged repeatedly. For example, this shortage has received special attention given past bioterrorism events and efforts to prepare for possible future attacks. The *Graduate Psychology Education Program* provides grants to doctoral, internship and postdoctoral programs in support of interdisciplinary training of psychology students with other health professionals for the provision of mental and behavioral health services to underserved populations (i.e., older adults, children, chronically ill, and victims of abuse and trauma, including returning military personnel and their families), especially in rural and urban communities.

- The **Health Professions Workforce 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 (NSSRN), the nation's most extensive and comprehensive source of statistics on registered nurses.

- The **Public Health Workforce Development** programs are designed to increase the number of individuals trained in public health, to identify the causes of health problems, and respond to such issues as managed care, new disease strains, food supply, and bioterrorism. The *Public Health Traineeships and Public Health Training Centers* seek to alleviate the critical shortage of public health professionals by providing up-to-date training for current and future public health workers, particularly in underserved areas. *Preventive Medicine Residencies*, which receive minimal funding through Medicare GME, provide training in the only medical specialty that teaches both clinical and population medicine to improve community health.

Dental Public Health Residency programs are vital to the nation's dental public health infrastructure. The *Health Administration Traineeships and Special Projects* grants are the only federal funding provided to train the managers of our health care system, with a special emphasis on those who serve in underserved areas.

- The **Nursing Workforce Development** programs under Title VIII provide training for entry-level and advanced degree nurses to improve the access to, and quality of, health care in underserved areas. 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 between 42,000 and 88,000 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 is expected to increase significantly over the next 20 years, with the demand for licensed, registered nurses projected to grow by over 29 percent within the next eight years alone. Congress responded to this dire national need by passing the *Nurse Reinvestment Act* (P.L. 107-205) in 2002, which increases nursing education, retention, and recruitment. The *Advanced Education Nursing* program, which the Administration's FY 2009 budget proposal seeks to eliminate, 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. Terminating this capacity-building program is inconsistent with the health care reality facing our nation. *Workforce Diversity* grants support opportunities for nursing education for disadvantaged students 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. Due to a lack of funding in FY 2007, 46 percent of the applicants were turned away from the loan repayment aspect of the program. These are nurses who could immediately begin practicing in a health care facility with a critical shortage of nurses. 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. In FY 2007, no new grants were awarded. The *Nurse Faculty Loan* program provides a student loan fund administered by schools of nursing to increase the number of qualified nurse faculty. In FY 2007, this program supported 729 future nurse faculty.

- The loan programs in the **Student Financial Assistance** support 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* (LDS) program provides grants to health professions institutions to make loans to health professions students from disadvantaged backgrounds.

These programs work collectively to fulfill their unique, three-pronged mission:

Title VII & VIII programs enhance the supply of the health professions workforce.

- A network of 50 Geriatric Education Centers has trained over 500,000 health practitioners in 35 health-related disciplines to better serve the burgeoning elderly population.
- As the largest source of federal funding for nursing education, the Nursing Workforce Development programs provided loan, scholarship, and programmatic support to 71,729 student nurses and nurses in FY 2007.

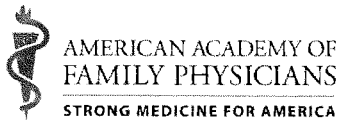
Title VII & VIII programs improve the distribution of health care providers.

- A study published in the Winter 2006 issue of the *Journal of Rural Health* reports that up to 83 percent of family medicine residents and 80 percent of nurse practitioners who went through a program with Title VII or VIII funding chose to practice in areas with health professions shortages or medically underserved practice locations.
- A study from the University of California, San Francisco shows that medical schools that receive primary care training dollars produce more physicians who work in CHCs and serve in the National Health Service Corps compared to schools without Title VII primary care funding.
- In FY 2007, the Advanced Education Nursing programs supported 16,092 nurses who will practice in underserved areas.

Title VII & VIII programs increase the representation of minority and disadvantaged students in the health professions.

- A study published in the September 2006 issue of the *Journal of the American Medical Association* finds that post-baccalaureate programs, which rely on Title VII among other sources of funding, are highly effective in increasing minority representation in medical school. The study concludes that enacted reductions in funding for Title VII may have negative consequences for these effective programs.
- A review of physician assistant graduates from 1990-2006 reveals that graduates of Title VII supported programs were 59 percent more likely to be from underrepresented minority backgrounds than graduates of non-Title VII supported programs.
- A survey of HCOP and COE program directors finds that the programs have served over 400,000 minority and disadvantaged aspiring health professionals.

HPNEC members respectfully urge support for funding of at least **$550 million** for the Title VII and VIII programs, an investment essential not only to the development and training of tomorrow's health care professionals but also to our nation's efforts to provide needed health care services to underserved and minority communities. We greatly appreciate the support of the Subcommittee and look forward to working with members of Congress to achieve these goals in FY 2009 and into the future.



Jim King, M.D., President
American Academy of Family Physicians
Public Witness Testimony for the House Appropriations
Labor/HHS/Education Subcommittee – March 31, 2008

As one of the largest national medical organizations, the American Academy of Family Physicians (AAFP), representing family physicians, residents, and medical students, urges the House Appropriations Subcommittee on Labor, Health and Human Services, and Education to increase funding for programs to support better health care for more people in this country. As the Subcommittee prepares the fiscal year 2009 spending bill, we strongly recommend that you restore funding for health professions training programs; continue support for rural health programs and increase our investment in the Agency for Healthcare Research and Quality.

HEALTH RESOURCES AND SERVICES ADMINISTRATION
The Health Resources and Services Administration (HRSA) is charged with improving access to health care services for people who are uninsured, isolated or medically vulnerable. One of the most critical aspects of this mission is ensuring a health care workforce which is sufficient to meet the needs of patients and communities

HRSA—HEALTH PROFESSIONS
For 40 years, the training programs authorized by Title VII of the *Public Health Services Act* evolved to meet our nation's health care workforce needs. It is increasingly clear that our nation has a worsening shortage of primary care physicians. Earlier this year, in testimony before the Senate HELP Committee, the General Accountability Office cited the "growing recognition that greater use of primary care services and less reliance on specialty services can lead to better health outcomes at lower cost."[1]

To improve how health care is delivered, we must modernize workforce and education policies to ensure an adequate number of primary care physicians trained to serve in a patient centered medical home. The patient centered medical home will give patients access to preventive care and coordination of the care needed to manage chronic diseases as well as appropriate care for acute illness. The patient centered medical home provides improved efficiency and better health because it serves as a principal source of access and care. As a result, duplication of tests and procedures and unnecessary emergency department visits and hospitalizations can be avoided

Section 747 of Title VII, the Primary Care Medicine and Dentistry Cluster, is aimed at increasing the number of primary care physicians (family physicians, general internists and pediatricians). Section 747 offers competitive grants for family medicine training programs in medical schools and in residency programs. Section 747 is vital to stimulate medical education, residency programs, as well as academic and faculty

[1] Steinwald, A. *Primary Care Professionals: Recent Supply Trends Projections, and Valuation of Services.* Testimony Before the Committee on Health Education, Labor, and Pensions, U.S. Senate, General Accountability Office GAO-08-472T February 2008.

development in primary care to prepare physicians to support the patient centered medical home medical practice model.

The value of Title VII grants extends far beyond the medical schools that receive them. The United States lags behind other countries in its focus on primary care. However, the evidence shows that countries with primary care-based health systems have population health outcomes that are better than those of the U.S. at lower costs.[2] Health Professions Grants are one important tool to help refocus the nation's health system on primary care.

The Health Professions programs have been targeted for elimination in the President's budget despite of the fact that they exceeded program goals in the following categories:

- In 2007, 57 percent of graduates and program completers of Titles VII and VIII supported programs were underrepresented minorities and/or from disadvantaged backgrounds. This exceeded the target by 17 percent.

- The proportion of trainees in Titles VII and VIII supported programs training in medically underserved communities was 43 percent in 2007 which exceeded the target of 41 percent.

- The percentage of health professionals supported by the program entering practice in underserved areas was 35 percent in 2007. This exceeded the target by 14 percent.[3]

The across-the-board cut reduced FY 2008 Section 747 funding below the House-passed level to under $48 million or $853,000 less than the FY 2007 level of $48.9 million. It falls far short of the $92 million provided for Primary Care Medicine and Dentistry Training in FY 2003. The nation needs significant additional support from Section 747 because it is the only national federally-funded program that provides resources for important innovations necessary to increase the number of physicians who will lead the primary care teams providing care in patient centered medical homes.

> **AAFP recommends an increase in the fiscal year 2008 appropriation bill for the Health Professions Training Programs authorized under Title VII of the Public Health Services Act. We respectfully suggest that the Committee provide at least $300 million for Title VII, including $92 million for the Section 747, the Primary Care Medicine and Dentistry Cluster, which will restore this vital program to its fiscal year 2003 level.**

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[2] Starfield B, et al. The effects of specialist supply on populations' health: assessing the evidence. *Health Affairs*. 15 March 2005.

[3] Department of Health and Human Services. Fiscal Year 2009 Health Resources and Services Administration Justification of Estimates for Appropriations Committee.

HRSA—NATIONAL HEALTH SERVICE CORPS
The National Health Service Corps (NHSC) offers scholarship and loan repayment awards to primary care physicians, nurse practitioners, dentists, mental and behavioral health professionals, physician assistants, certified nurse-midwives, and dental hygienists serving in underserved communities. The President has proposed a 2.4 percent decrease in NHSC to $121 million for FY09. The President's budget also proposes to decrease the NHSC field allocation, which provides funding for recruitment and retention administrative functions, by $14 million (35 percent) to $26 million. The AAFP supports the work of the NHSC toward the goal of full funding for the training of the health workforce and zero disparities in health care.

> **AAFP opposes the proposed cut in NHSC funding and respectfully requests that the Committee provide $150 million for NHSC in FY09.**

HRSA—RURAL HEALTH
Americans in rural areas face more barriers to care than those in urban and suburban areas. Rural residents also struggle with the higher rates of illness associated with lower socioeconomic status.

Family physicians provide the majority of care for America's underserved and rural populations.[4] Despite efforts to meet scarcities in rural areas, the shortage of primary care physicians continues. Studies, whether they be based on the demand to hire physicians by hospitals and physician groups or based on the number of individuals per physician in a rural area, all indicate a need for additional physicians in rural areas.

HRSA's Office of Rural Health administers a number of programs to improve health care services to the quarter of our population residing in rural communities. Rural Health Policy Development and Outreach Grants fund innovative programs to provide health care in rural areas. State rural health offices, funded through the National Health Services Corps budget, help states implement these programs so that rural residents benefit as much as urban patients. The President's budget proposes to cut the Rural Health Programs by 86 percent.

> **AAFP encourages the Subcommittee to oppose the President's request to terminate these important programs and provide for their continued funding the fiscal year 2009 appropriation bill. We respectfully suggest that the Committee provide at least $175 million for HRSA Rural Health.**

AGENCY FOR HEALTHCARE 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 AAFP's own mission. AHRQ is a small agency with a huge responsibility for

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[4] Hing E, Burt CW. Characteristics of office-based physicians and their practices: United States, 2003–04. Series 13, No. 164. Hyattsville, MD: National Center for Health Statistics. 2007.

research to support clinical decision-making, reduce costs, advance patient safety, decrease medical errors and improve health care quality and access.

AHRQ—COMPARATIVE EFFECTIVENSS RESEARCH

One of the hallmarks of the patient centered medical home is evidence-based medicine. Comparative effectiveness research, which compares the impact of different options for treating a given medical condition, is vital to quality care. Studies comparing various treatments (e.g. competing drugs) or differing approaches (e.g. surgery and drug therapy) can inform clinical decisions by analyzing not only costs but the relative medical benefits and risks for particular patient populations.

Comparative effectiveness research holds out the promise of reducing health care costs while improving medical outcomes. AHRQ's Effective Health Care Program is critical if we are to realize that promise. Although the President's budget request proposed to hold this important program at $30 million, the same as FY 2008, we hope that the Congress will increase our investment in comparative effectiveness research.

AHRQ—HEALTH INFORMATION TECHNOLOGY

AHRQ plays a key role in the adoption of the health information technology (HIT) which is a vital component of the patient centered medical home. HIT is important to improving patient safety by reducing medical errors and avoiding costly duplication of services. It also is a vital to managing a patient's care when numerous providers are required. AAFP recognizes that HIT, used effectively, has the potential to help physicians make continuing improvements in the quality of care. However, simply implementing current HIT tools will not bring about these results. HIT adoption must go hand in hand with the implementation of the patient centered medical home model.

It also is vital that AHRQ have the necessary resources to promote standards for portability and interoperability which ensure that health data is appropriately available and privacy protected. AAFP has called for HIT implementation which recognizes that over 80 percent of health care is delivered in doctors' offices.

Adoption of good information systems can lay the groundwork for decision support and high quality health care. However, the communities which would benefit the most from HIT face barriers to adoption. Physicians treating vulnerable populations should be our highest priority. Any payments to physicians to purchase HIT systems should go to those serving in underserved areas in small or medium-sized practices where the capital to purchase EHRs is hardest to secure. These payments should not go through third-parties such as hospitals, integrated health systems, or health plans, but directly to clinics and practices based on financial need.

> **AAFP recommends an increase in the fiscal year 2009 appropriation bill for the Agency for Healthcare Research and Quality (AHRQ). We respectfully suggest that the Committee provide at least $360 million for AHRQ, an increase of $26 million above the FY08 level.**

Testimony Submitted by the National Child Abuse Coalition, Washington, D.C., to the Subcommittee on Labor, HHS and Education Appropriations, U.S. House of Representatives, regarding the Department of Health and Human Services, Administration for Children and Families; March 31, 2008

The National Child Abuse Coalition, committed to strengthening the federal response to the protection of children and the prevention child abuse and neglect, urges FY08 funding for the Child Abuse Prevention and Treatment Act (CAPTA) programs at the authorized levels:

- **CAPTA basic state grants at $84 million;**
- **CAPTA community-based prevention grants at $80 million; and**
- **CAPTA research and demonstration grants at $37 million.**

1. Basic State Grants: At current funding, child protection agencies are unable to serve close to half the abused and neglected children in their caseloads.

CAPTA funding helps states improve the child protective services infrastructure for screening, assessing, investigating and providing services in response to more than 3 million reports each year of possible abuse and neglect of 6 million children. Yet, states are hard pressed to treat children or protect them from further harm. In fact, one-quarter of the children abused and neglected in 2005 were previously victims of maltreatment. In 2005, close to 1,500 children died as a result of abuse or neglect. The most endangered are the youngest: over three-quarters of the children killed were under age 4.

Funding for CAPTA's Basic State Grants has not kept pace with what states and communities need to protect children. At the current funding level – slightly more than one-fourth the authorized amount -- child protection agencies are unable to serve hundreds of thousands of abused and neglected children in their caseloads. In 2005, according to the most recent HHS data, almost 40 percent of the child victims received no services following a substantiated report of maltreatment: suspected abuse was reported, the report was investigated, the report was substantiated, and the case was closed.[1] Federal officials have repeatedly cited states for certain deficiencies: significant numbers of children suffering abuse or neglect more than once in a six-month period; caseworkers who are not visiting children often enough to assess needs; and failure to provide promised medical and mental health services. **We as a nation can do better.**

In 2008, many states are reporting their largest budget shortfalls in almost a decade and about half the state legislatures are looking to cut a variety of services to avoid spending deficits. As housing foreclosures and other economic stresses increase pressures on families, we are concerned that over the coming months children will suffer as the funds for necessary services will go down. Funding CAPTA state grants at $84 million would enable state child protective services to expand post-investigative services for child victims, shorten the time to the delivery of services, and increase services to at-risk families.

2. Community-Based Prevention Grants: For every federal dollar spent on foster care and adoption subsidies, we spend less than 13 cents in federal child welfare funding on preventing and treating child abuse and neglect.

Annual direct costs of child abuse and neglect in the U.S. total over $24 billion in hospitalizations, chronic health and mental health care, child welfare services, law enforcement, and courts. Indirect costs from special education, other health and mental health care, crime, and lost productivity, total more than $94 billion annually.[2] Community services to prevent child abuse are far less costly than the damage inflicted on children from abuse and neglect. A GAO evaluation of child abuse prevention efforts found "total

[1] U.S. Department of Health and Human Services, Administration on Children, Youth and Families. *Child Maltreatment 2005*. Washington, D.C., U.S. Government Printing Office, 2007.
[2] Fromm, S. (2001). *Total Estimated Cost of Child Abuse and Neglect in the United States*. Prevent Child Abuse America.

federal costs of providing prevention programs for low-income populations were nearly offset after four years."[3]

CAPTA's Prevention Grants help states to develop community-based prevention services, including parenting education, home visiting services, and respite care. We spend billions of dollars every year on foster care to protect the children who have been the most seriously injured; we can do a much better job at protecting children before the damage is so bad that we have no other choice than to remove them from their homes. Funding CAPTA prevention grants at $80 million would help communities support proven, cost-effective approaches to preventing child abuse and neglect.

3. Discretionary Research and Demonstration Grants: Current funding levels short-change community efforts to develop innovative programs to serve children and families and to improve our knowledge about child maltreatment.

We urge Congress to continue funding the President's proposal for $10 million to support home visitation programs, with funds available to promote an array of research- and evidence-based home visitation models that enable communities to provide the most appropriate services suited to the families needing them.

The U.S. Advisory Board on Child Abuse and Neglect recommended as the highlight of its 1991 report, *Creating Caring Communities,* the establishment of universal voluntary home visitor services. The Centers for Disease Control (CDC) Task Force on Community Preventive Services in its 2003 report evaluating the effectiveness of strategies for preventing child maltreatment "recommends early childhood home visitation for prevention of child abuse and neglect in families at risk for maltreatment, including disadvantaged populations and families with low-birth weight infants."[4]

Research evidence supports the value of a range of early childhood home visitation models using professionals, nurses, paraprofessionals, and trained volunteers from the community in improving parenting and family health and preventing child maltreatment.

For example, results from the randomized trial of the Healthy Families New York program based on the Healthy Families America model using Family Support Workers (specially trained paraprofessionals who live in the target community and share the same language and cultural background as program participants) showed that the program had positive effects in the areas of parenting and child abuse and neglect, birth outcomes, and health care. According to the research team analyzing the Healthy Families program in New York, the results for the subgroup of participants who resemble the clients typically served by the Nurse Family Partnership (NFP) model of home visiting by nurses are similar to those found in randomized trials of NFP.[5]

In another randomized trial, adolescent mothers who received case management services and Parents as Teachers (PAT) home visitors were significantly less likely to be subjected to child abuse investigations than control group mothers who received neither case management nor PAT home visitation.[6] Randomized trials of the Parent-Child Home Program, a home visitation early literacy and parenting program model, show significant ongoing positive effects on parents' interaction with their children, in contrast to control group families examined before and after completion of the program.[7]

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[3] U.S. General Accounting Office (1992). *Child Abuse: Prevention Programs Need Greater Emphasis* (GAO/HRD-92-99).

[4] Hahn, R.A., Bilukha, O.O., Crosby, A., Fullilove, M.T., Liberman, A., Moscicki, E.K., et al. (2003). *First reports evaluating the effectiveness of strategies for preventing violence: Early childhood home visitation.* Center for Disease Control, Morbidity and Mortality Weekly Report, 52, 109.

[5] DuMont, K., et al. (2006). *Healthy Families New York Randomized Trial: Impacts on Parenting After the First Two Years.* New York State Office of Children and Families. Working Paper Series.

[6] Wagner, M.M. & Clayton, S.L. (1999). The Parents as Teachers Program: Results from Two Demonstrations. *The Future of Children: Home Visiting: Recent Program Evaluations, 9*(1), 91-115.

[7] Joint Dissemination Review Panel of U.S. Department of Education. (1978). *Unanimous Approval of Research Findings, 1967-1978, Mother-Child Home Program of Verbal Interaction Project.* Freeport, NY: Verbal Interaction Project.

Funding research and program innovations at $37 million, as the President requests, would provide support for a diversity of home visitation models, as well as the field-initiated research, training, technical assistance, and data collection also authorized by CAPTA out of this money.

Child Welfare Spending: A Failure to Invest

Our failure to invest in our child protective service system and community-based programs for preventing child maltreatment has created a spending gap of almost $17 billion in services to intervene on behalf of children. Current available data peg federal, state and local dollars for child protective services and preventive services at only about $3.1 billion of the estimated $20.2 billion total cost of what we ought to be spending.

According to the Urban Institute, states reported spending $22 billion on child welfare in 2002, and they could categorize how $17.4 billion of the funds were used.[8] Of that amount, $10 billion was spent for out-of-home placements, $1.7 billion on administration, $2.6 billion on adoption, and **$3.1 billion (about 18 percent) on all other services, including prevention, family preservation and support services, and child protective services**.

Failure to invest in a working child protection system results in a national failure to keep children free from harm. The cost to child protective services in 2002 of investigating the 1.745 million children who were screened in for investigations, plus the expense that would have been incurred if services had been provided to all of the 896,000 substantiated child victims (as well as to the 708,000 children in unsubstantiated reports who also received some services), totals $7.2 billion. Second, consider the cost of preventive services -- $13 billion if offered to the three million child maltreatment victims identified in the HHS National Incidence Study III. That's a total cost of $18.4 billion. Yet, in 2002, states spent only $3.1 billion in federal, state and local funds on protective and preventive services for children. Our national child welfare policy represents a morally unacceptable failure to invest in this system.

These are conservative cost figures. When adjusted to account for inflation, data indicate that investigations by child protective service agencies cost approximately $1011 per case. The cost per case to provide basic in-home services such as homemaker assistance or family counseling is $3,360.[9] These costs are low to start with. Pay scales in child welfare are generally low and noncompetitive -- significantly lower, for example, than salaries for teachers, school counselors, nurses and public-health social workers[10] -- which brings these costs in at a low level.

What does the spending gap mean? States report having difficulty in recruiting and retaining child welfare workers,[11] because of issues like low salaries, high caseloads, insufficient training and limited supervision, and the turnover of child welfare workers -- estimated to be between 30 and 40 percent annually nationwide.[12] The average caseload for child welfare workers is double the recommended level, and obviously much higher in many jurisdictions.[13] Because our system is weighted toward protecting the most seriously injured children, we wait until it gets so bad that we have to step in. Far less attention in

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O'Hara, J.M. & Levenstein, P. (1981). *Second Year Progress Report: 9/15/80 - 9/14/81: Tracing the Parent-Child Network. Final Report, Grant No. NIEG 800042*, National Institute of Education, U.S. Department of Education.
Levenstein, P., O'Hara, J.M., & Madden, J. (1983) , "The Mother-Child Home Program of the Verbal Interaction Project", in Consortium for Longitudinal Studies, ed., *As the Twig is Bent* Hillsdale, NJ: Lawrence Erlbaum Associates.
Levenstein, P. & O'Hara, J.M., (1993) "The necessary lightness of mother-child play", in K.B. MacDonald, eds., *Parents and Children Playing* Albany, NY: State University of New York Press.

[8] Scarcella, C.A. (2004). *The Cost of Protecting Vulnerable Children IV: How Child Welfare Funding Fared during the Recession*, Washington, DC. Urban Institute.

[9] Courtney, M.E. (1998). *"The Costs of Child Protection in the Context of Welfare Reform"*. The Future of Children, Vol. 8, No. 1.

[10] U.S. General Accounting Office (2003). *HHS Could Play a Greater Role in Helping Child Welfare Agencies Recruit and Retain Staff* (GAO-03-357).

[11] U.S. General Accounting Office (1995). *Child Welfare: Complex Needs Strain Capacity to Provide Services* (GAO/HEHS-95-208).

[12] U.S. General Accounting Office (2003). *HHS Could Play a Greater Role in Helping Child Welfare Agencies Recruit and Retain Staff* (GAO-03-357).

[13] Alliance for Children and Families, American Public Human Services Association, Child Welfare League of America (2001). *The child welfare workforce challenge: Results from a preliminary study.* Dallas.

policy or funding is directed at preventing harm to children from ever happening in the first place or providing the appropriate services and treatment needed by families and children victimized by abuse or neglect.

Increasing funding for CAPTA's basic state grants and community-based prevention grants will help to begin to address the current imbalance. It is time to invest additional resources to work in partnership with the states to help families and prevent children from being abused and neglected.

The Case for Prevention

Our present system of treating abused and neglected children and offering some help to troubled families is overworked and inadequate to the task. Hundreds of thousands of children are currently identified as having been abused, but receive no services to prevent further abuse. We must focus attention on children and families known to the system in order to prevent reoccurrence of abuse, as well as provide services to families earlier, before problems become severe. Putting dollars aside for prevention is sound investing, not luxury spending.

We know that child abuse prevention fights crime, because research has shown us that victims of child abuse are more likely to engage in criminality later in life, and that childhood abuse increases the odds of future delinquency and adult criminality overall by 40 percent.[14] We know that preventing child maltreatment helps to prevent failure in school. Typically abused and neglected children suffer poor prospects for success in school, exhibiting poor initiative, language and other developmental delays, and a disproportionate amount of incompetence and failure.[15] Ensuring that children are ready to learn means ensuring that children are safe at home. We know that preventing child abuse can help to prevent disabling conditions in children. Physical abuse of children can result in brain damage, mental retardation, cerebral palsy, and learning disorders.[16]

Research conducted by CDC in collaboration with Kaiser Permanente shows us that childhood abuse is linked with behaviors later in life which result in the development of chronic diseases that cause death and disability, such as heart disease, cancer, chronic lung and liver diseases, and skeletal fracture, and that the adult victims of child maltreatment are more likely suffer from depression and suicide attempts.[17]

Community-based services to overburdened families are far less costly than the damage inflicted on children that leads to outlays for child protective services, law enforcement, courts, foster care, health care and the treatment of adults recovering from child abuse. A range of services, such as voluntary home-visiting, family support services, parent mutual support programs, parenting education, and respite care contribute to a community's successful strategy to prevent child abuse and neglect.

National Child Abuse Coalition Member Organizations: Alliance for Children and Families, American Academy of Pediatrics, American Bar Association, American Humane Association, American Professional Society on the Abuse of Children, American Psychological Association, Association of University Centers on Disabilities, Boys and Girls Clubs of America, CHILD Inc., Child Welfare League of America, Children's Defense Fund, Family Violence Prevention Fund, First Star, General Federation of Women's Clubs, National Alliance of Children's Trust and Prevention Funds, National Association of Children's Hospitals, National Association of Counsel for Children, National Association of Social Workers, Nat'l. Center for Child Traumatic Stress, National Center for State Courts, National CASA Association, National Education Association, National Exchange Club Foundation, National Network to End Domestic Violence, National Organization of Sisters of Color Ending Sexual Assault, National PTA, National Respite Coalition, Parents Anonymous, Prevent Child Abuse America, Stop It Now!, Voices for America's Children

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[14] C. S. Widom (1992). *The Cycle of Violence.* Washington, DC: National Institute of Justice.

[15] S.R. Morgan (1976). *The Battered Child in the Classroom.* Journal of Pediatric Psychology.

[16] H.P. Martin & M.A. Rodeheffer (1980). *The Psychological Impact of Abuse in Children.* In: G.J. Williams. Traumatic Abuse and Neglect of Children at Home. Baltimore, MD: Johns Hopkins University Press.

[17] V.J. Felitti, R.F. Anda, et al. (1998). *Relationship of Childhood Abuse and Household Dysfunction to Many of the Leading Causes of Death in Adults. The Adverse Childhood Experiences (ACE) Study.* American Journal of Preventive Medicine.

Testimony of

The Computing Technology Industry Association (CompTIA)

Roger J. Cochetti

Group Director-U.S. Public Policy

For the House Appropriation Committee

Subcommittee on Labor, Health, Education, and Related Agencies

"Opportunities Lost and Costs to Society: The Social and Economic Burden of Inadequate Education, Training, and Workforce Development"

Tuesday, February 26, 2008

Introduction

Good afternoon Chairman Obey, Ranking Member Walsh, and distinguished members of the Committee. I am Group Director for U.S. Public Policy of the Computing Technology Industry Association (CompTIA) and I am pleased to submit this testimony on behalf of our 20,000 member companies.

I want to thank Chairman Obey and Members of the Committee for holding this important hearing concerning the impacts of inadequate education, training, and workforce development. This is a real issue that impacts both the kitchen table budgets of American families and the American economy as a whole. We believe that your efforts to focus both Congressional and public attention on this issue are most important. Hopefully, CompTIA can be part of the solution.

CompTIA Overview

The Computing Technology Industry Association represents the business interests of the information technology industry. For over 25 years, CompTIA has provided research, networking, and partnering opportunities to its 20,000, mostly-American, member companies. Nearly 75% of our membership is comprised of American Value Added Resellers, or VARs. These small, system integrators set up and maintain computer systems and networks for small businesses. An estimated 32,000 American VARs sell some $43 billion dollars worth of computer hardware, software, and services -- mostly to the small businesses that drive the American economy. This means that around one-third of the computer hardware and software sold in the U.S. today is sold by VARs; again mostly to small businesses.

While CompTIA is distinct in its representation of America's tens of thousands of VARs, I wish to also emphasize that we represent technology workforce training schools, test sites, and curriculum developers, as well as most of America's principal computer hardware, software, and services companies. In addition to representing the interests of our members through our headquarters in Chicago and our public policy offices in Washington, Brussels, Hong Kong, and Sao Paulo, CompTIA works to provide global policy leadership for the IT industry.

Finally Mr. Chairman, for most people who work with computer technology, CompTIA is probably best known for the non-policy-related services that it provides to advance industry growth through standards, professional certifications, industry education, and business solutions. In order to most effectively serve the industry and our members, CompTIA has developed specialized initiatives and programs dedicated to major areas within the IT industry.

Today, over one million IT professionals – mostly American technology workers – possess one or more CompTIA certifications; and each month between 10,000 and 15,000 American IT workers take one or more of the CompTIA certification exams. And these CompTIA 'alumni' are an important source of insight and input for us as we address issues like workforce competitiveness. Now that they are business owners, many have told us that they are unable to find enough trained, qualified workers to fill the demand. Let me be clear, America does not have a worker shortage; it has an IT skilled worker shortage.

Of highest relevance to this hearing are our professional certifications for information technology (IT) workers. CompTIA offers 12 vendor-neutral professional certifications that test and validate a variety of baseline technical and professional IT skills. CompTIA A+, Network+, CDIA+, PDI+, Server+, Linux+, IT Project+, Convergence+, CTT+, DHTI+ (Home Technology Integrator), RFID+, and Security+ certifications provide credibility, recognition of achievement and quality assurance for employers and employees alike.

PROBLEM

The American marketplace faces many competitive pressures and the key to success lies in equipping our workforce with 21st Century skills. We know that the cost of inadequate education, training, and workforce development is a workforce that cannot compete globally; the solution is to ensure that American workers are able to acquire the skills they need to compete. Whether it is farming, parcel shipment tracking, military service, nursing, automobile repair, programming software, or working on the International Space Station, every American worker in the 21st century must have IT skills.

There are three main problems that I have identified regarding worker training in America: workers are not trained at all, they are inadequately trained, or they are poorly trained. Too many workers do not have access to training opportunities, or they are unaware of the training opportunities available to them. Interestingly, the US Department of Labor's Bureau of Labor Statistics predicted that by 2006, 92% of all U.S. workers would require some IT skills. Furthermore, according to the Department of Labor Employment and Training Administration, more than 90% of IT workers are employed outside the IT industry. Information Technology is no longer isolated to the Ph.D. students in computer science. It is a part of every industry and

most job functions; by increasing the prevalence of IT skills across the board, workers at all levels, in virtually every occupation, will become more productive and the economy and society as a whole will benefit. We must ensure that workers in all segments of our economy have access to the IT skills necessary to increase their productivity, efficiency, and effectiveness.

Furthermore, I would argue that too many workers are inadequately trained. They are not trained for 21st century careers. IT is the fastest growing sector of the US economy, with a projected 68% increase in output growth between 2002 and 2012. With this in mind, American workers should be encouraged to train for this growing field, not in sectors that have been continuously shrinking within the US.

And finally, there are no metrics in place to measure the quality of training received or the degree to which enrolled workers are learning what they have been taught. Because states and localities have such a strong influence over which institutions qualify as training centers, what programs qualify for vouchers or reimbursement, and who qualifies to attend, there is no way to comparatively measure outcomes. The result, as has been discussed, is the decreasing ability of American workers and companies to compete in the global marketplace.

SOLUTION

I am convinced that the American workforce is the most hard-working and able workforce in the world. With flexibility and the right tools available to our workers, there is no reason why China and the rest of the developing world should be able to challenge American production and innovation. However, we must train the untrained and re-train those whose skills are not in growing demand. We should focus on 21st century skills, encouraging workers to enter growing fields, and quantifying the education and training they receive.

The first step required to address the social and economic burden of inadequate education, training, and workforce development is to ensure that there is not an inadequacy of participation and knowledge about available programs. Two different GAO studies cited "lack of knowledge" as the main reason potential participants of Trade Adjustment Assistance did not avail themselves to benefits, which include training.[1] It is imperative that all workers have access to the skills training necessary to make them competitive with the global labor market.

For those in education and training programs, there must be policies in place to encourage education and training for 21st century jobs. Tech jobs are 21st century jobs, not simply because we have entered the digital era, but because that is where the demand is. By Bureau of Labor Statistics estimates, IT is the fast growing segment of the U.S. economy with 68% growth expected between 2002 and 2012.

[1] *Trade Adjustment Assistance: Most Workers in Five Layoffs Received Services, but Better Outreach Neeeded on New Benefits.* United States Government Accountability Office, Report to Congressional Requestors. GAO-06-043 (January 2006) and *Trade Adjustment Assistance: Labor Should Take Action to Ensure Performance Date Are Complete, Accurate, and Accessible.* United States Government Accountability Office, Report to the Committee on Finance, U.S. Senate. GAO-06-496 (April 2006).

Because the demand is higher, so are the wages. For example, the starting salary in the Chicago suburbs for a Precision Assembler is $31,900 per year and $44,000 per year for a Tool and Die Maker. By comparison, the starting annual salary for a Networking Specialist is $55,000.[2] Clearly, it makes more sense to encourage Americans to train for jobs that pay higher wages and in a field that is rapidly growing.

Additionally, as I stated above, there are few jobs in America that do not require some level of IT skills. As hospitals begin to digitize everything from scheduling to patient records, nurses and other health care workers will need both health care and IT knowledge. As digital tracking becomes even more prevalent shipping and supply chain logistics, truck drivers and warehouse managers will need IT skills. As global positioning devices, mp3 players, and all number of electronic elements are incorporated into mainline automobiles, mechanics will need IT skills. In fact, a recent CompTIA survey revealed that 63% of U.S. IT workers are not employed by IT companies.[3]

Similarly, Gartner, Inc., a technology consulting firm, recently found that during the late 1990s and early 2000s:

> *there were shortages of specific, technical skills, and domain-specific expertise. Today, by contrast, there are shortages of people with more general qualifications, experience and business insight. The focus is on understanding and managing business processes and technology.*[4]

There is a demand for IT skills in every workplace. To provide training in only the "traditional skills" of a particular job does a huge disservice to workers and the U.S. economy. To ensure that training coincides with demand, employers must be included as an integral part of the training planning process – especially employers who require 21st century skills.

And finally, to ensure the quality and adequacy of training there must be some metric in place to measure results. There must be some continuity across schools, training facilities, workforce investment boards, and one-stop centers. One of the key ways to ensure both quality education and training, and student information retention is to rely on certification at the completion of a training course. Industry recognized worker certifications are standard practice in many professional fields, including medicine, law, accounting, real estate, and IT. Unfortunately, when many workforce investment boards sponsor IT training, they do not include funding for the modest additional cost of certification testing.

It is one thing for a worker to say "I studied IT;" it is a very different statement to say, "I studied IT and have been certified according to professional industry standards." By ensuring that workers are not only trained, but also tested and certified in their chosen field they are of greater

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[2] Salaries based on information from www.salary.com for pay in the greater Chicago area.
[3] *IT Workers and the 2008 Elections.* CompTIA survey and report http://www.comptia.org/issues/docs/ITforweb.pdf (December 2007).
[4] *Gartner Warns of a Looming IT Talent Shortage.* Gartner, Inc. Egham, UK http://www.gartner.com/it/page.jsp?id=600009 (February 7, 2008).

value to prospective employers because their education is quantified. Any approach to address the inadequacies of education, training, and workforce development should include funding for relevant, widely recognized certifications as part of federal training funding.

These are just the first steps. In targeting low-level workers and the unemployed, it is imperative that those who currently have IT jobs also have the opportunity to continuously update and increase their IT skills. Similarly, the K-12 and post-secondary education systems must motivate more students to pursue STEM (science, technology, engineering, and math) courses to prepare them for the next generation of careers – careers that require IT skills regardless of industry.

CONCLUSION

We at CompTIA support training programs as the most effective way of ensuring the continued success and global competitiveness of the US workforce. However, training must be amply available and advertised, it must be targeted towards the right skills and careers, and the results must be quantifiable. To do so, employers must be involved in the planning process for training to ensure that there is a match between skills demand and supply. Specifically, as the fastest growing segment of the economy, the IT industry needs new skilled workers at virtually all levels. The U.S. workforce as a whole needs to be skilled in IT as this is the skill-set required by American employers, not just among IT companies, but also in the medical, financial, manufacturing, transportation, and service industries. With a growing shortage of skilled IT workers in the US economy, training programs must also allow America's current IT workers to update their skills and add value to all industries in which they work. CompTIA believes that training programs should be federally-funded and, where relevant and industry-appropriate, should lead to professional certifications widely recognized in the individual's given industry sector. These are the basic steps to countering the lost opportunities and costs to society of inadequate education, training, and workforce development.

It is hard to ignore the costs to society when so many are technologically illiterate and not contributing their full potential to the economy. The key questions now are not "What is wrong and what has it cost us", but rather "Where do we go from here and how do we fix the problems that threaten to further harm our economy?" While there is no silver bullet to eliminate the social and economic burden of training inadequacies, I am hopeful that this is not the end of the story for the American workforce. I encourage this Committee to act on these recommendations to strengthen the training and workforce development programs with the resources needed to continue America's economic leadership.

Mr. Chairman, I would like to again thank you and the Committee for holding such an important hearing, and I – along with our 20,000 members – look forward to working with you in the future.

Testimony Submitted for the Record to the Subcommittee on Labor, Health and Human Services, Education for FY 2009 Appropriations for HIV/AIDS Programs
Submitted by the HIV Medicine Association
Christine Lubinski, Executive Director
March 28, 2008

The HIV Medicine Association (HIVMA) of the Infectious Diseases Society of America (IDSA) represents more than 3,600 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. and the world, lead HIV prevention programs, and conduct research to advance HIV prevention and treatment options. They are medical providers that specialize in HIV medicine and work in communities across the country. We urge you to sustain the three-pronged response of the U.S. to the AIDS pandemic by adequately supporting:

- the research programs necessary to improve prevention and treatment options spearheaded by the National Institutes of Health (NIH);
- the surveillance and prevention programs that help to identify people with HIV and reduce HIV transmission led by the Centers for Disease Control and Prevention; and
- the health care safety-net programs that are critical to providing people with limited resources with access to lifesaving HIV treatment through the Ryan White CARE Act programs at the Health Resources and Services Administration (HRSA).

Past federal investments in HIV/AIDS programs have led to a revolution in HIV care. We developed treatments that effectively suppress this deadly virus and supported programs that provided lifesaving HIV treatment to people across the country regardless of their health insurance status. Many of our members have seen patients make remarkable recoveries that allow them to live healthier, more productive lives. However, we are concerned about our ability to sustain this success given our country's failure to prioritize support for domestic discretionary programs outside of defense and homeland security. The impact of our diminished investment in health is already being felt and will be far-reaching and long lasting as our communities' public health infrastructures weaken and our capacity to lead the world in discovering new therapies for controlling deadly diseases such as HIV erodes. If we do not act to increase our investments in these programs, we risk losing the next generation of scientists and clinicians necessary to continue the critical work of preventing new infections, providing effective care and treatment and advancing the science necessary to end the pandemic. The funding requests in our testimony largely reflect the consensus of the Federal AIDS Policy Partnership (FAPP), a coalition of HIV/AIDS organizations from across the country, and are estimated to be the amounts necessary to sustain and strengthen our investment in combating HIV disease.

CDC's National Center for HIV, STD, TB Prevention (NCHSTP)

HIVMA strongly supports substantial increases in funding for the CDC's NCHSTP. Our prevention efforts are stymied by insufficient funding to support a comprehensive HIV strategy. Meanwhile, the number of people living with HIV in the U.S. continues to grow and the CDC is expected to increase its estimate of the new HIV infections that are

occurring annually in the U.S. from 40,000 to 60,000. Resources are desperately needed to halt this trend and support a robust HIV prevention portfolio that includes identifying people with HIV earlier in infection through increased HIV screening. Tuberculosis is the major cause of AIDS-related mortality worldwide. It is critical that we shore up our ability as a nation to address tuberculosis, especially drug-resistant tuberculosis here in the U.S. and in the developing world. With regard to these programs, we urge at least an increase of $608 million for domestic HIV prevention and surveillance programs and a funding level of $300 million for CDC's Division of Tuberculosis Elimination.

A comprehensive prevention strategy is necessary to reduce the number of new HIV infections occurring each year. According to the CDC, at least 25 percent of people with HIV infection in the U.S. do not know it and more than 39 percent of people with HIV infection progress to AIDS within one year of diagnosis. We strongly support the CDC initiative to integrate HIV screening into medical care. The expansion of HIV testing is critical to identifying individuals with HIV earlier to prevent or delay disease progression and to reduce further transmission of the disease. We are seriously concerned about the lack of federal resources available to state health departments and institutions for implementing these programs.

A more robust HIV prevention budget also is needed to strengthen HIV surveillance systems and to target uninfected individuals who engage in high-risk behaviors. Both are important to dramatically reduce the 40,000 to 60,000 new HIV infections estimated to occur each year in the U.S.. We must increase support for science-based, comprehensive programs. We are seriously concerned that the resources committed to supporting a broad-based prevention agenda have diminished while funding for unproven and unscientific abstinence-only programs has increased. We strongly encourage Congress to halt this troubling trend. Additional resources are needed to address the high prevalence rates among vulnerable populations, e.g., men and women of color and men who have sex with men. It is short sighted to compromise these programs in order to support newer initiatives.

Funding for HIV prevention activities at the CDC should be increased by at least $608 million. These resources should be utilized to restore the cuts in HIV prevention cooperative agreements with state and local health departments; to enhance core surveillance cooperative agreements with health departments and to expand HIV testing in critical health care venues by funding testing infrastructure, the purchase of approved testing devices, including rapid tests and confirmatory testing.

Funding to support the prevention, control and elimination of tuberculosis must increase substantially if we are going to make headway against this deadly disease and to address the emerging threat of highly drug resistant tuberculosis. **HIVMA supports at least a $159.6 million increase in funding for the CDC's Division of Tuberculosis Elimination.**

HIV/AIDS Bureau of the Health Resources and Services Administration

HIVMA supports a total commitment of at least $2.78 billion, an increase of $614.5 million for the Ryan White CARE Act program. This recommendation includes a $134.6 million increase for the AIDS Drug Assistance Program (ADAP) and an increase of $100.5 million

for Part C (Title III). The Health Resources and Services Administration (HRSA) oversees programs that are vital to our communities' health care safety nets – and to the ability of our clinician members to provide HIV care and treatment to many of their patients living with HIV/AIDS. CARE Act funding helps us to meet the serious and complex needs of people with HIV/AIDS who are uninsured or underinsured by supporting the delivery of primary medical care, prescription drugs, diagnostic tests, mental health services, substance abuse treatment, and dental services in our communities.

We strongly support a substantial increase in CARE Act funding and would propose that the majority of new funding be targeted to HIV medical care. In particular, we support major increases for medical services offered under Parts A, B, C and D and to the AIDS Drug Assistance Program (ADAP) to ensure that individuals with HIV/AIDS have access to a base line of lifesaving medical care and prescription drugs regardless of where they live. Funding increases are urgently needed for Part C programs. Many of the programs are treating more patients with fewer grant dollars and are struggling to meet the growing demand for HIV care in their communities. **After several years of inadequate funding, we estimate that Part C programs require an increase of $83.3 million in federal funds.** HIV clinical programs depend on funding from multiple parts of the CARE Act to create the comprehensive services that our patients need. **We strongly encourage you to support funding increases of $213 million for Part A, $95 million for the Part B base and $48 million for Part D.**

More that a quarter century into the HIV epidemic, we are seeing the graying of our nation's HIV clinical workforce, and we have serious concerns about ensuring a new generation of HIV medical providers to care for Americans with HIV. We increasingly hear about HIV care coverage gaps and clinical programs with challenges in hiring and retaining medical staff. We must address this issue before its effects are felt in increases in morbidity and mortality from HIV. We are delighted that legislation reauthorizing the President's Emergency Program for AIDS Relief authorizes resources to ensure that there is an adequate workforce to provide prevention, care and treatment services in developing countries. We must also attend to HIV medical workforce needs at home. **We respectfully urge you to include at least $1 million in this year's Labor-HHS-Education appropriations bill for a study to evaluate the capacity of the HIV medical workforce as well as potential strategies to increase the numbers of young physicians, nurse practitioners and physician assistants entering HIV medicine.**

National Institutes of Health (NIH)

HIVMA strongly supports an increase of $4.38 billion for all research programs at the NIH including a $450 million increase for the NIH Office of AIDS. This level of increase is vital to halting the erosion of our nation's medical research programs and to sustain the pace of research that could improve the health and quality of life for millions of Americans. The failure to sustain the U.S. investment in biomedical research is taking its toll in deep cuts to clinical trials networks and significant reductions in the numbers of high quality, investigator-initiated grants that are approved. We are deeply concerned about the significant decrease in support for original research. With only one in four research applications receiving funding, the

pipeline for critical discoveries and HIV scientists is dwindling and our role as a leader in biomedical research is at serious risk.

In the arena of AIDS research, multiple years of inadequate funding levels that do not even keep pace with medical inflation threaten our ability to develop new therapeutics, to discover effective prevention technologies, and to finance vaccine development. A robust and 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. Additionally, our remarkable discoveries helped us to reduce the mother to child HIV transmission rate from 25% to nearly 1% in the U.S. and to very low levels in other countries where treatment is available.

A continued robust AIDS research effort is essential to sustain and to accelerate our progress in offering more effective prevention technologies; developing new and less toxic treatments for our; and supporting the basic research necessary to continue our work developing a vaccine that may end the deadliest pandemic in human history. Our failure to make an adequate investment in this lifesaving research compromises our ability to compare and evaluate optimum treatment and prevention strategies in resource-poor countries, and limits our ability to understand the appropriate role of new classes of antiretrovirals that are currently in development here at home for treatment and prevention. The sheer magnitude of the number of people still living with HIV/AIDS– more than one million people in the U.S.; 33 million people globally – demands an increased investment in AIDS research if we are going to truly eradicate this devastating disease.

We also strongly support the NIH's Fogarty International Center (FIC) and recommend an expansion of its programs and funding. The FIC training programs play a critical role in developing self-sustaining health care infrastructures in resource-limited countries. These important programs offer invaluable training and mentoring to indigenous physicians from the countries hardest hit by the HIV pandemic and other deadly infectious diseases, such as malaria and tuberculosis. Physicians trained through the FIC are able to develop research programs that more effectively address the health care, cultural and resource needs of their country's residents while also fostering the development of ongoing, robust research and clinical programs.

Our nation has made significant strides in responding to the HIV/AIDS 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. This retreat on past investments in AIDS research through NIH, surveillance and prevention programs through the CDC, and care and treatment through the Ryan White CARE Act program place the remarkable advancements of the past two decades in serious jeopardy. We have an opportunity to reverse this trend and to move forward with a budget that prioritizes funding for scientific discovery, public health, and care and treatment for those without resources or adequate insurance. With the support of this Congress, we have the opportunity to further 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 world.

Testimony of Mark Erstling, Acting President & CEO, Association of Public Television Stations

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

On behalf of the Association of Public Television Stations (APTS), I appreciate this opportunity to submit written testimony for the official record. In doing so, I urge the Subcommittee to support full funding for Public Broadcasting.

APTS is a nonprofit membership organization established in 1980 to support the continued growth and development of a strong and financially sound noncommercial television service for the American public. Our members are among the 361 Public Television stations that receive federal funds and serve your communities. As America's last locally-owned and controlled public service media, our stations take their universal service mandate seriously, reaching 99% of all U.S. households. As such, we are uniquely positioned to provide the Subcommittee with the stations' viewpoint and a clear picture of their needs and vision for the future of Public Service Media in a Digital Age.

Stations serve their respective communities in numerous important ways. These include unique, noncommercial, educational programming for adults and children, partnerships with educators and local first responders, and outreach into the community.

While public television continues to educate and enrich the lives of Americans, public broadcasting faces daunting challenges. Undoubtedly, the media landscape has changed and will continue to change dramatically as new technologies reshape the way all Americans—consumers, educators and students alike—use media in their everyday lives. In order to maximize the impact of the federal, state and local investment in public broadcasting, stations must redefine—and expand—the role of public service media for the 21st century. But we can't do it without the help of Congress.

Corporation for Public Broadcasting
More than 70% of funds appropriated to the Corporation for Public Broadcasting (CPB) reach local stations in the form of Community Service Grants (CSGs). These CSGs, while accounting for approximately 16% of the average station's overall budget, serve as the backbone of support for many stations. Stations are also able to leverage those CSGs to raise additional funds from state legislatures, private foundations and their viewers.

Public Television is requesting $483 million in CPB funding for FY 2011 to enable us to continue to provide the highest quality of services and to maximize the federal investment in Public Broadcasting. With $483 million, Public Broadcasters nationwide will be able to harness the power of digital to expand their programming and services through all platforms including broadcast, the Internet and mobile technologies to address three national priorities: *education improvement, local programming* and *health awareness.*

Public Television: Empowering Communities Through Education
U.S. students ranked lower, on average, than their peers in 16 other countries in science, out of 30 developed nations, taking part in the Program for International Student Assessment exam. In

math students ranked lower than 24 out of the 30 countries.

That's why Public Television considers education to be one of its core missions. In fact, 76 percent of stations partner with K-12 schools and districts; 85 percent of stations align their content to local, state or national standards; and 74 percent of stations create Science Technology Engineering and Math (STEM)-related content. With an increase in federal funding, many stations would expand partnerships with schools and districts, reinforce and create STEM content and programming, and utilize video-on-demand, online content depots and outreach to deliver content to teachers, students and parents to improve our global competitiveness.

For example, WPT of Wisconsin currently provides curriculum based, standards-driven educational resources reaching nearly 100% of classrooms. The station offers teacher training materials and delivers 26 credit bearing distance learning courses. With an increase in the federal investment, WPT would expand program offerings, professional development workshops, equip at least five more schools with datacasts, pursue digital rights for instructional material, and extend outreach and a partnership with the Wisconsin Library Association.

In addition, WXXI of Rochester, New York produces the award-winning program, Homework Hotline, for 4th-12th graders. With an increase in the federal funding, WXXI could provide more in-depth homework help and test prep services. These services would be highly utilized by students, teachers and schools. The potential audience for this programming is 2.2 million students and their teachers.

Public Television: Empowering Communities Through Civic Engagement
Despite the proliferation of communications platforms and sources in the U.S., the amount of in-depth, meaningful and local media coverage has sharply declined. A recent study by the National Alliance for Civic Education found that only nine percent of students could list two ways that democratic society benefits from the active participation of its citizens. At the same time, recent record-breaking turnout in the presidential primaries indicates that citizens, especially young Americans, are eager to become engaged in the democratic process.

That's why Public Television stations, as some of the last locally owned and controlled media outlets in the country, strive to serve as the local marketplaces of ideas, engaging, empowering and connecting citizens through the power of information. In fact, a 2003 study by the McGannon Center found that over a two-week period, commercial broadcasters aired, on average, only 45 minutes of local public affairs programming per week, in contrast to the 3.5 hours aired by public broadcasters.

For example, Connecticut Public Broadcasting Inc. (CPBI) provides 200+ hours of local programming dealing with topics such as disabilities, diversity, senior citizens, economic development, workforce development and Connecticut's heritage. With an increase in the federal investment, CPBI could produce 30% more local programming in public affairs, education and arts & culture and build outreach campaigns that extend the impact of series beyond television programming.

IdahoPTV offers the programs Outdoor Idaho, Dialogue (news and public affairs), Dialogue for Kids (D4K) (science program), Idaho Reports (legislative issue and analysis), Idaho Debates and Legislature Live (gavel-to-gavel legislative coverage, currently offered in analog transmitter areas and web only). All told, IdahoPTV is providing more than 2,900 hours of free local

programming available statewide and in portions of six surrounding states. With an increase in their the federal investment, IdahoPTV could secure permanent funding to support operating costs of Legislature Live— gavel-to-gavel coverage of the Idaho Legislature for statewide digital television broadcast and streaming.

Public Television: Empowering Communities Through Health Awareness
U.S. healthcare spending is projected to nearly double in the next decade, due in large part to unhealthy lifestyles. That's why stations have already made health awareness a priority in their communities. From regularly airing health-related programming to hosting outreach events around such critical issues as Alzheimer's disease, stations have been able to engage their communities and help their neighbors live healthier lives. With an increase in funding, many stations would increase partnerships to reach the widest range of their population served, including low-income, rural and minority populations covering a significant range of today's health issues.

WMHT of New York broadcasts a weekly program entitled Health Link which features discussions with local physicians and other experts on medical topics. With an increase in the federal investment, WMHT would partner with the New York State Department of Health to develop materials that could be quickly distributed in case of a pandemic flu outbreak or other health emergencies.

WXEL of Florida provided diabetes and high blood pressure screenings for the child care centers of the Hispanic Human Resources Council of Palm Beach County. These centers serve 300 children and families. With an increase in the federal investment, WXEL would produce additional health specials to air on South Florida Today, providing access to local medical professionals to citizens who might not otherwise have the resources to receive medical advice.

The examples above represent just a small portion of what our stations are doing in their communities every day.

CPB Digital
The "hard date" set by Congress for turning off analog signals—February 17, 2009—is just months away. Congress has wisely assisted Public Television with this transition, recognizing the many benefits digital signals offer viewers, as well as the hardship faced by non-profit stations in complying with this costly federal mandate. Stations, in turn, have raised approximately two-thirds of the total costs from non-federal sources to fund the transition.

APTS members are committed to meeting the hard date and are putting the final pieces in place to ensure that on February 17, 2009, no viewer will be left behind. APTS is requesting $40 million in CPB Digital funding to allow stations to at least meet the minimum requirements for the federally mandated transition. However; in order to fully replicate in digital the unique programming and content currently broadcast in analog, stations may need CPB Digital funding in the coming years. For example, while most stations' primary transmitters are broadcasting digital signals, local stations still need to convert towers and antennae, and address needs associated with power upgrades.

American Archive
Our request also includes funding so that CPB can continue to use a small share of funds to support pioneering digital content projects that leverage the new infrastructure. Working within

the industry, Public Television is creating the *American Archive*, a nationwide digital archive of local and national content from the past half-century, which would be accessible to students, teachers and the American public for a wide variety of educational purposes.

APTS greatly appreciates the House and Senate Appropriations Committees endorsement of this initiative through report language in the FY 2008 Labor-HHS-Education bill which allows CPB to use a portion of its digital funds to begin developing the archive. We are working diligently to create a blueprint that would include a cost assessment and a high-level tactical plan that meets the needs of the Public Broadcasting system and the American public.

Ready To Learn and Ready To Teach

A core mission of Public Television is education—providing quality programming and services for children and adults alike. Technological developments in the past two decades have made the world—and the global economy—more interconnected than ever before. In this new environment, it is vital that America's students keep up with their counterparts in other countries.

To meet our country's changing educational needs, we stand poised to expand our mission by increasing academic rigor and accelerating student achievement. We firmly believe that our educational resources will help America stay competitive throughout the 21st Century and beyond.

Public Television has a proven tack record of success in this area. Through programs like Ready To Learn and Ready To Teach, both authorized under No Child Left Behind, we've been able to leverage our expertise in education by creating high-quality, effective learning tools for students, teachers and parents. Our efforts in this field have garnered the attention of groups with expertise in early childhood development. Recently, the American Academy of Pediatrics released a report on the effect of advertising on children and adolescents, which specifically praised Public Television as "the sole source of high-quality, educational, noncommercial programming for children."

Ready To Learn

Ready To Learn focuses on preparing children for success in school. Since its launch in 1993, the program has helped more than seven million children and 650,000 educators and parents.

With research-based programming like *Between the Lions*, young children are exposed to key literacy skills, such as phonemic awareness, vocabulary, comprehension and fluency. In fact, four years of independent research including high-poverty, high-risk children in Kansas, Mississippi, and New Mexico confirm that young children who watch *Between the Lions* show dramatic improvements in their reading skills. Under this program, a new line of programming is on the way, including an updated version of *The Electric Company* and *Super Readers to the Rescue*. Broadcast throughout the Public Television system, Ready To Learn programming reaches 99% of the country's television households—as well as on-line, and on the ground in classrooms and communities.

In addition to the children's programming created under Ready To Learn, CPB and PBS are working in partnership with top academic institutions to determine the best practices to help children from low-income families learn to read using public broadcasting media.

Public Television has a strong record in helping our youngest children come to school ready to learn. Ready To Learn is looking forward to the digital future of Public Television by studying how this research based content can be shared on new media platforms and made available nationwide, as well as targeted distribution to leverage the greatest results. We ask Congress to increase funding of this program to $32 million for FY 2009 so that this proven program can continue to reach more kids.

Ready to Teach
Ready To Teach, Public Television's online professional development program, funds the development of digital educational services aimed at enhancing teacher performance so that teachers can raise student achievement through two distinct efforts: *PBS TeacherLine,* an online professional development program that improves teacher quality, particularly in the core areas of reading and math; and grants for station-based initiatives to provide professional development opportunities to local educators.

Studies show that high-quality teachers can achieve an entire year's worth of additional learning out of their students as compared to teachers near the bottom of the quality scale, within a single academic year. Ready To Teach helps teachers meet the Highly Qualified Teacher requirement in No Child Left Behind. It also reaches educators in rural and high-need districts where such professional development opportunities are limited.

APTS is requesting $17 million for Ready to Teach in FY 2009 to help build the library of professional development courses, resources and support materials, to increase the number of local stations able to participate in Ready to Teach and to expand all the Ready to Teach grants to five years, allowing for additional service development and effectiveness research.

Summary of Requests
The Public Broadcasting community respectfully requests the following funding levels for programs in the Labor, Health and Human Services, Education appropriations bill.

- $483 million for the Corporation for Public Broadcasting in FY 2011
- $40 million for CPB Digital in FY 2009
- $32 million for Ready To Learn in FY 2009
- $17 million for Ready To Teach in FY 2009

We truly believe the Digital Age has created boundless opportunities for Public Television and our support throughout the country has never been stronger. For the fourth year in a row, a 2007 Roper poll showed that the American public declared Public Television an excellent use of tax dollars, second only to military defense. The fact is, Americans treasure their public service media, despite the ever-increasing spectrum of commercial channels available. In fact, this proliferation of outlets makes our industry even more important. In a crowded media environment, there ought to be room for at least one source of high-quality news, information and cultural programming—including local content—that is available to all, regardless of ability to pay. Public Television continues, uniquely, to fill that important role.

APTS shares your commitment to the American public. We appreciate your past support, and look forward to working with the Subcommittee to preserve and expand Public Broadcasting for the benefit of current and future generations.

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