

**DEPARTMENT OF LABOR, HEALTH AND
HUMAN SERVICES, AND EDUCATION, AND
RELATED AGENCIES APPROPRIATIONS FOR
FISCAL YEAR 2015**

U.S. SENATE,
SUBCOMMITTEE OF THE COMMITTEE ON APPROPRIATIONS,
Washington, DC.

[CLERK'S NOTE.—The subcommittee was unable to hold hearings on departmental and nondepartmental witnesses. The statements and letters of those submitting written testimony are as follows:]

DEPARTMENTAL WITNESSES

PREPARED STATEMENT OF THE ASSOCIATION OF PUBLIC TELEVISION STATIONS AND
THE PUBLIC BROADCASTING SERVICE

On behalf of America's 170 public television licensees, we appreciate the opportunity to submit testimony for the record on the importance of Federal funding for local public television stations and PBS. We urge the Subcommittee to support level funding of \$445 million in 2-year advance funding for the Corporation for Public Broadcasting (CPB) in fiscal year 2017, and pre-sequester level funding of \$27.3 million for the Ready To Learn program at the Department of Education in fiscal year 2015.

Corporation for Public Broadcasting—fiscal year 2017 Request: \$445 million, 2-year advance funded

Local stations and PBS are committed to serving the public good in education, public safety, creating a well-informed citizenry, preserving and promoting American history and culture, and other essential fields. Federal funding for CPB makes these services possible and is deserving of continued support. The overwhelming majority of Americans agree. In a bi-partisan Hart Research Associates/American Viewpoint poll, nearly 70 percent of American voters, including majorities of self-identifying Republicans, Independents, and Democrats support continued Federal funding for public broadcasting. In addition, polls show that Americans consider PBS to be the second most appropriate expenditure of public funds, behind only military defense.

Over 70 percent of the Federal funding for CPB goes directly to local stations, resulting in a nationwide system of locally owned and controlled, trusted, community-driven and community-responsive media entities that form an incredibly successful public-private partnership providing unique and essential local public services.

Education

Local public television stations are America's largest classroom, meeting their communities' lifelong education needs by providing the highest quality educational content and resources on multiple media platforms and in person. Public television's exceptional content, available to nearly every household in America, has helped more than 90 million pre-school age children get ready to learn and succeed in school.

PBS, in partnership with local public television stations, has created PBS LearningMedia, an online portal where educators can access more than 35,000 standards-based, curriculum-aligned interactive digital learning objects created from public television content, as well as material from the Library of Congress, National Archives and other high-quality sources. More than 1.3 million teachers are reg-

istered to use PBS LearningMedia in K–12 classrooms serving millions of students throughout the country. In addition, twenty-eight thousand homeschoolers use PBS LearningMedia to enrich their curriculum in history, science, the arts and other subjects. Public television stations also operate virtual high schools that bring high-quality instruction in the most specialized fields to the most remote locations in our country.

Through the American Graduate Initiative, CPB and public media stations are working to confront the dropout crisis in America's high schools by providing resources and services to raise awareness, coordinate action with local community partners, and work directly with students, parents, teachers, mentors, volunteers and leaders to lower the drop-out rate in their respective communities. In addition, by operating one of the most comprehensive non-profit GED programs in the country, public television stations have helped hundreds of thousands of second-chance students and adult learners get their high-school equivalency certificates and prepare themselves for meaningful work in a competitive marketplace.

Public television stations have made it a top priority to help retrain the American workforce, including veterans, by providing digital learning opportunities for those looking for training, licensing, continuing education credits and more.

Partners in Public Safety

Public broadcasting stations throughout the country are also leading innovators and irreplaceable partners to local public safety officials—working in communities with schools, businesses and stakeholders to provide real-time emergency support for local law officials in times of crisis. In many communities, public broadcasting stations are the last locally-owned and operated media outlets—serving as a critical public safety life line.

The Nation's digital presidential alert and warning system depends on the backbone infrastructure of local public television stations to deliver critical national messages. This same digital infrastructure provides the backbone for emergency alert, public safety, first responder and homeland security services in many states and local communities. Stations are partnering with their local emergency responders to customize and utilize public television's infrastructure for public safety in a variety of critical ways: equipping police cars with school blueprints when a crisis arises, providing access to 24/7 camera feeds for a variety of security challenges, connecting public safety agencies in real time, and more. Local public television stations are also using their broadcast equipment to help send emergency alert text messages to cell phone subscribers through their providers—reaching citizens wherever they are, even when the power is out. Many local stations are serving as their states' primary Emergency Alert Service (EAS) hub for weather and AMBER alerts.

Supporting an Informed Citizenry

Public television strengthens the American democracy by providing citizens with access to the history, culture and civic affairs of their communities, their states and their country. Local public television stations serve as the “C-SPAN” of many state governments, providing the most remote corners of the country with access to the state legislative process, Governors' messages, court proceedings and more. As one of the only locally-owned and operated media remaining in America, public television provides more public affairs programming, local history, arts and culture, candidate debates, specialized agricultural news, and citizenship information of all kinds than anyone else in the media universe.

Public Broadcasting is a Smart Investment

All of this is made possible by the Federal funding to CPB which amounts to an annual cost of about \$1.35 per year for each American. On average, Federal funding for CPB makes up approximately 15 percent of local television station's budgets. However, for many smaller and rural stations, Federal funding represents more than 30–50 percent of their total budget. This funding is particularly important to rural stations that struggle to raise local funds from individual donors due to the smaller and often economically strained population base. At the same time it is often more costly to serve rural areas due to the topography and distances between communities. As a result, public broadcasters, with their commitment to universal service, are often the only local broadcaster serving rural communities. For all stations, Federal funding is the “lifeline” of public broadcasting, providing critical seed money to local stations that enables them to build additional support from state legislatures, private foundations and corporations, and “viewers like you.”

Public broadcasting creates important economic activity while providing an essential educational and cultural service. For every Federal dollar, local public media stations raise an additional six dollars in non-Federal funding, providing a strong public-private partnership and an impressive 6 to 1 return on investment. In addi-

tion, public broadcasting supports approximately 20,000 jobs, with the vast majority in local public television and radio stations in hundreds of communities across America.

Two-Year Advance Funding

Two-year advance funding is essential to the mission of public broadcasting. This longstanding practice, proposed by President Ford and embraced by Congress in 1976, establishes a firewall insulating programming decisions from political interference, enables the leveraging of funds to ensure a successful public-private partnership, and provides stations with the necessary lead time to plan in-depth programming and curriculum coordination with educational institutions.

Public television's history of editorial independence has been rewarded in unprecedented levels of public trust—for the eleventh consecutive year, the American people have ranked PBS as one of the most trusted national institutions. Advance funding and the firewall it provides between the development of content and extraneous interference and control is vital to maintaining this credibility among the American public.

In addition, local public broadcasting stations leverage the 2-year advance funding to raise state, local and private funds, ensuring the continuation of this strong public-private partnership. These Federal funds act as essential seed money for fund-raising efforts at every station, no matter its size, and since many state legislatures are part-time institutions that budget State funds on a 2-year cycle and relate state funding to Federal funding, advance Federal funding is essential to the success of this unique partnership.

Finally, the 2-year advance funding mechanism also gives stations and producers the critical lead time needed to partner with local community organizations and plan and produce high-quality programs. The signature series that demonstrate the depth and breadth of public television, like Ken Burns's *The Civil War*, take several years to produce. In addition, 2-year advance funding is essential to the creation of local programming over multiple fiscal years as stations convene the community to identify needs, recruit partners, conduct research, develop content and deliver services.

Ready To Learn—fiscal year 2015 Request: \$27.3 million (Department of Education)

The Ready To Learn (RTL) competitive grant program uses the power of public television's on-air, online, mobile, and on-the-ground educational content to build the literacy and STEM skills of children between the ages of two and eight, especially those from low-income families. Through their RTL grant, CPB and PBS are delivering evidence-based, innovative, high-quality transmedia content to improve the math and literacy skills of high-need children via broadcast television, the Internet, mobile and other dynamic new technologies. CPB and PBS, in partnership with local stations, have been able to ensure that the kids and families that are most in need have access to these groundbreaking and proven effective educational resources. In addition to the content, CPB and PBS are creating new tools like a sophisticated progress tracking system that gives parents the means to measure student progress, in real time.

Results

RTL is rigorously evaluated for its appeal and efficacy so the program can continue to offer America's youngest citizens the tools they need to succeed in school and in life. Studies show that RTL content has a significant and positive effect on the educational lives of children who use it. Highlights of recent studies show that: use of PBS KIDS content and games by low-income parents and their preschool children improves math learning and helps prepare children for entry into kindergarten;¹ use of RTL content has been associated with a 29 percent improvement in reading ability in children grades K–2;² and parents who used RTL math resources in the home became considerably more involved in supporting their children's learning outcomes.³ In combination, RTL games, activities and videos provide early

¹McCarthy, B., Li, L., Schneider, S., Sexton, U., & Tiu, M. (2013). PBS KIDS Mathematics Transmedia Suites in Preschool Homes and Communities. A Report to the CPB-PBS Ready to Learn Initiative. Redwood City, CA: WestEd. McCarthy, B., Li, L., Tiu, M. (2012). PBS KIDS Mathematics Transmedia Suites in Preschool Homes. Redwood City, CA: WestEd.

²Public Broadcasting Service (2012). KBTC Ready To Learn Initiative 2012 Summary Report, pp. 15,16.

³McCarthy, B., Li, L., Schneider, S., Sexton, U., & Tiu, M. (2013). PBS KIDS Mathematics Transmedia Suites in Preschool Homes and Communities. A Report to the CPB-PBS Ready to

learners with the critical math and literacy skills needed to succeed in school, and in the process, help level the academic playing field.

An Excellent Investment

In addition to being research-based and teacher tested, the RTL Television program also provides excellent value for our Federal dollars. In the last 5-year grant round, public broadcasting leveraged an additional \$50 million in funding to augment the \$73 million investment by the Department of Education for content production. Without the investment of the Federal government, this supplemental funding would likely end.

The Dangers of Consolidation

The President's fiscal year 2015 budget proposes consolidating RTL into a larger grant program. APTS and PBS oppose this proposal as it would abandon the unique national-local partnership that has resulted in RTL's ground-breaking educational impact on kids nationwide, particularly those with limited access to other educational resources. The current model effectively uses an economy of scale to create high-quality television and online content at the national level and then distribute it through local stations who can tailor outreach to the specific needs of their communities. This model allows PBS and local stations to annually reach 80 percent of America's children ages 2 to 8 through television and another 13 million per month online and on mobile apps. The national-local partnership has made RTL tremendously efficient and effective and consolidation or elimination of the program would severely affect the ability of local stations to respond to their communities' educational needs, eliminating the critical resources provided by this program for children, parents and teachers. RTL symbolizes the mission of public media and is a successful public-private partnership that leverages Federal funds to create the most appealing and impactful children's educational content that is supplemented by online and on-the-ground resources. Without the RTL program, millions of families would lose access to this incredible high-quality education content, especially the low-income and underserved households that are a particular focus of this program.

Conclusion

Americans across the political spectrum rely on public broadcasting—on television, on the radio, online, and in the classroom—because we provide essential education, public safety, and informed citizenry services that are not available anywhere else. And none of this would be possible without the Federal investment in public broadcasting. A 2007 GAO report concluded that these Federal Community Service Grants are an irreplaceable source of revenue for public broadcasting, and a 2012 study requested by this Subcommittee and conducted by an independent third party for CPB came to the same conclusion as the GAO: Federal funding for public broadcasting is irreplaceable.

For all of these reasons we request that Congress continue its commitment to the highly successful, hugely popular public-private partnership that is public broadcasting by providing level funding of \$445 million in fiscal year 2017 for the 2-year advance of the Corporation for Public Broadcasting and pre-sequester level funding of \$27.3 million in fiscal year 2015 for the stand alone Ready To Learn Program.

PREPARED STATEMENT OF THE NATIONAL PUBLIC RADIO

Dear Chairman Harkin, Ranking Member Moran and Members of the Subcommittee: Thank you for this opportunity to urge the Subcommittee's support for an annual Federal investment of \$445 million in America's public media system through annual appropriations to the Corporation for Public Broadcasting (CPB). With your support, the public radio system, consisting of some 950 locally managed, locally controlled and locally programmed stations, serves communities all across America. And these stations are as diverse as the communities they represent. Public radio is committed to being America's public radio, bringing the diverse and changing voices of Americans to the airwaves and the new platforms that so many Americans are using. We strive to create a more informed public, one challenged and invigorated by a deeper understanding and appreciation of events, ideas, and culture within the United States and across the globe.

The public radio system, a uniquely American public service, non-commercial, media enterprise, includes stations in every State capitol and hundreds of American

communities, large and small, urban and rural. Producers and distributors of public radio programming, including American Public Media (APM), Public Radio International (PRI), the Public Radio Exchange (PRX) and NPR are united by a commitment to the highest standards of journalist ethics. Every minute of every program broadcast to some 38 million Americans weekly is routed through the Public Radio Satellite System (PRSS), a content distribution utility owned by the public radio system.

Partnerships and collaborations are integral components of the programming and service found in the public radio system. Available on air, online, and on new and emerging mobile platforms, public radio is expanding its ability to reach audiences. And as traditional media undergoes dramatic changes, public radio is positioning itself to serve the needs of a growing audience in a shifting media landscape and rapidly changing world.

A clear example of these new adaptations to improve journalism and meet audience needs comes from the recently formed merger between St. Louis Public Radio and the St. Louis Beacon newspaper, the area's two largest nonprofit news organizations. This move combines newsrooms and significantly changes the face of independent local news in the region by providing more depth and perspective on issues and stories that impact the community. The consolidation creates an innovative model for a multiplatform news operation that results in more in-depth coverage of urban events and issues. St. Louis Public Radio's move to join forces and expand serves as an example of how public radio news organizations are adjusting to an ever-changing media environment that involves greater competition for consumers and financial support.

This new merger is just one among a growing list of public broadcasters teaming up with other nonprofit news outlets to beef up their local and investigative journalism. In Denver, Rocky Mountain PBS, public radio station KUVU, and I-News, the Rocky Mountain Investigative News Network, merged to create a cross-platform news operation that could better cover Colorado. WWNO in New Orleans hired its first-ever news director last spring to expand its coverage of stories. Oregon Public Broadcasting is building a statewide news network with 40 to 50 small news outlets across Oregon. Lastly, Harvest Public Media, a reporting collaboration of public radio stations KCUR, KBIA, Iowa Public Radio, Nebraska Public Broadcasting, KUNC and WUIS, focuses on issues of food, fuel and field. Based at KCUR in Kansas City, Harvest covers these agriculture-related topics through an expanding network of reporters and partner stations throughout the Midwest.

But the partnerships don't stop there for public radio. A recent collaboration includes Boston's WBUR and NPR joining forces to expand and re-launch the daily public radio show *Here & Now* as a two-hour national news program for audiences in the middle of the day. The program airs weekday afternoons and is aggressively updated to provide local audiences with live, updated news coverage during mid-day.

Public radio's partnerships with public safety officials play a critically important role when natural or man-made disasters strike. Public radio stations provide essential and timely public emergency information, such as evacuation routes, shelter locations and severe weather updates. Effective emergency warnings allow people to take actions that save lives, and reduce damage and human suffering. Federal funding helps to bring crucial news and alerts to millions of Americans.

Public radio's innovative partnerships also expand our public service mission by enabling radio reception to all Americans during local emergency situations. This year, 26 public radio stations based in Alabama, Florida, Louisiana, Mississippi and Texas are working with NPR Labs, the Public Radio Satellite System (PRSS) and the U.S. Department of Homeland Security/FEMA to demonstrate the delivery of emergency alerts to people who are deaf or hard-of-hearing. This is the first effort to deliver real-time accessibility-targeted emergency messages, such as weather alerts, via radio broadcast texts. Our hope is to expand the pilot over time to other regions of our country thru the use of radio equipment to reach people who are both deaf and blind and non-English speaking.

In addition, many public radio stations provide critical services through partnerships with radio reading services. These long established centers are in every major market in the United States to provide millions of visually impaired persons the ability to function more independently in their communities.

Music in America would sound very different without public radio. Local stations take creative risks, nurture new talent, and give emerging artists a chance to be heard. They celebrate traditional music genres like classical and jazz, and partner with local music organizations to take these art forms to new heights of performance excellence and new audiences. And they play a key role in their local music economies, sustaining and growing the careers of musicians by connecting them to local

listeners. Across the country, more than 180 local public radio stations have full-time music formats and more than 650 stations air play music as part of their programming lineups.

Mr. Chairman and Senator Moran, public radio is essential in providing news, information and cultural programming to America and connecting with audiences wherever they are. We're embracing America's changing demographics and using digital media to connect better, more quickly and in more diverse ways. Today's public radio isn't going away, it's going everywhere and we are working every day to earn the trust of the 38 million Americans who rely on us for news and insights that guide and inform. We ask for your continuing support in funding for stations that serve your communities, your constituents and America's Democracy.

[This statement was submitted by Michael Riksen, Vice President—Policy & Representation, National Public Radio.]

PREPARED STATEMENT OF THE RAILROAD RETIREMENT BOARD

Ms. Chairwoman and Members of the Committee: We are pleased to present the following information to support the Railroad Retirement Board's (RRB) fiscal year 2015 budget request of \$112,150,000 for our retirement, unemployment and other programs.

The RRB administers comprehensive retirement/survivor and unemployment/sickness insurance benefit programs for railroad workers and their families under the Railroad Retirement and Railroad Unemployment Insurance Acts. The RRB also has administrative responsibilities under the Social Security Act for certain benefit payments and Medicare coverage for railroad workers. The RRB has also administered special economic recovery payments and extended unemployment benefits under the American Recovery and Reinvestment Act of 2009 (Public Law 111-5) and extended unemployment benefits under the Worker, Homeownership, and Business Assistance Act of 2009 (Public Law 111-92). More recently, we have administered extended unemployment benefits under the Tax Relief, Unemployment Insurance Reauthorization, and Job Creation Act of 2010 (Public Law 111-312), the Temporary Payroll Tax Cut Continuation Act of 2011 (Public Law 112-78), the Middle Class Tax Relief and Job Creation Act of 2012 (Public Law 112-96) and the American Taxpayer Relief Act of 2012 (Public Law 112-240).

During fiscal year 2013, the RRB paid \$11.7 billion, net of recoveries, in retirement/survivor benefits to about 568,000 beneficiaries. We also paid \$84.5 million in net unemployment/sickness insurance benefits to more than 26,000 claimants. Temporary extended unemployment benefits paid were \$6.8 million. In addition, the RRB paid benefits on behalf of the Social Security Administration amounting to \$1.4 billion to about 113,000 beneficiaries.

PROPOSED FUNDING FOR AGENCY ADMINISTRATION

The President's proposed budget would provide \$112,150,000 for agency operations, which would enable us to maintain a staffing level of 860 full-time equivalent staff years (FTEs) in 2015. The proposed budget would also provide \$2,500,000 for information technology (IT) investments for the conversion of a legacy Program Accounts Receivable (PAR) system to a modern accounts receivable module within our cloud-based core financial system that was implemented October 1, 2013.

AGENCY STAFFING

The RRB's dedicated and experienced workforce is the foundation for our tradition of excellence in customer service and satisfaction. Like many Federal agencies, however, the RRB has a number of employees at or near retirement age. About 63 percent of our employees have 20 or more years of service, and over 28 percent of our current workforce will be eligible for retirement by fiscal year 2015. As we continue to modernize our information technology infrastructure to automate and convert manual workloads, our agency will also improve training delivery and reporting within our workforce. We plan to acquire and implement a Learning Management System that will provide a comprehensive functionality for training administration, documentation, tracking, reporting and delivery of e-learning education and training programs. This will allow the agency to improve all aspects involved in the learning process to meet our human capital needs as we experience a high rate of change in personnel. Furthermore, we will complement this initiative by implementing an executive training program to prepare and mentor future agency leaders that are ready to replace a significant number of senior leaders within the agency that are eligible to retire.

In connection with these workforce planning efforts, the President's budget request includes a legislative proposal to enable the RRB to utilize various hiring authorities available to other Federal agencies. Section 7(b) (9) of the Railroad Retirement Act contains language requiring that all employees of the RRB, except for one assistant for each Board Member, must be hired under the competitive civil service. We propose to eliminate this requirement, thereby enabling the RRB to use various hiring authorities offered by the Office of Personnel Management. Also, our budget request includes a legislative proposal to clarify the authority of the Railroad Retirement Board to retain in the competitive civil service attorneys hired prior to a change in OPM policy in 2013.

INFORMATION TECHNOLOGY IMPROVEMENTS

We are actively pursuing further automation and modernization of the RRB's various processing systems to support the agency's mission to administer benefit programs for railroad workers and their families. In fiscal year 2015, funding is included for contractor support to complete the full design of the Financial Management Integrated System (FMIS) by migrating a benefit payment feeder system named Program Accounts Receivable (PAR) to FMIS. FMIS migration from an obsolete financial system was started Oct 1, 2012 and completed Oct 1, 2013. Due to reduction in funds of the FMIS program during the sequestered fiscal year, PAR migration into FMIS was delayed. Once completed, the PAR migration to FMIS will enhance the processing of debt transactions for improper benefit payments in an integrated financial system hosted in a cloud environment. We expect PAR migration to FMIS to reduce staffing requirements and improve efficiency of the improper payment process.

OTHER REQUESTED FUNDING

The President's proposed budget includes \$34 million to fund the continuing phase-out of vested dual benefits, plus a 2 percent contingency reserve, \$680,000, which "shall be available proportional to the amount by which the product of recipients and the average benefit received exceeds the amount available for payment of vested dual benefits." In addition, the President's proposed budget includes \$150,000 for interest related to uncashed railroad retirement checks.

FINANCIAL STATUS OF THE TRUST FUNDS

Railroad Retirement Accounts—The RRB coordinates its financial needs with the National Railroad Retirement Investment Trust (Trust), the Trust was established by the Railroad Retirement and Survivors' Improvement Act of 2001 (RRSIA) to manage and invest railroad retirement assets. Pursuant to the RRSIA, the RRB has transferred a total of \$21.276 billion to the Trust. All of these transfers were made in fiscal years 2002 through 2004. The Trust has invested the transferred funds, and the results of these investments are reported to the RRB and posted periodically on the RRB's website. Through December 2013, the Trust had transferred approximately \$15.4 billion to the Railroad Retirement Board for payment of railroad retirement benefits. The net asset value of Trust-managed assets on September 30, 2013, was approximately \$25.0 billion, an increase of almost \$1.4 billion from the previous year.

In June 2012, we released the 25th Actuarial Valuation of the railroad retirement system required by Sections 15(g) of the Railroad Retirement Act of 1974. That report also met the requirements of Section 22 of the Railroad Retirement Act of 1974, and Section 502 of the Railroad Retirement Solvency Act of 1983. The report addressed the 75-year period 2011–2085, including projections of the status of the retirement trust funds under three employment assumptions. It concluded that barring a sudden, unanticipated, large decrease in railroad employment or substantial investment losses, the railroad retirement system would experience no cash flow problems for the next 23 years. Even under the most pessimistic assumption, the cash flow problems would not occur until the year 2035. The report did not recommend any change in the rate of tax imposed by current law on employers and employees.

The RRB's latest annual report required by Section 502 of the Railroad Retirement Solvency Act of 1983 was released in June 2013. The overall conclusion was that barring a sudden unanticipated, large decrease in railroad employment or substantial investment losses, the railroad system will experience no cash flow problems during the next 25 years.

Railroad Unemployment Insurance Account—The RRB's latest annual report on the financial status of the railroad unemployment insurance system was issued in June 2013. The report indicated that even as maximum daily benefit rates will rise

approximately 42 percent (from \$66 to \$94) from 2012 to 2023, experience-based contribution rates are expected to keep the unemployment insurance system solvent, except for small, short-term cash-flow problems in 2015 and 2016 under the most pessimistic assumption. However, projections show quick repayment of any loans by the end of each fiscal year.

Unemployment levels are the single most significant factor affecting the financial status of the railroad unemployment insurance system. However, the system's experience-rating provisions, which adjust contribution rates for changing benefit levels, and its surcharge trigger for maintaining a minimum balance, help to ensure financial stability in the event of adverse economic conditions. No financing changes were recommended at this time by the report.

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.

[This statement was submitted by Michael S. Schwartz, Chairman, Walter A. Barrows, Labor Member, and Jerome F. Kever, Management Member, Railroad Retirement Board.]

PREPARED STATEMENT OF THE INSPECTOR GENERAL, RAILROAD RETIREMENT BOARD

Mr. Chairman and Members of the Subcommittee: My name is Martin J. Dickman, and I am the Inspector General for the Railroad Retirement Board. I would like to thank you, Mr. Chairman, and the members of the Subcommittee for your continued support of the Office of Inspector General.

BUDGET REQUEST

The President's proposed budget for fiscal year 2015 would provide \$8,750,000 to the Office of Inspector General (OIG) to ensure the continuation of the OIG's independent oversight of the Railroad Retirement Board (RRB). During fiscal year 2015, the OIG will focus on areas affecting program performance; the efficiency and effectiveness of agency operations; and areas of potential fraud, waste and abuse.

OPERATIONAL COMPONENTS

The OIG has three operational components: the immediate Office of the Inspector General, the Office of Audit (OA), and the Office of Investigations (OI). The OIG conducts operations from several locations: the RRB's headquarters in Chicago, Illinois; an investigative field office in Philadelphia, Pennsylvania; and five domicile investigative offices located in Virginia, Texas, California, Florida, and New York. These domicile offices provide more effective and efficient coordination with other Inspector General offices and traditional law enforcement agencies, with which the OIG works joint investigations.

OFFICE OF AUDIT

The mission of the Office of Audit (OA) is to promote economy, efficiency, and effectiveness in the administration of RRB programs and detect and prevent fraud and abuse in such programs. To accomplish its mission, OA conducts financial, performance, and compliance audits and evaluations of RRB programs. In addition, OA develops the OIG's response to audit-related requirements and requests for information.

During fiscal year 2015, OA will focus on areas affecting program performance; the efficiency and effectiveness of agency operations; and areas of potential fraud, waste, and abuse. OA will continue its emphasis on long-term systemic problems and solutions, and will address major issues that affect the RRB's service to rail beneficiaries and their families. OA has identified four broad areas of potential audit coverage: Financial Accountability; Railroad Retirement Act and Railroad Unemployment Insurance Act Benefit Program Operations; Railroad Medicare Program Operations; and Security, Privacy, and Information Management. OA must also accomplish the following mandated activities with its own staff: Audit of the RRB's financial statements pursuant to the requirements of the Accountability of Tax Dollars Act of 2002, evaluation of information security pursuant to the Federal Information Security Management Act (FISMA), and an audit of the RRB's compliance with the Improper Payments Elimination and Recovery Act of 2010.

During fiscal year 2015, OA will complete the audit of the RRB's fiscal year 2014 financial statements and begin its audit of the agency's fiscal year 2015 financial statements. OA contracts with a consulting actuary for technical assistance in auditing the RRB's "Statement of Social Insurance", which became basic financial information effective in fiscal year 2006. In addition to performing the annual evaluation

of information security, OA also conducts audits of individual computer application systems which are required to support the annual FISMA evaluation. Our work in this area is targeted toward the identification and elimination of security deficiencies and system vulnerabilities, including controls over sensitive personally identifiable information.

OA undertakes additional projects with the objective of allocating available audit resources to areas in which they will have the greatest value. In making that determination, OA considers staff availability, current trends in management, Congressional and Presidential concerns.

OFFICE OF INVESTIGATIONS

The Office of Investigations (OI) focuses its efforts on identifying, investigating, and presenting cases for prosecution, throughout the United States, concerning fraud in RRB benefit programs. OI conducts investigations relating to the fraudulent receipt of RRB disability, unemployment, sickness, and retirement/survivor benefits. OI investigates railroad employers and unions when there is an indication that they have submitted false reports to the RRB. OI also conducts investigations involving fraudulent claims submitted to the Railroad Medicare Program. These investigative efforts can result in criminal convictions, administrative sanctions, civil penalties, and the recovery of program benefit funds.

OI INVESTIGATIVE RESULTS FOR FISCAL YEAR 2013

Civil Judgments	Indictments/Informations	Convictions	Recoveries/Receivables
37	47	81	¹ \$414,254,000

¹ This total includes the results of joint investigations with other agencies.

OI anticipates an ongoing caseload of about 400 investigations in fiscal year 2015. During fiscal year 2013, OI opened 156 new cases and closed 238. At present, OI has cases open in 48 States, the District of Columbia, and Canada with estimated fraud losses of nearly \$217 million. Disability fraud cases represent the largest portion of OI's total caseload. These cases involve more complicated schemes and often result in the recovery of substantial amounts for the RRB's trust funds. They also require considerable resources such as travel by special agents to conduct surveillance, numerous witness interviews, and more sophisticated investigative techniques. Additionally, these fraud investigations are extremely document-intensive and require forensic financial analysis.

Of particular significance is an ongoing disability fraud investigation in New York. To date, 33 individuals have been indicted; 28 of these have pleaded guilty and five more were convicted in Federal court. In addition, 44 former railroad employees avoided prosecution by admitting their role in the fraud and agreeing to the termination of their benefits. OI agents will likely have to spend a substantial amount of time traveling to New York for continuing investigations and trial preparation in fiscal year 2015.

During fiscal year 2015, OI will continue to coordinate its efforts with agency program managers to address vulnerabilities in benefit programs that allow fraudulent activity to occur and will recommend changes to ensure program integrity. OI plans to continue proactive projects to identify fraud matters that are not detected through the agency's program policing mechanisms.

CONCLUSION

In fiscal year 2015, the OIG will continue to focus its resources on the review and improvement of RRB operations and will conduct activities to ensure the integrity of the agency's trust funds. This office will continue to work with agency officials to ensure the agency is providing quality service to railroad workers and their families. The OIG will also aggressively pursue all individuals who engage in activities to fraudulently receive RRB funds. The OIG will continue to keep the Subcommittee and other members of Congress informed of any agency operational problems or deficiencies.

[This statement was submitted by Martin J. Dickman, Inspector General, Railroad Retirement Board.]

NONDEPARTMENTAL WITNESSES

PREPARED STATEMENT OF THE ACADEMY OF NUTRITION AND DIETETICS

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

The Academy of Nutrition and Dietetics appreciates the opportunity to submit testimony for the fiscal year 2015 appropriations. The Academy is the world's largest organization of food and nutrition professionals, and is committed to improving the Nation's health with nutrition services and interventions provided by registered dietitian nutritionists. Nationwide, The Academy has over 75,000 members.

As Congress begins work on fiscal year 2015 appropriations, we strongly urge you to fully fund Federal nutrition programs that will provide a return on investment to improve health. Investment in these programs through the appropriations process will help prevent costly healthcare expenses due to chronic diseases.

Senior Nutrition Funding: Administration for Community Living (ACL)

The congregate and home-delivered (commonly known as Meals on Wheels) senior nutrition programs, the Native American Nutrition Program, and the Nutrition Services Incentive Program (NSIP) are the largest and most visible components of the Older Americans Act. We strongly believe that the funding levels for the senior nutrition programs under the Administration for Community Living must be adequate, as these programs are key to keeping this population independent and in their homes. The President's budget proposes no increase for the senior nutrition programs in fiscal year 2015, yet we know that fuel and food costs—primary costs borne by senior nutrition programs—continue to increase. This is extremely alarming as these programs ensure that vulnerable older adults can continue to receive cost-effective nutrition services, ultimately saving Medicare and Medicaid dollars. Due to an ever-increasing demand for services, even flat funding will result in several million fewer home-delivered and congregate meals served, which could lead to more expensive hospitalizations or a need for long term care for older adults who cannot safely prepare meals themselves.

The Academy strongly supports the President's fiscal year 2015 request for \$20 million for Preventive Health Services under the Older Americans Act. This program provides grants to States and Territories to support activities that educate older adults about the importance of health lifestyles and promotes healthy behaviors that can help to prevent or delay chronic disease and disability, thereby reducing the need for costly medical interventions.

The Academy also supports the Administration's proposal for standalone funding of \$8 million for Chronic Disease Self-Management Programs (CDSMP) in the Administration for Community Living. CDSMP is a low-cost, evidence-based disease prevention model that utilizes state-of-the-art techniques to help older Americans with chronic diseases better manage their conditions and improve their health status, thus reducing their need for more costly medical care such as hospital care and hospital readmissions. According to the National Center for Chronic Disease Prevention and Promotion, seven out of ten deaths and more than three-quarters of all health expenditures for older adults are the result of preventable chronic conditions such as diabetes, obesity, cancer, arthritis and depression.

In addition, the Academy supports the President's fiscal year 2015 request for \$25 million in funding for the Elder Justice Act. Cases of elder abuse, neglect and exploitation are on the rise in this country; recent studies estimate that 14.1 percent of older adults face some sort of abuse, and another study estimates seniors lose a minimum of \$2.5 billion each year as a result (MetLife and the National Committee for the Prevention of Elder Abuse). Elder abuse is a major threat to the health of our elderly population.

Centers for Disease Control and Prevention (CDC) Funding

The Academy respectfully requests adequate funding for CDC's fiscal year 2015 "core programs." We strongly believe that the activities and programs supported by CDC are essential to protect the health of the American people. CDC is faced with enormous challenges and responsibilities, from bioterrorism preparedness to chronic disease prevention and eliminating health disparities. In addition, CDC funds effective community programs including health promotion efforts and nutrition interventions that help prevent heart and lung disease, cancer, diabetes, stroke, and other chronic diseases. More than 70 percent of CDC's budget supports State and local health organizations and academic institutions.

We support the President's budget proposal to reduce chronic diseases through diabetes funding totaling \$140 million and heart disease funding totaling \$130 mil-

lion. These expenditures will help reduce the heavy healthcare cost burden of these two diseases.

We also ask that you maintain the fiscal year 2014 funding of \$8 million (not the reduced level in the fiscal year 2015 President's Request) for Hospitals Promoting Breastfeeding. According to the CDC, childhood obesity is an epidemic. One in five preschoolers in our country is overweight, and half of these are obese. A baby's risk of becoming an overweight child is reduced with each month that the baby is breastfed. In the US, most babies start breastfeeding, but within the first week, half have already been given formula, and by 9 months, only 31 percent of babies are breastfeeding at all. Hospitals play a critical role in encouraging new moms to breastfeed.

Food and Drug Administration (FDA) Funding

The Academy supports the President's budget of \$1.48 billion for food safety. A robust food safety system and the continued implementation of the Food Safety Modernization Act will help reduce food-borne illness that costs the U.S. healthcare system \$88 billion annually.

Again, thank you for reviewing these comments and please feel free to contact us for any additional information.

[This statement was submitted by Mary Pat Raimondi MS, RD, Vice President, Strategic Policy and Partnerships Academy of Nutrition and Dietetics.]

PREPARED STATEMENT OF ACADEMYHEALTH

AcademyHealth is pleased to offer this testimony regarding funding for Federal agencies that support health services research and health data, including the Agency for Healthcare Research and Quality (AHRQ), the National Center for Health Statistics (NCHS), and the National Institutes of Health (NIH). AcademyHealth's mission is to support research that leads to accessible, high value, high-quality healthcare; reduces disparities; and improves health. We represent the interests of more than 5,000 scientists and policy experts and 180 organizations that produce and use health services research to improve our Nation's health and the performance of the healthcare and public health systems. For fiscal year 2015, we recommend funding levels of \$375 million for AHRQ, \$182 million for NCHS, and \$32 billion for NIH.

The United States spent \$2.8 trillion—17.2 percent of our economy—on healthcare in 2012. Finding new ways to get the most out of every healthcare dollar is critical to our Nation's long-term fiscal health. Like any corporation making sure it is developing and providing high quality products, the Federal Government—as the Nation's largest healthcare purchaser—has a responsibility to get the most value out of every taxpayer dollar it spends on Medicare, Medicaid, Children's Health Insurance Program, and veterans' and service members' health.

Health services research is our Nation's R&D enterprise for health improvement. Just as medical research discovers cures for disease, health services research discovers cures for the health system (see Figure 1). This research diagnoses problems in healthcare and public health delivery and identifies solutions to improve outcomes for more people, at greater value. And while biomedical and clinical research discoveries can take years and even decades to reach patients, discoveries from health services research can be used now by patients, healthcare providers, public health professionals, hospitals, employers, and public and private payers to improve care today.

Put plainly, health services research helps Americans get their money's worth when it comes to healthcare. We need more of it, not less. Despite the positive impact health services research has had on the U.S. healthcare system, and the potential for future improvements in quality and value, the United States spends less than one cent of every healthcare dollar on this research; research that can help Americans spend their healthcare dollars more wisely and make more informed healthcare choices.

AcademyHealth realizes the pressure Congress and the administration face to reduce the national debt. We respectfully ask that the subcommittee consider the value of health services research in achieving that goal, and to strengthen its capacity to address the pressing challenges America faces in providing access to high-quality, efficient care. The following list summarizes AcademyHealth's fiscal year 2015 funding recommendations for agencies that support health services research and health data under the subcommittee's jurisdiction.

Agency for Healthcare Research and Quality

AHRQ is the only Federal research agency with the sole purpose of producing evidence to make healthcare safer; higher quality; more accessible, equitable, and affordable; and to ensure that the evidence is understood and used. AHRQ funds health services research and healthcare improvement programs in universities, medical centers, research institutions, hospitals, health clinics, and medical practices that are transforming people's health in communities in every State around the Nation. The science funded by AHRQ provides consumers and their healthcare professionals with valuable evidence to make healthcare decisions. For example, medical societies use AHRQ-funded research to inform their recommendations for treatment of type 2 diabetes and rheumatoid arthritis. These evidence-informed recommendations give physicians a foundation for describing what the best care looks like, so millions of patients living with these and other conditions may determine what the right care might be for them.

AHRQ's research also provides the basis for strategies that prevent medical errors, reduce hospital-acquired infections (HAI), and improve patient experiences and outcomes. For example, AHRQ's evidence-based Comprehensive Unit-based Safety Program to Prevent Healthcare-Associated Infections (CUSP)—first applied on a large scale in 2003 across more than 100 ICUs across Michigan—saved more than 1,500 lives and nearly \$200 million in the program's first 18 months. The protocols have since been expanded to hospitals in all 50 States, the District of Columbia, and Puerto Rico to continue the national implementation of this approach for reducing HAIs.

AcademyHealth joins the Friends of AHRQ—an alliance of health professional, research, consumer, and employer organizations that support the agency—in recommending a base discretionary funding level of \$375 million for AHRQ in fiscal year 2015.

National Center for Health Statistics

NCHS is the Nation's principal health statistics agency. Housed within the Centers for Disease Control and Prevention (CDC), it provides critical data on all aspects of our healthcare system through data cooperatives and surveys that serve as a gold standard for data collection around the world. AcademyHealth appreciates the subcommittee's support of NCHS in recent years. Such efforts have allowed NCHS to reinstate data collection and quality control efforts, continue the collection of vital statistics, and modernize surveys to reflect changes in demography, geography, and health delivery.

We join the Friends of NCHS—an alliance of health professional, research, consumer, industry, and employer organizations that support the agency—in recommending an overall funding level of \$182 million for NCHS in fiscal year 2015. This funding level will support the agency's core data collection activities, as well as new initiatives to enhance death data timeliness and security, restore survey expansions to better assess access to and utilization of healthcare services, and determine "what works" in the organization, financing, and delivery of public health services.

National Institutes of Health

NIH spends approximately \$1 billion on health services research annually—roughly 3 percent of its entire budget—making it the largest Federal sponsor of health services research. We join the research community in seeking at least \$32 billion for NIH in fiscal year 2015. NIH has an important role in the Federal health services research continuum, and is well-positioned to ensure that discoveries from clinical trials are effectively translated into healthcare delivery. AcademyHealth supports efforts to help NIH foster greater coordination of its health services research investment among its institutes and across other Federal agencies to avoid duplication.

AcademyHealth also recommends that the Clinical and Translational Science Awards (CTSA) through the National Center for Advancing Translational Sciences (NCATS) sustain investment in the full spectrum of translational research (T1-T4). The CTSA program enables innovative research teams to speed discovery and advance science aimed at improving our Nation's health. The program encourages collaboration in solving complex health and research challenges and finding ways to turn their discoveries into practical solutions for patients. Finally, AcademyHealth supports continued investment by NIH and its many Institutes and Centers in dissemination and implementation research. This research helps us understand which approaches work to improve population health.

In conclusion, the accomplishments of the field of health services research would not be possible without the leadership and support of this subcommittee. We hope the subcommittee gives strong consideration to our fiscal year 2015 funding rec-

ommendations for the Federal agencies funding health services research and health data. If you have questions or comments about this testimony or wish to know more about health services research, please contact Dr. Lisa Simpson, President and CEO of AcademyHealth or lisa.simpson@academyhealth.org.

FIGURE 1: THE HEALTH RESEARCH CONTINUUM

These components of the health research continuum work in concert, and each plays an essential role—any one type of research on its own cannot effectively or appreciably improve health. Take heart disease as one example ...

Basic research discovered the contributions of elevated blood pressure, elevated cholesterol, and tobacco use to heart disease.	Clinical research determined which treatments were safe and effective to treat hypertension, hypercholesterolemia, tobacco addiction, and to prevent and treat heart disease, in general.	Population-based research identified strategies to reduce the risks of heart disease in communities through non-medical interventions, such as reduction of trans fats in food and tobacco control measures to reduce smoking.	Health services research determined how to best deploy these discoveries to achieve the best health outcomes. This research helped identify who had the least access, what barriers existed, and how to mitigate them. This research also led to the development of quality measures that are now used to report on the quality of cardiac care.
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Source: AHRQ: 15 Years of Transforming Care and Improving Health, AcademyHealth, Jan. 2014. Available at: <http://academyhealth.org/files/AHRQReport2014.pdf>.

[This statement was submitted by Dr. Lisa Simpson, President & CEO, AcademyHealth.]

PREPARED STATEMENT OF THE AD HOC GROUP FOR MEDICAL RESEARCH

The Ad Hoc Group for Medical Research is a coalition of patient and voluntary health groups, medical and scientific societies, academic and research organizations, and industry. We appreciate the opportunity to submit this statement in support of enhancing the Federal investment in biomedical, behavioral, social, and population-based research conducted and supported by the National Institutes of Health (NIH).

The Consolidated Appropriations Act of 2014 included a welcome and much needed increase for the NIH. However, this increase did not restore all of the funds cut by sequestration in fiscal year 2013 or the purchasing power NIH has lost over the past decade due to inflation. We hope fiscal year 2014 represents a first step toward restoring our Nation's preeminence in medical research.

The Ad Hoc Group for Medical Research recommends that NIH receive at least \$32 billion in fiscal year 2015 as the next step toward a multi-year increase in our Nation's investment in medical research. The Ad Hoc Group also urges Congress and the Administration to work in a bipartisan manner to end sequestration and the continued cuts to medical research that squander invaluable scientific opportunities, discourage young scientists, threaten medical progress and continued improvements in our Nation's health, and jeopardize our economic future.

The Ad Hoc Group is deeply grateful to the Subcommittee for its long-standing and bipartisan leadership in support of NIH. We continue to believe that science and innovation are essential if we are to continue to improve our Nation's health, sustain our leadership in medical research, and remain competitive in today's global information and innovation-based economy.

NIH: A Public-Private Partnership to Save Lives and Provide Hope

The partnership between NIH and America's scientists, medical schools, teaching hospitals, universities, and research institutions is a unique and highly-productive relationship, leveraging the full strength of our Nation's research enterprise to foster discovery, improve our understanding of the underlying cause of disease, and develop the next generation of medical advancements. Approximately 84 percent of the

NIH's budget goes to more than 300,000 research positions at over 2,500 universities and research institutions located in every state.

The Federal Government has an irreplaceable role in supporting medical research. No other public, corporate or charitable entity is willing or able to provide the broad and sustained funding for the cutting edge research necessary to yield new innovations and technologies of the future.

Research funded by NIH has contributed to nearly every medical treatment, diagnostic tool, and medical device developed in modern history, from a new treatment for cystic fibrosis to an awareness campaign that resulted in a dramatic decrease in the number of infants lost to Sudden Infant Death Syndrome to a new vaccine to prevent cervical cancer. We are all enjoying longer, healthier lives thanks to the Federal government's wise investment in this lifesaving agency. Examples of recent clinical breakthroughs made by NIH-supported scientists include:

- NIH-funded researchers have discovered a way to harness the body's own immune system to fight cancer. The promising results in both adults and children with leukemia lead Science Magazine to name Cancer Immunotherapy as the 2013 Breakthrough of the Year for all of science;
- NIH scientists have developed new treatments for hepatitis C—the leading reason for liver transplants in the U.S.—that have shortened treatment times and produced cures in 85 to 95 percent of patients, even those with advanced disease;
- NIH-funded researchers found that certain molecules in urine can provide an early sign of kidney transplant rejection, a test that allows doctors to act earlier to protect transplanted kidneys;
- An NIH-supported clinical trial demonstrated that an intensive early behavioral intervention delivered before the age of 2 years can improve symptoms as well as normalize brain activity in some children with autism; and
- NIH-funded scientists developed an innovative method to quickly identify antibiotics that can treat multidrug-resistant bacteria—and reveal how these bacteria-killing medications work.

For patients and their families, NIH is the “National Institutes of Hope.”

NIH is the world's premier supporter of merit-reviewed, investigator-initiated basic research. This fundamental understanding of how disease works and insight into the cellular, molecular, and genetic processes underlying life itself, including the impact of social environment on these processes, underpin our ability to conquer devastating illnesses. The application of the results of basic research to the detection, diagnosis, treatment, and prevention of disease is the ultimate goal of medical research. Ensuring a steady pipeline of basic research discoveries while also supporting the translational efforts absolutely necessary to bring the promise of this knowledge to fruition requires a sustained investment in NIH.

The research supported by NIH drives not only medical progress but also local and national economic activity, creating skilled, high-paying jobs and fostering new products and industries. According to a report released by United for Medical Research, a coalition of scientific advocates, institutions and industries, in fiscal year 2011, NIH-funded research supported an estimated 432,000 jobs all across the United States, enabled 13 states to experience job growth of more than 10,000 jobs, and generated more than \$62 billion in new economic activity.

Stagnant Funding Threatens Scientific Momentum

Despite the increase provided in the current year, over the past decade NIH has lost more than 22 percent of its budget after inflation, significantly impacting the Nation's ability to sustain the scientific momentum that has contributed so greatly to our Nation's health and our economic vitality. The leadership and staff at NIH and its Institutes and Centers has engaged patient groups, scientific societies, and research institutions to identify emerging research opportunities and urgent health needs, and has worked resolutely to prioritize precious Federal dollars to those areas demonstrating the greatest promise. But a continued erosion of our national commitment to medical research threatens our ability to support a medical research enterprise that is capable of taking full advantage of existing and emerging scientific opportunities.

Perhaps one of the greatest concerns is the obstacle these continued cuts will present to the next generation of scientists, who will see training funds slashed and the possibility of sustaining a career in research diminished. NIH plays a significant role in supporting the next generation of innovators, the young and talented scientists and physicians who will be responsible for the breakthroughs of tomorrow.

The challenges of maintaining a cadre of physician-scientists to facilitate translation of basic research to human medicine, ensuring a biomedical workforce that reflects the racial and gender diversity of our citizenry, and maximizing our Nation's

human capital to solve our most pressing health problems will only be addressed through continued support of NIH.

NIH is Critical to U.S. Competitiveness

Our country still has the most robust medical research capacity in the world, but that capacity simply cannot weather repeated blows such as persistent below-inflation funding levels and cuts of sequestration, which jeopardize our competitive edge in an increasingly innovation-based global marketplace.

Other countries have recognized the critical role that biomedical science plays in innovation and economic growth and have significantly increased their investment in biomedical science. Between 1999 and 2009, Asia's share (including China, India, Japan, Malaysia, Singapore, South Korea, Taiwan, and Thailand) of worldwide research and development (R&D) expenditures grew from 24 percent to 32 percent, while U.S. R&D expenditures declined from 38 percent to 31 percent. While the U.S. currently leads the world in R&D spending, China's increasing investment in R&D is projected to close the gap and surpass the U.S. in total R&D spending by about 2022. The European Commission also has recently urged its member Nations to increase their investment in research substantially, recommending budgets of 80 billion Euro (equivalent to \$108 billion) from 2014 to 2020, a 40 percent increase over the previous 7-year period.

This shift in funding raises the concern that talented medical researchers from all over the world, who once flocked to the U.S. for training and stayed to contribute to our innovation-driven economy, are now returning to better opportunities in their home countries. We cannot afford to lose that intellectual capacity, much less the jobs and industries fueled by medical research. The U.S. has been the global leader in medical research because of Congress's bipartisan recognition of NIH's critical role. To maintain our dominance, we must reaffirm this commitment to provide NIH the funds needed to maintain our competitive edge.

NIH: An Answer to Challenging Times

The Ad Hoc Group's members recognize the tremendous challenges facing our Nation's economy and acknowledge the difficult decisions that must be made to restore our country's fiscal health. Nevertheless, we believe strongly that NIH is an essential part of the solution to the Nation's economic restoration. Strengthening our commitment to medical research, through robust funding of the NIH, is a critical element in ensuring the health and well-being of the American people and our economy.

Therefore, the Ad Hoc Group for Medical Research recommends that NIH receive at least \$32 billion in fiscal year 2015 as the next step toward a multi-year increase in our Nation's investment in medical research.

PREPARED STATEMENT OF THE AIDS ALLIANCE FOR WOMEN, INFANTS, CHILDREN,
YOUTH & FAMILIES

Dear Chairman Harkin Ranking Moran, and Members of the Subcommittee: AIDS Alliance for Women, Infants, Children, Youth & Families was founded in 1994 to help respond to the unique concerns of HIV-positive and at-risk women, infants, children, youth, and families. AIDS Alliance conducts policy research, education, and advocacy on a broad range of HIV/AIDS prevention, care, and research issues. We are pleased to offer written testimony for the record in opposition of the fiscal year 2015 budget proposal consolidating Ryan White Part D funding into Part C and in support of maintaining Part D of the Ryan White Program as part of the fiscal year 2015 Labor, Health and Human Services, Education, and Related Agencies appropriations measure. This testimony also has the support of the Elizabeth Glaser Pediatric AIDS Foundation.

Ryan White Part D Funding Request

Sufficient funding of the Ryan White Program is necessary to provide quality care for individuals living with HIV/AIDS. We thank the Subcommittee for its continuous support of Ryan White Part D Programs, providing \$75 million to the program in fiscal year 2014. While the AIDS Alliance for Women, Infants, Children, Youth & Families understands that these are difficult economic times, we are requesting the Subcommittee to maintain its commitment to the Ryan White Part D program and restore its funding eliminated in the President's fiscal year 2015 budget proposal and increase Ryan White Part D funding by \$9.9 million in fiscal year 2015.

Ryan White Part D Background and History

Over concerns with the increase in the number of pediatric AIDS cases, Congress first acted to address pediatric cases in 1987 by providing \$5 million for the Pediatric AIDS Demonstration Projects in the fiscal year 1988 budget. Those demonstration projects became part of the Ryan White CARE Act of 1990 which today is known as Ryan White Part D and have served thousands of women, infants, children, youth and families. Since the program's inception in 1988, Part D programs have been and continue to be the entry point into medical care for women and youth and, in many communities or regions, Part D programs are the only perinatal clinical service available to serve HIV-positive pregnant women and youth when payments for such services are unavailable from other sources. Ryan White Part D programs have been extremely effective in bringing the most vulnerable populations into and retained in care and is the lifeline for women, infants, children and youth living with HIV/AIDS. The Part D programs are instrumental in preventing mother-to-child transmission of HIV and for ensuring that women, including HIV-positive pregnant women, HIV exposed infants, children and youth have access to quality HIV care. The program is built on a foundation of combining medical care and essential support services that are coordinated, comprehensive, and culturally and linguistically competent. This model of care addresses the healthcare needs of the most vulnerable populations living with HIV/AIDS in order to achieve optimal health outcomes.

In 2012, Part D provided funding to 114 community-based organizations, academic medical centers and hospitals, federally qualified health centers, and health departments in 39 States and Puerto Rico. These federally, directly-funded grantees provide HIV primary care, specialty and subspecialty care, oral health services, treatment adherence monitoring and education services pertaining to opportunities to participate in HIV/AIDS-related clinical research. These grantees also provide support services which include case management (medical, non-medical, and family-centered); referrals for inpatient hospital services; treatment for substance use, and mental health services. Part D grantees also receive assistance from other parts of the Ryan White Program that help support HIV testing and linkage to care services; provide access to medication; additional medical care, such as dental services; and key support services, such as case management and transportation, which all are essential components of the highly effective Ryan White HIV care model. This model has continuously provided comprehensive quality healthcare delivery systems that have been responsive to women, infants, children, youth and families for two decades.

A Response to Women, Infants, Children, and Youth

The Ryan White Program has been enormously successful in meeting its mission to provide life-extending care and services. Yet, even though we have made significant progress in decreasing HIV-related morbidity and mortality, much work remains to be done. While accounting for less than 6 percent of Ryan White direct care dollars (minus ADAP and Part F), Ryan White Part D programs have been extremely effective in bringing our most vulnerable populations into care and developing medical care and support services especially designed to reach women, children, youth, and families. Part D funded programs played a leading role in reducing mother-to-child transmission of HIV from as many as 2,000 babies born HIV positive in 1990 to roughly 200 cases in 2010 through aggressive efforts to reach out to pregnant women. Appropriate funding is critical to maintain and improve upon this success, as there are still approximately 8,000 HIV-positive women giving birth every year in the United States that need counseling, services and support to prevent pediatric HIV Infections. According to the CDC, youth account for 39 percent of all new HIV infections in the U.S. As of 2010, one in four new HIV infections occur among young people ages 13–24. Most new HIV infections in youth (about 70 percent) occur in gay and bisexual males, most of whom are African Americans. Of the new HIV infections among youth, 2,100 are among young women; two-thirds of these are among young African American women. Ryan White Part D programs are the entry point into medical care for many HIV positive youth and leads the Nation's effort in recruiting and retaining HIV positive youth to comprehensive medical care and support services. According to the Health Resources and Services Administration, more than 37 percent of women receiving medical care in Ryan White Programs do so through Part D. Additionally, Part D provides medical and supportive services to a large number of women over 50 who are heading into their senior years as HIV survivors which is a testament to the high standard of care provided to Ryan White Part D programs. Support and care through the Ryan White Part D program was and continues to be funding of last resort for the most vulnerable women and children, who often have fallen through the cracks of other public health safety nets.

Full implementation of the Affordable Care Act with continuation of the Ryan White Program will dramatically improve health access and outcomes for many more women, infants, children, and youth living with HIV disease.

Proposed Consolidation

The medical and supportive services provided by Ryan White Part D are unique and are not currently being provided by other parts of the Ryan White Program, including Ryan White Part C. These services are uniquely tailored to address the needs of women, including HIV positive pregnant women, HIV exposed infants, children and youth living with HIV/AIDS. The proposed consolidation of Part D funding into Part C in the Federal budget would eliminate a strong safety net for our most vulnerable populations and weaken the systems of care Part D programs have created and invested in for more than 25 years. Furthermore, the loss of Part D funds in some community areas would profoundly impact access to comprehensive HIV care and treatment for women, infants, children and youth. Many of the population served by Part D will be lost or never enter into care. We will not make progress in ending HIV/AIDS in this country without supporting all of the Parts of Ryan White.

Conclusion

These are difficult economic times, and we recognize the considerable fiscal constraints Congress faces in allocating limited Federal dollars as well as the need to reduce administrative burdens associated with the overall operational aspects of Ryan White programs. However, it is unclear how the proposed consolidation of Part D funding into Part C of the program will be implemented to ensure the continuation of the delivery of life-saving HIV/AIDS care and treatment to the most vulnerable populations without destabilizing existing models of care created to address the unique needs of these populations. Without the Ryan White Part D program, many of these medically-underserved women, infants, children and youth would not receive the vital primary care and support services traditionally provided to them.

The AIDS Alliance for Women, Infants, Children, Youth & Families respectfully requests that the Subcommittee consider this written testimony for the record as you develop your fiscal year 2015 appropriations bill. Thank you.

[This statement was submitted by Dr. Ivy Turnbull, Deputy Executive Director, AIDS Alliance for Women, Infants, Children, Youth & Families.]

PREPARED STATEMENT OF THE AIDS INSTITUTE

Dear Chairman Harkin and Members of the Subcommittee: The AIDS Institute, a national public policy, research, advocacy, and education organization, is pleased to offer comments in support of critical HIV/AIDS and hepatitis programs as part of the fiscal year 2015 Labor, Health and Human Services, Education, and Related Agencies appropriation measure. We thank you for supporting these programs over the years, and hope you will do your best to adequately fund them in the future in order to provide for and protect the health of many Americans.

HIV/AIDS remains one of the world's worst health pandemics. According to the CDC, in the U.S. over 636,000 people have died of AIDS and there are 50,000 new infections each year. A record 1.1 million people in the U.S. are living with HIV. Persons of minority races and ethnicities are disproportionately affected. African Americans, who make up just 12 percent of the population, account for 44 percent of new infections. HIV/AIDS disproportionately affects low income people; nearly 90 percent of Ryan White Program clients have a household income of less than 200 percent of the Federal Poverty Level.

The U.S. government has played a leading role in fighting HIV/AIDS, both here and abroad. The vast majority of the discretionary programs supporting domestic HIV/AIDS efforts are funded through this Subcommittee. We are keenly aware of current budget constraints and competing interests for limited dollars, but programs that prevent and treat HIV are inherently in the Federal interest as they protect the public health against a highly infectious virus. If not adequately funded, there will certainly be increased infections, more deaths, and higher health costs.

With the advent of antiretroviral medicines, HIV has turned from a near certain death sentence to a treatable chronic disease if people have access to consistent and affordable healthcare and medications. Through prevention, care and treatment, and research we now have the ability to actually end AIDS. In 2011, a ground-breaking clinical trial (HPTN 052)—named the scientific breakthrough of the year by Science magazine—found that HIV treatment not only saves the lives of people with HIV, but also reduces HIV transmission by more than 96 percent—proving that HIV

treatment is also HIV prevention. In order to realize these benefits, people with HIV must be diagnosed through testing, and linked to and retained in care and treatment.

We also have a National HIV/AIDS Strategy that sets clear goals and priorities, and brings the Federal agencies addressing HIV together to ensure resources are well coordinated. Over the past 30 years we have made great progress in the fight against HIV/AIDS and are truly at a tipping point. However, without stable and adequate funding that progress is in jeopardy, as well as the lives of millions who are or will be infected.

The Ryan White Program

The Ryan White HIV/AIDS Program provides some level of medical care, drug treatment, and support services to approximately 554,000 low-income, uninsured, and underinsured individuals with HIV/AIDS. With people living longer and continued new diagnoses, the demands on the program continue to grow and many needs remain unmet. According to the CDC, only 37 percent of people living with HIV in the U.S. are retained in HIV care, only 33 percent have been prescribed antiretroviral treatment, and only 25 percent are virally suppressed. We have a long way to go before we can realize the dream of an AIDS-free generation. With continued funding we can improve these numbers and health outcomes.

The AIDS Drug Assistance Program (ADAP), one component of the Ryan White Program, provides States with funds to pay for medications for over 200,000 people. Over the last couple of years, as more infections were identified due to increased HIV testing and people lost their jobs and health insurance, demand on the program far outpaced its budget. This led to ADAP wait lists of 9,300 people. We are thankful that President Obama and Congress allocated additional funds, which when combined with assistance from pharmaceutical companies has virtually eliminated the wait list. With inadequate funding that could all change.

We urge you to ensure that ADAP and the rest of the Ryan White Program receive adequate funding to keep up with the growing demand. According to NASTAD, enrollment in ADAP increased by 8 percent between fiscal year 2012 and fiscal year 2013, and utilization reached its highest level ever. With this increased demand for medications comes a corresponding increase in medical care and support services provided by all other parts of the program.

As the Affordable Care Act (ACA) is implemented, there will be expanded opportunities for healthcare coverage for some Ryan White clients. While it will result in some cost shifting for medications and primary care, it will never be a substitute for the Ryan White Program. Over 70 percent of Ryan White Program clients today have some sort of insurance coverage, mostly through traditional Medicaid and Medicare. Their coverage will not change with health reform; the Ryan White Program will be needed as it is today. The Medicaid expansion is a State option and not all States are moving forward with it at this time. As ACA is implemented, benefits will differ from State to State and there will be many gaps that will have to be filled by the Ryan White Program. Plans will not offer all of the comprehensive essential support services that the Program does, such as case management, transportation, and nutritional services, that are needed to ensure retention in medical care and adherence to drug treatment. This approach of coordinated, comprehensive, and culturally competent care leads to better health outcomes. Therefore, the Ryan White Program, while it may need to change in the future, must continue and must be adequately funded.

The AIDS Institute urges the Committee to reject the President's budget proposal to eliminate dedicated funding for Part D of the Ryan White Program and transfer it to Part C. Part D serves women, infants, children, and youth with HIV/AIDS and is a well-established system of care that has worked since 1988 in nearly eliminating perinatal infection and providing medical care and family-centered support that helps ensure these vulnerable populations remain in care and adherent to their medications. With youth, particularly black gay youth, being the only population experiencing an increase in HIV incidence, we cannot afford to dramatically alter the only Ryan White Program part dedicated to their care. While changes to the structure of the Ryan White Program might be needed in the future, it should not be done through the appropriations process and not without community input.

CDC HIV Prevention

As a Nation, we must do more to prevent new infections, but we only allocate 3 percent of our HIV/AIDS spending towards prevention. All the care and treatments costs would be saved if we did not have the infections in the first place. Preventing just one infection would save \$402,000 in future lifetime medical costs. Preventing

all the new 50,000 cases in just 1 year would translate into an astounding \$20 billion saved in lifetime medical costs.

With more people living with HIV than ever before, there are greater chances of HIV transmission. The CDC and its grantees have been doing their best with limited resources to keep the number of infections stable, but that is not good enough. It is focusing resources on those populations and communities most impacted by HIV and investing in those programs that will prevent the most number of infections. This includes young black gay men, who experienced a 38 percent increase in new infections from 2008–2010 and is a population which merits additional attention and resources.

With over 200,000 people living with HIV who are unaware of their infection, the CDC is also focused on increased testing programs. Testing people early and linking them to care and treatment is critical not only for their own health outcomes but also in preventing new infections.

The CDC estimates that in 2010, 26 percent of all new HIV infections occurred among youth ages 13 to 24. Nearly 75 percent of those infections were among young gay men. Clearly, we must do a better job of educating the youth of our Nation, including gay youth, about HIV. Adequately funding the HIV Division of Adolescent and School Health (DASH) will help address this critical need.

CDC Viral Hepatitis Prevention

Given that more than 5.3 million people in the U.S. are living with hepatitis B and/or C and 65–75 percent of them are undiagnosed, funding for the Hepatitis Prevention Division must be increased. With a 25 percent mortality rate among affected baby boomers—those born between 1945 and 1965—and with prevalence rates two times higher than whites for African Americans in that birth cohort, we cannot afford to inadequately fund this program. The current amount of only \$29 million is far too small to conduct testing, surveillance, and other hepatitis prevention and educational programs for the entire country. Currently there is no national surveillance system to track hepatitis infections and testing programs are inadequate; therefore the majority of the millions affected will never become aware of their disease until they present with liver cancer or cirrhosis. Increased funding for testing and surveillance could bring more people into care and treatment allowing them the chance to receive new and more effective treatments that actually can result in curing their hepatitis.

HIV/AIDS Research at the National Institutes of Health (NIH)

While we have made great strides in the area of HIV/AIDS, there is still a long way to go. Continued research at the NIH is necessary to learn more about the disease and to develop new treatments and prevention tools. Recent breakthroughs have provided functional cures in a few instances in infants and adults. Work also continues on vaccine research as scientists learn more about the disease, and combined with cure research it may be possible to see the end of AIDS if funding is maintained.

Again, we thank you for your continued support of these programs critical to so many individuals and communities nationwide. We have made great progress, but we are still far from achieving our goal of an AIDS-free generation. We now have the tools, but we need continued leadership and the necessary resources to realize our goal. Thank you.

[This statement was submitted by Carl E Schmid II, Deputy Executive Director, The AIDS Institute.]

PREPARED STATEMENT OF THE AIDS UNITED

I am Ronald Johnson, Vice President of Policy and Advocacy at AIDS United writing in reference to HIV funding at the Department of Health and Human Services, on behalf of the 32 organizational members of our Public Policy Committee and our over 90 programmatic directly funded organizational grantees all of whom are many of the leading AIDS Service Organizations across the Nation. AIDS United is a national organization that seeks to end the AIDS epidemic in the United States by combining private-sector fundraising, philanthropy, coalition building, public policy expertise, and advocacy—as well as a network of passionate local and State partners—to respond effectively and efficiently to the HIV/AIDS epidemic in the communities most impacted by the epidemic. Through its unique Public/Private Partnerships, Public Policy Committee and targeted special grant-making initiatives, AIDS United and its partners reach over 300 grassroots organizations. These organizations provide HIV prevention, care, treatment, and support services to underserved

individuals and populations most impacted by the HIV/AIDS epidemic including communities of color, women and gay and bisexual men and men who have sex with men (MSM) as well as education and training to providers of treatment services. It is our request that you increase funding for the Department of Health and Human Services by \$7.361 billion in fiscal year 2015. This request includes an increase of \$931 million over fiscal year 2014 throughout the detailed request listed below.

AIDS United understands the fiscal environment that the country is wrestling with right now is austere. However, we know that investment in prevention and retention in HIV care are critical in lowering the number of new infections in the domestic HIV epidemic. As competing budget priorities are weighed please keep in mind that HIV is 100 percent preventable, if we as a Nation muster the political will and funding to address domestic HIV on level that meets the needs of the epidemic. The increased funding for the domestic HIV/AIDS portfolio in fiscal year 2015 will help reach the National HIV/AIDS Strategy (NHAS). We look forward to working with you and your Administration in the coming year on the fiscal year 2015 budget.

The Ryan White Program

Early and reliable access to HIV care and treatment is cost effective and helps patients with HIV live healthy and productive lives. The needs of the Ryan White Program (RWP) continue to grow, even with the beginning of the implementation of the Affordable Care Act (ACA) and the integration of the RWP there may still be many needs unmet. In order to improve the continuum of care and progress toward an AIDS-free generation, continued, robust funding for all parts of the Ryan White Program in fiscal year 2015 will be necessary. The Ryan White Program works in conjunction with Medicaid, Medicare and now the Affordable Care Act, and as a result we believe more people living with HIV will be able to receive and remain in care and on treatment.

It will take some time for enrollment to occur and assess the impact of the ACA on the Ryan White Program. In the meantime, we urge you to fund the Ryan White Program at a total of \$2.44 billion in fiscal year 2015, an increase of \$123 million over fiscal year 2014, distributed in the following manner: Part A: \$687 million, Part B (Care): \$428 million, Part B (ADAP): \$943 million, Part C: \$225 million, Part D: \$85 million, Part F/AETC: \$35 million, Part F/Dental \$15 million.

AIDS United disagrees with the President's budget request and does not support the consolidation of Part D with Part C. We believe it should only be considered as part of a larger authorization process after key data questions about the value of consolidation are answered.

HIV Prevention

CDC HIV Prevention and Surveillance

There still are 50,000 new infections annually and about 1 in 6 people living with HIV do not know they have the virus. Gay, bisexual, and other men who have sex with men (MSM) account for 66 percent of all new HIV infections. Between 2008 and 2010, infections among MSM increased by 12 percent, and among MSM aged 13–24 years by 22 percent. Black and Latino MSM, and especially those who are young continue to be disproportionately affected. While we are making progress in decreasing new infections among women, black women accounted for 64 percent of women infected in 2010. Black and Hispanic women ages 13–24 accounted for 82 percent of young women living with HIV in 2010 even though together they represent only about 30 percent of women these ages.

Investing in HIV prevention today translates into less spending in the future on care and treatment. Most CDC funding is distributed to the primary implementers of prevention activities—State and local public health departments and community based organizations. Increased investments are critical to expand comprehensive prevention programs and to successfully reach individuals at highest risk for infection. Early detection of HIV, linkage and retention in care, and adherence to treatment will suppress individual and community viral loads. Adequate resources are necessary to carry out increased HIV testing programs, targeted interventions, public education campaigns, and surveillance activities needed to track new infections and CD4 and viral load reporting.

For fiscal year 2015, we request an increase of \$55 million over fiscal year 2014 for a total of \$812.7 million for the CDC Division of HIV prevention and surveillance activities.

Division of Adolescent and School Health (DASH)

One-third of all new HIV infections are among young people under the age of 29, the largest share of any age group. DASH is the only federally funded adolescent health program in our Nation's schools, helping education agencies provide school districts and individual schools with the tools to implement high-quality, effective, and sustainable programs to reduce HIV and other STD infections in adolescents. Increased funding would help expand this vital infrastructure beyond the currently funded 36 State or local education agencies.

We request that the CDC Division of Adolescent and School Health receive a total of \$50 million, an increase of \$21 million over fiscal year 2014 final funding. This request includes \$3 million in evaluation transfer funds.

CDC STD Prevention

Given the strong link between HIV and other STDs, including high rates of co-infection among certain populations, an increased investment in STD programs is an essential component of HIV prevention. Investments in STD prevention and treatment further the National HIV/AIDS Strategy's goal of reducing new infections.

We request an increase of \$54 million for a total of \$211 million for the CDC's Division of STD Prevention in fiscal year 2015.

CDC Viral Hepatitis Prevention

CDC estimates that up to 5.3 million people are living with hepatitis B (HBV) and/or hepatitis C (HCV) in the U.S., and as many as 75 percent are not aware of their infection. In 2010 alone, 35,000 Americans were newly infected with HBV and 17,000 with HCV. It is estimated that 10 percent of people living with HIV are co-infected with hepatitis B and 25 percent are co-infected with hepatitis C.

We request an increase of \$31 million above the fiscal year 2014 level, for a total of \$60 million for the CDC's Division of Viral Hepatitis.

Access to Sterile Syringes

About 1 of 12 new infections (8.6 percent) of HIV in 2011 was related to injection drug use, a 28 percent decrease from 2008. One factor leading to this reduction has been syringe exchange programs. Numerous studies have shown syringe exchange programs can be an evidence-based and cost-effective means to lower HIV and hepatitis infections, reduce the use of illegal drugs and help connect people to medical treatment, including substance abuse treatment. In a May 2012 letter, the President's Advisory Council on HIV/AIDS also supported ending the Federal ban on syringe exchange and noted that doing so is supported by public health, HIV/AIDS, viral hepatitis and harm reduction communities as well.

We urge you to add language to end the ban on the use of Federal funds for syringe exchange programs and to maintain language that allows the use of local funds for syringe exchange programs in the District of Columbia.

Abstinence-only

We also request that you eliminate the funding for failed abstinence-only-until-marriage programs.

HIV/AIDS Research at the National Institutes of Health (NIH)

Research continues until better, more effective and affordable prevention and treatment regimens—and eventually a cure—are developed and universally available. For the U.S. to maintain its position as the global leader in HIV/AIDS research for the 33 million people globally of whom 1.1 million are Americans living with HIV, we must invest adequate resources in the NIH. NIH AIDS research has produced startling advances, including the HPTN 052 study of the prevention effects of treatment that was named Breakthrough of the Year by Science magazine, improved treatment programming and the first partially effective HIV vaccine, continued AIDS research funding is essential.

In line with the Trans-NIH AIDS Research By-Pass Budget Estimate for fiscal year 2013, please include \$3.6 billion for HIV research at the NIH, an increase of \$610 million over fiscal year 2014.

Minority HIV/AIDS Initiative

HIV/AIDS continues to impact communities of color at an alarming rate. According to the CDC, African Americans, more than any other racial/ethnic group, continue to bear the greatest burden of HIV in the U.S. While blacks represent approximately 12 percent of the total population, they accounted for 44 percent of all new HIV infections in 2010. Hispanics represent approximately 16 percent of the total population, but accounted for 21 percent of all new HIV infections. In the Asian Pa-

cific Islander, and Native American communities the numbers of HIV infection are just as startling.

We request that the MAI be funded at \$610 million in fiscal year 2015. We note that most of these funds are contained within the budgets of the programs described above.

PREPARED STATEMENT OF THE ALZHEIMER'S ASSOCIATION

The Alzheimer's Association appreciates the opportunity to comment on the fiscal year 2015 appropriations for Alzheimer's disease research, education, outreach and support at the U.S. Department of Health and Human Services.

Founded in 1980, the Alzheimer's Association is the world's leading voluntary health organization in Alzheimer's care, support and research. Our mission is to eliminate Alzheimer's disease and other dementias through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health. As the world's largest non-profit funder of Alzheimer's research, the Association is committed to accelerating progress of new treatments, preventions and, ultimately, a cure. Through our funded projects and partnerships, we have been part of every major research advancement over the past 30 years. Likewise, the Association works to enhance care and provide support for all those affected by Alzheimer's and reaches millions of people affected by Alzheimer's and their caregivers.

Alzheimer's Impact on the American People and the Economy

In addition to the human suffering caused by the disease, Alzheimer's is creating an enormous strain on the healthcare system, families and the Federal budget. Alzheimer's is a progressive brain disorder that damages and eventually destroys brain cells, leading to a loss of memory, thinking and other brain functions. Ultimately, Alzheimer's is fatal. Currently, Alzheimer's is the sixth leading cause of death in the United States and the only one of the top ten without a means to prevent, cure or slow its progression. Over five million Americans are living with Alzheimer's, with 200,000 under the age of 65.

A Federal commitment can lower costs and improve health outcomes for people living with Alzheimer's today and in the future. By making Alzheimer's a national priority, we can create the same successes that we have been able to achieve in other diseases that have been prioritized by the Federal Government. Leadership from the Federal Government has helped to lower the number of deaths from other major diseases like heart disease, HIV/AIDS, many cancers, heart disease and stroke. While those deaths have declined, deaths from Alzheimer's have increased 68 percent between 2000 and 2010.

Alzheimer's is the most expensive disease in America. In fact, an NIH-funded study in the New England Journal of Medicine confirmed that Alzheimer's is the most costly disease in America, with costs set to skyrocket at unprecedented rates. If nothing is done, as many as 16 million Americans will have Alzheimer's disease by 2050 and costs will exceed \$1.2 trillion (not adjusted for inflation), creating an enormous strain on the healthcare system, families and the Federal budget. The expense involved in caring for those with Alzheimer's is not just a long-term problem. As the current generation of baby boomers age, near-term costs for caring for those with Alzheimer's will balloon, as Medicare and Medicaid will cover more than two-thirds of the costs for their care.

Due to these projected increases, the graying of America threatens the bankrupting of America. Caring for people with Alzheimer's will cost all payers—Medicare, Medicaid, individuals, private insurance and HMOs—\$20 trillion over the next 40 years, enough to pay off the national debt and still send a \$10,000 check to every man, woman and child in America. In 2014, America will spend an estimated \$214 billion in direct costs for those with Alzheimer's, including \$150 billion in costs to Medicare and Medicaid. Average per person Medicare costs for those with Alzheimer's and other dementias are three times higher than those without these conditions. Average per senior Medicaid spending is 19 times higher.

A primary reason for these costs is that Alzheimer's makes treating other diseases more expensive, as most individuals with Alzheimer's have one or more co-morbidity that complicate the management of the condition(s) and increase costs. For example, a senior with diabetes and Alzheimer's costs Medicare 81 percent more than a senior who only has diabetes. Nearly 30 percent of people with Alzheimer's or another dementia who have Medicare also have Medicaid coverage, compared with 11 percent of individuals without Alzheimer's or dementia. Alzheimer's disease is also ex-

tremely prevalent in nursing homes, where 64 percent of Medicare residents live with the disease.

With Alzheimer's, it is not just those with the disease who suffer—it is also their caregivers and families. In 2013, 15.5 million family members and friends provided unpaid care valued at over \$220 billion. Caring for a person with Alzheimer's takes longer, lasts longer, is more personal and intrusive, and takes a heavy toll on the health of the caregivers themselves. More than 60 percent of Alzheimer's and dementia caregivers rate the emotional stress of caregiving as high or very high, with one-third reporting symptoms of depression. Caregiving may also have a negative impact on health, employment, income and family finances. Due to the physical and emotional toll of caregiving on their own health, Alzheimer's and dementia caregivers had \$9.3 billion in additional health costs in 2013.

Changing the Trajectory of Alzheimer's

Until recently, there was no Federal Government strategy to address this looming crisis. In 2010, thanks to bipartisan support in Congress, the National Alzheimer's Project Act (NAPA) (Public Law 111–375) passed unanimously, requiring the creation of an annually-updated strategic National Alzheimer's Plan (Plan) to help those with the disease and their families today and to change the trajectory of the disease for the future. The Plan is required to include an evaluation of all federally-funded efforts in Alzheimer's research, care and services—along with their outcomes. In addition, the Plan must outline priority actions to reduce the financial impact of Alzheimer's on Federal programs and on families; improve health outcomes for all Americans living with Alzheimer's; and improve the prevention, diagnosis, treatment, care, institutional-, home-, and community-based Alzheimer's programs for individuals with Alzheimer's and their caregivers. NAPA will allow Congress to assess whether the Nation is meeting the challenges of this disease for families, communities and the economy. Through its annual review process, NAPA has enabled, for the first time, Congress and the American people to answer this simple question: Did we make satisfactory progress this past year in the fight against Alzheimer's?

As mandated by NAPA, the Secretary of Health and Human Services, in collaboration with the Advisory Council on Alzheimer's Research, Care and Services, has developed the first-ever National Plan to Address Alzheimer's Disease in May of 2012 and subsequently released the 2014 Update to the National Plan to Address Alzheimer's Disease this past April. The Advisory Council, composed of both Federal members and expert non-Federal members, is an integral part of the planning process as it advises the Secretary in developing and evaluating the annual Plan, makes recommendations to the Secretary and Congress, and assists in coordinating the work of Federal agencies involved in Alzheimer's research, care, and services.

Having a plan with measurable outcomes is important. But unless there are resources to implement the plan and the will to abide by it, we cannot hope to make adequate progress. If we are going to succeed in the fight against Alzheimer's, Congress must provide the resources the scientists need. Understanding this and following the recommendation of scientists at NIH, Congress passed the Consolidated Appropriations Act of 2014 (Public Law 113–76) which included a \$100 million increase for Alzheimer's research. These funds are a critically needed down payment for needed research and services for Alzheimer's patients and their families.

A disease-modifying or preventive therapy would not only save millions of lives but would save billions of dollars in healthcare costs. Specifically, if a treatment became available in 2015 that delayed onset of Alzheimer's for 5 years (a treatment similar to anti-cholesterol drugs), savings would be seen almost immediately, with Medicare and Medicaid spending reduced by \$42 billion in 2020.

Today, despite the Federal investment in Alzheimer's research, we are only just beginning to understand what causes the disease. Americans are growing increasingly concerned that we still lack effective treatments that will slow, stop, or cure the disease, and that the pace of progress in developing breakthrough discoveries is much too slow to significantly impact on this growing crisis. For every \$26,500 Medicare and Medicaid spends caring for individuals with Alzheimer's, the National Institutes of Health (NIH) spends only \$100 on Alzheimer's research. Scientists fundamentally believe that we have the ideas, the technology and the will to develop new Alzheimer's interventions, but that progress depends on a prioritized scientific agenda and on the resources necessary to carry out the scientific strategy for both discovery and translation for therapeutic development.

For too many individuals with Alzheimer's and their families, the system has failed them, and today we are unnecessarily losing the battle against this devastating disease. Despite the fact that an early and documented formal diagnosis allows individuals to participate in their own care planning, manage other chronic

conditions, participate in clinical trials, and ultimately alleviate the burden on themselves and their loved ones, as many as half of the more than five million Americans with Alzheimer's have never received a formal diagnosis. Unless we create an effective, dementia-capable system that finds new solutions to providing high quality care, provides community support services and programs, and addresses Alzheimer's health disparities, Alzheimer's will overwhelm the healthcare system in the coming years. For example, people with Alzheimer's and other dementias have more than three times as many hospital stays as other older people. Furthermore, one out of seven individuals with Alzheimer's or another dementia lives alone and up to half do not have an identifiable caregiver. These individuals are more likely to need emergency medical services because of self-neglect or injury, and are found to be placed into nursing homes earlier, on average, than others with dementia. Ultimately, supporting individuals with Alzheimer's disease and their families and caregivers requires giving them the tools they need to plan for the future and ensuring the best quality of life for individuals and families impacted by the disease. It is vital that we make the investments in Alzheimer's that will fulfill the goals of the National Alzheimer's Plan. The Alzheimer's Association urges Congress to support an additional \$200 million for research activities and priorities included in the National Alzheimer's Plan required under Public Law 111-375.

Additional Alzheimer's programs

National Alzheimer's Call Center: The National Alzheimer's Call Center, funded by the AoA, provides 24/7, year-round telephone support, crisis counseling, care consultation, and information and referral services in 140 languages for persons with Alzheimer's, their family members and informal caregivers. Trained professional staff and master's-level mental health professionals are available at all times. In the 12 month period ending July 31, 2013, the Call Center handled over 300,000 calls through its national and local partners, and its online message board received over 40,000 visits a month. Additionally, the Association provides a two-to-one match on the Federal dollars received for the call center. The Alzheimer's Association urges Congress to support \$1.3 million for the National Alzheimer's Call Center.

Healthy Brain Initiative (HBI): The Centers for Disease Control and Prevention's (CDC) HBI program works to educate the public, the public health community and health professionals about Alzheimer's as a public health issue. Although there are currently no treatments to delay or stop the deterioration of brain cells caused by Alzheimer's, evidence suggests that preventing or controlling cardiovascular risk factors may benefit brain health. In light of the dramatic aging of the population, scientific advancements in risk behaviors, and the growing awareness of the significant health, social and economic burdens associated with cognitive decline, the Federal commitment to a public health response to this challenge is imperative. The fiscal year 2014 omnibus funding bill increased funding for HBI by \$1.5 million in order to bolster caregiver surveillance. The Alzheimer's Association urges Congress to support \$3.3 million for the Healthy Brain Initiative.

Alzheimer's Disease Supportive Services Program (ADSSP): The ADSSP at the AoA supports family caregivers who provide countless hours of unpaid care, thereby enabling their family members with Alzheimer's and dementia to continue living in the community. The program develops coordinated, responsive and innovative community-based support service systems for individuals and families affected by Alzheimer's. The Alzheimer's Association urges Congress to support \$13.4 million for the Alzheimer's Disease Supportive Services Program.

Conclusion

The Association appreciates the steadfast support of the Subcommittee and its priority setting activities. We look forward to continuing to work with Congress in order to address the Alzheimer's crisis. We ask Congress to address Alzheimer's with the same bipartisan collaboration demonstrated in the passage of the National Alzheimer's Project Act (Public Law 111-375) and with a commitment equal to the scale of the crisis.

PREPARED STATEMENT OF THE ALZHEIMER'S FOUNDATION OF AMERICA

On behalf of the Alzheimer's Foundation of America (AFA), a national nonprofit organization that unites more than 1,600 member organizations nationwide with the goal of providing optimal care and services to individuals confronting dementia, and to their caregivers and families, we are making the following appropriations requests for programs impacting Alzheimer's disease caregiving services and research in the fiscal year 2015 budget. These Federal programs and support services are

vital to providing necessary care supports and promoting best practice tools to family caregivers, and advancing promising clinical research.

Specifically, AFA makes the following appropriations requests for these specific agencies and programs:

National Institutes of Health (NIH):

Adequate investment in scientific research that could lead to new treatments and cures is critical in order to reduce long-term healthcare costs. We appreciated Congress' efforts in the fiscal year 2014 budget which provided an additional \$80 million for clinical research into Alzheimer's disease. AFA urges the Committee to build on this modest increase and provide an additional \$500 million for Alzheimer's disease research and enhanced investments for caregiving supports and services in fiscal year 2015. Additional resources will fund effective pharmaceutical therapies to prevent, cure or slow the progression of Alzheimer's disease, and provide the necessary seed money to implement and facilitate the ambitious and laudable goals of the "National Plan to Address Alzheimer's Disease."

AFA also urges the Committee to include \$32 billion in total funding for NIH, as recommended by the Ad Hoc Group for Medical Research and a bi-partisan group of Members of Congress including Reps. McKinley, Davis, Carson and King. Even if funding remains flat, NIH's actual budget will still be effectively cut as spending will not be able to keep pace with biomedical inflation.

—National Institute on Aging (NIA): Since NIA is the primary agency responsible for Alzheimer's disease research, AFA urges the Committee to include a minimum budget appropriation of \$1.7 billion, an increase of \$500 million for NIA for fiscal year 2015.

NIA leads the national scientific effort to understand the nature of aging in order to promote the health and well-being of older adults, whose numbers are projected to rise dramatically in the coming years due to increased life expectancy and the aging of the baby boom generation.

This funding is essential to increase the NIA's baseline to a level consistent with comparable research initiatives conducted under the auspices of NIH, and to support additional research into Alzheimer's disease and related dementias. This is particularly vital, as Alzheimer's disease holds the infamous position of being the only one of the top ten leading causes of death with a rising death rate.

Administration on Community Living (ACL) programs:

AFA would like to single out the following programs within the ACL that are critical to individuals with Alzheimer's disease and their caregivers:

—National Family Caregiver Support Program (NFCSP): NFCSP provides grants to States and territories, based on their share of the population aged 70 and over, to fund a range of supportive services that assist family and informal caregivers in caring for their loved ones at home for as long as possible, thus providing a more person-friendly and cost-effective approach than institutional care. Last year's appropriation of \$146 million cannot possibly keep up with the need for respite care as our population ages. AFA urges that \$156 million be appropriated in fiscal year 2015 to support this important program.

—Lifespan Respite Care Program (LRCP): AFA urges the Committee to commit \$10 million to LRCP in fiscal year 2015. LRCP provides competitive grants to State agencies working with Aging and Disability Resource Centers and non-profit State respite coalitions and organizations to make quality respite care available and accessible to family caregivers regardless of age or disability by establishing State Lifespan Respite Systems.

—Alzheimer's Disease Demonstration Grants (ADDG): Existing resources for the Alzheimer's population and their caregivers are already tapped out, at a time when demand is continuing to rise in line with the skyrocketing incidence of this disease. AFA supports funding of \$9 million for the ADDG program which fosters the development of innovative models of care for persons with Alzheimer's disease and their caregivers and is designed to improve responsiveness of the home and community based care system to persons with dementia including underserved minority, rural and low-income persons.

—Alzheimer's Disease Initiative (ADI): AFA supports the President's fiscal year 2015 budget request of \$12 million for this program that for services such as support for caregivers in the community, improving healthcare provider training, and raising public awareness. Research shows that education, counseling and other support for family caregivers can delay institutionalization of loved ones and improve a caregiver's own physical and mental well-being—thus reducing costs to families and government. In addition, AFA supports an appropriation of \$5 million for the Alzheimer's Disease Communications Campaign.

Food and Drug Administration (FDA):

AFA supports FDA funding in fiscal year 2015 that fully restores the agency's base lost in the fiscal year 2013 sequester and provides for a modest additional funding above that level. Specifically, we are requesting budget authority appropriations of \$2.78 billion for FDA, \$223 million above fiscal year 2014 appropriated spending.

FDA activities are necessary to ensure proper evaluation and testing of pharmaceutical treatments for Alzheimer's disease before these drugs enter the market. In addition, with the science of this disease becoming more complex, FDA plays an increasingly important and often resource-intensive role in pharmaceutical innovation. AFA's request is in line with the appropriations request being recommended by the Alliance for a Stronger FDA and the Coalition to Accelerate Cure/Treatments for Alzheimer's Disease (ACT-AD).

As we work toward meeting the goal of the historic "National Plan to Address Alzheimer's Disease" to prevent and effectively treat Alzheimer's disease by 2025, adequate resources must be committed to meet the pending challenge. Taken together, these programs represent a lifeline to families who care for a loved one with Alzheimer's disease and provide hope to Americans living with the disease and those who face it in the future that there will be funding for a cure.

AFA thanks the Committee for the opportunity to present its recommendations and looks forward to working with you through the appropriations process. Please contact me or Eric Sokol, AFA's vice president of public policy, at esokol@alzfdn.org if you have any questions or require further information.

[This statement was submitted by Hon. Charles J. Fuschillo, Jr., Chief Executive Officer, Alzheimer's Foundation of America.]

PREPARED STATEMENT OF THE AMERICA ACHIEVES

Chairman Harkin and Ranking Member Moran: Results for America (RFA), an initiative of America Achieves, is pleased to present our recommendations for fiscal year 2015 to the Senate Appropriations Subcommittee on the Departments of Labor, Health and Human Services, and Education.

The attached letter and table outline the evidence-based policies and programs RFA and our coalition partners are requesting from your Subcommittee for fiscal year 2015 to help improve outcomes for young people, their families, and communities.

Over the last several years, all levels of government have taken critical steps to change the way taxpayer dollars are invested to ensure limited resources are driven toward high-impact solutions that get results. To significantly improve outcomes for young people, their families, and communities in the context of constrained resources and mounting demands, the Federal Government should identify and invest in "what works," and be a catalyst for, and funder of, effective and innovative solutions that produce greater social impact. While public debate focuses on more or less resources, it is critical to identify how to get better results from existing resources. This approach has a strong history of bipartisan support. President George W. Bush's Administration put a priority on improving the performance of Federal programs and encouraged more rigorous evaluations to assess their effectiveness. The Obama Administration has built on this effort by supporting an increasing number of evidence and evaluation-based policies and programs. Mayors and governors from both parties across the country are also increasingly using data and evidence to steer public dollars to more effectively address needs in their communities and States.

I want to thank you for the positive steps you have taken over the last several years toward building a strong evidence-based, results-driven policy agenda and look forward to working with you in the months and years ahead.

On March 13, 2014, the following 72 organizations sent a letter to Chairwoman Mikulski, Chairman Rogers, and Ranking Members Shelby and Lowey requesting bill and report language to invest Federal funds in what works. The letter and a summary of our recommendations for fiscal year 2015 for the House Appropriations Subcommittee on the Departments of Labor, Health and Human Services, and Education follow:

INVEST IN WHAT WORKS

Dear Chairwoman Mikulski, Chairman Rogers, Ranking Member Shelby, and Ranking Member Lowey:

We are writing to urge you to include the attached “Invest in What Works” provisions in the subcommittee appropriations bills and reports for the Departments of Labor, Health and Human Services, Education, and Related Agencies, and the Departments of Commerce, Justice, Science, and Related Agencies for fiscal year 2015.

America is facing enormous social and economic shifts, budget constraints at all levels of government, significant demographic changes, and an increasingly globally competitive, changing workforce. While the recently-enacted fiscal year 14 omnibus appropriations law includes an unprecedented commitment to evidence and evaluation, we must continue to focus on improving the ways in which Federal taxpayer dollars are spent in fiscal year 15 and beyond in order to be able to significantly improve outcomes for young people, their families, and communities.

We thank you for the positive steps you have taken over the last several years toward building a strong evidence-based, results-driven policy agenda and encourage you to reaffirm your commitment to improving outcomes for all Americans by incorporating the attached “Invest in What Works” recommendations in the fiscal year 2015 appropriations bills and committee reports.

Thank you for your consideration of our requests.

Sincerely,

AdvancEd	Jane Addams Resource Corporation (IL)
AIDS United	KIPP
Alliance College-Ready Public Schools	Knowledge Alliance
Amos House (RI)	LISC
Aspire Public Schools	Metropolitan Family Services (IL)
BELL	Mile High United Way
Breakthrough Schools	National Forum to Accelerate Middle-
Brighton Center, Inc. (KY)	Grades Reform
Capital Impact Partners	National Fund for Workforce Solutions
Center for Employment Opportunities	New Profit Inc.
Center for Research and Reform in	North County Lifeline (CA)
Education, Johns	Operation ABLE (MI)
Hopkins University	Project for Pride in Living, Inc. (MN)
Champlain Housing Trust (VT)	Providence Housing Authority
Cincinnati Works	Reading Partners
Citizen Schools	REDF
City First Homes and City First	Results for America
Enterprises (DC)	Rocketship Education
City Year, Inc.	Rubicon Programs
CLUE (Comunidades Latinas Unidas En	Safer Foundation (IL)
Servicio) (MN)	Santa Maria Community Services (OH)
CommonBond Communities (MN)	SER-Jobs for Progress of the Texas Gulf
Communities in Schools	Coast, Inc.
Community Action Duluth	SER Metro Detroit, Jobs for Progress,
Community Training and Assistance	Inc.
Center (CTAC)	Southeast Community Services Inc. (IN)
Congreso de Latinos Unidos Inc.	Southwest Solutions (MI)
CSH	StriveTogether
Edna Martin Christian Center (IN)	Success for All Foundation
Education Northwest	Teach For America
Emerge Community Development (MN)	Teach Plus
Family Resources Community Action	The SEED Foundation
(RI)	Turnaround For Children
Focus: HOPE (MI)	United Way of Greater Cincinnati
Gestalt Community Schools	United Way for Southeastern Michigan
Greater Southwest Development	Urban Alliance
Corporation (IL)	U.S. Soccer Foundation
GreenLight Fund	Venture Philanthropy Partners
Home Start, Inc. (CA)	Volunteers of America Texas Inc.
Housing Leadership Council, Inc. (FL)	Year Up
IDEA Public Schools	Youth Villages

RECOMMENDATIONS FOR FISCAL YEAR 2015

U.S. DEPARTMENT OF LABOR

Workforce Innovation Fund—with up to \$10,000,000 for Pay for Success initiatives	\$60,000,000
Agency-Wide Evaluation Set-Aside—1 percent of discretionary funds to be used by the	
Chief Evaluation Office for program evaluations	

RECOMMENDATIONS FOR FISCAL YEAR 2015—Continued

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

Head Start Designation Renewal System—set-aside within the total provided for Head Start	\$25,000,000
Mental Health Service Block Grant Program—at least 5 percent set-aside for evidence-based programs to address the needs of individuals with early serious mental illness	

U.S. DEPARTMENT OF EDUCATION

First in the World—with \$20,000,000 set-aside for minority-serving institutions	\$100,000,000
Investing in Innovation (i3)—language directing the Department to provide continuation grants to certain current i3 grantees that are demonstrating strong interim outcomes but have not had sufficient time to achieve their program goals	\$215,000,000
Replication and Expansion of High Quality Charter Schools—set-aside within the total provided for the Charter School Program	\$75,000,000
Title II-A—Effective Teachers and Leaders—language requiring the Secretary to set aside 25 percent of ESEA Title II-A funds for competitive grants to States, high need local school districts, and national non-profit organizations, including 10 percent set-aside for the Supporting Effective Educator Development (SEED) program	
Titles I and II—language directing States to set-aside 1 percent of Title I and II funds, prior to distribution to local school districts (LSD), and to award these funds on a competitive basis to the 25 percent of LSD's with the highest poverty levels through a tiered funding frame-work	
IDEA Results-Driven Accountability Grants—set-aside to implement promising evidence-based reforms	\$100,000,000
Agency-Wide Evaluation Set-aside—1 percent of discretionary funds (not including Pell Grants) for program evaluations	
Title II—Whole School Reform—language allowing local school districts to use School Improvement Grants to implement a whole-school reform strategy for a school using an evidence-based strategy that ensures whole-school reform is undertaken in partnership with a strategy developer offering a whole-school reform program that is based on at least a moderate level of evidence that the program will have a statistically significant effect on student outcomes as defined by the Department's General Administrative Regulations	

CORPORATION FOR NATIONAL AND COMMUNITY SERVICE

Social Innovation Fund—including up to 20 percent set-aside for Pay for Success initiatives and language directing CNCS to (1) provide renewal grants to current SIF grantees that are demonstrating significant interim outcomes but have not had sufficient time to achieve their program goals and (2) permit current SIF grantees to be eligible to apply for additional SIF funds for projects not currently funded by SIF	\$80,000,000
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GENERAL PROVISION

Performance Partnership Pilot—language establishing up to 10 Performance Partnership Pilots to improve outcomes for disconnected youth	
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[This statement was submitted by Michele Jolin, Managing Partner, America Achieves.]

PREPARED STATEMENT OF THE AMERICAN ACADEMY OF FAMILY PHYSICIANS

The American Academy of Family Physicians (AAFP), representing 110,600 family physicians and medical students nationwide, urges the Senate Appropriations Subcommittee on Labor, Health and Human Services, and Education to invest in our Nation's primary care physician workforce in the fiscal year 2015 appropriations bill to promote the efficient, effective delivery of healthcare by providing these appropriations for the Health Resources and Services Administration and the Agency for Healthcare Research and Quality:

—\$71 million for Health Professions Primary Care Training and Enhancement authorized under Title VII, Section 747 of the Public Health Service Act (PHSA);

- \$10 million for Teaching Health Centers development grants (PHSA Title VII, § 749A);
- \$4 million for Rural Physician Training Grants (PHSA Title VII, § 749B);
- \$100 million for the National Health Service Corps (PHSA § 338A, B, & I);
- \$375 million for the Agency for Healthcare Research and Quality (PHSA § 487(d)(3), SSA § 1142); and
- \$3 million for the National Health Care Workforce Commission (ACA § 5101).

Founded in 1947, the AAFP is dedicated to preserving and promoting the science and art of family medicine and ensuring high-quality, cost-effective healthcare for patients of all ages. The AAFP appreciates the opportunity to comment on the fiscal year 2015 appropriations levels needed to achieve those important goals.

HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA)

Our Nation faces a shortage of primary care physicians. The total number of office visits to primary care physicians is projected to increase from 462 million in 2008 to 565 million in 2025 requiring nearly 52,000 additional primary care physicians by 2025.¹ The Health Resources and Services Administration (HRSA) is the Federal agency charged with administering the health professions training programs authorized under Title VII of the Public Health Services Act and first enacted in 1963. We urge the Committee to restore funding for discretionary HRSA programs to the fiscal year 2010 level of \$7.48 billion in the fiscal year 2015 bill.

Title VII Health Professions Training Programs.—In the last 50 years, Congress has revised the Title VII authority in order to meet our Nation's changing healthcare workforce needs. We now face burgeoning demand for family physicians and must work to increase their number in the United States. As the only medical specialty society devoted entirely to primary care, the AAFP is gravely concerned that a failure to provide adequate funding for the Title VII, Section 747 Primary Care Training and Enhancement (PCTE) program, will destabilize education and training support for family physicians. Between 1998 and 2008, in spite of persistent primary care physician shortages, family medicine lost 46 training programs and 390 residency positions, and general internal medicine lost nearly 900 positions.² A study published in the *Annals of Family Medicine* on the impact of Title VII training programs found that physicians who work with the underserved in Community Health Centers and National Health Service Corps sites are more likely to have trained in Title VII-funded programs.³ Title VII primary care training grants are vital to departments of family medicine, general internal medicine, and general pediatrics; they strengthen curricula; and they offer incentives for training in underserved areas. In the coming years, medical services utilization is likely to rise given the increasing and aging population as well as the insured status of more people. These demographic trends will exacerbate family physician shortages. Although PCTE grants are important to family medicine, there has not been a competitive cycle for these grants since fiscal year 2010. The AAFP urges the Committee to increase the level of Federal funding for primary care training to at least \$71 million in fiscal year 2015 to allow for a robust new grant cycle to support family medicine education and training in the new competencies required to meet the needs of patients of all ages.

Teaching Health Centers.—The AAFP has long called for reforms to graduate medical education programs to encourage the training of primary care residents in non-hospital settings where most primary care is delivered. An excellent first step is the innovative Teaching Health Centers (THC) program authorized under Title VII, § 749A to increase primary care physician training capacity that HRSA administers. Federal financing of graduate medical education has led to training mainly in hospital inpatient settings even though most patient care is delivered outside of hospitals in ambulatory settings. The THC program provides resources to any qualified community based ambulatory care setting that operates a primary care residency. We believe that this program requires an investment of \$10 million in fiscal year 2015 for planning grants.

Rural Physician Workforce Needs.—HRSA's Office of Rural Health focuses on rural health policy issues and administers rural grant programs. As the medical specialty most likely to enter rural practice, family physicians recognize the impor-

¹Petterson, S, et al. Projecting U.S. Primary Care Physician Workforce Needs: 2010–2015. *Ann Fam Med* 2012; vol.10 no. 6:503–509.

²Phillips RL and Turner, BJ. The Next Phase of Title VII Funding for Training Primary Care Physicians for America's Health Care Needs. *Ann Fam Med* 2012; vol.10 no. 2:163–168.

³Rittenhouse DR, et al. Impact of Title VII training programs on community health center staffing and national health service corps participation. *Ann Fam Med* 2008; vol. 6 no. 5:397–405.

tance of dedicating appropriate resources to rural health needs. A recent study found that medical school rural programs have had a significant impact on rural family physician supply and called for wider adoption of that model to substantially increase access to care in rural areas compared to a greater reliance on international medical graduates or unfocused expansion of traditional medical schools.⁴ HRSA's Rural Physician Training Grant program will help medical schools recruit students most likely to practice medicine in rural communities. This program will help provide rural-focused experience and increase the number of medical school graduates who practice in underserved rural communities. The AAFP recommends that the Committee provide \$4 million for Rural Physician Training Grants in fiscal year 2015 as called for in the President's budget request.

Primary Care in Underserved Areas.—The National Health Service Corps (NHSC) recruits and places medical professionals in Health Professional Shortage Areas to meet the need for healthcare in rural and medically underserved areas. The NHSC offers scholarships or loan repayment as incentives for physicians to enter primary care and provide healthcare to Americans in Health Professional Shortage Areas. By addressing medical school debt burdens, the NHSC also helps to ensure wider access to medical education opportunities. The President's budget request includes \$810 million for the NHSC, of which \$710 million is mandatory funding. If the NHSC is funded at the President's requested level in fiscal year 2015, underserved patients will benefit from an NHSC field strength of more than 15,400 primary care clinicians compared to the fiscal year 2013 field strength of 8,899. The AAFP supports the President's budget request for this important program and recommends that the Committee provide an appropriation of \$100 million for the NHSC in fiscal year 2015 to supplement the authorized and requested mandatory funds.

AGENCY FOR HEALTHCARE RESEARCH AND QUALITY (AHRQ)

AHRQ is the only Federal agency responsible for generating evidence to make healthcare safer; better; and more accessible, equitable and affordable. AHRQ provides the critical evidence reviews that the AAFP and other physician specialty societies use to produce clinical practice guidelines. These evidence-informed guidelines are important to family physicians as well as to patients and their families. AHRQ takes the results from the NIH whose research restricts subjects to limit the variables in clinical studies and brings the practical information to the practicing physicians who treat patients without those clinical restrictions. AHRQ supports critical primary care investigations through Practice-based Research Networks that examine practice transformation, patient quality and safety in non-hospital settings, multi-morbidity research, as well as mental and behavioral healthcare in communities and primary care practices. The AAFP asks that the Committee provide \$375 million in base discretionary funding for AHRQ in fiscal year 2015.

NATIONAL HEALTH CARE WORKFORCE COMMISSION

Appointed on September 30, 2010, the 15-member National Health Care Workforce Commission was intended to serve as a resource with a broad array of expertise. The Commission was directed to analyze current workforce distribution and needs; evaluate healthcare education and training; identify barriers to improved coordination at the Federal, State, and local levels and recommend ways to address them; and encourage innovations. There is broad consensus about the waning availability of primary care physicians in the United States, but estimates of the severity of the regional and local shortages vary. The AAFP supports the work of the Commission to analyze primary care shortages and propose innovations to help produce the physicians that our Nation needs and will need in the future. We request that the Committee provide \$4 million in fiscal year 2015 so that this important Commission can finally begin this important work.

PREPARED STATEMENT OF THE AMERICAN ACADEMY OF PEDIATRICS

The American Academy of Pediatrics (AAP), a non-profit professional organization of 62,000 primary care pediatricians, pediatric medical subspecialists, and pediatric surgical specialists dedicated to the health, safety, and well-being of infants, children, adolescents, and young adults, appreciates the opportunity to submit this statement for the record in support of strong Federal investments in children's

⁴Rabinowitz, HK, et al. Medical School Rural Programs: A Comparison With International Medical Graduates in Addressing State-Level Rural Family Physician and Primary Care Supply. *Academic Medicine*, Vol. 87, No. 4/April 2012.

health in fiscal year 2015 and beyond. AAP urges all Members of Congress to put children first when considering short and long-term Federal spending decisions. AAP supports robust investment in programs that help ensure the health, safety and well-being of children, including \$5 million for the Pediatric Subspecialty Loan Repayment Program at the Health Resource Services Administration (HRSA), \$21 million for the Emergency Medical Services for Children (HRSA), \$139 million for the National Center for Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention (CDC), and \$160 million for Polio Eradication and \$49 million for the Measles program within CDC.

Every adult was once a child. Many adult diseases have their origins in childhood. Early and continued investments in our children's health are needed to prevent obesity, heart disease, substance use, and other chronic conditions that threaten America's health and fiscal solvency. As clinicians we not only diagnose and treat our patients, we also promote preventive interventions to improve overall health. Likewise, as policymakers, you have an integral role in ensuring the health of future generations through adequate and sustained funding of vital Federal programs.

Pediatric Subspecialty Loan Repayment Program

The United States' supply of pediatric subspecialists is inadequate to meet children's health needs. Many children must wait more than 3 months for an appointment with a pediatric subspecialist. Approximately 1 in 3 children must travel 40 miles or more to receive care from a pediatrician certified in adolescent medicine, developmental behavioral pediatrics, neurodevelopment disabilities, pulmonology, emergency medicine, nephrology, rheumatology, and sports medicine. This problem is compounded by the fact that fewer medical residents are choosing careers in pediatric subspecialties, and the existing subspecialist workforce continues to age. There is also a significant disparity in the geographic distribution of pediatric subspecialists across the country, resulting in many underserved rural and urban areas.

The Pediatric Subspecialty Loan Repayment Program (PSLRP) seeks to expand children's access to healthcare by creating a more robust pediatric work force. In the program, eligible participants must agree to practice full-time for not less than 2 years in a pediatric medical specialty, surgical specialty, or a child or adolescent mental and behavioral subspecialty in a health professional shortage area or a medically underserved area. In return, the program will pay up to \$35,000 in loan repayment for each year of service, for a maximum of 3 years.

Fiscal year 2015 Request: \$5 million; fiscal year 2014 Level: Not Funded.

Emergency Medical Services for Children

Established by Congress in 1984 and last reauthorized in 2010, the Emergency Medical Services for Children (EMSC) Program is the only Federal program that focuses specifically on improving the pediatric components of the emergency medical services (EMS) system. Currently celebrating its 30th year, the EMSC program has made landmark improvements to the emergency care delivered to children all across the Nation. EMSC aims to ensure that state of the art emergency medical care for the ill and injured child or adolescent is well integrated into an EMS system. Every State has received EMSC funds, which they have used to ensure that hospitals and ambulances are properly equipped to treat pediatric emergencies, to provide pediatric training to paramedics and first responders, and to improve the systems that allow for efficient, effective pediatric emergency medical care.

Continued support for EMSC has allowed the program to maintain its existing activities, improve pediatric capacity and transport of pediatric patients, and address emerging issues such as pediatric emergency care readiness and pediatric emergency medical services in rural and remote areas.

Fiscal year 2015 Request: \$21 million; fiscal year 2014 Level: \$20.1 million.

National Center for Birth Defects and Developmental Disabilities

The National Center for Birth Defects and Developmental Disabilities is a center within CDC that seeks to promote the health of babies, children, and adults and enhance the potential for full, productive living. According to the CDC, birth defects affect 1 in 33 babies and are a leading cause of infant death in the United States; the center has done tremendous work in the way of identifying the causes of birth defects and developmental disabilities, helping children to develop and reach their full potential. The center also conducts important research on fetal alcohol syndrome, infant health, autism, congenital heart defects, and other conditions like Tourette Syndrome, Fragile X, Spina Bifida and Hemophilia. NCBDDD has proven to be an asset to children and their families and supports extramural research in every State.

Fiscal year 2015 Request: \$139 million; fiscal year 2014 Level: \$122.4 million.

Global Health at CDC

The AAP calls on Congress to support and resource Health and Human Services to implement the recommendations of the National Vaccine Advisory Committee of the Global Immunizations Working Group on enhancing the work of the HHS National Vaccine Program in Global Immunizations. This includes support for HHS' role in building international cooperation for the common goal of reducing the burden of vaccine-preventable diseases. HHS has unique and timely opportunities to eradicate polio, to reduce measles mortality, and to ensure that the routine immunization systems at the front lines of these efforts are maintained. The funding that Congress provides to CDC's Global Immunization account is also necessary to act on the Advisory Committee's recommendations that HHS enhance its ongoing efforts to strengthen global immunization systems, enhance global capacity for vaccine safety monitoring and post-marketing surveillance, build global immunization research and development capacity, and strengthen countries' capacity for vaccine decisionmaking.

Since 1988 a coordinated global immunization campaign has reduced the number of polio cases globally by more than 99 percent, saving more than 10 million children from paralysis and bringing the disease close to eradication. Expanded immunization has reduced the global mortality attributed to measles by 74 percent between 2000 and 2010.

Polio fiscal year 2015 Request: \$160 million; fiscal year 2014 Level: \$146 million
Measles fiscal year 2015 Request: \$49 million; fiscal year 2014 Level: \$42.2 million

America's children deserve better

Twenty 2 percent of children in the United States now live in poverty—up from 17 percent in 2007. Many children suffer from food insecurity, unstable housing, family dysfunction, abuse and neglect. Such adverse childhood experiences are linked with “toxic stress,” a biologic phenomenon associated with profound and irreversible changes in brain anatomy and chemistry that have been implicated in the development of health-threatening behaviors and medical complications later in life including drug use, obesity, and altered immune function. Adults affected by such adverse childhood experiences are more likely to have experienced school failure, gang membership, unemployment, violent crime, and incarceration.

Healthier children, healthier future

On behalf of the 75 million American children and their families that we serve and treat, the Nation's pediatricians expect Congress to respond to mounting evidence that child health has life-long impacts and put children first during appropriations negotiations. Investing in children is not only the right thing to do for the long-term physical, mental, and emotional health of the population, but is imperative for the Nation's long-term fiscal health as well. In addition to the programs we have specifically mentioned in this testimony, Federal support for children's health programs, such as early brain and child development, parenting and health education, and preventive health services, will yield high returns for the American economy. Cuts to these areas in the short-term will blunt the possible long-term savings these programs could achieve.

We fully recognize the Nation's fiscal challenges and respect that difficult budgetary decisions must be made; however, we do not support funding decisions made at the expense of the health and welfare of children and families. Rather, a focus on the long-term needs of children and adolescents will ensure that the United States can compete in the modern, highly-educated global marketplace. Strong and sustained financial investments in children's healthcare, research, and prevention programs will help keep our children healthy and pay dividends for years to come.

The American Academy of Pediatrics looks forward to working with Members of Congress to prioritize the health of our Nation's children in fiscal year 2015 and beyond. If we may be of further assistance please contact Pat Johnson at the AAP Department of Federal Affairs at 202-347-8600 or pjohnson@aap.org. Thank you for your consideration.

[This statement was submitted by James, Perrin, MD, FAAP, President, American Academy of Pediatrics.]

PREPARED STATEMENT OF THE AMERICAN ACADEMY OF PHYSICIAN ASSISTANTS

On behalf of the more than 95,000 clinically practicing physician assistants in the United States, the American Academy of Physician Assistants (AAPA) is pleased to submit comments on fiscal year 2015 appropriations for Physician Assistant (PA)

educational programs that are authorized through Title VII of the Public Health Service (PHS) Act. AAPA respectfully requests the Senate Appropriations Committee to approve funding at existing levels for the Title VII health professions education program—\$280,000,000, with an allocation of 15 percent of the Primary Care Training and Enhancement program line for PA educational programs.

Federal support for Title VII is authorized through section 747 of the PHS Act. It is the only continuing Federal funding available to PA educational programs. Unfortunately, in recent years, PA educational programs have received reduced support from Title VII funding, which is designed to educate PAs in primary care and to prepare PAs for practice in urban or rural medically underserved areas.

This funding is essential to the development and training of the Nation's health workforce, and is critical to providing continued access to health services in underserved and minority communities. It also encourages PAs to return to these environments with the greatest need after they have completed their educational preparation, being one of the best recruitment tools to date. According to the Health Resources and Services Administration (HRSA), 37 percent of PAs practice in medically underserved counties, including medically underserved areas and medically underserved populations.

Additionally, Title VII funding has helped PA Programs expand clinical rotations in rural and underserved areas that have been in critically short supply and has enhanced primary care curriculum to better address the needs of disadvantaged populations.

While the purview of the Title VII programs grant funding has expanded to include assisting returning combat veterans, funding for PA educational programs has been significantly reduced. Additional reductions to this budget will disadvantage new PA programs that need these funds to help with student recruitment, faculty development, and establishing clinical rotation sites.

Diverse clinical rotation sites and recruitment programs are critical to PA education and are paramount to the Title VII primary care medicine program. A review of PA graduates from 1990–2009 demonstrated that PAs who have graduated from PA educational programs supported by Title VII are 67 percent more likely to be from underrepresented minority populations and 47 percent more likely to work in a rural health clinic than graduates of programs that were not supported by Title VII. We wish to thank the members of this subcommittee for your historical role in supporting funding for the health professions programs, and we hope that we can count on your support to augment funding to these important programs in fiscal year 2015.

Overview of PA Education

The existing 181 accredited PA educational programs are all located within schools of medicine or health sciences, universities, teaching hospitals, and the Armed Services. All PA educational programs are accredited by the Accreditation Review Commission on Education for the Physician Assistant.

The typical PA program consists of 26 months of instruction, and the typical student has a bachelor's degree and about 4 years of prior healthcare experience. The PA curriculum includes 400 hours of basic sciences and nearly 1,600 hours of clinical medicine. On average, students devote more than 2,000 hours, or 50 to 55 weeks, to clinical education, divided between primary care medicine—family medicine, internal medicine, pediatrics, and obstetrics and gynecology—and various specialties, including surgery and surgical specialties, internal medicine subspecialties, emergency medicine, and psychiatry.

After graduating from an accredited PA program, PAs must pass a national certifying examination developed by the National Commission on Certification of Physician Assistants and become licensed by the State to provide medical care. To maintain certification, PAs must log 100 continuing medical education hours every 2 years, and they must take a recertification exam every 10 years.

PA Practice

PAs are licensed health professionals who practice medicine as members of a healthcare team. PAs exercise autonomy in medical decisionmaking and provide a broad range of medical and therapeutic services to diverse populations in rural and urban settings. PAs perform physical examinations, diagnose and treat illnesses, order and interpret lab tests, assist in surgery, provide patient education and counseling, and make rounds in nursing homes and hospitals. PAs are nationally certified and State licensed to practice medicine and prescribe medication in all fifty States, the District of Columbia, the Commonwealth of the Northern Mariana Islands, Guam, and the U.S. Virgin Islands.

PAs in Primary Care

An estimated 30,000 PAs (32 percent of the profession) work in primary care across the Nation—38.2 percent work in private practice (multi-and single specialty and solo practices); 23.3 percent in Family Medicine, 3.0 percent practice in community health centers, 3.3 percent practice in certified rural health clinics, and 2.7 percent work in a federally qualified health center.

PAs are also one of three primary care providers who provide medical care through the National Health Service Corps (NHSC). The NHSC is an important Federal program with nearly 10,000 healthcare providers, like PAs, who benefit from the program's loan-forgiveness and scholarship awards to those providers and students who commit 2 years to provide medical, dental, and mental healthcare in medically underserved areas.

Additionally, PAs provide medical care in community health centers (CHCs), some as CHC medical directors. CHCs provide cost-effective healthcare throughout the country and serve as medical homes for millions in medically underserved areas. CHCs offer a wide variety of healthcare services through team-based care, providing high quality healthcare to CHC patients and significantly reducing medical expenses.

Critical Role of the Title VII PHS Act Programs

According to the Health Resources and Services Administration (HRSA), an additional 31,000 healthcare providers are needed to alleviate existing professional shortages. This existing shortage, combined with faculty shortages across PA education, the need to build greater diversity among healthcare providers, and an increasingly aging healthcare workforce, creates challenges in growing the primary healthcare workforce.

Title VII programs are the only Federal educational programs that are designed to address the supply and distribution imbalances in the health professions. Since the establishment of Medicare, the costs of physician residencies, nurse training, and some allied health professions training have been paid through Graduate Medical Education (GME) funding; however, GME has not been available to support PA education. More importantly, GME was not intended to generate a supply of providers who are willing to work in the Nation's medically underserved communities—the purpose of Title VII.

Furthermore, Title VII programs seek to recruit students who are from underserved minority and disadvantaged populations, which is a critical step towards reducing persistent health disparities among certain racial and ethnic U.S. populations. Research shows racial and ethnic health disparities cost the economy more than \$230 billion in lost productivity and up to \$1.24 trillion in indirect costs over 3 years; and studies have found that health professionals from disadvantaged regions of the country are three to five times more likely to return to underserved areas to provide care which would help alleviate the current health disparity crisis in America.

Support for educating PAs to practice in underserved communities is particularly important given the market demand for PAs. Title VII funding is a critical link in addressing the natural geographic mal-distribution of healthcare providers by exposing students to underserved sites during their training, where they frequently choose to practice following graduation. Currently, 36 percent of PAs met their first clinical employer through their clinical rotations.

Supplementary Recommendations on fiscal year 2015 Funding

AAPA urges members of the Appropriations Committee to consider the inter-dependency of all public health agencies and programs when determining funding for fiscal year 2015. For instance, while it is critical, now more than ever, to fund clinical research at the National Institutes of Health (NIH) and to have an infrastructure at the Centers for Disease Control and Prevention (CDC) that ensures a prompt response to an infectious disease outbreak or bioterrorist attack, the good work of both of these agencies will go unrealized if HRSA is inadequately funded.

HRSA administers the “people” programs, such as Title VII, that bring the results of cutting edge research at NIH to patients through providers such as PAs who have been educated in Title VII-funded programs. Likewise, the CDC is heavily dependent upon an adequate supply of healthcare providers to be sure that disease outbreaks are reported, tracked, and contained.

Thank you for the opportunity to present the AAPA's views on fiscal year 2015 appropriations concerning HRSA's Title VII Health Professions Program.

[This statement was submitted by Sandy Harding, MSW, Senior Director, Federal Advocacy.]

PREPARED STATEMENT OF THE AMERICAN ALLIANCE OF MUSEUMS

Chairman Harkin, Ranking Member Moran, and members of the Subcommittee, my name is Don Wildman, and for six highly rated seasons, I've had the extreme honor of hosting a television show, *Mysteries at the Museum* (Thursday nights on the Travel Channel), which tells the stories behind artifacts in museum collections. My testimony today is presented on behalf of the American Alliance of Museums, the largest organization of museums and museum professionals in the world, and we are respectfully asking the Subcommittee to provide \$38.6 million for the Office of Museum Services (OMS) at the Institute of Museum and Library Services (IMLS), its fully-authorized amount, in fiscal year 2015.

Museums are among our Nation's most popular, most trusted and most beloved institutions. There are approximately 850 million visits to American museums each year, more than the attendance for all major league sporting events and theme parks combined. Museums also spend over \$2 billion on educational programming, and a total of \$21 billion in their local economies. Clearly museums are economic engines and job creators.

IMLS is the primary Federal agency that supports the museum field, and OMS awards grants to help museums digitize, enhance and preserve their collections; provide teacher training; and create innovative, cross-cultural and multi-disciplinary programs and exhibits for schools and the public.

It's no surprise that the appropriations bill that funds education supports this agency, because museums are indeed key education providers. They design exhibitions, educational programs, classroom kits, and online resources in coordination with State, local and common core curriculum standards in math, science, art, literacy, language arts, history, civics and government, economics and financial literacy, geography, and social studies. Museums also offer experiential learning opportunities, STEM education, mentoring, and job preparedness.

Whatever education looks like in the future, one component will certainly be the development of a core set of skills: critical thinking; the ability to synthesize information; and the ability to innovate, to be creative and to collaborate. Museums are uniquely situated to help learners develop these core skills.

In late 2010, legislation to reauthorize IMLS for 5 years was enacted (by voice vote in the House and by unanimous consent in the Senate). The bipartisan reauthorization included several provisions proposed by the museum field, including enhanced support for conservation and preservation, emergency preparedness and response and statewide capacity building. The reauthorization also specifically supports efforts at the State level to leverage museum resources, including statewide needs assessments and the development of State plans to improve and maximize museum services throughout the State. The bill (now Public Law 111-340) authorized \$38.6 million for the IMLS Office of Museum Services to meet the growing demand for museum programs and services. The fiscal year 2014 appropriation of \$30,131,000 represents a nearly 15 percent decrease from the fiscal year 2010 appropriation of \$35,212,000.

Grants are awarded in every State, but perhaps the best way to demonstrate the importance of the IMLS Office of Museum Services is to highlight just a few of the grants awarded in 2013 to museums in States represented by Subcommittee members:

Public Programs and Energy Efficiency—Reiman Gardens, Iowa State University of Science and Technology (Ames, IA) was awarded \$95,040 to develop a comprehensive landscape design, architectural, and engineering plan. Designs will address community programming needs, visitor experience, facilities and maintenance needs, and energy efficiency standards.

Recognizing Excellence—The National Czech & Slovak Museum & Library (Cedar Rapids, IA) received \$5,000 and the 2013 National Medal for Museum and Library Service. When the worst disaster in State history destroyed entire areas of Cedar Rapids in 2008, the National Czech & Slovak Museum & Library was instrumental in leading its devastated ethnic neighborhood in recovery, rebuilding, and revitalization.

Youth Programs and Collections Care—The Kansas African American Museum (Wichita, KS) was awarded \$149,950 to create a public history youth program in partnership with the University of Kansas Libraries, serving 60 youth and training 25 volunteer docents annually. The museum is also using the grant to upgrade its collections management system and to address its most critical collections care and security needs.

Environmental Science—The Calvert Marine Museum Society (Solomons, MD) was awarded \$142,500 to develop and install an exhibit on the ecosystem of the Patuxent River and Chesapeake Bay. They are partnering with local schools and com-

munity groups to facilitate lifelong learning of scientific concepts and environmental stewardship.

Collections Care—The Birmingham Civil Rights Institute (Birmingham, AL) was awarded \$74,277 to safeguard its collections to ensure that they will be available for use by current and future students, the general public, researchers and staff.

STEM Education—The University of Alabama/Alabama Museum of Natural History (Tuscaloosa, AL) was awarded \$99,998 to create the Discovery Learning Lab to give middle and high school-aged students access to “geek” mentors who will guide them in explorations of digital technologies not readily available at home or school in low-income areas. This program exposes teens to STEM disciplines, skills, activities, and software at the lab and in a cyberspace environment.

Science and Ocean Literacy—The Seattle Aquarium (Seattle, WA) was awarded \$103,821 to design, implement, and evaluate an aquarium classroom program. The museum will develop the program in cooperation with practicing scientists, emphasizing both the scientific process and content based on sea otter and ocean acidification research. The project will also produce materials to help interpret its findings both in the museum and in the larger community.

Cultural Identity—The Wing Luke Museum of the Asian Pacific American Experience (Seattle, WA) was awarded \$150,000 to produce a newly designed tour program that emphasizes community storytelling and audience engagement. The Chinatown International District is Seattle’s lowest-income neighborhood, and will benefit from increased museum attendance and enhanced community involvement.

Recognizing Excellence—The Delta Blues Museums (Clarksdale, MS) was awarded \$5,000 and the 2013 National Medal for Museum and Library Service for its work celebrating and nurturing this American art form. Participants young and old, from diverse economic and ethnic backgrounds participate in the museum’s popular music classes while its travelling trunk exhibit inspires blues appreciation nationwide.

3D Printing—The Art Institute of Chicago (Chicago, IL) was awarded \$25,000 to reach audiences of all ages by using 3D printing technologies. The museum will evaluate the potential impact of this technology on engagement with museum collections, and will develop guidelines to be shared with other museums and educators.

Collections Care—The Hermann-Grima and Gallier Historic Houses (New Orleans, LA) were awarded \$22,830 to develop a plan to improve their interior environments to better conserve collections and the historical buildings.

Professional Development—The Newport Art Museum and Art Association (Newport, RI) was awarded \$24,028 for an initiative that orients high school students to cultural administration careers through classroom learning, site visits, and mentoring. The grant will allow the museum to expand the reach of this initiative and establish paid internships for students, helping them develop their interests and build valuable skills for the future.

Mobile Science Classroom—The Discovery Center at Murfree Spring (Murfreesboro, TN) was awarded \$103,849 to convert a school bus into a mobile science classroom for elementary school students.

Digitization—The Country Music Hall of Fame (Nashville, TN) was awarded \$150,000 for a digitization initiative to preserve and increase access to the museum’s unparalleled collection.

Collections Care—The University Museum, University of Arkansas (Fayetteville, AR) was awarded \$31,464 to improve its zoology collection and make it more accessible to researchers.

I am aware that this subcommittee wants to ensure that its investments in Federal grant programs have measurable and significant impact. I believe that the grants listed above demonstrate the value of investing in museums as a means of investing in our communities. Further, it should be noted that each time a Federal grant is awarded, additional local and private funds are also leveraged. Two-thirds of IMLS grantees report that their Museums for America grant positioned the museum to receive additional private funding.

Even the most ardent deficit hawks view the IMLS grant-making process as a model for the Nation. Each grant is selected through a rigorous, peer-reviewed process. And due to the large number of grant applications and the limited funds available, many highly-rated grant proposals go unfunded each year.

- Only 28 percent of Museums for America/Conservation Project Support project proposals were funded;
- Only 15 percent of National Leadership project proposals were funded;
- Only 15 percent of Sparks Ignition Grants for Museums project proposals were funded;
- Only 46 percent of Native American/Hawaiian Museum Services project proposals were funded; and

—Only 31 percent of African American History and Culture project proposals were funded.

On a final and personal note, the interviews I conduct with museum professionals for my television show have confirmed for me what I've known since I was a kid—that museums are cool, really cool. If there's one thing Americans young and old love, it's a good story about America and that's what museums have to offer.

American museums do this job and they do it extremely well. They collect the stories by preserving and curating the objects—documents, inventions, clothing, paintings, sculptures and skeletons—which explain who we've been, who we are and how we survive.

I was raised outside of Philadelphia. Without museums, I'd have never walked through the left ventricle of the super-sized heart in the Ben Franklin Institute. But for the Academy of Natural Sciences, I'd have never understood the difference between a stegosaurus and a triceratops. I wouldn't have had that first encounter with Vincent van Gogh at the Philadelphia Museum of Art. It's impossible to imagine my childhood without museums or to imagine my adulthood. They're our lifeline to the past—and an inspiration for the future.

We hope you'll support our cause, and provide at least \$38.6 million in fiscal year 2015 for the Office of Museum Services (OMS) at the Institute of Museum and Library Services (IMLS), its fully-authorized amount.

[This statement was submitted by Don Wildman, Host, Travel Channel's Mysteries at the Museum, American Alliance of Museums.]

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION FOR DENTAL RESEARCH

On behalf of the 3,500 individual and 44 institutional members of the American Association for Dental Research (AADR), I am pleased to submit testimony describing AADR's fiscal year 2015 requests, which include \$32 billion for the National Institutes of Health (NIH) and \$425 million for the National Institute of Dental and Craniofacial Research (NIDCR). These funding recommendations represent the true needs of the research community while at the same time taking into consideration the continued tight budget climate dictated by the caps established by the Bipartisan Budget Act of 2013. I want to emphasize the recent Federal austerity measures—sequestration, government shutdown and the continued uncertainty—had a significant impact on our members, universities and research supported via NIDCR. In actual dollars, NIDCR lost \$23 million in funding in fiscal year 2013 and only \$10 million was restored in fiscal year 2014. However, when adjusted for inflation, the NIDCR budget is 22 percent, or \$75 million, less than it was in 2002, resulting in the lowest number of research grants awarded in 13 years. This creates an atmosphere that is very discouraging to new scientific investigators whose research proposals are good enough to be funded but were not because of the budget cuts. We are at risk of losing them and their promising research ideas—ideas that might lead to significant advances in dental, oral health and craniofacial health.

The downward trend in lost purchasing power is particularly troubling because the improvements in oral health during the last half century are largely credited to research supported by NIDCR. It is therefore reasonable to assume that these declines in funding will slow or limit future breakthroughs. NIDCR is the largest institution in the world dedicated exclusively to research to improve dental, oral and craniofacial health. The health of the mouth and surrounding craniofacial (skull and face) structures is central to a person's overall health and well-being. Left untreated, oral diseases and poor oral conditions go untreated, make it difficult to eat, drink, swallow, smile, talk and maintain proper nutrition. Scientists also have discovered important linkages between gum disease, or periodontal disease, and heart disease, stroke, diabetes and pancreatic cancer.

In spite of these improvements, however, treating oral health conditions is costly with \$110.9 billion in expenditures on dental services in 2012. While tooth decay and gum disease remain the most prevalent, complete tooth loss, oral cancer, and craniofacial congenital anomalies, like cleft lip and palate are also health and economic burdens to the American people. Moreover, oral health disparities exist for many racial and ethnic groups. By providing \$425 million in fiscal year 2015, NIDCR, dental, oral and craniofacial researchers will be able to build upon the gains of the past decades, creating less invasive, cost effective and more efficient ways to improve oral health. Below are some examples highlighting the important work supported by NIDCR:

—Point of Care Diagnostics: Salivary diagnostics are measures that draw and analyze saliva to test for conditions such as HIV, HPV, substance abuse, caries, periodontitis and oral cancer. Through the work and support of NIDCR over the

last decade, these diagnostics are showing great promise in screening for diabetes, heart disease, lung cancer, ovarian cancer and pancreatic cancer. Salivary diagnostics only require withdrawing saliva, unlike traditional methods that rely on withdrawing blood or on doing tissue biopsy. As a result, salivary diagnostics are less invasive. In addition, they are relatively inexpensive and have the potential of showing more immediate results which is particularly beneficial when results are urgently needed.

- Periodontal Disease: Periodontal or gum disease is a chronic inflammatory disease that affects the gum tissue and bone supporting the teeth. Approximately 47.2 percent of Americans have mild, moderate or severe periodontitis. If left untreated, periodontal disease can lead to tooth loss. Research has shown that periodontal disease is associated with other chronic inflammatory diseases such as diabetes and cardiovascular disease. To date, the prevention of gum disease has been limited to successful oral hygiene and regular professional care. Recently, however, scientists reported the discovery of resolvins, a biologically active product that has the potential to protect against soft tissue and bone loss associated with gum disease. More research is needed to further intensify efforts to apply the novel biological approach to treating inflammatory diseases.
- Dental Caries: Dental caries, or tooth decay, remains the most prevalent chronic disease in both children and adults resulting in a substantial economic and health burden to the American people. Although caries has significantly decreased for most Americans over the past four decades, disparities remain among some population groups. In addition, this downward trend has recently reversed for young children. More research is needed to enhance efforts to address dental caries.
- HPV-Related Oral Cancer: This type of cancer is caused by the human papillomavirus (HPV). It is predicted that this cancer will be the most common HPV-related cancer by 2020. HPV-induced oral cancers among men are likely to exceed HPV-induced cervical cancers within the next 8 years. In fact, HPV is now causing more oral cancers than smoking. Identifying the presence of HPV in a mouth swab or a blood draw does not definitively indicate the impending presence of cancer. As a result, more research is needed for the early detection of HPV-related oral cancer, and for the development of therapies that would lead to the prevention of cancer progression.
- Evidenced-Based Practice: NIDCR recently awarded a seven-year grant that consolidates its dental practice-based research network initiative into a unified nationally coordinated effort. The consolidated initiative, the National Dental Practice Based Research Network (NDPBRN) is headquartered at the University of Alabama at Birmingham School of Dentistry. A dental practice-based research network is an investigative union of practicing dentists and academic scientists. The network provides practitioners with an opportunity to propose or participate in research studies that address daily issues in oral healthcare. These studies help to expand the profession's evidence base and further refine care.
- Cleft Lip and/or Cleft Palate—Craniofacial anomalies such as cleft lip and/or cleft palate (CLP) are among the most common birth defects. Both genetic and environmental factors contribute to oral clefts. Cleft lip is an abnormality in which the lip does not completely form during fetal development and cleft palate occurs when the roof of the mouth does not fully close, leaving an opening that can extend into the nasal cavity. Genome-wide association studies (GWAS) of cleft lip and/or cleft palate supported by NIDCR are providing important new leads about the role genetic factors and gene-environment interactions play in the development of these conditions. In addition, a DNA sequencing study is underway to identify less common genetic variants that influence the risk of developing cleft lip and/or cleft palate. NIDCR will continue to support the best science to understand craniofacial structures and anomalies more completely.

Our members remain concerned that unless Congress fully reverses the erosion caused by sequestration our ability to attract the next generation of scientists will stall; our standing as a world leader in science will decline; and innovation necessary to push the boundaries of research will be stymied. Accordingly, I strongly urge you work in a bipartisan manner to prioritize funding for dental, oral and craniofacial research this year and undo sequestration permanently in fiscal year 2016 and beyond. Future advances in healthcare depend on a sustained investment in basic research to identify the fundamental causes and mechanisms of disease, accelerate technological development and discovery, and ensure a robust pipeline of creative and skillful biomedical researchers. For these reasons, I implore you to work in a bipartisan manner and provide funding increases for NIH and NIDCR in fiscal year 2015.

In addition to the NIH, AADR members care deeply about the Title VII Health Resources and Services Administration (HRSA) programs training the dental health workforce; the Centers for Disease Control and Prevention (CDC) Division of Oral Health's public health prevention efforts; data from the National Center for Health Statistics (NCHS) and the Agency for Healthcare Research & Quality (AHRQ). Please support AADR's funding recommendations for these agencies depicted in the chart below.

[In millions of dollars]

Agency	Fiscal year 2012	Fiscal year 2013	Fiscal year 2014	Fiscal year 2015 PBR	Fiscal year 2015 AADR
NIH	30,702	29,070	30,020	30,220	32,000
NIDCR	410.3	386.8	397.10	397.13	425.0
NCATS	574.8	542.1	633.3	657.5	657.5
AHRQ	405.1	429.4	364	334	375
CDC, Oral Health	14.6	13.8	15.8	15.8	19.0
CDC, NCHS	153.8	153.8	155.3	155.4	182
HRSA, Title VII Oral Health	32.4	30.7	32	32	32.4

[This statement was submitted by Timothy DeRouen, PhD, President, American Association for Dental Research.]

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF COLLEGES OF NURSING

As the national voice for baccalaureate and graduate nursing education, the American Association of Colleges of Nursing (AACN) represents 750 schools of nursing that educate over 450,000 students and employ more than 17,000 full-time faculty members. Collectively, these institutions produce approximately half of our Nation's Registered Nurses (RNs) and all nurse faculty, Advanced Practice Registered Nurses (APRNs), and nurse scientists. AACN requests that nursing education, research, and practice are strongly supported in fiscal year 2015 through an investment of \$251 million for HRSA's Nursing Workforce Development programs (authorized under Title VIII of the Public Health Service Act [42 U.S.C. 296 et seq.]), \$150 million for the National Institute of Nursing Research (NINR) within NIH, and \$20 million in authorized funding for the Nurse-Managed Health Clinics (NMHCs) (Title III of the Public Health Service Act). These levels will ensure that our Nation's nurses are prepared to care for the growing number of patients requiring a complex range of healthcare services.

DEMAND FOR NURSING CARE

The Bureau of Labor Statistics' (BLS) publication Employment Projections for 2012–2022 anticipates significant growth in the nursing workforce from 2.71 million in 2012 to 3.24 million by 2022. This surge in demand translates to 526,800 nurses, or an increase of 19.4 percent. When considering the number of job openings for RNs due to the increasing demand for nursing care and replacements in an aging nursing workforce, more than one million nurses will be needed by 2022. In fact, according to the The U.S. Nursing Workforce: Trends in Supply and Education released by HRSA in 2013, over the next 10 to 15 years, the nearly 1 million RNs older than age 50—about one-third of the current workforce—will reach retirement age. The retirement decisions of these experienced RNs may be influenced by the pace of economic recovery and have the potential to create a serious deficit in the nursing pipeline.

Moreover, the BLS projects a need for 47,600 additional Nurse Practitioners, Certified Registered Nurse Anesthetists, and Certified Nurse-Midwives (or APRNs) to meet the call for more primary and acute care services, particularly due to the aging baby boomer population and increased access to health insurance coverage. The BLS' Occupational Outlook Handbook reported that there will be a 31 percent increase in this sector of the workforce between 2012–2022. Investments are necessary to educate the RNs and APRNs who will provide the care that Americans need now and in the future.

TITLE VIII NURSING WORKFORCE DEVELOPMENT PROGRAMS

For fifty years, the Nursing Workforce Development programs, authorized under Title VIII of the Public Health Service Act, have helped build the supply and distribution of qualified nurses to meet our Nation's healthcare needs. Between fiscal year 2006 and 2012 alone, the Title VIII programs supported over 450,000 nurses and nursing students, as well as numerous academic nursing institutions and healthcare facilities. The programs bolster nursing education at all levels, from entry-level preparation through graduate study, and provide support to educate nurses for practice in rural and medically underserved communities. Today, the Title VIII programs are essential to ensuring that the demand for nursing care is met by supporting future practicing nurses and the faculty who educate them.

However, faculty vacancies have repeatedly been cited as a fundamental obstacle to maximizing nursing school enrollment. According to the American Association of Colleges of Nursing's 2013–2014 Enrollment and Graduations in Baccalaureate and Graduate Programs in Nursing survey, 78,089 qualified applications were turned away from nursing schools in 2013 alone. A primary barrier to accepting all qualified students at nursing colleges and universities continues to be a shortage of faculty. To counter this disparity, the Title VIII Nurse Faculty Loan Program aids in increasing nursing school enrollment capacity by supporting students pursuing graduate education, provided they serve as faculty for 4 years after graduation.

The Title VIII programs also increase the number of practicing nurses entering the pipeline and the placement of these nurses into medically-underserved areas. AACN's Title VIII Student Recipient Survey, which gathers information annually about Title VIII funding and outcomes related to nursing education and career trajectories, provides evidence on the effectiveness of these programs in recruiting more students to the nursing profession and, more importantly, practice in rural and underserved areas. Results of the 2013–2014 Title VIII Student Recipient Survey included responses from 850 students who noted that these programs played a critical role in funding their nursing education. The survey showed that for 67 percent of respondents, Title VIII funding impacted their decision to enter nursing school. Moreover, 76 percent of the students receiving Title VIII funding are able to attend school full-time through this Federal support. By facilitating full-time education, the Title VIII programs are helping to ensure that students enter the workforce without delay. In addition, personal testimony of several survey respondents revealed that many Title VIII recipients intend to practice in the community in which they were educated—a direct State investment. AACN respectfully requests \$251 million for the Nursing Workforce Development programs authorized under Title VIII of the Public Health Service Act in fiscal year 2015.

NATIONAL INSTITUTE OF NURSING RESEARCH: ADVANCING NURSING SCIENCE

The healthcare community is investigating methods to improve the delivery of high-quality care in a financially sustainable manner. As one of the 27 Institutes and Centers at the NIH, the NINR is dedicated to providing the healthcare workforce with evidence-based knowledge and the resources needed to accomplish this goal. Research conducted at NINR addresses disease prevention and health promotion efforts that improve quality of life and alleviate financial burden on individuals and the system. Specific areas targeted by NINR include chronic illness management, disease prevention, pain management, and care-giver support. Nursing research is a critical compliment to biomedical research as it investigates how to prevent disease and promote healthy living. Moreover, research funded at NINR helps to integrate biology and behavior as well as design new technology and tools. At a time when healthcare needs are changing, nursing care must be firmly grounded in nursing science.

NINR also allocates a generous 6 percent of its overall budget to the education and training of nurse researchers, many of whom dually serve as nurse faculty within our Nation's nursing schools. Increased investments must be made in the scientists that improve healthcare delivery through their groundbreaking discoveries. AACN respectfully requests \$150 million for the NINR in fiscal year 2015.

NURSE-MANAGED HEALTH CLINICS: EXPANDING ACCESS TO CARE

Managed by APRNs and staffed by an interdisciplinary health provider team, NMHCs provide necessary primary care services to medically-underserved communities and serve as critical access points to keep patients out of the emergency room, saving the healthcare system millions of dollars annually. NMHCs provide care to vulnerable populations in a host of regions of the country, including rural communities, Native American reservations, senior citizen centers, elementary schools, and

urban housing developments. These communities are the most susceptible to developing chronic illnesses that create heavy financial burdens on patients and the healthcare system. NMHCs aim to reduce disease and create healthier communities through improved patient education and health practices.

Often associated with a school, college, university, department of nursing, federally qualified health center, or independent nonprofit healthcare agency, NMHCs also serve as clinical education training sites for students of nursing, medicine, physical therapy, social work, and ancillary healthcare services. Moreover, by serving as clinical training sites, NMHCs help foster interprofessional education and practice so that patients receive individualized care from an array of providers. According to AACN, the lack of clinical training sites is often pointed to as a top reason for turning away qualified applications in nursing programs. AACN respectfully requests \$20 million for the Nurse-Managed Health Clinics in fiscal year 2015.

AACN recognizes that the Subcommittee and Congress will need to make difficult decisions regarding appropriations for fiscal year 2015. AACN respectfully requests Congress to continue a strong investment in the health of our Nation by providing \$251 million for the Title VIII Nursing Workforce Development programs, \$150 million for the National Institute of Nursing Research, and \$20 million for Nurse-Managed Health Clinics in fiscal year 2015. If you have any questions, or if AACN can be of assistance, please contact AACN's Director of Government Affairs and Health Policy, Dr. Suzanne Miyamoto, at Smiyamoto@aacn.nche.edu.

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF COLLEGES OF
OSTEOPATHIC MEDICINE

The American Association of Colleges of Osteopathic Medicine (AACOM) strongly supports restoring funding for discretionary Health Resources and Services Administration (HRSA) programs to the fiscal year 2010 level of \$7.48 billion; funding of \$520 million for HRSA's Title VII and VIII programs under the Public Health Service Act; \$10 million minimally for the Teaching Health Center Graduate Medical Education (THCGME) Development Grants; sustainment of student scholarship and loan repayment programs; \$4 million for the Rural Physician Training grants; \$3 million for the National Health Care Workforce Commission; \$32 billion for the National Institutes of Health (NIH); and \$375 million in base discretionary funding, restoring the base to fiscal year 2011 levels for the Agency for Healthcare Research and Quality (AHRQ).

AACOM represents the 30 accredited colleges of osteopathic medicine in the United States. These colleges are accredited to deliver instruction at 42 teaching locations in 28 States. In the 2013–2014 academic year these colleges are educating over 23,000 future physicians—more than 20 percent of U.S. medical students. Six of the colleges are publicly controlled; 24 are private institutions.

The Title VII health professions education programs, authorized under the Public Health Service Act and administered through HRSA, support the training and education of health practitioners to enhance the supply, diversity, and distribution of the healthcare workforce, acting as an essential part of the healthcare safety net and filling the gaps in the supply of health professionals not met by traditional market forces. Title VII and Title VIII nurse education programs are the only Federal programs designed to train clinicians in interdisciplinary settings to meet the needs of special and underserved populations, as well as increase minority representation in the healthcare workforce.

As demand for health professionals increase in the face of impending shortages combined with faculty shortages across health professions disciplines, racial and ethnic disparities in healthcare, a growing, aging population, and the anticipated demand for increased access to care, these needs strain an already fragile healthcare system. AACOM appreciates the investments that have been made in these programs, and we urge the Subcommittee to fund \$520 million for the Title VII and VIII programs to include support for the following programs in order to include: the Primary Care Training and Enhancement (PCTE) Program, the Health Careers Opportunity Program (HCOP), the Centers of Excellence (COE), the Geriatric Education Centers (GECs) and the Area Health Education Centers (AHECs). We strongly oppose the Administration's proposals to eliminate funding for AHECs and the HCOP.

AACOM has serious concerns with the Administration's budget request that would cut nearly \$15 billion from Medicare graduate medical education (GME). Because GME funding is critical to addressing the existing physician workforce shortage and ensuring patient access to our Nation's healthcare, AACOM believes that current GME funding should not be sacrificed and simply shifted to other healthcare

workforce programs of importance. Instead, additional investments in GME are critical to an already insufficiently-funded system.

AACOM strongly supports the continuation of the THCGME Program, which provides funding to support primary care medical and dental residents training in community-based settings. THCs currently train more than 350 medical and dental residents and are providing more than 700,000 primary care visits in underserved rural and urban communities. This program will also provide long-term benefits. According to the HRSA, physicians who train in THCs are three times more likely to work in such centers and more than twice as likely to work in underserved areas as physicians who train in other settings. The THCGME Program's 5-year authorization expires in fiscal year 2015, but the recruitment of new residents is being impacted now. We support an investment of \$10 million in fiscal year 2015 for development grants minimally.

Through scholarships and loan repayment, the National Health Service Corps (NHSC) supports the recruitment and retention of primary care clinicians to practice in underserved communities. Approximately 50 million Americans live in communities with a shortage of health professionals, lacking adequate access to primary care. The self-reported average medical education debt of graduates of colleges of osteopathic medicine who borrowed to attend medical school has increased by almost \$85,000 in the last decade. Today, there are more than 23,000 students enrolled at osteopathic medical schools across the Nation. Recent graduates report graduating with an average medical education debt of \$211,423.

Today, there are nearly 8,900 NHSC members providing culturally competent care to more than 9.3 million people. Care is provided at 5,100 NHSC-approved healthcare sites in urban, rural, and frontier areas. In addition to Corps providers currently providing care, nearly 1,100 students, residents, and health providers receive scholarships or participate in the Student to Service Loan Repayment program to prepare to practice, which provides loan repayment assistance to medical students in their last year of education in return for their commitment to practice. AACOM appreciates the Administration's continued investment in the NHSC and strongly supports the preservation of student scholarship and loan repayment programs. Furthermore, we encourage congressional authorizers and appropriators to work together before current mandatory funding for the NHSC expires at the end of fiscal year 2015. This critical funding works to address the primary care workforce shortage and advances innovative models of service.

HRSA's Rural Physician Training grants will help rural-focused training programs recruit and graduate students most likely to practice medicine in underserved rural communities. HRSA's Office of Rural Health Policy analyzes potential effects of policy on residents of rural communities and administers grant programs designed to build healthcare capacity at both the local and State levels. Health professions workforce shortages are exacerbated in rural areas, where communities struggle to attract and keep well-trained providers. According to HRSA, approximately 65 percent of primary care health professional shortage areas are rural. AACOM supports the President's fiscal year 2015 budget request of \$4 million for the Rural Physician Training grants.

The National Health Care Workforce Commission was designed to develop and evaluate training activities to meet demand for healthcare workers. Without funding, the Commission cannot identify barriers that may create and exacerbate workforce shortages and improve coordination on the Federal, State, and local levels. Having this type of coordinating body in place is becoming more critical as more Americans have insurance coverage and as the population ages, requiring access to care. As the United States struggles to address healthcare provider shortages in certain specialties and in rural and underserved areas, the country lacks a defined policy to address these critical. For these reasons, AACOM recommends that \$3 million be appropriated to fund the Commission so it can begin its important work.

Research funded by the NIH leads to important medical discoveries regarding the causes, treatments, and cures for common and rare diseases, as well as disease prevention. These efforts improve our Nation's health and save lives. To maintain a robust research agenda, further investment will be needed. AACOM recommends \$32 billion for the NIH.

In today's increasingly demanding and evolving medical curriculum, there is a critical need for more research geared toward evidence-based osteopathic medicine. AACOM believes that it is vitally important to maintain and increase funding for biomedical and clinical research in a variety of areas related to osteopathic principles and practice, including osteopathic manipulative medicine and comparative effectiveness. In this regard, AACOM encourages support for the NIH's National Center for Complementary and Alternative Medicine (NCCAM) to continue fulfilling this essential research role.

AHRQ supports research to improve healthcare quality, reduce costs, advance patient safety, decrease medical errors, and broaden access to essential services. AHRQ plays an important role in producing the evidence base needed to improve our Nation's health and healthcare. The incremental increases for AHRQ's Patient Centered Health Research Program in recent years will help AHRQ generate more of this research and expand the infrastructure needed to increase capacity to produce this evidence; however, more investment is needed. AACOM recommends \$375 million in base discretionary funding, restoring the base to fiscal year 2011 levels for the AHRQ. This investment will preserve AHRQ's current programs while helping to restore its critical healthcare safety, quality, and efficiency initiatives.

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

[This statement was submitted by Stephen C. Shannon, D.O., M.P.H., President and Chief Executive Officer, American Association of Colleges of Osteopathic Medicine.]

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF IMMUNOLOGISTS

The American Association of Immunologists (AAI), the world's largest professional society of research scientists and physicians who study the immune system, respectfully submits this testimony regarding fiscal year 2015 appropriations for the National Institutes of Health (NIH). AAI recommends an appropriation of at least \$32 billion for NIH for fiscal year 2015 to support important ongoing research, fund a reasonable number of outstanding new grant applications, and restore NIH funding to a level that can sustain a robust and dynamic biomedical research enterprise in the United States.

NIH'S CRUCIAL ROLE IN ADVANCING BIOMEDICAL RESEARCH

NIH is essential to the advancement of biomedical research in the United States, where virtually all biomedical scientists rely on NIH leadership and funding.¹ Academic scientists, many of whom conduct research while teaching the next generation of doctors and scientists, depend on NIH grants to support their research at universities, colleges and research institutions all around the country. NIH intramural scientists require funding to do their own research as well as collaborate with their private sector colleagues.² And scientists employed by industry, who generally do not receive NIH grants or awards, depend on NIH-funded scientific discoveries to develop products that bring research to the bedside. A strong NIH budget, therefore, is essential to all sectors of the U.S. biomedical research enterprise, and has enabled NIH to remain the key international leader influencing biomedical research around the globe.

NIH BUDGET WOES SLOW RESEARCH AND THREATEN U.S. PREEMINENCE

The slow growth of the NIH budget in recent years, exacerbated by the impact of biomedical research inflation,³ has significantly reduced NIH's purchasing power, and in turn, the purchasing power of its grantees. According to the Congressional Research Service (CRS), "[i]n constant 2003 dollars, fiscal year 2014 funding is 22

¹After a highly competitive peer review process, which includes comprehensive review by panels of extramural scientists, NIH awards more than 80 percent of its ~\$30.1 billion budget to "more than 300,000 researchers at more than 2,500 universities, medical schools, and other research institutions in every State and around the world." About 10 percent of its budget supports the work of the approximately 6,000 scientists who work in NIH's own laboratories. (<http://www.nih.gov/about/budget.htm>).

²AAI is concerned that a Federal policy limits government scientists' ability to attend privately sponsored scientific meetings and conferences. (See http://www.hhs.gov/travel/policies/2012_policy_manual.pdf AAI believes that "the rules have had an unintended and deleterious effect . . . [and] made government scientists feel cut off from the rest of the scientific community, wreaked havoc with their ability to fulfill professional commitments, and undermined the morale of some of the government's finest minds." Testimony (Amended) of Lauren G. Gross, J.D., on behalf of The American Association of Immunologists (AAI), Submitted to the Senate Homeland Security and Governmental Affairs Committee for the Hearing Record of January 14, 2014: "Examining Conference and Travel Spending Across the Federal Government" (http://aai.org/Public_Affairs/Docs/2014/AAI_Testimony_to_Senate_HSGAC_01142014.pdf).

³The Biomedical Research and Development Price Index (BRDPI) "is developed each year for NIH by the Bureau of Economic Analysis of the Department of Commerce. It reflects the increase in prices of the resources needed to conduct biomedical research, including personnel, services, supplies, and equipment. It indicates how much the NIH budget must change to maintain purchasing power." Johnson, Judith A., "A History of NIH Funding: Fact Sheet," Congressional Research Service, R43341, p. 2 (2014).

percent lower than the fiscal year 2003 level.”⁴ How many avenues of research have not been followed because of this reduction? How many potential treatments and cures have been delayed or not discovered? These are questions that cannot be answered definitively, but we do know that NIH budget reductions have already caused real and lasting damage: the loss of grant funding, even among the most highly qualified scientists; the closure of labs; the termination or interruption of important research; and the emigration of talented scientists to other countries. And we do know that many scientists are spending too much time in a constant chase for funding, rather than conducting research and mentoring the Nation’s future researchers, inventors and innovators. These budget woes threaten America’s preeminence in advancing basic biomedical research, discovering urgently needed treatments and cures, and “growing” brilliant young scientists.

RESEARCH ON THE IMMUNE SYSTEM: ESSENTIAL TO OUR HEALTH, CRUCIAL TO OUR FUTURE

The immune system is the body’s primary defense against viruses, bacteria, and parasites that cause disease in millions of people every year. When the immune system is operating properly, it provides powerful protection against a wide variety of illnesses, including cancer, Alzheimer’s disease, and cardiovascular disease. The immune system can, however, perform poorly, leaving the body vulnerable to infections, including influenza, HIV/AIDS, tuberculosis, malaria, and the common cold. It can also become overactive, damaging normal organs and tissues, and causing autoimmune diseases, such as allergy, asthma, inflammatory bowel disease, lupus, multiple sclerosis, rheumatoid arthritis, and type 1 diabetes. Research scientists and clinicians are working to harness this powerful system to protect people and animals from infectious diseases, cancer, and many other illnesses, and to protect against natural or man-made infectious organisms (including plague, smallpox and anthrax) that could be used for bioterrorism.⁵

RECENT IMMUNOLOGICAL ADVANCES AND THEIR PROMISE FOR TOMORROW

1. *Cancer Immunotherapies: Offering Hope of Conquering Cancer*

NIH-funded scientists recently identified inhibitory receptors which suppress immune cell activation. Blocking these receptors can allow the immune system to destroy tumor cells.⁶ Today, therapeutics targeted against inhibitory receptors like CTLA4 are undergoing rigorous clinical trials against a variety of cancers. The success rates for these therapies have been astounding and unprecedented: for example, rates of tumor regression in patients with metastatic melanoma have increased from ~10 percent to ~50 percent.⁷ With this level of success, immunotherapy is one of the most exciting and promising areas of cancer treatment.

2. *Early Antiretroviral Therapy: Eliminating HIV, Ending AIDS?*

NIH-funded researchers have discovered that early administration of antiviral medication, known as anti-retroviral therapy (ART), can have lasting effects on an HIV-infected patient’s long-term prognosis. In one study,⁸ an infant born to an HIV-infected mother began receiving ART within hours of birth. The infant tested positive for HIV and continued treatment for 18 months. Despite the HIV diagnosis and subsequent discontinuation of ART, the child remained virus-free 1 year later. A second baby with a similar history also showed an absence of HIV.⁹ Together with several additional unconfirmed cases of babies “cured” of HIV infection, these findings offer hope to the ~250,000 babies born each year infected with HIV.¹⁰

⁴ Ibid.

⁵ NIH should robustly fund and primarily rely on individual investigator-initiated research, in which researchers working in institutions across the Nation submit applications to, and following independent peer review, receive grants from, NIH. Biomedical innovation and discovery are less likely to be achieved through “top-down” science, in which the government specifies the type of research it wishes to fund.

⁶ Couzin-Frankel, Jennifer. “Cancer Immunotherapy.” *Science* 342.6165 (2013): 1432–433.

⁷ Wolchok, J. D. et al. “Nivolumab plus Ipilimumab in Advanced Melanoma.” *N Engl J Med* 369.2 (2013): 122–33.

⁸ Deborah, Persaud et al. “Absence of Detectable HIV–1 Viremia after Treatment Cessation in an Infant.” *N Engl J Med* 369 (2013): 1828–835.

⁹ Conference on Retroviruses and Opportunistic Infections, March 3–6, 2014, Boston, MA (<http://www.croi2014.org/>) (See also <http://www.nytimes.com/2014/03/06/health/second-success-raises-hope-for-a-way-to-rid-babies-of-hiv.html>).

¹⁰ A clinical trial following 60 babies born infected with HIV and being treated with antiretroviral medication will begin soon. (See <http://www.nytimes.com/2014/03/06/health/second-success-raises-hope-for-a-way-to-rid-babies-of-hiv.html>) A second study found that adult HIV-infected patients who were treated with ART within 4 months of infection display significantly

3. Gut (Intestinal) Bacteria: The Microbiome Role in Autoimmune Disease

NIH-funded research has shown that gut bacteria (the intestinal “microbiome”), which aid in food digestion, may impact the development of autoimmune diseases, including rheumatoid arthritis, type 1 diabetes, multiple sclerosis and inflammatory bowel disorders.¹¹ Current research is exploring changes in gut bacteria from diet, hormones, antibiotics, and infections, and the effect of gut bacteria based therapeutics [for example, the ingestion of healthy gut bacteria (probiotics) in yogurt]. One study involving fecal transplantation (which includes the transfer of intestinal bacteria from one person to another) has found that such transplantation in pill form is well tolerated and is 98–100 percent efficacious in curing infections with *Clostridium difficile*, a bacterium linked to ~14,000 diarrheal deaths in the U.S. per year.¹²

4. RSV Vaccine: Saving Infants’ Lives

Millions of infants are hospitalized and 160,000 children die each year each from pneumonia and other lung diseases caused by respiratory syncytial virus (RSV).¹³ Until recently, however, a vaccine for RSV has been elusive. In an important breakthrough, scientists at the NIH discovered antibodies—protective molecules produced by the immune system—that helped identify a key protein for use in vaccine development.¹⁴ The NIH scientists were then able to engineer this protein and demonstrate its ability to produce a strong protective immune response against RSV in animals.¹⁵ This molecule is expected to be ready soon for testing in humans. Importantly, the approach developed in this case can be applied to vaccine design for numerous other viruses, such as HIV, hepatitis C, dengue, and West Nile viruses, that have evaded the body’s protective immune responses, and will provide insight into how viruses evade the immune system.

CONCLUSION

AAI thanks the members and staff of the subcommittee for their ongoing, strong bipartisan support for biomedical research, and recommends an appropriation of at least \$32 billion for NIH for fiscal year 2015 to fund important ongoing research, strengthen the biomedical research enterprise, and ensure that the brightest scientists, trainees, and students are able to pursue careers in biomedical research in the United States.

[This statement was submitted by Elizabeth J. Kovacs, Ph.D., American Association of Immunologists.]

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF NURSE ANESTHETISTS

FISCAL YEAR 2015 APPROPRIATIONS REQUEST SUMMARY

[Dollars in millions]

	Fiscal year 2013 actual	Fiscal year 2014 enacted	AANA fiscal year 2015 request
HHS/HRSA/BHPr Title 8 Advanced Education Nursing, Nurse Anesthetist Education Reserve.	\$2.25	\$2.25	\$4 million for nurse anesthesia education
Total for Advanced Education Nursing, from Title 8	59.4	61.581	83.925 million for advanced education nursing
Title 8 HRSA BHPr Nursing Education Programs	220.4	223.841	251

About the American Association of Nurse Anesthetists (AANA) and Certified Registered Nurse Anesthetists (CRNAs)

improved response to treatment. [See Le, Tuan, et al. “Enhanced CD4+ T-Cell Recovery with Earlier HIV-1 Antiretroviral Therapy.” *N Engl J Med* 368 (2013): 218–30].

¹¹ Sorini, C., and M. Falcone. “Shaping the (auto)immune Response in the Gut: The Role of Intestinal Immune Regulation in the Prevention of Type 1 Diabetes.” *Am J Clin Exp Immunol* 2.2 (2013): 156–71.

¹² Infectious Diseases Society of America. “Fecal Transplant pill knocks out recurrent *C. diff* infection.” *Science Daily* (2013) (See http://www.cdc.gov/hai/organisms/cdiff/cdiff_infect.html).

¹³ Couzin-Frankel, Jennifer. “Cancer Immunotherapy.” *Science* 342.6165 (2013): 1432–433.

¹⁴ McLellan, J. S. et al. “Structure of RSV Fusion Glycoprotein Trimer Bound to a Pre-fusion Specific Neutralizing Antibody.” *Science* 340.6136 (2013): 1113–117.

¹⁵ McLellan, J. S. et al. “Structure-Based Design of a Fusion Glycoprotein Vaccine for Respiratory Syncytial Virus.” *Science* 342.6158 (2013): 592–98.

The AANA is the professional association for more than 47,000 CRNAs and student nurse anesthetists, representing over 90 percent of the nurse anesthetists in the United States. Today, CRNAs deliver approximately 34 million anesthetics to patients each year in the U.S. CRNA services include administering the anesthetic, monitoring the patient's vital signs, staying with the patient throughout the surgery, and providing acute and chronic pain management services. CRNAs provide anesthesia for a wide variety of surgical cases and in some States are the sole anesthesia providers in almost 100 percent of rural hospitals, affording these medical facilities obstetrical, surgical, and trauma stabilization, and pain management capabilities. CRNAs work in every setting in which anesthesia is delivered, including hospital surgical suites and obstetrical delivery rooms, ambulatory surgical centers (ASCs), pain management units and the offices of dentists, podiatrists and plastic surgeons.

Nurse anesthetists are experienced and highly trained anesthesia professionals whose record of patient safety is underscored by scientific research findings. The landmark Institute of Medicine report *To Err is Human* found in 2000 that anesthesia was 50 times safer then than in the 1980s. (Kohn L, Corrigan J, Donaldson M, ed. *To Err is Human*. Institute of Medicine, National Academy Press, Washington DC, 2000.) Though many studies have demonstrated the high quality of nurse anesthesia care, the results of a new study published in *Health Affairs* led researchers to recommend that costly and duplicative supervision requirements for CRNAs be eliminated. Examining Medicare records from 1999–2005, the study compared anesthesia outcomes in 14 States that opted-out of the Medicare physician supervision requirement for CRNAs with those that did not opt out. (To date, 17 States have opted-out.) The researchers found that anesthesia has continued to grow more safe in opt-out and non-opt-out States alike. (Dulisse B, Cromwell J. *No Harm Found When Nurse Anesthetists Work Without Supervision By Physicians*. *Health Aff.* 2010;29(8):1469–1475.)

CRNAs provide the lion's share of anesthesia care required by our U.S. Armed Forces through active duty and the reserves, staffing ships, remote U.S. military bases, and forward surgical teams without physician anesthesiologist support. In addition, CRNAs predominate in rural and medically underserved areas, and where more Medicare patients live (Government Accountability Office. *Medicare and private payment differences for anesthesia services*. GAO–07–463, Washington DC, Jul. 27, 2007. <http://www.gao.gov/products/GAO-07-463>).

Importance of and Request for HRSA Title 8 Nurse Anesthesia Education Funding

Our profession's chief request of the Subcommittee is for \$4 million to be reserved for nurse anesthesia education and \$83.925 million for advanced education nursing from the HRSA Title 8 program, out of a total Title 8 budget of \$251 million. We request that the Report accompanying the fiscal year 2014 Labor-HHS-Education Appropriations bill include the following language: "Within the allocation, the Committee encourages HRSA to allocate funding at least at the fiscal year 2014 level for nurse anesthetist education." This funding request is justified by the safety and value proposition of nurse anesthesia, and by anticipated growth in demand for CRNA services as baby boomers retire, become Medicare eligible, and require more healthcare services. In making this request, we associate ourselves with the request made by The Nursing Community with respect to Title 8 and the National Institute of Nursing Research (NINR) at the National Institutes of Health.

The Title 8 program, on which we will focus our testimony, is strongly supported by members of this Subcommittee in the past, and is an effective means to help address nurse anesthesia workforce demand. In expectation for dramatic growth in the number of U.S. retirees and their healthcare needs, funding the advanced education nursing program at \$83.925 million is necessary to meet the continuing demand for nursing faculty and other advanced education nursing services throughout the U.S... The program funds competitive grants that help enhance advanced nursing education and practice, and traineeships for individuals in advanced nursing education programs. It also targets resources toward increasing the number of providers in rural and underserved America and preparing providers at the master's and doctoral levels, thus increasing the supply of clinicians eligible to serve as nursing faculty, a critical need.

Demand remains high for CRNA workforce in clinical and educational settings. A 2007 AANA nurse anesthesia workforce study found a 12.6 percent CRNA vacancy rate in hospitals and a 12.5 percent faculty vacancy rate. The supply of clinical providers has increased in recent years, stimulated by increases in the number of CRNAs trained. From 2002–2012, the annual number of nurse anesthesia educational program graduates increased from 1,362 to 2,469, according to the Council on Accreditation of Nurse Anesthesia Educational Programs (COA). The number of

accredited nurse anesthesia educational programs grew from 85 to 114. We anticipate increased demand for anesthesia services as the population ages, the number of clinical sites requiring anesthesia services grows, and a portion of the CRNA workforce retires.

The capacity of our 114 nurse anesthesia educational programs to educate qualified applicants is limited by the number of faculty, the number and characteristics of clinical practice educational sites, and other factors—and they continue turning away hundreds of qualified applicants. A qualified applicant to a CRNA program is a bachelor's educated registered nurse who has spent at least 1 year serving in an acute care healthcare practice environment. They are prepared in nurse anesthesia educational programs located all across the country, including Arkansas, California, Connecticut, Georgia, Kentucky, Maryland, New York, Ohio, and Tennessee. To meet the nurse anesthesia workforce challenge, the capacity and number of CRNA schools must continue to grow and modernize with the latest advancements in simulation technology and distance learning consistent with improving educational quality and supplying demand for highly qualified providers. With the help of competitively awarded grants supported by Title 8 funding, the nurse anesthesia profession is making significant progress, but more is required.

This progress is extremely cost-effective from the standpoint of Federal funding. Anesthesia can be provided by nurse anesthetists, physician anesthesiologists, or by CRNAs and anesthesiologists working together. Of these, the nurse anesthesia practice model is by far the most cost-effective, and ensures patient safety. (Hogan P et al. Cost effectiveness analysis of anesthesia providers. *Nursing Economics*, Vol. 28 No. 3, May–June 2010, p. 159 et seq.) Nurse anesthesia education represents a significant educational cost-benefit for competitively awarded Federal funding in support of CRNA educational programs.

Support for Safe Injection Practices and the Alliance for Injection Safety

As a leader in patient safety, the AANA has been playing a vigorous role in the development and projects of the Alliance for Injection Safety, intended to reduce and eventually eliminate the incidence of healthcare facility acquired infections. In the interest of promoting safe injection practice, and reducing the incidence of healthcare facility acquired infections, we associate ourselves with the AIS recommendation.

Support Effective Implementation of Provider Non-Discrimination

AANA applauds the Committee for including report language in its fiscal year 2014 bill directing the Administration to implement the provision in a manner consistent with its intent, to promote competition, quality and choice in a way that supports access and controls costs.

The AANA is firmly committed to supporting competition, access and choice within the healthcare delivery system and has been working to ensure effective implementation of the Federal provider nondiscrimination provision in the Patient Protection and Affordable Care Act (ACA). This provision, which prohibits health plans from discriminating against qualified licensed healthcare professionals solely on the basis of their licensure, went into effect on January 1, 2014.

Proper implementation of the ACA provider nondiscrimination provision is crucial because health plans today may discriminate against whole classes of healthcare professionals based solely on their licensure or certification, limiting or denying patient choice and access to beneficial, safe and cost-efficient healthcare professionals, impairing competition, patient access to care, and optimal healthcare delivery. For example, a commercial carrier in South Carolina stated in its policy manual that it will not reimburse CRNAs for monitored anesthesia care (MAC), but that it will pay anesthesiologists for these same services. Not only does such a policy impair patient access to care provided by CRNAs; it expressly impairs competition and choice and contributes to unjustifiably higher healthcare costs without improving quality or access to care.

The AANA urges the committee to include the following report language with the House Appropriation, Health and Human Services, Education and Related Agencies Subcommittee legislation. The Committee directs HHS to continue its work with the Departments of Labor and Treasury to implement the provider non discrimination law to reflect the original Congressional intent of the provision.

[This statement was submitted by Dennis Bless, CRNA, MS, President, American Association of Nurse Anesthetists.]

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF NURSE PRACTITIONERS

On behalf of the American Association of Nurse Practitioners (AANP), the largest full service professional organization representing the 189,000 nurse practitioners

across the country, we would like to submit the below noted funding requests for fiscal year 2015. Nurse Practitioners (NPs) have been providing primary, acute, and specialty healthcare to patients of all ages for nearly half a century. As you know, in addition to treating acute and chronic illnesses of patients coming to them for care, they emphasize health promotion and disease prevention in all their undertakings. This includes assessments, ordering, performing, supervising and interpreting diagnostic and laboratory tests, making diagnoses, initiating and managing treatment which includes prescribing medications as well as non-pharmacologic treatments, counselling and educating patients, their families and communities. They are the healthcare providers of choice for millions of patients; in fact last year they conducted over 900 million patient visits across the Nation.

The vast majority of nurse practitioners throughout the United States are primary care providers. Eighty 8 percent are prepared to be primary care clinicians and nearly seventy percent are currently practicing in a primary care setting. As clinicians that blend clinical expertise in diagnosing and treating health conditions with an added emphasis on disease prevention and health promotion, NPs bring a comprehensive perspective to healthcare that enhances health and well-being among their patients. Given the demand for primary care providers, NPs are and will continue to fill a critical role in the American healthcare system. Likewise the need to create and fund more nurse managed clinics is critical. As the need for primary care services grows, funding such clinics becomes increasingly necessary. The need to adequately prepare nurse practitioners and facilitate the high quality outcomes of these clinics is clear. Equally clear is the need for funding assistance to nurse practitioner educational programs, students and nurse managed clinics. We are anxious to include among our ranks, students who would not be able to enter our programs without assistance as well as clinic sites that serve as clinical education sites and meet the unmet healthcare needs of a wide variety of populations throughout the country. Therefore we ask that at the very least the following funding be appropriated:

For fiscal year 2015, AANP respectfully requests \$251 million for the Health Resources and Services Administration's (HRSA) Nursing Workforce Development programs (authorized under Title VIII of the Public Health Service Act [42 U.S.C. 296 et seq.]), \$150 million for the National Institute of Nursing Research (NINR) within the National Institutes of Health (NIH), and \$20 million in authorized funding for the Nurse-Managed Health Clinics (Title III of the Public Health Service Act). These investments made through the appropriation process will help to ensure that our Nation's population receives high quality, cost effective healthcare.

AANP would like to work closely with the committee on areas of common interest. We are happy to serve as a resource to the committee as you make decisions about these investments. We thank you for the opportunity to share our concerns with you and look forward to continuing to work with you and your staff on issues affecting our profession. Please contact AANP's Federal Government Affairs department at: governmentaffairs@aanp.org should you have any questions or need further information.

PREPARED STATEMENT OF THE AMERICAN CONGRESS OF OBSTETRICIANS AND GYNECOLOGISTS

The American Congress of Obstetricians and Gynecologists (ACOG), representing 58,000 physicians and partners in women's healthcare, is pleased to offer this statement to the Senate Committee on Appropriations, Subcommittee on Labor, Health and Human Services, and Education. We thank Chairman Harkin, and the entire Subcommittee for the opportunity to provide comments on some of the most important programs to women's health.

Today, the U.S. lags behind many other Nations in healthy births. ACOG's Making Obstetrics and Maternity Safer (MOMS) Initiative would help improve maternal and infant health through Federal research investments, including comprehensive data collection and surveillance, biomedical research, and translating research into evidence-based care for women and babies. We urge you to make funding of the following programs and agencies a top priority in fiscal year 2015.

Data Collection and Surveillance at the Centers for Disease Control and Prevention (CDC)

In order to conduct robust research, uniform, accurate and comprehensive data and surveillance are critical. The National Center for Health Statistics is the Nation's principal health statistics agency and collects State data from records like birth certificates that give us raw, vital statistics. Information from birth and death

certificates is key to gathering vital information about both mother and baby during pregnancy and labor and delivery. Uniform, accurate data collection depends on all States and territories using electronic birth and death records based on the 2003 US-standard birth and death certificates, yet 4 States are still not using the electronic birth registries and 12 States are still not using the electronic death registries.

States not using the standard records likely underreport maternal and infant deaths and complications from childbirth; causes of these deaths remain unknown. Previous appropriations have helped increase the number of States using electronic birth and death registries, but NCHS needs increased resources to help enroll the remaining States, and to improve the accuracy of birth and death data, including through linking data from Electronic Health Records to State vital records systems. For fiscal year 2015, ACOG requests \$182 million for the National Center for Health Statistics, \$5 million of which we urge you to designate to modernize the National Vitals Statistics System, helping States update their birth and death records systems.

The Pregnancy Risk Assessment Monitoring System (PRAMS) at CDC extends beyond vital statistics and surveys new mothers on their experiences and attitudes during pregnancy, with questions on a range of topics, including what their insurance covered, whether they had stressful experiences during pregnancy, when they initiated prenatal care, and what kinds of questions their doctor covered during prenatal care visits. By identifying trends and patterns in maternal health, CDC researchers and State health departments are better able to identify behaviors and environmental and health conditions that may lead to preterm births. Only 40 States use the PRAMS surveillance system today. ACOG requests adequate funding to expand PRAMS to all U.S. States and territories.

Biomedical Research at the National Institutes of Health (NIH)

Biomedical research is critically important to understanding the causes of maternal and infant mortality and morbidity, and developing effective interventions to lower the incidence of mortality and morbidity. The National Institute on Child Health and Human Development's (NICHD's) 2012 Scientific Vision identified the most promising research opportunities for the next decade. Goals include determining the complex causes of prematurity and developing evidence-based measures for its prevention within the next 10 years, understanding the long term health implications of assisted reproductive technology, and understanding the role of the placenta in fetal health outcomes. The placenta, one of the least studied human organs, is essential to the viability and proper growth of the fetus. NICHD's Human Placenta Project will help discover the causes of placental failures, and ultimately ways to prevent failure and improve maternal and fetal birth outcomes.

Another major issue that merits attention is that of clinical trials involving pregnant women. Pregnant women have historically been excluded from most research trials due to concern that trial participation could harm the fetus. Although there has been substantial progress in the inclusion of women in federally funded research, pregnant women are still excluded, even from research that would advance our knowledge of medical conditions and treatments in pregnancy. Mindful of the important considerations of clinical trials on pregnant women, we support establishment of a Federal work group to propose how clinical research might be done appropriately in this area.

Adequate levels of research require a robust research workforce. The years of training combined with uncertainty in getting grant funding are huge disincentives for students considering a career in bio-medical research. This has resulted in a huge gap between the too-few women's reproductive health researchers being trained and the immense need for research. We urge continued investments in the Women's Reproductive Health Research (WRHR) Career Development program, Reproductive Scientist Development Program (RSDP), and the Building Interdisciplinary Research Careers in Women's Health (BIRCWH) programs to address the shortfall of women's reproductive health researchers. ACOG supports a minimum of \$32 billion for NIH and \$1.37 billion within that funding request for NICHD in fiscal year 2015.

Public Health Programs at the Health Resources and Services Administration (HRSA) and the Centers for Disease Control and Prevention (CDC):

Projects at HRSA and CDC are integral to translating research findings into evidence-based practice changes in communities. Where NIH conducts research to identify causes of maternal and infant mortality and morbidity, CDC and HRSA help ensure those research findings lead to improved maternal and infant health outcomes.

Maternal Child Health Block Grant (HRSA): The Maternal Child Health Block Grant at HRSA is the only Federal program that exclusively focuses on improving the health of mothers and children. State and territorial health agencies and their partners use MCH Block Grant funds to reduce infant mortality, deliver services to children and youth with special healthcare needs, support comprehensive prenatal and postnatal care, screen newborns for genetic and hereditary health conditions, deliver childhood immunizations, and prevent childhood injuries.

These early healthcare services help keep women and children healthy, eliminating the need for later costly care. Every \$1 spent on preconception care for a woman with diabetes can save up to \$5.19 by preventing costly complications. Over \$90 million has been cut from the Block Grant since 2003. ACOG requests \$639 million for the Block Grant in fiscal year 2015 to maintain its current level of services.

Title X Family Planning Program (HRSA): Family planning and interconception care are essential to helping ensure healthy women and healthy pregnancies. The Title X Family Planning Program provides services to more than 5 million low income men and women who may not otherwise have access to these services. Title X clinics accounting for \$3.4 billion in healthcare savings in 2008 alone. ACOG supports \$327 million for Title X in fiscal year 2015 to sustain its level of services.

Fetal Infant Mortality Review (HRSA): HRSA's Healthy Start Program promotes community-based programs to reduce infant mortality and racial disparities. These programs are encouraged to use the Fetal and Infant Mortality Review (FIMR) which brings together ob-gyn experts and local health departments to address local issues contributing to infant mortality. Today, more than 220 local programs in 42 States find FIMR a powerful tool to help reduce infant mortality and address issues related to preterm delivery. For over 20 years, ACOG has partnered with the Maternal and Child Health Bureau to sponsor the National FIMR Program. ACOG supports \$0.5 million in fiscal year 2015 for HRSA to increase the number of Healthy Start programs that use FIMR.

Maternal Health Initiative (HRSA): The Maternal Child Health Bureau launched the Maternal Health Initiative to foster the notion of "healthy moms make healthy babies." As part of this effort, ACOG has convened the National Partnership on Maternal Safety to identify key factors to reduce maternal morbidity and mortality. ACOG requests at a minimum level funding for MCHB to advance this important work.

Safe Motherhood, Maternity and Perinatal Collaboratives (CDC): The Safe Motherhood Initiative at CDC works with State health departments to collect information on pregnancy-related deaths, track preterm births, and improve maternal outcomes. Through Safe Motherhood, CDC funds State-based Maternity and Perinatal Collaboratives that improve birth outcomes by encouraging use of evidence-based care, including reducing early elective deliveries. Through the Ohio Perinatal Quality Collaborative, started in 2007 with funding from CDC, 21 OB teams in 25 hospitals have significantly decreased early non-medically necessary deliveries, in accordance with ACOG guidelines, reducing costly and dangerous pre-term births. Avalere estimated that reducing early elective can save from \$2.4 million to \$9 million a year. The PREEMIE Reauthorization Act, enacted in 2013, authorizes funding to increase the number of States receiving assistance for perinatal collaboratives. ACOG urges you to re-instate the pre-term birth sub-line as authorized by PREEMIE and provide an additional \$16 million to Safe Motherhood to implement PREEMIE and help States expand or establish maternity perinatal care collaboratives.

Again, we would like to thank the Committee for commitment to improving women's health, and we urge you to fund programs we've identified in our MOMS Initiative in fiscal year 2015.

PREPARED STATEMENT OF THE AMERICAN COLLEGE OF PHYSICIANS

The American College of Physicians (ACP) is pleased to submit the following statement for the record on its priorities, as funded under the U.S. Department of Health & Human Services, for fiscal year 2015. ACP is the largest medical specialty organization and the second-largest physician group in the United States. ACP members include 137,000 internal medicine physicians (internists), related subspecialists, and medical students. Internal medicine physicians are specialists who apply scientific knowledge and clinical expertise to the diagnosis, treatment, and compassionate care of adults across the spectrum from health to complex illness. As the Subcommittee begins deliberations on appropriations for fiscal year 2015, ACP is urging funding for the following proven programs to receive appropriations from the Subcommittee:

- Title VII, Section 747, Primary Care Training and Enhancement, at no less than \$71 million;
- National Health Service Corps, \$810 million in funding, including the \$310 million in enhanced funding through the Community Health Centers Fund;
- National Health Care Workforce Commission, \$3 million;
- Agency for Healthcare Research and Quality, \$375 million; and
- Centers for Medicare and Medicaid Services, Program Management for Marketplaces, \$629 million.

The United States is facing a growing shortage of physicians in key specialties, most notably in general internal medicine and family medicine—the specialties that provide primary care to most adult and adolescent patients. With enactment of the Affordable Care Act (ACA), we expect the demand for primary care services to increase with the addition of 25 million Americans receiving access to health insurance, including an additional 13 million under Medicaid/CHIP, once the law is fully implemented. With increased demand, current projections indicate there will be a shortage of over 45,000 primary care physicians by 2020, growing to a shortage of over 65,000 primary care physicians by 2025. (AAMC Center for Workforce Studies with the Lewin Group. *The Impact of Health Care Reform on the Future Supply and Demand of Physicians Updated Projections Through 2025*. June 2010. Accessed at: https://www.aamc.org/download/158076/data/updated_projections_through_2025.pdf). Without critical funding for vital workforce programs, this physician shortage will only grow worse. A strong primary care infrastructure is an essential part of any high-functioning healthcare system, with over 100 studies showing primary care is associated with better outcomes and lower costs of care (http://www.acponline.org/advocacy/where_we_stand/policy/primary_shortage.pdf).

The health professions' education programs, authorized under Title VII of the Public Health Service Act and administered through the Health Resources and Services Administration (HRSA), support the training and education of healthcare providers to enhance the supply, diversity, and distribution of the healthcare workforce, filling the gaps in the supply of health professionals not met by traditional market forces, and are critical in helping institutions and programs respond to the current and emerging challenges of ensuring that all Americans have access to appropriate and timely health services. Within the Title VII program, we urge the Subcommittee to fund the Section 747, Primary Care Training and Enhancement program at \$71 million, in order to maintain and expand the pipeline for individuals training in primary care. The Section 747 program is the only source of Federal training dollars available for general internal medicine, general pediatrics, and family medicine. For example, general internists, who have long been at the frontline of patient care, have benefitted from Title VII training models emphasizing interdisciplinary training that have helped prepare them to work with other health professionals, such as physician assistants, patient educators, and psychologists. Without a substantial increase in funding, for the fourth year in a row, HRSA will not be able to carry out a competitive grant cycle for physician training; the Nation needs new initiatives supporting expanded training in multi-professional care, the patient-centered medical home, and other new competencies required in our developing health system.

The College urges \$810 million in funding for the National Health Service Corps (NHSC), as requested in the President's fiscal year 2015 budget; this amount includes the \$310 million in enhanced funding the Health and Human Services Secretary has been given the authority to provide to the NHSC through the Community Health Centers Fund. Since the enactment of the ACA, the NHSC has awarded over \$1 billion in scholarships and loan repayment to healthcare professionals to help expand the country's primary care workforce and meet the healthcare needs of underserved communities across the country. With field strength of nearly 9,000 clinicians, NHSC members are providing culturally competent care to more than 10.4 million people at nearly 14,000 NHSC-approved healthcare sites in urban, rural, and frontier areas. The increase in funds would expand NHSC field strength to 15,000 and would serve the needs of more than 16 million patients, helping to address the health professionals' workforce shortage and growing maldistribution. The programs under NHSC have proven to make an impact in meeting the healthcare needs of the underserved, and with increased appropriations, they can do more.

We urge the Subcommittee to fully fund the National Health Care Workforce Commission, as authorized by the ACA, at \$3 million. The Commission is authorized to review current and projected healthcare workforce supply and demand and make recommendations to Congress and the Administration regarding national healthcare workforce priorities, goals, and policies. Members of the Commission have been appointed, but have not begun work due to a lack of funding. The College believes the Nation needs a comprehensive workforce policy founded on sound research to deter-

mine the Nation's current and future needs for physicians by specialty and geographic areas; the work of the Commission is imperative to ensure Congress is creating the best policies for our Nation's needs.

The Agency for Healthcare Research and Quality (AHRQ) is the leading public health service agency focused on healthcare quality. AHRQ's research provides the evidence-based information needed by consumers, clinicians, health plans, purchasers, and policymakers to make informed healthcare decisions. The College is dedicated to ensuring AHRQ's vital role in improving the quality of our Nation's health and recommends a budget of \$375 million. This amount will allow AHRQ to help providers help patients by making evidence-informed decisions, fund research that serves as the evidence engine for much of the private sector's work to keep patients safe, make the healthcare market place more efficient by providing quality measures to health professionals, and ultimately, help transform health and healthcare.

Finally, ACP supports \$629 million in funding for the Centers for Medicare and Medicaid Services, Program Management for Marketplaces as requested in the President's fiscal year 2015 budget in order to carry out its duties as necessary. Such funding would allow the Federal Government to continue to administer the insurance marketplaces as authorized by the ACA if a State has declined to establish an exchange that meets Federal requirements. CMS now manages and operates some or all marketplace activities in over 30 States. If the Subcommittee decides to deny the requested funds, it will be much more difficult for the Federal Government to operate and manage a federally-facilitated exchange in those States, raising questions about where and how their residents would obtain and maintain coverage. It is ACP's belief that all legal Americans—regardless of income level, health status, or geographic location—must have access to affordable health insurance.

In conclusion, the College is keenly aware of the fiscal pressures facing the Subcommittee today, but strongly believes the United States must invest in these programs in order to achieve a high performance healthcare system and build capacity in our primary care workforce and public health system. The College greatly appreciates the support of the Subcommittee on these issues and looks forward to working with Congress as you begin to work on the fiscal year 2015 appropriations process.

PREPARED STATEMENT OF THE AMERICAN COLLEGE OF PREVENTIVE MEDICINE

The American College of Preventive Medicine (ACPM) urges the Senate Labor, Health and Human Services, Education, and Related Agencies Appropriations Subcommittee to reaffirm its support for training preventive medicine physicians and other public health professionals by providing \$10 million in fiscal year 2015 for preventive medicine residency training under the public health and preventive medicine line item in Title VII of the Public Health Service Act. We further respectfully request that funds allocated for "public health and preventive medicine" be separated into two distinct line items, with separation of funds for preventive medicine residency training from other funds allocated to the "public health and preventive medicine" line-item. In conjunction, ACPM also supports the recommendation of the Health Professions and Nursing Education Coalition of \$520 million in fiscal year 2015 to support all health professions and nursing education and training programs authorized under Titles VII and VIII of the Public Health Service Act.

In today's healthcare environment, the tools and expertise provided by preventive medicine physicians play an integral role in ensuring effective functioning of our Nation's public health system. These tools and skills include the ability to deliver evidence-based clinical preventive services, expertise in population-based health sciences, and knowledge of the social and behavioral determinants of health and disease. These are the tools employed by preventive medicine physicians who practice at the health system level where improving the health of populations, enhancing access to quality care, and reducing the costs of medical care are paramount. As the body of evidence supporting the effectiveness of clinical and population-based interventions continues to expand, so does the need for specialists trained in preventive medicine.

Organizations across the spectrum have recognized the growing demand for preventive medicine professionals. The Institute of Medicine released a report in 2007 calling for an expansion of preventive medicine training programs by an "additional 400 residents per year," and the Accreditation Council on Graduate Medical Education (ACGME) recommends increased funding for preventive medicine residency training programs. Additionally, the Association of American Medical Colleges released statements in 2011 that stressed the importance of incorporating behavioral and social sciences in medical education as well as announcing changes to the Med-

ical College Admission Test that would test applicants on their knowledge in these areas. Such measures strongly indicate increasing recognition of the need to take a broader view of health that goes beyond just clinical care—a view that is a unique focus and strength of preventive medicine residency training.

In fact, preventive medicine is the only one of the 24 medical specialties recognized by the American Board of Medical Specialties that requires and provides training in both clinical and population-based medicine. Preventive medicine residency training programs provide a blueprint on how to train our future physician workforce; physicians trained to zoom in on individual patient care needs and zoom out to the community and population level to identify and treat the social determinants of health. Preventive medicine physicians have the training and expertise to advance the population health outcomes that public and private payers are increasingly promoting to their providers. These physicians have a strong focus on quality care improvement and are at the forefront of efforts to integrate primary care and public health.

According to the Health Resources and Services Administration (HRSA) and health workforce experts, there are personnel shortages in many public health occupations, including epidemiologists, biostatisticians, and environmental health workers among others. According to the 2012 Physician Specialty Data Book released by the Association of American Medical Colleges, preventive medicine had one of the biggest decrease (-25 percent) in the number of first-year ACGME residents and fellows between 2005 and 2010. ACPM is deeply concerned about the shortage of preventive medicine-trained physicians and the ominous trend of even fewer training opportunities. This deficiency in physicians trained to carry out core public health activities will lead to major gaps in the expertise needed to deliver clinical prevention and community public health. The impact on the health of those populations served by HRSA may be profound.

Despite being recognized as an underdeveloped national resource and in shortage for many years, physicians training in the specialty of Preventive Medicine are the only medical residents whose graduate medical education (GME) costs are not supported by Medicare, Medicaid or other third party insurers. Training occurs outside hospital-based settings and therefore is not financed by GME payments to hospitals. Both training programs and residency graduates are rapidly declining at a time of unprecedented national, State, and community need for properly trained physicians in public health and disaster preparedness, prevention-oriented practices, quality improvement, and patient safety.

Currently, residency programs scramble to patch together funding packages for their residents. Limited stipend support has made it difficult for programs to attract and retain high-quality applicants. Support for faculty and tuition has been almost non-existent. Directors of residency programs note that they receive many inquiries about and applications for training in preventive medicine; however, training slots often are not available for those highly qualified physicians who are not directly sponsored by an outside agency or who do not have specific interests in areas for which limited stipends are available (such as research in cancer prevention).

HRSA—as authorized in Title VII of the Public Health Service Act—is a critical funding source for several preventive medicine residency programs, as it represents the largest Federal funding source for these programs. HRSA funding (\$3.8 million in fiscal year 2014) currently supports only 55 preventive medicine residents across 8 residency training programs. An increase of roughly \$6 million will allow HRSA to support nearly 120 new preventive medicine residents.

Of note, the preventive medicine residency programs directly support the mission of the HRSA health professions programs by facilitating practice in underserved communities and promoting training opportunities for underrepresented minorities:

- Thirty-five percent of HRSA-supported preventive medicine graduates practice in medically underserved communities, a rate of almost 3.5 times the average for all health professionals. These physicians are meeting a critical need in these underserved communities.
- Nearly one in five preventive medicine residents funded through HRSA programs are under-represented minorities, which is almost twice the average of minority representation among all health professionals.
- Fourteen percent of all preventive medicine residents are under-represented minorities, the largest proportion of any medical specialty.

In addition to training under-represented minorities and generating physicians who work in medically underserved areas, preventive medicine residency programs equip our society with health professionals and public health leaders who possess the tools and skills needed in the fight against the chronic disease epidemic that is threatening the future of our Nation's health and prosperity. Correcting the root causes of this critical problem of chronic diseases will require a multidisciplinary ap-

proach that addresses issues of access to healthcare; social and environmental influences; and behavioral choices. ACPM applauds the initiation of programs such as the Community Transformation Grant that take this broad view of the determinants of chronic disease. However, any efforts to strengthen the public health infrastructure and transform our communities into places that encourage healthy choices must include measures to strengthen the existing training programs that help produce public health leaders.

Many of the leaders of our Nation's local and State health departments are trained in preventive medicine. Their unique combination of expertise in both medical knowledge and public health makes them ideal choices to head the fight against chronic disease as well as other threats to our Nation's health. Their contributions are invaluable. Investing in the residency programs that provide physicians with the training and skills to take on these leadership positions is an essential part of keeping Americans healthy and productive. As such, the American College of Preventive Medicine urges the Labor, Health and Human Services, Education, and Related Agencies Appropriations Subcommittee to reaffirm its support for training preventive medicine physicians and other public health professionals by providing \$10 million in fiscal year 2015 for preventive medicine residency training under the public health and preventive medicine line item in Title VII of the Public Health Service Act.

PREPARED STATEMENT OF THE AMERICAN COLLEGE OF RADIOLOGY

The American College of Radiology (ACR)—a professional organization serving more than 35,000 radiologists, radiation oncologists, interventional radiologists, nuclear medicine physicians, and medical physicists—recommends increased funding for the National Institutes of Health (NIH) in fiscal year 2015 appropriations legislation. Specifically, the ACR endorses the position of the Ad Hoc Group for Medical Research—a coalition of more than 300 patient and voluntary health groups, medical and scientific societies, academic and research organizations, and industry—that NIH receive at least \$32 billion in fiscal year 2015 as the next step toward a multi-year increase in our Nation's investment in medical research. That recommended funding level is approximately \$1.874 billion above the President's Budget request for fiscal year 2015. Additionally, the ACR joins the Ad Hoc Group in urging Congress and the Administration to work in a bipartisan manner to end sequestration and the continued cuts to medical research that squander invaluable scientific opportunities, discourage young scientists, jeopardize our economic future, and threaten medical progress and continued improvements in our Nation's health.

The value of the NIH to American taxpayers is immeasurable, and there have been several recent examples of impactful science in the biomedical imaging domain that would not have been realized and translated swiftly into patient care without NIH support and involvement. For instance, the NIH National Cancer Institute's (NCI) nearly decade-long National Lung Screening Trial—conducted by the American College of Radiology Imaging Network (ACRIN) and Lung Screening Study group—found that computed tomography (CT) screening of high risk patients could reduce deaths from lung cancer by 20 percent versus chest X-ray screening. Another NCI-supported success, the National CT Colonography Trial—also conducted by ACRIN—found that virtual colonoscopy was effective as a screening method for colorectal cancer thanks to its accuracy, safety, cost-effectiveness, and patient acceptability compared to more invasive and potentially intimidating screening options. The Radiation Therapy Oncology Group (RTOG) now a member of the NRG Oncology Group in the new National Clinical Trials Network (NCTN), is the international leader in investigating the appropriateness of advanced technologies such as proton therapy and intensity modulated radiation therapy (IMRT) in multi-center randomized trials examining the safety, effectiveness, and quality of life implications of these treatments. Additional ACRIN (now ECOG-ACRIN in the NCTN) and NRG activities under NCI's purview promise to advance the areas of personalized early cancer detection, identify biomarkers to predict treatment effectiveness, reduce the rate of false-positive imaging examinations, and improve cancer screening outcomes. However, NCI's funding of cooperative groups in the evolved National Clinical Trials Network (NCTN) has been severely cut and the groups' planned budgets are considerably below expectations. We urge Congress to restore the full funding approved by the NCI's Board of Scientific Advisors for the organizations that transitioned from the cooperative group program into the new NCTN.

Although smaller than NCI, the NIH National Institute of Biomedical Imaging and Bioengineering (NIBIB) has likewise been successful in advancing the science behind evolving biomedical imaging technologies and techniques. The ACR played

a key role in NIBIB's creation through co-founding a coalition of likeminded organizations and working with Federal policymakers to successfully advance the establishing legislation in 2000. Since its inception, NIBIB has been particularly effective in supporting training initiatives, educational symposia, and international collaborations, as well as fostering future generations of biomedical imaging and bioengineering scientists via innovative initiatives and communications.

Without significantly increased funding levels for NIH in fiscal year 2015 and beyond, America's leadership in biomedical research will decline, scientists will be increasingly discouraged by the lack of funding opportunities, and innovative technologies and techniques (such as those supported through NCI and NIBIB) will not be appropriately researched and translated into patient care. Therefore, the ACR endorses the Ad Hoc Group for Medical Research's recommendation that NIH receive at least \$32 billion in fiscal year 2015 as part of a multi-year increase, and that Congress and the Administration work together to decisively end sequestration.

Thank you for your consideration.

[This statement was submitted by Gloria R. Romanelli, JD, Senior Director of Legislative and Regulatory Relations, and Michael Peters, Director of Legislative and Regulatory Affairs.]

PREPARED STATEMENT OF THE AMERICAN DENTAL EDUCATION ASSOCIATION

The American Dental Education Association (ADEA), on behalf of all 65 U.S. dental schools, 700 dental residency training programs, nearly 600 allied dental programs, as well as more than 12,000 faculty who educate and train the nearly 50,000 students and residents attending these institutions, submits this statement for the record and for your consideration as you begin to prioritize fiscal year 2015 appropriation requests. ADEA urges you to protect the funding and fundamental structure of Federal programs that provide access to oral healthcare to millions of American, train the next generation of healthcare providers and fund cutting-edge dental and craniofacial research.

At ADEA's academic dental institutions, future practitioners and researchers are trained and significant dental safety-net care is provided. Services are provided through campus and offsite dental clinics where students and faculty provide oral healthcare to the uninsured and underserved populations. And, in light of the findings that good oral health is inextricably linked to good systemic health, the need to provide access to oral healthcare is critical. However, in order to provide these services, there must be adequate funding.

We are asking the committee to help ADEA's member institutions continue to provide care to all segments of the population by maintaining adequate funding for programs focused on access to oral healthcare, dental and craniofacial research, and training for oral healthcare providers. Specifically we request that you maintain and protect funding for Title VII of the Public Health Service Act; the National Institutes of Health (NIH) and the National Institute of Dental and Craniofacial Research (NIDCR); the Dental Health Improvement Act; Part F of the Ryan White HIV/AIDS Treatment and Modernization Act; the Dental Reimbursement Program and the Community-Based Dental Partnerships Program; and State-Based Oral Health Programs at the Centers for Disease Control and Prevention (CDC). These programs enhance and sustain State oral health departments, fund public health programs proven to prevent oral disease, fund research to eradicate dental disease and detect certain cancers, and fund programs to develop an adequate workforce of dentists with advanced training to serve American citizens including the underserved, the elderly, and those suffering from chronic immune-compromised conditions and life-threatening diseases.

We respectfully make the following requests:

—\$32 million for Oral Health Training Programs

The dental programs in Title VII, Section 748 of the Public Health Service Act that provide training in general, pediatric, and public health dentistry and dental hygiene are critical. Support for these programs will help to ensure there will be an adequate oral healthcare workforce. The funding supports pre-doctoral oral health education and postdoctoral pediatric, general, and public health dentistry training. The investment that Title VII makes not only helps to educate dentists and dental hygienists, but also expands access to care for underserved communities.

Additionally, Section 748 addresses the shortage of professors in dental schools with the dental faculty loan repayment program and faculty development courses for those who teach pediatric, general, or public health dentistry or dental hygiene. There are currently almost 200 open budgeted faculty positions in dental schools. These two programs provide schools with assistance in recruiting and retaining fac-

ulty. ADEA is increasingly concerned that with projected restrained funding, the oral health research community will not be able to grow and that the pipeline of new researchers will be inadequate to the future need.

Title VII Diversity and Student Aid programs play a critical role in helping to diversify the health profession's student body and thereby the healthcare workforce. For the last several years, these programs have not received adequate funding to sustain the progress that is necessary to meet the challenges of an increasingly diverse U.S. population. ADEA is most concerned that the Administration did not request any funds for the Health Careers Opportunity Program (HCOP). This program provides a vital source of support for oral health professionals serving underserved and disadvantaged patients by providing a pipeline for such individuals from these populations to learn about careers in healthcare generally and dentistry specifically that is not available through other workforce programs.

For example, a collaboration between the University of Connecticut's Schools of Dental Medicine and Medicine have used HCOP grants to perform extensive outreach to colleges and Historically Black Colleges and Universities (HBCU); support 30 week and 6 week summer science enrichment programs in middle schools; support several high school programs, including a Bridge to the Future Science Mentoring, support mini dental and medical programs, and in support of a Junior and Senior Doctors' Academy program. And at the college level the two schools continue the Bridge to the Future Science Mentor program and conduct a 7 week Health Disparities Clinical Summer Research Fellowship program that explores an introduction to health disparities, cross cultural issues, principles of clinical medicine and skills for public health research and interventions, techniques for work with diverse populations and interventions, techniques for work with diverse populations.

UCONN's program is illustrative of programs that dental schools at the University of Iowa, Kansas University, University of Maryland-Baltimore, the University of South Alabama, Marquette University, the University of Michigan, and many others have sponsored. HRSA reports that the average grant is only \$670,000 and reaches over 7,100 students from underserved and disadvantaged background.

If policy makers are serious about reversing health disparities and providing opportunity for underrepresented minorities and economically disadvantaged individuals they will continue this program at current levels, if not expand it.

Another vital program targeted at enhancing high quality culturally competent care in community-based interprofessional clinical training settings is the Area Health Education Centers (AHEC) program. Again the Administration's has not requested any funds. The infrastructure development grants and point of service maintenance and expansion grants ensure that patients from underserved populations receive quality care in a technologically current setting and that health professionals receive training in treating such diverse populations.

The reason given by HRSA in not requesting any appropriations for next fiscal year is short-sighted and counterproductive. HRSA states that funding priorities is being redirected to programs that directly increase the number of primary care health professionals. Increasing the number of providers without the adequate opportunities to treat underrepresented populations in their communities makes little clinical or cultural sense. This is the case especially if the policy goals remain to increase the number coming from those populations and practicing in rural and underserved areas. Exposure to the rewards and professional challenges of such care is a powerful enducement to accomplishing the goal. ADEA encourages the Committee, in the strongest possible terms, to continue funding the AHEC program.

—\$18 million for Part F of the Ryan White HIV/AIDS Treatment and Modernization Act: Dental Reimbursement Program (DRP) and the Community-Based Dental Partnerships Program

Patients with compromised immune systems are more prone to oral infections like periodontal disease and tooth decay. By providing reimbursement to dental schools and schools of dental hygiene, the Dental Reimbursement Program (DRP) provides access to quality dental care for people living with HIV/AIDS while simultaneously providing educational and training opportunities to dental residents, dental students, and dental hygiene students who deliver the care. DRP is a cost-effective Federal/institutional partnership that provides partial reimbursement to academic dental institutions for costs incurred in providing dental care to people living with HIV/AIDS. This program, in fiscal year 2013, only reimbursed dental schools for the unreimbursed costs at 23 percent of those costs, continuing the shift of the cost burden to the schools. This path is not sustainable to provide the necessary care. The increase requested would reimburse barely half of the dental school's incurred costs of care.

—\$425 million for the National Institute of Dental and Craniofacial Research (NIDCR)

Discoveries stemming from dental research have reduced the burden of oral diseases, led to better oral health for millions of Americans, and uncovered important associations between oral and systemic health. Dental researchers are poised to make breakthroughs that can result in dramatic progress in medicine and health, such as repairing natural form and function to faces destroyed by disease, accident, or war injuries; diagnosing systemic disease from saliva instead of blood samples (such as HIV, and certain types of cancer); and deciphering the complex interactions and causes of oral health disparities involving social, economic, cultural, environmental, racial, ethnic, and biological factors. Dental research is the underpinning of the profession of dentistry. With grants from NIDCR, dental researchers in academic dental institutions have built a base of scientific and clinical knowledge that has been used to enhance the quality of the Nation's oral health and overall health.

Also, dental scientists are putting science to work for the benefit of the healthcare system through translational research, comparative effectiveness research, health information technology, health research economics, and further research on health disparities.

—\$19 million for the Division of Oral Health at the Centers for Disease Control and Prevention (CDC)

The CDC Division of Oral Health expands the coverage of effective prevention programs. The program increases the basic capacity of State oral health programs to accurately assess the needs of the State, organize and evaluate prevention programs, develop coalitions, address oral health in State health plans, and effectively allocate resources to the programs. This strong public health response is needed to meet the challenges of oral disease affecting children and vulnerable populations.

The level of funds available in recent fiscal years are below the level needed to adequately sustain an appropriately staffed State dental program, provide a robust surveillance system to monitor and report disease, and support State efforts with other governmental, non-profit, and corporate partners. The current path of funding will continue to have a negative effect upon the overall health and preparedness of the Nation's States and communities.

Thank you for your consideration of these requests. ADEA looks forward to working with you to ensure the continuation of congressional support for these critical programs. Also, please feel free to use ADEA as a resource on any matter pertaining to academic dentistry under your purview.

PREPARED STATEMENT OF THE AMERICAN DENTAL HYGIENISTS' ASSOCIATION

On behalf of the American Dental Hygienists' Association (ADHA), thank you for the opportunity to submit testimony regarding fiscal year 2015 appropriations. ADHA appreciates the Subcommittee's past support of programs that seek to improve the oral health of Americans and to bolster the oral health workforce. Oral health is a part of total health and authorized oral healthcare programs require appropriations support in order to increase the accessibility of oral health services, particularly for the underserved. ADHA urges that the block on funding for Section 340G-1 of the Public Health Service Act—a much needed dental workforce demonstration program—be lifted and that \$1.25 million be appropriated. Lifting the block on this dental workforce grants program, officially titled the Alternative Dental Health Care Providers Demonstration Program, would send an important signal to States and to HRSA that innovation in dental workforce is a meritorious undertaking. Importantly, the authorizing language requires that the grants be conducted in compliance with State law and that they must increase access to dental healthcare in rural and other underserved communities. Further, the Institute of Medicine is required to provide a qualitative and quantitative evaluation of the grants.

Congress recognized the need to improve the oral healthcare delivery system when it authorized the Alternative Dental Health Care Provider Demonstration Grants, Section 340G-1 of the Public Health Service Act. The Alternative Dental Health Care Providers Demonstration Grants program is a Federal grant program that recognizes the need for innovations to be made in oral healthcare delivery to bring quality care to the underserved by pilot testing new models. The authorizing statute makes clear that pilots must “increase access to dental care services in rural and underserved communities” and comply with State licensing requirements.

New dental providers are already authorized in Minnesota and are under consideration in a number of States, including Connecticut, Kansas, Maine, Massachusetts, New Hampshire, New Mexico, Vermont, and Washington State. Both the W.K. Kellogg Foundation and the PEW Charitable Trust Dental Campaign are investing in State efforts to increase oral healthcare access by adding new types of dental pro-

viders to the dental team. Further, the U.S. Federal Trade Commission supported dental workforce expansion in December 2013, noting that “expanding the supply of dental therapists . . . is likely to increase the output of basic dental services, enhance competition, reduce costs and expand access to dental care.” The National Governors Association’s January 2014 issue brief on “The Role of Dental Hygienists in Providing Access to Oral Health Care” found that “innovative State programs are showing that increased use of dental hygienists can promote access to oral healthcare, particularly for underserved populations, including children” and that “such access can reduce the incidence of serious tooth decay and other dental disease in vulnerable populations.”

The fiscal year 2014 HHS funding bill included language designed to block funding for this important demonstration program. We seek your leadership in removing this unjustified prohibition on funding for the Alternative Dental Health Care Providers Demonstration Grants. Further, because the authorizing language required HRSA to begin the dental workforce grant program under Section 340G–1 within 2 years of its 2010 enactment (i.e., by 2012) and to conclude it within 7 years of enactment (2017), language directing HRSA to move forward with Section 340G–1 grants despite this timeline is needed. ADHA, along with more than 60 other oral healthcare organizations, advocated for funding of this important program. Without the appropriate supply, diversity and distribution of the oral health workforce, the current oral health access crisis will only be exacerbated. ADHA recommends funding at a level of \$1.25 million for fiscal year 2015 to support these vital dental workforce demonstration projects.

Additionally, ADHA joins the American Dental Association, the American Dental Education Association and others in the oral health community, in recommending \$32 million for Title VII Program Grants to expand and educate the dental workforce; \$19 million for oral health programming at CDC, and funding of \$425 million for National Institute of Dental and Craniofacial Research.

ADHA urges funding of all authorized oral health programs and describes some of the key oral health programs below:

Title VII Program Grants to Expand and Educate the Dental Workforce—Fund at a level of \$32 million in fiscal year 2015

A number of existing grant programs offered under Title VII support health professions education programs, students, and faculty. ADHA is pleased dental hygienists are recognized as primary care providers of oral health services and are included as eligible to apply for several of the grants offered under “General, Pediatric, and Public Health Dentistry.” With millions more Americans eligible for dental coverage in coming years, it is critical that the oral health workforce is bolstered. Dental and dental hygiene education programs currently struggle with significant shortages in faculty and there is a dearth of providers pursuing careers in public health dentistry and pediatric dentistry. Securing appropriations to expand the Title VII grant offerings to additional dental hygienists and dentists will provide much needed support to programs, faculty, and students in the future.

Oral Health Programming within the Centers for Disease Control—Fund at a level of \$19 million in fiscal year 2015

ADHA joins with others in the dental community in urging \$19 million for oral health programming within the Centers for Disease Control. This funding level will enable CDC to continue its vital work to control and prevent oral disease, including vital work in community water fluoridation. Federal grants will serve to facilitate improved oral health leadership at the State level, support the collection and synthesis of data regarding oral health coverage and access, promote the integrated delivery of oral health and other medical services, enable States to be innovative, and promote a data-driven approach to oral health programming.

National Institute of Dental and Craniofacial Research—Fund at a level of \$425 million in fiscal year 2015

The National Institute of Dental and Craniofacial Research (NIDCR) cultivates oral health research that has led to a greater understanding of oral diseases and their treatments and the link between oral health and overall health. Research spurs innovation and efficiency, both of which are vital to improving access to oral healthcare services and improved oral status of Americans in the future. ADHA joins with others in the oral health community to support NIDCR funding at a level of \$425 million in fiscal year 2015.

ADHA is the largest national organization representing the professional interests of more than 150,000 licensed dental hygienists across the country. In order to become licensed as a dental hygienist, an individual must graduate from one of the Nation’s 335 accredited dental hygiene education programs and successfully com-

plete a national written and a State or regional clinical examination. Dental hygienists are primary care providers of oral health services and are licensed in each of the 50 States. Hygienists are committed to improving the Nation's oral health, a fundamental part of overall health and general well-being. In the past decade, the link between oral health and total health has become more apparent and the significant disparities in access to oral healthcare services have been well documented. At this time, when 130 million Americans struggle to obtain the oral healthcare required to remain healthy, Congress has a great opportunity to support oral health prevention, infrastructure and workforce efforts that will make care more accessible and cost-effective.

Conclusion

ADHA appreciates the difficult task appropriators face in prioritizing and funding the many meritorious programs and grants offered by the Federal Government. ADHA urges the Committee to lift the block on funding for Section 340G-1 of the PHSA, dental workforce demonstration grants. Lifting the block on funding for these dental workforce grants would be an important signal to States and to healthcare stakeholders that exploring new ways of bringing oral health services to the underserved is a meritorious expenditure of resources. In addition to the items listed, ADHA also supports full funding for community health centers, and urges HRSA be directed to further bolster the delivery of oral health services at community health centers, including the use of new types of dental providers. ADHA remains a committed partner in advocating for meaningful oral health programming that makes efficient use of the existing oral health workforce and delivers high quality, cost-effective care.

[This statement was submitted by Denise Bowers, RDH, PHD, President, American Dental Hygienists' Association.]

PREPARED STATEMENT OF THE AMERICAN FOUNDATION FOR SUICIDE PREVENTION

Dear Chairman Harkin and Ranking Moran: As you begin work on the fiscal year 2015 Labor, Health and Human Services, and Education Appropriations bill, the American Foundation for Suicide Prevention (AFSP) respectfully urges you to support investments in public health research by including \$40 million for the National Institute of Mental Health to conduct suicide prevention and brain research including studies designed to reduce the risk of self-harm, suicide, and interpersonal violence; \$25 million for the National Violent Death Reporting System (NVRDS) at the Centers for Disease Control and Prevention (CDC); \$60.15 million for suicide prevention programs under the Garrett Lee Smith Memorial Act (GLSMA) through the Substance Abuse Mental Health Services Administration (SAMHSA); and \$20 million for the Mental Health First Aid Program (MHFA).

\$40 Million in Funding for Suicide Prevention Research

Suicide, already the 10th leading cause of death overall in the U.S., the 3rd leading cause of death among 15-24 year olds, and the 2nd leading cause of death among 24-34 year olds; continues to take more and more lives each year. In 2010 (latest available data), suicide took the lives of more than 38,000 Americans, up 31 percent from 2000.

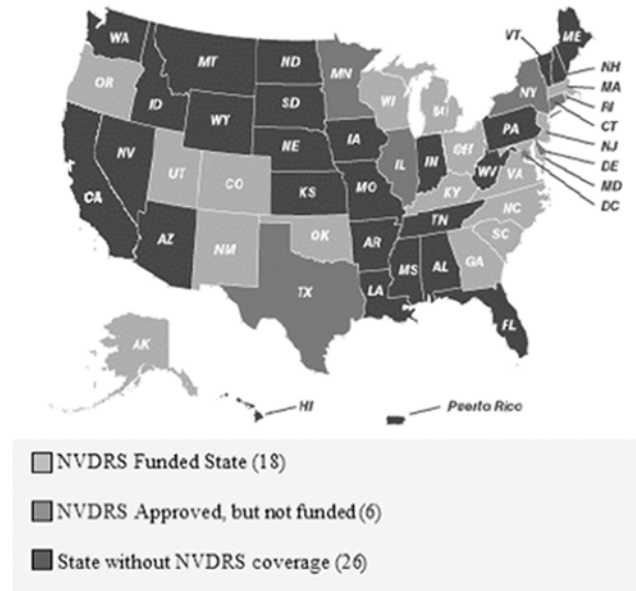
AFSP supports at a minimum a \$40 million investment in suicide prevention research as recommended by Representative Ron Barber in H.R. 4075 (the Suicide Prevention Research Innovation Act or SPRINT Act) so we can obtain similar reductions in suicide mortality that have resulted from strategic investments in other major public health concerns.

Full Funding of \$25 Million for the National Violent Death Reporting System (NVRDS)

The NVRDS collects in-depth information on the details of and circumstances surrounding each suicide, which goes beyond the basic information collected through the CDC's National Vital Statistics Reports/Fatal Injury Report and implementing the NVRDS nationwide is essential to developing, informing and evaluating suicide prevention programs.

Currently, the National Violent Death Reporting System collects surveillance data in only 18 States (Alaska, Colorado, Georgia, Kentucky, Maryland, Massachusetts, Michigan, New Jersey, New Mexico, North Carolina, Ohio, Oklahoma, Oregon, Rhode Island, South Carolina, Utah, Virginia and Wisconsin). The data collected helps inform policy makers on trends and characteristics of violent deaths within

specific communities so they can design appropriate prevention measures and evaluate ongoing efforts to curb violence.



Included in the fiscal year 2014 omnibus appropriations bill was an additional \$7.7 million (bringing the program total to \$11.2 million) in funding to expand the program; however, AFSP requests the full \$25 million be provided so the CDC would have the resources to scale up this effort to include all 50 States. Today, there exists no other data surveillance system that offers this benefit for such a modest investment. No other data collection or centralization effort carries the inherent value associated with NVDRS and, in fact, no other effort has the ability to directly inform and impact State and Federal suicide prevention activities.

Funding of \$60.15 Million for GLSMA Suicide Prevention Programs

Since its creation in 2004, GLSMA has provided resources to communities and college campuses all across the country, and supported needed technical assistance to develop and disseminate effective strategies and promising practices related to youth suicide prevention. To date, the GLSMA has supported youth suicide prevention grants in 49 States, the District of Columbia and Guam, 48 Tribes or Tribal organizations, and 138 institutions of higher education.

AFSP requests that the Committee approve \$60.15 million for GLSMA programs in fiscal year 2015 to ensure a continuation of these critically important youth and college suicide prevention programs.

Funding of \$20 Million for Mental Health First Aid (MHFA)

Sometimes, first aid isn't a bandage, or CPR, or the Heimlich, or calling 911. Sometimes, first aid is you. While many Americans know how to administer first aid and seek medical help should they come across a person having a heart attack, few are trained to provide similar help to someone experiencing a mental health or substance abuse crisis.

Mental Health First Aid is a public education program that helps people identify, understand, and respond to signs of mental illnesses and substance abuse. The course teaches participants a 5-step action plan to reach out to a person in crisis and connect them with professional, peer, or other help.

AFSP requests that \$20 million be approved for MHFA training programs around the country that would train participants in recognizing the symptoms of common mental illnesses and addiction disorders, de-escalating crisis situations safely, and initiating timely referral to mental health and substance abuse resources available in the community.

Thank you for your time and consideration of these requests by the American Foundation for Suicide Prevention. Should you have any questions I can be reached at jmadigan@afsp.org.

[This statement was submitted by John Madigan, Vice President, Public Policy.]

PREPARED STATEMENT OF THE AMERICAN GERIATRICS SOCIETY

Mr. Chairman and Members of the Subcommittee: We submit this testimony on behalf of the American Geriatrics Society (AGS), a non-profit organization of over 6,000 geriatrics healthcare professionals dedicated to improving the health, independence and quality of life of all older Americans. As the Subcommittee works on its fiscal year 2015 Labor-HHS-Education Appropriations bill, we ask that you prioritize funding for the geriatrics education and training programs under Title VII and Title VIII of the Public Health Service Act and for research funding within the National Institutes of Health/National Institute on Aging.

We ask that the subcommittee consider the following recommended funding levels for these programs in fiscal year 2015:

- \$39.7 million for Title VII Geriatrics Health Professions Programs
- \$5.0 million for Title VIII Comprehensive Geriatric Education Nursing Program
- An increase of \$500 million for aging research within the National Institutes of Health

While we recognize the fiscal challenges facing our Nation, sustained and enhanced Federal investments in these initiatives are essential to delivering higher quality, better coordinated and more cost effective care to our Nation's seniors. We request that Congress provide the additional investments necessary to expand and enhance the geriatrics workforce, which is an integral component of the primary care workforce, and to foster groundbreaking medical research so that our Nation is prepared to meet the unique healthcare needs of the rapidly growing population of seniors.

PROGRAMS TO TRAIN GERIATRICS HEALTH CARE PROFESSIONALS

Our Nation is facing a critical shortage of geriatrics faculty and healthcare professionals across disciplines. This trend must be reversed if we are to provide our seniors with the quality care they need and deserve. Care provided by geriatric healthcare professionals, who are trained to care for individuals who are the most complex and frail and who account for 80 percent of our Medicare expenditures, has been shown to reduce common and costly conditions that are often preventable with appropriate care, such as falls, polypharmacy, and delirium.

Title VII Geriatrics Health Professions Programs (\$39.7 million)

These programs support three initiatives: the Geriatric Academic Career Awards (GACAs), the Geriatric Education Center (GEC) program, and geriatric faculty fellowships. These are the only programs specifically designed to address the well-documented shortage of geriatrics healthcare professionals in the U.S. We ask the subcommittee to provide a fiscal year 2015 appropriation of \$39.7 million for Title VII Geriatrics Health Professions Programs.

Our funding request breaks down as follows:

- Geriatric Academic Career Awards (GACAs) (\$5.5 million)

GACAs support the development of newly trained geriatric clinicians in academic medicine who are committed to teaching geriatrics in medical schools across the country. GACA recipients are required to provide training in clinical geriatrics, including the training of interdisciplinary teams of healthcare professionals. HRSA, through the Affordable Care Act, expanded the awards to other disciplines—a change long supported by AGS—and requests adequate funding to reflect this. In addition, new awardees are only selected every 5 years and we believe that these awards should be available annually in order to ensure that we have an adequate number of faculty available to provide training in the principles of geriatric medicine. Our budget request of \$5.5 million would support GACA program awardees in their development as clinician educators.

Program Accomplishments.—In Academic Year 2012–2013, the GACA program funded 62 full-time junior faculty. These awardees delivered over 1,100 different courses, workshops and other types of training activities to over 53,000 trainees across the health professions—the most common of which included medical school students, residents in internal medicine and residents in geriatrics. In addition, GACA awardees are highly encouraged to engage in professional development and scholarly activities during each academic year as a way of advancing the field of geriatrics. Results showed that the awardees conducted presentations about their own

research and other related topics at over 215 conferences at the local, State or national level and published a total of 108 peer-reviewed publications.

—Geriatric Education Centers (GECs) (\$20.0 million)

GECs provide grants to support collaborative arrangements involving several health professions, schools and healthcare facilities to provide multidisciplinary training in geriatrics, including assessment, chronic disease syndromes, care planning, emergency preparedness, and cultural competence unique to older Americans. Our funding request of \$20.0 million includes continued support for the core work of 45 GECs (\$20.0).

Program Accomplishments.—In Academic Year 2012–2013, the GECs supported various types of geriatrics-specific training for health professions students and faculty, as well as for current community-based providers—delivering over 1,650 different continuing education courses to over 94,000 trainees. This exceeded the program's performance target by 58.5 percent. GEC grantees also partnered with over 650 healthcare delivery sites across the country to provide clinical and experiential training, in areas such as nursing homes and chronic and acute disease hospitals, to over 25,000 trainees. It is estimated that 2 out of every 5 sites used by GEC grantees for the purposes of offering these types of training were primary care settings and/or were located in a medically underserved community.

—*Alzheimer's Disease Prevention, Education, and Outreach Program.*—Funding for this program was included in the President's fiscal year 2015 budget request and allows HRSA to expand efforts to provide interprofessional continuing education to healthcare practitioners on Alzheimer's disease and related dementias through the already existing GECs. We are requesting \$5.3 million to support this program.

—Geriatric Training for Physicians, Dentists, Behavioral/Mental Health Professions (\$8.9 million)

This program is designed to train physicians, dentists, and behavioral and mental health professionals who choose to teach geriatric medicine, dentistry or psychiatry. The program provides fellows with exposure to older adult patients in various levels of wellness and functioning, and from a range of socioeconomic and racial/ethnic backgrounds. Our funding request of \$8.9 million will support this important faculty development program.

Program Accomplishments.—In Academic Year 2012–2013, a total of 64 physicians, psychiatrists, dentists, and psychologists, were supported through this program. These fellows received clinical training in over 200 different healthcare delivery sites across the country; the most common types of sites where fellows trained included Veteran's Affairs hospitals and clinics, private hospitals, and academic centers. It is estimated that nearly half of the sites (49 percent) where GTPD fellows received clinical training were located in a medically underserved community. Additionally, results showed that GTPD fellows delivered over 275 courses, workshops and other training activities focused on topics including oral health, chronic disease management and geriatric medicine, among others. It is estimated that over 5,600 trainees were trained as a result of these activities—the most common of which included medical school students, dental school students, residents in geriatrics and residents in geriatric psychiatry.

Title VIII Comprehensive Geriatric Education Nursing Program (\$5.0 million)

The American healthcare delivery system for older adults will be further strengthened by Federal investments in Title VIII Nursing Workforce Development Programs, specifically the comprehensive geriatric education grants, as nurses provide cost-effective, quality care. This program supports additional training for nurses who care for the elderly, development and dissemination of curricula relating to geriatric care, and training of faculty in geriatrics. It also provides continuing education for nurses practicing in geriatrics. Our funding request of \$5.0 million includes funds to continue the training of nurses caring for older Americans.

Program Accomplishments.—In Academic Year 2012–2013, the Comprehensive Geriatric Education Program (CGEP) supported numerous types of geriatric-related training programs and activities for health professions students and their faculty, as well as for community-based healthcare providers across the country. CGEP grantees offered over 150 different continuing education (CE) courses to over 11,600 trainees across the health professions. In addition, 74 students received traineeships—the majority of which (81 percent) are pursuing a Masters Degree in Nursing to become Nurse Practitioners in the fields of Adult Gerontology or Acute Care in Adult Gerontology.

Grantees of the CGEP also developed and implemented over 120 different geriatric-focused training activities to include new continuing education courses for current providers, as well as new academic courses and clinical rotations for health pro-

fessions students, residents and fellows across the country focused on these issues. It is estimated that a total of 4,500 trainees were reached as a result of these activities. Lastly, CGEP grantees supported over 40 different faculty development activities and programs. It is estimated that over 300 faculty-level trainees were trained on emerging issues in the field of geriatrics (e.g., pain management among the elderly, advances in patient engagement, among others) as a result of these activities.

RESEARCH FUNDING INITIATIVES—NATIONAL INSTITUTES OF HEALTH/NATIONAL INSTITUTE ON AGING

The institutes that make up the NIH, and in particular the NIA, lead a broad scientific effort to understand the nature of aging and to extend the healthy, active years of life. As a member of the Friends of the NIA, a broad-based coalition of aging, disease, research, and patient groups committed to the advancement of medical research that affects millions of older Americans, AGS urges an increase in NIH funding of \$500 million to support aging research across all institutes.

Considering what the Federal Government spends on the healthcare costs associated with age-related diseases, it makes sound economic sense to increase Federal resources for aging research. Chronic diseases associated with aging afflict 80 percent of the age 65+ population and account for more than 75 percent of Medicare and other Federal health expenditures. Continued Federal investments in scientific research, including comparative effectiveness initiatives, will ensure that the NIH has the resources to succeed in its mission to establish research networks, assess clinical interventions and disseminate credible research findings to patients, providers and payers of healthcare.

In closing, geriatrics is at a critical juncture, with our Nation facing an unprecedented increase in the number of older patients with complex health needs. Strong support such as yours will help ensure that every older American is able to receive high-quality healthcare.

Thank you for your consideration.

PREPARED STATEMENT OF THE AMERICAN HEART ASSOCIATION

Although great progress has been made in prevention and treatment of cardiovascular disease, including stroke, there is no cure and CVD remains America's No. 1 killer, costing a projected \$315 billion in medical expenses and lost productivity each year. Stroke, alone, is our No. 4 killer, costing an estimated \$37 billion a year. Both remain major causes of disability.

Nearly 84 million U.S. adults suffer from some form of CVD. It is projected that by the year 2030, more than 44 percent of U.S. adults will live with CVD at a cost exceeding \$1 trillion annually. So, it is disturbing that CVD research, prevention and treatment remain disproportionately underfunded with no sustained and stable funding from the National Institutes of Health. NIH is key for the U.S. to mount an ongoing and effective crusade against these devastating diseases.

We appreciate Congress' and the Administration's partial stay of sequestration. These cuts jeopardize the health of tens of millions of CVD sufferers and weaken our fragile economy and erode our global leadership in medical research. We challenge Congress to appropriate stable and sustained funding for CVD research, prevention and treatment. NIH funding is not only important for the health of our Nation, but also supports our economy through research-related employment opportunities it provides.

FUNDING RECOMMENDATIONS: INVESTING IN THE HEALTH OF OUR NATION

Research that could move us closer to a cure for heart disease and stroke goes unfunded. Congress must capitalize on 50 years of progress or our Nation will pay more in lives lost and healthcare costs. Our recommendations tackle the topics in a fiscally responsible way.

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

AHA is disappointed Congress did not fully restore sequester cuts for NIH in Public Law 113-76. NIH funded studies help prevent and cure disease, revolutionize patient care, drive economic growth, advance innovation, and sustain U.S. leadership in pharmaceuticals and biotechnology. NIH is the world's leader of basic research—the starting point for all medical progress and an indispensable Federal Government role that the private sector cannot fill. The U.S. is in jeopardy of losing our competitive edge in scientific research.

In addition to improving health, NIH creates a solid return on investment. In fiscal year 2012, NIH supported 400,000 U.S. jobs and produced nearly \$60 billion in

new economic activity. Every \$1 in NIH funding produced \$2 in economic activity in 2007. Yet, for the past decade, the NIH's budget has not kept pace with medical research inflation, resulting in more than a 20 percent loss in purchasing power. Such reductions, along with only a 50 percent restoration of sequester cuts, have occurred during a time of remarkable heightened scientific opportunity and when other countries have been increasing investment in science—some by double digits. These cutbacks have also demoralized early career investigators who, sadly, may leave and never return to research. We cannot afford to lose one of our Nation's most valuable resources—an innovative biomedical research workforce.

American Heart Association Advocates: We ask Congress to appropriate \$32 billion for NIH to restore sequester cuts, provide for modest growth, and advance CVD research.

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

Declining death rates from CVD is directly related to NIH research, with scientists on the verge of discoveries that could lead to groundbreaking treatments and even cures. In addition to saving lives, NIH research is cost-effective. For example, the first NIH tPA drug trial resulted in a 10-year net \$6.47 billion drop reduction in stroke healthcare costs.

Cardiovascular Disease Research: National Heart, Lung, and Blood Institute (NHLBI)

CVD death rates have greatly declined, with much of the reduction traced to research emanating from the NHLBI. Stable and sustained NHLBI funding is key to capitalize on investments that have led to major discoveries. For example, 10 percent of genetic changes leading to severe congenital heart disease are new and not passed down by a parent; people who maintained ideal health had better brain function in mid-life; digestive system bacteria may cause red meat to raise two chemicals linked to CVD; and post-traumatic stress disorder may be a heart disease risk factor. Sustained funding will allow robust implementation of priority CVD strategic plan initiatives.

Stroke Research: National Institute of Neurological Disorders and Stroke (NINDS)

An estimated 795,000 Americans will suffer a stroke this year and more than 129,000 will die. Many of the 7 million survivors face grave physical and mental disabilities and emotional trauma. In addition to the physical and emotional toll, stroke costs an estimated \$37 billion in medical expenses and lost productivity each year. Moreover, the future looks grim. A study projects that direct costs of stroke will triple between 2010 and 2030.

Stable and sustained NINDS funding is needed to capitalize on investments, including one showing aggressive medical treatment is better than stents in preventing a second stroke, and to advance the BRAIN Initiative. More resources are required to facilitate the NIH Stroke Trials Network and other priorities in stroke prevention, treatment and recovery research. They include: hastening translation of preclinical animal models into clinical studies; preventing vascular cognitive damage; expediting comparative effectiveness research trials; developing imaging biomarkers; refining clot-busting treatments; achieving robust brain protection; targeting early stroke recovery; and using neural interface devices.

American Heart Association Advocates: We recommend that NHLBI be funded at \$3.2 billion and NINDS at \$1.7 billion for fiscal year 2015.

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

Prevention is the best way to promote good health and reduce the costs of heart disease and stroke. Yet, proven prevention approaches are not implemented due to limited funds. We applaud Congress for providing in Public Law 113–76 the Division for Heart Disease and Stroke Research with a much needed boost. In addition to supporting research and evaluation and developing a surveillance system, the DHDSP administers Sodium Reduction Communities and the Paul Coverdell National Acute Stroke Registry. DHDSP, with the Centers for Medicare and Medicaid Services, implements Million Hearts™ to prevent 1 million heart attacks and strokes by 2017.

DHDSP runs WISEWOMAN, serving uninsured and under-insured, low-income women ages 40 to 64. It helps them from becoming heart disease and stroke statistics by offering preventive health services, referrals to local healthcare, and tailored lifestyle programs to promote lasting behavioral change.

American Heart Association Advocates: We join with the CDC Coalition in asking for \$7.8 billion for CDC's program level. AHA requests \$130.188 million for the DHDSP to sustain its participation in the State Public Health Actions to Prevent

and Control Diabetes, Heart Disease, Obesity and Associated Risk Factors and Promote School Health and \$37 million for WISEWOMAN. We ask for \$3 million for Million Hearts™ to better control blood pressure.

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

About 90 percent of cardiac arrest victims die outside of a hospital. Yet, early CPR and use of an automated external defibrillator can more than double survival. Communities with full AED programs have survival rates near 40 percent. HRSA's Rural and Community AED Program awards competitive grants to States to buy AEDs, tactically place them, and train lay rescuers and first responders in their use. Nearly 800 patients were saved from August 1, 2009 to July 31, 2010. But scarce resources let only 22 percent of approved applicants in 6 States receive funds in fiscal year 2013.

American Heart Association Advocates: We ask for a fiscal year 2015 appropriation of \$8.927 million to return this life-saving AED program to fiscal year 2005 levels when 47 States were funded.

CONCLUSION

Cardiovascular disease, including stroke, still wreak a deadly, disabling and costly toll on Americans. Our recommendations for NIH, CDC and HRSA will save lives and slash escalating healthcare costs. We challenge Congress to carefully study our requests that signify a wise investment for our country and for the health and well-being of this and future generations.

[This statement was submitted by Mariell Jessup, M.D., President, American Heart Association.]

PREPARED STATEMENT OF THE AMERICAN INDIAN HIGHER EDUCATION CONSORTIUM

This statement includes the fiscal year 2015 recommendations of the Nation's Tribal Colleges and Universities (TCUs), in two areas of the Department of Education: Office of Postsecondary Education and Office of Vocational Education.

HIGHER EDUCATION ACT PROGRAMS

Strengthening Developing Institutions.—Titles III and V of the Higher Education Act support institutions that enroll large proportions of financially disadvantaged students and have low per-student expenditures. The TCUs, which by any definition are truly developing institutions, funded under Title III—A Sec. 316 are providing quality higher education opportunities to some of the most rural/isolated, impoverished, and historically underserved areas of the country. The goal of HEA—Titles III/V programs is “to improve the academic quality, institutional management and fiscal stability of eligible institutions, in order to increase their self-sufficiency and strengthen their capacity to make a substantial contribution to the higher education resources of the Nation.” The TCU Title III—A program is specifically designed to address the critical, unmet needs of their American Indian students and communities, in order to effectively prepare them to succeed in a globally competitive workforce. Yet, in fiscal year 2011 this critical program was cut by over 11 percent, by another 4 percent in fiscal year 2012, and hit by sequestration—on the lowered baseline—in fiscal year 2013. Although sequestration was not imposed in fiscal year 2014, the TCUs have not recovered from the earlier cuts to this vitally important program. The TCUs urge the Subcommittee to restore the discretionary funding for HEA Title III—A, Sec. 316 to \$30,000,000 in fiscal year 2015.

TRIO.—Retention and support services are vital to achieving the national goal of having the highest proportion of college graduates in the world by 2020. TRIO programs, such as Student Support Services and Upward Bound, were created out of recognition that college access is not enough to ensure advancement and that multiple factors work to prevent the successful completion of postsecondary programs for many low-income and first-generation students and students with disabilities. Therefore, in addition to providing the maximum Pell Grant award level, it is critical that Congress also sustain student assistance programs, such as Student Support Services and Upward Bound so that low-income and minority students have the Federal support necessary to allow them to remain enrolled in and ultimately complete their higher education degrees.

Pell Grants.—The importance of Pell Grants to TCU students cannot be overstated. Approximately, 80 percent of TCU students receive Pell Grants, primarily because student income levels are so low and they have far less access to other

sources of financial aid than students at State-funded and other mainstream institutions. Within the TCU system, Pell Grants are doing exactly what they were intended to do—they are serving the needs of the lowest income students by helping them gain access to quality higher education, an essential step toward becoming active, productive members of the workforce. However, the U.S. Department of Education has changed its regulations to limit Pell eligibility from 18 to 12 full-time semesters, without any consideration of those already in the process of earning a postsecondary degree. This change in policy has impeded some TCU students from completing a postsecondary degree, which is widely recognized as being critical for access to, and advancement in, today's highly technical workforce.

TCUs are open enrollment institutions. Recent placement tests administered at TCUs to first-time entering students indicated that 74 percent required remedial math, 54 percent required remedial reading, and 57 percent needed remedial writing. These results clearly illustrate just how serious this new Pell Grant eligibility limit is to the success of TCU students in completing a postsecondary degree. Students requiring remediation can use as much as a full year of eligibility enhancing their math, and/or reading/writing skills, thereby hampering their future postsecondary degree plans. A prior national goal was to provide access to quality higher education opportunities for all students regardless of economic means, at which TCUs have been extremely successful. While the new national goal intends to produce graduates with postsecondary degrees by 2020, this change in policy does not advance that objective. On the contrary, the new regulations will cause many low-income students to once again abandon their dream of a postsecondary degree, as they will simply not have the means to continue to pursue it. The goal of a well-trained technically savvy workforce will be greatly compromised. This new policy evokes the adage “penny wise—pound foolish.” The TCUs urge the Subcommittee to continue to fund this essential program at the highest possible level, and to direct the Secretary of Education to implement a process to waive the very restrictive 12 semester Pell Grant eligibility for TCU students.

PERKINS CAREER AND TECHNICAL EDUCATION PROGRAMS

Tribally-Controlled Postsecondary Career and Technical Institutions.—Section 117 of the Carl D. Perkins Career and Technical Education Act provides a competitively awarded grant opportunity for tribally chartered and controlled career and technical institutions. AIHEC requests \$8,200,000 to fund grants under Sec. 117 of the Perkins Act.

Native American Career and Technical Education Program (NACTEP).—NACTEP (Sec. 116) reserves 1.25 percent of appropriated funding to support American Indian career and technical programs. The TCUs strongly urge the Subcommittee to continue to support NACTEP, which is vital to the continuation of career and technical education programs offered at TCUs that provide job training and certifications to remote reservation communities.

AMERICAN INDIAN ADULT AND BASIC EDUCATION (OFFICE OF VOCATIONAL AND ADULT EDUCATION)

This program supports adult basic education programs for American Indians offered by State and local education agencies, Indian tribes, agencies, and TCUs. Despite the absence of dedicated funding, TCUs must find a way, often using already insufficient institutional operating funds, to continue to provide adult basic education classes for those American Indians that the present K–12 Indian education system has failed. Before many individuals can even begin the course work needed to learn a productive skill, they first must earn a GED or, in some cases, even learn to read. The new GED exam, which was instituted in January 2014, has a much stronger focus on mathematics. As noted earlier, placement tests for TCU entering students reveal a tremendous need for math remediation. Additionally, the new GED test is fully computerized. While younger GED seekers may be well versed and comfortable with computer-based testing, older and poorer citizens may not be. These factors indicate a further and growing need for adult basic educational programs and GED preparation on Indian reservations. TCUs must have sufficient and stable funding to continue to provide these essential activities and to ensure their communities residents have the same chances to succeed as others throughout the country have. TCUs request that the Subcommittee direct that \$8,000,000 of the funds appropriated annually for the Adult Education State Grants be made available to make competitive awards to TCUs to help meet the growing demand for adult basic education and remediation program services on their respective Reservations.

FURTHER JUSTIFICATIONS FOR FISCAL YEAR 2015 APPROPRIATIONS REQUESTS FOR TCUS

Tribal colleges and our students are already being disproportionately impacted by ongoing efforts to reduce the Federal budget deficit and control Federal spending. The fiscal year 2011 Continuing Resolution eliminated all of the Department of Housing and Urban Development's Minority Serving Institutions (MSIs) community-based programs, including a critically needed TCU-HUD facilities program. TCUs were able to maximize leveraging potential, often securing even greater non-Federal funding to construct and equip Head Start and early childhood centers; student and community computer laboratories and public libraries; and student and faculty housing in rural and remote communities where few and sometimes none of these facilities existed. Important STEM programs, administered by the National Science Foundation and NASA were cut, and for the first time since the NSF program was established in fiscal year 2001, no new TCU-STEM awards were made in fiscal year 2011. While NSF-TCUP grants resumed in fiscal year 2012, a year of grant opportunity was lost. TCUs Additionally, TCUs and their students suffer the realities of cuts to programs such as GEAR-UP, TRIO, SEOG, and as noted earlier, are seriously impacted by the new highly restrictive Pell Grant eligibility criteria more profoundly than mainstream institutions of higher education, which can realize economies of scale due to large endowments, alternative funding sources, including the ability to charge higher tuition rates and enroll more financially stable students, and access to affluent alumni. The loss of opportunities that cuts to DoEd, HUD, NSF, and NASA programs represent to TCUs, and to other MSIs, is magnified by cuts to workforce development programs within the Department of Labor, nursing and allied health professions tuition forgiveness and scholarship programs operated by the Department of Health and Human Services, and an important TCU-based nutrition education program planned by USDA. Combined, these cuts strike at the most economically disadvantaged and health-challenged Americans.

We respectfully request that the Members of the Subcommittee continue the Federal investment in the Nation's Tribal Colleges and Universities and full consideration of our fiscal year 2015 appropriations needs and recommendations.

PREPARED STATEMENT OF THE AMERICAN PHYSIOLOGICAL SOCIETY

The American Physiological Society (APS) thanks the subcommittee for its ongoing support of the National Institutes of Health (NIH). Research carried out by the NIH contributes to our understanding of health and disease, which allows all Americans to look forward to a healthier future. The APS urges you to make every effort to provide the NIH with a net funding level of \$32 billion in fiscal year 2015. This is necessary to prevent further erosion of research capacity.

Federal investment in research is critically important because breakthroughs in basic and translational research are the foundation for new drugs and therapies that help patients, fuel our economy, and provide jobs. The Federal Government is the primary funding source for discovery research through competitive grants awarded by the NIH. Although the private sector partners with academic researchers to develop research findings into new treatments, industry relies upon federally funded research to identify where innovation opportunities can be found. This system of public-private partnership has been critical to U.S. leadership in the biomedical sciences. However, this position of leadership is at risk as other nations, including China, increase their investments in research and development while the United States investment has lagged in recent years.

Federal research dollars also have a significant impact at the local level: Approximately 85 percent of the NIH budget is awarded throughout the country to researchers who use grant funds to pay research and administrative staff, purchase supplies and equipment, and cover other costs associated with their research.

NIH funds outstanding science

As a result of improved healthcare, Americans in the 21st century are living longer and healthier lives than ever before. However, chronic conditions such as cardiovascular disease, diabetes, respiratory illnesses, Alzheimer's and cancer continue to inflict a heavy burden in the United States and around the world. As the U.S. population ages, the prevalence and cost of these diseases will increase exponentially. The NIH invests heavily in basic research to understand the physiological mechanisms at work in health and disease. This knowledge is crucial to the development of safe and effective interventions and prevention strategies.

Exciting new initiatives are underway at the NIH to advance science, including the Brain Research through Advancing Innovative Neurotechnologies ("BRAIN") initiative and the Big Data 2 Knowledge project (BD2K). The BRAIN initiative will

bring together researchers from diverse disciplines to tackle major gaps in current knowledge about the brain and brain diseases. BD2K will explore ways to capitalize on the immense volume of data being created by biomedical scientists, ultimately enhancing the work of the entire community by providing new tools and resources to make better use of that data. These important projects require significant resources, and at a time of constrained budgets, that will further diminish funding for investigator-initiated grants. The NIH system of allowing investigators to develop and propose ideas which are then evaluated by their peers and selected for funding based on their merit has fostered a research enterprise that is second to none. Increasing the NIH budget to \$32 billion would provide funding for large projects as described above, while also providing resources for individual scientists to pursue creative new avenues of research.

NIH nurtures the biomedical research enterprise

In addition to supporting research, the NIH must also address workforce issues to ensure that our Nation's researchers are ready to meet the challenges they will face in the future. The pressures placed on the biomedical research enterprise after years of sub-inflationary budget increases were severely compounded by sequestration cuts in fiscal year 2013. One analysis showed that NIH supported approximately 1000 fewer investigators in fiscal year 2013 as a result of its declining budget.¹ Researchers who lose their funding face an uncertain future as there are few options to sustain their research without Federal grants. Losing Federal support puts at risk the investment that it took to build those programs over many years. It also means that talented individuals working in those labs will have to look elsewhere for increasingly scarce jobs. As a result of stagnant funding for NIH, scientists at all stages of their careers struggle to maintain their research programs.

Scientists in the early stages of their careers face a particular set of challenges as they work to establish themselves during a time of dwindling resources. To address some of these problems, the NIH is continuing its commitment to fund new investigators at approximately the same rate as established investigators. The NIH is also developing three new efforts to ensure a diverse and sustainable future biomedical workforce. The National Research Mentoring Network (NRMN) and the Building Infrastructure Leading to Diversity (BUILD) initiative are complementary programs that will develop innovative new mentorship programs to engage individuals from diverse backgrounds and help them prepare to succeed in biomedical research careers. The Coordination and Evaluation Center (CEC) will play a role in coordinating and assessing NRMN and BUILD, providing program-wide goals and tools to assess progress. These efforts are critical to helping young scientists launch their careers. However, to sustain a talented workforce the NIH needs predictable and sustainable budget growth. If the current funding crisis is not resolved, the continued loss of senior researchers will begin to erode the pool of experienced mentors for early career scientists on which the BUILD and NRMN programs rely.

The NIH also uses the Institutional Development Award (IDeA) Program to broaden the geographic distribution of NIH funds by providing support to researchers and institutions in areas that have not previously received significant NIH funding. IDeA builds research capacity and improves competitiveness in those States by developing shared resources, infrastructure and expertise. Networks established through this program expand research opportunities for students and faculty at predominantly undergraduate institutions and enhance the level of science and technology knowledge of the workforce in IDeA States. The program currently serves institutions and researchers in 23 States and Puerto Rico. The APS believes this program is an important way to broaden participation in the scientific workforce.

The APS appreciates the support of the committee in continuing the Science Education Partnership Awards (SEPA) program at the NIH. This program was slated for elimination last year under the proposed consolidation of science education programs across Federal agencies. The SEPA program fosters important connections between biomedical researchers and K-12 students and teachers, providing an opportunity for students at the earliest levels to learn about STEM careers. No other Federal STEM program addresses biomedicine or provides this kind of outreach concerning what NIH does to promote the health of our citizens. Thus, SEPA programs promote health literacy among young individuals, who will increasingly be expected to manage their own healthcare. Many of the programs sponsored by SEPA, including those at the APS, disproportionately reach underrepresented and disadvantaged students. The APS believes that the SEPA program helps establish the groundwork to address issues of workforce diversity and health literacy.

¹ <http://www.asbmb.org/asbmbtoday/201403/PresidentsMessage/>

The APS is a professional society dedicated to fostering research and education as well as the dissemination of scientific knowledge concerning how the organs and systems of the body work. The Society was founded in 1887 and now has more than 10,000 member physiologists. APS members conduct NIH-supported research at colleges, universities, medical schools, and other public and private research institutions across the U.S.

The APS joins the Federation of American Societies for Experimental Biology (FASEB) in urging that NIH be provided with no less than \$32 billion in fiscal year 2014.²

[This statement was submitted by Kim E. Barrett, Ph.D., President, American Physiological Society.]

PREPARED STATEMENT OF THE AMERICAN PSYCHOLOGICAL ASSOCIATION

The American Psychological Association (APA) is the largest scientific and professional organization representing psychology in the U.S.: its membership includes nearly 130,000 researchers, educators, clinicians, consultants and students. APA works to advance the creation, communication and application of psychological knowledge to benefit society and improve people's lives. Many programs in the Labor-HHS-Education bill impact science, education, and the populations served by clinical psychologists.

National Institutes of Health.—The Consolidated Appropriations Act of 2014 increase for NIH did not give back all of the funds cut by sequestration in fiscal year 2013 nor did it restore the purchasing power lost over the past decade. As a member of the Ad Hoc Group for Medical Research, APA recommends that NIH receive at least \$32 billion in fiscal year 2015 as the next step toward a multi-year increase in our Nation's investment in health research. APA also urges Congress and the Administration to work in a bipartisan manner to end sequestration and the continued cuts to health research that squander invaluable scientific opportunities, discourage young scientists, threaten or slow improvements in our Nation's health, and jeopardize our economic future.

Psychological scientists are supported by research grants or training programs in almost all of NIH's 27 institutes and centers. They are working with animal models or human participants to improve diagnosis and treatment of Alzheimer's disease and autism, to understand the mechanisms underlying adoption of healthy behaviors, and to help prevent transmission of HIV and unhealthy behaviors such as substance abuse. Behavioral research is critical to NIH's mission: approximately 40 percent of premature mortality in the U.S. is due to behaviors such as smoking, sedentary lifestyle, and alcohol and other drug consumption. APA encourages continued support for OppNet, the trans-institute initiative funded through the Office of Behavioral and Social Sciences Research that has led to some \$90 million in funding of basic research through fiscal year 2013 on critical issues such as sleep, stress, and multisensory perception. As NICHD develops initiatives to understand and prevent harmful and costly preterm births, APA encourages that institute to enhance research on psychological factors that may contribute.

There remains a disturbing paucity of scientific evidence about the effects of sporadic vs. regular use of marijuana, alcohol, nicotine and other substances on the developing brain. A large-scale, prospective study that (a) includes brain imaging and (b) begins in late childhood (prior to substance exposure) and continues into early adulthood is urgently needed. Now is the time to begin an in-depth and definitive longitudinal study to document the short- and long-term effects of substance use and, in particular, the impact on young brains to inform future drug policy decisions. By tracking brain development and various life outcomes alongside behavioral data on substance use, the study would also illuminate the developmental effects of individual substances as well as substance interactions, as well as better establish the relationship between substance use and other mental disorders (e.g., does substance use predispose adolescent users to mental illness; do subclinical or premorbid symptoms of mental illness lead to substance use; or are associations due to a shared vulnerability?). APA urges the NIH to conduct such a study as part of the Collaborative Research on Addictions at NIH (CRAN initiative) to comprehensively document the biological and behavioral effects of substance use on the developing brain by conducting a longitudinal naturalistic study monitoring a nationally representative sample of 10,000 healthy 10-year-old children over the course of 10 years.

² www.faseb.org/fundingreport

Centers for Disease Control and Prevention.—As a member of the CDC Coalition, APA supports at least \$7.8 billion for core programs in fiscal year 2015. Rather than relying on the Prevention Fund and other transfers, APA urges the committee to restore CDC's budget authority. As a member of the Friends of NCHS, APA recommends a program level of \$182 million for the National Center on Health Statistics. APA strongly supports the President's request for increased funding for the National Injury Prevention and Control Center, including \$10 million research into the causes and prevention of gun violence, to allow the CDC to carry out the critical research agenda developed last year by the Institute of Medicine and the National Research Council, and for \$23.57 million for the National Violent Death Reporting System, to allow for its expansion to all 50 States and DC. APA is pleased that the Committee provided an increase in funding for the Prevention Research Centers program in fiscal year 2014, and urges that funding be restored for the program to at least \$28 million in fiscal year 2015, consistent with the fiscal year 2011 funding level, to support research essential to the focus on prevention. APA supports the President's request of \$360.7 million for surveillance, research and programs to support HIV prevention in the Division of HIV/AIDS Prevention, an increase of \$4.3 million above fiscal year 2014. Additional resources should be directed toward behavioral and social science research that optimizes outcomes along the HIV care continuum; implementation science to enhance linkage and retention in care; research on adherence to treatment; developing and scaling up interventions for most the impacted persons living with HIV/AIDS; development, adaptation and implementation of innovative strategies to address stigma and discrimination; and research into structural and environmental factors that drive the HIV epidemic.

Substance Abuse and Mental Health Services Administration.—APA strongly supports:

- The National Child Traumatic Stress Network (NCTSN) program. APA recommends increased support for the Network's efforts on behalf of the recovery of children, families, and communities affected by physical and sexual abuse, school and community violence, natural disasters, sudden death of a loved one, war's impact on military families, and other trauma.
- Garrett Lee Smith Memorial Act programs—Campus Suicide Prevention, State and Tribal Youth Suicide Prevention and the Suicide Prevention Resource Center. These effective national programs help meet the mental and behavioral health needs of youth and young adults through access to prevention, education, and outreach services to reduce suicide risk in these populations. First authorized in 2004, the Garrett Lee Smith Memorial Act has supported youth suicide prevention grants in 49 States, 48 Tribes or Tribal organizations, and 138 institutions of higher education.
- Minority Fellowship Program. APA remains concerned that while minorities represent 30 percent of the population and are projected to increase to 40 percent by 2025, only 23 percent of recent doctorates in psychology, social work and nursing were awarded to minorities. We encourage the Committee to support the Administration's \$5 million increase for the MFP as requested in the fiscal year 2015 budget proposal. The increase reflects the need to continually grow the pool of culturally competent mental health professionals.
- Mental Health Care Provider Education in HIV/AIDS Program, in CMHS. Continuing education for mental health providers in these crucial clinical issues remains a high priority. APA urges Congress to maintain level funding in CMHS for the training of psychologists, social workers, and psychiatrists in mental health and psychosocial issues related to HIV/AIDS.
- SAMHSA-funded programs providing vital substance abuse and mental health services to people with HIV/AIDS.
- SAMHSA's Safe Schools/Healthy Students program that expands access to mental and behavioral health services in schools and reduces violence through prevention and early intervention supports.

Health Resources and Services Administration.—APA recommends funding SSA Section 512 regarding services to individuals with a postpartum condition. Postpartum Depression (PPD) is one of the most common and frequently undiagnosed conditions associated with childbirth. In the U.S. approximately one in five women suffers from PPD each year. While PPD is a widespread problem, under the current USPSTF guidelines, depression screening is available as an Essential Health Benefit to all non-pregnant adults, yet excludes the vulnerable population of pregnant women. APA supports funding for this as-yet unfunded provision that supports PPD research and treatment and the incorporation of screening and linkages to behavioral health treatment for families affected by this condition. APA encourages the Committee to support incorporation of PPD screening into the Title V programs administered by HRSA as well as Healthy Start. APA also encourages the

Committee to urge the Secretary to prioritize the issue of PPD by raising awareness, expanding research, and establishing grants for the operation and coordination of cost-effective services to afflicted women and their families.

APA recommends continued investments in the mental and behavioral health workforce, including \$6.9 million for the Graduate Psychology Education program to increase the number of health service psychologists trained to provide services to high-need and high-demand underserved populations in both urban and rural communities. This program supports the training of doctoral psychology students, interns and postdoctoral residents with other health professionals while they provide supervised mental and behavioral health services to underserved and vulnerable populations, including: children, older adults, veterans and their families, individuals with chronic illnesses, and victims of abuse and trauma. In 2010–2011 alone, the GPE program supported the training of 620 graduate psychology students and provided mental and behavioral health services to over 46,000 underserved persons. APA encourages HRSA to maintain a strong emphasis on serving rural veteran populations and their families. There is a growing need for highly trained mental and behavioral health professionals to deliver evidence-based services to the rapidly aging population. APA encourages HRSA to reinstate the geropsychology component, and help integrate health service psychology trainees at federally Qualified Health Centers.

HHS programs on aging.—Given that approximately 20–25 percent of older adults have a mental or behavioral health problem, and older white males (age 85 and over) currently have the highest rates of suicide of any group in the U.S. APA supports an expanded effort to address the mental and behavioral health needs of older adults including implementation of the mental and behavioral health provisions in the Older Americans Act Amendments of 2006, grants to States for the delivery of mental health screening, and treatment services for older individuals and programs to increase public awareness and reduce the stigma associated with mental disorders in older individuals.

APA also recommends continued support of the HHS's Lifespan Respite Program. Respite care can provide family caregivers with relief necessary to maintain their own health, bolster family stability and well-being, and avoid or delay more costly nursing home or foster care placements.

Department of Education.—APA supports strengthening our Federal investment in gifted and talented education and encourages Congress to fund the Javits Gifted and Talented Education Program in fiscal year 2015, funded last year at \$5 million. And, as a member of the Friends of the Institute of Education Sciences (IES), APA supports \$202.3 million for IES's research, development and dissemination portfolio, consistent with the Administration's 2013 and 2014 requests. This would support critical investments to provide evidence-based information on effective educational practices to parents, teachers and schools, and new research to fill gaps in knowledge.

Thank you for the opportunity to submit testimony for the record in support of critical program areas funded by the Labor-Health and Human Services-Education appropriations bill.

PREPARED STATEMENT OF THE AMERICAN PUBLIC HEALTH ASSOCIATION

The American Public Health Association is a diverse community of public health professionals who champion the health of all people and communities. We are pleased to submit our request to fund the Centers for Disease Control and Prevention at \$7.8 billion and the Health Resources and Services Administration at \$7.48 billion in fiscal year 2015. We urge you to take our recommendations to restore funding to at least fiscal year 2010 levels into consideration as you move forward with writing the fiscal year 2015 Labor-HHS-Education Appropriations bill.

Centers for Disease Control and Prevention

APHA believes Congress should support CDC as an agency, not just the individual programs that it funds. Given the challenges and burdens of chronic disease and disability, public health emergencies, new and reemerging infectious diseases and other unmet public health needs, we urge a funding level of \$7.8 billion for CDC's programs in fiscal year 2015. We appreciate some of the important new investments in President Obama's fiscal year 2015 budget proposal; however, under the president's proposal, CDC's total budget would be cut by nearly \$243 million compared to fiscal year 2014. CDC's budget authority under the president's budget is lower than fiscal year 2003 levels. State and local health departments continue to operate on tight budgets and with a smaller workforce, losing more than 50,000

public health jobs since 2008. These cuts will reduce the ability of CDC and its State and local grantees to investigate and respond to public health emergencies, ensure adequate immunization rates and track environmental hazards.

By translating research findings into effective intervention efforts, CDC is a critical source of funding for many of our State and local programs that aim to improve the health of communities. Perhaps more importantly, Federal funding through CDC provides the foundation for our State and local public health departments, supporting a trained workforce, laboratory capacity and public health education communications systems. It is notable that more than 70 percent of CDC's budget supports public health and prevention activities by State and local health organizations and agencies, national public health partners and academic institutions.

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

CDC serves as the lead agency for bioterrorism and other public health emergency preparedness and response programs and must receive sustained support for its preparedness programs in order for our Nation to meet future challenges. Given the challenges of terrorism and disaster preparedness, and our many unmet public health needs and missed prevention opportunities we urge you to provide adequate funding for State and local capacity grants. Unfortunately, this is not a threat that is going away.

CDC plays a significant role in addressing chronic diseases such as heart disease, stroke, cancer, diabetes and arthritis that continue to be the leading causes of death and disability in the United States. These diseases, many of which are preventable, are also among the most costly to our health system. CDC's National Center for Chronic Disease Prevention and Health Promotion provides critical funding for State programs to prevent chronic disease, conducts surveillance to collect data on disease prevalence and monitor intervention efforts and translates scientific findings into public health practice in our communities.

CDC's National Center for Environmental Health is essential to protecting the health and well being of the public by helping to control asthma, protect from threats associated with climate change and reduce exposure to lead and other hazards. We urge the subcommittee to provide adequate funding for NCEH which has been significantly cut in recent years.

Health Resources and Services Administration

HRSA operates programs in every State and U.S. territory and is a national leader in improving the health of Americans through the delivery of quality health services and supporting a well prepared workforce. The agency serves the health needs of people who are medically vulnerable, low-income and geographically isolated. The Nation faces a shortage of health professionals and continues to experience an ever growing, aging and increasingly diverse population, alongside health professionals that are nearing retirement age. We are deeply concerned that since fiscal year 2010, HRSA's discretionary budget authority has been cut by 19 percent in nominal dollars and 25 percent when adjusted for inflation. Funding for HRSA is far too low and keeping austerity measures in place will threaten the agency's ability to address the present and growing health needs of the U.S. To respond to the needs of our Nation, APHA recommends restoring funding to the fiscal year 2010 level of \$7.48 billion for discretionary HRSA programs in fiscal year 2015.

HRSA programs have a strong history of providing quality care to keep people healthy and improve health equity for those living outside of the economic and medical mainstream. HRSA has contributed to the decrease in infant mortality rate, a widely used indicator of the Nation's health, which is now at an all-time low. Most recently, preliminary data indicates that the infant mortality rate for black infants has decreased, resulting in a narrowing of the gap that exists between racial groups. HIV/AIDS programs administered by HRSA provide access to regular care and ensure adherence to antiretroviral treatment for people living with HIV, which reduces HIV transmission by 96 percent and greatly contributes to the prevention of new HIV infections. A committed investment from Congress is required to continue achieving the health improvements HRSA has made and to pave the way for new achievements.

Our recommendation is based on the need to continue improving the health of Americans by supporting critical HRSA programs, including:

- Health Professions supports the education and training of a broad range of health professionals. With a focus on primary care and training in interdisciplinary, community-based settings, these are the only Federal programs focused on filling the gaps in the supply of health professionals, as well as improving the distribution and diversity of the workforce so health professionals are well-equipped to care for the growing and changing population.
- Primary Care supports 9,200 health sites in every State and U.S. territory, improving access to care for more than 21 million patients in geographically isolated and economically distressed communities. Close to half of these health centers serve rural populations. In addition, health centers target populations with special needs, including migrant and seasonal farm workers, homeless individuals and families and those living in public housing.
- Maternal and Child Health including the Title V Maternal and Child Health Block Grant, Healthy Start and others support initiatives designed to promote optimal health, reduce disparities, combat infant mortality, prevent chronic conditions and improve access to quality healthcare for more than 43 million women and children, including children with special healthcare needs.
- HIV/AIDS provides assistance to States and communities most severely affected by HIV/AIDS. The programs deliver comprehensive care, prescription drug assistance and support services for about half of the total population—1.1 million people—living with HIV/AIDS in the U.S. Additionally, the programs provide education and training for health professionals treating people with HIV/AIDS and work toward addressing the disproportionate impact of HIV/AIDS on racial and ethnic minorities.
- Family Planning Title X services ensure access to a broad range of reproductive, sexual and related preventive healthcare for over 5 million poor and low-income women, men and adolescents at nearly 4,400 health centers nationwide. This program helps improve maternal and child health outcomes and promotes healthy families.
- Rural Health improves access to care for the nearly 50 million people living in rural areas that experience a persistent shortage of healthcare services. These programs are designed to support community-based disease prevention and health promotion projects, help rural hospitals and clinics implement new technologies and strategies and build health system capacity in rural and frontier areas.

Conclusion

In closing, we emphasize that the public health system requires stronger financial investments at every stage. This funding makes up less than 1 percent of Federal spending and continued austerity measures that cut funding for public health and prevention programs will not balance our budget and will only lead to increased costs to our healthcare system. Successes in biomedical research must be translated into tangible prevention opportunities, screening programs, lifestyle and behavior changes and other population-based interventions that are effective and available for everyone. Without a robust and sustained investment in our public health agencies, we will fail to meet the mounting health challenges facing our Nation.

[This statement was submitted by Georges Benjamin, MD, Executive Director American Public Health Association.]

PREPARED STATEMENT OF THE AMERICAN SOCIETY FOR MICROBIOLOGY

The American Society for Microbiology (ASM), the largest single life science Society with over 39,000 members, wishes to submit a statement in support of increased funding in the fiscal year 2015 budget for the Centers for Disease Control and Prevention (CDC). As the Nation's health protection Agency, the CDC's programs are critical to preventing disease and injury. The CDC conducts scientific investigations, develops public health guidelines and provides information and expertise in response to threats against public health in the United States and worldwide.

The ASM urges Congress to approve the requested budget of \$445.3 million for the National Center for Emerging and Zoonotic Infectious Diseases (EZID), an overall increase of \$54.9 million over fiscal year 2014. The EZID budget includes an increase of \$31 million for Core Infectious Diseases. A funding level of \$30 million is included for Advanced Molecular Detection (AMD), year 2 of the 5 year initiative to enhance CDC's microbiology and bioinformatics capabilities to detect and respond to infectious disease outbreaks. The AMD initiative will improve pathogen identification and detection; adapt new diagnostics to meet evolving public health needs; help States meet future reference testing needs in a coordinated manner; implement

enhanced, sustainable and integrated laboratory information systems; and develop prediction modeling and early recognition tools. Advances in biotechnology and computing must be part of CDC efforts against the threat of infectious diseases. Because of the need for better molecular sequencing tools and bioinformatics, last year CDC proposed the AMD initiative, integrating cutting edge laboratory and computer tools to enhance infectious disease prevention and control. A 2013 pilot study tracking a *Listeria* outbreak demonstrated that AMD technologies and methods could detect outbreaks sooner, halting disease faster. The study used whole genome sequencing with diagnostic testing for the first time to help clarify which patients' illnesses were related to a listeriosis outbreak linked to contaminated cheese. *Listeria* ranks third as a cause of death from foodborne pathogens in the United States and sickens about 1,600 people each year.

The EZID budget includes a \$10 million increase for CDC's Food Safety program. This increase is essential to enhance national surveillance outbreak detection and response and food safety prevention efforts. It will help modernize PulseNet and apply advanced DNA technology and expand sites for FoodCORE to improve outbreak detection and response. It will improve foodborne disease tracking, detection and response through the Integrated Food Safety Center of Excellence. Food safety is one of CDC's foremost strategic goals and heavily reliant upon state of the art surveillance. Last year, the CDC published first ever estimates of which food types were causing foodborne illnesses in the United States. These attribution estimates guide regulators, industry and consumers toward more precise and effective measures to prevent food contamination. In June, a new CDC report identified the key demographic groups most affected by *Listeria* bacteria infections. During 2009–2011, twelve *Listeria* outbreaks sickened people in 38 States. CDC partnerships with other public health agencies clearly extend the CDC's ability to prevent disease. For example, data from the Foodborne Diseases Active Surveillance Network (FoodNet) are the source for CDC's most recent annual food safety report, which showed that 2012 rates of infection for two foodborne pathogens (*Campylobacter* and *Vibrio*) had increased significantly when compared to 2006–2008, while rates of most others have not changed during the same period. FoodNet involves CDC, ten State health departments, the Department of Agriculture and the Food and Drug Administration.

The ASM strongly supports the fiscal year 2015 EZID budget request of \$30 million for the Antibiotic Resistance (AR) Strategy, which will speed up outbreak detection through regional labs, support development of new antibiotics and diagnostics and improve infection prevention and antibiotic prescribing. With a \$30 million annual funding for 5 years, the AR initiative could achieve reductions in many infections, including *C. difficile*, carbapenem resistant *Enterobacteriaceae* (CRE), Multidrug Resistant (MDR) *Pseudomonas*, Invasive Methicillin-resistant *Staphylococcus aureus* (MRSA) and MDR *Salmonella*.

CDC efforts have intensified against microbial pathogens that have evolved resistance against known drug therapies. In September, a landmark CDC report warned that antimicrobial resistant infections infect more than two million people in the United States every year, causing at least 23,000 deaths. CDC ranked AR threats into three categories: urgent, serious and concerning. Infections classified as urgent include CRE, drug resistant gonorrhea and *Clostridium difficile*, a diarrheal infection that causes about 250,000 U.S. hospitalizations and at least 14,000 deaths annually. Last year, CDC data showed more patients at hospitals and long term care facilities are being diagnosed with CRE infections; other AR reports are equally alarming.

In November, CDC joined with the American Academy of Pediatrics to slow AR expansion with new guidelines, "Principles of Judicious Antibiotic Prescribing for Bacterial Upper Respiratory Tract Infections in Pediatrics." Every year, up to 10 million children in the United States risk side effects from antibiotic prescriptions unlikely to help their respiratory symptoms. Many of these infections are caused by viruses not treatable by antibiotics. Antibiotic use is the single most important factor in antibiotic resistance, with up to 50 percent of prescriptions unnecessary or prescribed inappropriately. Studies estimate that AR adds \$20 billion in excess direct health costs, with additional costs to Society for lost productivity as high as \$35 billion a year.

CDC guidelines that include science based prevention protocols can be very effective, for example, the ongoing battle against healthcare acquired infections (HAIs). About 1 in every 20 hospitalized patients develops an infection caused by receiving medical care. Many of these are drug resistant (e.g., three quarters of *Staphylococcus aureus* infections in hospital ICUs are methicillin resistant MRSA). CDC aggressively promotes use of prevention protocols in all facilities in the United States. In 2013, CDC found that bloodstream infections in patients with central IV

lines had decreased by over 40 percent and surgical site infections by 20 percent since 2008 and that following CDC protocols could cut dialysis related bloodstream infections in half. Another CDC coauthored report last fall concluded that there were an estimated 30,800 fewer invasive MRSA infections in 2011 compared with 2005. More than 12,000 healthcare facilities now track HAI infections using CDC's National Healthcare Safety Network (NHSN).

Surveillance and Response

CDC depends upon extensive surveillance networks and unique rapid response mobilization. Sustaining these CDC capabilities is critical to detect health threats, halt outbreaks and prevent illness and injury. Familiar threats like hepatitis and HIV/AIDS continue to affect lives. Public health institutions also are repeatedly challenged by emerging infectious diseases (EIDs), unexpected and often dangerous. CDC regularly confronts new threats, including the following EIDs in the past year:

- CDC scientists traced the newly discovered Heartland virus that infected two men from Missouri to lone star ticks in the region, adding another tick borne disease to those the CDC monitors.
 - NCEZID helped identify a novel poxvirus (the same genus as smallpox) afflicting shepherds in the Republic of Georgia and is developing new diagnostic tests.
 - International travel advisories released by CDC address threats posed by the new coronavirus MERS-CoV, first reported by Saudi Arabia in 2012. CDC is working with health departments, hospitals and other partners to prepare for possible cases in the United States.
 - CDC is monitoring new reports of the mosquito borne chikungunya virus among residents of St. Martin in the Caribbean, the first time the disease has been detected among non-travelers in the Western Hemisphere.
- In 2013, CDC updated new surveillance results on several infectious diseases with serious healthcare and economic consequences in the United States:
- Each year there are about 19 to 21 million cases of norovirus illness, about 570 to 800 people die, and many thousands more are hospitalized or visit emergency rooms and outpatient clinics. Another CDC study found that the contagious stomach virus is now the leading cause of acute gastroenteritis among children less than 5 years of age who seek medical care. It caused nearly one million U.S. pediatric visits in 2009—2010.
 - About 300,000 people are diagnosed with Lyme disease each year in the United States, making it the most commonly reported tick borne illness. The early estimate is based on findings from three ongoing CDC studies. It suggests that the total number is roughly 10 times higher than the number reported to CDC by healthcare providers.
 - Valley Fever, a fungal respiratory infection, dramatically increased in several southwestern States, from 2,265 in 1998 to more than 22,000 in 2011. CDC is investigating whether the increase is related to changes in weather, rising populations or changes in the way the disease is detected and reported to the States or CDC.

Each year, CDC gives financial support to all 50 State health departments, six local departments, and eight territories or affiliates. Since 2010, CDC has provided funds to 57 State, local and territorial health departments to increase the use of electronic lab reporting (ELR). About 10,400 labs send reportable data to health agencies but many do not report electronically.

Global Health

With globalization of our food supply and frequent travel to and from the United States, health security threats can come from anywhere. CDC's Center for Global Health and Office of Infectious Diseases oversee Agency efforts to prevent, detect and respond to outbreaks in other countries. There are more than 1,600 CDC employees located in over 60 countries. At present, only 1 in 5 countries can rapidly detect, respond to or prevent global health threats caused by emerging infections. Improvements overseas, such as strengthening surveillance and lab systems or training investigators, make both the United States and the rest of the world more secure against infectious disease.

In January, CDC reported results from pilot projects in Uganda and Vietnam to improve disease detection and response capabilities. Work in Uganda modernized diagnostic testing, developed real time information systems for faster outbreak response and improved emergency operations procedures. It focused on three priority diseases, drug resistant tuberculosis, cholera and viral hemorrhagic fever caused by Ebola virus. The Vietnam project trained Vietnamese health officials in advanced PCR techniques to detect H7N9 influenza, enterovirus 71 and respiratory viruses.

The ASM strongly urges Congress to increase CDC's budget in fiscal year 2015 to the highest level possible and approve funding increases for infectious diseases.

PREPARED STATEMENT OF THE AMERICAN SOCIETY FOR MICROBIOLOGY

The American Society for Microbiology (ASM), the largest single life science Society with over 39,000 members, wishes to submit the following comments and recommendations for the record on the fiscal year 2015 budget for the National Institutes of Health (NIH). The ASM commends Congress for passage of the fiscal year 2014 Omnibus Appropriations Bill which represents a step in the right direction although funding for NIH remains too low in view of the gaps in our knowledge of disease and the abundance of scientific opportunities that cannot be pursued because of lack of funding. The ASM recommends that NIH receive at least \$32 billion in fiscal year 2015 as the next step toward a multi-year increase in the Nation's investment in medical research.

The ASM is very concerned about the future of biomedical research in the United States. NIH support for basic research is critical to health and security, job creation and growing the U.S. economy. In fiscal year 2013, the success rate for NIH research grant applicants fell to an historic low 16.8 percent. The average size of research project grants (RPGs) decreased to the lowest ever since 1999. During last year's sequestration, there were reports of delayed research projects, enforced layoffs of technical staff and waning innovation. Such stagnation undercuts biomedical research progress in the United States at a time when the opportunities are great and other Nations are growing their investment in basic and translational biomedical research.

NIH is the primary supporter of biomedical research in the Nation. In 2012 alone, NIH funding supported more than 402,000 jobs and \$57.8 billion in new economic activity nationwide. Among NIH's investments are those in the rapidly advancing field of genomics. A recent report from the nonprofit United for Medical Research (UMR) spotlighted the economics of Federal investment in the human genome project, which has generated \$965 billion in economic impact, more than 53,000 direct genomics related jobs and \$293 billion in personal income.

Current trends in the Nation's R&D investments clearly do not bode well for future innovation and global competition. Federal R&D expenditures declined by 16.3 percent between fiscal years 2010 and 2013, while China's investment jumped more than 400 percent over the past decade. Since 2001, the U.S. share of global R&D performed has decreased from 37 percent to 30 percent. The Science Coalition Report in 2013 highlighted the importance of federally funded university research in creating new companies and R&D jobs. The report profiles R&D companies launched by relatively small Federal investment in university research, including NIH grants funding rapid pathogen detection technologies, vaccine development and advances in food and water safety.

Several UMR reports from last year underscore how NIH supported research can propel private sector growth and innovation. U.S. biotech companies catalyzed by NIH funding illustrate the productive collaborations among NIH, university research scientists and the private sector. These companies are reshaping lucrative R&D sectors like gene sequencing and therapeutics for human disease, taking basic research to the marketplace. NIH support is responsible for several of Science magazine's top ten 2013 discoveries, all expected to return huge dividends, including the "breakthrough of the year" cancer immunotherapy, the new gene editing CRISPR technique and the astoundingly important human microbiome project.

Also included was the first use of structural biology techniques to custom design a powerful immunogen with vaccine potential, in this case against respiratory syncytial virus (RSV). Worldwide, about 64 million cases of RSV infection occur each year, responsible for 160,000 deaths, making it the most common cause of severe respiratory illness in infants and young children. There is no approved vaccine, but the team led by NIAID Vaccine Research Center identified 3-D structures of attachment sites on the virus surface and potent antibodies against those sites, offering new tools to develop new or improved vaccines.

NIH investments build the scientific foundation for the Nation's valuable biomedical R&D sector, which employs 7 million and exports \$90 billion in goods and services. In 2013, all three recipients of the Nobel Prize in Physiology or Medicine and all three winners of the Nobel Prize in Chemistry had at some point received NIH funding (for a total of 144 NIH supported Nobel laureates). Four NIH funded scientists also won prestigious 2013 Lasker Foundation awards.

As the Nation's largest funder of biomedical research, NIH leads the Nation's efforts to discover new cures, preventions and therapies for difficult disease challenges

by funding intramural and extramural projects to combat infectious diseases that kill millions of people worldwide. The National Institute of Allergy and Infectious Diseases (NIAID) and the National Institute of General Medical Sciences (NIGMS) contribute to new, paradigm shifting technologies like high throughput genomic sequencing, as well as new multidisciplinary research approaches like systems biology.

NIAID funded scientists have discovered therapies, vaccines, diagnostic tests and other biomedical tools that improve human health. Lifesaving examples are vaccines for rabies, meningitis, whooping cough, hepatitis A and B, chickenpox and pneumococcal pneumonia. Developing new influenza vaccines is a high priority for NIAID, which has supported a health provider consortium for clinical trials since the 1960s. The NIAID Vaccine Research Center's influenza research has produced multiple promising advances like a DNA vaccine against H5N1 avian influenza and it helped establish the Southeast Asia Influenza Clinical Research Network to address global influenza threats. Ongoing NIAID research is making progress toward the highly significant goal of a universal influenza vaccine that would confer decades long protection from any flu virus strain.

In February, NIAID reported on its latest contributions in the battle to halt antimicrobial resistance (AR) spreading among pathogens, which is creating ever more dangerous diseases like multidrug resistant gonorrhea and extensively drug resistant tuberculosis. Each year, there are 2 million drug resistant infections and 23,000 deaths in the United States. Annual costs are an estimated \$20 billion in added healthcare and \$35 billion in lost productivity. NIAID leads U.S. research against drug resistant pathogens, making major investments in basic, translational and clinical research. Results include advances in prevention, diagnosis and treatment of AR infections, as well as greater support for new drug discovery. The agency has helped support R&D of at least 25 percent of the antibiotics currently in clinical testing. Basic AR research funded by NIAID is detailing the ways that pathogens evade host defenses, to identify new therapeutic and diagnostic targets. Using the latest in technological tools, NIAID supported researchers are developing novel diagnostics platforms for more rapid and accurate detection of emerging AR infections. NIAID's expansive AR portfolio also includes vaccine development against increasingly common AR threats like drug resistant staph and gonorrhea bacteria.

One of NIAID's greatest challenges for the 21st century is developing defenses against familiar enemies, the world's three greatest microbial killers, HIV/AIDS, malaria and tuberculosis. Recent research advances include the following:

- A novel compound, from a new class of potential antimalarial drugs, appears effective against multiple life stages of the malaria causing *Plasmodium* parasite. Most antimalarials only target the parasite as it grows in the host's bloodstream, giving the parasite more chances to spread and acquire drug resistance.
- After designing nanoparticles loaded with copies of mutated HIV selected via computerized screening, scientists have activated host immune cells to produce VRC01 neutralizing antibodies. The approach offers a new tool to potentially reverse engineer neutralizing antibodies against HIV and other viruses.
- Using a systems biology approach, scientists have identified interactions among genetic regulators in *Mycobacterium tuberculosis* (Mtb), the bacterium that causes tuberculosis (TB). The results help explain how Mtb lies latent for long periods in otherwise healthy people, then becomes active and transmissible TB. About one third of the world's population is infected, making Mtb switches between different stages crucial to public health.

Research strategies clearly rely upon previous scientific successes. Ever shifting influenza viruses and steady evolution of AR pathogens illustrate how any effort must build upon the past, respond to the present and plan for the future. New microbial threats emerge as old threats persist, the recent spread of dengue fever, detection of influenza H7N9 last year and the newly emerging coronavirus caused Middle East respiratory syndrome (MERS). First identified in 2012, MERS-CoV infection has been implicated in 181 cases (as of February 4) and 79 deaths. With high mortality and no treatments, the disease's spread from the Middle East to Europe has health officials concerned. NIAID funded researchers now have reported some laboratory success using potential MERS-CoV therapy that combines two licensed antiviral drugs routinely used to treat diseases such as hepatitis C.

At NIGMS, microbial genetics and cell/molecular biology are principal research emphases, recognition that microbiology not only provides insights to human health and biology in general, but also stimulates innovation in U.S. biotechnology. Each year, NIGMS awards more than 4,500 research grants and supports one fourth (~4,000) of the NIH supported technical trainees.

NIGMS funded research has generated high value technologies like PCR, high throughput DNA sequencing, and the human genome project. The latest exciting biotech tool to emerge is CRISPR technology (Clustered Regularly Interspaced Short

Palindromic Repeats, DNA loci in bacterial genomes), innovation that evolved from basic research in both phage biology and advanced computing genomics. With huge potential for improved genome editing essential to the biotech industry, today the CRISPR system is increasingly used in gene cutting and other customized gene targeting.

Without sustained NIH funding in diverse fields like microbiology, ASM strongly believes there will be fewer new discoveries and innovation in the United States. We urge Congress to build on bipartisan efforts to replace the random cuts of sequestration that have been devastating to basic research in the United States and to increase funding for the National Institutes of Health. Increased investment will enable the scientific progress that is needed to improve the health, security and economic growth of the country.

PREPARED STATEMENT OF THE AMERICAN SOCIETY FOR NUTRITION

Dear Chairwoman Mikulski and Ranking Member Shelby: Thank you for the opportunity to provide testimony regarding fiscal year 2015 appropriations. The American Society for Nutrition (ASN) respectfully requests \$32 billion dollars for the National Institutes of Health (NIH) and \$182 million dollars for the Centers for Disease Control and Prevention/National Center for Health Statistics (CDC/ NCHS) in Fiscal Year 2015. ASN is dedicated to bringing together the world's top researchers to advance our knowledge and application of nutrition, and has more than 5,000 members working throughout academia, clinical practice, government, and industry.

National Institutes of Health (NIH)

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

Investment in biomedical research generates new knowledge, improved health, and leads to innovation and long-term economic growth. A decade of flat-funding, followed by sequestration cuts, has taken a significant toll on NIH's ability to support research. Such economic stagnation is disruptive to training, careers, long-range projects and ultimately to progress. Increasing the NIH budget to \$32 billion dollars would fully restore the funding that was lost to sequestration and support at least 600 additional competing research project grants. As a first step toward sustainable growth, ASN recommends a minimum of \$32 billion dollars for NIH in fiscal year 2015. NIH needs sustainable and predictable budget growth in order to fulfill the full potential of biomedical research, including nutrition research, and to improve the health of all Americans.

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

The National Center for Health Statistics, housed within the Centers for Disease Control and Prevention, is the Nation's principal health statistics agency. ASN recommends a fiscal year 2015 funding level of \$182 million dollars for NCHS, consistent with the President's budget request, to help ensure uninterrupted collection of vital health and nutrition statistics, and help cover the costs needed for technology and information security maintenance and upgrades that are necessary to replace aging survey infrastructure. More than half of NCHS's budget is supported through the evaluation tap. Therefore, ASN does not support efforts to eliminate the evaluation tap—in part or in full—unless a viable alternative funding mechanism is put in place to continue these important functions.

The NCHS provides critical data on all aspects of our health care system, and it is responsible for monitoring the Nation's health and nutrition status through surveys such as the National Health and Nutrition Examination Survey (NHANES), that serve as a gold standard for data collection around the world. Nutrition and health data, largely collected through NHANES, are essential for tracking the nutrition, health and well-being of the American population, and are especially important for observing nutritional and health trends in our Nation's children.

Nutrition monitoring conducted by the Department of Health and Human Services in partnership with the U.S. Department of Agriculture/Agricultural Research Service is a unique and critically important surveillance function in which dietary intake, nutritional status, and health status are evaluated in a rigorous and standardized manner. Nutrition monitoring is an inherently governmental function and findings are essential for multiple government agencies, as well as the public and private sector. Nutrition monitoring is essential to track what Americans are eating, inform nutrition and dietary guidance policy, evaluate the effectiveness and efficiency of nutrition assistance programs, and study nutrition-related disease outcomes. Funds are needed to ensure the continuation of this critical surveillance of the Nation's nutritional status and the many benefits it provides.

Through learning both what Americans eat and how their diets directly affect their health, the NCHS is able to monitor the prevalence of obesity and other chronic diseases in the U.S. and track the performance of preventive interventions, as well as assess 'nutrients of concern' such as calcium, which are consumed in inadequate amounts by many subsets of our population. Data such as these are critical to guide policy development in the area of health and nutrition, including food safety, food labeling, food assistance, military rations and dietary guidance. For example, NHANES data are used to determine funding levels for programs such as the Supplemental Nutrition Assistance Program (SNAP) and the Women, Infants, and Children (WIC) clinics, which provide nourishment to low-income women and children.

To continue support for the agency and its important mission, ASN recommends an FY 2015 funding level of \$162 million for NCHS. Sustained funding for NCHS can help to ensure uninterrupted collection of vital health and nutrition statistics, and will help to cover the costs needed for technology and information security upgrades that are necessary to replace aging survey infrastructure.

Thank you for the opportunity to submit testimony regarding fiscal year 2015 appropriations for the National Institutes of Health and the CDC/National Center for Health Statistics. Please contact John E. Courtney, Ph.D., Executive Officer, if ASN may provide further assistance.

[This statement was submitted by Gordon M. Jensen, M.D., Ph.D., 2013–2014 ident, American Society for Nutrition.]

PREPARED STATEMENT OF THE AMERICAN SOCIETY FOR PHARMACOLOGY &
EXPERIMENTAL THERAPEUTICS

The American Society for Pharmacology and Experimental Therapeutics (ASPET) is pleased to submit written testimony in support of the National Institutes of Health (NIH) fiscal year 2015 budget. ASPET recommends a fiscal year 2015 NIH budget of at least \$32 billion.

Sustained growth for the NIH should be an urgent national priority. Congress showed bipartisan support for the agency in fiscal year 2014 as evidenced by the \$1 billion increase above the fiscal year 2013 sequestered level. While this 3.5 percent increase helps put NIH on the path to more sustainable funding levels, it does not begin to make up for a lost decade of funding. Adjusting for inflation, the fiscal year 2013 budget for the NIH is less than it was in 2003. For NIH to meet its vital role in improving public health, stimulating our economy, and improving global competitiveness it is critical that the agency continue to receive steady and sustainable increases.

Additionally, if funding for the next 10 years is similar to that of the past decade, the Nation will lose a generation of young scientists. Increasingly, these individuals, seeing no prospects for careers in biomedical research, will leave the research enterprise or look for employment in foreign countries. Not only are jobs increasingly limited in the academic sector, but industry too is under stress. The "brain drain" of young scientific talent jeopardizes the Nation's leadership in biomedical research. A survey of ASPET's own graduate students and post-doctoral researchers indicates that 45 percent of post-doctoral trainees and 25 percent of graduate students say they are no longer considering a career in biomedical research due to the restrictive funding environment; 50 percent of graduate students and 29 percent of post-doctoral trainees say they are willing to consider leaving the United States to pursue a career in biomedical research.

A \$32 billion budget for the NIH in fiscal year 2015 is a start to help restore NIH's biomedical research capacity. Currently, the NIH only can fund one in six grant applications, the lowest rate in the agency's history. Furthermore, the number of research project grants funded by NIH has declined every year since 2004.

A budget of at least \$32 billion in fiscal year 2015 will help the agency manage its research portfolio more effectively without having to withhold funding for existing grants to researchers throughout the country. Only through steady, sustained and predictable funding increases can NIH continue to fund the highest quality biomedical research to help improve the health of all Americans and continue to make significant economic impact in many communities across the country.

There is no substitute for a steady, sustained Federal investment in biomedical research. Industry, venture capital, and private philanthropy can supplement research but cannot replace the investment in basic, fundamental biomedical research provided by NIH. Neither the private sector nor industry will be able to fill a void for NIH funded basic biomedical research. Much of industry support is applied research that builds upon the discoveries generated from NIH-funded projects. The majority of the investment in basic biomedical research that NIH provides is broad and long-term providing a continuous development platform for industry, which would not typically invest in research that may be of higher risk and require several years to fully mature. In addition to this long term view, NIH also has mechanisms in place to rapidly build upon key technologies and discoveries that have the ability to have significant impact on the health and well being of our citizens.

Many of the basic science initiatives supported by NIH have led to totally unexpected discoveries and insight that have transformed our mechanistic understanding of and our ability to treat a wide range of diseases

Diminished Support for NIH will Negatively Impact Human Health

Continued diminishment of funding and loss of purchasing power will mean a loss of scientific opportunities to discover new therapeutic targets. Without a steady, sustained Federal investment in fundamental biomedical research, scientific progress will be slower and potentially helpful therapies or cures will not be developed. For example, more research is needed on Parkinson's disease to help identify the causes of the disease and help develop better therapies; discovery of gene variations in age-related macular degeneration could result in new screening tests and preventive therapies; more basic research is needed to focus on new molecular targets to improve treatment for Alzheimer's disease; and diminished support for NIH will prevent new and ongoing investigations into rare diseases that the Food and Drug Administration estimates almost 90 percent are serious or life-threatening.

Historically, our past investment in basic biological research has led to many innovative medicines. The National Research Council reported that of the 21 drugs with the highest therapeutic impact, only five were developed without input from the public sector. The significant past investment in the NIH has provided major gains in our knowledge of the human genome, resulting in the promise of pharmacogenomics and a reduction in adverse drug reactions that currently represent a major worldwide health concern. Several completed human genome sequence analyses have pinpointed disease-causing variants that have led to improved therapy and cures but further advances and improvements in technology will be delayed or obstructed with diminished NIH funding.

Investing in NIH Helps America Compete Economically

A \$32 billion budget in fiscal year 2015 will also help the NIH train the next generation of scientists and provide a platform for broader workforce development that is so critical to our Nation's growth. Many individuals trained in the sciences through NIH support become educators in high schools and colleges. These individuals also enter into other aspects of technology development and evaluation in public and private sectors to further enrich the community and accelerate economic development.

This investment will help to create jobs and promote economic growth. A stagnating NIH budget will mean forfeiting future discoveries and jobs to other countries.

The U.S. share of global research and development investment from 1999–2009 is now only 31 percent, a decline of 18 percent. In contrast, other nations continue to invest aggressively in science. China has grown its science portfolio with annual increases to the research and development budget averaging over 23 percent annually since 2000, including a 26 percent increase in 2012. Russia plans to increase support for research by 65 percent over the next 5 years. The European Union, despite great economic distress among its member nations, has proposed to increase spending on research and innovation by 45 percent between 2014 and 2020.

NIH research funding catalyzes private sector growth. More than 83 percent of NIH funding is awarded to over 3,000 universities, medical schools, teaching hospitals and other research institutions in every State. One national study by an economic consulting firm found that Federal (and State) funded research at the Na-

tion's medical schools and hospitals supported almost 300,000 jobs and added nearly \$45 billion to the U.S. economy. NIH funding also provides the most significant scientific innovations of the pharmaceutical and biotechnology industries.

Conclusion

ASPET appreciates the many competing and important spending decisions the Subcommittee must make. However, the NIH's contribution to the Nation's economic and physical well being should make it one of the Nation's top priorities. With enhanced and sustained funding, NIH can begin to reverse its decline and help meet its potential to address many of the more promising scientific opportunities that currently challenge medicine. A budget of at least \$32 billion in fiscal year 2015 will allow the agency to begin moving forward to full program capacity, exploiting more scientific opportunities for investigation, and increasing investigator's chances of discoveries that prevent, diagnose and treat disease. NIH should be restored to its role as a national treasure, one that attracts and retains the best and brightest to biomedical research and provides hope to millions of individuals afflicted with illness and disease.

ASPET is a 5,100 member professional society whose members conduct basic, translational, and clinical pharmacological research within the academic, industrial and government sectors. Our members discover and develop new medicines and therapeutic agents that fight existing and emerging diseases, as well as increase our knowledge regarding how therapeutics affects humans.

[This statement was submitted by James S. Bernstein, Director, Government and Public Affairs, American Society for Pharmacology & Experimental Therapeutics.]

PREPARED STATEMENT OF THE AMERICAN SOCIETY OF CLINICAL ONCOLOGY

The American Society of Clinical Oncology (ASCO), the world's leading professional organization representing nearly 35,000 physicians and other professionals who treat people with cancer, appreciates this opportunity to provide the following recommendations for fiscal year 2015 (fiscal year 2015) funding:

—National Institutes of Health (NIH): \$32 billion

—National Cancer Institute (NCI): \$5.26 billion

ASCO's members set the standard for cancer care world-wide and lead the way in carrying out translational and clinical research aimed at improving the screening, prevention, diagnosis and treatment of cancer. ASCO advocates for policies that provide access to high-quality care for all patients with cancer. ASCO's efforts are also directed toward supporting oncology clinical and translational research that is critical to improving the lives of our citizens and that can inform cancer services for people worldwide.

Cancer's Growing Footprint and the Importance of Federal Cancer Research

According to ASCO's State of Cancer Care in America report (<http://www.asco.org/practice-research/cancer-care-america>) released earlier this year, cancer will surpass heart disease as the leading cause of death in the United States (US) over the next 16 years. While cancer deaths in the US are declining for all populations, the number of new cancer cases is expected to increase nearly 45 percent by 2030, from 1.6 million cases to 2.3 million cases annually. The leading overall risk factor for cancer is aging and these numbers reflect overall progress in healthcare, enabling more Americans to live longer.

While we have made great strides in cancer treatment, now is not the time to cut back as cancer impacts more and more Americans. We now have more cancer survivors alive today than at any point in our history and understand more about the diseases that make up cancer than ever before. This is largely because of Federal investment in cancer research, but we will not be able to harness the opportunities this new knowledge provides without further investment. Adjusting for inflation, funding for the NIH is down 23 percent since 2003. In addition, the NCI has become a smaller share of NIH's total budget. If NCI was funded as the same percentage of overall NIH spending that it was in 2003, it would mean an additional \$350 million for cancer research.

ASCO thanks the subcommittee for its past commitment to cancer research through the appropriations process and appreciates the unique effort made by the subcommittee in this challenging budget environment. We recognize the challenging environment, but caution that the current path of investment in cancer research will be devastating to attempts to find future cures. ASCO calls on this subcommittee to renew the commitment to clinical cancer research—without which our basic science findings would never help improve the lives of patients.

While we appreciate the bipartisan efforts that led to a brief reprieve from sequester in fiscal year 2015, the lasting effects of these draconian cuts, exacerbated by years of stagnant funding, will be felt for decades to come if the trend is not reversed. ASCO released a survey (<http://www.asco.org/press-center/asco-survey-under-scores-%E2%80%9Cdevastating%E2%80%9D-impact-stagnant-funding-cancer-research>) of its members in September 2013 that showed the profound impact of sequester on the U.S. cancer research enterprise.

A large majority, 75 percent, of survey respondents, reported that the current Federal funding situation is having a direct impact on their ability to conduct cancer research, in many cases triggering “devastating” changes. Delayed clinical trials, the elimination of research staff positions, and the halting or slowing of promising research that could lead to new therapies for cancer were cited as specific results of stagnant funding.

In order to stop these devastating trends and capitalize on forward progress, the NIH and the NCI must have sustained and predictable increases in funding. While private industry is a strong partner in cancer research, they do not conduct the broad scope of clinical research that is important to cancer patients. In contrast, the NCI conducts the high risk, high reward research that leads to practice-changing advancements that industry is often unwilling to undertake—such as pediatric applications, direct comparisons of approved drugs, and providing drugs in combination with or prior to radiation or surgical treatments. Progress in fighting cancer would be faster, more efficient, and more sustainable if funding were steady and sustained.

Our prior investments established the global leadership of American cancer research and care. Without maintenance of those investments, our global leadership and the benefits it offers everyday Americans in both health and economically are profoundly threatened.

Clinical Trials and Translational Research

NIH-funded translational research and clinical trials have significantly improved the standard of care in many diseases. At the same time, they also have demonstrated more cost-effective treatment options for many common cancers. Unfortunately, these trials are at risk, due to funding concerns that slow the launch and completion of trials. Of great concern is the deterioration of NCI support for federally funded trials that take place in virtually every community in which cancer providers treat patients. On March 1, 2014, the NCI launched the reorganized National Clinical Trials Network (NCTN). The program currently involves over 3,000 institutions and community-based investigators in the US and provides approximately 17,000 patients with access to promising new treatments each year, at a \$243 million annual cost to taxpayers. Due to funding constraints, the number of patients enrolled in clinical trials has fallen from a peak of almost 30,000 patients in 2009 to a planned enrollment of only 12,000 adults in the current fiscal year and some trials may be forced to close early potentially depriving patients of access to life-prolonging treatments. Please note that without patient accrual to clinical trials, there can be no changes in routine care, practice, and outcomes. This is where science becomes practice changing for patients in America.

We understand that March 1 also marked the end of funding for the NCI Community Clinical Oncology Program (CCOP). NCI is transforming this program into the NCI Community Oncology Research Program (NCORP). NCI is currently reviewing NCORP applications and does not expect to issue notices of award until September 2014. In the meantime, CCOP sites have ongoing ethical obligations to active trial participants to continue clinical trial procedures and required follow-up. At present, community practice sites are expected to do so without any transition in funding. These community sites are crucial to making cutting edge cancer care available to patients in the communities where they live. Without any assurance of sustained funding, some community sites will no longer be able to offer clinical trials to patients.

Clinical trials supported by Federal funding have led to important breakthroughs in cancer care that touch every American family and often these are in areas that industry has no incentive to pursue. Typically, the trial concepts are proposed directly by clinician investigators who hypothesize ways to improve treatments for their patients and want to test those hypotheses through rigorously designed prospective clinical trials. Just as the NIH RO1 and R21 grant mechanisms inspire researcher creativity and innovation, the NCTN and NCORP programs are important in fostering research initiatives directly from clinician investigators who see firsthand the importance of answering questions vital to their patients. Publicly funded clinical trials involve establishing comparative effectiveness, examining promising regimens, optimizing multimodality treatments, developing therapies for rare can-

cers, and studying prevention and survivorship strategies. These research goals may run parallel to those of commercial sponsors, but publicly funded trials are designed to benefit patients—not intended to achieve regulatory approval or shareholder interest. Many of these trials are at risk due to funding constraints and the pace of further progress, especially against the most common cancers in America, will slow. For example, at the present time there is no publically funded breast cancer adjuvant treatment trial available in the US.

ASCO's Clinical Cancer Advances report (<http://www.cancerprogress.net/clinical-cancer-advances-2013>) provides annual recognition of the major advances in patient treatments and care. The 2013 report details 76 research advances, 27 of which received NIH funding, in diseases impacting an estimated 1.6 million patients last year alone. Its top areas of progress include: using genomics to make treatment decisions for individual patients, discovering new cancer subtypes specifically associated with potential new therapies, tackling treatment resistant forms of cancer through precision medicine approaches, enhancing the ability of patients' own immune systems to fight cancer, and implementing new cancer screening paradigms to reduce disparities.

To maintain global American scientific leadership, ASCO urges a substantial increase in funding for the National Clinical Trials Network and NCI Community Oncology Research Program, as well as transition funding for CCOP sites until NCORP launches. ASCO is very concerned that the Federal funding situation is causing NCI to propose capping patient participation in clinical trials in order to stretch an ever-shrinking funding pot. NCI acknowledges that current payments are inadequate to cover the costs of conducting trials because they have not increased over nearly a decade. Making the needed increases at the expense of new scientific opportunities, however, is short-sighted and has long-term negative implications. The Institute of Medicine (IOM) recognized this in its 2010 report, *A National Cancer Clinical Trials System for the 21st Century: Reinvigorating the NCI Cooperative Group Program*. The IOM pointed to the notable achievements of Cooperative Group trials that have dramatically improved the outcomes of today's cancer patients and recognized that increases in funding should accompany the changes that the NCI and Cooperative Groups have already implemented to increase the efficiency of their operations and to keep pace with scientific opportunity. An increase in NCI funding would enable the Institute to maintain or increase the number of accruals to trials at the same time as it increases payments to cover the cost of conducting the research.

Threat to America's Global Leadership

While the United States is slowing its investment in medical research, countries around the globe are making significant increases to theirs. Russia is increasing basic research funding by 65 percent, European investments are increasing by 40 percent over 7 years, South Korea has pledged a 50 percent increase, and China announced a 26 percent boost in basic research funding in 2012. These investments result not only in additional research in these countries, but are attracting the best and brightest American-trained scientists to work abroad. The long-term consequences are easy to predict. If scientific progress is achieved elsewhere, Americans will be asked to import new treatments including drugs, intellectual property, and products.

The previously referenced ASCO survey also revealed the disturbing finding that many young investigators are leaving the field altogether due to lack of funding. This too is a predictable effect of funding limits. With more than 35 percent of survey participants reporting having to lay off skilled staff, many appear to be questioning the viability of a career in research and raising serious concerns about the ultimate impact of budget cuts on patient care and outcomes.

Declining Federal funding for clinical trials, coupled with the rising costs of increasingly complex studies, will severely harm the nation's clinical research enterprise by limiting opportunities for innovation and demoralizing young clinical investigators. As opportunities to develop and lead trials diminish and institutional pressures to generate research funding and clinical revenue continue to grow, young investigators may leave the field of research, or choose to pursue research opportunities in other countries. Not only does this threaten our progress against cancer, but it also diminishes the overall scientific workforce in America.

In addition, clinical trials are increasingly being conducted overseas, due to the costs and regulatory complexities of conducting trials in the US. This denies your constituents the opportunity to participate, either as a patient receiving the most promising potential treatment or as a physician or research nurse conducting the clinical trial. Congress should demonstrate a continued commitment to ensure biomedical research is federally funded.

Because of the incredible scientific opportunities facing us and the current threats to this opportunity, ASCO urges the NIH and NCI to focus more of its resources in the area of clinical trials and translational research.

ASCO again thanks the Subcommittee for its continued support of cancer patients in the US through funding for the NIH and the NCI. We look forward to working with all members of the subcommittee to advance US cancer research.

[This statement was submitted by Clifford A. Hudis, MD, FACP, President, American Society of Clinical Oncology.]

PREPARED STATEMENT OF THE AMERICAN SOCIETY OF HEMATOLOGY

The American Society of Hematology (ASH) thanks the Subcommittee for the opportunity to submit written testimony on the fiscal year 2015 Departments of Labor, Health and Human Services, and Education Appropriations bill.

ASH represents more than 15,000 clinicians and scientists committed to the study and treatment of blood and blood-related diseases. These diseases encompass malignant disorders such as leukemia, lymphoma, and myeloma; life-threatening conditions, including thrombosis and bleeding disorders; and congenital diseases such as sickle cell anemia, thalassemia, and hemophilia. In addition, hematologists have been pioneers in the fields of bone marrow transplantation, stem cell biology and regenerative medicine, gene- and immunotherapy, and the development of many drugs for the prevention and treatment of heart attacks and strokes.

Funding for Hematology Research: An Investment in the Nation's Health

Over the past 60 years, American biomedical research has led the world in probing the nature of human disease. This research has led to new medical treatments, saved innumerable lives, reduced human suffering, and spawned entire new industries. This research would not have been possible without support from the National Institutes of Health (NIH).

Funding for hematology research has been an important component of this investment in the Nation's health. Most of the research that produced cures and treatments for hematologic diseases has been funded by the NIH. The study of blood and its disorders is a trans-NIH issue involving many institutes at the NIH, including the National Heart, Lung and Blood Institute (NHLBI), the National Cancer Institute (NCI), the National Institute of Diabetes, Digestive and Kidney Diseases (NIDDK), and the National Institute on Aging (NIA).

With the advances gained through an increasingly sophisticated understanding of how the blood system functions, hematologists have changed the face of medicine through their dedication to improving the lives of patients. As a result, children are routinely cured of acute lymphoblastic leukemia (ALL); more than 90 percent of patients with acute promyelocytic leukemia (APL) are cured with a drug derived from vitamin A; older patients suffering from previously lethal chronic myeloid leukemia (CML) are now effectively treated with well-tolerated pills; and patients with multiple myeloma are treated with new classes of drugs.

Additionally, as NIH Director Francis Collins recently noted in his testimony to the Subcommittee, researchers are "aiming to harness the body's own immune system to fight cancer." One such method, known as chimeric antigen receptor (CAR) cell engineering, extracts T cells (naturally occurring immune cells) from the blood of a cancer patients and modifies the cells to produce special proteins on their surface. With these new engineered features, the T cells are injected back into the patient, now primed to seek and destroy cancer cells. Preliminary studies have found that this process may generate responses in as many as two-thirds of cases in which all other treatment options have failed. Further, because the cells are derived from the patient, there is an inherently lower risk of toxicity because the cells are less likely to attack the host tissue than cells introduced from a foreign body. Promising results in patients with leukemia prompted Science magazine to name this its 2013 "Breakthrough of the Year."

Hematology advances also help patients with other types of cancers, heart disease, and stroke. Even modest investments in hematology research have yielded large dividends for other disciplines. Basic research on blood has aided physicians who treat patients with heart disease, strokes, end-stage renal disease, cancer, and AIDS. Blood thinners effectively treat or prevent blood clots, pulmonary embolism, and strokes. Death rates from heart attacks are reduced by new forms of anticoagulation drugs.

Sequestration Threatens Scientific Momentum

ASH is particularly concerned about the impact of continued cuts on biomedical research supported by the NIH. NIH's ability to continue current research capacity and encourage promising new areas of science is, and will be, significantly limited. At a time when we should be investing more in research to save lives, research funding remains in serious jeopardy. Trials to find new therapies and cures for millions of Americans with blood cancers, bleeding disorders, clotting problems, and genetic diseases are just a few of the important projects that could be delayed unless NIH continues to receive predictable and sustained funding.

Additionally, perhaps one of the greatest concerns is the obstacle these continued cuts will present to the next generation of scientists, who will see training funds slashed and the possibility of sustaining a career in research diminished. The Society is especially concerned about the number of scientists who have abandoned research careers; continued cuts will exacerbate this exodus, forcing researchers to abandon potentially life-enhancing research.

Fiscal year 2015 NIH Funding Request

ASH appreciates the welcome and much needed funding increase for the NIH that Congress provided in the Consolidated Appropriations Act of 2014. However, this increase did not give back all of the funds cut by sequestration in fiscal year 2013 nor did it restore the purchasing power lost over the past decade. ASH supports the Ad Hoc Group for Medical Research recommendation that NIH receive at least \$32 billion in fiscal year 2015 as the next step toward a multi-year increase in our Nation's investment in medical research. ASH also urges Congress and the Administration to work in a bipartisan manner to end sequestration and the continued cuts to medical research that squander invaluable scientific opportunities, discourage young scientists, threaten medical progress and continued improvements in our Nation's health, and jeopardize our economic future.

Centers for Disease Control and Prevention (CDC) Public Health Response for Blood Disorders

The Society also recognizes the important role of the Centers for Disease Control and Prevention (CDC) in preventing and controlling clotting, bleeding, and other hematologic disorders. Blood disorders—such as sickle cell disease, anemia, blood clots, and hemophilia—are a serious public health problem and affect millions of people each year in the United States, cutting across the boundaries of age, race, sex, and socioeconomic status. Men, women, and children of all backgrounds live with the complications associated with these conditions, many of which are painful and potentially life-threatening.

CDC is uniquely positioned to reduce the public health burden resulting from blood disorders by contributing to a better understanding of these conditions and their complications; ensuring that prevention programs are developed, implemented, and evaluated; ensuring that information is accessible to consumers and healthcare providers; and encouraging action to improve the quality of life for people living with or affected by these conditions. The Society is concerned that the Division of Blood Disorders was cut by nearly \$6 million in the Consolidated Appropriations Act of 2014 and the President's Budget for fiscal year 2015 did not restore this funding. ASH respectfully requests that the Division of Blood Disorders be funded in fiscal year 2015 at \$19 million to assure that the programs funded by the Division for Hemophilia, Thalassemia, Sickle Cell Disease, and DVT/PE can be maintained. This funding will allow CDC to improve health outcomes and limit complications to those who are at risk or currently have blood disorders, by promoting a comprehensive care model; identifying and evaluating effective prevention strategies; and increasing public and healthcare provider awareness of bleeding and clotting disorders such as such as hemophilia and thrombosis, and hemoglobinopathies, including sickle cell disease and thalassemia.

Thank you again for the opportunity to submit testimony. Please contact Tracy Roades, ASH Legislative Advocacy Manager, at troades@hematology.org, if you have any questions or need further information concerning hematology research or ASH's fiscal year 2015 funding request.

PREPARED STATEMENT OF THE AMERICAN SOCIETY OF NEPHROLOGY

The American Society of Nephrology (ASN) is the world's largest kidney health professional organization in the world, representing 15,000 physicians, other healthcare providers, and scientists, and committed to advancing research, prevention, and treatment options for the more than 20 million adults, children, and ado-

lescents with kidney disease in the United States today. The society requests at least \$2.066 billion for the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) at the National Institutes of Health (NIH). The society also requests an additional \$150 million/year over 10 years for kidney research above current funding for NIDDK.

ASN believes these are crucial and necessary investments for preventing illness and maintaining fiscal responsibility. Investing in research to slow the progression of kidney disease and identify new therapies will save Medicare spending for the End-Stage Renal Disease (ESRD) Program in the long run.

In 1972, Congress made a commitment to treat all Americans with kidney failure through the Medicare ESRD Program—the only health entitlement program that provides coverage regardless of age or disability. Today, ESRD patients account for less than 1 percent of the Medicare population but 7 percent of the Medicare budget. Meanwhile, at approximately \$650 million per year, total Federal funding for kidney research is equivalent to less than 1 percent of the nearly \$77 billion Medicare spends annually for the care of patients with kidney disease.

Given that the Medicare ESRD Program is unique in that it covers treatment for all patients with kidney failure regardless of age or disability, preventing kidney disease and improving therapy—starting with innovative research at NIDDK—would yield significant savings to the Centers for Medicare and Medicaid Services.

The vast majority of Federal research leading to advances in the care and treatment of patients with kidney disease is funded by NIDDK. Examples of critical discoveries arising from NIDDK-funded research are numerous.

For instance, investigative studies supported by NIDDK led to a groundbreaking discovery that helps explain racial and ethnic disparities that increase risks for kidney disease, which can lead to earlier detection and treatment. The finding that African Americans with two variants of the APOL1 gene are likely to progress to kidney failure faster than other ethnicities paves the way for future research to unlock better preventive therapies and gene-based cures.

Recent findings from NIDDK's Chronic Renal Insufficiency Cohort (CRIC) Study led to the discovery that the progression of kidney disease is associated with less efficient pumping of blood by the heart. Further research exploring the mechanisms for this development could lead to new interventions that could slow down the progression of kidney disease.

Scientists supported by NIDDK have pursued cutting-edge basic, clinical, and translational research. While ASN fully understands the difficult economic environment, the society firmly believes that funding NIDDK is a sound investment to create jobs, support the next generation of investigators, and ultimately provide quality care that is less expensive in order to improve the public health of Americans.

Medical research is a major force in the economic health of communities nationwide: every dollar invested in medical research generates \$2.60 in economic activity. America must continue to capitalize on previous investments to drive research progress, train the next generation of scientists, create new jobs, promote economic growth, and maintain leadership in the global innovation economy—particularly as other countries increase their investments in scientific research. Most important, a failure to maintain and strengthen NIDDK's ability to support the groundbreaking work of researchers across the country carries a palpable human toll, denying hope to the millions of patients awaiting the possibility of a healthier tomorrow.

ASN urges Congress to uphold its longstanding legacy of bipartisan support for biomedical research. Should you have any questions or wish to discuss NIDDK or kidney research in more detail, please contact ASN Manager of Policy and Government Affairs Rachel Meyer at (202) 640-4659 or rmeyer@asn-online.org.

ABOUT ASN

The American Society of Nephrology (ASN) is a 501(c)(3) non-profit, tax-exempt organization that leads the fight against kidney disease by educating the society's 15,000 physicians, scientists, and other healthcare professionals, sharing new knowledge, advancing research, and advocating the highest quality care for patients. For more information, visit ASN's website at www.asn-online.org.

PREPARED STATEMENT OF THE AMERICAN SOCIETY OF PLANT BIOLOGISTS

On behalf of the American Society of Plant Biologists (ASPB), we would like to thank the Subcommittee for its support of the National Institutes of Health (NIH). ASPB and its members strongly believe that sustained investments in scientific research will be a critical step toward economic recovery and job creation in our Nation. ASPB supports the maximum fiscal year 2015 appropriation for NIH and asks

that the Subcommittee Members encourage increased support for plant-related research within the agency; 25 percent of our medicines originate from discoveries related to plant natural products, and such research has contributed in innumerable ways to improving the lives and health of Americans and people throughout the world.

ASPB is an organization of some 4,500 professional plant biology researchers, educators, students, and postdoctoral scientists with members across the Nation and throughout the world. A strong voice for the global plant science community, our mission—achieved through work in the realms of research, education, and public policy—is to promote the growth and development of plant biology, to encourage and communicate research in plant biology, and to promote the interests and growth of plant scientists in general.

Plant Biology Research and America's Future

Among many other functions, plants form much of the base of the food chain upon which all life depends. Importantly, plant research is also helping make many fundamental contributions in the area of human health, including that of a sustainable supply and discovery of plant-derived pharmaceuticals, nutraceuticals, and alternative medicines. Plant research also contributes to the continued, sustainable, development of better and more nutritious foods and the understanding of basic biological principles that underpin improvements in the health and nutrition of all Americans.

Plant Biology and the National Institutes of Health

Plant science and many of our ASPB member research activities have enormous positive impacts on the NIH mission to pursue “fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to extend healthy life and reduce the burdens of illness and disability.” In general, plant research aims to improve the overall human condition—be it food, nutrition, medicine or agriculture—and the benefits of plant science research readily extend across disciplines. In fact, plants are often the ideal model systems to advance our “fundamental knowledge about the nature and behavior of living systems” as they provide the context of multi-cellularity while affording ease of genetic manipulation, a lesser regulatory burden, and maintenance requirements that are less expensive than those required for the use of animal systems.

Many fundamental biological components and mechanisms (e.g., cell division, viral and bacterial invasion, polar growth, DNA methylation and repair, innate immunity signaling and circadian rhythms) are shared by both plants and animals. For example, a process known as RNA interference, which has potential application in the treatment of human disease, was first discovered in plants. Subsequent research eventually led to two American scientists, Andrew Fire and Craig Mello, earning the 2006 Nobel Prize in Physiology or Medicine. More recently scientists engineered a class of proteins called TALENs capable of precisely editing genomes to potentially correct mutations that lead to disease. That these therapeutic proteins are derived from others initially discovered in a plant pathogen exemplifies the application of plant biology research to improving human health. These important discoveries again reflect the fact that some of the most important biological discoveries applicable to human physiology and medicine can find their origins in plant-related research endeavors.

Health and Nutrition—Plant biology research is also central to the application of basic knowledge to “extend healthy life and reduce the burdens of illness and disability.” Without good nutrition, there cannot be good health. Indeed, a World Health Organization study on childhood nutrition in developing countries concluded that over 50 percent of child deaths under the age of five could be attributed to malnutrition's effects in weakening the immune system and exacerbating common illnesses such as respiratory infections and diarrhea. Strikingly, most of these deaths were not linked to severe malnutrition, but chronic nutritional deficiencies brought about by overreliance on single crops for primary staples. Plant researchers are working today to address the root cause of this problem by balancing the nutritional content of major crop plants to provide the full range of essential micronutrients in plant-based diets.

By contrast to developing countries, obesity, cardiac disease, and cancer take a striking toll in the developed world. Research to improve and optimize concentrations of plant compounds known to have, for example, anti-carcinogenic properties, will hopefully help in reducing disease incidence rates. Ongoing development of crop varieties with tailored nutraceutical content is an important contribution that plant biologists can and are making toward realizing the long-awaited goal of personalized medicine, especially for preventative medicine.

Drug Discovery—Plants are also fundamentally important as sources of both extant drugs and drug discovery leads. In fact, 60 percent of anti-cancer drugs in use within the last decade are of natural product origin—plants being a significant source. An excellent example of the importance of plant-based pharmaceuticals is the anti-cancer drug taxol, which was discovered as an anti-carcinogenic compound from the bark of the Pacific yew tree through collaborative work involving scientists at the NIH National Cancer Institute and plant natural product chemists. Taxol is just one example of the many plant compounds that will continue to provide a fruitful source of new drug leads.

While the pharmaceutical industry has largely neglected natural products-based drug discovery in recent years, research support from NIH offers yet another paradigm. Multidisciplinary teams of plant biologists, bioinformaticians, and synthetic biologists are being assembled to develop new tools and methods for natural products discovery and creation of new pharmaceuticals. We appreciate NIH's current investment into understanding the biosynthesis of natural products through transcriptomics and metabolomics of medicinal plants. The recently released "Genomes to Natural Products" funding opportunity is also to be applauded as a potential avenue for new plant-related medicinal research, and we strongly encourage the continuation of these types of investments and other plant-related initiatives which can help further achievement of the NIH mission.

Conclusion

Although NIH does recognize that plants serve many important roles, the boundaries of plant-related research are expansive and integrate seamlessly and synergistically with many different disciplines that are also highly relevant to NIH. As such, ASPB asks the Subcommittee to provide the maximum appropriation and direction to NIH to support additional plant research in order to continue to pioneer new discoveries and new methods with applicability and relevance in biomedical research.

Thank you for your consideration of ASPB's testimony. For more information about ASPB, please see www.aspb.org.

[This statement was submitted by Tyrone C. Spady, Ph.D., Director of Legislative and Public Affairs American Society of Plant Biologists.]

PREPARED STATEMENT OF THE AMERICAN THORACIC SOCIETY

SUMMARY: FUNDING RECOMMENDATIONS

[In millions of dollars]

	Amount
National Institutes of Health	32,000
National Heart, Lung & Blood Institute	3,214
National Institute of Allergy & Infectious Disease	4,701
National Institute of Environmental Health Sciences	717.7
Fogarty International Center	72.7
National Institute of Nursing Research	151
Centers for Disease Control and Prevention	7,800
National Institute for Occupational Safety & Health	292.3
Asthma Programs	28
Div. of Tuberculosis Elimination	243
Office on Smoking and Health	250
National Sleep Awareness Roundtable (NSART)	1

The ATS's 15,000 members help prevent and fight respiratory disease through research, education, patient care and advocacy.

LUNG DISEASE IN AMERICA

Diseases of breathing constitute the third leading cause of death in the U.S., responsible for one of every seven deaths. Diseases affecting the respiratory (breathing) system include chronic obstructive pulmonary disease (COPD), lung cancer, tuberculosis, influenza, sleep disordered breathing, pediatric lung disorders, occupational lung disease, asthma, and critical illness.

National Institutes of Health

The NIH is the world's leader in groundbreaking biomedical health research into the prevention, treatment and cure of diseases such as lung cancer, COPD and tuberculosis. But due to eroded funding, the success rate for NIH research grants has plummeted to below 13 percent, which means that more than 85 percent of meritorious research is not being funded. The implementation of budget sequestration in fiscal year 2013 cut NIH by an additional \$1.5 billion, which resulted in the elimination of at least 1,000 grant opportunities and cuts of up to 10 percent for continuing grants. These cuts will result in the halting of vital research into diseases affecting millions around the world. We ask the subcommittee to provide \$32 billion in funding for the NIH in fiscal year 2015.

Despite the rising lung disease burden, lung disease research is underfunded. In fiscal year 2012, lung disease research represented just 23.2 percent of the National Heart Lung and Blood Institute's (NHLBI) budget. Although lung disease is the third leading cause of death in the U.S., research funding for the disease is a small fraction of the money invested for the other three leading causes of death. In order to stem the devastating effects of lung disease, research funding must continue to grow.

Centers for Disease Control and Prevention

In order to ensure that health promotion and chronic disease prevention are given top priority in Federal funding, the ATS supports a funding level for the Centers for Disease Control and Prevention (CDC) that enables it to carry out its prevention mission, and ensure a translation of new research into effective State and local public health programs. We ask that the CDC budget be adjusted to reflect increased needs in chronic disease prevention, infectious disease control, including TB control and occupational safety and health research and training. The ATS recommends a funding level of \$7.8 billion for the CDC in fiscal year 2015.

CHRONIC OBSTRUCTIVE PULMONARY DISEASE

COPD is the third leading cause of death in the United States and the third leading cause of death worldwide, yet the disease remains relatively unknown to most Americans. CDC estimates that 12 million patients have COPD; an additional 12 million Americans are unaware that they have this life threatening disease. In 2010, the estimated economic cost of lung disease in the U.S. was \$186 billion, including \$117 billion in direct health expenditures and \$69 billion in indirect morbidity and mortality costs.

The NHLBI is developing a national action plan on COPD, in coordination with the Centers for Disease Control and Prevention (CDC) to expand COPD surveillance, development of public health interventions and research on the disease and increase public awareness of the disease and we urge Congress to support it. We also urge CDC to include COPD-based questions to future CDC health surveys, including the National Health and Nutrition Evaluation Survey (NHANES) and the National Health Information Survey (NHIS).

TOBACCO CONTROL

Cigarette smoking is the leading preventable cause of death in the U.S., responsible for one in five deaths annually. The ATS is pleased that the Department of Health and Human Services has made tobacco use prevention a key priority. The CDC's Office of Smoking and Health coordinates public health efforts to reduce tobacco use. In order to significantly reduce tobacco use within 5 years, as recommended by the subcommittee in fiscal year 2010, the ATS recommends a total funding level of \$250 million for the Office of Smoking and Health in fiscal year 2015.

ASTHMA

Asthma is a significant public health problem in the United States. Approximately 25 million Americans currently have asthma. In 2010, 3,388 Americans died as a result of asthma exacerbations. Asthma is the third leading cause of hospitalization among children under the age of 15 and is a leading cause of school absences from chronic disease. The disease costs our healthcare system over \$50.1 billion per year. African Americans have the highest asthma prevalence of any racial/ethnic group and the age-adjusted death rate for asthma in this population is three times the rate in whites. A study published in the American Journal of Respiratory Critical Care in 2012 found that for every dollar invested in asthma interventions, there was a \$36 benefit. We ask that the subcommittee's appropriations request for fiscal year

2015 that funding for CDC's National Asthma Control Program be maintained at a funding level of at least \$28 million.

SLEEP

Several research studies demonstrate that sleep-disordered breathing and sleep-related illnesses affect an estimated 50–70 million Americans. The public health impact of sleep illnesses and sleep disordered breathing is still being determined, but is known to include increased mortality, traffic accidents, cardiovascular disease, obesity, mental health disorders, and other sleep-related comorbidities. The ATS recommends a funding level of \$1 million in fiscal year 15 to support activities related to sleep and sleep disorders at the CDC, including for the National Sleep Awareness Roundtable (NSART), surveillance activities, and public educational activities. The ATS also recommends an increase of funding for research on sleep disorders at the National Center for Sleep Disordered Research (NCSDR) at the NHLBI.

TUBERCULOSIS

Tuberculosis (TB) is the second leading global infectious disease killer, claiming 1.3 million lives each year. In the U.S., every State reports cases of TB annually. Drug-resistant TB poses a particular challenge to domestic TB control due to the high costs of treatment and intensive healthcare resources required. Treatment costs for multidrug-resistant (MDR) TB range from \$100,000 to \$300,000. The global TB pandemic and spread of drug resistant TB present a persistent public health threat to the U.S.

The Comprehensive Tuberculosis Elimination Act (CTEA, Public Law 110–392), enacted in 2008, reauthorized programs at CDC with the goal of putting the U.S. back on the path to eliminating TB. The ATS, recommends a funding level of \$243 million in fiscal year 2015 for CDC's Division of TB Elimination, as authorized under the CTEA, and encourages the NIH to expand efforts to develop new tools to reduce the rising global TB burden.

PEDIATRIC LUNG DISEASE

The ATS is pleased to report that infant death rates for various lung diseases have declined for the past 10 years. In 2009, of the 10 leading causes of infant mortality, 4 were lung diseases or had a lung disease component. Many of the precursors of adult respiratory disease start in childhood. Many children with respiratory illness grow into adults with COPD. It is estimated that 7.1 million children suffer from asthma. While some children appear to outgrow their asthma when they reach adulthood, 75 percent will require life-long treatment and monitoring of their condition. The ATS encourages the NHLBI to continue with its research efforts to study lung development and pediatric lung diseases.

CRITICAL ILLNESS

The burden associated with the provision of care to critically ill patients is enormous, and is anticipated to increase significantly as the population ages. Approximately 200,000 people in the United States require hospitalization in an intensive care unit because they develop a form of pulmonary disease called Acute Lung Injury. Despite the best available treatments, 75,000 of these individuals die each year from this disease. This is the approximately the same number of deaths each year due to breast cancer, colon cancer, and prostate cancer combined. Investigation into diagnosis, treatment and outcomes in critically ill patients should be a priority, and the NIH should be encouraged and funded to coordinate investigation in this area in order to meet this growing national imperative.

FOGARTY INTERNATIONAL CENTER

The Fogarty International Center (FIC) provides training grants to U.S. universities to teach AIDS treatment and research techniques to international physicians and researchers. Because of the link between AIDS and TB infection, FIC has created supplemental TB training grants for these institutions to train international health professionals in TB treatment and research. The ATS recommends Congress provide \$72.8 million for FIC in fiscal year 2015, to allow expansion of the TB training grant program from a supplemental grant to an open competition grant.

RESEARCHING AND PREVENTING OCCUPATIONAL LUNG DISEASE

As Congress considers funding priorities for fiscal year 2015, the ATS urges the subcommittee to provide at least level funding for the National Institute for Occupa-

tional Safety and Health (NIOSH). NIOSH, within the Centers for Disease Control and Prevention (CDC), is the primary Federal agency responsible for conducting research and making recommendations for the prevention of work-related illness and injury.

The ATS appreciates the opportunity to submit this statement to the subcommittee.

[This statement was submitted by Thomas Ferkol, MD, President, American Thoracic Society.]

PREPARED STATEMENT OF THE AMERICANS FOR NURSING SHORTAGE RELIEF

The organizations of the ANSR Alliance greatly appreciate the opportunity to submit written testimony recommending \$251 million in fiscal year 2015 for the Title VIII Nursing Workforce Development Programs at the Health Resources and Services Administration (HRSA) and \$20 million for the Nurse Managed Health Clinics as authorized under Title III of the Public Health Service Act. We represent a diverse cross-section of healthcare and other related organizations, healthcare providers, and supporters of nursing issues (<http://www.ansralliance.org/Members.html>) that have united to address the national nursing shortage. ANSR stands ready to work with Congress to advance programs and policy that will ensure our Nation has a sufficient and adequately prepared nursing workforce to provide quality care to all well into the 21st century.

The Nursing Shortage

Nursing is the largest healthcare profession in the United States and work in a variety of settings, including primary care, public health, long-term care, surgical care facilities, schools, and hospitals. In the Bureau of Labor Statistics (BLS) Employment Projections for 2012–2022, the total employment of registered nurses (RNs) and advanced practice registered nurses (APRNs) will increase by 574,400 jobs. With upcoming RN retirements in the mix, the Nation will need to produce 1.13 million new RNs by 2022 to fill those jobs. Because of the retirements, the projected number of RNs needed to fully staff healthcare facilities is virtually double the number of increased jobs due to expanded demand from new patients coupled with the aging baby boomer population wanting healthcare services. More new RNs are graduating from nursing programs than had been observed in the early 2000's but not sufficient numbers to make up the difference over the long-term. The Title VIII Nursing Workforce Education Programs will help fill these vacancies by supporting training programs designed to meet these healthcare needs.

The Title VIII Nursing Workforce and Education programs provide training for entry-level and advanced degree nurses to improve the access to, and the quality of, healthcare in underserved areas. These programs provide the largest source of Federal funding for nursing education, providing loans, scholarships, traineeships, and programmatic support that, between fiscal year 2005 and 2010, supported over 400,000 nurses and nursing students as well as numerous academic nursing institutions and healthcare facilities.

The Desperate Need for Nurse Faculty

Nursing vacancies exist throughout the entire healthcare system, including long-term care, home care and public health. Government estimates indicate that this situation only promises to worsen due to an insufficient supply of individuals matriculating in nursing schools, an aging existing workforce, and the inadequate availability of nursing faculty to educate and train the next generation of nurses. At the exact same time that the nursing shortage is expected to worsen, the baby boom generation is aging and the number of individuals with serious, life-threatening, and chronic conditions requiring nursing care will increase.

Each year, nursing schools turn away tens of thousands of qualified applications at all degree levels due to an insufficient number of faculty, clinical sites, classroom space, clinical preceptors, and budget constraints. Securing and retaining adequate numbers of faculty is essential to ensure that all individuals interested in—and qualified for—nursing school can matriculate in the year that they are accepted.

ANSR supports the need for sustained attention on the efficacy and performance of existing and proposed programs to improve nursing practices and strengthen the nursing workforce. The support of research and evaluation studies that test models of nursing practice and workforce development is integral to advancing healthcare for all in America. Investments in research and evaluation studies have a direct effect on the caliber of nursing care. Our collective goal of improving the quality of patient care, reducing costs, and efficiently delivering appropriate healthcare to

those in need is served best by aggressive nursing research and performance and impact evaluation at the program level.

The Nursing Supply Impacts the Nation's Health and Economic Safety

The demand for primary care services in the US is expected to increase over the next few years, particularly with the aging and growth of the population. One study projects that by the year 2019, the demand for primary care in the United States will increase by between 15 million and 25 million visits per year. HRSA estimates that more than 35.2 million people living within the 5,870 Health Professional Shortage Areas nationwide do not currently receive adequate primary care services. Research suggests that nurses and other health professionals are trained to and already do deliver many primary care services and may therefore be able to help increase access to primary care, particularly in underserved areas.

ANSR applauds the subcommittee's bipartisan efforts to recognize that a strong nursing workforce is essential to a health policy that provides high-value care for every dollar invested in capacity building for a 21st century nurse workforce. For 50 years, the Title VIII Nursing Workforce Development Programs have responded to the Nation's evolving workforce needs by providing education and training opportunities to nurses. These programs are the only Federal programs focused on filling gaps in the supply of nurses not met by traditional market forces, as well as producing a workforce prepared to care for the Nation's increasingly diverse and aging population. Numerous studies have demonstrated that the Title VIII programs graduate more minority and disadvantaged students more likely to serve in community health centers as well as rural and underserved areas. In a difficult economy, the Title VIII Nursing Workforce Education Programs help schools offer scholarships and affordable loans to nursing students, making such educational opportunities available to aspiring nurses of all backgrounds. By guiding job seekers to high-demand nursing jobs, the programs fulfill both their individual career goals and a community's health needs.

Summary

HRSA's Title VIII Nursing Workforce Education programs contribute to a sufficient nursing workforce to meet the demands of a highly diverse and aging population is an essential component to improving the health status of the Nation and reducing healthcare costs. While the ANSR Alliance understands the immense fiscal pressures facing the Nation, we respectfully urge support for \$251 million in funding for Nursing Workforce Development Programs under Title VIII of the Public Health Service Act at HRSA and \$20 million for the Nurse Managed Health Clinics under Title III of the Public Health Service Act in fiscal year 2015. We look forward to working with the Subcommittee to prioritize the Title VIII programs in fiscal year 2015 and the future.

ANSR ALLIANCE CO-CHAIRS

Christine Murphy, ANSR Alliance Co-Chair Senior Public Policy Specialist National League for Nursing	Wade Delk, ANSR Alliance Co-Chair Government Affairs Director American Society for Pain Management Nursing & International Nurses Society on Addictions
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LIST OF ANSR MEMBER ORGANIZATIONS:

Academy of Medical-Surgical Nurses	American Society of PeriAnesthesia Nurses
American Academy of Ambulatory Care Nursing	American Society of Plastic Surgical Nurses
American Academy of Nurse Practitioners	Association for Radiologic & Imaging Nursing
American Academy of Nursing	Association of Pediatric Hematology/Oncology Nurses
American Association of Nurse Anesthetists	Association of State and Territorial Directors of Nursing
American Association of Nurse Assessment Coordination	Association of Women's Health, Obstetric & Neonatal Nurses
American Association of Occupational Health Nurses	Citizen Advocacy Center
American College of Nurse-Midwives	Dermatology Nurses' Association
American Organization of Nurse Executives	Developmental Disabilities Nurses Association
American Society for Pain Management Nursing	Emergency Nurses Association

Infusion Nurses Society	National Council of Women's Organizations
International Association of Forensic Nurses	National Gerontological Nursing Association
International Nurses Society on Addictions	National League for Nursing
International Society of Nurses in Genetics, Inc.	National Nursing Centers Consortium
Legislative Coalition of Virginia Nurses	National Nursing Staff Development Organization
National Association of Clinical Nurse Specialists	National Organization for Associate Degree Nursing
National Association of Hispanic Nurses	National Student Nurses' Association, Inc.
National Association of Neonatal Nurses	Nurses Organization of Veterans Affairs
National Association of Neonatal Nurse Practitioners	Pediatric Endocrinology Nursing Society
National Association of Nurse Massage Therapists	Preventive Cardiovascular Nurses Association
National Association of Nurse Practitioners in Women's Health	RN First Assistants Policy & Advocacy Coalition
National Association of Orthopedic Nurses	Society of Gastroenterology Nurses and Associates, Inc.
National Association of Registered Nurse First Assistants	Society of Pediatric Nurses
National Association of School Nurses	Society of Trauma Nurses
National Black Nurses Association	Women's Research & Education Institute
National Council of State Boards of Nursing	Wound, Ostomy and Continence Nurses Society

PREPARED STATEMENT OF THE ANIMAL PROTECTION OF NEW MEXICO AND ANIMAL PROTECTION VOTERS

On behalf of the board, staff, members and supporters of Animal Protection of New Mexico (APNM) and Animal Protection Voters (APV), we sincerely appreciate the opportunity to provide testimony on our top NIH funding priority for the House Labor, Health and Human Services, Education and Related Agencies Appropriations Subcommittee in fiscal year 2015.

CAPACITY FOR FEDERALLY-OWNED CHIMPANZEES RETIRED BY THE NATIONAL INSTITUTES OF HEALTH

APNM and APV request NIH be given authority to use \$5 million of funds appropriated in this and subsequent appropriations bills for extramural construction and renovation within the National Chimpanzee Sanctuary System.

In 2013, NIH announced their plan to retire hundreds of government owned chimpanzees to sanctuary. This decision followed years of scientific review that determined chimpanzees are not necessary for research to advance human health along with broad public outcry over the ethics of holding chimpanzees in labs. Additional sanctuary construction is needed to enable NIH to move forward with their plan to retire the vast majority of government owned chimpanzees. Even taking into account upfront construction expenditures, the sooner the construction is completed and the chimpanzees are moved to sanctuary, the more the government will save over the lifetimes of the chimpanzees—which can be 60 years or more.

Detailed information on the request follows.

Background information

In June of 2010, the National Institutes of Health proposed a plan to move 202 aging, sick chimpanzees from a facility New Mexico where they had not been used for invasive research for years to a laboratory in Texas for further research. Intense public scrutiny over the animal cruelty issues and taxpayer waste of this plan was bolstered by involvement from New Mexico Governor Bill Richardson, Dr. Jane Goodall, and many more. In December 2010 U.S. Senators Tom Udall, Tom Harkin, and Jeff Bingaman requested an independent study from the National Academy of Sciences on whether chimpanzees are necessary as invasive research subjects.

The December 2011 Institute of Medicine study found that chimpanzees are not necessary for the vast majority of research and noted the serious ethical objections raised by keeping chimps in research labs. Immediately following the announcement of the IOM study results, NIH accepted the findings and assembled a panel of experts to advise them on the best way to implement the IOM findings. NIH accepted

nearly all of the expert panel's recommendations in their final decision. In June of 2013, the National Institutes of Health announced their plan to retire all but 50 government-owned chimpanzees to sanctuary, significantly curtail the use of chimps in NIH funded studies and not to revitalize breeding of chimpanzees for research.

NIH had already begun the transfer of the 110 government owned chimpanzees at the New Iberia Research Center in Louisiana to Chimp Haven (the National Chimpanzee Sanctuary), also located in Louisiana. This transfer is on schedule to be completed by the end of fiscal year 2014. At that point, approximately 350 government-owned chimpanzees will remain in laboratories—300 of whom are slated for retirement to sanctuary per NIH's plan.

In late November of 2013, the President signed into law amendments to the Chimpanzee Health Improvement Maintenance and Protection (CHIMP Act) which continued funding for the care, maintenance and transportation of federally owned chimpanzees over the next 5 years. These amendments have enabled NIH to provide funds for basic care for chimpanzees the agency already approved into sanctuary and also set the stage for NIH to move forward with their plan to retire hundreds more chimpanzees.

Costs in laboratories vs. sanctuary

Accredited sanctuaries provide the highest welfare standards for chimps at a lower cost to taxpayers than housing chimpanzees in research laboratories (see attached chart). It is estimated that transferring the 300 government-owned chimpanzees who are slated for retirement from the laboratories where they are currently housed to the national sanctuary will save taxpayers \$1.7 million to \$2.7 million per year in care and maintenance costs.

Construction to house more chimpanzees in sanctuary will require an upfront expenditure. However, due to the lower per diem cost in sanctuary, retiring chimpanzees to sanctuary will still yield a significant savings to taxpayers. The sooner construction is completed and the chimpanzees are moved to sanctuary, the more the taxpayers will save.

We respectfully request the subcommittee to consider the following language for inclusion in the appropriations bill:

Of the funds appropriated to NIH, \$5,000,000 shall be for grants or contracts for construction, renovation, or repair of the sanctuary system established by Section 404K of the Public Health Service Act.

Estimated Costs Related to Care and Maintenance of Government Owned Chimpanzees:

Government Owned Chimpanzees in Research Facilities and Research Reserve Facilities

Facility	Number of chimpanzees	NIH cost, \$M/year	NIH cost, \$/chimpanzee/day
New Iberia Research Center	^{1,2} 59	³ 1.01	⁴ 46.7
Keeling Center for Comparative Medicine and Research	² 147	³ 2.44	45.4
Keeling Center for Comparative Medicine and Research, DVR grant	² 16	² 0.4	68.8
Southwest National Primate Research Center, U42 grant ⁵	² 22	³ 0.65	80.9
Alamogordo Primate Facility	² 162	² 3.60	61.3
Totals	406	8.10	Average: 54.7

Government Owned Chimpanzees in Sanctuary

Facility	Number of chimpanzees	NIH cost, \$M/year	NIH cost, \$/animal/day,
Chimp Haven	⁶ 118–153	⁷ 1.7	30–39

¹ The remaining 59 chimpanzees at New Iberia Research Center are scheduled to be moved to Chimp Haven by the end of fiscal year 2014

² Based on information available on NIH website regarding chimpanzee maintenance costs for fiscal year 2014

³ Based on data available in NIH Research Portfolio Online Reporting Tools (RePORT) for fiscal year 2014

⁴ Figure expected to increase significantly as chimpanzees move to Chimp Haven and funds are spread over fewer chimpanzees

⁵ In addition to this grant, NIH also supports an additional 91 chimpanzees at the facility. These chimpanzees are owned by the laboratory and are not under the control of NIH.

⁶ Fifty chimpanzees from New Iberia Research Center were transferred to Chimp Haven during this contract year.

⁷ Unlike the other facilities, Chimp Haven has a cost reimbursement contract in which they are reimbursed for costs incurred. This number represents actual costs billed to NIH over the most recently completed contract year (06/30/2012–06/29/2013)

We appreciate the opportunity to share this testimony with the Labor, Health and Human Services, Education and Related Agencies Appropriations Act for fiscal year 2015. We hope the Committee will be able to accommodate this request. Thank you for your consideration.

PREPARED STATEMENT OF THE ASSOCIATION OF AMERICAN CANCER INSTITUTES

The Association of American Cancer Institutes (AACI), representing 93 of the Nation's premier academic and free-standing cancer centers, appreciates the opportunity to submit this statement for consideration by the subcommittee. AACI submits this request for the Department of Health and Human Services budget for the National Institutes of Health (NIH) in the amount of \$32 billion for fiscal year 2015.

AACI thanks Congress for its long-standing commitment to ensuring quality care for cancer patients, as well as for providing researchers with the resources that they need to develop better cancer treatments and, ultimately, to find cures for this deadly disease. The partnership between the Federal Government and our Nation's cancer centers is mutually beneficial, and cancer centers continue to make strides in biomedical research thanks to a partnership with the Federal Government. Without such support, research projects with the potential to discover breakthrough therapies would not be possible.

The President's fiscal year 2015 budget proposes \$30.2 billion for the NIH, an increase of \$200 million (0.7 percent) over the fiscal year 2014 level. This amount includes \$4.931 billion for the National Cancer Institute (NCI), a \$7.5 million increase over fiscal year 2014 (0.2 percent). Though we appreciate the president's support, NIH and NCI continue to endure a lag in funding. The fiscal year 2015 proposal falls far short of the inflation rate of 2.9 percent, a figure that NIH projected last year for the Biomedical Research and Development Price Index (BRDPI) for fiscal year 2015. AACI joins with our colleagues in the biomedical research community in recommending that the subcommittee recognize NIH as a critical national priority by providing at least \$32 billion in funding in the fiscal year 2015 Labor-HHS-Education Appropriations bill, including an equivalent percentage increase in funding for NCI. This funding level represents the minimum investment necessary to avoid further loss of promising research.

CANCER CENTERS MUST BE SUPPORTED IN ORDER TO MOVE RESEARCH FORWARD

America's standing in research and scientific discovery is threatened with each dollar slashed from the NIH budget. The budgetary pain in fiscal year 2014 has been less intense than in recent years but still remains for cancer centers striving both to keep gifted scientists at their institutions and to resume halted research projects due to sequestration. For some labs, recovery is nowhere in sight. Many have closed their doors, while some scientists have taken early retirement or simply left the field. Even some well-established labs claim they will never recover from the damage caused by sequestration.

With cancer centers challenged to provide infrastructure resources necessary to support researchers, the failure to keep pace with the biomedical inflation rate will limit AACI members' ability to provide well-functioning shared resources to investigators who depend on them to complete their research. For most academic cancer centers, the majority of NCI grant funds are used to sustain shared resources that are essential to basic, translational, clinical and population cancer research, or to provide matching dollars which allow departments to recruit new cancer researchers to a university and support them until they receive their first grants. Center infrastructure is expensive and it is not clear where cancer centers would acquire alternative funding if NCI grants for these efforts continue to dwindle.

AACI cancer centers are at the forefront of the national effort to eradicate cancer. The cancer centers that AACI represents house more than 20,000 scientific, clinical and public health investigators who work collaboratively to translate promising research findings into new approaches to prevent and treat cancer. Making progress against cancer is complex and time-intensive. However, the pace of discovery and translation of novel basic research to new therapies could be quickened if researchers could count on an appropriate and predictable investment in Federal cancer funding. As research costs and patient need increase, cancer centers continue to be highly dependent on Federal cancer center grants.

CANCER CENTERS ARE PIONEERS IN RESEARCH

The negative effects of diminished biomedical research funding reach beyond the lab as AACI cancer center directors have vocalized their concerns. The impact of flat

funding to the NIH continues to disturb advances in biomedical research and is of paramount concern to cancer center leaders.

While AACI President Michelle M. Le Beau, PhD, director of the University of Chicago Comprehensive Cancer Center, applauded the president's budget proposal, she asked that Congress build upon that budget. Dr. Le Beau has said that at a time when cancer centers continue to address the losses sustained due to budget sequestration, research institutions rely on robust aid from their partnership with the Federal Government. She said, "Cancer centers have served as pioneers in biomedical research, improving patient care and gaining a deeper understanding of the molecular basis of cancer through research. Advances in science are within reach, but without sufficient funding at the NIH and ultimately, the NCI, such progress in research will move at a slower pace."

Speaking at a meeting of the AACI Government Relations Forum in Houston, TX, University of Texas MD Anderson Cancer Center president Ronald DePinho, MD, echoed Dr. Le Beau's concerns. Dr. DePinho underscored the need for increased Federal funding for cancer research, noting that cancer incidence in the U.S. is projected to increase 45 percent between today and 2030. Dr. DePinho has acknowledged that the major solutions for patients will come from scientific innovations that will lead to transformation in cancer prevention, early detection and definitive cures. He said that academic medical centers are the engines for such discoveries. Dr. DePinho stressed that it is "critical that we vigorously support these national treasures to deal with the onslaught of people who will need cancer services."

University of New Mexico Cancer Center researchers, physicians, and staff work tirelessly to provide vital patient care and breakthrough cancer technology to a richly diverse and widely dispersed population. Cancer center director and CEO Cheryl Lynn Willman, MD is dedicated to ensuring all patients who enter UNM Cancer Center receive unsurpassed care, yet she is troubled by worries that not everyone in New Mexico has the ability and means to seek care at the NCI-designated center. While Willman and her team at UNM Cancer Center devote their time, effort, and hard work to bringing the most advanced cancer treatments available to the public, providing all potential patients with access to care is not achieved without high costs. Without sustained and stable NIH funding UNM Cancer Center and other centers across the country will struggle to uphold their devoted mission in cancer care and research to the people of New Mexico.

Robert S. DiPaola, MD, director of Rutgers Cancer Institute of New Jersey, knows the strides that can be made within cancer research due to increased NIH funding. Recently, Rutgers was awarded a competitive grant by the NCI to support their precision experimental therapeutics endeavor. Dr. DiPaola was proud to announce their collaboration with investigators from the University of Wisconsin Carbone Cancer Center as well as with a network of cancer centers. Though Dr. DiPaola and his team are grateful for the NCI funding that has made this work possible, they are increasingly aware that without adequate increases to NIH funding, the future of cancer research collaboration could suffer. He asserted that, "Ensuring that NIH acquires an increase at least relative to the inflation rate of 2.9 percent will help to keep the progress we are making in cancer research nationwide moving in the right direction."

Samir N. Khleif, MD, director of GRU Cancer Center at Georgia Regents University, testified before the appropriations subcommittee on March 25, noting that decades of sustained strong investment in NIH and NCI have sparked remarkable progress in cancer research and treatment. Dr. Khleif asked for increased funding at the NIH and the NCI in order to "keep our best and brightest minds focused on developing the biomedical research breakthroughs that save lives." He requested that support for NIH not falter in order for the U.S. to maintain its global edge in scientific discovery and innovation and maintain its progress in reducing the burden of cancer and other diseases.

AACI President-Elect George Weiner, MD, director of the Holden Comprehensive Cancer Center at the University of Iowa, agreed with Dr. Khleif's testimony. Dr. Weiner's greatest concern stems from the decrease in funding for the NIH and the NCI and the impact reduced Federal funding will have on young scientists and he has blogged about scientific and budgetary concerns. Dr. Weiner fears young scientists might not chose to conduct their research in the U.S. in the future, instead opting to go overseas as U.S. support for innovation has been flat or dropped and other countries begin to make progress. Dr. Weiner knows that the U.S. remains the world leader in biomedical research, but feels that "ongoing success will be dependent on outstanding physicians and scientists, born here and abroad, having the collaborative culture, resources and infrastructure needed to accelerate progress toward our shared mission of reducing the burden of cancer." Dr. Weiner stated that providing these tools will have a positive impact on our Nation's ability to care for

patients, our ability to conduct research, and our economy. Dr. Weiner stressed the need to continue to emphasize the importance of investing in innovation through education and research. He maintained that a commitment to investing in the NIH and the NCI is vital to the successes achieved through science.

CANCER RESEARCH IS IMPROVING AMERICA'S HEALTH

The broad portfolio of research supported by NIH and NCI is essential for improving our basic understanding of diseases and has paid off considerably in terms of improving Americans' health. The 5-year relative survival rate for all cancers diagnosed between 2002 and 2008 is 68 percent, up from 49 percent in 1975–1977. In addition, cancer death rates have dropped 11.4 percent among women and 19.2 percent among men over the past 15 years.¹ The improvement in survival reflects both progress in diagnosing certain cancers at an earlier stage and better treatment.

Despite that success, cancer remains the second leading cause of death in the U.S., with almost 1,600 deaths per day. More than 1.6 million new cancer cases will be discovered in 2014 and over 580,000 cancer deaths are expected.² NCI estimates that 41 percent of individuals born today will receive a cancer diagnosis at some point in their lifetime.³

CONCLUSION

NIH estimates that the overall costs of cancer in 2008 were \$201.5 billion: \$77.4 billion for direct medical costs (total of all health expenditures) and \$124 billion for indirect mortality costs (cost of lost productivity due to premature death).⁴ The cost of cancer continues to rise, but the investment in cancer research will one day eliminate such economic burdens on Americans and the cancer center researchers who work tirelessly to find a cure for this deadly disease. Failure to keep pace with the biomedical rate of inflation will only hinder our Nation's cancer center researchers from grasping future knowledge that will aid in the prevention, detection and treatment of cancer.

As Congress makes difficult appropriations decisions for fiscal year 2015 and beyond, AACI asks that it recall that the Nation's financial support of NIH and NCI has paid dividends by introducing innovative therapies for cancers that years ago cut short far too many American lives. The future of scientific discovery in cancer research is in the hands of the scientists whose research is conducted in labs across the country. NIH's full support of NCI-designated centers and their programs remains a top priority for our Nation's research institutions and we ask that Congress aid our Nation's cancer centers in their goal to eradicate cancer.

[This statement was submitted by Barbara Duffy Stewart, MPH, Executive Director, Association of American Cancer Institutes.]

PREPARED STATEMENT OF THE ASSOCIATION OF AMERICAN MEDICAL COLLEGES

The Association of American Medical Colleges (AAMC) is a not-for-profit association representing all 141 accredited U.S. and 17 accredited Canadian medical schools; nearly 400 major teaching hospitals and health systems; and nearly 90 academic and scientific societies. Through these institutions and organizations, the AAMC represents 128,000 faculty members, 75,000 medical students, and 110,000 resident physicians. The AAMC requests the following for Federal priorities essential in assisting medical schools and teaching hospitals to fulfill their missions of education, research, and patient care: at least \$32 billion for the National Institutes of Health (NIH); \$375 million for the Agency for Healthcare Research and Quality (AHRQ); \$520 million for the Title VII and VIII health professions workforce programs the Health Resources and Services Administration (HRSA)'s Bureau of Health Professions; and student aid through the Department of Education and HRSA's National Health Service Corps. The AAMC appreciates the Subcommittee's longstanding, bipartisan efforts to strengthen these programs.

National Institutes of Health—Congress's long-standing bipartisan support for medical research through the NIH has created a scientific enterprise that is the envy of the world and has contributed greatly to improving the health and well-

¹American Cancer Society. Facts and Figures, 2014. <http://www.cancer.org/research/cancerfactsstatistics/cancerfactsfigures2014/>.

²American Cancer Society. Facts and Figures.

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

⁴American Cancer Society. Facts and Figures.

being of all Americans. The foundation of scientific knowledge built through NIH-funded research drives medical innovation that improves health through new and better diagnostics, improved prevention strategies, and more effective treatments.

Nearly 84 percent of NIH research funding is awarded to more than 2,500 research institutions in every state. At least half of this funding supports life-saving research at America's medical schools and teaching hospitals, where scientists, clinicians, fellows, residents, medical students, and trainees work side-by-side to improve the lives of Americans through research. This successful partnership between the Federal Government and academic medicine not only lays the foundation for improved health and quality of life, it also strengthens the Nation's long-term economy.

The Consolidated Appropriations Act of 2014 included a welcome and much needed increase for NIH. However, this increase did not restore the funding cut from sequestration in fiscal year 2013 or the purchasing power lost over the past decade. The AAMC hopes fiscal year 2014 represents a first step toward restoring our Nation's preeminence in medical research. The AAMC supports the Ad Hoc Group for Medical Research recommendation that NIH receive at least \$32 billion in fiscal year 2015 as the next step toward a multi-year increase in our Nation's investment in medical research. The AAMC also urges Congress and the Administration to work in a bipartisan manner to end sequestration and the continued cuts to medical research that squander invaluable scientific opportunities, discourage young scientists, threaten medical progress and continued improvements in our Nation's health, and jeopardize our economic future.

The AAMC thanks the Subcommittee for its efforts to retain the limit on salaries that can be drawn from NIH extramural awards at Executive Level II of the Federal Executive Pay Scale. Medical schools' and teaching hospitals' discretionary funds from clinical revenues and other sources have become increasingly constrained and less available to invest in research. If institutions and departments divert funds to compensate for a reduction in the salary limit, they have less funding for critical activities such as bridge funding to investigators between grants and start-up packages to young investigators to launch their research programs. A lower salary cap also will disproportionately affect physician investigators, who will be forced to make up salaries from clinical revenues, thus leaving less time for research. This may serve as a deterrent to their recruitment into research careers. The AAMC urges the Subcommittee to continue its efforts to retain the limit at Executive Level II.

Agency for Healthcare Research and Quality—Complementing the medical research supported by NIH, AHRQ sponsors health services research designed to improve the quality of healthcare, decrease healthcare costs, and provide access to essential healthcare services by translating research into measurable improvements in the healthcare system. The AAMC firmly believes in the value of health services research as the Nation continues to strive to provide high-quality, evidence-based, efficient, and cost-effective healthcare to all of its citizens. The AAMC joins the Friends of AHRQ in recommending \$375 million in base discretionary funding for the agency in fiscal year 2015.

As the only Federal agency with the sole purpose of generating evidence to make healthcare safer; higher quality; and more accessible, equitable, and affordable, AHRQ also works to ensure such evidence is available across the continuum of healthcare stakeholders, from patients to payers to providers. These research findings will better guide and enhance consumer and clinical decisionmaking, provide improved healthcare services, and promote efficiency in the organization of public and private systems of healthcare delivery.

Health Professions Funding—HRSA's Title VII health professions and Title VIII nursing education programs are the only Federal programs designed to improve the supply, distribution, and diversity of the Nation's primary care workforce. Through loans, loan guarantees, and scholarships to students, and grants and contracts to academic institutions and non-profit organizations, the Title VII and Title VIII programs fill the gaps in the supply of health professionals not met by traditional market forces.

Titles VII and VIII are structured to allow grantees to test educational innovations, respond to changing delivery systems and models of care, and address timely topics in their communities. By assessing the needs of the communities they serve and emphasizing interprofessional education and training, Title VII and VIII programs bring together knowledge and skills across disciplines to provide effective, efficient and coordinated care. Further, numerous studies demonstrate that the programs graduate more minority and disadvantaged students and prepare providers that are more likely to serve in Community Health Centers (CHC) and the National Health Service Corps (NHSC).

The AAMC joins the Health Professions and Nursing Education Coalition (HPNEC) in recommending \$520 million for these important workforce programs in fiscal year 2015. This funding level is necessary to ensure continuation of all Title VII and Title VIII programs while also supporting promising initiatives such as the Pediatric Subspecialty Loan Repayment program, the Clinical Training in Inter-professional Practice program, the Rural Physician Training Grants, and other efforts to bolster the workforce.

The AAMC strongly objects to the Administration's proposal to eliminate the Area Health Education Centers (AHEC), which, in 2012 alone, trained more than 20,000 health professions students in community-based settings, and the Health Careers Opportunity Program (HCOP), which research shows has helped students from disadvantaged backgrounds achieve higher grade point averages and matriculate into health professions programs. Continued support for these and the full spectrum of Title VII and programs is essential to prepare our next generation of medical professionals to adapt to the evolving healthcare needs of the changing population.

In addition to funding for Title VII and Title VIII, HRSA's Bureau of Health Professions also supports the Children's Hospitals Graduate Medical Education (CHGME) program. This program provides critical Federal graduate medical education support for children's hospitals to prepare the future primary care and specialty care workforce for our Nation's children. At a time when the Nation faces a critical physician shortage, the AAMC has serious concerns about the proposed elimination of the CHGME program in the president's budget. We strongly support full funding for the Children's Hospitals Graduate Medical Education program at \$300 million in fiscal year 2015.

Student Aid and the National Health Service Corps (NHSC)—The AAMC urges the committee to sustain student loan and repayment programs for graduate and professional students at the Department of Education. The average graduating debt of medical students is currently \$175,000, and typical repayment can range from \$326,000 to \$492,000.

The AAMC urges Congress to reauthorize the National Health Service Corps (NHSC) Fund, created under the Affordable Care Act (ACA, Public Law 111-142 and Public Law 111-152) and set to expire at the end of fiscal year 2015. In the absence of continued mandatory funding, the committee must address the NHSC funding shortfall in the already strained Labor-HHS spending bill. To date, the steady, sustained, and certain growth established by this mandatory funding for the NHSC has resulted in program expansion and innovative pilots such as the Student to Service (S2S) Loan Repayment Program that incentivizes fourth-year medical students to practice primary care in underserved areas after residency training.

Once again, the AAMC appreciates the opportunity to submit this statement for the record and looks forward to working with the Subcommittee as it prepares its fiscal year 2015 spending bill.

PREPARED STATEMENT OF THE ASSOCIATION OF INDEPENDENT RESEARCH INSTITUTES

The Association of Independent Research Institutes (AIRI) thanks the Subcommittee for its long-standing and bipartisan leadership in support of the National Institutes of Health (NIH). We continue to believe that science and innovation are essential if we are to continue to improve our Nation's health, sustain our leadership in medical research, and remain competitive in today's global information and innovation-based economy. The Consolidated Appropriations Act of 2014 included a welcome and much needed increase for NIH. However, this increase did not give back all of the funds cut by sequestration in fiscal year 2013 nor did it restore the purchasing power NIH has lost over the past decade. We hope fiscal year 2014 represents a first step toward restoring our Nation's preeminence in medical research. AIRI recommends that NIH receive at least \$32 billion in fiscal year 2015 as the next step toward a multi-year increase in our Nation's investment in medical research.

AIRI is a national organization of more than 80 independent, non-profit research institutes that perform basic and clinical research in the biological and behavioral sciences. AIRI institutes vary in size, with budgets ranging from a few million to hundreds of millions of dollars. In addition, each AIRI member institution is governed by its own independent Board of Directors, which allows our members to focus on discovery-based research while remaining structurally nimble and capable of adjusting their research programs to emerging areas of inquiry. Researchers at independent research institutes consistently exceed the success rates of the overall NIH grantee pool, and they receive about 10 percent of NIH's peer-reviewed, competitively-awarded extramural grants.

The partnership between NIH and America's scientists, research institutions, universities, and medical schools is a unique and highly-productive relationship, leveraging the full strength of our Nation's research enterprise to foster discovery, improve our understanding of the underlying cause of disease, and develop the next generation of medical advancements that deliver more treatments and cures to patients. Not only is NIH research essential to advancing health, it also plays a key economic role in communities nationwide. Approximately 84 percent of the NIH's budget goes to more than 300,000 research positions at over 2,500 universities and research institutions located in every State.

The Federal Government has an irreplaceable role in supporting medical research. No other public, corporate or charitable entity is willing or able to provide the broad and sustained funding for the cutting edge research necessary to yield new innovations and technologies of the future. NIH supports long-term competitiveness for American workers, forming one of the key foundations for U.S. industries like biotechnology, medical device and pharmaceutical development, and more. Unfortunately, continued erosion of the national commitment to medical research threatens our ability to support a medical research enterprise that is capable of taking full advantage of existing and emerging scientific opportunities.

The NIH model for conducting biomedical research, which involves supporting scientists at universities, medical centers, and independent research institutes, provides an effective approach to making fundamental discoveries in the laboratory that can be translated into medical advances that save lives. AIRI member institutions are private, stand-alone research centers that set their sights on the vast frontiers of medical science. AIRI institutes are specifically focused on pursuing knowledge around the biology and behavior of living systems and applying that knowledge to improve human health and reduce the burdens of illness and disability. Additionally, AIRI member institutes have championed (and very frequently are called upon to lead) technologies and research centers to collaborate on biological research for all diseases. Using shared resources—specifically, advanced technology platforms or “cores”—as well as genomics, next-generation sequencing, electron and light microscopy, high-throughput compound screening, bioinformatics, imaging, and other technologies, AIRI researchers advance therapeutics development and drug discovery.

AIRI member institutes are especially vulnerable to reductions in the NIH budget, as they do not have other reliable sources of revenue to make up the shortfall. In addition to concerns over funding, AIRI member institutes oppose legislative provisions—such as directives to reduce the salary limit for extramural researchers—which would harm the integrity of the research enterprise and disproportionately affect independent research institutes. Such prescriptive policies hinder AIRI members' research missions and their ability to recruit and retain talented researchers. AIRI also does not support legislative language limiting the flexibility of NIH to determine how to most effectively manage its resources while funding the best scientific ideas.

AIRI member institutes' flexibility and research-only missions provide an environment particularly conducive to creativity and innovation. Independent research institutes possess a unique versatility and culture that encourages them to share expertise, information, and equipment across research institutions, as well as neighboring universities. These collaborative activities help minimize bureaucracy and increase efficiency, allowing for fruitful partnerships in a variety of disciplines and industries. Also, unlike institutes of higher education, AIRI member institutes focus primarily on scientific inquiry and discovery, allowing them to respond quickly to the research needs of the country.

AIRI members are located in 25 States, including many smaller or less-populated States that do not have major academic research institutions. In many of these regions, independent research institutes are major employers and local economic engines, and they exemplify the positive impact of investing in research and science.

The biomedical research community depends upon a knowledgeable, skilled, and diverse workforce to address current and future critical health research questions. While the primary function of AIRI member institutions is research, most are highly involved in training the next generation of biomedical researchers, ensuring that a pipeline of promising scientists is prepared to make significant and potentially transformative discoveries in a variety of areas. AIRI supports policies that promote the ability of the United States to maintain a competitive edge in biomedical science. The NIH initiatives focusing on career development and recruitment of a diverse scientific workforce are important to innovation in biomedical research and public health.

AIRI thanks the Subcommittee for its important work dedicated to ensuring the health of the Nation, and we appreciate this opportunity to urge the Subcommittee to provide \$32 billion for NIH in the fiscal year 2015 appropriations bill. AIRI also

urges Congress and the Administration to work in a bipartisan manner to end sequestration and the continued cuts to medical research that squander valuable scientific opportunities, discourage young scientists, threaten medical progress and continued improvements in our Nation's health, and jeopardize our economic future.

PREPARED STATEMENT OF THE ASSOCIATION OF UNIVERSITY PROGRAMS IN
OCCUPATIONAL HEALTH AND SAFETY

On behalf of the Association of University Programs in Occupational Health and Safety (AUPOHS), an organization representing the 18 multidisciplinary, university-based Education and Research Centers (ERCs) and the ten Agricultural Centers for Disease and Injury Research, Education, and Prevention funded by the National Institute for Occupational Safety and Health (NIOSH), we respectfully request that the fiscal year 2015 Labor, Health and Human Services Appropriations bill include level funding of \$27 million for the Education and Research Centers and \$24 million for the Agriculture, Forestry and Fishing (AFF) Program within the NIOSH budget.

NIOSH is the Federal agency responsible for supporting education, training, and research for the prevention of work-related injuries and illnesses in the United States. The ERCs are regional resources for parties involved with occupational health and safety—industry, labor, government, academia, and the public. Collectively, the ERCs provide training and research resources to every Public Health Region in the United States. ERCs contribute to national efforts to reduce losses associated with work-related illnesses and injuries by offering:

- Prevention Research: Developing the basic knowledge and associated technologies to prevent work-related illnesses and injuries.
- Professional Training: ERCs support 86 graduate degree programs in Occupational Medicine, Occupational Health Nursing, Safety Engineering, Industrial Hygiene, and other related fields to provide qualified professionals in essential disciplines.
- Research Training: Preparing doctoral-trained scientists who will respond to future research challenges and who will prepare the next generation of occupational health and safety professionals.
- Continuing Education: Short courses designed to enhance professional skills and maintain professional certification for those who are currently practicing in occupational health and safety disciplines. These courses are delivered throughout the regions of the 18 ERCs, as well as through distance learning technologies.
- Regional Outreach: Responding to specific requests from local employers and workers on issues related to occupational health and safety.

Occupational injury and illness represent a striking burden on America's health and well-being. Despite significant improvements in workplace safety and health over the last several decades, each year nearly 1.2 million workers are injured seriously enough to require time off work and, daily, an average of 11,000 U.S. workers sustain disabling injuries on the job, 13 workers die from an injury suffered at work, and 146 workers die from work-related diseases. This burden costs industry and citizens an estimated \$4 billion per week—\$250 billion dollars per year. This is an especially tragic situation because work-related fatalities, injuries and illnesses are preventable with effective, professionally directed, health and safety programs.

The rapidly changing workplace continues to present new health risks to American workers that need to be addressed through occupational safety and health research. For example, between 2000 and 2015, the number of workers 55 years and older will increase 72 percent to over 31 million. Work related injury and fatality rates increase at age 45, with rates for workers 65 years and older nearly three times greater than younger workers. In addition to changing demographics, the rapid development of new technologies (e.g., nanotechnology) poses many unanswered questions with regard to workplace health and safety that require urgent attention.

The heightened awareness of terrorist threats, and the increased responsibilities of first responders and other homeland security professionals, illustrates the need for strengthened workplace health and safety in the ongoing war on terror. The NIOSH ERCs play a crucial role in preparing occupational safety and health professionals to identify and mitigate vulnerabilities to terrorist attacks and to increase readiness to respond to biological, chemical, or radiological attacks. In addition, occupational health and safety professionals have worked for several years with emergency response teams to minimize disaster losses. For example, NIOSH took a lead role in protecting the safety of 9/11 emergency responders in New York City and Virginia, with ERC-trained professionals applying their technical expertise to meet

immediate protective needs and to implement evidence-based programs to safeguard the health of clean-up workers.

Additionally, NIOSH is now administering grants to provide health screening of World Trade Center responders. We need manpower to address these challenges and it is the NIOSH ERCs that train the professionals who fill key positions in health and safety programs, regionally and around the Nation. And because ERCs provide multi-disciplinary training, ERC graduates protect workers in virtually every walk of life. Despite the success of the ERCs in training such qualified professionals, the country continues to have ongoing manpower shortages.

The Agricultural Safety and Health Centers program was established by Congress in 1990 (Public Law 101-517) in response to evidence that agricultural workers were suffering substantially higher rates of occupational injury and illness than other U.S. workers.

Today the NIOSH Agriculture, Forestry, and Fishing (AFF) Initiative includes nine regional Centers for Agricultural Disease and Injury Research, Education, and Prevention and one national center to address children's farm safety and health. The AFF program is the only substantive Federal effort to meet the obligation to ensure safe working conditions for workers in this most vital production sector. While agriculture, forestry, and fishing constitute one of the largest industry sectors in the U.S. (DOL 2011), most AFF operations are themselves small: nearly 78 percent employ fewer than 10 workers, and most rely on family members and/or immigrants, part-time, contract and seasonal labor. Thus, many AFF workers are excluded from labor protections, including many of those enforced by OSHA.

In 2012 the AFF sector had a work-related fatality rate of 22 per 100,000 workers, the highest of any sector in the Nation. More than 1 in 100 AFF workers incur nonfatal injuries resulting in lost work days each year. These reported figures do not even include men, women, and youths on farms with fewer than 11 full-time employees. In addition to the harm to individual men, women, and families, these deaths and injuries inflict serious economic losses including medical costs and lost capital, productivity, and earnings. The life-saving, cost-effective work of the NIOSH AFF program is not replicated by any other agency:

- State and Federal OSHA personnel rely on NIOSH research in the development of evidence-based standards for protecting agricultural workers and would not be able to fulfill their mission without the NIOSH AFF program.
- While committed to the well-being of farmers, the USDA has little expertise in the medical or public health sciences. USDA no longer funds, as it did historically, land grant university-based farm safety specialists.
- Staff members of USDA's National Institute of Food and Agriculture interact with NIOSH occupational safety and health research experts to keep abreast of cutting-edge research and new directions in this area.

NIOSH Agricultural Center activities include:

- AFF research has shown that the use of rollover protective structures (ROPS or rollbars) and seatbelts on tractors can prevent 99 percent of overturn-related deaths. A New York program has increased the installation of ROPS by 10-fold and recorded over 140 close calls with no injuries among farmers who had installed ROPS. 99 percent of program participants said they would recommend the program to other farmers.
- Working in partnership with producers and farm owners, the NIOSH AFF Centers have developed evidence-based solutions for reducing exposure to pesticides and other farm chemicals among farmers, farm workers and their children.
- Commercial Fishing had a reported annual fatality rate 58 times higher than the rate for all U.S. workers in 2009. Research has shown that knowledge of maritime navigation rules and emergency preparedness means survival. A NIOSH AFF-funded team produced an interactive navigation training CD in three languages, demonstrated the effectiveness of refresher survival drill instruction, and assisted the US Coast Guard's revision of regulations requiring commercial fishing vessel captains complete navigation training.
- The Centers have partnered with producers, employers, the Federal migrant health program, physicians, nurses, and Internet Technology specialists to educate farmers, employers, and healthcare providers about the best way to treat and prevent agricultural injury and illness.
- In 2010, the logging industry had a reported fatality rate of 91.9 deaths per 100,000 workers (preliminary data), a rate more than 25 times higher than that of all US workers. NIOSH AFF Centers, including the Southeast and the Northwest, are uniquely positioned to ensure the safety of our Nation's 86,000 workers in forestry & logging.

Thank you for the opportunity to present testimony on behalf of the many individuals committed to working to improve the safety and well being of others in our communities.

PREPARED STATEMENT OF THE ASSOCIATION OF ZOOS AND AQUARIUMS

Thank you Chairman Harkin and Ranking Member Moran for allowing me to submit testimony on behalf of the Nation's 213 U.S. accredited zoos and aquariums. Specifically, I want to express my support for the inclusion of \$38.6 million for the Institute of Museum and Library Services' (IMLS) Office of Museum Services in the fiscal year 2015 Labor, Health and Human Services, Education, and Related Agencies appropriations bill.

Founded in 1924, the Association of Zoos and Aquariums (AZA) is a nonprofit 501c(3) organization dedicated to the advancement of zoos and aquariums in the areas of conservation, education, science, and recreation. Accredited zoos and aquariums annually see more than 182 million visitors, collectively generate more than \$21 billion in annual economic activity, and support more than 204,000 jobs across the country. Over the last 5 years, AZA-accredited institutions supported more than 4,000 field conservation and research projects with \$160,000,000 annually in more than 100 countries. In the last 10 years, accredited zoos and aquariums formally trained more than 400,000 teachers, supporting science curricula with effective teaching materials and hands-on opportunities. School field trips annually connect more than 12,000,000 students with the natural world.

Aquariums and zoological parks are defined by the "Museum and Library Services Act of 2003" (Public Law 108-81) as museums. The Office of Museum Services awards grants to museums to support them as institutions of learning and exploration, and keepers of cultural, historical, and scientific heritages. Grants are awarded in several areas including educational programming, professional development, and collections management, among others.

The Nation's accredited zoos and aquariums, even while facing budget limitations, are thriving during these uncertain economic times. As valued members of local communities, zoos and aquariums offer a variety of programs ranging from unique educational opportunities for schoolchildren to conservation initiatives that benefit both local and global species. The competitive grants offered by the IMLS Office of Museum Services ensure that many of these programs, which otherwise may not exist because of insufficient funds, positively impact local communities and many varieties of species.

For example, with a 2013 Museums for America—Collections Stewardship grant the Toledo Zoo will obtain new life support systems for an interactive visitor touch tank containing invertebrates and another holding sharks and stingrays. The exhibits provide multi-sensory experiences that connect people with animals, while the systems ensure the animals are properly cared for. Through its 2012 Museums for America grant, the Birmingham Zoo supported its Africa Zoo School program, which is serving 1,200 students over 2 years. Partnering with Birmingham City School, seventh-grade students from low-performing schools attend a week-long "Zoo School" session, where they learn about the crisis of the elephant species' survival in Africa, the cultures of people in Africa, and the scientific and engineering research involved in sustaining these populations. Finally, a 2011 Museums for America grant enabled The National Aquarium in Baltimore to create a more robust volunteer program by developing and testing new techniques to attract, train, engage, and retain a new generation of more diverse volunteers.

Unfortunately, current funding has allowed IMLS to fund only a small fraction of all highly-rated grant applications. Despite this funding shortfall, zoo and aquarium attendance has increased and the educational services zoos and aquariums provide to schools and communities are in greater demand than ever. Zoos and aquariums are essential partners at the Federal, State, and local levels in providing education and cultural opportunities that adults and children may otherwise never enjoy.

As museums, zoos and aquariums share the same mission of preserving the world's great treasures, educating the public about them, and contributing to the Nation's economic and cultural vitality. Therefore, I strongly encourage you to include \$38.6 million for the Institute of Museum and Library Services' Office of Museum Services in the fiscal year 2015 Labor, Health and Human Services, Education, and Related Agencies appropriations bill.

Thank you.

[This statement was submitted by Jim Maddy, President and CEO, Association of Zoos and Aquariums.]

PREPARED STATEMENT OF THE BRAIN INJURY ASSOCIATION OF AMERICA

Chairman Harkin and Ranking Member Moran, thank you for the opportunity to submit this written testimony with regard to the fiscal year 2015 Labor-HHS-Education appropriations bill. This testimony is on behalf of the Brain Injury Association of America (BIAA), our network of State affiliates, and hundreds of local chapters and support groups from across the country.

In the civilian population alone every year, more than 2.5 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.

Increasing numbers of service members returning from the conflicts in Iraq and Afghanistan with TBI and their families are seeking resources for information to better understand TBI and to obtain vital support services to facilitate successful reintegration into their communities.

Since 1997, Congress has provided minimal funding through the Health Resources and Services Administration (HRSA) Federal TBI Program to assist States in developing services and systems to help individuals with brain injuries and their families who have a broad range of service and support needs. Similarly, Congress has appropriated funds to HRSA for grants to State Protection and Advocacy Systems to assist individuals with TBI in accessing services through education, legal and advocacy remedies, but the program is woefully underfunded. Rehabilitation, community support and long-term care systems are still developing in many States, while stretched to capacity in others. Additional numbers of individuals with TBI as the result of war-related injuries only adds more stress to these inadequately funded systems.

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

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

- \$10 million (+ \$4 million) for the Centers for Disease Control and Prevention TBI Registries and Surveillance, Brain Injury Acute Care Guidelines, Prevention and National Public Education/Awareness
- \$12 million (+ \$1 million) for the Health Resources and Services Administration (HRSA) Federal TBI State Grant Program
- \$4 million (+ \$1 million) for the HRSA Federal TBI Protection & Advocacy (P&A) Systems Grant Program

CDC—National Injury Center—The Centers for Disease Control and Prevention's National Injury Center is responsible for assessing the incidence and prevalence of TBI in the United States. The CDC estimates that 2.5 million TBIs occur each year and 5.3 million Americans live with a life-long disability as a result of TBI. The TBI Act as amended in 2008 requires the CDC to coordinate with the Departments of Defense and Veterans Affairs to include the number of TBIs occurring in the military. This coordination will likely increase CDC's estimate of the number of Americans sustaining TBI and living with the consequences.

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

HRSA TBI State Grant Program—The TBI Act authorizes HRSA to award grants to (1) States, American Indian Consortia and territories to improve access to service delivery and to (2) State Protection and Advocacy (P&A) Systems to expand advocacy services to include individuals with traumatic brain injury. Since 1997, the HRSA Federal TBI State Grant Program has supported State efforts to address the needs of persons with brain injury and their families and to expand and improve services to underserved and unserved populations including children and youth; veterans and returning troops; and individuals with co-occurring conditions.

In fiscal year 2009, HRSA reduced the number of State grant awards to 21, in order to increase each monetary award from \$118,000 to \$250,000. This means that many States that had participated in the program in prior years have now been forced to close down their operations, leaving many individuals with brain injury and their families unable to access needed care and supports.

Increasing the program to \$8 million will provide funding necessary to sustain the grants for the 21 States currently receiving funding along with the three additional States added this year and to ensure funding for four additional States. Steady in-

creases over 5 years for this program will provide for each State including the District of Columbia and the American Indian Consortium and territories to sustain and expand State service delivery; and to expand the use of the grant funds to pay for such services as Information & Referral (I&R), systems coordination and other necessary services and supports identified by the State.

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

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

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

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

In order to make this program more comprehensive, Congress should provide \$13 million (+ \$1.5 million) in fiscal year 2015 for NIDRR's TBI Model Systems of Care program, in order to add two new Collaborative Research Projects. In addition, given the national importance of this research program, the TBI Model Systems of Care should receive "line-item" status within the broader NIDRR budget.

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

PREPARED STATEMENT OF THE CALIFORNIA ASSOCIATION OF PSYCHIATRIC TECHNICIANS

INTRODUCTION

On behalf of approximately 14,000 California Licensed Psychiatric Technicians representing the Nation's "gold standard" in direct-care nursing services for people with developmental disabilities and mental illnesses, I am writing to respectfully request that the Subcommittee, Committee and Congress as a whole end the practice of using Federal funds to downsize and close federally regulated and accredited homes for Americans with developmental disabilities.

INDIVIDUALS AND FAMILIES CAUGHT IN A FEDERAL WEB OF IRONIES

In recent years, the national demand for developmental centers' closure has come perhaps most strongly—and, perhaps, most surprisingly—from the Federal Government: the very Federal Government which requires developmental centers to meet its own regulatory standards.

To be federally certified through the U.S. Centers for Medicare and Medicaid Services, State developmental centers must meet eight major criteria on management, client protections, facility staffing, active treatment, client behavior and facility practices, healthcare services, physical environment and dietetic services. To meet all of these major criteria, developmental centers must comply with 378 specific Federal standards and elements. Failure to comply with any one of these hundreds of requirements or to swiftly correct any deficiencies means the loss of Federal certification as well as Federal Medicaid funding.

But in an interesting twist, other Federal funds go to support the efforts of the Protection and Advocacy system. Created by Congress, this federally mandated system acts as a legally based advocacy provider for people with developmental disabilities and other mental and physical disabilities throughout the Nation. Each State

has a P&A branch to investigate allegations of discrimination, abuse or other concerns affecting Americans with disabilities, wherever they reside.

The P&A system and other Federal laws arose as responses to widespread concerns of neglect and abuse at an unlicensed New York developmental center called Willowbrook State School more than 40 years ago. The system and laws are the bases for the regulations that today's developmental centers must follow to achieve and continue Federal accreditation. However, nothing in this system or laws require the closure of developmental centers. In the case of the Federal law which creates P&As—the Developmental Disabilities Assistance and Bill of Rights Act (often called the “DD Act”)—P&As’ board charge is to “protect and advocate” for people with disabilities regardless of where they reside. In the DD Act’s legislative history, Congress expressly cautioned against interpreting the act as mandating closures: “The goals expressed in this act to promote the greatest possible integration and independence for some individuals with developmental disabilities may not be read as a Federal policy supporting the closure of residential institutions... .” This Congressional intent is reinforced in the act itself, where individuals and their families, and no one else, are named as the “primary decisionmakers” regarding services (including residential supports) and policies.

U.S. SUPREME COURT SUPPORTS RESIDENTIAL CHOICE

To add to the paradox, another Federal group—none other than the U.S. Supreme Court—made key points in its touchstone 1999 *Olmstead* ruling:

“We emphasize that nothing in the [Americans with Disabilities Act] or its implementing regulations condone termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any Federal requirement that community-based treatment be imposed on patients who do not desire it.”

The overall tragic irony of this Kafkaesque situation is not lost on those advocating for loved ones to have the choice of living in federally regulated and certified facilities. Adding to the personal and emotional toll of advocating to keep their loved ones’ developmental-center homes open, family members must use their own personal funds to fight the deep pockets of federally funded P&A and DOJ attorneys seeking center closures that families and residents often do not wish. Federal funds are being used by one Federal agency to sue another Federal agency for the purpose of evicting our Nation’s most vulnerable people from their homes. In addition to wasting taxpayer dollars, it defies common sense and human decency.

WHAT DOES ‘MOST INTEGRATED’ MEAN?

Those taking aim at developmental centers, in the Federal Government or elsewhere, feel that the centers are not the most integrated settings possible for those with developmental disabilities. But the ADA defines “most integrated setting” to be “a setting that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible [emphasis added].”

Families with loved ones in developmental centers who wish to continue their services strongly disagree with any interpretation that their family members are, in any way, restricted. They feel that the many on-site services offered at a developmental center provide the most integrated environments possible, allowing their loved ones live securely and to meet their fullest potentials.

Professional developmental-center staff also echo families’ concerns about how many group homes and placements with less safety and oversight and fewer programs can be less “restrictive.” Developmental centers are required by Federal and State regulations to have dozens and dozens of federally regulated state-of-the-art therapeutic and rehabilitative programs in place, right there on grounds as well as in the broader community; but somehow a developmental center is always painted as “less integrated” and “more restrictive” than a house on a busy street with a postage-stamp yard, occasional visits by licensed staff, few or no programs and infrequent and pre-announced visits by State regulators.

California’s Licensed Psychiatric Technicians are not “anti-“community””—in fact, we actively advocate for group-home placements when it is in the clients’ best interests and is what they and their families wish. However, when taken as a whole, how is having more space, more programs both on and off the center campus, higher regulatory standards and a whole community of professionals there to help Americans enjoy the healthiest, happiest and most active life possible necessarily “more restrictive?”

END THE PARADOX: STOP FUNDING RESTRICTIONS ON FEDERAL CHOICES

On behalf of CAPT and its dedicated professional membership, I wish to respectfully request that the Subcommittee and Congress as a whole end the use of Federal

appropriations to discourage, downsize and close federally regulated developmental centers ("ICF/DDs and ICF/MRs") throughout the country. It is the legal and moral choice and right for people with developmental disabilities and their loved ones to make decisions on their individual residential, service and support needs, and the choice of federally regulated developmental centers and related congregate settings should remain an option for them. Our Federal Government should not play a role in restricting or eliminating any viable, recognized and desired option for Americans with developmental disabilities.

[This statement was submitted by Juan Nolasco, PT, State President, California Association of Psychiatric Technicians.]

PREPARED STATEMENT OF THE CALIFORNIA ASSOCIATION OF STATE HOSPITAL PARENT COUNCILS FOR THE RETARDED

Dear Chairman Harkin and Members of the Subcommittee: The California Association of State Hospital Parent Councils for the Retarded (CASHPCR) represents the families, friends, and advocates of loved ones living at Porterville Developmental Center and Fairview Developmental Center.

As President of CASHPCR, a healthcare professional, and the sister of someone with a developmental disability, I am writing to urge the Senate Appropriations Labor, Health and Human Services (HHS), Education and Related Agencies to prohibit the use of Federal HHS appropriations in support of deinstitutionalization activities which evict, without regard to individual choice, eligible individuals with intellectual and developmental disabilities (I/DD) from their HHS-licensed and funded homes.

The ability of our family members and others with developmental disabilities to achieve their full potential is greatly dependent upon the services and supports that they receive, including housing, medical care, and developmental programs. The homes licensed and funded by HHS are an important option for many individuals—in some cases, the only option.

VOR, a national nonprofit organization advocating for high quality care and human rights for all people with I/DD, has submitted written testimony for the record with this same request.

I support VOR's testimony and request.

[This statement was submitted by Theresa DeBell, R.N., California Association of State Hospital Parent Councils for the Retarded.]

PREPARED STATEMENT OF THE CENTERS FOR DISEASE CONTROL AND PREVENTION COALITION

The Centers for Disease Control and Prevention (CDC) Coalition is a nonpartisan coalition of more than 140 organizations committed to strengthening our Nation's prevention programs. We represent millions of public health workers, clinicians, researchers, educators and citizens served by CDC programs.

We believe Congress should support CDC as an agency, not just the individual programs that it funds. Given the challenges and burdens of chronic disease and disability, public health emergencies, new and reemerging infectious diseases and other unmet public health needs, we urge a funding level of \$7.8 billion for CDC's programs in fiscal year 2015. We appreciate some of the important new investments in President Obama's fiscal year 2015 budget proposal including those for prescription drug overdose prevention, antimicrobial resistance and global health security; however, under the president's proposal, CDC's budget would be cut by nearly \$243 million compared to fiscal year 2014. CDC's budget authority under the president's budget is lower than fiscal year 2003 levels. State and local health departments continue to operate on tight budgets and with a smaller workforce, losing more than 50,000 public health jobs since 2008. These cuts will reduce the ability of CDC and its State and local grantees to investigate and respond to public health emergencies, ensure adequate immunization rates and track environmental hazards.

CDC is a key source of funding and technical assistance for State and local programs that aim to improve the health of communities. CDC funding provides the foundation for State and local public health departments, supporting a trained workforce, laboratory capacity and public health education communications systems. CDC serves as the command center for our Nation's public health defense system, conducting surveillance and detection of emerging and reemerging infectious diseases. With the potential onset of a worldwide influenza pandemic, in addition to the many other natural and man-made threats that exist in the modern world, CDC

is the Nation's expert resource and response center, coordinating communications and action and serving as the laboratory reference center for identifying, testing and characterizing potential agents of biological, chemical and radiological terrorism, emerging infectious diseases and other public health emergencies. CDC serves as the lead agency for bioterrorism and public health emergency preparedness and must receive sustained support for its preparedness programs to meet future challenges. We urge you to provide adequate funding for CDC's emergency preparedness and response activities.

Heart disease is the Nation's No. 1 killer. In 2010, over 597,000 people in the U.S. died from heart disease, accounting for nearly 25 percent of all U.S. deaths. More males than females died of heart disease in 2010, while more females than males died of stroke that year. Stroke is the fourth leading cause of death and is a leading cause of disability. In 2010, more than 129,000 people died of stroke, accounting for about one of every 19 deaths. CDC's Heart Disease and Stroke Prevention Program, WISEWOMAN, and the Million Hearts program work to improve cardiovascular health.

Cancer is the second most common cause of death in the U.S. More than 1.6 million new cancer cases and 585,720 deaths from cancer are expected in 2014. In 2009 the overall cost for cancer in the U.S. was more than \$216.6 billion: \$86.6 billion for direct medical costs, \$130 billion for indirect mortality costs. CDC's National Breast and Cervical Cancer Early Detection Program helps millions of low-income, uninsured and medically underserved women gain access to lifesaving breast and cervical cancer screenings and provides a gateway to treatment upon diagnosis. CDC also funds grants to all 50 States to develop comprehensive cancer control plans, bringing together a broad partnership of public and private stakeholders to set joint priorities and implement specific cancer prevention and control activities customized to address each State's particular needs.

An estimated 443,000 people die prematurely every year due to tobacco use. CDC's Office of Smoking and Health funds important programs and campaigns to prevent tobacco addiction and to help those who want to quit. We must continue to support these vital programs to reduce the enormous health and economic costs of tobacco use in the U.S.

Of the 25.8 million Americans who have diabetes, nearly 7 million cases are undiagnosed. In 2010, about 1.9 million people aged 20 years or older were newly diagnosed with diabetes. Diabetes is the leading cause of kidney failure, nontraumatic lower-limb amputations, and new cases of blindness among adults in the U.S. The total direct and indirect costs associated with diabetes were \$245 billion in 2012. The Division of Diabetes Translation funds critical diabetes prevention, surveillance and control programs.

Obesity prevalence in the U.S. remains high. While the obesity rates among children between the ages of 2-5 have significantly decreased over the past decade, more than one-third of adults are obese and 17 percent of children are obese. Obesity, diet and inactivity are cross-cutting risk factors that contribute significantly to heart disease, cancer, stroke and diabetes. CDC funds programs to encourage the consumption of fruits and vegetables, encourage sufficient exercise and develop other habits of healthy nutrition and physical activity.

Arthritis is the most common cause of disability in the U.S., striking more than 52 million Americans of all ages, races and ethnicities. CDC's Arthritis Program plays a critical role in addressing this growing public health crisis and working to improve the quality of life for individuals affected by arthritis.

CDC provides national leadership in helping control the HIV epidemic by working with community, State, national, and international partners in surveillance, research, prevention and evaluation activities. CDC estimates that about 1.1 million Americans are living with HIV, 16 percent of who are undiagnosed. The number of people living with HIV is increasing as new drug therapies are keeping HIV-infected persons healthy longer and dramatically reducing the death rate. Prevention of HIV transmission is the best defense against the AIDS epidemic that has already killed more than 636,000 in the U.S. and is devastating populations around the globe.

The U.S. has the highest rates of sexually transmitted diseases in the industrialized world. Nearly 20 million new infections occur each year. CDC estimates that STDs, including HIV, cost the U.S. healthcare system almost \$16 billion annually. An adequate investment in CDC's STD prevention programs could save millions in annual healthcare costs in the future.

The National Center for Health Statistics collects data on chronic disease prevalence, health disparities, emergency room use, teen pregnancy, infant mortality and causes of death. The health data collected through the Behavioral Risk Factor Surveillance System, Youth Risk Behavior Survey, Youth Tobacco Survey, National Vital Statistics System, and National Health and Nutrition Examination Survey are

an essential part of the Nation's statistical and public health infrastructure and must be adequately funded.

CDC oversees immunization programs for children, adolescents and adults, and is a global partner in the ongoing effort to eradicate polio worldwide. Influenza vaccination levels remain low for adults. Levels are substantially lower for pneumococcal vaccination among adults as well, with significant racial and ethnic disparities in vaccination levels persisting among the elderly. Childhood immunizations provide one of the best returns on investment of any public health program. For every dollar spent on childhood vaccines to prevent thirteen diseases, \$10.20 is saved in direct and indirect costs. An estimated 20 million cases of disease and 42,000 deaths are prevented each year through timely immunization.

Injuries are the leading causes of death for people ages 1–44. Unintentional injuries and violence, such as older adult falls, prescription drug overdose, child maltreatment and sexual violence, account for approximately 29 percent of emergency department visits each year. Annually, injury and violence cost the U.S. approximately \$406 billion in direct and indirect medical costs. The National Center for Injury Prevention and Control works to prevent injuries and minimize their consequences by researching the problem, identifying the risk and protective factors, developing and testing interventions and ensuring widespread adoption of proven prevention strategies.

Birth defects affect one in 33 babies and are a leading cause of infant death in the U.S. Children with birth defects who survive often experience lifelong physical and mental disabilities. Over 500,000 children are diagnosed with a developmental disability and more than 50 million people in the U.S. currently live with a disability. The National Center on Birth Defects and Developmental Disabilities conducts important programs to prevent birth defects and developmental disabilities and promote the health of people living with disabilities and blood disorders.

The National Center for Environmental Health works to protect public health by helping to control asthma, protecting from threats associated with natural disasters and climate change and reducing exposure to lead and other environmental hazards. To ensure it can carry out these vital programs, we ask you to support and restore adequate funding for NCEH.

In order to meet the many ongoing public health challenges outlined above, we urge you to support our fiscal year 2015 request of \$7.8 billion for CDC's programs.

[This statement was submitted by Donald Hoppert, Director, Government Relations, American Public Health Association.]

PREPARED STATEMENT OF THE CHILDREN'S ENVIRONMENTAL HEALTH NETWORK

The Children's Environmental Health Network (CEHN or the Network) is pleased to have this opportunity to submit testimony on fiscal year 2015 appropriations for the following programs and activities that safeguard the health and future of all of our children:

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

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

Today's children are facing the distressing possibility that they may be the first generation to see a shorter life expectancy than their parents due to poor health. Key contributors to this trend are the modern pediatric epidemics of obesity, asthma, learning disabilities, and autism. For all of these conditions, the child's environment plays a role in causing, contributing to or mitigating these chronic conditions.

The estimated costs of environmental disease in children (such as lead poisoning, childhood cancer, and asthma) were \$76.6 billion in 2008.¹

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

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

Centers for Disease Control and Prevention (CDC)

As the Nation's leader in public health promotion and disease prevention, the CDC should receive top priority in Federal funding. CDC continues to be faced with unprecedented challenges and responsibilities. CEHN applauds your support for CDC in past years and urges you to support a funding level of \$7.8 billion for CDC's core programs in fiscal year 2015.

The National Center for Environmental Health (NCEH) is particularly important in protecting the environmental health of young children. Current research is uncovering the extensive role that environment plays in human health and development. As a result, NCEH partners with public health agencies and a wide range of other organizations to bring their expertise and support to an expanding scope of environmental-human health challenges. NCEH's programs are key national assets. Yet in recent years, NCEH funding has been drastically cut. We urge the Subcommittee to at least restore NCEH to its fiscal year 2010 funding level of \$181.1 million.

We were deeply concerned with the fiscal year 2012 gutting of the Healthy Homes and Lead Poisoning Prevention Program and we commend you for the substantial increase the program received in fiscal year 2014. This program helps to prevent lead poisoning and helps children who have already been exposed to lead. Much more needs to be done just to return it to fiscal year 2011 levels. Millions of American children remain at risk of lead poisoning and need this program, which supports effective local and State efforts. As evidence increasingly demonstrates no safe level of lead exposure for children, this funding is all the more essential. We join with the National Safe and Healthy Housing Coalition to urge a funding level of \$29 million in fiscal year 2015.

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

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

National Institute of Environmental Health Science (NIEHS)

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

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

Children's Environmental Health Research Centers of Excellence

The Children's Environmental Health & Disease Prevention Research Centers, jointly funded by the NIEHS and the U.S. Environmental Protection Agency (EPA) and located at research institutions across the Nation, play a vital role in providing the scientific basis for protecting children from environmental hazards. With their modest budgets, these centers are generating invaluable research. For example, these centers conducted the recent research that found links between prenatal exposures to either a common air pollutant or a common pesticide to lower IQs and poorer working memory at age 7.

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

Pediatric Environmental Health Specialty Units

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

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

 PREPARED STATEMENT OF THE CHILDREN'S HOSPITAL ASSOCIATION

The Children's Hospital Association advances child health through innovation in the quality, cost and delivery of care. Representing more than 220 children's hospitals, the Association is the voice of children's hospitals nationally. As institutions dedicated to protecting and advancing the health of America's children, we thank the Subcommittee for its longstanding bipartisan support of the Children's Hospital Graduate Medical Education program (CHGME).

CHGME is an essential investment in our children's healthcare—in promoting prevention and primary care, expanding healthcare for vulnerable and underserved children, and ensuring access to care for all children. The Children's Hospitals Association urges the Subcommittee to protect this important program and provide \$300 million in funding for CHGME in fiscal year 2015.

The CHGME program protects children's access to high-quality medical care by providing independent children's hospitals with funding to support the training of pediatric providers, much as Medicare supports training in adult teaching hospitals. CHGME funding has had a tremendous impact, enabling children's hospitals to increase their overall training by more than 45 percent since the program began in 1999. In addition, the CHGME program has accounted for more than 74 percent of the growth in the number of new pediatric subspecialists being trained nationwide.

Today, the 55 hospitals that receive CHGME, less than 1 percent of all hospitals, train over 6,000 residents annually, and 49 percent of all pediatric residents in the country, including 45 percent of general pediatricians and 51 percent of pediatric specialists. CHGME benefits all children, supporting the training of doctors who go on to care for children living in every State—in cities, rural communities, suburbs and everywhere in between. Furthermore, CHGME is an example of a well-functioning public-private partnership; each of the participating children's hospitals invests significant resources into the success of their training programs along with the Federal dollars they receive.

Since the program's beginning, CHGME has enjoyed strong, bipartisan support in Congress, under both Republican and Democratic leadership. Congress created CHGME because it recognized that the absence of dedicated GME support for independent children's teaching hospitals created gaps in the training of pediatric pro-

viders, which potentially threatened access to care for children. At that time, independent children's hospitals were effectively left out of Federal GME support provided through Medicare because children's hospitals treat children and not the elderly, and received less than 0.5 percent of the GME support of other teaching hospitals.

CHGME has helped close the gap, but support for training of pediatric providers in children's hospitals still lags significantly behind Medicare support for graduate medical education. Analysis commissioned by the Children's Hospitals Association shows that in 2014 CHGME provides children's hospitals, on a per-resident basis, about 45 percent of the support Medicare provides to adult teaching hospitals.

Continued funding is essential to maintaining the gains that have been achieved under CHGME and strengthening the pediatric workforce pipeline. While much has been achieved, much remains to be done, as serious shortages persist in many pediatric specialties. The shortages affect children and their families' ability to receive timely, appropriate care, including surgery. Children's hospital clinics use a two-week benchmark when scheduling non-emergency appointments, but certain pediatric specialties experiencing physician shortages have wait times of 14.5 weeks or more, far exceeding the two-week standard.

Unfortunately, funding for the CHGME program has been significantly reduced in recent years, from \$317.5 million in fiscal year 2010 to \$265 million in 2014, a 17 percent reduction. These cuts hurt the ability of children's hospitals to train enough pediatricians and pediatric specialists to keep up with growing demand at local, State and national levels.

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

The White House's fiscal year 2015 budget proposes eliminating funding for CHGME and incorporating support for training at children's hospitals into a new competitive grant program under the Health Resources and Services Administration (the program would have to be created by Congress), funded from Medicare trust fund dollars, with \$100 million set aside specifically for children's hospitals in fiscal year 2015 and fiscal year 2016. While we recognize that the White House includes funding for training in children's hospitals in the budget, the administration's proposal continues to underfund pediatric training. Furthermore, children's hospitals have strong concerns that replacing the current system with competitive grants that are limited in duration puts at risk the gains that have been made for children's health under CHGME. Children's hospitals welcome the idea of engaging with the administration and Congress on ways to strengthen the pediatric workforce for the future. In the present, however, financial support for GME in children's hospitals needs to be uninterrupted and undiminished.

We recognize that the current budget climate is extraordinarily challenging and that Congress has a responsibility to carefully consider the Nation's spending priorities. However, now is not the time to take a step backwards in pediatric medicine. The CHGME program is critical to protecting gains in pediatric health and ensuring access to care for children nationwide.

We respectfully request that the Subcommittee continue its history of bipartisan support for the CHGME program and include \$300 million in funding in the fiscal year 2015 Labor-HHS appropriations bill for this vital program.

The Children's Hospital Association, and the children and families we serve, thank you for your past support for this critical program and your leadership in protecting children's health.

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

PREPARED STATEMENT OF THE COALITION FOR CLINICAL AND TRANSLATIONAL
SCIENCE

Chairman Harkin and distinguished members of the Subcommittee, thank you for your time and your consideration of the priorities of the clinical and translational research community as you work to craft the fiscal year 2015 Labor, Health and Human Services Appropriations Bill. The community would like to thank you for your past support of the full spectrum of medical research.

ABOUT THE COALITION FOR CLINICAL AND TRANSLATIONAL SCIENCE

Coalition for Clinical and Translational Science (CCTS) is the unified voice of the clinical and translational science research community. CCTS is a nationwide, grassroots network of dedicated individuals who work together to educate Congress and the Administration about the value and importance of Federal clinical and translational research and research training and career development activities. CCTS's goals are to ensure that the full spectrum of medical research is adequately funded, the next generation of researchers is well-prepared, and the regulatory and public policy environment facilitates ongoing expansion and advancement of the field of clinical and translational science.

Association for Clinical and Translational Science (ACTS)

ACTS supports investigations that continually improve team science, integrating multiple disciplines across the full translational science spectrum: from population based and policy research, through patient oriented and human subject clinical research, to basic discovery. Our goal is to improve the efficiency with which health needs inform research and new therapies reach the public.

ACTS is the academic home for the disciplines of research education, training, and career development for the full spectrum of translational scientists. Through meetings, publications, and collaborative efforts, ACTS will provide a forum for members to develop, implement, and evaluate the impact of research education programs.

ACTS provides a strong voice to advocate for translational science, clinical research, patient oriented research, and research education support. We will engage at the local, State, and Federal levels and coordinate efforts with other professional organizations.

ACTS will promote investigations and dissemination of effective models for mentoring future generations of translational scientists. Through collaborative efforts, ACTS will provide a forum for members to share studies, promote best practices, and optimize professional relationships among trainees and mentors.

The Clinical Research Forum (CRF)

CRF was formed in 1996 to discuss unique and complex challenges to clinical research in academic health centers. Over the past decade, it has convened leaders in clinical research annually and has provided a forum for discussing common issues and interests in the full spectrum of research. Through its activities, the Forum has enabled sharing of best clinical practices and increasingly has played a national advocacy role in support of the broader interests and needs of clinical research.

Governed by a Board of Directors constituted of clinical researchers from thirteen member institutions, CRF has grown to sixty members from academia, industry, and volunteer health organizations. CRF engages leaders in the clinical research enterprise including leaders from government, foundations, other not-for-profit organizations, and industry in addressing the challenges and opportunities facing the clinical research enterprise.

Parallel with our widening focus upon the broad needs of the entire national clinical research enterprise, CRF is committed to working in those areas where it is uniquely positioned to have a significant impact. Collaboration with other organizations with similar goals and synergizing with their efforts strengthens all approaches to the issues facing clinical research.

SEQUESTRATION

Thank you for providing sequestration relief in fiscal year 2014 and fiscal year 2015.

Federal medical research programs form the cornerstone of our Nation's biotech sector. In addition to undermining active and emerging research projects, across the board funding cuts create widespread disruption. Due to a number of factors, this disruption compounds significant challenges facing the clinical and translational research training and career development pipeline.

Recent years of near-level funding have curtailed NIH's ability to issue funding opportunities. As a result, the pay line at NIH has decreased substantially while the average age of an investigator receiving their first award has increased significantly. This dynamic creates a strong disincentive for young people to pursue a career in this field. Prior to sequestration, NIH would often discuss the decline in young investigators entering the research training and career development pipeline.

Beyond public health, our country needs to ensure that we are adequately preparing the next generation of medical investigators for reasons related to both the economy and national security. Last year, China announced a \$300 billion 5-year investment in medical research; this amount is double the current NIH budget over the same period of time. With strong competition from foreign countries, we run the risk of a researcher brain-drain from the U.S. to other Nations. Scientific breakthroughs and innovation will continue, but our loss in this area will mean gains for other Nations. Foreign economies will benefit from the significant return-on-investment that occurs through robust support of research.

Sequestration has the potential to severely exacerbate an already difficult task of recruiting and training the next generation of scientific investigators. In order to ensure that the U.S. maintains a strong research training and career development pipeline, please eliminate the threat of sequestration and further support key activities.

NATIONAL INSTITUTES OF HEALTH

This Nation has a proud history as a global leader in medical research and biotechnology. This leadership has provided our country with cutting-edge patient care, high-quality jobs, and meaningful economic growth. The Milliken Institute recently calculated that every dollar invested in NIH returns about a \$1.70 in economic output in the short term and as much as \$3.20 long-term. Crucially, through a robust external research program, NIH resources flow out to the States where the benefit of the funding infusion is felt on the local level.

NIH's impact on public health has been profound. Conditions once considered a death-sentence can now be managed, survival rates for patients with life-threatening diseases have increased dramatically, and additional innovative therapies and diagnostic tools come to market each year. NIH has been successful, but much more can be done. Please provide NIH with at least \$32 billion in fiscal year 2015 so ongoing research projects can be adequately supported and new research activities can be initiated.

Clinical and Translational Science Awards (CTSA)

NIH's CTSA Program, which is housed within the National Center for Advancing Translational Sciences (NCATS), is transforming the efficiency and effectiveness of clinical and translational research. Since its establishment with 13 centers, the CTSA program has expanded to 62 medical research institutions located across the country. These centers are linked together and work in concert to improve human health by energizing the research and training environment to innovate and enhance the quality of clinical and translational research.

Last year, the Institute of Medicine (IOM) released a review of the CTSA program. The report entitled, *The CTSA Program at NIH: Opportunities for Advancing Clinical and Translational Research*, spoke favorably of the CTSA effort and made the following recommendations to improve the program:

(1) Strengthen NCATS leadership of the CTSA program, (2) reconfigure and streamline the CTSA Consortium, (3) build on the strengths of individual CTSA across the spectrum of clinical and translational research, (4) formalize and standardize evaluation processes for individual CTSA and the CTSA Program, (5) advance innovation in education and training programs, (6) ensure community engagement in all phases of research, (7) strengthen clinical and translational research relevant to child health.

CCTS supports the recommendations of the IOM report and the organization is hopeful these changes will be implemented quickly. Further, when the CTSA program was authorized, Congress indicated that the consortium would be considered fully-funded when it received an annual appropriation of \$750 million. For fiscal year 2015, as part of an overall funding increase for NIH, please provide CTSA with at least \$500 million to ensure the program can continue to grow and advance. Additionally, we hope you will continue working over the coming years to provide CTSA with \$750 million to fully fund the program and establish a robust home for clinical and translational research.

Additional Programs

In recent years, Congress and NIH have made important investments to support the full spectrum of medical research. Key clinical and translational research programs at NIH include Research Centers at Minority Institutions (RCMI), Institutional Development Awards (IDeA), and the new Accelerating Medicine Partnership (AMP). Supporting the full spectrum of medical research encourages outcomes-oriented investigation where breakthroughs in basic science are translated to new diagnostic tools and treatments that improve health and lower healthcare expenses. In recognition of the future of the overall field of medical research, most individual NIH Institutes and Centers now provide some level of support for translational and clinical research activities.

In order to ensure that clinical and translational research programs at NIH have adequate support to facilitate ongoing growth, please provide \$32 billion for NIH in fiscal year 2015 with proportional increases for individual Institutes, Centers, and Offices.

FEDERAL RESEARCH TRAINING AND CAREER DEVELOPMENT PROGRAMS

As we discussed previously, the future of our Nation's biomedical research enterprise relies heavily on the maintenance and continued recruitment of promising young investigators. The "T" and "K" series awards at NIH and AHRQ provide much-needed support for the career development of young investigators. As clinical and translational medicine takes on increasing importance, there is a great need to grow these programs. Career development grants are crucial to the recruitment of promising young investigators, as well as to the continuing education of established investigators. Reduced commitment to the K and T awards would have a devastating impact on our pool of highly trained clinical researchers. CCTS urges you to support the ongoing commitment to research training through adequate funding for T and K series awards and a meaningful fiscal year 2015 funding increase for AHRQ.

Thank you for the opportunity to present the views and recommendations of the clinical and translational research and research training and career development community.

PREPARED STATEMENT OF THE COALITION FOR USHER SYNDROME RESEARCH

My name is Mark Dunning from the State of Massachusetts. As Chairman of the Coalition for Usher Syndrome Research, I am here on behalf of the Usher syndrome community to respectfully request this committee encourage NIH to prioritize research that will eventually expand treatment options for individuals suffering from the severe hearing and vision loss related to Usher syndrome. We also respectfully request that the committee direct NIH to move expeditiously to direct additional resources to respond to any deficiencies in the funding level or the manner in which various ICs coordinate on common goals and objectives related to Usher syndrome.

Usher syndrome is the leading cause of deaf-blindness. In the United States, it is estimated that about 45,000 people have this rare genetic disorder. My fifteen year old daughter Bella is one of them. She has Usher syndrome type 1b. She was born profoundly deaf and now she is losing her vision to retinitis pigmentosa. She also suffers from the severe balance issues common in her type of Usher syndrome.

Imagine yourself as a fifteen year old girl. Adulthood stands before you. You dream of getting your driver's license, of the freedom it provides, of the limits it removes. We live in a small town. There is no public transportation. A car is the only way to get to work, to visit friends, to shop for food. But Bella's vision is too poor for driving. How will she survive?

Or imagine yourself as a sophomore in high school. You dream of college, of the freedom it provides, of the limitless career opportunities. Only hard work and desire stand between you and your dreams. Unless, like Bella, you have Usher syndrome. Then you also face the barriers of access to information. You cannot hear the professor or see the board as well as your peers. You work many times harder to get the same grades. And some trades are closed to you before you start. Can you be an architect if you are losing your vision? Can you be a salesperson if you have no hearing? Can you dare to dream of an unfettered future? Is the American dream available to you if you have Usher syndrome?

My daughter is an asset to this country. She is kind and empathetic. She puts all others before herself. She is hard working and fearless. She has been honored with a John F. Kennedy award for leadership and a StayClassy award for philanthropy. She is the type of fifteen year old we should be grooming as a future leader in the country.

But Bella has Usher syndrome. She was born profoundly deaf and she is going blind. She will fight it every step of the way, but without increased Federal funding, she will eventually lose. And when Bella loses, we all lose. Kids like Bella are our future. Unless they have Usher syndrome. Then they are not, and we are all the worse for it.

People with Usher syndrome share the same range of intelligence and work ethic as any other slice of America. Yet they suffer from an 82 percent unemployment rate. People with Usher syndrome are born with the same emotional strength as any other American. Yet they have a suicide rate that is 2½ times greater than the general population. People with Usher syndrome not only have the capacity to contribute to America's future, they thirst for it. They want to be active members of society. Yet our country spends an estimated \$139 billion annually in direct and indirect costs for people with eye disorders and vision loss.¹ That doesn't even include the costs associated with hearing impairment.

In my role as the Chairman of the Coalition for Usher Syndrome Research, I have spoken with or met hundreds of people who are determined, focused, and working everyday to help themselves, their loved one, or in some cases complete strangers, figure out how to treat this syndrome. Usher genes are complex, long protein cells which require significant investment in research if we are ever to find a cure or treatment. We can't do it alone.

Through the Coalition, we have brought the Usher community and researchers together by:

- Establishing a registry of individuals with Usher syndrome which is available for research or clinical trials at no cost. Our registry currently has families from each of the 50 States and 29 countries.
- Sponsoring an International Symposium on Usher Syndrome at the Harvard Medical School in July 2014 to develop a roadmap for future research projects to bring us closer to viable clinical trials.
- Sponsoring annual family conferences, webinars and monthly conferences that provide information and support to all of those living with Usher.

With this in place, we have begun bringing brilliant researchers together who are working on developing treatments every day. Researchers like those in Oregon and Pennsylvania who are working on gene therapy treatments, one of which began clinical trials last year. Researchers in Louisiana, who have been able to rescue the hearing in mice with Usher syndrome using a drug therapy that holds promise for rescuing vision as well. Researchers in Iowa, California, Nebraska, Massachusetts, Florida, Texas, and many other States, who are collaborating with each other and with families through the Coalition to advance all kinds of Usher syndrome research.

But still this is not enough. We cannot help any of the tens of thousands who have Usher, or countless others that will be born in the future with this devastating genetic disorder without Federal support. There are dozens of different mutations that cause Usher syndrome, and the pace of research is slowed dramatically by the lack of researchers and funding. The infrastructure is there to find treatments, but the significant financial support is not. We are asking you to supply this last critical resource to help us find a cure.

When you review the report on categorical spending by the NIH, Usher syndrome is not even listed. Rare diseases with similar incident rates average around \$50 million annually. These investments have resulted in significant discoveries for these diseases and there is reason to believe that we can see these same results or better for Usher syndrome. We do not ask that the committee throw dollars at the problem. Only that they ensure the appropriate funding is available. The researchers are there, waiting to discover what now is just a dream. All we are asking for is a chance; a chance for deaf children and adults who are going blind, a chance to see. With your help, my daughter and others like her can once again dare to dream.

I will leave you with the words of America's most famous deaf-blind person, Helen Keller. "Alone we can do so little; together we can do so much." Only together can we find a way to end deaf-blindness. I thank you on behalf of all those with Usher syndrome, their families, and most importantly to me, my daughter Bella.

[This statement was submitted by Mark Dunning, Chairman, Coalition for Usher Syndrome Research.]

¹ Wittenborn, John S. & Rein, David B. "Cost of Vision Problems: The Economic Burden of Vision Loss and Eye Disorders in the United States." NORC at the University of Chicago. Prepared for Prevent Blindness America, Chicago, IL. June 11, 2013. <http://costofvision.preventblindness.org>.

PREPARED STATEMENT OF THE COALITION OF NORTHEASTERN GOVERNORS

The Coalition of Northeastern Governors (CONEG) is pleased to share with the Subcommittee on Labor, Health and Human Services, Education, and Related Agencies its views regarding the fiscal year 2015 appropriations for the Low-Income Home Energy Assistance Program (LIHEAP).

The CONEG Governors appreciate the Subcommittee's long-standing support for this vital program, and recognize the difficult fiscal decisions that face the Subcommittee. In recognition of the on-going challenges that the most vulnerable low-income households in our region face in heating their homes, the Governors urge the Subcommittee to fund the LIHEAP core block program in fiscal year 2015 at the authorized level of \$5.1 billion but not less than \$4.7 billion. In addition, the Governors request sufficient contingency funds to address unforeseen energy emergencies such as prolonged severe weather or price spikes in home heating fuels. Adequate, predictable and timely Federal funding is essential for LIHEAP to provide a vital lifeline to those households struggling to afford the basic necessity of home energy. The Governors urge the Subcommittee to provide these funds in a manner consistent with the LIHEAP statutory objective: "to assist low-income households, particularly those with the lowest incomes that pay a high proportion of household income for home energy, primarily in meeting their immediate home energy needs."

LIHEAP funds are targeted to those households with the greatest energy burden. Most LIHEAP assistance is targeted to households whose income is less than 150 percent of the Federal poverty level, which for a two-person household is \$23,595 in 2014. However the majority of LIHEAP recipients have incomes far below that level. Many of these households live on fixed incomes and are not likely to benefit from improvements in the job market and the national economy. More than ninety percent of LIHEAP households have at least one vulnerable member—the elderly or disabled and young children—for whom temperature extremes could have serious health and safety consequences. Approximately 20 percent of LIHEAP households contain at least one member who is a military veteran.

Low-income households across the Nation spend a disproportionate amount of their income on home energy, often over three times more than non-low-income households. The AARP estimates low-income senior households (age 65 and older) heating with fuel oil will spend almost 20 percent of household income on heating costs, while all other households heating with fuel oil will spend roughly 5 percent of their income to heat their homes. In the colder climates of the Northeast, the average household typically uses 800 gallons of heating oil per winter. At EIA's projected average cost of \$3.83 per gallon, an elderly LIHEAP recipient whose primary income is a Social Security check would need to spend almost 3 months of income to heat her home this winter. Many seniors will spend more than one-third of their monthly income just to get the minimum 100-gallon delivery of heating oil.

The energy burden faced by low-income households is particularly acute in the Northeast. This region experiences some of the Nation's highest home heating bills due to a combination of the extended winter heating season and heating fuel expenditures that typically exceed national averages. According to the Energy Information Administration (EIA), the average consumer expenditures for heating fuels in the Northeast have consistently and significantly exceeded similar expenditures in all other regions regardless of the type of fuel used—natural gas, heating oil, propane, or electricity.

Low-income households in the Northeast experience another aspect of "energy burden". More than any other region of the country, Northeast households are dependent upon delivered fuels—heating oil, propane and kerosene. The 30 percent of Northeast households that rely upon delivered fuels account for approximately 80 percent of the homes nationwide that use home heating oil. These heating fuels are also the most expensive and volatile in price. The EIA estimates that households using heating oil can expect to pay \$2,243 to keep warm this winter. The EIA also finds that households using delivered fuels see any change in wholesale prices reflected in their energy bills almost immediately, unlike natural gas and electricity retail customers. These "delivered fuel" households experience another vulnerability compared to natural gas and electricity customers. Low-income households that use delivered fuels are less likely to have the option of payment plans, access to utility assistance programs, and the protection of utility service shut-off moratoria during the heating season. If LIHEAP funds are not available to these households, the fuel delivery truck simply does not come.

The Northeast has some of the country's oldest homes and coldest climates. Reducing home energy costs presents unique challenges to northeast states. State LIHEAP programs, often working with their Weatherization Assistance Programs,

help low-income households take steps to reduce their energy use and lower their energy bills. Unlike the Federal weatherization program, LIHEAP funds can be used to provide repair or replace inefficient, unsafe and non-working home heating systems—improvements that enhance the safety and reduce the energy use of low-income households.

Even with these programs to reduce energy use, many of the lowest income families that benefit from LIHEAP have limited options to reduce their energy bills. Some older homes, especially older manufactured homes, have structural issues that make them ineligible for weatherization assistance. Throughout the region, many LIHEAP households have limited ability to switch to more energy efficient heating systems due to the lack of adequate resources for the upfront costs and the lack of access to less expensive heating fuels. For example, natural gas may provide a less expensive energy source to heat homes, but conversion is neither simple nor affordable for low-income households. The New England Fuel Institute estimates that converting a complete home heating system from oil to natural gas can cost as much as \$10,000. In addition, homes in rural and metropolitan areas throughout the Northeast are not served by natural gas infrastructure.

State LIHEAP programs continue to seek innovative and efficient ways to “do more with less” and stretch scarce LIHEAP dollars to ensure that meaningful assistance can be provided to those households with the greatest needs. For example, LIHEAP funds are frequently leveraged by utility assistance programs for low-income households. States in the Northeast have worked with utilities to develop payment plans to reduce arrearages and lessen the prospect of utility shut-offs after the heating season ends. They have negotiated with fuel dealers to receive discounts on deliverable fuels, and have entered into agreements to purchase fuel in the summer when prices are lowest. LIHEAP is one of the most efficiently run programs with low overhead costs. Even after taking significant cost-cutting steps, States have had to take actions such as tightening program eligibility, closing the program early, and reducing benefit levels.

In summary, the CONEG Governors appreciate the Subcommittee’s continued support for LIHEAP, and urge you to fund the core block grant at the authorized level of \$5.1 billion, but not less than \$4.7 billion, and sufficient contingency funds to address unforeseen energy emergencies.

PREPARED STATEMENT OF THE COLLEGE ON PROBLEMS OF DRUG DEPENDENCE

Mr. Chairman and Members of the Subcommittee, thank you for the opportunity to submit testimony to the Subcommittee in support of the National Institute on Drug Abuse. The College on Problems of Drug Dependence (CPDD), a membership organization with over 1000 members, has been in existence since 1929. It is the longest standing group in the United States addressing problems of drug dependence and abuse. The organization serves as an interface among governmental, industrial and academic communities maintaining liaisons with regulatory and research agencies as well as educational, treatment, and prevention facilities in the drug abuse field. CPDD also often works in collaboration with the World Health Organization.

Recognizing that so many health research issues are inter-related, we request that the subcommittee provide at least \$32 billion for the National Institutes of Health (NIH) and within that amount a proportionate increase for the National Institute on Drug Abuse, in your Fiscal 2015 Labor, Health and Human Services, Education and Related Agencies Appropriations bill. We also respectfully request the inclusion of the following NIDA specific report language.

Marijuana Research. Efforts to legalize or “medicalize” marijuana continue across the United States. The Committee understands that research from different areas of science is converging on the fact that regular marijuana use by young people can have a long-lasting negative impact on the structure and function of their brains, resulting in lower educational achievement, reduced IQ, etc. Research clearly demonstrates that marijuana has the potential to cause problems in daily life or make a person’s existing problems worse. NIDA is encouraged to continue to fund research on preventing and treating marijuana abuse and addiction, and the possible health and policy implications of proposals to implement “medical marijuana” or marijuana legalization programs across the U.S.

Opiate Abuse and Addiction. The Committee is concerned about the continued crisis of prescription drug abuse in the U.S. In particular, the June 2011 IOM report on pain indicates that abuse and misuse of prescription opioid drugs resulted in an annual estimated cost to the Nation of \$72,500,000,000. Further, the Committee is very concerned with the potential rise in heroin abuse and addiction as a result of

successful efforts to combat the prescription drug side of this issue. The Committee urges NIDA to 1) continue funding research on medications to alleviate pain, including the development of pain medications with reduced abuse liability; 2) as appropriate, work with private companies to fund innovative research into such medications; and 3) report on what we know regarding the transition from opiate analgesics to heroin abuse and addiction within affected populations.

Medications Development. The Committee recognizes that next-generation pharmaceuticals will surely take advantage of new technologies. In the context of NIDA funding, chief among these are NIDA's current approaches to develop viable immunotherapeutic or biologic (e.g., bioengineered enzymes) approaches for treating addiction. The goal of this active area of research is the development of safe and effective vaccines or antibodies that target specific drugs, like nicotine, cocaine, and heroin, or drug combinations. The Committee is excited by this approach—if successful, immunotherapies, alone or in combination with other medications, behavioral treatments, or enzymatic approaches, stand to revolutionize how we treat, and, maybe even someday, prevent addiction. The Committee looks forward to hearing more about work in this area.

Nurturing Talent and Innovation in Research. The Committee commends NIDA for its continued support of innovative research on drug addiction and related health problems such as pain and HIV/AIDS, and the Institute's effort to be at the forefront of training the next generation of innovative researchers. The 6 year-old Avant-Garde award is a good example of a program that stimulates high-impact research that could lead to groundbreaking opportunities for the prevention and treatment of HIV/AIDS in drug abusers. The Committee understands that NIDA is now crafting a new kind of award, which would blend NIH's Pioneer and New Innovator award mechanisms. This new opportunity, called "AVENIR" awards, is designed to attract creative young investigators into HIV/drug abuse public health research. The Committee strongly supports this effort, and asks the Institute to report on its progress in future appropriations and related requests.

Research to Assist Military Personnel, Veterans, and Their Families. The Committee recognizes the significant health challenges, including substance abuse and addiction, faced by military personnel, veterans, and their families. Many of these individuals need help confronting war-related problems including traumatic brain injury, PTSD, depression, anxiety, sleep disturbances, and substance abuse and addiction. The Committee commends NIDA for its successful efforts to coordinate and support research with the Department of Veterans Affairs, Department of Defense, and other NIH Institutes focusing on these populations, and strongly urges NIDA to continue work in this area.

Raising Awareness and Engaging the Medical Community in Drug Abuse and Addiction Prevention and Treatment. The Committee is very pleased with NIDAMed, an initiative designed to reach out to physicians, physicians in training, and other healthcare professionals. The Committee urges the Institute to continue its focus on activities to provide physicians and other medical professionals with the tools and skills needed to incorporate drug abuse screening and treatment into their clinical practices.

Drug abuse is costly to Americans; it ruins lives, while tearing at the fabric of our society and taking a huge financial toll on our resources. Beyond the unacceptably high rates of morbidity and mortality, drug abuse is often implicated in family disintegration, loss of employment, failure in school, domestic violence, child abuse, and other crimes. Placing dollar figures on the problem; smoking, alcohol and illegal drug use results in an exorbitant economic cost on our Nation, estimated at over \$600 billion annually. We know that many of these problems can be prevented entirely, and that the longer we can delay initiation of any use, the more successfully we mitigate future morbidity, mortality and economic burdens.

Over the past three decades, NIDA-supported research has revolutionized our understanding of addiction as a chronic, often-relapsing brain disease —this new knowledge has helped to correctly situate drug addiction as a serious public health issue that demands strategic solutions. By supporting research that reveals how drugs affect the brain and behavior and how multiple factors influence drug abuse and its consequences, scholars supported by NIDA continue to advance effective strategies to prevent people from ever using drugs and to treat them when they cannot stop.

NIDA supports a comprehensive research portfolio that spans the continuum of basic neuroscience, behavior and genetics research through medications development and applied health services research and epidemiology. While supporting research on the positive effects of evidence-based prevention and treatment approaches, NIDA also recognizes the need to keep pace with emerging problems. We have seen encouraging trends—significant declines in a wide array of youth drug

use—over the past several years that we think are due, at least in part, to NIDA's public education and awareness efforts. However, areas of significant concern include the recent increase in lethalties due to heroine, as well as the continued abuse of prescription opioids and the recent increase in designer drugs availability and their deleterious effects. The need to increase our knowledge about the effects of marijuana is most important now that decisions are being made about its approval for medical use and/or its legalization. We support NIDA in its efforts to find successful approaches to these difficult problems.

The Nation's previous investment in scientific research to further understand the effects of abused drugs on the body has increased our ability to prevent and treat addiction. As with other diseases, much more needs be done to improve prevention and treatment of these dangerous and costly diseases. Our knowledge of how drugs work in the brain, their health consequences, how to treat people already addicted, and what constitutes effective prevention strategies has increased dramatically due to support of this research. However, since the number of individuals continuing to be affected is still rising, we need to continue the work until this disease is both prevented and eliminated from society.

We understand that the fiscal year 2015 budget cycle will involve setting priorities and accepting compromise, however, in the current climate we believe a focus on substance abuse and addiction, which according to the World Health Organization account for nearly 20 percent of disabilities among 15–44 year olds, deserves to be prioritized accordingly. We look forward to working with you to make this a reality. Thank you for your support for the National Institute on Drug Abuse.

PREPARED STATEMENT OF THE CONSORTIUM OF SOCIAL SCIENCE ASSOCIATIONS

Mr. Chairman and Members of the Subcommittee, the Consortium of Social Science Associations (COSSA) appreciates and welcomes the opportunity to comment on the fiscal year 2015 appropriations for the National Institutes of Health (NIH), Centers for Disease Control and Prevention (CDC) and the Agency for Healthcare Research and Quality (AHRQ). COSSA joins the Ad Hoc Group for Medical Research in recommending that NIH receive at least \$32 billion in fiscal year 2015 as the next step toward a multi-year increase in our Nation's investment in medical research. As a member of the CDC Coalition, COSSA requests \$7.8 billion in funding for the CDC in fiscal year 2015. We join the Friends of AHRQ in requesting a funding level of \$375 million for AHRQ in fiscal year 2015.

COSSA is an advocacy group for the social and behavioral sciences supported by more than 100 professional associations, scientific societies, universities and research centers. It serves as a bridge between the academic research and Washington policy-making community. Our organizations are appreciative of the Subcommittee's and the Congress' continued support of NIH, CDC, and AHRQ. Strong, sustained funding for these agencies is essential to the national priorities of better health and economic revitalization.

NIH BEHAVIORAL AND SOCIAL SCIENCES RESEARCH

As this Committee knows, the NIH mission is to support scientifically rigorous, peer/merit-reviewed, investigator-initiated research, including basic and applied behavioral and social science research in fulfilling its mission: "Science in pursuit of fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life and reduce illness and disability."

The fundamental understanding of how disease works, including the impact of social environment on these disease processes, underpins our ability to conquer devastating illnesses. Perhaps the grandest challenge we face is to understand the brain, behavior, and society— from responding to short-term pleasures to self-destructive behavior, such as addiction, to lifestyle factors that determine the quality of life, infant mortality rate and longevity. And while Americans have achieved very high levels of health over the past century and are healthier than people in many other Nations, according to the 2013 National Academies' (NAS) report, U.S. Health in International Perspective: Shorter Lives, Poorer Health, "a growing body of research suggests that the health of the U.S. population is not keeping pace with the health of people in other economically advanced, high-income countries."

Nearly 125 million Americans are living with one or more chronic conditions, including heart disease, cancer, diabetes, kidney disease, arthritis, asthma, mental illness and Alzheimer's disease. At the same time, healthcare spending in the United States is being driven up by the aging of the U.S. population and the rapid rise in chronic diseases, many of which are caused or exacerbated by behavioral factors—

including, obesity, caused by sedentary behavior and poor diet, and addictions resulting from health problems caused by tobacco and other drug use. As the NAS report notes, “the United States is losing ground in the control of diseases, injuries, and other sources of morbidity.”

The behavioral and social sciences regularly make important contributions to the well-being of this Nation. Due in large part to the behavioral and social science research sponsored by the NIH, we are now aware of the enormous role behavior plays in our health. At a time when genetic control over disease is tantalizingly close but not yet possible, knowledge of the behavioral influences on health is a crucial component in the Nation’s battles against the leading causes of morbidity and mortality: obesity, heart disease, cancer, AIDS, diabetes, age-related illnesses, accidents, substance abuse, and mental illness.

As a result of the strong Congressional commitment to the NIH in years past, our knowledge of the social and behavioral factors surrounding chronic disease health outcomes is steadily increasing. The NIH’s behavioral and social science portfolio has emphasized the development of effective and sustainable interventions and prevention programs targeting those very illnesses that are the greatest threats to our health, but the work is just beginning. This includes NIH’s support of economic research, specifically, research on the linkages between socioeconomic status and health outcomes in the elderly and achievement and health outcomes in children. This research has been an integral part of the interdisciplinary science NIH has historically supported. Accordingly, the agency’s investment has yielded key data, methodologies and substantive insights on some of the most important and pressing issues facing the U.S. For example, NIH-funded surveys such as the Health and Retirement Survey, the Panel Study of Income Dynamics (PSID), parts of the National Longitudinal Survey of Labor Market Experiences, and surveys on international aging and retirement provide data necessary to monitor and detect changes in important socioeconomic trends in health. This in turn allows NIH to support research that will provide the greatest return on its investment when it comes to the health of our citizens.

CDC BEHAVIORAL AND SOCIAL SCIENCE RESEARCH

As the country’s leading health protection and surveillance agency, the Centers for Disease Control and Prevention (CDC) works with State, local, and international partners to protect Americans from infectious diseases; prevent the leading causes of disease, disability, and death; protect Americans from natural and bioterrorism threats; monitor health and ensure laboratory excellence; keep Americans safe from environmental and work-related hazard; and ensure global disease protection.

Social and behavioral science research plays a crucial role in helping the CDC carry out its mission. Scientists in fields ranging from psychology, sociology, anthropology, and geography to health communications, social work, and demography work in every CDC Center to design, analyze, and evaluate behavioral surveillance systems, public health interventions, and health promotion and communication programs using a variety of both quantitative and qualitative methods. These scientists play a key role in the CDC’s surveillance and monitoring efforts, which collect and analyze data to better target public health prevention efforts. Another vital contribution of the social and behavioral sciences to CDC activities is in identifying and understanding health disparities. Finally, the social and behavioral sciences play an important role in the evaluation of CDC programs, helping policymakers make informed, evidence-based decisions on how to prioritize in a resource-scarce environment.

The CDC is also the home of the Nation’s principal health statistics agency, the National Center for Health Statistics (NCHS). NCHS collects data on chronic disease prevalence, healthcare disparities, emergency room use, teen pregnancy, infant mortality, causes of death and rates of insurance, to name a few. It provides critical data on all aspects of our healthcare system through data cooperatives and surveys that serve as the gold standard for data collection around the world. Data from NCHS surveys like the National Health Interview Survey (NHIS), the National Health and Nutrition Examination Survey (NHANES) and the National Vital Statistics System (NVSS) are used by agencies across the Federal Government, State and local governments, public health officials, Federal policymakers, and demographers, epidemiologists, health services researchers, and other scientists.

AHRQ HEALTH SERVICES RESEARCH

AHRQ’s sole purpose is to improve healthcare in America. Just as biomedical research helps us find cures for disease, the health services research AHRQ supports helps find ways to cure our healthcare system—improving its quality, safety, and

efficiency for the benefit of patients. AHRQ's research identifies what works and what doesn't in healthcare to improve patient care and provide policymakers and other healthcare leaders with the information needed to make critical healthcare decisions.

AHRQ helps providers help patients. AHRQ's research generates valuable evidence to help providers help patients make the right healthcare decisions for themselves and their loved ones. The science funded by AHRQ ensures patients receive high quality, appropriate care every time they walk through the hospital, clinic, and medical office doors. AHRQ's research provides the basis for protocols that prevent medical errors and reduce healthcare-associated infections (HAIs), and improve patient experiences and outcomes. AHRQ helps healthcare providers—from private practice physicians to large hospital systems—understand how to deliver the best care most efficiently. The breadth of evidence available from AHRQ empowers healthcare providers to understand not just how they compare to their peers, but also how to improve their performance to be more competitive.

COSSA expects this testimony to be only the beginning of an ongoing conversation between the Subcommittee and stakeholders on the fiscal year 2015 funding needs of these agencies.

We would be pleased to provide any additional information.

PREPARED STATEMENT OF THE CORPORATION FOR PUBLIC BROADCASTING

Chairman Harkin and distinguished members of the subcommittee, thank you for allowing me to submit this testimony on behalf of America's public media service—public television and public radio—on-air, online and in the community. The Corporation for Public Broadcasting (CPB) requests level funding of \$445 million for fiscal year 2017 and \$27.3 million for the Department of Education's Ready To Learn program in fiscal year 2015.

Forty-six years after passage of the Public Broadcasting Act, this uniquely American public-private partnership is keeping its promise to the American people by providing a safe place where children can learn on-air and online; providing high-quality educational content for teachers in the classroom and children schooled at home; providing reliable and trusted news and information; and providing emergency alert services. Either by looking at each station individually or public media as a whole, this public-private partnership is making a big difference in the lives of individuals and communities.

Today we are a system that comprises more than 1,400 locally owned and locally operated public radio and television stations serving rural and urban communities throughout the country. More than 98 percent of the American people turn to American public media for high quality content that educates, informs, inspires and entertains. Public media's commitment to early and lifelong learning, available to all citizens, helps strengthen our civil society and our democracy. Our trusted, non-commercial services available for free to all Americans is especially important to those living in rural communities where the local public media station is sometimes the only source of broadcast news, information and educational programming.

I understand that this committee is faced with the challenging task of allocating scarce Federal resources to a number of organizations, all doing worthy and important work. The financial support for the public broadcasting system that is derived from the Federal appropriation is the essential investment keeping public media free and commercial free for all Americans. Former President Ronald Reagan said, "Government should provide the spark and the private sector should do the rest." And what stations do, with the spark of Federal dollars that amounts to approximately 10 to 15 percent of a stations' budget, results in a uniquely entrepreneurial and American public media system with a track record of proven benefits delivered through stations to the American people.

The Federal investment through CPB is the foundation on which the entire system is built. These critical funds leverage vital investments from other sources. Undermining this foundation would put the entire structure in jeopardy. While private donations and existing funding sources can help defray considerable costs for the much-honored programs of public television and radio—nonFederal funding represents five of every six dollars invested annually in public broadcasting—the Federal investment is indispensable to sustaining the operations of public broadcasting stations, the public service mission they pursue, local community-based accountability, and the universal service to which the Public Broadcasting Act aspires.

Further, it is this initial investment in public media that keeps it commercial free and available to all Americans for free. However, smaller stations serving rural, mi-

nority and other underserved communities are hard pressed to raise six times the Federal appropriation, which can represent as much as 40 percent of their budget.

Public media's contribution to education—from early childhood through adult learning—is well documented. We are America's largest classroom, with proven content available to all children, including those who cannot afford preschool. Our content is repeatedly regarded as “most trusted” by parents, caregivers and teachers.

CPB's work with the Department of Education's Ready To Learn program is an excellent example of how public media brings together high-quality educational content with on-the-ground work in local communities. We also invest in research that demonstrates and promotes the effectiveness of this content in formal and informal educational settings.

We talk a lot about content that matters and engagement that counts, further defining public media from commercial media. An example of this is CPB's “American Graduate: Let's Make it Happen” Initiative, which tells the story behind the statistic of one million American young people failing to graduate every year from high school. Our stations told the stories and communities throughout the country responded. More than 75 public media stations located in 33 States with at-risk communities are working with more than 1000 national and community-based partners to bring together diverse stakeholders and community organizations; filling gaps in information, resources and solutions; sharing best practices for teacher training and student engagement; creating local programming around the dropout issue unique to their communities, and leveraging digital media and technology to engage students in an effort to keep them on the path to graduation. Those numbers are now declining because what our stations do, counts. But American Graduate is just one example of how public media stations are using their spectrum for the public good.

Building on our education commitment, CPB recently announced that it will expand on these successful models to bring meaningful impact and change to more communities at risk. Through the recently created \$20 million American Graduate/PBS KIDS Fund, CPB and PBS will invest in the development of new tools to help parents better prepare their children ages 2–8 for educational success, to support teacher development, and to engage middle and high school youth to improve learning.

Public media is utilizing today's technology to provide content of value to millions of citizens who trust us to deliver content that matters and is relevant to their lives today. CPB strategically focuses investments through the lens of what we refer to as the “Three D's” —Digital, Diversity and Dialogue. This refers to support for innovation on digital platforms, extending public media's reach and service over multiple platforms; content that is for, by and about Americans of all backgrounds; and services that foster dialogue between the American people and the public service media organizations that serve them. CPB funding enables stations to provide content of consequence and to keep faith with the visions of political, educational, philanthropic and community leaders who have seen in public broadcasting the potential to strengthen our nation by promoting lifelong learning and an informed citizenry.

As the steward of these important taxpayer dollars, CPB ensures that 95 cents of every dollar received goes to support local stations and the programs and services they offer to their communities; no more than five cents of every dollar goes to the administration of funding programs and overhead.

The Public Broadcasting Act ensures diversity in this programming by requiring CPB to fund independent and minority producers. CPB fulfills this obligation, in part, by funding the Independent Television Service, the five Minority Consortia entities in television (African American, Latino, Asian American, Native American and Pacific Islander), several public radio consortia (Latino Public Radio Consortia, African American Public Radio Stations, and Native Public Media) and numerous minority public radio stations. In addition, CPB, through its Diversity and Innovation fund, makes direct investments in the development of diverse primetime and children's broadcast programs as well as innovative digital content.

As newspapers across the country have scaled back their operations, public media has stepped into the void. Local stations have been working to fill the gap with creative ventures and partnerships, such as our seven multimedia local journalism centers (LJCs) that are providing their communities with much-needed local, regional and statewide coverage.

For an investment of approximately \$1.35 per American per year, public media stations are able to train teachers and help educate America's children; provide in-depth journalism that informs citizens about issues in their neighborhoods, their country, and around the globe; make the arts accessible to all Americans; and provide emergency alert services for their communities.

CPB's fiscal year 2017 request of \$445 million balances the fiscal reality facing our nation with our statutory mandate to provide a valuable and trusted service to

all Americans. Today, the challenges we face are more complex than ever and require new levels of thinking, innovation, and collaboration. Community organizations often work in isolation, shouldering the burden of solving societal problems. But public media is the essential link, uniquely poised to add real value. CPB's fiscal year 2017 request will allow stations to enhance their role as a trusted source of information and as a convener, help communities understand issues, and mobilize them toward positive, sustainable outcomes.

Mr. Chairman and members of the subcommittee, this is only part of the story of our public media system in America. Public media is a national treasure that is available and accessible to all Americans. Every day public media works to strengthen and advance our civil society. I thank you for allowing me to submit this testimony and urge you to consider our request for funding.

[This statement was submitted by Patricia Harrison, President and CEO, Corporation for Public Broadcasting.]

PREPARED STATEMENT OF COUNCIL OF ACADEMIC FAMILY MEDICINE

We urge the Committee to appropriate at least \$71 million for the health professions program, Primary Care Training and Enhancement, authorized under Title VII, Section 747 of the Public Health Service Act, under the jurisdiction of the Health Resources and Services Administration (HRSA.) In addition, we recommend the Committee fund the Agency for Healthcare Research and Quality (AHRQ) at no less than \$375 million in base discretionary funding to support research vital to primary care.

The member organizations of the Council of Academic Family Medicine (CAFM) are pleased to submit testimony on behalf of programs under the jurisdiction of the Health Resources and Services Administration (HRSA) and the Agency for Healthcare Research and Quality (AHRQ). The programs we support in our testimony are ones that deliver an investment in our Nation's workforce and health infrastructure. They are a down payment on a U.S. healthcare system with a foundation of primary care that will produce better health outcomes and reduce the ever rising costs of healthcare. We understand that hard decisions must be made in these difficult fiscal times, but even in this climate, we hope the Committee will recognize that the production of a robust primary care workforce for the future is a necessary investment that cannot wait and will ultimately produce long term savings.

Primary Care Training and Enhancement

The Primary Care Training and Enhancement Program (Title VII, Section 747 of the Public Health Service Act) has a long history of providing indispensable funding for the training of primary care physicians. With each successive reauthorization, Congress has modified the Title VII health professions programs to address relevant workforce needs. The most recent authorization directs the Health Resources and Services Administration (HRSA) to prioritize training in the new competencies relevant to providing care in the patient-centered medical home model. It also calls for the development of infrastructure within primary care departments for the improvement of clinical care and research critical to primary care delivery, as well as innovations in team management of chronic disease, integrated models of care, and transitioning between healthcare settings. Departments of family medicine and family medicine residency programs often rely on Title VII, Section 747, grants to help develop curricula and research training methods for transforming practice delivery.

There has not been a competitive cycle for these grants since fiscal year 2010. There are currently over 200 grants, completing their cycle in fiscal year 2014 who will be eligible to apply in fiscal year 2015, as well as numerous other potential applicants who did not receive funding in fiscal year 2010. The current funding level (approximately \$36.9 million) is not enough to allow for the pent up demand. More importantly, the vital work of these grants to help reform primary care education and the health delivery system needs to be prioritized.

As implementation of the Affordable Care Act proceeds with increasing numbers of insured persons, the Nation will need new initiatives relating to increased training in inter-professional care, the patient-centered medical home, and other new competencies required in our developing health system. Such initiatives will be impossible to implement without a competitive grant cycle with enough funding to allow for a robust result of new grants. Now is the time to ensure that critical funding for the Primary Care Training and Enhancement program takes place. Title VII has a profound impact on States across the country and is vital to the continued development of a workforce designed to care for the most vulnerable populations

and meet the needs of the 21st century. We cannot allow the primary care pipeline to dry up.

Below are some examples of how these grants have made lasting contributions:

“With funding from a Title VII Medical Student Education grant, we were able to expand our existing medical student family medicine clerkship clinic to include students from pharmacy, nursing, occupational and physical therapy, and law, who see patients together under the supervision of faculty from all disciplines. This has allowed us to create one of the few truly interprofessional clinical experiences.” Joshua Freeman, MD, Chair, Department of Family Medicine, University of Kansas School of Medicine

“Our AAU HRSA Title VII Grant has allowed us to transform the education of medical students and residents at Brown University around the patient centered medical home, including new curricula and rotations, as well as the facilitation work to transform 10 family medicine teaching practices. In addition, we have run 3 national “think tanks” to discuss practical and theoretical issues related to models for practice transformation, PCMH evaluation, and the Adolescent PCMH. This grant has had huge impact and the work could not have been done without it. Jeffrey Borkan, MD, PhD, Chair, Department of Family Medicine, Brown University

“Previous grants included starting a resident continuity clinic at an FQHC, and preparation for rural training (rural continuity clinic, curriculum, rural mentoring program, rural medicine interest group). More distant grants help set up rural training sites for medical students and residents in 1975 and 1980, both of which are still providing that important function. Steven C. Zweig, MD, MSPH, Chair, Department of Family Medicine, University of Missouri”

“We have used HRSA funding to transform our curriculum and our Family Medicine Center using the principles of PCMH. We have partnered with a local income based elderly housing complex to provide clinical services on-site. We have partnered with a community senior center to provide on-site instruction to elderly community dwelling individuals. We have added instruction in quality and safety throughout the residency and using the PDSA cycle we improve care in asthma, asthma, and hypertension as well as our preventive care. As a consequence we have put ourselves in a position to become NCQA Level 3 certified by December 31.” In addition, we were able to partner with the local FQHCs and create a longitudinal patient care track in the first 2 years of medical school. Beginning October of the first year, the students are placed in a primary care (and most in an underserved) site on an ongoing, monthly basis. They are given the skills to be a member of the care team and participate in all aspects of patient care.” Allen Perkins, MD, Professor and Chair, Department of Family Medicine, University of South Alabama College of Medicine

“Title VII funding has allowed our residency site to implement an interprofessional team-based care curriculum as part of our patient-centered medical home transformation. Residents work with nurses, social workers, nurse midwives, community health workers, nutritionists and certified diabetes educators and learn about optimal team communication and care for their patients through participation in several group visit programs (centering pregnancy, well baby visits and diabetes group visits). Their learning is also supplemented by a longitudinal video feedback to improve doctor-patient communication, which includes 360 degree feedback and preceptor training.” Michelle Roett, MD, MPH, FAAFP, Residency Program Director, Georgetown University-Providence Hospital FMR, in Colmar Manor, MD

Agency for Health Care Research and Quality (AHRQ)

Two years ago, we were disappointed to see the subcommittee eliminate funding for AHRQ in its draft bill. We understand that in our current budgetary climate it is important to leverage research funding in the most effective ways possible. However, the majority of research funding supports research of one specific disease, organ system, cellular, or chemical process—not for primary care. This is in spite of the fact that the overall health of a population is directly linked to the strength of its primary healthcare system. Primary care research includes: translating science into the practice of medicine and caring for patients, understanding how to better organize healthcare to meet patient and population needs, evaluating innovations to provide the best healthcare to patients, and engaging patients, communities, and practices to improve health. AHRQ is uniquely positioned to support this sort of best practice research and to help advance its dissemination to improve primary care nationwide.

There are six areas that we believe AHRQ excels at—and that are not available elsewhere in the biomedical research infrastructure: primary care research through Practice-based Research Networks (PBRNs), practice transformation, patient quality

and safety in non-hospital settings, multi-morbidity research, mental and behavioral health provision in communities and primary care practices, and training future primary care investigators. Critical to the successful engagement and development of primary care research is the constraint of not having an adequate cadre of well-trained researchers. We believe there is a need to deliberately promote this training as a way to aid in the development of all the areas we have emphasized. AHRQ has researcher training mechanisms in place, which we believe are important, and need to be expanded.

Some examples from the field regarding the utility of AHRQ-funded grants:

“Three AHRQ grants supported the development of patient centered personal health records in 2007, 2009, and 2010, and studied whether these tools increased prevention. In our studies we found increases in important tests like colon and breast cancer screening as well as immunizations, blood pressure and cholesterol control. In addition, we were able to leave the functionality in place—permanently—for 191 doctors and now 60,000 patients. One result is that the practices are now using the AHRQ created portal as their sole patient portal and abandoned the commercial portal that did not work as well.” Alex Krist, M.D., M.P.H., Virginia Commonwealth University

“The AHRQ-sponsored series of grants on Multiple Chronic Condition research were transformative for that field. They also sponsored regular meetings among grantees and established the Multiple Chronic Conditions Research Network, which has fostered many collaborations between researchers with shared expertise.” Elizabeth A. Bayliss, MD, MSPH, Kaiser Permanente Colorado

“Our AHRQ grant to study the transformation of medical practices into patient-centered medical homes allowed us to develop a good partnership with the Minnesota Dept. of Health and Dept. of Human Services to evaluate a State experiment certifying primary care practices as medical homes. That partnership facilitated access to information and practices and helped us learn many lessons about this transformation and its impacts. These lessons were then provided to those MN departments and to the practices that were becoming medical homes, with the purpose of improving quality, cost, and access.” Leif I. Solberg, MD, Director for Care Improvement Research, HealthPartners Institute for Education and Research, Bloomington, MN

Research related to the most common acute, chronic, and comorbid conditions that primary care clinicians treat is lacking. AHRQ supports research to improve healthcare quality, reduce costs, advance patient safety, decrease medical errors, and broaden access to essential services. This research is essential to create a robust primary care system for our Nation—one that delivers higher quality of care and better health while reducing the rising cost of care. Despite this need, little is known about how patients can best decide how and when to seek care, how to introduce and disseminate new discoveries into real life practice, and how to maximize appropriate care. This type of research requires sufficient funding for AHRQ, so it can help researchers address the problems confronting our health system today.

We recommend the Committee fund AHRQ at a base, discretionary level of at least \$375 million for fiscal year 2015.

[This statement was submitted by Grant Hoekzema, MD, Chair, Council of Academic Family Medicine.]

PREPARED STATEMENT OF THE COUNCIL ON SOCIAL WORK EDUCATION

On behalf of the Council on Social Work Education (CSWE), I am pleased to offer this written testimony to the Senate Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies for inclusion in the official Committee record. I will focus my testimony on the importance of fostering a skilled, sustainable, and diverse social work workforce to meet the healthcare needs of the nation through professional education, training, and financial support programs for social workers at the Department of Health and Human Services (HHS) and the Department of Education (ED).

CSWE is a nonprofit national association representing more than 2,500 individual members and more than 700 master's and baccalaureate programs of professional social work education. Founded in 1952, this partnership of educational and professional institutions, social welfare agencies, and private citizens houses the sole accrediting body for social work education in the United States. Social work education prepares students for leadership and professional interdisciplinary practice with individuals, families, groups, and communities in a wide array of service sectors, including health, mental health, adult and juvenile justice, PK-12 education, child

welfare, aging, and others. Social work practice is facilitated by a longstanding tradition of collaborative relationships working with health professions colleagues including direct care workers, families, doctors, nurses, pharmacists and others yielding a result that empowers individuals to be healthy, productive, contributing members of their communities. Social workers recognize that social determinants of health are a critical component in meeting the health needs of certain populations, and social work education and practice follow this framework. As Federal agencies look to reduce cost and improve quality, social workers can help lead in this area.

Recruitment and retention in social work continues to be a serious challenge that threatens the workforce's ability to meet societal needs. The U.S. Bureau of Labor Statistics estimates that employment for social workers is expected to grow faster than the average for all occupations through 2022, particularly for social workers specializing in the aging population and working in rural areas. In addition, the need for social workers specializing in mental health and substance use is expected to grow by 23 percent over the 2012–2022 decade.¹

CSWE understands the difficult funding decisions Congress is faced with. In these challenging times, it is my hope that the Committee will prioritize funding for health professions training in fiscal year (FY) 2015 to help to ensure that the nation continues to foster a sustainable, skilled, and culturally competent workforce that will be able to keep up with the increasing demand for social work services and meet the unique healthcare needs of diverse communities.

HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA)

TITLE VII AND TITLE VIII HEALTH PROFESSIONS PROGRAMS

CSWE urges the Committee to provide \$520 million in fiscal year 2015 for the health professions education programs authorized under Titles VII and VIII of the Public Health Service Act and administered through HRSA, which is equal to the fiscal year 2012 enacted level. HRSA's Title VII and Title VIII health professions programs represent Federal programs designed to train healthcare providers in an interdisciplinary way to meet the healthcare needs of all Americans, including the underserved and those with special needs. These programs also serve to increase minority representation in the healthcare workforce through targeted programs that improve the quality, diversity, and geographic distribution of the health professions workforce. The Title VII and Title VIII programs provide loans, loan guarantees and scholarships to students, and grants to institutions of higher education and non-profit organizations to help build and maintain a robust healthcare workforce. Social workers and social work students are eligible for funding from the suite of Title VII health professions programs.

The Title VII and Title VIII programs were reauthorized in 2010, which helped to improve the efficiency of the programs as well as enhance efforts to recruit and retain health professionals in underserved communities. Recognizing the severe shortages of mental and behavioral health providers within the healthcare workforce, a new Title VII program was authorized in the Patient Protection and Affordable Care Act (Public Law 111–148). The Mental and Behavioral Health Education and Training Grants program provides grants to institutions of higher education (schools of social work and other mental health professions) for faculty and student recruitment and professional education and training. The program received first-time funding of \$10 million in the final fiscal year 2012 appropriations bill. The President's fiscal year 2015 budget request would continue to support the program at HRSA and also through a partnership with the Substance Abuse and Mental Health Services Administration (SAMHSA) to expand the mental health workforce by almost 3,500 professionals focused on transition-age youth (16–25). CSWE urges the Committee to maintain funding at HRSA for this critically important program at the highest level possible in fiscal year 2015 and include schools of social work as eligible entities. CSWE supports the proposed expansion of the program but encourages the committee to be inclusive of non-youth populations needing mental and behavioral health services and not to reduce the scope of the original intent of the program through the expansion.

¹U.S. Bureau of Labor Statistics. 2012. Occupational Outlook Handbook: Social Workers, <http://data.bls.gov/cgi-bin/print.pl/oco/ocos060.htm>. Retrieved March 21, 2014.

SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION (SAMHSA)

MINORITY FELLOWSHIP PROGRAM

CSWE urges the Committee to appropriate the highest level possible for the Minority Fellowship Program (MFP) in fiscal year 2015. The goal of the SAMHSA Minority Fellowship Program (MFP) is to achieve greater numbers of minority doctoral students preparing for leadership roles in the mental health and substance use fields.² CSWE is one of six grantees of this critical program and administers funds to exceptional minority doctoral social work students. Other grantees include national organizations representing nursing, psychology, psychiatry, marriage and family therapy, and professional counselors. SAMHSA makes grants to these six organizations, who in turn recruit minority doctoral students into the program from the six distinct professions. CSWE administers the funds to qualified doctoral students and helps facilitate mentoring and networking throughout the duration of the fellowship as well as facilitates an alumni group to help continue to engage former fellows long after their formal fellowship has ended.

Since its inception in 1974, the MFP has helped support doctoral-level professional education for over 1,000 ethnic minority social workers, psychiatrists, psychologists, psychiatric nurses, and family and marriage therapists. Still, the program continues to struggle to keep up with the demands facing these health professions. Severe shortages of mental health professionals often arise in underserved areas due to the difficulty of recruitment and retention in the public sector. Nowhere are these shortages more prevalent than within Tribal communities, where mental illness and substance use go largely untreated and incidences of suicide continue to increase. Studies have shown that ethnic minority mental health professionals practice in underserved areas at a higher rate than non-minorities. Furthermore, a direct positive relationship exists between the numbers of ethnic minority mental health professionals and the utilization of needed services by ethnic minorities.³ The President's fiscal year 2015 budget request includes \$10 million for MFP activities. CSWE urges the committee to support this request, including at least \$5.4 million for MFP core activities.

DEPARTMENT OF EDUCATION

STUDENT AID PROGRAMS

CSWE supports full funding to keep the maximum Pell Grant at \$5,830 in fiscal year 2015. While Congress is understandably focused on identifying a solution that will place the Pell Grant program on solid ground in regards to its fiscal future, we urge you to remember that these grants help to ensure that all students, regardless of their economic situation, can achieve higher education. Moreover, as described above with regard to the SAMHSA Minority Fellowship Program, one goal of social work education is recruiting students from diverse backgrounds (which includes racial, economic, religious, and other forms of diversity) with the hope that they will return to serve diverse communities once they have completed their education. In many cases, this includes encouraging social workers to return to their own communities and apply the skills they have acquired through their social work education to individuals, groups, or families in need. Without support such as Pell Grants, many low-income individuals would not be able to access higher education, and in turn, would not acquire skills needed to best serve in the communities that would most benefit from their service.

The Graduate Assistance in Areas of National Need (GAANN) program provides graduate traineeships in critical fields of study. Currently, social work is not defined as an area of national need for this program; however it was recognized by Congress as an area of national need in the Higher Education Opportunity Act of 2008. We encourage ED to recognize the importance of including social work in the GAANN program in future years. Inclusion of social work would help to significantly enhance graduate education in social work, which is critically needed in the country's efforts to foster a sustainable health professions workforce. CSWE urges the Subcommittee to provide \$31 million for the GAANN Program and include social as an area of national need.

² According to SAMHSA, minorities make up over one-fourth of the population, but less than 20 percent of behavioral health providers come from ethnic minority communities. Retrieved from SAMHSA Minority Fellowship Program, <http://www.samhsa.gov/minorityfellowship/>.

³ U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services. (2001). *Mental Health: Culture, Race, and Ethnicity—A Supplement to Mental Health: A Report of the Surgeon General*. Retrieved from <http://www.surgeongeneral.gov/library/mentalhealth/crc/sma-01-3613.pdf>.

CSWE supports efforts at ED to help students with high debt loads serve in low paying positions. The Income-Based Repayment (IBR) program and the Public Service Loan Forgiveness programs in particular help students graduating from social work programs who wish to serve in high-needs communities, often at a low salary level. CSWE urges the Subcommittee to support loan repayment programs without a cap on repayment support at ED.

Thank you for the opportunity to express these views. Please do not hesitate to call on the Council on Social Work Education should you have any questions or require additional information.

[This statement was submitted by Dr. Darla Spence Coffey, President, Council on Social Work Education.]

PREPARED STATEMENT OF THE CROHN'S AND COLITIS FOUNDATION OF AMERICA
SUMMARY OF FISCAL YEAR 2015 RECOMMENDATIONS

- \$32 Billion for the National Institutes of Health (NIH) at an increase of \$1 billion over fiscal year 2014. Increase funding for the National Cancer Institute (NCI), the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and the National Institute of Allergy and Infectious Diseases (NIAID) by 12 percent.
 - Continued focus on Digestive Disease Research and Education At NIH, including Inflammatory Bowel Disease (IBD) and Colorectal Cancer.
 - \$6,860,000 For the Centers For Disease Control and Prevention's (CDC) IBD Epidemiology Activities.
 - \$50 Million For the Center for Disease Control and Prevention's (CDC) Colorectal Cancerscreening and Prevention Program.
-

Thank you for the opportunity to submit testimony to the Subcommittee. CCFA has remained committed to its mission of finding a cure for Crohn's disease and ulcerative colitis and improving the quality of life of children and adults affected by these diseases for over 46 years. Impacting an estimated 1.4 million Americans, 30 percent of whom are diagnosed in their childhood years, Inflammatory Bowel Diseases (IBD) are chronic disorders of the gastrointestinal tract which cause abdominal pain, fever, and intestinal bleeding. IBD represents a major cause of morbidity from digestive illness and has a devastating impact on both patients and their families.

The social and economic impact of digestive disease is enormous and difficult to grasp. Digestive disorders afflict approximately 65 million Americans. This results in 50 million visits to physicians, over 10 million hospitalizations, collectively 230 million days of restricted activity. The total cost associated with digestive diseases has been conservatively estimated at \$60 billion a year.

The CCFA would like to thank the subcommittee for its past support of digestive disease research and prevention programs at the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC).

Specifically the CCFA recommends:

- \$32 billion for the NIH.
- \$2.16 billion for the National Institute of Diabetes and Digestive and Kidney Disease (NIDDK).

We at the CCFA respectfully request that any increase for NIH does not come at the expense of

other Public Health Service agencies. With the competing and the challenging budgetary constraints the Subcommittee currently operates under, the CCFA would like to highlight the research being accomplished by NIDDK which warrants the increase for NIH.

INFLAMMATORY BOWEL DISEASE

In the United States today about one million people suffer from Crohn's disease and ulcerative colitis, collectively known as IBD. These are serious diseases that affect the gastrointestinal tract causing bleeding, diarrhea, abdominal pain, and fever. Complications arising from IBD can include anemia, ulcers of the skin, eye disease, colon cancer, liver disease, arthritis, and osteoporosis. The cause of IBD is still unknown, but research has led to great breakthroughs in therapy.

In recent years researchers have made significant progress in the fight against IBD. The CCFA encourages the subcommittee to continue its support of IBD re-

search at NIDDK and NIAID at a level commensurate with the overall increase for each institute. The DDNC would like to applaud the NIDDK for its strong commitment to IBD research through the Inflammatory Bowel Disease Genetics Research Consortium. The CCFA urges the Consortium to continue its work in IBD research.

CENTERS FOR DISEASE CONTROL AND PREVENTION IBD EPIDEMIOLOGY

CDC, in collaboration with a nationwide, geographically diverse network of large managed healthcare delivery systems, has led an epidemiological study of IBD to understand IBD incidence, prevalence, demographics, and healthcare utilization. The group, comprised of investigators at the Massachusetts General Hospital in Boston, Rhode Island Hospital, the Crohn's and Colitis Foundation of America, and CDC, has piloted the Ocean State Crohn's and Colitis Registry (OSCAR), which includes both pediatric and adult patients. Since 2008, the OSCAR investigators have recruited 22 private-practice groups and hospital based physicians in Rhode Island and are that enrolling newly diagnosed patients into the registry. This study found an average annual incidence rate of 8.4 per 100,000 people for Crohn's disease and 12.4 per 100,000 for Ulcerative Colitis; published in *Inflammatory Bowel Disease Journal*, April 2007.

—Over the course of the initial 3-year epidemiologic collaboration, CDC laboratory scientists and epidemiologists worked to improve detection tools and epidemiologic methods to study the role of infections (infectious disease epidemiology) in pediatric IBD, collaborating with extramural researchers who were funded by a National Institutes of Health (NIH) research award.

—Since 2006, CDC epidemiologists have been working in conjunction with the Crohn's and Colitis Foundation of America and a large health maintenance organization to better understand the natural history of IBD and factors that predict the course of disease.

The Crohn's and Colitis Foundation of America encourages the CDC to continue to support a nationwide IBD surveillance and epidemiological program in fiscal year 2014.

COLORECTAL CANCER PREVENTION

Colorectal cancer is the third most commonly diagnosed cancer for both men and woman in the United States and the second leading cause of cancer-related deaths. Colorectal cancer affects men and women equally.

The CCFA recommends a funding level of \$50 million for the CDC's Colorectal Cancer Screening and Prevention Program. This important program supports enhanced colorectal screening and public awareness activities throughout the United States. The DDNC also supports the continued development of the CDC-supported National Colorectal Cancer Roundtable, which provides a forum among organizations concerned with colorectal cancer to develop and implement consistent prevention, screening, and awareness strategies.

CONCLUSION

The CCFA understands the challenging budgetary constraints and times we live in that this Subcommittee is operating under, yet we hope you will carefully consider the tremendous benefits to be gained by supporting a strong research and education program at NIH and CDC. Millions of Americans are pinning their hopes for a better life, or even life itself, on digestive disease research conducted through the National Institutes of Health. Mr. Chairman, on behalf of our patients, we appreciate your consideration of our view. We look forward to working with you and your staff.

PREPARED STATEMENT OF THE CYSTIC FIBROSIS FOUNDATION

On behalf of the Cystic Fibrosis Foundation (CFF) and the 30,000 people with cystic fibrosis (CF) in the United States, we submit the following testimony to the Senate Appropriations Committee's Subcommittee on Labor, Health and Human Services, Education, and Related Agencies on our funding requests for fiscal year 2015. The Foundation requests the highest possible funding level for the National Institutes of Health (NIH), particularly the National Center for Advancing Translational Sciences (NCATS) and programs under its jurisdiction, including the Cures Acceleration Network (CAN) and the Clinical and Translational Science Awards (CTSA).

Collaboration and Innovation: The Future of Drug Development

NIH uses appropriated funds wisely and effectively by supporting programs that promote efficiency and innovation in drug discovery and encouraging collaboration across sectors. Many of these effective, collaborative ventures aim to translate basic research into promising potential treatments, speeding the discovery of therapies for those with serious illnesses like cystic fibrosis. We urge you to ensure that these critical programs are sufficiently funded and receive the support they need. For those with rare genetic diseases like CF, treatments and cures cannot wait.

As an example of the NIH's cooperative, innovative approach, in February the agency announced the establishment of the Accelerating Medicines Partnership (AMP), a joint venture between NIH, pharmaceutical companies, and several non-profit organizations to characterize biomarkers and distinguish biological targets that are most likely to respond to new therapies. The AMP will begin with three to five year pilot projects in Alzheimer's disease, type 2 diabetes, rheumatoid arthritis and systemic lupus erythematosus.

Through this cross-sector partnership, NIH and industry partners share expertise, resources, and data in order to speed the development of treatments. Furthermore, industry partners have agreed to make AMP data and analyses available to the biomedical community for use in future study.

Drug development is risky, expensive, and time-consuming, and there is a 95 percent failure rate for drug candidates. This kind of cross-sector partnership aims to reduce the time, cost, and risk of drug development by sharing resources so diseases can be analyzed in ways that drug companies have not been able to do on their own.

Importantly, industry will fund one-half of the \$230 million budget while NIH will provide the other half. The Federal money used for this project acts as seed money, a jumping off point for private sector investment in drug discovery for serious diseases. This type of cooperative approach saves taxpayer funds in the long run and can save lives.

While AMP is not administered by the National Center for Advancing Translational Sciences (NCATS), this NIH center spearheads similarly innovative programs that encourage collaboration, improve the process by which diagnostics and therapeutics are developed, and improve the efficiency of the translation of basic scientific discoveries into new therapies.

For example, the Cures Acceleration Network (CAN), a program under the umbrella of NCATS, funds a variety of initiatives designed to address scientific and technical challenges that hinder transitional research. For instance, CAN provides funding for the Tissue Chip for Drug Screening Initiative, a joint project with the Defense Advanced Research Projects Agency (DARPA) and the Food and Drug Administration (FDA) to develop 3-D human tissue chips. These chips, composed of diverse human cells and tissues, mimic how drugs interact with the human body. If successful, these chips could make drug safety and efficacy assessments possible at an earlier stage in drug development, enabling investigators to concentrate on the most promising new drugs.

Unfortunately, CAN has been chronically underfunded. Since its inception as part of the Patient Protection and Affordable Care Act in 2010, it has been funded at approximately \$10 million per year for fiscal years 2012, 2013, and 2014. We urge the Committee to provide at least the funding level requested in the President's fiscal year 2015 budget—\$29.8 million. CAN needs additional funding for projects that will help move new treatments to patients.

Similarly, the Clinical and Translational Science Awards (CTSA) program in the NCATS Division of Clinical Innovation demonstrates NCATS' innovative, collaborative approach. This program supports a national consortium of more than 60 medical research institutions that work together on research. Its goals are to accelerate the process of translating laboratory discoveries into treatments for patients, train a new generation of researchers, and engage communities in clinical research efforts.

Institutional CTSA awards provide academic homes for translational sciences and support research resources needed by local and national research communities to improve the quality and efficiency of all phases of translational research. They also support the training of clinical and translational scientists and the development of all disciplines needed for a robust translational research workforce.

CTSA funds have the potential to be used in new ways. For example, CTSA's academic homes can serve as a platform for sharing patient registry data. As the CF Foundation has seen with its Therapeutics Development Network of clinical trial sites, the sharing of patient registry information, including demographics and health outcomes, among sites is integral to conducting CF research. This strategy could be beneficial in the wider disease community.

A Culture of Collaboration: The Cystic Fibrosis Model

The Cystic Fibrosis Foundation has long been engaged in partnerships with industry and supports a collaborative network of care centers and clinical trial sites. As such, CFF knows firsthand that this type of cooperation can lead to the targeted treatments that change the face of many life-threatening diseases.

Because drug research and development is a lengthy, expensive and risky process, CFF pioneered a successful “venture philanthropy” business model to drive drug development for this rare disease. By collaborating with pharmaceutical companies and providing financial, scientific, and clinical support in order to “de-risk” the development process, CFF speeds development of much-needed treatments.

Through its venture philanthropy model, the Foundation is able to invest in promising CF research and a robust pipeline of potential therapies that target the disease from every angle. Nearly every CF drug available today was made possible because of the Foundation’s support and ongoing work with researchers and the pharmaceutical industry to find a cure.

In January 2012, the Food and Drug Administration approved Kalydeco, a groundbreaking cystic fibrosis drug developed by Vertex Pharmaceuticals in partnership with the CF Foundation. This targeted drug is the first to address the underlying genetic cause of cystic fibrosis in a subset of the CF population.

Kalydeco was approved in only 3 months, one of the fastest approvals in the FDA’s history. According to Margaret A. Hamburg, M.D., Commissioner of the FDA, “The unique and mutually beneficial partnership that led to the approval of Kalydeco serves as a great model for what companies and patient groups can achieve if they collaborate on drug development.”

Throughout Kalydeco’s review, the Cystic Fibrosis Foundation and renowned CF experts worked closely with Vertex Pharmaceuticals and the FDA, providing valuable insight on specific issues related to CF, clinical research on CF treatments, and other issues related to the product and its review. We believe that this collaborative process contributed to a more efficient evaluation, and is a testament to what can be achieved when stakeholders collaborate across sectors on critical drugs for patients.

Akin to AMP, the Cystic Fibrosis Foundation also recognizes the profound importance of data sharing, which is a critical way to enable efficient drug development. The Cystic Fibrosis Foundation Therapeutics Development Network (TDN) of clinical trial centers has accumulated data from over 40 cystic fibrosis studies in the last 15 years. This data resides in a repository specifically meant to facilitate sharing among our research community.

As the Committee determines its funding levels for fiscal year 2015, we request your attention to the critical nature of NIH’s work and the innovation it supports, and urge robust funding for this important agency. The CF Foundation stands ready to work with the Committee, NIH, and Congressional leaders on the challenges ahead. Thank you for your consideration.

PREPARED STATEMENT OF THE DIGESTIVE DISEASE NATIONAL COALITION

SUMMARY OF FISCAL YEAR 2015 RECOMMENDATIONS

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- \$32 Billion for the National Institutes of Health (NIH) at an increase of \$1 billion over fiscal year 2014. Increase funding for the National Cancer Institute (NCI), the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and the National Institute of Allergy and Infectious Diseases (NIAID) by 12 percent.
 - Continue focus on Digestive Disease Research and Education at NIH, including Inflammatory Bowel Disease (IBD), Hepatitis and other Liver Diseases, Irritable Bowel Syndrome (IBS), Colorectal Cancer, Endoscopic Research, Pancreatic Cancer, and Celiac Disease.
 - \$50 Million for the Centers For Disease Control and Prevention’s (CDC) Hepatitis Prevention and Control Activities.
 - \$50 Million for the Center for Disease Control and Prevention’s (CDC) Colorectal Cancerscreening and Prevention Program.
-

Chairman Harkin, thank you for the opportunity to again submit testimony to the Subcommittee. Founded in 1978, the Digestive Disease National Coalition (DDNC)

is a voluntary health organization comprised of 35 professional societies and patient organizations concerned with the many diseases of the digestive tract. The DDNC promotes a strong Federal investment in digestive disease research, patient care, disease prevention, and public awareness. The DDNC is a broad coalition of groups representing disorders such as Inflammatory Bowel Disease (IBD), Hepatitis and other liver diseases, Irritable Bowel Syndrome (IBS), Pancreatic Cancer, Ulcers, Pediatric and Adult Gastroesophageal Reflux Disease, Colorectal Cancer, and Celiac Disease.

The social and economic impact of digestive disease is enormous and difficult to grasp. Digestive disorders afflict approximately 65 million Americans. This results in 50 million visits to physicians, over 10 million hospitalizations, collectively 230 million days of restricted activity. The total cost associated with digestive diseases has been conservatively estimated at \$60 billion a year.

The DDNC would like to thank the Subcommittee for its past support of digestive disease research and prevention programs at the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC).

Specifically the DDNC recommends:

—\$2 billion for the NIH.

—\$2.16 billion for the National Institute of Diabetes and Digestive and Kidney Disease (NIDDK).

We at the DDNC respectfully request that any increase for NIH does not come at the expense of

other Public Health Service agencies. With the competing and the challenging budgetary constraints the Subcommittee currently operates under, the DDNC would like to highlight the research being accomplished by NIDDK which warrants the increase for NIH.

INFLAMMATORY BOWEL DISEASE

In the United States today about one million people suffer from Crohn's disease and ulcerative colitis, collectively known as Inflammatory Bowel Disease (IBD). These are serious diseases that affect the gastrointestinal tract causing bleeding, diarrhea, abdominal pain, and fever. Complications arising from IBD can include anemia, ulcers of the skin, eye disease, colon cancer, liver disease, arthritis, and osteoporosis. The cause of IBD is still unknown, but research has led to great breakthroughs in therapy.

In recent years researchers have made significant progress in the fight against IBD. The DDNC encourages the subcommittee to continue its support of IBD research at NIDDK and NIAID at a level commensurate with the overall increase for each institute. The DDNC would like to applaud the NIDDK for its strong commitment to IBD research through the Inflammatory Bowel Disease Genetics Research Consortium. The DDNC urges the Consortium to continue its work in IBD research. Therefore the DDNC and its member organization the Crohn's and Colitis Foundation of America encourage the CDC to continue to support a nationwide IBD surveillance and epidemiological program in fiscal year 2015.

VIRAL HEPATITIS: A LOOMING THREAT TO HEALTH

The DDNC applauds all the work NIH and CDC have accomplished over the past year in the areas of hepatitis and liver disease. The DDNC urges that funding be focused on expanding the capability of State health departments, particularly to enhance resources available to the hepatitis State coordinators. The DDNC also urges that CDC increase the number of cooperative agreements with coalition partners to develop and distribute health education, communication, and training materials about prevention, diagnosis and medical management for viral hepatitis.

The DDNC supports \$50 million for the CDC's Hepatitis Prevention and Control activities. The hepatitis division at CDC supports the hepatitis C prevention strategy and other cooperative nationwide activities aimed at prevention and awareness of hepatitis A, B, and C. The DDNC also urges the CDC's leadership and support for the National Viral Hepatitis Roundtable to establish a comprehensive approach among all stakeholders for viral hepatitis prevention, education, strategic coordination, and advocacy.

COLORECTAL CANCER PREVENTION

Colorectal cancer is the third most commonly diagnosed cancer for both men and woman in the United States and the second leading cause of cancer-related deaths. Colorectal cancer affects men and women equally.

The DDNC recommends a funding level of \$50 million for the CDC's Colorectal Cancer Screening and Prevention Program. This important program supports en-

hanced colorectal screening and public awareness activities throughout the United States. The DDNC also supports the continued development of the CDC-supported National Colorectal Cancer Roundtable, which provides a forum among organizations concerned with colorectal cancer to develop and implement consistent prevention, screening, and awareness strategies.

PANCREATIC CANCER

In 2013, an estimated 33,730 people in the United States will be found to have pancreatic cancer and approximately 32,300 died from the disease. Pancreatic cancer is the fifth leading cause of cancer death in men and women. Only 1 out of 4 patients will live 1 year after the cancer is found and only 1 out of 25 will survive five or more years.

The National Cancer Institute (NCI) has established a Pancreatic Cancer Progress Review Group charged with developing a detailed research agenda for the disease. The DDNC encourages the Subcommittee to provide an increase for pancreatic cancer research at a level commensurate with the overall percentage increase for NCI and NIDDK.

IRRITABLE BOWEL SYNDROME (IBS)

IBS is a disorder that affects an estimated 35 million Americans. The medical community has been slow in recognizing IBS as a legitimate disease and the burden of illness associated with it. Patients often see several doctors before they are given an accurate diagnosis. Once a diagnosis of IBS is made, medical treatment is limited because the medical community still does not understand the pathophysiology of the underlying conditions.

Living with IBS is a challenge, patients face a life of learning to manage a chronic illness that is accompanied by pain and unrelenting gastrointestinal symptoms. Trying to learn how to manage the symptoms is not easy. There is a loss of spontaneity when symptoms may intrude at any time. IBS is an unpredictable disease. A patient can wake up in the morning feeling fine and within a short time encounter abdominal cramping to the point of being doubled over in pain and unable to function.

The DDNC recommends that NIDDK increase its research portfolio on Functional Gastrointestinal Disorders and Motility Disorders.

CONCLUSION

The DDNC understands the challenging budgetary constraints and times we live in that this Subcommittee is operating under, yet we hope you will carefully consider the tremendous benefits to be gained by supporting a strong research and education program at NIH and CDC. Millions of Americans are pinning their hopes for a better life, or even life itself, on digestive disease research conducted through the National Institutes of Health. Mr. Chairman, on behalf of the millions of digestive disease sufferers, we appreciate your consideration of the views of the Digestive Disease National Coalition. We look forward to working with you and your staff.

PREPARED STATEMENT OF DYSTONIA MEDICAL RESEARCH FOUNDATION

SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2015

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- \$32 billion for the National Institutes of Health (NIH) and proportional increases across its institutes and centers.
 - Continue to support the Dystonia Coalition Within the Rare Disease Clinical Research Network (RDCRN) coordinated by the Office of Rare Diseases Research (ORDR) in the National Center for Advancing Translational Sciences (NCATS).
 - Expand Dystonia Research supported by NIH through the National Institute on Neurological Disorders and Stroke (NINDS), the National Institute on Deafness and Other Communication Disorders (NIDCD) and the National Eye Institute (NEI).
-

Dystonia is a neurological movement disorder characterized by involuntary muscle spasms that cause the body to twist, repetitively jerk, and sustain postural deformities. Focal dystonia affects specific parts of the body, while generalized dystonia affects multiple parts of the body at the same time. Some forms of dystonia are genetic but dystonia can also be caused by injury or illness. Although dystonia is a

chronic and progressive disease, it does not impact cognition, intelligence, or shorten a person's life span. Conservative estimates indicate that between 300,000 and 500,000 individuals suffer from some form of dystonia in North America alone. Dystonia does not discriminate, affecting all demographic groups. There is no known cure for dystonia and treatment options remain limited.

Although little is known regarding the causes and onset of dystonia, two therapies have been developed that have demonstrated a great benefit to patients and have been particularly useful for controlling patient symptoms. Botulinum toxin (e.g., Botox, Xeomin, Disport and Myobloc) injections and deep brain stimulation have shown varying degrees of success alleviating dystonia symptoms. Until a cure is discovered, the development of management therapies such as these remains vital, and more research is needed to fully understand the onset and progression of the disease in order to better treat patients.

DYSTONIA RESEARCH AT THE NATIONAL INSTITUTES OF HEALTH (NIH)

Currently, dystonia research at NIH is supported by the National Institute of Neurological Disorders and Stroke (NINDS), the National Institute on Deafness and Other Communication Disorders (NIDCD), the National Eye Institute (NEI), and the Office of Rare Diseases Research (ORDR) within the National Center for Advancing Translational Sciences (NCATS).

ORDR coordinates the Rare Disease Clinical Research Network (RDCRN) which provides support for studies on the natural history, epidemiology, diagnosis, and treatment of rare diseases. RDCRN includes the Dystonia Coalition, a partnership between researchers, patients, and patient advocacy groups to advance the pace of clinical research on cervical dystonia, blepharospasm, spasmodic dysphonia, craniofacial dystonia, and limb dystonia. The Dystonia Coalition has made tremendous progress in preparing the patient community for clinical trials as well as funding promising studies that hold great hope for advancing our understanding and capacity to treat primary focal dystonias. DAN urges the subcommittee to continue its support for the Dystonia Coalition, part of the Rare Disease Clinical Research Network coordinated by ORDR within NCATS.

The majority of dystonia research at NIH is supported by NINDS. NINDS has utilized a number of funding mechanisms in recent years to study the causes and mechanisms of dystonia. These grants cover a wide range of research including the genetics and genomics of dystonia, the development of animal models of primary and secondary dystonia, molecular and cellular studies in inherited forms of dystonia, epidemiology studies, and brain imaging. DAN urges the subcommittee to support NINDS in conducting and expanding critical research on dystonia.

NIDCD and NEI also support research on dystonia. NIDCD has funded many studies on brainstem systems and their role in spasmodic dysphonia, or laryngeal dystonia. Spasmodic dysphonia is a form of focal dystonia which involves involuntary spasms of the vocal cords causing interruptions of speech and affecting voice quality. NEI focuses some of its resources on the study of blepharospasm. Blepharospasm is an abnormal, involuntary blinking of the eyelids which can render a patient legally blind due to a patient's inability to open their eyelids. DAN encourages partnerships between NINDS, NIDCD and NEI to further dystonia research.

In summary, DAN recommends the following for fiscal year 2015:

- \$32 billion for NIH and a proportional increase for its Institutes and Centers
- Support for the Dystonia Coalition within the Rare Diseases Clinical Research Network coordinated by ORDR within NCATS
- Expansion of the dystonia research portfolio at NIH through NINDS, NIDCD, NEI, and ORDR

THE DYSTONIA ADVOCACY NETWORK

The Dystonia Medical Research Foundation submits these comments on behalf of the Dystonia Advocacy Network (DAN), a collaborative network of five patient organizations: the Benign Essential Blepharospasm Research Foundation, the Dystonia Medical Research Foundation, the National Spasmodic Dysphonia Association, the National Spasmodic Torticollis Association, and ST/Dystonia, Inc. DAN advocates for all persons affected by dystonia and supports a legislative agenda that meets the needs of the dystonia community.

DMRF was founded in 1976. Since its inception, the goals of DMRF have remained to advance research for more effective treatments of dystonia and ultimately find a cure; to promote awareness and education; and support the needs and well being of affected individuals and their families.

Thank you for the opportunity to present the views of the dystonia community, we look forward to providing any additional information.

[This statement was submitted by Janet Hieshetter, Executive Director, Dystonia Medical Research Foundation.]

PREPARED STATEMENT OF THE ELDER JUSTICE COALITION

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

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

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

The \$25 million requested in the President's fiscal year 2015 budget for an Elder Justice Initiative which if approved by Congress would be the first direct appropriation for the bipartisan Elder Justice Act sponsored in the Senate by Senators Breaux, Hatch and Baucus.

The funding request includes:

- \$13.8 million for Adult Protective Services, including an APS National Data System and Technical Assistance and national demonstration grants to both enhance APS data systems and development of program standards as well as an full evaluation of APS practices.

- \$11.2 million for research including elder abuse screening and to establish a better knowledge base about elder abuse, neglect and exploitation.

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

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

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

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

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

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

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

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

Just as 40 years ago when witnesses came to this Subcommittee seeking initial funding for the Child Abuse Prevention and Treatment Act of 1974 we come today

asking for this initial \$25 million for elder justice. What is common? A victim of child abuse, like a victim of elder abuse, is never the same. The role of government should always be to help the vulnerable of all ages.

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

PREPARED STATEMENT OF THE ELDERCARE WORKFORCE ALLIANCE

Mr. Chairman, Ranking Member Moran, and Members of the Subcommittee: We are writing on behalf of the Eldercare Workforce Alliance (EWA), which is comprised of 30 national organizations united to address the immediate and future workforce crisis in caring for an aging America. As the Subcommittee begins consideration of funding for programs in fiscal year 2015, the Alliance** urges you to provide adequate funding for programs designed to increase the number of healthcare professionals prepared to care for America's growing senior population and to support family caregivers in the essential role they play in this regard.

Today's healthcare workforce is inadequate to meet the special needs of older Americans, many of whom have multiple chronic physical and mental health conditions and cognitive impairments. It is estimated that an additional 3.5 million trained healthcare workers will be needed by 2030 just to maintain the current level of access and quality. Without a national commitment to expand training and educational opportunities, the workforce will be even more constrained in its ability to care for the growth in the elderly population as the baby boom generation ages. Reflecting this urgency, the Health Resources and Services Administration (HRSA) has identified "enhancing geriatric/elder care training and expertise" as one of its top five priorities.

Of equal importance is supporting the legions of family caregivers who annually provide billions of hours of uncompensated care that allows older adults to remain in their homes and communities. The estimated economic value of family caregivers' unpaid care was approximately \$450 billion in 2009.

The number of Americans over age 65 is expected to reach 70 million by 2030, representing a 71 percent increase from today's 41 million older adults. That is why Title VII and Title VIII geriatrics programs and Administration for Community Living (ACL) programs that support family caregivers are so critical to ensure that there is a skilled eldercare workforce and knowledgeable, well-supported family caregivers available to meet the complex and unique needs of older adults.

We hope you will support a total of \$44.7 million in funding for geriatrics programs in Title VII and Title VIII of the Public Health Service Act, \$172.9 million in funding for programs administered by the Administration on Aging that support the vital role of family caregivers in providing care for older adults, and \$3 million to convene a White House Conference on Aging. Specifically, we recommend the following levels:

- \$39.7 million for Title VII Geriatrics Health Professions Programs;
- \$5 million for Title VIII Comprehensive Geriatric Education Programs;
- \$172.9 million for Family Caregiver Support Programs; and
- \$3 million for a White House Conference on Aging.

Geriatrics health profession training programs are integral to ensuring that America's healthcare workforce is prepared to care for the Nation's rapidly expanding population of older adults.

In light of current fiscal constraints, EWA specifically requests \$44.7 million in funding for the following programs administered through the Health Resources and Services Administration (HRSA) under Title VII and VIII of the Public Health Service Act. In the 2012–2013 Academic Year, these geriatrics and gerontology programs provided training to more than 200,000 individuals.

Title VII Geriatrics Health Professions: Appropriations Request: \$39.7 Million

Title VII Geriatrics Health Professions programs are the only Federal programs that seek to increase the number of faculty with geriatrics expertise in a variety

**The positions of the Eldercare Workforce Alliance reflect a consensus of 75 percent or more of its members. This testimony reflects the consensus of the Alliance and does not necessarily represent the position of individual Alliance member organizations.

The Eldercare Workforce Alliance is a project of The Advocacy Fund.

of disciplines. These programs offer critically important training for the healthcare workforce overall to improve the quality of care for America's elders.

—*Geriatric Academic Career Awards (GACA)*.—The goal of this program is to promote the development of academic clinician educators in geriatrics. Program Accomplishments: In the Academic Year 2012–2013, the GACA program funded 62 full-time junior faculty. These awardees delivered over 1,100 interprofessional continuing education courses specific to geriatric-related topics to over 53,000 students and providers. Additionally, they presented on research and other topics at 215 local, State and national conference and published 108 peer-reviewed publications. HRSA, through the Affordable Care Act (ACA), expanded the awards to be available to more disciplines. EWA strongly supports this expansion and requests adequate funding to reflect this change. Currently, new awardees are selected only every 5 years. To meet the need for clinician educators in all disciplines, EWA believes that awards should be made available to clinical educators annually in order to develop an adequate number of faculty that can provide geriatric instruction and training. EWA's fiscal year 2015 request of \$5.5 million will support GAC Awardees in their development as clinician educators.

—*Geriatric Education Centers (GEC)*.—The goal of Geriatric Education Centers is to provide high quality interprofessional geriatric education and training to current members of the health professions workforce, including geriatrics specialists and non-specialists. Program Accomplishments: In Academic Year 2012–2013, the 45 GEC grantees developed and provided over 1,650 different continuing education and clinical training offerings to more than 135,000 health professionals, students, faculty, and practitioners, significantly exceeding the program's performance target. Three quarters of the continuing education offerings were interprofessional in focus. Of the sites that offered clinical training sessions, 2 out of every 5 of these sites were in a medically underserved community and/or Health Professional Shortage Area. The GECs provide much needed education and training. Our funding request of \$20 million includes support for the core work of these 45 GECs.

—*Alzheimer's Disease Prevention, Education, and Outreach Program (GECs)*.—These funds, included in the President's fiscal year 2015 budget request, allow HRSA to expand efforts to provide interprofessional continuing education to healthcare practitioners on Alzheimer's disease and related dementias, utilizing the already existing Geriatric Education Centers (GECs). EWA Requests \$5.3 million.

—*Geriatric Training Program for Physicians, Dentists, (GTPD) and Behavioral and Mental Health Professions*.—The goal of the GTPD program is to increase the number and quality of clinical faculty with geriatrics and cultural competence, including retraining mid-career faculty in geriatrics. Program Accomplishments: In Academic Year 2012–2013, a total of 64 physicians-including psychiatrists-, dentists, and psychologists, were supported through this fellowship program. Fellows delivered over 275 courses to 5,600 trainees. This program supports training additional faculty in medicine, dentistry, and behavioral and mental health so that they have the expertise, skills, and knowledge to teach geriatrics and gerontology to the next generation of health professionals in their disciplines. EWA's funding request of \$8.9 million will support this important faculty development program.

Title VIII Geriatrics Nursing Workforce Development Programs: Appropriations Request: \$5 million

Title VIII programs, administered by the HRSA, are the primary source of Federal funding for advanced education nursing, workforce diversity, nursing faculty loan programs, nurse education, practice and retention, comprehensive geriatric education, loan repayment, and scholarship.

—*Comprehensive Geriatric Education Program*.—The goal of this program is to provide quality geriatric education and training to individuals caring for the elderly. Program Accomplishments: In Academic Year 2012–2013, a total of 18 Comprehensive Geriatric Education Program (CGEP) grantees provided a variety of services, including over 150 different continuing education courses to over 11,600 trainees. This program supports additional training for nurses who care for the elderly; development and dissemination of curricula relating to geriatric care; training of faculty in geriatrics; and continuing education for nurses practicing in geriatrics.

—*Traineeships for Advanced Practice Nurses*.—Through the ACA, the Comprehensive Geriatric Education Program was expanded to include advanced practice nurses who are pursuing long-term care, geropsychiatric nursing, or other nurs-

ing areas that specialize in care of older adults. In Academic Year 2012–2013, a total of 74 grantees were awarded traineeships. One in every 4 grantee is considered an underrepresented minority in their prospective profession. EWA's funding request of \$5 million will support the education and training of individuals who provide geriatric care.

Administration for Community Living Family Caregiver Support and White House Conference on Aging: Appropriations Request: \$175.9 million

These programs support caregivers, elders, and people with disabilities by providing critical respite care and other support services for family caregivers, training and recruitment of care workers and volunteers, information and outreach, counseling, and other supplemental services.

—*Family Caregiver Support Services.*—This program provides a range of support services to approximately 700,000 family and informal caregivers annually in States, including counseling, respite care, training, and assistance with locating services that help family caregivers in caring for their loved ones at home for as long as possible. EWA requests \$154.5 million.

—*Native American Caregiver Support.*—This program provides a range of services to Native American caregivers, including information and outreach, access assistance, individual counseling, support groups and training, respite care and other supplemental services. EWA requests \$6.4 million.

—*Alzheimer's Disease Support Services.*—One critical focus of this program is to support the family caregivers who provide countless hours of unpaid care, thereby enabling their family members with dementia to continue living in the community. Funds go towards evidence-based interventions and expand the dementia-capable home and community-based services, enabling older adults to remain in the community for as long as possible. EWA requests \$9.5 million.

—*Lifespan Respite Care.*—This program funds grants to improve the quality of and access to respite care for family caregivers of children or adults of any age with special needs. EWA requests \$2.5 million.

—*White House Conference on Aging.*—As recommended by the bi-partisan Commission on Long-Term Care, the President's fiscal year 2015 budget request includes \$3 million for the convening of a decennial White House Conference on Aging to bring together stakeholders and consumers from across the country to discuss the range of aging issues they face. EWA requests \$3 million.

On behalf of the members of the Eldercare Workforce Alliance, we commend you on your past support for geriatrics workforce programs and ask that you join us in supporting the eldercare workforce at this critical time—for all older Americans deserve quality care, now and in the future. Thank you for your consideration.

[This statement was submitted by Nancy Lundebjerg, MPA, and Michèle Saunders, DMD, MS, MPH, Alliance Co-Convener.]

PREPARED STATEMENT OF THE EMERGENCY NURSES ASSOCIATION

The Emergency Nurses Association (ENA), with more than 40,000 members worldwide, is the only professional nursing association dedicated to defining the future of emergency nursing and emergency care through advocacy, expertise, innovation, and leadership. Founded in 1970, ENA develops and disseminates education and practice standards and guidelines, and affords consultation to both private and public entities regarding emergency nurses and their practice. ENA has a great interest in the work of the Senate Labor, Health and Human Services, Education Subcommittee and especially its efforts to improve the quality of emergency care for patients in the United States.

For fiscal year 2015, ENA respectfully requests \$28 million for Trauma and Emergency Care Programs (HHS; ASPR/HRSA), \$251 million for Nursing Workforce Development programs (HHS; HRSA), \$21.116 million for the Emergency Medical Services for Children program (HHS; HRSA), \$30.1 million to fund poison control centers (HHS; HRSA), \$150 million for the National Institute of Nursing Research (HHS; NIH), and \$8.927 million for Rural Health—Access to Emergency Devices (HHS; HRSA).

TRAUMA AND EMERGENCY CARE PROGRAMS

Trauma is the leading cause of death for persons younger than 44 and the fourth-leading cause of death for all ages. In States with an established trauma system, patients are 20 percent more likely to survive a traumatic injury. Victims of traumatic injury treated at a Level I trauma center are 25 percent more likely to survive than those treated at a general hospital.

Our trauma and emergency medical systems are designed to transport seriously injured individuals to trauma centers quickly. However, due to a lack of financial resources, 45 million Americans do not have access to a major trauma center within the “golden hour” following an injury when chances of survival are highest.

Trauma and emergency care programs, which are authorized under the Public Health Service Act, provide much-needed money to the States to develop and enhance of trauma systems. These programs are critical to the efficient delivery of services through trauma centers, as well as to the development of regionalized systems of trauma and emergency care that ensure timely access for injured patients to appropriate facilities. This modest investment can yield substantial returns in terms of cost efficiencies and, most importantly, saved lives.

Therefore, ENA respectfully requests \$28 million in fiscal year 2015 for trauma and emergency care programs.

NURSING WORKFORCE DEVELOPMENT PROGRAMS

The nursing profession faces significant challenges to ensure that there will be an adequate number of qualified nurses to meet the growing healthcare needs of Americans. It is estimated that 80 million Baby Boomers turned 65 last year. This growing elderly population will seek healthcare services in a multitude of settings and the care they depend upon will require a highly educated and skilled nursing workforce. A 2014 projection from the U.S. Bureau of Labor Statistics’ 2013–2014 Employment Outlook Handbook anticipates that the number of practicing RNs will grow 19 percent by 2022.

The aging of the Baby Boom generation will deplete the nursing ranks as well. During the next 10 to 15 years, approximately one-third of the current nurse workforce will reach retirement age. The retirement of these experienced nurses has the potential to create a serious deficit in the nursing pipeline. At the same time, our colleges cannot keep up with the demand for new nurses. According to the American Association of Colleges of Nursing’s (AACN) 2013–2014 Enrollment and Graduations in Baccalaureate and Graduate Programs in Nursing survey, 78,089 qualified applications were turned away from nursing schools in 2013 alone.

Title VIII Nursing Workforce Development programs address these factors and help support the training of qualified nurses. They not only enhance nursing education at all levels, from entry-level to graduate study, but they also support nursing schools that educate nurses for practice in rural and medically underserved communities. Another important part of Title VIII is the Faculty Loan Program which is critical to alleviating the large shortage in nursing faculty. Overall, more than 80,000 nurses and nursing students were trained and educated last year with the help of Title VIII nursing workforce development programs.

Therefore, ENA respectfully requests \$251 million in fiscal year 2015 for the Nursing Workforce Development programs authorized under Title VIII of the Public Health Service Act.

EMERGENCY MEDICAL SERVICES FOR CHILDREN

The Emergency Medical Services for Children (EMSC) program is the only Federal program that focuses specifically on improving the pediatric components of the emergency medical services (EMS) system. EMSC aims to ensure state-of-the-art emergency medical care for ill and injured children or adolescents; that pediatric services are well integrated into an EMS system backed by optimal resources; and that the entire spectrum of emergency services is provided to children and adolescents no matter where they live, attend school, or travel.

The Federal investment in the EMSC program produces a wide array of benefits to children’s health through EMSC State Partnership Grants, EMSC Targeted Issue Grants, the Pediatric Emergency Care Applied Research Network, and the National EMSC Data Analysis Resource Center.

Therefore, ENA respectfully requests \$21.116 million in fiscal year 2015 for the EMSC program.

POISON CONTROL CENTERS

Poisoning is the second most common form of unintentional death in the United States. In 2009, 31,768 deaths nationwide were attributed to unintentional poisoning. Children are especially vulnerable to injury by poisoning and each day 300 children are treated for poisoning in emergency departments across the country and two die.

The Nation’s 56 poison control centers handle 3.4 million calls each year, including approximately 680,000 calls from nurses and doctors who rely on poison centers for an immediate assessment and expert advice on poisoning cases.

Not only are America's network of poison centers invaluable for treating victims of poisonings, but the work of the centers also results in substantial savings to our healthcare system. About 90 percent of people who call with poison emergencies are treated at home and do not have to visit an emergency department. In more severe poisoning cases, the expertise provided by poison control centers can decrease the length of hospital stays. It has been estimated that every dollar spent on America's poison control centers saves \$13.39 in healthcare costs and lost productivity. The positive impact to the Federal budget is also significant. A 2012 study by the Lewin Group found that poison control centers resulted in \$313.5 million in savings to Medicare and \$390.2 million in savings to Medicaid.

Therefore, ENA respectfully requests \$30.1 million in fiscal year 2015 for poison control centers

THE NATIONAL INSTITUTE OF NURSING RESEARCH (NINR)

As one of the 27 Institutes and Centers at the NIH, NINR funds research that lays the groundwork for evidence-based nursing practice. NINR's mission is to promote and improve the health of individuals, families, communities, and populations. The Institute supports and conducts clinical and basic research on health and illness to build the scientific foundation for clinical practice, prevent disease and disability, manage and eliminate symptoms caused by illness, and improve palliative and end-of-life care.

NINR nurse-scientists examine ways to improve care models to deliver safe, high-quality, and cost-effective health services to the Nation. Our country must look toward prevention as a way of reducing healthcare expenditures and improving outcomes. The work of NINR is an important part of this effort.

Moreover, NINR helps to provide needed faculty to support the education of future generations of nurses. Training programs at NINR develop future nurse-researchers, many of whom also serve as faculty in our Nation's nursing schools.

Therefore, ENA respectfully requests \$150 million in fiscal year 2015 for the NINR.

RURAL AND COMMUNITY ACCESS TO EMERGENCY DEVICES PROGRAM

Fewer than 10 percent of people who suffer a cardiac arrest outside of a hospital setting survive. According to a 2011 study published in the New England Journal of Medicine, immediate CPR and prompt defibrillation using an automated external defibrillator (AED) can more than double a patient's chance of survival.

The Health Resources and Services Administration (HRSA)'s Rural and Community Access to Emergency Devices Program saves lives of patients with cardiac arrest. Between August 1, 2008, and July 31, 2010, nearly 800 cardiac arrest victims were reportedly saved through this program. Funding for this initiative is used to buy AEDs, locate them in public places where cardiac arrests are more likely to happen, and instruct lay rescuers and first responders in their use. Between March 1, 2010, and Feb. 28, 2011, 3,928 AEDs were placed and 28,776 people were trained in their use.

Therefore, ENA respectfully requests \$8.927 million in fiscal year 2015 for the Rural and Community Access to Emergency Devices Program.

PREPARED STATEMENT OF THE ENDOCRINE SOCIETY

The Endocrine Society is pleased to submit the following testimony regarding fiscal year 2015 Federal appropriations for biomedical research, with an emphasis on appropriations for the National Institutes of Health (NIH). The Endocrine Society is the world's largest and most active professional organization of endocrinologists representing more than 17,000 members worldwide. Our organization is dedicated to promoting excellence in research, education, and clinical practice in the field of endocrinology. The Society's membership includes thousands of basic and clinical scientists who receive Federal support from the NIH to fund endocrine-related research on topics such as diabetes, cancer, fertility, aging, obesity and bone disease. The Society's membership also includes clinicians who depend on new scientific advances to better treat and cure their patients' diseases. As a result of Federal investment in endocrine research, individuals with diabetes have made dramatic improvements in managing their disease, and the obesity rate for children age 2 to

5 years old has dropped 43 percent.^{1,2} The Endocrine Society recommends that the NIH receive at least \$32 billion in fiscal year 2015. This funding recommendation represents the minimum investment necessary to avoid further erosion of national research priorities and global preeminence, while allowing the NIH's budget to keep pace with biomedical inflation.

Sustained investment by the United States Federal government in biomedical research has dramatically advanced the health and improved the lives of the American people. The United States' NIH-supported scientists represent the vanguard of researchers making fundamental biological discoveries and developing applied therapies that advance our understanding of, and ability to treat human disease. In the past year NIH funded scientists have made fundamental insights into how mild traumatic brain injury causes brain damage; identified potential drug targets for Parkinson's disease; and identified a safe and protective candidate malaria vaccine.³ In the field of endocrinology, NIH-funded researchers have made remarkable contributions in areas of critical national interest, for example:

- Endocrinologists have made insightful discoveries describing newly understood contributors to body weight and obesity.⁴ Obesity is a growing national concern, with related medical costs in the United States as high as \$190 billion in 2005 alone.⁵
- Endocrinologists have discovered that higher vitamin D levels are associated with increased mobility and physical function in older individuals. As the population of the United States increasingly lives longer, this research has the potential to dramatically improve the quality of life for Americans.⁶
- Endocrinologists are also at the leading edge of research on testosterone therapy and maintaining appropriate levels of sex hormones. For instance, endocrinologists are investigating links between testosterone levels and heart disease in men.⁷

These discoveries represent but a fraction of the contributions made by endocrinologists and other NIH funded scientists in the past year. The foundation for these research products are the NIH research grants that support the basic and clinical research done by scientists. Since 2004, the number of NIH research grants to scientists in the United States has been declining. Consequently, the likelihood of a scientist with a highly-regarded grant application successfully being awarded a grant has dropped from 31.5 percent in 2000 to an historic low of 16.8 percent in 2013.⁸ This means that experienced scientists are increasingly spending time writing grant applications instead of applying their expertise to productive research. Additionally, younger scientists struggle to find a job in the United States that makes use of the unique skills generated during graduate training.

The lack of sustained government support compounded by austerity measures such as sequestration has created an environment that is leading to a "brain drain" as brilliant scientists pursue other careers or leave the United States to develop impactful research products elsewhere. In 2013, the number of NIH supported scientists declined significantly, with nearly 1,000 NIH scientists dropping out of the workforce.⁹ NIH scientists run labs that support high-quality jobs and education while generating breakthrough innovations. In 2011, the NIH directly or indirectly supported over 432,000 jobs across the country.¹⁰ As a result of sequestration,

¹ Casagrande et al., "The Prevalence of Meeting A1C, Blood Pressure, and LDL Goals Among People With Diabetes, 1988–2010." *Diabetes Care*, Aug 36;8 (2013) 2271–9.

² Sabrina Tavernise, "Obesity Rate for Young Children Plummets 43 percent in a Decade." *The New York Times*, Feb 25, 2014.

³ "2013 Research Highlights". December 23, 2013. <http://www.nih.gov/researchmatters/january2014/researchmatters2013recap.htm> Accessed March 23, 2013.

⁴ Mathur et al., "Methane and hydrogen positivity on breath test is associated with greater body mass index and body fat." *J Clin Endocrinol Metab*. 98;4 (2013) 698–702.

⁵ Cawley and Meyerhoefer, "The medical care costs of obesity: an instrumental variables approach." *J Health Econ*. 31;(2012) 219–30.

⁶ Wohl et al., "Vitamin D status is associated with functional limitations and functional decline in older individuals." *J Clin Endocrinol Metab*. 98;9 (2013) 1483–90.

⁷ Ruige et al., "Beneficial and Adverse Effects of Testosterone on the Cardiovascular System in Men." *J Clin Endocrinol Metab*. 98;11 (2013) 4300–10.

⁸ Salley Rockey, "fiscal year 2013 By The Numbers: Research Applications, Funding, and Awards," *Rock Talk*, January 10, 2014. <http://nexus.od.nih.gov/all/2014/01/10/fy2013-by-the-numbers/> Accessed March 20, 2014.

⁹ Jeremy Berg "The impact of the sequester: 1,000 fewer funded investigators." *ASBMB Today*, March (2014). <https://www.asbmb.org/asbmbtoday/201403/PresidentsMessage/Accessed> March 20, 2014.

¹⁰ Everett Ehrlich "Engine Stalled: Sequestration's Impact on NIH and the Biomedical Research Enterprise." *United for Medical Research*. (2012).

States such as Georgia and Connecticut lost \$62 million and \$32 million respectively.¹¹

We may never be able to quantify the opportunities we have missed to improve the health and economic status of the United States due to persistent underinvestment in research. We do know however, that when “laboratories lose financing, they lose people, ideas, innovations and patient treatments.”¹² Based on the personal stories of researchers who have been forced to curtail research programs, we know that research programs to understand how genetics can influence heart disease, develop therapeutic treatments for Parkinson’s disease, and evaluate the effect of metal contaminants on reproductive health; among many others, are delayed or terminated.¹³

As the world’s largest source of funding for medical research, the NIH is vitally important to the United States’ global preeminence in research. However, this global preeminence is being tested due to flat funding that has reduced the inflation-adjusted budget of the NIH to a level that is nearly 22 percent below the NIH budget in fiscal year 2003.¹⁴ As a consequence of this underinvestment, the United States’ global share of pharmaceutical industry output has declined, our global share of biopharmaceutical patents has declined, and our trade balance in pharmaceutical products is worsening.¹⁵ While the Bipartisan Budget Act of 2013 and omnibus appropriations bill have provided some much needed additional resources, overall levels of funding remain well below the \$32 billion required for adequate, sustainable growth in biomedical research.

We live during an age of tremendous scientific opportunity that can only be realized through Federal funding of biomedical research. Researchers are only beginning to harness the power of big data to solve complicated problems. Innovative new experiments and clinical research hold promise to solve some of the United States’ greatest medical challenges and discover new ways to improve our quality of life. Government support is critical to these opportunities, and we encourage the Appropriations Committee to actively support promising and innovative research.

As the Appropriations Committee considers funding for the NIH, the Endocrine Society also asks the Committee to encourage the NIH to look at ways to increase data reporting to address gaps in gender and sex differences in research. Sex differences need to be acknowledged as a critical biological variable.¹⁶ In addition to including more women in clinical research, the Endocrine Society believes sex differences should be a part of the design of all basic biological studies and clinical research. If the NIH required researchers to consider sex differences in grant applications when appropriate, and incorporate data on sex as a biological variable in animal and human studies, more appropriate conclusions could be drawn from basic research, and clinical research would provide more representative data on safety and efficacy of drugs.¹⁷

The Endocrine Society remains deeply concerned about the future of biomedical research in the United States without sustained support from the Federal government. Flat funding in recent years, combined with the impact of sequestration, threaten the Nation’s scientific enterprise and make adequate fiscal year 2015 appropriations for the NIH increasingly important. The Society strongly supports increased Federal funding for biomedical research in order to provide the additional resources needed to enable American scientists to address scientific opportunities and maintain the country’s status as the preeminent research engine. The Endocrine Society therefore asks that the NIH receive at least \$32 billion in fiscal year 2015.

¹¹ “NIH State Information Factsheets.” <http://www.faseb.org/Policy-and-Government-Affairs/Advocacy-on-Capitol-Hill/Advocacy-Resources-for-Scientists/NIH-State-Information-Factsheets.aspx>. Federation of American Societies for Experimental Biology. Accessed March 19, 2014.

¹² Teresa K. Woodruff “Budget Woes and Research.” The New York Times. September 10, 2013.

¹³ Sequester Profiles: How Vast Budget Cuts to NIH are Plaguing U.S. Research Labs. United for Medical Research. http://www.unitedformedicalresearch.com/advocacy_reports/sequestration-profiles/Accessed March 20, 2014.

¹⁴ “Budget Cuts in 2013 Reduced Biomedical Research” Federation of American Societies for Experimental Biology. <http://www.faseb.org/pdfviewer.aspx?loadthis=http%3A%2F%2Fwww.faseb.org%2FPortals%2F2%2FPDFs%2Fopa%2F2014%2F1.21.14%2520NIH%2520Funding%2520Cuts%2520-pager.pdf> Accessed March 19, 2014.

¹⁵ Atkinson et al., “Leadership in Decline, Assessing U.S. International Competitiveness in Biomedical Research.” The Information Technology and Innovation Foundation and United for Medical Research. May 2012.

¹⁶ Woodruff et al., “Leaning in’ to Support Sex Differences in Basic Science and Clinical Research.” *Endocrinology*. 155;4 (2014) 1181–3

¹⁷ Kim et al., “Sex Bias in Trials and Treatment Must End.” *Nature*. 465;7299 (2010) 688–9.

[This statement was submitted by Teresa K. Woodruff, PhD, President, The Endocrine Society.]

PREPARED STATEMENT OF THE ENTOMOLOGICAL SOCIETY OF AMERICA

The Entomological Society of America (ESA) respectfully submits this statement for the official record in support of funding for insect-borne disease research at the U.S. Department of Health and Human Services (HHS). ESA requests a robust fiscal year 2015 appropriation for the National Institutes of Health (NIH), including increased funding for insect-borne disease research at the National Institute of Allergy and Infectious Diseases (NIAID). The Society also supports increased investment in the core infectious diseases budget and the global health budget within the Centers for Disease Control and Prevention (CDC) in order to fund scientific activities related to vector-borne diseases.

Advances in the biological sciences, including the field of entomology, help to address some of our most pressing societal needs related to environmental and human health. Certain species of insects carry, spread, and transmit an array of infectious diseases that threaten populations across the globe, including those in the United States as well as U.S. military personnel undertaking missions abroad. Insect-borne diseases can present an especially challenging health problem; few vaccines have been developed against them, and insects are often difficult to control and can develop resistance to insecticides. The risk of emerging infectious diseases grows as global travel becomes easier and environmental factors continue to change. For example, West Nile virus, which is transmitted by mosquitoes and was not present in the U.S. before 1999, infected 5,674 Americans in 2012.¹ Entomological research to understand the biological relationship between insect vectors and the infectious diseases they carry—such as dengue, malaria, West Nile virus, and Lyme disease—can significantly contribute to our ability to monitor and predict outbreaks, prevent disease spread and transmission, and more reliably diagnose and treat infection. Given the important role that insect vectors play in impacting human health, ESA urges the subcommittee to support vector-borne disease research programs that incorporate the entomological sciences as part of a comprehensive approach to addressing infectious diseases.

NIH, the Nation's premier medical research agency, advances human health by funding research on basic human biology and disease and the development of prevention and treatment strategies. In fiscal year 2012, about 84 percent of NIH funding was competitively awarded to scientists at approximately 2,500 universities, medical schools, and other research institutions across the Nation. As one of NIH's 27 institutes and centers, NIAID conducts and supports fundamental and applied research related to the understanding, prevention, and treatment of infectious, immunologic, and allergic diseases. One example of NIAID-funded research on infectious diseases is a recent study examining the mechanism by which certain species of mosquitoes known to transmit dengue and malaria are attracted to humans. The scientists discovered that specific types of nerve cells in the insects act as sensitive detectors of human odors. With this knowledge, the researchers were able to identify safe and natural chemical compounds with the potential to neutralize or overwhelm the specific insect nerve cells, a discovery that could have implications for the control of mosquitoes and their associated diseases.² In another recent study supported by NIAID, researchers determined that live, disease-free ticks can be used as a safe tool for testing for the presence of Lyme disease bacteria in patients who have completed antibiotic therapy.³ To ensure funding for future groundbreaking projects like these, ESA requests increased funding for NIAID and encourages the committee to support insect-borne disease research at NIH.

CDC, serving as the Nation's health protection agency, conducts science and provides health information to prevent and respond to infectious diseases and other global health threats, whether naturally arising or related to bioterrorism. Within the core infectious diseases budget of CDC, the Division of Vector-Borne Diseases (DVBD) seeks to protect our Nation from the threat of viruses and bacteria transmitted primarily by mosquitoes, ticks, and fleas. DVBD's mission is carried out by a staff of experts in several scientific disciplines, including entomology. For example, among the activities supported by DVBD are the ArboNET surveillance system for

¹ CDC DVBD factsheet: http://www.cdc.gov/ncezid/dvbd/pdf/dvbd_factsheet.pdf.

² Tauxe, GM, et al. Targeting a dual detector of skin and CO₂ to modify mosquito host seeking. *Cell* (2013).

³ Marques, A, et al. Xenodiagnosis to detect *Borrelia burgdorferi* infection: A first-in-human study. *Clinical Infectious Diseases* (2014).

mosquito-borne diseases and the TickNET system for tick-borne diseases. ArboNET is a nationwide network that monitors West Nile virus and other diseases through activities such as the collection and testing of mosquitoes, and TickNET is a partnership between 16 States to track tick-borne-diseases like Lyme disease and test preventions. Furthermore, a component of CDC's global health budget supports activities on parasitic diseases and malaria; this includes the maintenance of a global reference insectary that houses colonies of mosquitoes from around the world to be used by the agency for studies on malaria transmission. Given the important contributions of CDC, ESA requests that the committee provide increased support for CDC programs addressing vector-borne diseases and malaria.

ESA, headquartered in Annapolis, Maryland, is the largest organization in the world serving the professional and scientific needs of entomologists and individuals in related disciplines. Founded in 1889, ESA has nearly 7,000 members affiliated with educational institutions, health agencies, private industry, and government. Members are researchers, teachers, extension service personnel, administrators, marketing representatives, research technicians, consultants, students, pest management professionals, and hobbyists.

Thank you for the opportunity to offer the Entomological Society of America's support for HHS research programs.

[This statement was submitted by Frank G. Zalom, PhD, President, Entomological Society of America.]

PREPARED STATEMENT OF FAMILIES & FRIENDS OF CARE FACILITY RESIDENTS

Chairman Harkin, Ranking Member Moran, Members of the Subcommittee: Thank you for this opportunity to provide information to the Senate Appropriations Subcommittee on Labor, Health & Human Services Education & Related Agencies. This is a letter-request that the Subcommittee cease funding Federal programs which use public funds to achieve public policies of deinstitutionalization of persons identified as benefiting from congregate (institutional) care, typically those with severe forms of cognitive-developmental disabilities.

I am the mother and co-guardian of an adult son, aged 45, who from birth has lived with the effects of severe brain injuries. John is a large, mobile and nonverbal man with pica behavior who functions on the mental level of a young toddler. Our son has slight or little awareness of danger and his direct care is beyond our family's capacities. For many years John's safe home has been a state-operated congregate care program, an intermediate care facility for persons with intellectual disabilities (formerly known as a medical diagnosis of mental retardation). The future viability of John's home is in jeopardy due to the undermining work of federally funded entities and programs in the U.S. Department of Health and Human Services and the Department of Justice/Civil Rights Division.

I represent as public affairs chairman Families and Friends of Care Facility Residents (FF/CFR), Arkansas' statewide parent-guardian association. FF/CFR is an all-volunteer organization; we employ no lobbyist; we receive no public funds.

I have reviewed the testimonies of Department of Health and Human Services representatives presented before this subcommittee for the past several years. DHHS did not disclose that the Department is engaged in a social experiment to dismantle the States' residential safety net programs for persons who have been adjudicated incompetent and that the Department is using public funds to support organizations which lobby decision-makers to deinstitutionalize persons who are without self-preservation skills, who cannot assist in their own care and who cannot communicate their hurts and needs or who can do so only in limited ways.

The following are examples of how government dollars are spent in the wrong way by the Department of Health and Human Services:

- (1) *National Council on Disability (NCD), an independent Federal agency engaged in disability policy recommendations.*

On Tuesday, October 23, 2012, the National Council on Disability (NCD) released its policy project—"Deinstitutionalization: Unfinished Business." The press release read: "NCD Launches Toolkit to Speed Closure of State-Run Institutions." Although NCD is a Federal agency, it has no congressional oversight and is not accountable for its actions, except as Congress may provide. Prior to releasing its deinstitutionalization policy recommendations and documents, there were no public hearings or Notice to those most affected. There was no public in-put process. Arkansas' statewide parent-guardian association, FF-CFR, is comprised of volunteer advocates who work in behalf of the vulnerable people who live and receive services at our State's five human development centers (HDCs). Arkansas' five HDCs provide 24/

7 care for 950 individuals. Over 64 percent of the residents function in the profound range of cognitive ability. We object to use of a Federal agency/Federal funds to promote public policies which are harmful. We object to empowerment of Federal agencies to formulate public policies in camera without public hearings and without the easy involvement of those most affected. NCD inappropriately collaborates with others in promoting its national de-institutionalization agenda out of the public eye.

REQUEST: Public funds should not be used to support National Council on Disability and its extreme agendas. Please discontinue its funding.

(2) *Programs funded under Public Law 106 402, Developmental Disabilities Assistance and Bill of Rights Act (DD Act). The DD Act funds three discretionary programs which operate in every State: (1) State Councils on Developmental Disabilities, (2) Protection & Advocacy Systems for Developmental Disabilities (P&As) and (3) University Centers for Excellence in Developmental Disabilities. The DD Act also funds a fourth program, Projects of National Significance. The four DD Act programs are administered by DHHS/Adm. on Community Living/Adm. on Intellectual-Developmental Disabilities*

Through litigation, lobbying and other strategies, DD Act programs and their national organizations have used and are using public funds to achieve forced-deinstitutionalization of individuals with profound cognitive-developmental disabilities from their congregate care homes and the closures of Medicaid-certified public facilities for these individuals with profound disabilities. The DD Act programs' administrative office (Adm-IDD) has embraced an extreme agenda and is not responsive to the complaints and concerns of families, friends and legal guardians of individuals with disabilities who require close 24/7 care.

The DD Act was last re-authorized in 2000; its current authorization ended in 2007. At the last reauthorization, there was no public hearing and no opportunity to object to the ways in which grantees (State Councils on DD, Protection & Advocacy (P&A) systems and University Centers on DD) were collaborating with each other and with others for use of Federal appropriations to undermine and close congregate care programs for those persons with the most severe forms of developmental disabilities. There have been no hearings on reauthorization of the DD Act where families might participate and provide information about and objections to the programs' activities. The Arkansas DD Act P&A system has: (1) joined with Arc in a Federal lawsuit to close all Arkansas human development centers (HDCs), (2) brought 3 Federal lawsuits in succession seeking to change our AR HDC admission and discharge policies naming HDC residents as plaintiffs without notice or consent of their legal guardians (in two of the cases the AR P&A sought class certification with no opportunity for residents to opt out of the class); (3) filed a complaint with Civil Rights Division-U.S. Dept. of Justice regarding care at our HDCs without consulting families of HDC residents and cheered in the media when DOJ brought a systems-change lawsuit against all HDCs; (4) testified against AR HDC funding before State legislative panels; (5) organized a public rally calling on the AR Governor to close one of our HDCs; (6) denigrated congregate care and AR HDC programs in the media during a Federal trial, *USA v. State of AR (Conway HDC)*; (7) provided erroneous information to AR policy makers regarding cost of care and the U.S. Supreme Court decision in *Olmstead v. L. C.* (119 S. Ct. 2176); and (8) sent financial support to its Washington D.C.-based national organization, National Disability Rights Network (NDRN), an organization with no oversight which lobbies the Administration, Congress and CMS, collaborating with other organizations in campaigns to shift Medicaid funding from congregate care programs for persons with life-long cognitive and other developmental disabilities. Most recently (January & February, 2014), the Arkansas DD Act P&A in testimony before a legislative panel and in a letter to members of the State legislature worked against funding for capital improvements at our State's five human development centers. Families with whom I correspond in other States report that DD Act programs have used grant funds to fund other organizations to plan and lobby for the closure of State-operated congregate care programs for individuals with cognitive-developmental disabilities. In November and December, 2012, the national organizations for two DD Act programs (Association of University Centers on Disabilities (AUCD) and protection and advocacy (National Disability Rights Network—NDRN) led the work of lobbying to prevent the mark-up of H.R. 2032 in the U.S. House Judiciary Committee. Had 2032 passed, some egregious protection and advocacy activities employing litigation as a tactic to undermine and close congregate care centers might have been addressed and prohibited.

REQUEST: Public funds should not be used to support the DD Act Programs' extreme agendas of deinstitutionalization. Please discontinue funding the groups' harmful deinstitutionalization work.

(3) *DHHS Financial incentive grants—Money Follows the Person (MFP), Balance Incentive Payment Plan (BIP), Community First Choice Option (CFCO)*

Through generous financial incentive demonstration grants (Money Follows the Person, Balance Incentive Plan, Community First Choice Option), CMS is promoting thoughtless policies of de-institutionalization for persons with developmental disabilities by funding generous incentive grants for one needed program (home and community based waiver care) but not another needed program (licensed safety-net congregate care facilities). The majority of persons with cognitive-developmental disabilities can and are being served through States' home and community based waiver programs. There is no "institutional bias" in our State of Arkansas for persons with developmental disabilities: 74.2 percent of Medicaid dollars are spent on home and community based waiver programs. Over 4,000 individuals with developmental disabilities are served in Arkansas' community-based waiver programs versus approximately 950 residents in the State's public safety-net institutions for people with developmental disabilities. For clinically complex cases and for people with profound cognitive and other severe forms of developmental disabilities requiring 24/7 supervision whose needs cannot be successfully met at home, or whose families can no longer provide their care, the option of institutional programs such as Arkansas' Human Development Centers (HDCs) is life-saving. HDCs are cost-efficient and they also provide a proven safe model of long term care. When all costs are taken into account, there are no cost savings to shift from institutional care to community care for this vulnerable population. Persons with little or no awareness of danger who cannot or who cannot adequately communicate their hurts and needs will be at greater risk of abuse, exploitation and death when they are forced from their safe congregate care homes. The testimony of Secretary HHS Kathleen Sebelius before House Committee on Appropriations (April 25, 2013, "Protecting Vulnerable Populations") does not comport with our family's experiences with the outcomes of DHS/CMS financial incentive grants and other DHHS de-institutionalization programs. The push by CMS to entice States through financial rewards to shift from providing care for persons in specialized residential programs does not comport with realities in the field of long-term care. The American Medical Association (AMA) has designated persons with intellectual—developmental disabilities (formerly termed mental retardation) as a medically underserved population. The AMA Policy (CMS Rep. 3–1–11) "encourages support for healthcare facilities whose primary mission is to meet the healthcare needs of persons with profound developmental disabilities." The National Crime Victimization Survey (Feb. 2014) found that "Individuals with disabilities encountered violent crime at nearly three times the rate of those in the general population Those with cognitive disabilities had the highest rate of victimization and about half of violent crime victims with disabilities had multiple conditions."

The use by CMS of public funds—through financial incentive grants—to reward States when they shift Medicaid long-term care funding from institutional care programs to community programs which generally have less oversight and accountability is misguided and dangerous. Families of individuals who require close care had little or no opportunity to review, comment and object that CMS incentive grants favor one needed program over another critically needed program. The extension of Federal funding for Money Follows the Person (MFP) grants and Community First Choice Option (CFCO) are optional programs offered to the States in the voluminous Affordable Care Act, inserted without adequate review, without debate, and without adequate notice to families most affected. Extension of MFP, BIP, and CFCO were created by DHHS out of the public eye with inadequate opportunity for the public to review, comment or object.

DHHS is too far removed from the realities which families understand and which are based on their years of experiences with their disabled family members.

REQUEST: Public funds should not be used to promote DHHS policies of deinstitutionalization. Please address the unfair, unsafe CMS de-institutionalization incentive grants.

SUMMARY

Policy decisions which destroyed the Nation's safety net programs for persons with mental illness are now understood to be disastrous and ill-conceived for a small but significant percent of persons living with severe, chronic mental illness.

Please resist funding DHHS programs and policies which promote harmful deinstitutionalization of persons with severest forms of developmental disabilities. My son and his peers cannot appear before committees, engage in protests or advocate for their health and safety. Please use your powerful authority to direct DHHS to cease its partisan use of public funds to achieve deinstitutionalization.

[This statement was submitted by Carole L. Sherman, Arkansas' statewide parent-guardian association.]

PREPARED STATEMENT OF THE FEDERATION OF AMERICAN SOCIETIES FOR
EXPERIMENTAL BIOLOGY

The Federation of American Societies for Experimental Biology (FASEB) respectfully requests a minimum of \$32 billion in fiscal year 2015 for the National Institutes of Health (NIH) within the Department of Health and Human Services. Increasing the NIH budget to \$32 billion would support vital initiatives to train the next generation of scientists, and fund at least 600 additional competing research grants.

FASEB, a federation of 26 scientific societies, represents more than 115,000 life scientists and engineers, making it the largest coalition of biomedical research associations in the United States. Our mission is to advance health and welfare by promoting progress and education in biological and biomedical sciences.

NIH has produced an outstanding legacy of discoveries that have generated new knowledge, improved health, and saved lives. Many of these advances arose from investigations designed to explain basic molecular, cellular, and biological mechanisms. In addition, research supported by NIH led to innovative technologies and created entirely new global industries resulting in economic growth and new, high-tech jobs.

As a result of our prior investment in NIH, we have reduced the death toll of many diseases and reduced the disability and suffering from many others. For example, U.S. death rates from heart disease and stroke have decreased by more than 60 percent in the last 50 years, the rate of acute hepatitis B has been reduced by 80 percent since the 1980's, and the proportion of older people with chronic disabilities has dropped by one-third over the last quarter century. Research funded by NIH helped develop new treatments that have significantly reduced the transmission of human immunodeficiency virus from mother to child and provided insights into traumatic brain injury. In addition, with the completion of the Human Genome Project and subsequent technological advances in rapidly sequencing DNA, scientists have been able to identify genes that are responsible for more than half of the 7,000 rare diseases known to affect humans and evaluate the genetic composition of various cancers with the hopes of pinpointing the most effective therapy for each individual patient.

NIH-supported research is continuing to produce the insights that are needed for tomorrow's improvements in health and clinical care. Recent discoveries include:

- Advances in Treating Melanoma: Years of basic research supported by NIH have provided insights into biological changes that occur in the development of cancer, including the observation that a protein called b-Raf appears in a mutated form in more than 50 percent of melanomas, the most aggressive form of skin cancer. Studies showing that this protein plays a critical role in melanoma led pharmaceutical companies to develop drugs to inhibit mutant b-Raf. These drugs can improve quality of life and prolong survival in the majority of patients with advanced melanoma who harbor b-Raf mutations. Since most of these patients eventually relapse and die from their disease, studies are underway to understand why melanomas become resistant to treatment. It is hoped that this will lead to new treatments that can overcome or bypass resistance, with the goal of achieving long-term remissions and cures.
- Developing Structure-Based Vaccines: Respiratory syncytial virus (RSV) is responsible for nearly 7 percent of deaths of infants under 12 months of age. It also causes death and disability in the elderly. NIH-funded research has illuminated many aspects of RSV infection and pathogenesis, yet an effective vaccine has remained elusive. Recently, investigators made a breakthrough by determining the three-dimensional structure of an RSV protein required for cell entry. This structural information was then used to design a stabilized vaccine antigen that elicited high titers of protective antibodies in mice and non-human primates. In the next few years, this promising vaccine candidate will be tested in clinical trials, and it is hoped that this structure-based approach to vaccine design will be successful for other viruses, such as HIV-1.
- Testing New Anti-Inflammatory Drugs: In the 1990's, NIH supported a few academic researchers to study molecules called glycans for their function in inflammation, the process the body uses to fight infection. In 2013, these studies came to fruition with the first tests of a new, glycan-based anti-inflammatory drug. In an initial test to fight inflammation during the painful crises that occur in sickle cell disease, both children and adult patients who got this treatment had

shorter disease crises, spent less time in the hospital, and needed fewer narcotics for pain relief. This new drug that will benefit tens of thousands of people in the U.S. each year could never have been developed without NIH's investment in exploratory basic research.

—*Harnessing the Immune System to Fight Cancer*: Science magazine named cancer immunotherapy—using the immune system to attack tumors—the 2013 Breakthrough of the Year. The early work that led to the development of immunotherapy was made possible by NIH-funded research on many basic biological processes, including the biology of T cells, a family of cells that are critical to the immune system. Researchers discovered that when a certain receptor on the outside of T cells is activated, cells cannot mount an effective immune response. They then reasoned that if an antibody blocked the activation of this receptor, T cells could be induced to attack tumor cells. Ongoing clinical trials testing antibody immunotherapies in individuals found that tumors shrunk by almost 50 percent in 31 percent of those with melanoma and 29 percent in those with kidney cancer.

Further Progress Depends on Sustained Investment

Research supported by NIH advances our understanding of the nature of living systems and enables us to apply that knowledge to the improvement of human health. In a recent op-ed in *The Washington Post*, NIH Director Francis S. Collins, MD, PhD, wrote, “Biomedical research is at a critical juncture—a moment of exceptional opportunities that demand exceptional attention if their promise is to be fully realized.”¹ But without continued support for basic biomedical research, Dr. Collins fears that we will miss out on new discoveries that will give us the next generation of cures and therapies for such conditions as Parkinson's disease and Alzheimer's disease, as well as a universal vaccine to protect adults and children against all flu strains without needing an annual shot.

While the opportunities to increase our understanding of diseases and develop new therapies are unprecedented, a decade of flat-funding—followed by \$1.55 billion in sequestration cuts in fiscal year 2013—have taken a significant toll on NIH's ability to support research. In constant dollars (adjusted for inflation), the fiscal year 2013 budget for NIH was the lowest in thirteen years. The number of competing R01-equivalent grants, the primary mechanism for supporting investigator-initiated research, awarded each year fell by 34 percent between 2003 and 2013. The current situation is decimating the ranks of our scientific workforce, causing productive scientists to seek alternative careers and discouraging talented trainees from pursuing jobs in academic research. It surrenders our future leadership in medical research.

As a first step toward a multi-year program of sustainable growth, FASEB recommends a minimum of \$32 billion for NIH in fiscal year 2015. Thank you for the opportunity to offer FASEB's fiscal year 2015 funding recommendation for NIH.

PREPARED STATEMENT OF CHERYL FELAK

Dear Committee Members: Thank you very much for the opportunity to submit personal and professional testimony to this committee.

I am writing as a healthcare professional with an abundance of experience working with clients and family members who experience life with developmental disabilities. I am also the parent of a young man who has profound developmental disabilities due to a rare genetic condition which is similar to pediatric Alzheimer's.

I would like you to be aware that many of the advocacy agencies in this country (The Arc and its many State and local chapters), Developmental Disability Councils and affiliates, all who receive Federal funds for advocacy, are forgetting that our citizens with developmental disabilities live on a continuum and have a large variation in support needs.

It is shameful that these so-called advocacy groups forget about those with the most profound needs, misinterpret the 1999 U.S. Supreme Court *Olmstead* decision on choice and community, and force their opinions regarding these issues discriminatory practices.

It is a fact that people need communities—yet why are these so called advocacy groups allowed to determine what “community” is for those with developmental disabilities. Rather than allowing choice and opportunities, they are restricting choice and opportunities to this group of people. This is discrimination.

I am not aware of any other population which has “community” defined for them, which has funds for housing, medical care, education, vocational support tied to the

¹ Collins, F. (2013, December 24). Investing in the Nation's Health at NIH. *Washington Post*.

artificial definition of “community” which is made up for people with developmental disabilities.

I believe it is time to go back and really read the Olmstead Decision—not just take for granted what is heard because what is heard is not what the decision States. We need to honor this decision and stop discriminating against our most vulnerable citizens.

Thank you very much.

[This statement was submitted by Cheryl Felak, RN, BSN, Because We Care—Beyond Inclusion.]

PREPARED STATEMENT OF THE FRIENDS OF THE HEALTH RESOURCES AND SERVICES
ADMINISTRATION

The Friends of HRSA is a non-partisan coalition of more than 170 national organizations representing millions of public health and healthcare professionals, academicians and consumers invested in HRSA’s mission to improve health and achieve health equity. For fiscal year 2015, we recommend restoring HRSA’s discretionary budget authority to the fiscal year 2010 level of \$7.48 billion. We are deeply concerned that since fiscal year 2010, HRSA’s discretionary budget authority has been cut by 19 percent in nominal dollars and 25 percent when adjusted for inflation. Funding for HRSA is far too low and keeping austerity measures in place will threaten the agency’s ability to address the present and growing health needs of the U.S. Of additional concern, cuts will be compounded by the fact that multiple mandatory programs are set to expire at the end of fiscal year 2015. In the absence of continued mandatory funding for the National Health Service Corps Fund and Community Health Center Fund, the committee will be faced with addressing these shortfalls in the following Labor-HHS-Education appropriations bill.

The Nation faces a shortage of health professionals and continues to experience an ever growing, aging and increasingly diverse population, alongside health professionals that are nearing retirement age. Additionally, national estimates of workforce shortages are often masked by significant distributional disparities—particularly in rural and certain inner-city populations that experience greater shortages. By restoring funding to HRSA, the agency will be able to more effectively fill the primary and preventive care gaps for people living outside of the medical and economic mainstream through supporting a well prepared workforce and high-quality health services.

HRSA operates programs in every State and U.S. territory and is a national leader in improving the health of Americans. HRSA programs have reduced AIDS-related deaths through providing drug treatment regimens for people living with HIV and have the potential to prevent the spread of HIV by 96 percent by ensuring that people living with HIV have access to regular care and adhere to their antiretroviral medications. Less than 10 percent of people who experience a cardiac arrest outside of a hospital setting survive. HRSA provides rural communities with training and access to emergency devices which can more than double a patient’s chance of survival. HRSA has contributed to the decrease in infant mortality rate, a widely used indicator of the Nation’s health, which is now at an all-time low. Most recently, preliminary data indicates that the infant mortality rate for black infants has decreased, resulting in a narrowing of the gap that exists between racial groups.

Now is the time to make a strong investment in a robust workforce and to improve access to care to continue achieving the health improvements HRSA has made and to pave the way for new achievements. The Nation only stands to benefit from a healthier population through a thriving workforce and reduced healthcare costs. Our recommendation is based on the need to continue improving the health of Americans by supporting critical HRSA programs including:

- Health professions programs support the education and training of primary care physicians, nurses, oral health professionals, optometrists, physician assistants, nurse practitioners, clinical nurse specialists, public health personnel, mental and behavioral health professionals, pharmacists and other allied health providers. With a focus on primary care and training in interdisciplinary, community-based settings, these are the only Federal programs focused on filling the gaps in the supply of health professionals, as well as improving the distribution and diversity of the workforce so health professionals are well-equipped to care for the Nation’s growing, aging and increasingly diverse population. Additionally, HRSA provides interdisciplinary training to health professionals to accurately screen, diagnose and treat children with autism and other developmental disabilities.

- Primary care programs support nearly 9,200 service delivery sites in every State and territory, improving access to preventive and primary care to more than 21 million patients in geographically isolated and economically distressed communities. Close to half of the health centers serve rural populations. The health centers coordinate a full spectrum of health services including medical, dental, behavioral and social services—often delivering the range of services in one location. In addition, health centers target populations with special needs, including agricultural workers, homeless individuals and families and those living in public housing. Following health insurance reform in Massachusetts, health centers experienced a substantial increase in newly-insured patients. We expect the same will be true nationally, as health insurance expands to millions of Americans who were previously uninsured. Health centers and other programs administered by HRSA will remain vital sources of care for patients and continue to reduce costs to the health system.
 - Maternal and child health programs, including the Title V Maternal and Child Health Block Grant, Healthy Start and others, support initiatives designed to promote optimal health, reduce disparities, combat infant mortality, prevent chronic conditions and improve access to quality healthcare for 43 million women and children. MCH programs help assure that nearly all babies born in the U.S. are screened for a range of serious genetic or metabolic diseases and that a community-based system of family centered services is available for coordinated long-term follow up for babies with a positive screen and for all children with special healthcare needs.
 - HIV/AIDS programs provide the largest source of Federal discretionary funding assistance to States and communities most severely affected by HIV/AIDS. The Ryan White HIV/AIDS Program delivers comprehensive care, prescription drug assistance and support services for more than half a million low-income people impacted by HIV/AIDS, which accounts for about half of the total population living with the disease in the U.S. Additionally, the programs provide education and training for health professionals treating people with HIV/AIDS and work toward addressing the disproportionate impact of HIV/AIDS on racial and ethnic minorities.
 - Family planning Title X services ensure access to a broad range of reproductive, sexual and related preventive healthcare for over 5 million poor and low-income women, men and adolescents at nearly 4,400 health centers nationwide. Healthcare services include patient education and counseling, cervical and breast cancer screening, sexually transmitted disease prevention education, testing and referral, as well as pregnancy diagnosis and counseling. This program helps improve maternal and child health outcomes and promotes healthy families. Often, Title X service sites provide the only continuing source of healthcare and education for many individuals.
 - Rural health programs improve access to care for the nearly 50 million people living in rural areas that experience a persistent shortage of healthcare services. The Office of Rural Health Policy serves as the Nation's primary voice for programs and research on rural health issues. Rural Health Outreach and Network Development Grants, Rural Health Research Centers, Rural and Community Access to Emergency Devices Program and other programs are designed to support community-based disease prevention and health promotion projects, help rural hospitals and clinics implement new technologies and strategies and build health system capacity in rural and frontier areas.
 - Special programs include the Organ Procurement and Transplantation Network, the National Marrow Donor Program, the C.W. Bill Young Cell Transplantation Program and National Cord Blood Inventory. These programs maintain and facilitate organ marrow and cord blood donation, transplantation and research, along with efforts to promote awareness and increase organ donation rates. Special programs also include the Poison Control Program, the Nation's primary defense against injury and death from poisoning. For every dollar spent on the poison center system, \$13.39 is saved in medical costs and lost productivity, totaling more than \$1.8 billion every year in savings.
- While the Bipartisan Budget Act of 2013 and Consolidated Appropriations Act of 2014 provided modest and temporary relief from sequestration, austerity measures remain firmly in place, which pose serious threats for the viability of HRSA's important programs and compromise the agency's ability to address our Nation's health needs. We urge you to consider HRSA's central role in strengthening the Nation's health and advise you to adopt our fiscal year 2015 request of \$7.48 billion for HRSA's discretionary budget authority. Thank you for the opportunity to submit our recommendation to the subcommittee.

PREPARED STATEMENT OF FRIENDS OF THE NATIONAL INSTITUTE OF CHILD HEALTH
AND HUMAN DEVELOPMENT

My name is Kate Ryan. I currently serve as Co-Chair of the Friends of the National Institute of Child Health and Human Development (NICHD). On behalf of the Friends, I urge the Labor, Health and Human Services, Education Appropriations Subcommittee to support at least \$32 billion for the NIH, including \$1.37 billion for NICHD for fiscal year 2015. Our coalition includes over 100 organizations representing scientists, physicians, healthcare providers, patients and parents concerned with the health and welfare of women, children, families, and people with disabilities. We are pleased to support the extraordinary work of the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD).

Since its establishment in 1963, NICHD has achieved great success in meeting the objectives of its broad biomedical and behavioral research mission, which includes research on child development before and after birth; maternal, child, and family health; learning and language development; women's health and reproductive biology; population issues; and medical rehabilitation. With sufficient resources, NICHD could build upon the promising initiatives described in this testimony and produce new insights into human development and solutions to health and developmental problems throughout the world, including for women, children and families in your districts. Scientific breakthroughs supported by NICHD serve to prevent and treat many of the Nation's most devastating health problems including infant mortality and low birthweight, birth defects, intellectual and developmental disabilities, and the reproductive and gynecologic health of women throughout their lifespan, among others. Some of these research areas are described below.

Preterm Birth.—NICHD supports a comprehensive research program to study the causes of preterm birth and prevention strategies and treatment regimens. Pre-term birth costs our Nation \$26 billion annually and is a leading cause of infant mortality and intellectual and physical disabilities. Continued prioritization of extramural preterm birth prevention research, the Maternal-Fetal Medicine Units Network, the Neonatal Research Network and intramural research program related to prematurity are necessary to further this work. Resources also should be available to support transdisciplinary science as recommended in NICHD's Scientific Vision to study and identify the complex causes of preterm birth.

NICHD supports research on the causes of preterm birth with the goal of discovering effective ways to prevent it. In the U.S., the rate of preterm birth is approximately 12 percent, one of the highest rates in all industrialized countries, resulting in neonatal death, infant mortality and severe neurological disability, including cerebral palsy, mental retardation, and visual/auditory problems. Preterm birth also significantly impacts families emotionally and financially. Although research has identified some factors that influence preterm birth (e.g., multiple gestation, infections, diabetes, high blood pressure), it cannot be fully explained by physical health. There is growing evidence of the role of psychological factors such as pregnancy-related anxiety and stress, behavioral issues such as substance abuse, and sociological issues such as cultural disparities. Thus, support is needed for research on the complex interaction of factors including psychological, behavioral, social, and environmental factors in addition to genetic and biological influences, with the ultimate goal of developing efficacious interventions to decrease this country's epidemic of babies being born far too soon.

National Children's Study (NCS).—The NCS is the largest and most comprehensive study of children's health and development ever planned in the United States. The Friends of NICHD thank the Committee for its longstanding support of the NCS. The Friends look forward to roll-out of the main study that includes a science-based design and recruitment strategy. When fully implemented, this study will inform the work of scientists in universities and research organizations, helping them identify precursors to disease and to develop new strategies for prevention and treatment. Identifying the root causes of many childhood diseases and conditions, including preterm birth, developmental delay, asthma, obesity, heart disease, injury and diabetes, will reduce healthcare costs and improve the health of children. NCS also provides an opportunity to collect data on social and behavioral aspects of child and adolescent health, such as important information on the sexual and reproductive health of adolescents.

Contraceptive Research and Development.—NICHD's Contraceptive Discovery and Development Branch supports basic, applied and clinical research on contraceptive methods, including mechanisms of action, the effects of contraceptive hormones and drugs, and optimal formulations of contraceptive agents. Through its investment in contraceptive evaluation research, NICHD plays a key leadership role in ensuring acceptability and effective use of existing products in various settings and popu-

lations and in addressing behavioral issues related to fertility and contraceptive use. Specific opportunities and research priorities in the area of contraceptive evaluation include evaluation of the safety and effectiveness of hormonal contraceptive options for women who are overweight or obese. The Institute's investment in contraceptive research and development is critical for producing new contraceptive modalities that are more effective, affordable, acceptable, and easier to deliver, by, for example, offering couples options with fewer side-effects and addressing women's other concerns about contraceptive use. Specific opportunities and research priorities in the area of contraceptive research and development include the need for non-hormonal contraception, pericoital contraception, and multipurpose prevention technologies that would prevent both pregnancy and sexually transmitted infections.

Reproductive Sciences.—Through its investment in reproductive science, NICHD conducts research to improve women's health by developing innovative medical therapies and technologies and improving existing treatment options for gynecological conditions affecting overall health and fertility. The Institute's reproductive science research makes a vital contribution to women's health by focusing on serious conditions that have been overlooked and underfunded, despite the fact that they impact many women. Future work could focus on infertility research into the need for treatments for disorders such as endometriosis, polycystic ovarian syndrome (PCOS) and uterine fibroids which can prevent couples from achieving desired pregnancies.

Pelvic Floor Disorders Network (PFDN).—Female pelvic floor disorders (PFD) represent an under-appreciated but major public health burden with high prevalence, impaired quality of life and substantial economic costs affecting approximately 25 percent of American women. The PFDN is conducting research to improve treatment of these extremely painful gynecological conditions. Current research is aimed at improving female urinary incontinence outcome measures and ensuring high quality patient-centered outcomes.

Development of the Research Workforce.—Adequate levels of research require a robust research workforce. The years of training combined with uncertainty in getting grant funding are huge disincentives for students considering a career in biomedical research. This has resulted in a huge gap between the too-few women's reproductive health researchers being trained and the immense need for research. NICHD's Women's Reproductive Health Research (WRHR) Program and Reproductive Scientist Development Program (RSDP), both aimed at obstetrician-gynecologists to further their education and experience in basic, translational, and clinical research, provide training grants to hundreds of researchers and provide new insight into a host of diseases, such as ovarian cancer. Continued investment in these training programs is critical to helping ensure future scientific advances in women's health research.

Population Research.—The NICHD Population Dynamics branch supports a diverse portfolio of scientific research and research training programs, exploring the social, economic and health-related impacts of population change on families, children, and communities. The branch is well respected for investing wisely in the development of longitudinal, representative surveys, providing scientists with reliable data that can be used to examine the influence of early life course events on long-term health and achievement outcomes in particular. As an example, in 2012, NICHD-supported demographers using data from the Panel Study of Income Dynamics survey found that growing up in poor neighborhoods throughout the entire childhood life course can have a devastating effect on educational attainment. In another study, using data from the National Study of Adolescent Health, researchers found that women who are overweight or obese years during the transition from adolescence to adulthood are more likely to later deliver babies with a higher birth weight, putting the next generation at a higher risk of obesity-related health outcomes.

Sex Differences in Research.—The Friends encourages NICHD to look at ways to increase data reporting to address gaps in gender and sex differences in research. Sex differences need to be acknowledged as a critical biological variable. In addition to including more women in clinical research, we believe sex differences should be included as part of the design of all basic biological studies and clinical research. If the researchers were to consider sex differences in the design of basic science studies, and incorporate data on sex as a biological variable in animal and human studies, more appropriate conclusions could be drawn from basic research, and clinical research would provide more representative data on safety and efficacy of drug.

Clinical Trials in Pregnant Women.—Pregnant women have historically been excluded from most research trials due to concern that trial participation could harm the fetus. Although there has been substantial progress in the inclusion of women in federally funded research, pregnant women are still excluded, even from research

that would advance our knowledge of medical conditions and treatments in pregnancy. Mindful of the important considerations of clinical trials on pregnant women, we support establishment of a Federal work group to propose how clinical research might be done appropriately in this area.

Data on Pediatric Enrollment in NIH Trials.—NIH policy mandates the inclusion of women, minorities, and children in clinical trials whenever appropriate. While NIH collects enrollment data on sex/gender and race, it does not collect enrollment data broken down by age. We urge NIH, with leadership from NICHD, to improve data collection and reporting on pediatric enrollment sufficient to determine if children are appropriately represented in trials with relevance to child health.

Best Pharmaceuticals for Children Act (BPCA).—NICHD funds meaningful research into pediatric pharmacology through the BPCA program. This program provides for the study of drug products that are important to children but have been inadequately studied in pediatric populations. We urge continued funding and support for this important research, as well as for training the next generation of pediatric clinical investigators.

Brain Development.—Research on learning disabilities—neurological disorders that can make it difficult to acquire certain academic and social skills—shows that they can be prevented through effective evidence-based programs in school and that when children improve their reading and math skills, brain function normalizes.

Rehabilitation Science.—The National Center for Medical Rehabilitation Research (NCMRR) currently resides within NICHD, yet there is a strong need for elevating the stature of NCMRR. We recommend moving the NCMRR to an independent Institute or Center reporting directly to the NIH Director, or to establish a new Office of Rehabilitation Research within the Office of the NIH Director. Implementation of this structural recommendation would require a statutory change. Elevation of NCMRR has been viewed from the start as a critical step in achieving sufficient critical mass to coordinate rehabilitation science across all the Independent Centers at NIH that conduct and support research directly addressing or related to rehabilitation science.

These research efforts have made significant contributions to the well-being of all Americans, but there is still much to discover. We support the NICHD's recently released Scientific Vision and urge you to support NICHD at funding levels that meet current needs for addressing health issues across the lifespan. Thank you for your consideration and we look forward to working with you on these critical issues.

PREPARED STATEMENT OF THE FRIENDS OF THE NATIONAL INSTITUTE OF DENTAL AND CRANIOFACIAL RESEARCH

Mr. Chairman, Ranking Member, and distinguished Members of the Subcommittee, the members of the Friends of the National Institute of Dental and Craniofacial Research (FNIDCR), a leading broad-based consortium of individuals, academic institutions, patient advocate groups, dental societies, and corporations, that understands the importance of dental, oral and craniofacial health to our society, are requesting fiscal year 2015 funding under section 301 and Title IV of the Public Health Service Act for the National Institute of Dental and Craniofacial Research (NIDCR) to be appropriated at a recommended level of 1.33 percent of the National Institutes of Health's (NIH's) total fiscal year 2015 funding level.

The fiscal year 2014 level enacted by the omnibus bill is \$398.65 million for NIDCR. After transfers, NIDCR's total amount for obligation in fiscal year 2014 is \$397.10 million. President Barack Obama's fiscal year 2015 budget proposal for NIDCR, \$397.13, is at best stagnant if compared to total obligations, and at worse, a decrease of \$1,519,000 if compared to the level Congress appropriated in the fiscal year 2014 omnibus bill. The end result is ongoing diminished grant opportunities that will only discourage young and talented researchers. Also, stagnated funding means NIDCR will not be able to keep up with the increasing rate of medical inflation.

Background

From 1998 to 2011, NIDCR's percentage of total NIH funding decreased from 1.53 percent to 1.33 percent, its lowest percentage, amid a period when NIH's budget doubled. Save for a slight bump in 2012, this percentage remains at 1.33 percent. The Friends of NIDCR has been working to reverse this troublesome trend—and return NIDCR research to a percentage of total NIH funding that is more appropriate and proper. For fiscal year 2014, NIDCR's percentage of total NIH funding is 1.33 percent.

—If Congress enacts the president’s fiscal year 2015 budget figures for NIH and NIDCR, then NIDCR’s percentage of total NIH funding would be at an all-time low, 1.31 percent.

The Friends of NIDCR would welcome the opportunity to work with members of this Subcommittee to ensure NIDCR funding realizes a percentage of total NIH funding that is appropriate, yet realistic. The research performed by NIDCR justifies this approach. This is why the Friends of NIDCR recommends a modest increase in NIDCR’s percentage of total NIH funding for fiscal year 2015 of 1.33 percent based upon the president’s fiscal year 2015 budget request. This is also a consistent recommendation based upon the level enacted by Congress for fiscal year 2014.

NIDCR: A Renown Leader in Research

For 66 years, NIDCR has been the leading sponsor of research and research training in biomedical and behavioral sciences. Its mission is to “improve oral, dental and craniofacial health through research, research training, and the dissemination of health information.”

NIDCR meets its mission by:

- Performing and supporting basic and clinical research;
- Conducting and funding research training and career development programs to ensure an adequate number of talented, well-prepared and diverse investigators is sustained;
- Coordinating and assisting relevant research and research-related activities among all sectors of the research community; and
- Promoting the timely transfer of knowledge gained from research and its implications for health to the public, health professionals, researchers, and policy-makers.

In addition, NIDCR’s Gold Standard Peer Review System ensures that taxpayers’ dollars are being utilized in a wise, effective and productive manner.

NIDCR Research Benefits All Americans

Proper Federal funding of NIDCR will transform the future of medical and dental practice to the benefit of our society and ease the burden on our Nation’s healthcare system. Examples of where NIDCR research has and will benefit society are:

Tooth Decay: Fluorides and sealants have cut the rate of the number of American adults, aged 45 and older, who are without teeth by more than half since the 1950s. Government investment in oral health research saved Americans \$3 for every \$1 invested.

Oral Cancer Detection: Oral cancer affects 38,000 Americans each year and approximately 22 Americans die each day from it. Survival rates are among the lowest of all the major cancers. It is difficult to detect and hard to predict its outcome. However, if detected in early stages, the 5-year survival rate is 83 percent. NIDCR-supported research has yielded initial success with developing new diagnostic techniques that can lead to early detection and life-saving interventions. For example, oral cancer is the first cancer to have its biomarkers mapped using Salivary Diagnostics and the presence of these biomarkers resulted in an early diagnosis of oral cancer 93 percent of the time. Furthermore, as a testament to scientific discoveries, oral researchers have confirmed that oral cancer (traditionally thought of as being driven by extensive use of tobacco and alcohol) possesses a strong and growing link to Human Papilloma Virus (HPV). HPV is now the cause of more oral cancers than smoking. NIDCR supports research aimed to gain a clearer take on HPV-related oral cancers, including their incidence, risk factors, natural history and biology.

Craniofacial Biology. Scientists are defining the genetics that underlie the formation of the head and skull, and researchers are identifying the key areas for craniofacial malformations. For example, NIDCR-supported research has detected proteins associated with craniosynostosis, which is the premature fusion of a baby’s skull bones that causes asymmetric skull growth. NIDCR believes this research could provide the foundation for the development of early detection methods and more effective treatments.

Genome-wide Association Studies. NIDCR supports the first genome-wide association studies (“GWAS”) of cleft lip and/or palate and dental caries. The studies offer significant potential for understanding the molecular and genetic basis of cleft lip and/or palate and dental caries with the goal of improving the ability to predict and manage them by providing the first comprehensive compilation of the biological instructions required to construct the middle region of the human face and to define the genetics that create its developmental disorders, according to NIDCR. The dental caries GWAS revealed areas of the genome that make an individual more likely

to develop decay. Moreover, NIDCR researchers have identified six areas of the genome that may put a person at risk for moderate or severe periodontal disease and patients afflicted with Sjögren's Syndrome and TMJD can benefit from this program.

Moreover, NIDCR research benefits millions of Americans with:

- Periodontal Disease,
- Chronic Dry Mouth,
- Chronic Facial and Oral Pain, such as TMJD, and
- Bone and Cartilage Regeneration.

How NIDCR Research Makes a Difference

Because Friends of NIDCR is a broad-based coalition of members, we are able to share first-hand perspectives from across the spectrum of the oral health community.

The TMJ Association:

During the past decade, NIDCR-funded research directed toward Temporomandibular Disorders has been a “game changer.” Previously thought to be a condition about teeth and jaws, research has demonstrated that this is a complex condition mediated by genes, sex, age, and epigenetics. We now also know that for many, TMD is a chronic pain condition and that in addition these patients also present with other comorbid pain conditions that co-occur more than by chance. These findings have truly revolutionized the way that these conditions are researched and will ultimately be treated. It is important to note that the National Institutes of Health are the only sources of funding of TM Disorders in the United States. We rely on their resources to improve the healthcare and quality of life for the 35 million TMJ patients in this country. Our hope is in science and the NIH, through its Institutes such as NIDCR, provides us with that hope.

Ostrow School of Dentistry of the University of Southern California:

NIDCR funding is essential to the success of several areas of research at USC that directly impact millions of people in the U.S. and worldwide. First, thanks to the NIDCR, we have made progress in understanding cleft lip and palate, craniosynostosis, and other birth defects of the craniofacial region. According to the CDC, the lifetime cost of treating the children born each year in the U.S. with cleft lip or palate is \$697 million. Every day, our researchers come closer to better treatments and preventive measures to help reduce this cost and improve quality of life. Moreover, we are working to leverage the dramatic potential of stem cells to regenerate bone and other tissues that may be lost due to birth defects, trauma, or disease. The NIDCR also funds our efforts to prevent dental caries, which is a major global health concern affecting 92 percent of American adults. Finally, the NIDCR supports our community outreach program in California's diverse population, through which we are investigating how to improve oral health for everyone in America.

Research Drives the Economy, Innovates

Despite the fact 54 percent of Americans thought Federal spending for medical and health research should be exempt from across-the-board cuts outlined in the Budget Control Act of 2011¹, the ramifications of sequestration still linger. However, Friends of NIDCR maintains that investment in medical research powers our innovation economy and provides life-saving treatments and cures. For example, a typical NIH grant supports the salaries of about seven high-tech jobs. Moreover, cuts or stagnate funding will only set the U.S. back at a time when other countries are rapidly increasing investment in research. Eighty-five percent of likely voters are concerned about the impact of a decreased Federal investment in research, including the possibility of scientists leaving their profession or moving abroad to countries with a stronger investment in research.² NIDCR-funded grants contribute to our Nation's economy and keep scientists from looking abroad for work. fiscal year 2013 NIDCR-funded grants had a presence in 120 congressional districts (often multiple awards for a congressional district) in 43 States and territories. This equates to 75 percent of NIDCR-funded research being distributed to grantees at universities, dental schools, and medical schools, primarily in the U.S. Therefore, a significant portion of NIDCR-funded research occurs away from the NIH campus. However, this nationwide NIDCR presence will surely decline with decreased investment in research.

¹“More than Half of Americans Doubt U.S. Global Leadership in 2020,” Research!America press release, March 14, 2012, <http://www.researchamerica.org/release> —14march12—poll.

² Ibid.

Health Disparities Research Program

Finally, through the NIDCR Health Disparities Research Program, a difference is being made in meeting the health needs of our Nation's low-income, underserved, and high-risk populations. Sadly, this need was made apparent with the tragic passing of 12-year-old Deamonte Driver who died from a tooth infection in 2007. As a result of the program, tailored interventions to prevent dental caries and oral cancer are being tested in community settings such as urban public housing, community health centers, rural Project Head Start centers, low-income senior housing facilities, and primary medical care offices.

RECOMMENDATION

Eighty-five percent of Americans are concerned about stagnate funding for medical research.³ Proper funding of medical and health research is essential to the overall health and well-being of our fellow Americans. We firmly contend that medical discoveries and advances from NIDCR funding lead to improvements in dental practices and change the scope of public health policies across the Nation. Whether it is detecting a clear link between bacteria in the mouth and heart disease—or discovering early stages of oral cancer—or searching for breakthroughs to help combat facial and oral pain—we all benefit when we make NIDCR a priority. Therefore, based upon the merits of the research conducted by NIDCR, and its demonstrated benefits to the lives of countless Americans, we respectfully request the Subcommittee to fund NIDCR at 1.33 percent of NIH's funding level, so that it can realize the full potential of its worthy mission and sustain its beneficial scientific research.

Thank you for the opportunity to present our written testimony before the Subcommittee.

[This statement was submitted by Christian Stohler, D.D.S., DrMedDent, President, Friends of the National Institute of Dental and Craniofacial Research.]

PREPARED STATEMENT OF THE FRIENDS OF THE NATIONAL INSTITUTE ON DRUG ABUSE

Mr. Chairman and Members of the Subcommittee, thank you for the opportunity to submit testimony to the Subcommittee in support of the National Institute on Drug Abuse (NIDA). The Friends of the National Institute on Drug Abuse is a coalition of over 150 scientific and professional societies, patient groups, and other organizations committed to preventing and treating substance use disorders as well as understanding their causes through the research agenda of the National Institute on Drug Abuse (NIDA).

We are pleased to provide testimony in support of the work carried out by scholars around the country whose work is supported by NIDA. Recognizing that so many health research issues are inter-related, we request that the subcommittee provide at least \$32 billion for the National Institutes of Health (NIH) and within that amount a proportionate increase for the National Institute on Drug Abuse, in your Fiscal 2015 Labor, Health and Human Services, Education and Related Agencies Appropriations bill. We also respectfully request the inclusion of the following NIDA specific report language.

Marijuana Research. Efforts to legalize or “medicalize” marijuana continue across the United States. The Committee understands that research from different areas of science is converging on the fact that regular marijuana use by young people can have a long-lasting negative impact on the structure and function of their brains, resulting in lower educational achievement, reduced IQ, etc. Research clearly demonstrates that marijuana has the potential to cause problems in daily life or make a person's existing problems worse. NIDA is encouraged to continue to fund research on preventing and treating marijuana abuse and addiction, and the possible health and policy implications of proposals to implement “medical marijuana” or marijuana legalization programs across the U.S.

Opiate Abuse and Addiction. The Committee is concerned about the continued crisis of prescription drug abuse in the U.S. In particular, the June 2011 IOM report on pain indicates that abuse and misuse of prescription opioid drugs resulted in an annual estimated cost to the nation of \$72,500,000,000. Further, the Committee is very concerned with the potential rise in heroin abuse and addiction as a result of successful efforts to combat the prescription drug side of this issue. The Committee

³“America Speaks,” Poll Data Summary Volume 13, Research!America, <http://www.researchamerica.org/uploads/AmericaSpeaksV13.pdf>.

urges NIDA to 1) continue funding research on medications to alleviate pain, including the development of pain medications with reduced abuse liability; 2) as appropriate, work with private companies to fund innovative research into such medications; and 3) report on what we know regarding the transition from opiate analgesics to heroin abuse and addiction within affected populations.

Medications Development. The Committee recognizes that next-generation pharmaceuticals will surely take advantage of new technologies. In the context of NIDA funding, chief among these are NIDA's current approaches to develop viable immunotherapeutic or biologic (e.g., bioengineered enzymes) approaches for treating addiction. The goal of this active area of research is the development of safe and effective vaccines or antibodies that target specific drugs, like nicotine, cocaine, and heroin, or drug combinations. The Committee is excited by this approach—if successful, immunotherapies, alone or in combination with other medications, behavioral treatments, or enzymatic approaches, stand to revolutionize how we treat, and, maybe even someday, prevent addiction. The Committee looks forward to hearing more about work in this area.

Nurturing Talent and Innovation in Research. The Committee commends NIDA for its continued support of innovative research on drug addiction and related health problems such as pain and HIV/AIDS, and the Institute's effort to be at the forefront of training the next generation of innovative researchers. The 6 year-old Avant-Garde award is a good example of a program that stimulates high-impact research that could lead to groundbreaking opportunities for the prevention and treatment of HIV/AIDS in drug abusers. The Committee understands that NIDA is now crafting a new kind of award, which would blend NIH's Pioneer and New Innovator award mechanisms. This new opportunity, called "AVENIR" awards, is designed to attract creative young investigators into HIV/drug abuse public health research. The Committee strongly supports this effort, and asks the Institute to report on its progress in future appropriations and related requests.

Research to Assist Military Personnel, Veterans, and Their Families. The Committee recognizes the significant health challenges, including substance abuse and addiction, faced by military personnel, veterans, and their families. Many of these individuals need help confronting war-related problems including traumatic brain injury, PTSD, depression, anxiety, sleep disturbances, and substance abuse and addiction. The Committee commends NIDA for its successful efforts to coordinate and support research with the Department of Veterans Affairs, Department of Defense, and other NIH Institutes focusing on these populations, and strongly urges NIDA to continue work in this area.

Raising Awareness and Engaging the Medical Community in Drug Abuse and Addiction Prevention and Treatment. The Committee is very pleased with NIDAMed, an initiative designed to reach out to physicians, physicians in training, and other healthcare professionals. The Committee urges the Institute to continue its focus on activities to provide physicians and other medical professionals with the tools and skills needed to incorporate drug abuse screening and treatment into their clinical practices.

Drug abuse is costly to Americans; it ruins lives, while tearing at the fabric of our society and taking a huge financial toll on our resources. Beyond the unacceptably high rates of morbidity and mortality, drug abuse is often implicated in family disintegration, loss of employment, failure in school, domestic violence, child abuse, and other crimes. Placing dollar figures on the problem; smoking, alcohol and illegal drug use results in an exorbitant economic cost on our nation, estimated at over \$600 billion annually. We know that many of these problems can be prevented entirely, and that the longer we can delay initiation of any use, the more successfully we mitigate future morbidity, mortality and economic burdens.

Over the past three decades, NIDA-supported research has revolutionized our understanding of addiction as a chronic, often-relapsing brain disease —this new knowledge has helped to correctly situate drug addiction as a serious public health issue that demands strategic solutions. By supporting research that reveals how drugs affect the brain and behavior and how multiple factors influence drug abuse and its consequences, scholars supported by NIDA continue to advance effective strategies to prevent people from ever using drugs and to treat them when they cannot stop.

NIDA supports a comprehensive research portfolio that spans the continuum of basic neuroscience, behavior and genetics research through medications development and applied health services research and epidemiology. While supporting research on the positive effects of evidence-based prevention and treatment approaches, NIDA also recognizes the need to keep pace with emerging problems. We have seen encouraging trends—significant declines in a wide array of youth drug use—over the past several years that we think are due, at least in part, to NIDA's

public education and awareness efforts. However, areas of significant concern include the recent increase in lethalties due to heroine, as well as the continued abuse of prescription opioids and the recent increase in designer drugs availability and their deleterious effects. The need to increase our knowledge about the effects of marijuana is most important now that decisions are being made about its approval for medical use and/or its legalization. We support NIDA in its efforts to find successful approaches to these difficult problems.

The Nation's previous investment in scientific research to further understand the effects of abused drugs on the body has increased our ability to prevent and treat addiction. As with other diseases, much more needs to be done to improve prevention and treatment of these dangerous and costly diseases. Our knowledge of how drugs work in the brain, their health consequences, how to treat people already addicted, and what constitutes effective prevention strategies has increased dramatically due to support of this research. However, since the number of individuals continuing to be affected is still rising, we need to continue the work until this disease is both prevented and eliminated from society.

We understand that the fiscal year 2015 budget cycle will involve setting priorities and accepting compromise, however, in the current climate we believe a focus on substance abuse and addiction, which according to the World Health Organization account for nearly 20 percent of disabilities among 15–44 year olds, deserves to be prioritized accordingly. We look forward to working with you to make this a reality. Thank you for your support for the National Institute on Drug Abuse.

PREPARED STATEMENT OF THE FSH SOCIETY, INC.

Honorable Chairwoman Mikulski and Ranking Member Harkin, thank you for the opportunity to submit this testimony. Facioscapulohumeral muscular dystrophy (FSHD), is one of the most common adult muscular dystrophies with a prevalence of 1:15,000–1:20,000.^{1,2} For a half-million men, women, and children worldwide the major consequence of inheriting this genetic form of muscular dystrophy is a lifelong progressive loss of all skeletal muscles. FSHD is a crippling and life shortening disease. No one is immune. It is both genetically and spontaneously transmitted to children. It can affect multiple generations and entire families.

With FSHD there is a loss of muscle strength that ranges between one and 4 percent a year during a lifetime. In terms of functional impairment, 20 percent of FSHD-affected individuals over age fifty will require the use of a wheelchair. FSHD also has very specific non-muscular manifestations; hearing-loss, restrictive lung disease, supraventricular arrhythmias (rare), and retinal vasculopathy. 95 percent of individuals with FSHD have the FSHD1 (FSHD1A OMIM: 158900) genetic variation—caused by the contraction of DNA macrosatellite repeat units, termed D4Z4 repeats, on chromosome 4, leading to the release of transcriptional repression of a retrogene (DUX4) believed to be associated with the cause of disease. Of the 5 percent of FSHD individuals remaining, 80 percent of those are the FSHD2 (FSHD1B OMIM: 158901) genetic variation—caused by mutations in the SMCHD1 gene on chromosome 18 that helps to maintain the structure of the D4Z4 repeats on the long arm of chromosome 4.

The National Institutes of Health (NIH) is the principal source of funding of research on FSHD currently at the \$5 million level. For nearly two decades, this Committee has supported the incremental growth in funding for FSHD research. I am pleased to report that this modest investment has produced huge scientific returns.

1. Congress has made a major difference in muscular dystrophy. I have testified many times before Congress, nearly fifty. When I first testified, we did not know the mechanism of this disease. Now we do. When I first testified, we assumed that FSHD was a rare form of muscular dystrophy. Now we understand it to be one of the most prevalent forms of muscle disease, if not the most prevalent muscle disease based on new ways of evaluating the disease clinically within families. Congress is responsible for this success, through its sustaining support of the NIH and the enactment of the Muscular Dystrophy CARE Act. We are aware that MD Care Act does not set the amount of spending on FSHD or the other dystrophies at the NIH and we recognize that funding levels are determined in the appropriations process and the numbers of grant applications received and funded by the NIH on FSHD. Even though it is a technically separate legislative process, the reauthorization of

¹Flanigan KM, et al. Genetic characterization of a large, historically significant Utah kindred with facioscapulohumeral dystrophy. *Neuromuscul Disorders* 2001;11:525–529.

²Mostacciolo ML, et al. Facioscapulohumeral muscular dystrophy: epidemiological and molecular study in a north-east Italian population sample. *Clinical Genetics* 2009;75:550–555.

the MD Care Act does raise the visibility of all the muscular dystrophies which can be of help in the appropriations process—and we thank you for your support of the MD Care Act. Further, we recognize and feel at this time in FSHD research that there are additional efforts and pathways that Congress can request and the NIH can enact to increase the amount of research funding on FSHD in the NIH portfolio that neither increases the NIH budget required nor takes money from another area of research.

2. Quantum leaps in our understanding of FSHD have occurred in past three and a half years. The past three and a half years have seen remarkable contributions made by researchers funded by NIH.

—On August 19, 2010, American and Dutch researchers published a paper which dramatically expanded our understanding of the mechanism of FSHD.³ A front page story in the New York Times quoted the NIH Director Dr. Francis Collins saying, “If we were thinking of a collection of the genome’s greatest hits, this would go on the list.”⁴

—Two months later, another paper was published that made a second critical advance in determining the cause of FSHD.⁵ The research shows that FSHD is caused by the inefficient suppression of a gene that may be normally expressed only in early development.

—On January 17, 2012, an international team of researchers based out of Seattle discovered a stabilized form of a normally suppressed gene called DUX4 required to develop chromosome 4 linked FSHD.⁶

—Six months later, another high profile paper produced by a Senator Paul A. Wellstone Cooperative Research Center of the NIH, used sufficiently “powered” large collections of genetically matched FSHD cell lines generated by the NIH center that are both unique in scope and shared with all researchers worldwide, to improve on the Seattle group’s finding by postulating that DUX4-fl expression is necessary but not sufficient by itself for FSHD muscle pathology.⁷ This work was also supported by a NIH cooperative research center grant mandated by MD CARE Act.

—On July 13, 2012, a team of researchers from the, United States, Netherlands and France identified mutations in a gene causing 80 percent of another form of FSHD. This paper furthers our understanding of the molecular pathophysiology of FSHD. This work too was supported in part by a program project grant from NIH.⁸

—In 2013 and continuing into 2014, papers have been published clearly documenting functional impairment in FSHD, clinical and genetic features of hearing loss FSHD, restrictive lung disease and respiratory insufficiency, Coats syndrome and vision loss in FSHD, high-throughput screening that identify inhibitors of DUX4-induced myoblast toxicity, better definition of epigenetic features of FSHD, Pain and FSHD, MRI/MRS studies, biomarkers for FSHD, the demonstration that although the transcription of the toxic protein DUX4 occurs in only a limited number of nuclei, the resulting protein diffuses into nearby nuclei within the myotubes, thus spreading aberrant gene expression throughout a muscle, to name a few.

Many of these researchers have started their efforts in FSHD with seed funding from the FSH Society and have received continued support from the FSH Society, the NIH, and the Muscular Dystrophy Association and other partners.

3. Remarkable progress in FSHD research and the need to keep moving forward. Last October, nearly 100 researchers from around the world gathered under the direction of Massachusetts Institute of Technology professor, David Housman, PhD, Chair of the FSH Society’s Scientific Advisory Board, at the David H. Koch Center

³Lemmers, R.J., et al, A Unifying Genetic Model for Facioscapulohumeral Muscular Dystrophy Science 24 September 2010: Vol. 329 no. 5999 pp. 1650–1653.

⁴Kolata, G., Reanimated ‘Junk’ DNA Is Found to Cause Disease. New York Times, Science. Published online: August 19, 2010 <http://www.nytimes.com/2010/08/20/science/20gene.html>.

⁵Snider, L., Geng, L.N., Lemmers, R.J., Kyba, M., Ware, C.B., Nelson, A.M., Tawil, R., Filippova, G.N., van der Maarel, S.M., Tapscott, S.J., and Miller, D.G. (2010). Facioscapulohumeral dystrophy: incomplete suppression of a retrotransposed gene. PLoS Genet. 6, e1001181.

⁶Geng et al., DUX4 Activates Germline Genes, Retroelements, and Immune Mediators: Implications for Facioscapulohumeral Dystrophy, Developmental Cell (2012), doi:10.1016/j.devcel.2011.11.013.

⁷Jones TL, et al, Facioscapulohumeral muscular dystrophy family studies of DUX4 expression: evidence for disease modifiers and a quantitative model of pathogenesis. Hum Mol Genet. 2012 Oct 15;21(20):4419-30. Epub 2012 Jul 13.

⁸Lemmers, R.J., et al, Digenic inheritance of an SMCHD1 mutation and an FSHD-permissive D4Z4 allele causes facioscapulohumeral muscular dystrophy type 2. Nat Genet. 2012 Dec;44(12):1370-4. doi: 10.1038/ng.2454. Epub 2012 Nov 11.

for Integrative Cancer Research on the campus of M.I.T. for the annual FSH Society International Research Consortium meeting; there was a palpable feeling of FSHD research having “arrived” in the big time. The general discussion of day two covered four major areas. With respect to the first area, called DUX4, the unanimous conclusion of the general discussion was that over-expression of the toxic transcription factor DUX4 is at the root of FSHD1 and FSHD2 and that DUX4 expression is necessary but not always sufficient to cause FSHD. Research should focus on upstream and downstream molecular pathways and mechanisms as they form the most plausible intervention targets. The group also discussed needs and priorities in three additional areas: disease models, intervention, clinical studies and trial readiness. The priorities stated for 2014, at the October 21–22, 2013, FSH Society FSHD IRC meetings are as follows:⁹

- The DUX4 interactome
- Understanding DUX4 manifestation and variation
- Additional genetic heterogeneity; non-FSHD1 and FSHD2
- Disease models
- Well documented natural history with reliable endpoints; modulating mechanisms/genes
- Increasing data depth of patient databases with extensive (follow-up) clinical data
- Prepare for clinical trials: reliable and meaningful outcome measures; with access to discreet patient populations and disease mechanism of action classes.
- Therapy; proof-of-principle experiments
- Focus on translational research; from clinic to bench and back
- Understanding pathophysiology of FSHD: connection to DUX4, heterogeneity, asymmetry, role of inflammation; infiltrates and etiology

Given the recent developments, there is a need to ramp up the preclinical enterprise and build/organize infrastructure needed to conduct clinical trials. Our immediate priorities should be to confirm the new hypotheses and targets. We need to be prepared for this new era in the science of FSHD. Many leading experts are now turning to work on FSHD not only because it is one of the most complicated and challenging problems seen in science, but because it represents the potential for great discoveries, insights into stem cells, transcriptional processes, new ways of thinking about disease of epigenetic etiology, and for treating diseases.

4. NIH Funding for Muscular Dystrophy. Mr. Chairman, these major advances in scientific understanding and epidemiological surveillance are not free. They come at a cost. Since Congress passed the MD CARE Act, research funding at NIH for muscular dystrophy has increased 4-fold. While FSHD research funding has increased 12-fold during this period, the level of funding is still anemic and, for FSHD, has been astonishingly flat for the past 6 years.

⁹2013 FSH Society FSHD International Research Consortium, held October 22–23, 2013 co-sponsored by DHHS NIH NICHD University of Massachusetts School of Medicine Senator Paul D. Wellstone MD CRC for FSHD. To read the expanded summary and recommendations of the group see: <http://www.fshsociety.org/pages/sciConsortium.html>.

[Dollars in millions]

	Fiscal Year													
	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014 e	2015 e	
All MD	39.1	38.7	39.5	39.9	47.2	56	83	86	75	75	76	78	78	
FSHD	1.5	2.2	2.0	1.7	3	3	5	6	6	5	5	6	6	
FSHD (percent total MD)	4	6	5	4	5	5	6	7	8	7	7	8	8	

FSHD Research Dollars (in millions) and FSHD as a Percentage of Total NIH Muscular Dystrophy Funding.
 Sources: NIH/OD Budget Office and NIH OCPL and NIH RCDC RePORT (e = estimate).

Despite the great success of the past three and a half years in the science of FSHD brought about by Congress we are concerned that under the current funding environment that new research projects will not be funded or existing programs will not be renewed. We have conveyed to the NIH leadership at the Office of the Director, NIAMS, NINDS, NICHD, NHLBI and the Executive Secretary of the MDCC our grave concern that FSHD research is way too under-represented in the NIH portfolio and needs a proactive effort on the part of NIH.

Alan E. Guttmacher, MD., Director, NICHD and chair of the Muscular Dystrophy Coordinating Committee (MDCC) recently wrote to me in response to a letter I sent to NIH Director, Dr. Francis Collins asking for a significant improvement in the overall level of funding for FSHD, that though "it is notable that NIH funding for all forms of muscular dystrophy has nearly doubled since the 2006 NIH Action Plan on Muscular Dystrophy was released. [and] Since this has been a period of relatively flat funding for NIH, increased funding for anyone area speaks to the excellent quality of the research applications received during that time, and this is true of FSHD research applications where funding has almost tripled. We believe that the 2006 Action Plan was instrumental in improving coordination among the Institutes and Centers at NIH that support research on the muscular dystrophies, so that scarce resources are well-spent. We plan to revise the Action Plan this year, with a meeting in July to discuss what research opportunities have emerged; the goal is to ask the MDCC to approve the revised plan at its Fall 2014 meeting." While we wholeheartedly agree with these statements and we are instrumental and involved in the MD CARE Act and most appreciative of all of NIH's efforts and Congress' work in this area—we do not however agree on the plus one order of magnitude (x10) of difference between muscular dystrophy funding and FSHD funding. While all muscular dystrophy increased from \$39.9 million to \$78 million; FSHD increased from \$1.7 million to \$6 million. The economy of scale is so different in particular for FSHD, being equally devastating and burdensome as the disease receiving the most funding in this category, and though it functions in the exact same U.S. Federal research infrastructure. NIH needs to redress the imbalance of funding in the muscular dystrophy portfolio by fostering opportunities for multidisciplinary research on FSHD, a common and complex form of dystrophy, commensurate with its prevalence and disease burden. The future action plan should address this issue head-on.

We request for fiscal year 2015, a tripling of the NIH FSHD research portfolio to \$18 million or a level of approximately 20 percent of the total muscular dystrophy funding at NIH. This will allow an expansion of basic research awards, expansion of post-doctoral and clinical training fellowships, dedicated centers to design and conduct clinical trials on FSHD and more U.S. DHHS NIH Senator Paul D. Wellstone Muscular Dystrophy Cooperative Research Centers.

Agency: National Institutes of Health (NIH)

Account: National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), and the National Institute of Neurological Disorders and Stroke (NINDS), and the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)

Fiscal year 2015 Report Language: The Committee encourages the NIH to foster opportunities for multidisciplinary research on facioscapulohumeral muscular dystrophy (FSHD), a common and complex form of muscular dystrophy, commensurate with its prevalence and disease burden. The Committee hopes such advances will be utilized to help advance treatments and access to therapies for this grave disease.

We are aware of the great pressures on the Federal budget, but NIH can easily help increase its portfolio on FSHD given the breakneck speed of discovery in FSHD. These are easy ways for NIH to convey to researchers that it has a revised plan and an interest in funding research in FSHD. There are no quotas on peer-reviewed research above pay line at the NIH, and NIH can help by issuing written announcements that efforts invested in writing FSHD grant applications will be met with interest. This is the time to fully and expeditiously exploit the advances for which the American taxpayer has paid. Thank you for this opportunity to testify before your committee.

[This statement was submitted by Daniel Paul Perez, President & CEO, FSH Society.]

PREPARED STATEMENT OF THE GBS/CIDP FOUNDATION INTERNATIONAL

Chairman Harkin and distinguished members of the Subcommittee, thank you for your time and your consideration of the priorities of the community of individuals impacted by Guillain-Barré Syndrome (GBS), Chronic Inflammatory Demyelinating

Polyneuropathy (CIDP), and related conditions as you work to craft the fiscal year 2015 Labor, Health and Human Services Appropriations Bill.

ABOUT GBS AND CIDP

Guillain-Barré Syndrome

GBS is an inflammatory disorder of the peripheral nerves outside the brain and spinal cord. It's also known as Acute Inflammatory Demyelinating Polyneuropathy and Landry's Ascending Paralysis.

The cause of GBS is unknown. We do know that about 50 percent of cases occur shortly after a microbial infection (viral or bacterial), some as simple and common as the flu or food poisoning. Some theories suggest an autoimmune trigger, in which the patient's defense system of antibodies and white blood cells are called into action against the body, damaging myelin (nerve covering or insulation), leading to numbness and weakness.

GBS in its early stages is unpredictable, so except in very mild cases, most newly diagnosed patients are hospitalized. Usually, a new case of GBS is admitted to ICU (Intensive Care) to monitor breathing and other body functions until the disease is stabilized. Plasma exchange (a blood "cleansing" procedure) and high dose intravenous immune globulins are often helpful to shorten the course of GBS. The acute phase of GBS typically varies in length from a few days to months, with over 90 percent of patients moving into the rehabilitative phase within four weeks. Patient care involves the coordinated efforts of a team such as a neurologist, physiatrist (rehabilitation physician), internist, family physician, physical therapist, occupational therapist, social worker, nurse, and psychologist or psychiatrist. Some patients require speech therapy if speech muscles have been affected.

Recovery may occur over 6 months to 2 years or longer. A particularly frustrating consequence of GBS is long-term recurrences of fatigue and/or exhaustion as well as abnormal sensations including pain and muscle aches. These can be aggravated by 'normal' activity and can be alleviated by pacing activity and rest.

Chronic Inflammatory Demyelinating Polyneuropathy

CIDP is a rare disorder of the peripheral nerves characterized by gradually increasing weakness of the legs and, to a lesser extent, the arms.

It is the gradual onset as well as the chronic nature of CIDP that differentiates it from GBS. Fortunately, CIDP is even rarer than GBS. The incidence of new cases is estimated to be between 1.5 and 3.6 in a million people (compare to GBS: 1–2 in 100,000).

Like GBS, CIDP is caused by damage to the covering of the nerves, called myelin. It can start at any age and in both genders. Weakness occurs over two or more months.

Unlike GBS, CIDP is not self-limiting (with an end to the acute phase). Left untreated, 30 percent of CIDP patients will progress to wheelchair dependence. Early recognition and treatment can avoid a significant amount of disability.

Post-treatment life depends on whether the disease was caught early enough to benefit from treatment options. Patients respond in various ways. The gradual onset of CIDP can delay diagnosis by several months or even years, resulting in significant nerve damage that may take several courses of treatment before benefits are seen. The chronic nature of CIDP differentiates long-term care from GBS patients. Adjustments inside the home may need to be made to facilitate a return to normal life.

ABOUT THE FOUNDATION

The Foundation's vision is that every person afflicted with GBS, CIDP, or variants has convenient access to early and accurate diagnosis, appropriate and affordable treatments, and dependable support services.

The Foundation's mission is to improve the quality of life for individuals and families across America affected by GBS, CIDP, and their variants by:

- Providing a network for all patients, their caregivers and families so that GBS or CIDP patients can depend on the Foundation for support, and reliable up-to-date information.
- Providing public and professional educational programs worldwide designed to heighten awareness and improve the understanding and treatment of GBS, CIDP and variants.
- Expanding the Foundation's role in sponsoring research and engaging in patient advocacy.

SEQUESTRATION

We have heard from the medical research community that sequestration and deficit reduction activities have created serious issues for Federal funding opportunities and the career development pipeline. In order to ensure that research into GBS, CIDP, and related disorders can continue to move forward, and, more importantly, to ensure that our country is adequately preparing the next generation of young investigators, we urge you to avert, mitigate, or otherwise eliminate the specter of sequestration. While the Foundation has anecdotal accounts of the harms of sequestration, the Federated American Societies for Experimental Biology has reported:

- In constant dollars (adjusted for inflation), the NIH budget in fiscal year 2013 was \$6 billion (22.4 percent) less than it was in fiscal year 2003.
- The number of competing research project grants (RPGs) awarded by NIH has also fallen sharply since fiscal year 2003. In fiscal year 2013, NIH made 8,283 RPG awards, which is 2,110 (20.3 percent) fewer than in fiscal year 2003.
- Awards for R01-equivalent grants, the primary mechanism for supporting investigator-initiated research, suffered even greater losses. The number awarded fell by 2,528 (34 percent) between fiscal year 2003 and fiscal year 2013.

The pay line for some NIH funding mechanisms has fallen from 18 percent to 10 percent while the average age for a researcher to receive their first NIH-funded grant has climbed to 42. These are strong disincentives to choosing a career as a medical researcher. Our scaling-back is occurring at a time when many foreign countries are investing heavily in their biotechnology sectors. China alone plans to dedicate \$300 million to medical research over the next 5 years; this amount is double the current NIH budget over the same period of time. Scientific breakthroughs will continue, but America may not benefit from the return-on-investment of a robust biotechnology sector. For the purposes of economic and national security, as well as public health, the Foundation asks that you work with your colleagues to eliminate sequestration and recommit to supporting this Nation's biomedical research enterprise.

CENTERS FOR DISEASE CONTROL AND PREVENTION

CIDP is a progressive condition with serious health impacts. Patients can end up almost completely paralyzed and on a ventilator. The key to limiting serious health impacts is an early and accurate diagnosis. The time it takes for a CIDP patient to begin therapy is linked to the length of therapy and the seriousness of the health impacts. An early diagnosis can mean the difference between a 3 month or 18 month hospital stay, or no hospitalization at all. For the Federal healthcare system, there is an economic incentive to ensure early and accurate diagnosis as longer hospitalizations equate to higher costs.

CDC and NCCDPHP have resources that could be brought to bear to improve public awareness and recognition of CIDP and related conditions. In order to initiate new, potentially cost-saving programs, CDC requires meaningful funding increases to support crucial activities.

NATIONAL INSTITUTES OF HEALTH

NIH hosts a modest research portfolio focused on GBS, CIDP, and related conditions. This research has led to important scientific breakthroughs and is well positioned to vastly improve our understanding of the mechanism behind these conditions. In fact, NINDS, NIAID, and the Office of Rare Diseases Research (ORDR) housed within NCATS have expressed interest in hosting a State-of-the-Science Conference on autoimmune peripheral neuropathies. This conference would allow intramural and extramural researchers to develop a roadmap that would lead research into these conditions into the next decade. While such a conference would not require additional appropriations, the Foundation urges you to provide NIH with meaningful funding increases to facilitate growth in the GBS, CIDP, and related conditions research portfolio.

Thank you for your time and your consideration of the community's requests.

PREPARED STATEMENT OF GIRL SCOUTS OF THE USA

As the preeminent leadership development organization for girls, Girl Scouts of the USA (Girl Scouts) serves over two million girls each year, ages 5 to 17, from every corner of the United States and its territories, with value placed on diversity and inclusiveness. We also serve nearly 17,000 American girls living outside of the United States in over 90 countries. Through our 112 councils and USA Girl Scouts Overseas, and more than 800,000 dedicated volunteers, we continue to deliver the

Girl Scout Leadership Experience (GSLE)—the world's most comprehensive and best program for girls' leadership development.

BUILDING GIRLS LEADERSHIP

Girl Scout experiences through GSLE are, as much as possible, girl-led and encourage hands-on and cooperative learning. Our framework specifies 15 outcomes—behaviors, attitudes, skills and values—that develop girls of courage, confidence and character. We provide significant financial assistance to vulnerable girls who cannot afford to pay to belong to Girl Scouts. In many communities, Girl Scouts is the single most visible and viable positive choice for these girls as opposed to negative behavior. Girl Scouts plays a major role in helping girls find their voice in a positive and productive way.

Women today are well educated but still underrepresented in high-paying positions and positions of leadership, facing societal barriers to leading and achieving success in everything from technology and science to business and industry. With this in mind, we need a bold policy shift so that girls are able to achieve their full leadership potential now and later in life, as women. Girl Scouts is eager to work with policymakers to create opportunities and environments that foster girls' leadership development.

PENSION RELIEF

Under Department of Labor, General Provisions, Girl Scouts respectfully requests the insertion of the following language as our highest priority request:

SEC.—ELECTION NOT TO BE TREATED AS AN ELIGIBLE CHARITY PLAN.—A plan sponsor of an eligible charity plan (as defined in subsection (d) of section 104 of the Pension Protection Act of 2006) may elect, effective for the first plan year beginning after December 31, 2013, to have section 104 of such Act not apply to such plan. In the case of such an election, solely for plan years beginning after December 31, 2013, section 430(c) of the Internal Revenue Code of 1986 and section 303(c) of the Employee Retirement Income Security Act of 1974 shall apply as if such sections had applied to the first two plan years beginning after December 31, 2009, and as if the plan sponsor had elected to apply section 430(c)(2)(D)(iii) of such Code and section 303(c)(2)(D)(iii) of such Act with respect to those two plan years.

The proposed language, which would only affected eligible charities and thus should not have an associated cost, would modify the rule established by section 202(b) of the Preservation of Access to Care for Medicare Beneficiaries and Pension Relief Act of 2010, Public Law 111–192. The effect of the proposed language is similar in effect to section 2 of H.R. 4915, as passed by the Senate in December of 2010, which also allowed a plan sponsor of an eligible charity plan not to have section 104 of the Pension Protection Act of 2006 apply.

Girl Scouts organization, on behalf of the millions of girls we serve, respectfully requests this technical fix. The language simply says that as of 2014, we, and all similarly structured charities, be permitted to elect in to the Pension Protection Act funding rules, which are the Federal pension rules applicable to corporate America.

In addition to our request pertaining to pension relief, the following are the key policy priority areas where we can offer research and programmatic success stories:

STEM EDUCATION

As the preeminent organization for girls and a leader on informal STEM education, Girl Scouts is committed to ensuring that every girl has the opportunity to explore and build an interest in science, technology, engineering and mathematics. The strength of our Nation depends on increasing girls' involvement in STEM, to develop critical thinking, problem solving and collaboration skills that are important throughout life.

In 2012, the Girl Scout Research Institute released *Generation STEM: What Girls Say about Science, Technology, Engineering and Math*, which found girls are interested in STEM and aspire to STEM careers, but need further exposure and education about what STEM careers can offer and how STEM can help girls make a difference in the world.

Among some of *Generation STEM's* other findings:

- 74 percent of teen girls are interested in the field of STEM and STEM subjects.
- Girls like the process of learning, asking questions, and problem solving.
- Girls who are interested in STEM are significantly better students, have higher confidence in their abilities, and higher academic goals.
- But while 81 percent say they are interested in pursuing STEM careers, only 13 percent say it's their first choice. About half of all girls feel that STEM isn't

a typical career path for girls. 57 percent of girls say that if they went into a STEM career, they'd have to work harder than a man just to be taken seriously. —African American and Hispanic girls have high interest in STEM, high confidence and work ethic, but say they have fewer supports and less STEM exposure than Caucasian girls.

Research shows that girl-only settings not only provide a sense of belonging, but are more effective environments for personal development, including learning new skills and building self-confidence. In emotionally and physically safe environments, like those provided by Girl Scouts, girls partner with positive role models in a range of activities not limited by gender stereotypes. Girl Scout programs also emphasize partnerships, public education campaigns, mentorship programs, career exploration, traditional badges, and innovative new programming.

—As Congress considers consolidations and a redesign of existing Federal STEM programs, we urge you to invest more of a focus on engaging and motivating girls in STEM, in particular girls in underrepresented minorities and at younger ages before their interest wanes in middle school. Strategies include introducing girls to diverse role models and mentors; promoting proven techniques for engaging girls in STEM including, single-gender learning; and, hands-on and experiential learning opportunities in after-school or out-of-school environments.

FINANCIAL LITERACY

The world's current economic challenges have made financial literacy skills matter now more than ever. Girl Scouts offers a financial literacy program at every grade level from K–12. Through our Girl Scout financial education programming, girls learn to handle money and the basics of budgeting, banking, saving, using credit and planning for retirement and even practicing philanthropy.

Additionally, the Girl Scout Cookie Program is often girls' first introduction to business planning and entrepreneurship. The \$790 million Girl Scout Cookie Program is the largest girl-led business in the country.

While lack of financial literacy is a growing concern, relatively little research has been conducted on how girls think about and experience money and finances. To address this gap, the Girl Scout Research Institute recently conducted a study, *Having It All: Girls and Financial Literacy*, with girls and their parents. It found girls need and want financial literacy skills to help them achieve their dreams, with 90 percent saying it is important for them to learn how to manage money; however, just 12 percent of girls surveyed feel very confident about making financial decisions.

—To be successful and sustainable, financial education must begin early, continue throughout elementary and secondary education, and be relevant. And although 93 percent of the public believes all high school students should be required to take a class in financial education, only four States have made a semester-long course in financial literacy a graduation requirement.¹ In addition to providing teachers with training and materials, we believe policy support for after-school and community-based programs is critical if girls are to learn money-management skills and have real-world financial literacy experiences that will serve them throughout their lives.

HEALTHY LIVING—BULLYING AND RELATIONAL AGGRESSION

As exemplified through our program experience and research, Girl Scouts understands the complex issue of healthy living and what motivates youth—especially girls—to adopt healthy lifestyles. Improving youths' physical health and emotional well-being are not mutually exclusive. Youth, especially girls, experience them in an interrelated fashion. Girls place the same or even greater emphasis on social and emotional health as physical health.

The Girl Scout Research Institute's original research report, *Feeling Safe: What Girls Say*, found that nearly half (46 percent) of girls define safety as not having their feelings hurt, and approximately one-third of all girls worry about being teased, bullied, threatened, or having their feelings hurt when spending time with peers, participating in groups, and trying new things. Our report, *The New Normal? What Girls Say About Healthy Living*, tells us that a girl's relationships with her peers are critical components of her health and safety.

Our BFF (Be a Friend First) curriculum is focused on middle-school girls and designed to easily integrate into existing health or character education classes, or can even serve as an after-school program in the community.

¹ Back to School Survey Shows Americans Want Personal Finance Taught in the Classroom, Visa, July 20, 2010.

—As the Department of Education has proposed a safe schools initiative that includes a positive school climate focus, Girl Scouts supports this kind of effort that embraces a holistic definition of health that addresses both the physical health and emotional wellness of youth. National youth serving organizations such as Girl Scouts, should be seen as vital partners for schools in developing relevant solutions such as policies to address relational aggression and evaluating and implementing programs that prevent relational aggression and build healthy relationships.

CLOSING

We look forward to being a partner with Congress as you make difficult funding decisions in the areas of supporting healthy living, improving financial education of our youth, and building a pipeline of girls and underrepresented minorities in STEM careers. Thank you, and please consider us a resource in these areas.

[This statement was submitted by Anna Maria Chávez, Girl Scouts of the USA.]

PREPARED STATEMENT OF GLOBAL HEALTH TECHNOLOGIES COALITION

Chairman Harkin, Ranking Member Moran, and members of the Committee, thank you for the opportunity to provide testimony on the fiscal year 2015 appropriations funding for the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC). We appreciate your leadership in promoting the importance of international development, in particular global health. We hope that your support will continue. I am submitting this testimony on behalf of the Global Health Technologies Coalition (GHTC), a group of nearly 30 nonprofit organizations working together to promote policies that advance research and development (R&D) of new global health innovations—including new vaccines, drugs, diagnostics, microbicides, and other tools—to combat global health diseases. The GHTC's members strongly believe that to meet the global health needs of tomorrow, it is critical to invest in research today so that the most effective health solutions are available when we need them. My testimony reflects the needs expressed by our member organizations which work with a wide variety of partners to develop new and more effective life-saving technologies for the world's most pressing health issues. We strongly urge the Committee to continue its established support for global health R&D by 1) sustaining and supporting U.S. investment in global health research and product development and fully funding the NIH at a level of at least \$32 billion, and providing robust funding for the CDC, with \$464 million for the CDC Center for Global Health and \$445 million for the CDC Center for Emerging Zoonotic and Infectious Diseases (NCEZID), 2) requiring leaders at the NIH, CDC, the Food and Drug Administration (FDA), and the Secretariat of the U.S. Department of Health and Human Services to join leaders of other U.S. agencies to develop a cross-U.S. government global health R&D strategy to ensure that U.S. investments in global health research are efficient, coordinated, and streamlined, and 3) removing the clinical trial phase restriction from the legal language dictating the activities of the National Center for Advancing Translational Sciences (NCATS).

Critical need for new global health tools

Our Nation's investments have made historic strides in promoting better health around the world: nearly ten million people living with HIV/AIDS now have access to life-saving medicines; new, cost-effective tools help us diagnose diseases quicker and more efficiently than ever before; and innovative new vaccines are making significant dents in childhood mortality. While we must increase access to these and other proven, existing health tools to tackle global health problems, it is just as critical that we continue to invest in developing the next generation of tools to stamp out disease and address current and emerging threats. For instance, newer, more robust, and easier to use antiretroviral drugs—particularly for infants and young children—are needed to treat and prevent HIV, and even an AIDS vaccine that is 50 percent effective has the potential to prevent one million HIV infections every year. Drug-resistant tuberculosis (TB) is on the rise globally, including in the United States, however the only vaccine on the market is insufficient at 90 years old, and most therapies available today are more than 50 years old, extremely toxic, and too expensive. New tools are also urgently needed to address fatal neglected tropical diseases (NTDs) such as sleeping sickness, for which diagnostic tools are inadequate and the few drugs available are toxic or difficult to use. There are many very promising technology candidates in the R&D pipeline to address these and other health issues; however, these tools will never be available if the support needed to continue R&D is not supported and sustained.

Research and U.S. global health efforts

The United States is at the forefront of innovation in global health technologies. The U.S. government is involved in 200 of the 365 global health products currently in the pipeline, with the NIH and CDC involved in much of this research.

NIH

The NIH has helped make the United States a leader in research globally. Dr. Francis Collins, director of the NIH, has named global health as one of the agency's five top priorities, and recent NIH global health research activities helped lead to the development of the first-ever microbicide gel effective in preventing HIV/AIDS and the development of new tools to combat neglected diseases, including vaccines for dengue fever and trachoma, as well as new drugs to treat malaria and TB.

Under the purview of the NIH, NCATS was established to accelerate new treatments and cures for diseases. NCATS has the potential to play a much needed role in global health research, but we remain concerned about the legislative mandate limiting NCATS in their clinical trial work. NCATS is the only NIH center to be limited by a legislative mandate in its clinical trial work. There is no risk of NCATS duplicating the global health activities of private industry as this sector does not typically target neglected diseases due to small commercial markets. We hope you will consider removing this statutory barrier. We must not lose traction on the investments made in global health at NIH. Robust investment is needed to ensure that new global health tools are available to address current and future health challenges.

CDC

The CDC also plays a critical role in global health and contributes to valuable surveillance and health research systems—strengthening programs that ensure the sustainability of global health R&D. The work of its scientists has led to major advancements against devastating diseases, including the eradication of smallpox and early identification of the disease that became known as AIDS. Within the CDC, the efforts of the Center for Global Health and NCEZID are critical to protecting lives and must be continued. Ongoing investments in the development of new vaccines, drugs, microbicides and other tools have the potential to greatly accelerate efforts to combat HIV/AIDS, TB, malaria, diarrheal disease, pneumonia, and other less well known diseases such as leishmaniasis, dengue fever, schistosomiasis, hookworm, sleeping sickness, and Chagas disease, as well as help prevent maternal and reproductive health challenges.

Leveraging the private sector for innovation

The NIH, CDC, and other U.S. agencies involved in global health R&D regularly collaborate with the private sector in developing, manufacturing, and introducing important technologies such as those described above through public-private partnerships, including product development partnerships. These partnerships leverage public-sector expertise in developing new tools, partnering with academia, large pharmaceutical companies, the biotechnology industry, and governments in developing countries to drive greater development of products for neglected diseases in which private industries have not historically invested. This unique model has generated 42 new global health products and has enormous potential for continued success if robustly supported. NIH Director Francis Collins has stated that such partnership is key to the development of therapies and health tools based on NIH-funded research.

Innovation as a smart economic choice

Global health R&D brings life-saving tools to those who need them most. However, the benefits these efforts bring are much broader than preventing and treating disease. Global health R&D is also a smart economic investment in the United States, where it drives job creation, spurs business activity, and benefits academic institutions. Biomedical research, including global health, is a \$100 billion enterprise in the United States. Sixty-four cents out of every U.S. dollar invested in global health R&D goes directly to U.S.-based researchers. In a time of global financial uncertainty, it is important that the United States support industries, such as global health R&D, which build the economy at home and abroad.

An investment made today can help save significant money in the future. The recently released meningitis A vaccine, MenAfriVac, is on course to save nearly \$570 million in healthcare costs over the next decade. In addition, new therapies to treat drug-resistant TB have the potential to reduce the price of TB treatment by 90 percent and cut health system costs significantly. The United States has made smart investments in research in the past that have resulted in lifesaving breakthroughs for global health diseases, as well as important advances in diseases endemic to the

United States. We must now build on those investments to turn those discoveries into new vaccines, drugs, tests, and other tools.

Recommendations

In this time of fiscal constraint, support for global health research that improves the lives of people around the world—while at the same time creating jobs and spurring economic growth at home—should unquestionably be among the Nation’s highest priorities. In keeping with this value, the GHTC respectfully requests that the Committee do the following: 1) sustain and support U.S. investments in global health research and product development and fully fund the NIH at a level of at least \$32 billion, and provide robust funding for the CDC, with \$464 million for the CDC Center for Global Health and \$445 million for the NCEZID, 2) require leaders at the NIH, CDC, the FDA and the Office of Global Affairs to collaborate with the U.S. Agency for International Development, the State Department, the Department of Defense, and Office of the U.S. Global AIDS Coordinator to develop a cross-U.S. government global health R&D strategy to ensure that U.S. investments in global health research are efficient, coordinated, and streamlined, and 3) remove current statutory and legislative barriers limiting NCATS’ clinical trial mandate and require NCATS to develop and report on a plan to include initiatives targeted at neglected diseases and global health conditions. As a leader in science and technology, the United States has the ability to capitalize upon our strengths to help reduce illness and death and ultimately eliminate disabling and fatal diseases for people worldwide, contributing to a healthier world and a more stable global economy. Sustained investments in global health research to develop new drugs, vaccines, tests, and other health tools—combined with better access to existing methods to prevent and treat disease—present the United States with an opportunity to dramatically alter the course of global health while building political and economic security across the globe. On behalf of the members of the GHTC, I would like to extend my gratitude to the Committee for the opportunity to submit written testimony for the record.

[This statement was submitted by Kaitlin Christenson, Coalition Director, Global Health Technologies Coalition.]

PREPARED STATEMENT OF THE GOVERNMENT RELATIONS EASTER SEALS, INC.

Mr. Chairman and Members of the Subcommittee: Thank you for the opportunity to speak on behalf of Easter Seals about our Federal funding priorities for fiscal year 2015. Easter Seals is a national nonprofit organization that provides essential community-based services to individuals with disabilities, older adults, veterans and other underserved populations to help them live, learn, work and contribute to their communities. Easter Seals’ top priorities are in the people we serve like Arlena, Ben, Elijah and Donald whose lives have been impacted or could be through Federal investments made by this subcommittee. Easter Seals respectfully asks that you consider these stories and the critical programs these individuals as the subcommittee develops its fiscal year 2015 bill. Specifically Easter Seals requests that the Senior Community Service Employment Program be funded at \$434,371,000 for fiscal year 2015, the Homeless Veterans’ Reintegration Program be funded at \$50,000,000 for fiscal year 2015, the Early Intervention Grants for Infants and Families be funded at \$458,498,000 for fiscal year 2015, and the Department of Education Transition Model System be funded at \$15,000,000 for 2015.

Meet Arlena: Arlena is an older worker who is contributing to her New Jersey community as a full-time security supervisor at a major airport. Her success may have seemed out-of-reach less than 2 years earlier when the 55-year-old single mother faced dual challenges. Arlena had lost her temporary job and was out of work for about a year when Hurricane Sandy hit and further complicated matters. She lost her home and all of her belonging in the 2012 storm, which left her homeless. She was forced to move in with her daughter’s family. Eventually her daughter moved and gave her the apartment. However, with no job she fell behind in her rent and utilities. She turned to Easter Seals for help after hearing about the Senior Community Service Employment Program (SCSEP) through a friend. The Department of Labor program supports employment of older workers by providing part-time, paid community service positions and work-based training for unemployed, low-income individuals, age 55 and older. Through the Federal program, Easter Seals connected Arlena to supportive services to help her maintain an apartment, boosted her computer skills and matched her with on-the-job training at three different community locations. After 9 months in the program, she applied for and secured an entry level security position. Based on her previous work history, Arlena was promoted to a supervisory position. SCSEP helped to provide Arlena the tools

and opportunities she needed to prove she could bounce back from adversity and contribute again to her community. Easter Seals asks that the subcommittee supports a fiscal year 2015 funding level of \$434,371,000 for SCSEP, the same level the program received in fiscal year 2014.

Meet Ben: Ben was almost among the one million children under age 5 with disabilities who go undiagnosed every year. Ben's mom felt uneasy about her son's language progress when he was 18 months. But her doctor attributed the speech delays to being raised in a bilingual household. After the birth of Ben's brother 6 months later, Ben's mom became more concerned about Ben's development, this time related to his behavior. "I knew that Ben needed help." So she reached out to her State's Birth to Three program—which is funded through Part C of the Individuals with Disabilities Education Act—and soon Ben was receiving needed speech and occupational services from Easter Seals and was diagnosed with a form of autism called PDD-NOS. Within 6 months of receiving early intervention services, Ben was able to communicate in sentences. Now 4 years old, he continues to work hard and is making enormous progress. As a result of these early intervention investments, Ben continues to reach major milestones which will fundamentally change his life and allow him to fully participate in his community. Easter Seals asks that you increase funding by \$20 million for the Part C Early Intervention grants to \$458,498,000 in fiscal year 2015 so more children like Ben can access the services and supports they need when they need them to succeed.

Meet Elijah: Elijah achieved academic success most parents dream for their children. He was high school class valedictorian and a college honors student with a Master's Degree. However, his transition into the workplace has been challenging. He can't find a job. Elijah lives with Asperger's syndrome and, in fact, benefited from early intervention services through Easter Seals when he was a child. However, Elijah has struggled during this adult transition, particularly in job interviews where the repetitive nature of Asperger's syndrome makes it challenging for him to stay succinct and on track. Elijah is not alone. The Government Accountability Office (GAO-12-594) found that students with disabilities face "several longstanding challenges" during their transition from high school into postsecondary education or the workforce. Among the challenges the GAO cited was accessing services, such as transportation education and travel instruction. The U.S. Department of Education has proposed in its fiscal year 2015 budget to test a coordinated model of transition planning, services, and supports through a new Transition Model System (TMS). The goal of TMS is to help address the many challenges faced by youth with disabilities like Elijah. Easter Seals asks that the subcommittee to fully support the Administration's fiscal year 2015 funding request of \$15,000,000 for the Transition Model System and asks that you include report language to strengthen the connection and importance of transportation education and travel instruction within TMS to increase and improve postsecondary outcomes for students with disabilities.

Meet Donald: Donald was a proud veteran of the Air National Guard but—at age 48—he found himself unemployed for more than 5 years and living on the street. Despite the national push to end homelessness among veterans, far too many men and women who served our Nation like Donald did are among the ranks of America's homeless. Donald was connected to Easter Seals, who utilized the holistic, supportive services care coordination model used in the Department of Labor's Homeless Veterans Reintegration Program (HVRP) to help get Donald back on his feet. Easter Seals connected Donald to transitional housing, provided him with a monthly bus pass so he could easily attend required meetings and trainings, and linked him to the local U.S. Department of Veterans Affairs medical center for other services. Donald also received individualized training and assistance in creating a resume and cover letter and in updating his job search, networking and interview skills. Based on his strengths and employment background, Easter Seals assisted Donald in a series of temporary jobs through staffing agencies, one of which turned into a full time permanent job, with benefits, at a local manufacturing company. Donald cited "networking skills, online job search assistance, resume update, housing stabilization, reliable transportation, and encouragement" as key Easter Seals HVRP services that helped him get employed again. HVRP is the only Federal nationwide program focusing exclusively on the employment of veterans who are homeless. The program works, in large part, due to the holistic, person-centered care coordination model that Easter Seals has used for several decades in helping individuals with disabilities achieve their dreams. Easter Seals asks that the subcommittee supports the authorized level of \$50,000,000 for HVRP in fiscal year 2015.

Thank you for the opportunity to share with you Easter Seals' appropriations priorities for the fiscal year 2015 Labor, Health and Human Services, Education, and Related Agencies appropriations bill. We hope that you consider these programs and the thousands of people with disabilities, veterans and older adults who are fully

participating and contributing to their communities as a result of these early Federal investments that continue to pay dividends. Thank you again for your time and consideration.

[This statement was submitted by Katy Beh Neas, Senior Vice President, Government Relations Easter Seals, Inc.]

PREPARED STATEMENT OF THE HARM REDUCTION COALITION

We are requesting \$5 million for the Substance Abuse and Mental Health Services Administration at the Center for Substance Abuse Treatment, and \$5 million for the Centers for Disease Control and Prevention at the office of Unintentional Injury Prevention, to address the opioid overdose epidemic.

The opioid overdose epidemic has reached crisis proportions in recent years. The Centers for Disease Control and Prevention reports that in 2010, opioids—including both prescription painkillers and heroin—were responsible for nearly 20,000 overdose deaths. While prescription painkillers continue to account for the majority of opioid overdoses, deaths from heroin overdose increased by 45 percent between 2006 and 2010, fueling concerns in several parts of the country that progress in reducing prescription painkiller misuse is being offset by a dramatic rise in heroin use and its attendant social and health consequences, including addiction, hepatitis C, and overdose. For example, in Kentucky, a State on the forefront of comprehensive approaches to the prescription drug overdose epidemic, the Kentucky Injury Prevention and Research Center recently reported that while overall drug overdose deaths have leveled off from 2011 to 2012 after a decade of dramatic increases, promising declines in the number of prescription painkiller deaths have been accompanied by a 207 percent increase in heroin-related overdose deaths from 2011 to 2012.

For these reasons, Harm Reduction Coalition believes that as efforts continue to mount a comprehensive response to prescription painkiller overdoses, it is necessary to incorporate the intertwined rise in heroin misuse and adopt a broader strategic framework to address all opioids. An opioid epidemic framework would maintain and intensify the array of activities such as those aimed at opioid prescribing practices and monitoring programs, safe disposal, patient and public education, regulatory and enforcement actions, and expansion of effective addiction treatment and recovery services. At the same time, the broader opioid epidemic framework recognizes the vital need for additional public health interventions and opportunities, including the role of expanded access to naloxone, alongside heightened attention to the risks of hepatitis C and other blood-borne viruses transmissible through injection drug use.

Naloxone is a generic medication which acts as an opioid antagonist, blocking the effects of opioids such as painkillers or heroin and capable of reviving individuals from opioid overdoses. A substantial body of research and practice has demonstrated that naloxone is safe and effective in the hands of laypersons; in the words of Dr. Nora Volkow, Director of the National Institute on Drug Abuse, “several experimental overdose education and naloxone distribution (OEND) programs have issued naloxone directly to opioid users and their friends or loved ones, or other potential bystanders, along with brief training in how to use these emergency kits. Such programs have been shown to be an effective, as well as cost-effective, way of saving lives.”

Dr. Volkow cites data published by CDC showing that through 2010, overdose education and naloxone distribution programs reported preventing over 10,000 opioid overdose deaths across the country. As of this month, eighteen States have passed legislation to facilitate broader access and utilization of naloxone, ranging from Kentucky to Connecticut, Ohio to California; Georgia passed naloxone legislation on March 18th, which now awaits the governor’s signature. These overdose education and naloxone distribution programs vary in setting and scope. In North Carolina, Project Lazarus trains physicians to co-prescribe naloxone to pain patients receiving opioids. In Massachusetts, support groups for parents with children struggling with opioid dependence are trained and provided with naloxone. In Rhode Island, naloxone is provided through pharmacies. In Kentucky, some of the strongest advocates for naloxone have been the addiction recovery community. In New York, my organization has provided naloxone training to dozens of drug treatment programs, syringe exchange programs, shelters, and law enforcement agencies. In other parts of the country, overdose education and naloxone distribution programs are launching in emergency departments, jails, and Veterans Administration Medical Centers.

These programs are gaining increased Federal attention; in the last month, the Attorney General echoed the Office of National Drug Control Policy in calling upon

first responders and law enforcement officers to be trained and equipped with naloxone. The Agency for Healthcare Research and Quality highlighted the Massachusetts overdose education and naloxone distribution program and featured accompanying quality tools, including an overdose and naloxone program manual from the Harm Reduction Coalition. Last year, the Substance Abuse and Mental Health Services Administration (SAMHSA) released an opioid overdose toolkit featuring naloxone. NIDA and FDA have worked to support and facilitate the development of new, consumer-friendly formulations of naloxone. The Ohio Department of Health's Violence and Injury Prevention Program has used a portion of its CDC injury prevention funding to expand Project DAWN, an overdose education and naloxone distribution program, to additional counties.

The President's fiscal year 2015 budget requests \$26 million to prevent prescription drug overdose, of which \$16 million would expand CDC's Core Violence and Injury Prevention Program grants to States, with an expected \$10 million directed to prescription drug overdose activities, and \$10 million to SAMHSA would fund State planning grants to develop prevention strategies for prescription drug abuse. The Harm Reduction Coalition supports these proposals, and believes that these resources would be valuable in establishing a foundation to reverse the prescription drug overdose epidemic. We also believe that additional emergency funding is necessary to stem the tide of opioid overdose from both prescription opioids and, increasingly, heroin. Within the context of a comprehensive approach to the opioid epidemic, including expanding access to addiction treatment and recovery, the Harm Reduction Coalition views the rapid expansion and scale up of overdose education and naloxone distribution programs as an urgent and underfunded priority to save lives.

To that end, we request that \$5 million be provided to CDC Injury Prevention and Control to support opioid overdose fatality prevention efforts within State and local health departments and community-based organizations to strengthen their ability to deliver overdose recognition and intervention training and education, and expand access to rescue medications and other evidence-based strategies. We also request that \$5 million be provided to SAMHSA's Center for Substance Abuse Treatment to support community-based opioid overdose fatality prevention efforts, with a focus on those initiatives that provide overdose recognition and intervention training and education, access to rescue medications, and facilitate linkage to treatment and recovery services.

Across the country, emerging overdose education and naloxone distribution programs rely on limited funding to meet a growing need. The availability of targeted Federal funds through both the public health and addiction treatment and recovery communities would hasten the expansion of these programs to meet growing need and demand.

In the battle against opioid overdose, there is much to be done, and no time to lose. We need a twofold approach of long-range efforts to address the underlying causes and factors which led to the initial rise in prescription opioid misuse, coupled with immediate actions to avert additional deaths and tragedies in the short-term. As a person who has lost friends and loved ones to opioid overdose, and listened to the stories of grieving parents who only wish someone had told them about naloxone before it was too late for their children, I respectfully ask for your consideration of our requests.

If you have any questions, or would like more information or data on naloxone, please feel free to contact: Daniel Raymond, Harm Reduction Coalition. Thank you for your attention and consideration.

PREPARED STATEMENT OF THE HEALTH PROFESSIONS AND NURSING EDUCATION
COALITION

The members of the Health Professions and Nursing Education Coalition (HPNEC) are pleased to submit this statement for the record recommending \$520 million in fiscal year 2015 for the health professions education programs authorized under Titles VII and VIII of the Public Health Service Act and administered through the Health Resources and Services Administration (HRSA).

HPNEC is an alliance of national organizations dedicated to ensuring the healthcare workforce is trained to meet the needs of the country's growing, aging, and diverse population. Titles VII and VIII are the only federally-funded programs that seek to improve the supply, distribution, and diversity of the health professions workforce, with a focus on primary care and interdisciplinary training. By providing educational and training opportunities to aspiring and practicing health profes-

sionals, the programs also play a critical role in helping the workforce adapt to meet the Nation's changing healthcare needs.

Titles VII and VIII are structured to allow grantees to test educational innovations, respond to changing delivery systems and models of care, and address timely topics in their communities. By assessing the needs of the communities they serve, Titles VII and VIII are well positioned to fill gaps in the workforce and increase access to care for all populations. Further, the programs emphasize interprofessional education and training, bringing together knowledge and skills across disciplines to provide effective, efficient and coordinated care.

While HPNEC recognizes the Subcommittee faces difficult decisions in a constrained budget environment, a continued commitment to programs supporting healthcare workforce development should remain a high priority. The Nation faces a shortage of health professionals, which will be exacerbated by the addition of millions of Americans to the healthcare system. Failure to fully fund the Title VII and Title VIII programs would jeopardize activities to fill these vacancies and to prepare the next generation of health professionals.

The Title VII and Title VIII programs can be considered in seven general categories:

- The Primary Care Medicine and Oral Health Training programs support education and training of primary care professionals to improve access and quality of healthcare in underserved areas. Two-thirds of Americans interact with a primary care provider every year. Over one-third of primary care providers trained through these programs work in underserved areas, compared to 10 percent of those trained in other traditional programs. The General Pediatrics, General Internal Medicine, and Family Medicine programs provide critical funding for primary care physician training in community-based settings and support a range of initiatives, including medical student and residency training, faculty development, and the development of academic administrative units. The Rural Physician Training Grants focus on increasing the number of medical school graduates practicing in rural communities. The primary care cluster also provides grants for Physician Assistant programs to encourage and prepare students for primary care practice in rural and urban Health Professional Shortage Areas. The General Dentistry, Pediatric Dentistry, Dental Public Health, and Dental Hygiene programs provide grants to dental schools, dental hygiene schools, and hospitals to create or expand primary care dental training.
- Because much of the Nation's healthcare is delivered in remote areas, the Interdisciplinary, Community-Based Linkages cluster supports community-based training of health professionals. These programs are designed to encourage health professionals to return to such settings after completing their training and to encourage collaboration between two or more disciplines. The Clinical Training in Interprofessional Practice program supports interdisciplinary training opportunities that prepare providers to deliver coordinated, efficient, and high-quality care. The Area Health Education Centers (AHECs) offer clinical training opportunities to health professions and nursing students in rural and other underserved communities by extending the resources of academic health centers to these areas. AHECs improve health by leading the Nation in the recruitment, training, and retention of a diverse health workforce for underserved communities. By leveraging State and local matching funds to form networks of health-related institutions, AHECs also provide education services to students, faculty, and practitioners. The Geriatric Health Professions programs, including the Geriatric Academic Career Award program and Geriatric Education Centers, are all designed to bolster the number and quality of healthcare providers caring for the rapidly growing number of older adults and to expand geriatrics training to all healthcare professionals. For example, the programs provide interprofessional education and training on Alzheimer's disease and related dementias. The Graduate Psychology Education (GPE) program is the Nation's only Federal program dedicated solely to the education and training of doctoral-level psychologists. GPE supports the interprofessional training of doctoral-level psychology students in providing supervised 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) in rural and urban communities. The Mental and Behavioral Health Education and Training Grant Program supports the training of psychologists, social workers, and child and adolescent professionals. These programs together work to close the gap in access to quality mental and behavioral healthcare services by increasing the number of qualified mental health clinicians.
- The Minority and Disadvantaged Health Professionals Training cluster helps improve healthcare access in underserved areas and the representation of mi-

nority and disadvantaged individuals in the health professions. Diversifying the healthcare workforce is a central focus of the programs, making them a key player in mitigating racial, ethnic, and socio-economic health disparities. Further, the programs emphasize cultural competency for all health professionals, an important role as the Nation's population is growing and becoming increasingly diverse. Minority Centers of Excellence support increased research on minority health, establish educational pipelines, and provide clinical experiences in community-based health facilities. The Health Careers Opportunity Program helps to improve the development of a competitive applicant pool through partnerships with local educational and community organizations and extends the healthcare pipeline to the K-12 level. The Faculty Loan Repayment and Faculty Fellowship programs provide incentives for schools to recruit underrepresented minority faculty. The Scholarships for Disadvantaged Students supports students from disadvantaged backgrounds who are eligible and enrolled as full-time health professions students.

- The Health Professions Workforce Information and Analysis program provides grants to institutions to collect and analyze data to advise future decision-making on the health professions and nursing programs. The Health Professions Research and Health Professions Data programs have developed valuable, policy-relevant studies on the distribution and training of health professionals. The National Center for Workforce Analysis performs research and analysis on health workforce issues, including supply and demand, to help inform both public and private decisionmaking.
- The Public Health Workforce Development programs help increase the number of individuals trained in public health, identify the causes of health problems, and respond to such issues as managed care, new disease strains, food supply, and bioterrorism. The Public Health Traineeships and Public Health Training Centers seek to alleviate the critical shortage of public health professionals by providing up-to-date training for current and future public health workers, particularly in underserved areas. Preventive Medicine Residencies, which do not receive funding through Medicare GME, provide training in the only medical specialty that teaches both clinical and population medicine to improve community health. This cluster also includes a focus on loan repayment as an incentive for health professionals to practice in disciplines and settings experiencing shortages. The Pediatric Subspecialty Loan Repayment Program offers loan repayment for pediatric medical subspecialists, pediatric surgical specialists, and child and adolescent mental and behavioral health specialists, in exchange for service in underserved areas.
- The Nursing Workforce Development programs under Title VIII provide support for nursing students across the entire education spectrum improve the access to, and quality of, healthcare in underserved areas. These programs provide the largest source of Federal funding for nursing education, providing loans, scholarships, traineeships, and programmatic support that, between fiscal year 2006 and 2012, supported over 450,000 nurses and nursing students as well as numerous academic nursing institutions and healthcare facilities. Each year, nursing schools turn away tens of thousands of qualified applications at all degree levels due to an insufficient number of faculty, clinical sites, classroom space, clinical preceptors, and budget constraints. At the same time, the need for nursing services and licensed, registered nurses is expected to increase significantly over the next 20 years. The Advanced Education Nursing program awards grants to train a variety of nurses with advanced education, including clinical nurse specialists, nurse practitioners, certified nurse-midwives, nurse anesthetists, public health nurses, nurse educators, and nurse administrators. Workforce Diversity grants support opportunities for nursing education for students from disadvantaged backgrounds through scholarships, stipends, and retention activities. Nurse Education, Practice, and Retention grants help schools of nursing, academic health centers, nurse-managed health centers, State and local governments, and other healthcare facilities to develop programs that provide nursing education, promote best practices, and enhance nurse retention. The Loan Repayment and Scholarship Program repays up to 85 percent of nursing student loans and offers full-time and part-time nursing students the opportunity to apply for scholarship funds in exchange for 2 years of practice in a designated nursing shortage area. The Comprehensive Geriatric Education grants are used to train nursing professionals who will provide direct care to older Americans, develop and disseminate geriatric curricula, train faculty members, and provide continuing education. The Nurse Faculty Loan program provides a student loan fund administered by schools of nursing to increase the number of qualified nurse faculty.

—The loan programs under Student Financial Assistance support financially disadvantaged health professions students. The NURSE Corps supports undergraduate and graduate nursing students with a preference for those with the greatest financial need. The Primary Care Loan (PCL) program provides loans in return for dedicated service in primary care. The Health Professional Student Loan (HPSL) program provides loans for financially needy health professions students based on institutional determination. These programs are funded out of each institution's revolving fund and do not receive Federal appropriations. The Loans for Disadvantaged Students program provides grants to institutions to make loans to disadvantaged students.

Title VII and Title VIII programs guide individuals to high-demand health professions jobs, helping individuals reach their goals and communities fill their health needs. Further, numerous studies demonstrate that the Title VII and Title VIII programs graduate more minority and disadvantaged students and prepare providers that are more likely to serve in Community Health Centers (CHC) and the National Health Service Corps (NHSC).

The multi-year nature of health professions education and training, coupled with provider shortages across many disciplines and in many communities, necessitate a strong, continued, and reliable commitment to the Title VII and Title VIII programs.

While HPNEC members understand the budget limitations facing the Subcommittee, we respectfully urge support for \$520 million for the Title VII and VIII programs. We look forward to working with the Subcommittee to prioritize the health professions programs in fiscal year 2015 and into the future.

PREPARED STATEMENT OF THE HIV MEDICINE ASSOCIATION

The HIV Medicine Association (HIVMA) of the Infectious Diseases Society of America (IDSA) represents more than 5,000 physicians, scientists and other healthcare professionals who practice on the frontline of the HIV/AIDS pandemic. Our members provide medical care and treatment to people with HIV/AIDS in the U.S. and globally, lead HIV prevention programs and conduct research that has led to the development of effective HIV prevention and treatment options. We urge you to invest in the medical research supported by the National Institutes of Health and sustain and grow funding for the Ryan White Program at the Health Resources and Services Administration and the Centers for Disease Control and Prevention's (CDC) HIV and STD prevention programs.

Early access to effective HIV treatment helps patients with HIV live healthy and productive lives and is cost effective.¹ Treatment not only saves the lives of individuals with HIV but has critical benefits to public health in that it reduces risk of transmitting HIV to near zero.² However, despite our remarkable progress in HIV prevention, diagnosis and treatment, HIV/AIDS remains a serious epidemic in the United States with a record 1.1 million people living with HIV and an estimated 50,000 new infections occurring annually. In our country, HIV infection disproportionately impacts racial and ethnic minority communities and low income people who depend on public services for their life-saving healthcare and treatment. The rate of new HIV infection in African Americans is 8 times that of whites based on population size.³ Globally there are more than 35.3 million people living with HIV, the great majority of them in Sub-Saharan Africa. We are beginning to see improvements thanks in large part to U.S. investments in programs like PEPFAR: HIV prevalence has leveled to about 0.8 percent, the number of deaths have declined by 30 percent since 2005 and new infections have declined by 33 percent since 2001. Still there are 2.3 million new infections each year—more than 6,300 each day.

The funding requests in our testimony largely reflect the consensus of the Federal AIDS Policy Partnership (FAPP), a coalition of HIV organizations from across the country, and are estimated to be the amounts necessary to mount an effective response to the domestic HIV epidemic and meet the need in communities across the country.

National Institutes of Health (NIH)—Office of AIDS Research (OAR): HIVMA strongly supports an fiscal year 2015 funding level of at least \$32 billion for the NIH, including at least \$3.2 billion for the NIH Office of AIDS Research. This level

¹ Kitahata, Gange, Abraham, et al. Effect of early versus deferred antiretroviral therapy for HIV on survival. *New Engl J Med* 2009;360:1815–26.

² Cohen, Myron S., et al. Prevention of HIV-1 Infection with Early Antiretroviral Therapy. 2011 *New England Journal of Medicine* 493–505: V365, no 6, <http://www.nejm.org/doi/full/10.1056/NEJMoa11052>.

³ CDC Fact Sheet, February, 2014, accessed online at: <http://www.cdc.gov/hiv/risk/raciaethnic/aa/facts/index.html>.

of funding is vital to sustain the pace of research that will improve the health and quality of life for millions of men, women and children in the U.S. and in the developing world. Years of flat funding for biomedical research has eroded our capacity to sustain our Nation's historic worldwide leadership in HIV/AIDS research and innovation, and is discouraging cultivation of the next generation of scientists.

Our past investment in comprehensive HIV/AIDS research paid off enormously in dramatic gains that resulted in reductions in mortality from AIDS of nearly 80 percent in the U.S. and in other countries where treatment is available. This research also helped reduce the mother to child HIV transmission rate from 25 percent to less than 1 percent in the U.S. and to very low levels in other countries where treatment is available.

Strong, sustained NIH funding is a critical national priority that will foster better health, economic revitalization and help realize the goals of the National HIV/AIDS Strategy. Sustained increases in funding are also essential to train the next generation of scientists and prepare them to make tomorrow's HIV discoveries. Congress should ensure the Nation does not delay vital HIV/AIDS research progress.

HIV/AIDS Bureau of the Health Resources and Services Administration: We strongly urge you to increase funding for the Ryan White Program by \$123.2 million in fiscal year 2015. For Ryan White Part C programs in fiscal year 2015, we urge an allocation of at least \$225.1 million, or a \$24 million increase over the fiscal year 2014 level for Part C. The comprehensive HIV care model or "medical home" that is supported by the Ryan White Program has been highly successful at achieving positive clinical outcomes with a complex patient population. The annual healthcare costs for HIV patients who are not able to achieve viral suppression (often due to delayed diagnosis and care) are nearly 2.5 times that of healthier HIV patients.⁴

The HIV medical clinics funded through Part C have been struggling to meet the increased demand for patients making an increase in funding critical to prevent additional staffing, laboratory and service cuts. At a bare minimum, we strongly urge you to support an increase of \$24 million over fiscal year 2014 appropriated funding for Ryan White Part C.

While HIVMA welcomes the \$4 million increase for Part C programs proposed in the President's fiscal year 2015 budget, we are concerned about the proposal to consolidate Ryan White Part D funding into Part C. Our specific concerns include:

- Part D funding supports effective HIV care and treatment services for vulnerable populations, including women and adolescents. With adolescents accounting for 39 percent of new HIV infections in the U.S., it is critical to target resources effectively.
- A loss of a Part D program could reduce the community's access to HIV care and treatment as programs are forced to compete or consolidate with Part C clinics.
- Since most Ryan White medical clinics receive funding from multiple parts of the Ryan White Program, reduction of funding to one part can have damaging and unintended consequences to the overall services provided.

While the ACA provides important new healthcare coverage options for many patients, most health insurers fail to support the comprehensive care and treatment necessary for many patients to manage HIV infection. High cost sharing, benefit gaps and limited state uptake of the Medicaid expansion necessitate a vital and ongoing role for the Ryan White Program.

Center for Disease Control and Prevention's (CDC) National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP): HIVMA strongly urges total fiscal year 2015 funding of \$1.319 billion for the CDC's NCHHSTP, an increase of \$198.2 million over the fiscal year 2014 level, including increases of: \$55.1 million for HIV prevention and surveillance, \$16.4 million for viral hepatitis and \$57.4 million for tuberculosis prevention. We also support a funding level of at least \$464.3 million for CDC's global health programs, which includes resources for the agency's essential role in implementing PEPFAR programs in developing Nations. We are especially concerned about flat funding of CDC's global HIV programs, and request an increase of at least \$3.3 million to that line item for a total of \$132 million.

Policy Riders—Remove the Harmful Ban on Federal Funding for Syringe Exchange Programs: HIVMA strongly urges re-instatement in fiscal year 2015 report language of policy previously enacted into law in fiscal year 2010 and fiscal year 2011 allowing Federal funding to be used for syringe exchange programs. Such action will support local control by letting local communities make their own decisions about how best to prevent new HIV and viral hepatitis infections. We cannot afford

⁴ Based on data from Gilman BH, Green, JC. Understanding the variation in costs among HIV primary care providers. AIDS Care.2008;20:1050–6.

to forego any of the scientifically proven tools in the HIV prevention tool box if we are going to end AIDS in the U.S. and around the globe.

Conclusion: Historically, our Nation has made significant strides in responding to the HIV pandemic here at home and around the world, but years of flat funding is now causing us to lose ground, as funding priorities have shifted away from public health and research programs. We must seize the opportunity to limit the toll of this deadly infectious disease on our planet, to save the lives of millions who are infected or at risk of infection here in the U.S. and around the globe, and to realize the vision of an AIDS-free generation.

[This statement was submitted by Jeanne Keruly, MS, CRNP, Johns Hopkins University, HIV Medicine Association.]

PREPARED STATEMENT OF THE HUMANE SOCIETY OF THE UNITED STATES AND THE
HUMANE SOCIETY LEGISLATIVE FUND

On behalf of The Humane Society of the United States (HSUS) and the Humane Society Legislative Fund (HSLF), we appreciate the opportunity to provide testimony on our top NIH funding priorities for the Senate Labor, Health and Human Services, Education and Related Agencies Appropriations Subcommittee in fiscal year 2015.

CAPACITY AT THE NATIONAL CHIMPANZEE SANCTUARY FOR FEDERALLY OWNED
CHIMPANZEES RETIRED BY THE NATIONAL INSTITUTES OF HEALTH

The HSUS and HSLF request NIH be given authority to use \$5 million of funds appropriated in this and subsequent appropriations bills for extramural construction and renovation within the National Chimpanzee Sanctuary System. In 2013, NIH announced their plan to retire hundreds of government owned chimpanzees to sanctuary. This decision followed years of scientific review which determined chimpanzees are not necessary for research. Additional sanctuary construction is needed to enable NIH to move forward with their plan to retire the vast majority of government owned chimpanzees to sanctuary. Even with upfront construction expenditures, transferring government owned chimpanzees from laboratories to sanctuaries will save significant taxpayer funds over the lifetimes of the chimpanzees due to the lower cost of sanctuary care.

Further basis of our request can be found below.

Background information

In June of 2013, the National Institutes of Health announced their plan to retire all but 50 government-owned chimpanzees to sanctuary, significantly curtail the use of chimpanzees in NIH funded studies and not to revitalize breeding of chimpanzees for research. These decisions resulted from an Institute of Medicine study in 2011 which found that chimpanzees are not necessary for the vast majority of research. Immediately following the announcement of the IOM study results, NIH accepted the findings and assembled a panel of experts to advise them on the best way to implement the IOM findings. NIH ultimately accepted nearly all of the expert panel's recommendations in their final decision.

Prior to announcing their plan, NIH had already begun the transfer of the 110 government owned chimpanzees at the New Iberia Research Center in Louisiana to Chimp Haven (the National Chimpanzee Sanctuary), also located in Louisiana. The transfer is expected to be completed by the end of fiscal year 2014. At that point, approximately 350 government-owned chimpanzees will remain in laboratories—300 of whom will be slated for retirement to sanctuary per NIH's plan.

In late November of 2013, the President signed into law amendments to the Chimpanzee Health Improvement Maintenance and Protection (CHIMP Act) which provided continued funding for the care, maintenance and transportation of federally owned chimpanzees over the next 5 years. These amendments have enabled NIH to use their funding judiciously by continuing to support chimpanzees in sanctuary and also set the stage for NIH to move forward with their plan to retire hundreds more chimpanzees.

Costs in laboratories vs. sanctuary

Accredited sanctuaries provide the highest welfare standards for chimps at a lower cost to taxpayers than housing chimpanzees in barren labs (see chart below). It is estimated that transferring the 300 government-owned chimpanzees who are slated for retirement from the laboratories where they are currently housed to the national sanctuary would save taxpayers anywhere from \$1.7 million to \$2.7 million per year in care and maintenance costs.

Construction to house more chimpanzees in sanctuary will require an upfront expenditure. However, due to the lower per diem cost in sanctuary, retiring chimpanzees to sanctuary will still yield a significant savings to taxpayers over the long term. The sooner the construction is completed and the chimpanzees are moved to sanctuary, the more the government will save over the lifetimes of the chimpanzees—which can be up to 60 years.

Estimated Costs Related to Care and Maintenance of Government Owned Chimpanzees:

Facility	Number of chimpanzees	NIH cost, millions in dollars/year	NIH cost, \$/chimpanzee/day
Government Owned Chimpanzees in Research Facilities and Research Reserve Facilities			
New Iberia Research Center	¹ 59	³ 1.01	⁴ 46.7
Keeling Center for Comparative Medicine and Research	² 147	³ 2.44	45.4
Keeling Center for Comparative Medicine and Research, DVR grant	² 16	² 0.4	68.8
Southwest National Primate Research Center, U42 grant ⁵	² 22	³ 0.65	80.9
Alamogordo Primate Facility	² 162	² 3.60	61.3
Totals	406	8.10	⁶ 54.7

¹ The remaining 59 chimpanzees at New Iberia Research Center are scheduled to be moved to Chimp Haven by the end of fiscal year 2014

² Based on information available on NIH website regarding chimpanzee maintenance costs for fiscal year 2014

³ Based on data available in NIH Research Portfolio Online Reporting Tools (RePORT) for fiscal year 2014

⁴ Figure expected to increase significantly as chimpanzees move to Chimp Haven and funds are spread over fewer chimpanzees

⁵ In addition to this grant, NIH also supports an additional 91 chimpanzees at the facility. These chimpanzees are owned by the laboratory and are not under the control of NIH.

⁶ Average total.

Facility	Number of chimpanzees	NIH cost, millions in dollar/year	NIH cost, \$/animal/day
Government Owned Chimpanzees in Sanctuary			
Chimp Haven	⁶ 118–153	⁷ 1.7	30–39

⁶ Fifty chimpanzees from New Iberia Research Center were transferred to Chimp Haven during this contract year.

⁷ Unlike the other facilities, Chimp Haven has a cost reimbursement contract in which they are reimbursed for costs incurred. This number represents actual costs billed to NIH over the most recently completed contract year (06/30/2012–06/29/2013)

We respectfully request the subcommittee to consider the following language for inclusion in the appropriations bill:

Of the funds appropriated to NIH, \$5,000,000 shall be for grants or contracts for construction, renovation, or repair of the sanctuary system established by Section 404K of the Public Health Service Act.

We appreciate the opportunity to share our views for the Labor, Health and Human Services, Education and Related Agencies Appropriations Act for fiscal year 2015. We hope the Committee will be able to accommodate this request. Thank you for your consideration.

HIGH THROUGHPUT SCREENING, TOXICITY PATHWAY PROFILING, AND BIOLOGICAL INTERPRETATION OF FINDINGS

NATIONAL INSTITUTES OF HEALTH—OFFICE OF THE DIRECTOR

In 2008, NIH, NIEHS and EPA signed a memorandum of understanding to collaborate with each other to identify and/or develop high throughput screening assays that investigate “toxicity pathways” that contribute to a variety of adverse health outcomes (e.g., from acute oral toxicity to long-term effects like cancer). In addition, the MOU recognized the necessity for these Federal research organizations to work with “acknowledged experts in different disciplines in the international scientific community.” Much progress has been made, including FDA joining the MOU, but there is still a significant amount of research, development and translational science needed to bring this vision forward to where it can be used with confidence for safety determinations by regulatory programs in the government and product stewardship programs in the private sector. In particular, there is a growing need to support research to develop the key science-based interpretation tools which will accelerate using 21st century approaches for predictive risk analysis. We believe the Office of the Director at NIH can play a leadership role for the entire US government by funding both extramural and intramural research.

We respectfully request the following committee report language as a placeholder, which is supported by The HSUS, HSLF, and the American Chemistry Council.

NIH Director

The Committee supports NIH's leadership role in modernizing the approach for evaluating the safety of pharmaceuticals and chemicals based on the incorporation of advanced molecular biological and computational methods that envisions a move away from animal tests. NIH has indicated that development of this science is critical to several of its priorities, from personalized medicine to tackling specific diseases such as cancer and diabetes and including critical initiatives such as BRAIN and the National Center for Advancing Translational Science. The Committee encourages NIH to continue to expand both its intramural and extramural support for the use of human biology-based experimental and computational approaches in health research to further define human biology, disease pathways, and toxicity and to develop tools for their integration into clinical strategies and safety determination paradigms. Extramural and intramural funding should be made available for the development and evaluation of the relevance and reliability of human biology-based and pathway approaches and prediction tools to assure readiness and utility for regulatory and clinical applications, including pilot studies of pathway-based risk assessments. The Committee requests an update on current activities, a plan for future activities, and the fiscal year 2015 funding level for this area of research in the fiscal year 2016 congressional budget justification.

PREPARED STATEMENT OF THE INFECTIOUS DISEASES SOCIETY OF AMERICA'S

On behalf of the Infectious Diseases Society of America (IDSA), I am pleased to provide testimony in support of the U.S. Department of Health and Human Services (HHS) components that work to prevent, detect and treat infectious diseases (ID). IDSA represents more than 10,000 ID physicians and scientists devoted to patient care, prevention, public health, education, and research. As communicated to the full Senate Appropriations Committee through testimony for the record in advance of its April 29th hearing "Driving Innovation through Federal Investments," IDSA recommends increased fiscal year 2015 Federal investments in public health and biomedical research to save lives, contain healthcare costs, and promote economic growth. More specifically, IDSA encourages the Subcommittee to provide a program level of \$7.8 billion for the Centers for Disease Control and Prevention (CDC) as well as \$32 billion for the National Institutes of Health (NIH). IDSA is particularly supportive of the proposed CDC Detect and Protect Against Antibiotic Resistance Initiative and requests that it be fully funded at \$30 million. We ask that the Subcommittee also advance fiscal year 2015 appropriations that reflect the national security and public health significance of the Biomedical Advanced Research and Development Authority (BARDA). All of these investments are a necessary part of a Federal strategy to decrease the incidence and fatality of infectious diseases in our population.

CENTERS FOR DISEASE CONTROL AND PREVENTION

The ID community's partnership with the CDC has never been more necessary, as we work to address the public health crisis of rising antibiotic resistance while continuing efforts in other important areas such as increasing immunization rates and slowing the spread of HIV.

Last fall, CDC issued a report, Antibiotic Resistance Threats in the United States, 2013 that for the first time ranked and detailed the threats posed by antibiotic resistant microbes. Conservative estimates reveal that more than two million Americans suffer antibiotic resistant infections each year, which result in approximately 23,000 deaths. The actual numbers are likely far higher, as our surveillance and data collection capabilities cannot yet capture the full disease burden. These infections due to antibiotic resistant microbes cost tens of billions of dollars to the U.S. healthcare system annually, and the problem is worsening. The CDC recommended actions in four core areas to address the problem, including prevention, tracking, antibiotic stewardship, and development of new antibiotics and rapid diagnostics. The CDC has proposed fiscal year 2015 activities in each of these areas.

National Center for Emerging and Zoonotic Infectious Diseases (NCEZID)

The NCEZID plays a leading role in CDC efforts to address antibiotic resistance. As such, we ask that it be provided at least the \$445 million requested by the Administration, including at least \$30 million for the Detect and Protect Against Antibiotic Resistance Initiative. This initiative, which is supported by many stakeholders in the health community, would establish regional prevention collaboratives to implement best practices for antibiotic use and infection prevention, create a detection network of five regional labs to speed up identification of the most concerning

threats, improve antibiotic stewardship, and develop an isolate library that will help facilitate the development of desperately needed new antibiotics and diagnostics. The initiative directly addresses the recommended actions from the CDC 2013 report. The CDC projects that over 5 years the initiative will lead to a 50 percent reduction in health-care associated *Clostridium difficile* (C. diff), 50 percent decline in health-care associated carbapenem-resistant Enterobacteriaceae (CRE), 30 percent decline in invasive methicillin-resistant *Staphylococcus aureus* (MRSA), 30 percent decline in health-care associated drug-resistant *Pseudomonas* sp., and 25 percent reduction in drug-resistant *Salmonella* infections. These bacteria claim thousands of lives annually. CRE, for one, have become resistant to all or nearly all currently available antibiotics. Further, nearly 50 percent of those who develop bloodstream infections from CRE die.

IDSA and numerous other stakeholders support the proposed \$14 million increase for the National Healthcare Safety Network (NHSN), which would increase the number of healthcare facilities reporting antibiotic use and antibiotic resistance data and would develop and evaluate new infection prevention strategies.

IDSA thanks Congress for funding the Advanced Molecular Detection (AMD) initiative in fiscal year 2014 and recommends that at least \$30 million be allocated for it in fiscal year 2015. AMD strengthens CDC's molecular sequencing tools and bioinformatics capacity to more rapidly and accurately detect infectious diseases and resistance.

A recent World Health Organization report on antimicrobial resistance reiterates that we are in the midst of a public health crisis that is impacting all regions of the world and requires immediate action on the part of governments and society. IDSA applauds the Administration for launching a Global Health Security Agenda, which would strengthen the capacity of nations to prevent, detect and slow the spread of infectious diseases across borders, simultaneously reducing threats to the United States. We ask that you provide the initiative with funding allocated in the fiscal year 2015 PBR.

National Center for Immunization and Respiratory Diseases (NCIRD)

We know that vaccines are among the most cost-effective clinical preventative services. However, according to the February 2014 CDC Morbidity and Mortality Weekly Report (MMWR), adult immunization rates remain low for most routinely recommended vaccines and considerably short of Healthy People 2020 targets. Each year in the United States, more than 40,000 adults die from illnesses that are preventable through vaccination.

IDSA opposes the \$51 million program level reduction to the CDC Immunization Grant Program (Section 317) contained in the PBR. Although the Affordable Care Act requires insurers to cover immunizations, this alone will not guarantee access or utilization. The Section 317 funds are critical to help providers obtain and store vaccines; establish and maintain vaccine registries; as well as to educate providers and the public about vaccine recommendations, effectiveness and safety; and promote universal vaccination of healthcare workers.

CDC plays a critical role in seasonal and pandemic influenza preparedness and response, including conducting important surveillance activities that better inform response efforts and providing public communications regarding influenza prevention and treatment. Lack of sufficient funding for these efforts could lead to an increased incidence and severity of influenza, as well as increased hospitalization costs and mortality. In the long term, continuously funded efforts will be more cost-effective than the periodic emergency supplemental funding approach that historically has been used to fund such efforts. IDSA supports the proposed fiscal year 2015 increase of \$15 million for these efforts.

NATIONAL INSTITUTES OF HEALTH

National Institute of Allergy and Infectious Diseases (NIAID)

Within NIH, we believe that the National Institute of Allergy and Infectious Diseases (NIAID) should be funded at least at the \$4.58 billion requested by the Administration in the fiscal year 2014 PBR. Nearly flat-funding NIAID limits investment in new research and serves as a disincentive for young people to pursue ID research careers so critical to the discovery of new therapies, new diagnostic approaches, and new preventive strategies.

The NIAID recently began funding a new clinical trials network focused on antibiotic-resistant bacterial infections. With sufficient funding, the new research network/infrastructure will conduct critical studies to address antibiotic resistance as well as begin to answer questions that will help fill the nearly empty antibiotic R&D pipeline. Severe economic disincentives have caused a mass exodus of private com-

panies from the antibiotics market, making federally funded research in this area more critical than ever. An IDSA report issued in April 2013 identified only seven new drugs in development for the treatment of infections caused by multidrug-resistant Gram-negative bacilli (GNB). The Transatlantic Task Force on Antimicrobial Resistance (TATFAR) also recently issued a report, which identified the broken pipeline of new antibacterial drugs as a key obstacle in dealing with resistance. The TATFAR report highlighted NIAID support of clinical research aimed at filling gaps in drug R&D and lowering the associated economic risk to industry. We applaud NIAID's initiative in launching the new network. However, IDSA recommends increased investment in this area.

A recent IDSA report, *Better Tests, Better Care: Improved Diagnostics for Infectious Diseases*, highlighted the need for advancements in diagnostic tools to address bacterial, viral and fungal infections and recommends strengthened NIAID funding for this priority. Faster, more accurate diagnostics lead to better treatments and improved patient outcomes. In addition, new diagnostics are needed to identify patients with highly contagious illnesses so that containment and prevention measures can be undertaken. Diagnostics can improve physicians' ability to discern which infections need antibiotics, and thereby help reduce the unnecessary use of antibiotics that drives the development of antibiotic resistance.

ASSISTANT SECRETARY FOR PREPAREDNESS AND RESPONSE (ASPR)

Biomedical Advanced Research and Development Authority (BARDA)

ASPR plays a key leadership role in coordinating Federal efforts to sufficiently protect the Nation from biothreats, pandemics and emerging infections. IDSA recommends increased funding for BARDA, which has been flat-funded for several years. Additional investment in medical countermeasure development is critical to prepare for both intentional attacks and naturally emerging infections. BARDA is a critical source of funding for public-private collaborations for antibiotic, diagnostic and vaccine R&D.

We ask that the Subcommittee move forward with a sense of urgency to bolster Federal initiatives aimed at dealing with issues such as antimicrobial resistance, antibiotics and rapid diagnostics R&D, adult immunizations, and biodefense. The appropriation of sufficient fiscal year 2015 resources to address ID issues is a necessary complement to efforts that are currently underway within the Senate and House authorizing committees.

Thank you for the opportunity to submit this statement on behalf of the Nation's ID physicians and scientists. Please forward any questions to Jonathan Nurse.

[This statement was submitted by Jonathan Nurse, Director, Government Relations, Public Policy and Government Relations, Infectious Diseases Society of America.]

PREPARED STATEMENT OF THE INTERNATIONAL FOUNDATION FOR FUNCTIONAL GASTROINTESTINAL DISORDERS

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- \$32 Billion for the National Institutes of Health (NIH) at an increase of \$1 billion over fiscal year 2012. Increase funding for the National Cancer Institute (NCI), The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and the National Institute of Allergy and Infectious Diseases (NIAID) by 12 percent.
 - Continue focus on Digestive Disease Research and Education at NIH, Including, Irritable Bowel Syndrome (IBS), Fecal Incontinence Gastroesophageal Reflux Disease (Gerd) Gastroparesis, and Cyclic Vomiting Syndrome (CVS).
-

Thank you for the opportunity to present the views of the International Foundation for Functional Gastrointestinal Disorders (IFFGD) regarding the importance of functional gastrointestinal and motility disorders (FGIMD) research. Established in 1991, IFFGD is a patient-driven nonprofit organization dedicated to assisting individuals affected by FGIMDs, and providing education and support for patients, healthcare providers, and the public. IFFGD also works to advance critical research on FGIMDs in order to develop better treatment options and to eventually find cures. IFFGD has worked closely with the National Institutes of Health (NIH) on many priorities, and I served on the National Commission on Digestive Diseases (NCDD), which released a long-range plan in 2009, entitled *Opportunities and Challenges in Digestive Diseases Research: Recommendations of the National Commission on Digestive Diseases*.

The need for increased research, more effective and efficient treatments, and the hope for discovering a cure for FGIMDs are close to my heart. My own experiences of suffering from FGIMDs motivated me to establish IFFGD, and I was shocked to discover that despite the high prevalence of FGIMDs among all demographic groups, such a lack of research existed. This translates into a dearth of diagnostic tools, treatments, and patient supports. Even more shocking is the lack of awareness among the medical community and the public, leading to significant delays in diagnosis, frequent misdiagnosis, and inappropriate treatments including unnecessary surgery. Most FGIMDs have no cure and limited treatment options, so patients face a lifetime of chronic disease management. The costs associated with these diseases range from \$25–\$30 billion annually; economic costs are also reflected in work absenteeism and lost productivity.

IRRITABLE BOWEL SYNDROME

IBS affects 30 to 45 million Americans, conservatively at least 1 out of every 10 people. It is a chronic disease that causes abdominal pain and discomfort associated with a change in bowel pattern, such as diarrhea and/or constipation. As a “functional disorder,” IBS affects the way the muscles and nerves work, but the bowel does not appear to be damaged on medical tests. Without a diagnostic test, IBS often goes undiagnosed or misdiagnosed for years. Even after IBS is identified, treatment options are limited and vary from patient to patient. Due to persistent pain and bowel unpredictability, individuals may distance themselves from social events and work. Stigma surrounding bowel habits may act as barrier to treatment, as patients are not comfortable discussing their symptoms with doctors. Many people also dismiss their symptoms or attempt to self-medicate with over-the-counter medications. Outreach to physicians and the general public remain critical to overcome these barriers to treatment and assist patients.

FECAL INCONTINENCE

At least 12 million Americans suffer from fecal incontinence. Incontinence crosses all age groups, but is more common among women and the elderly of both sexes. Often it is associated with neurological diseases, cancer treatments, spinal cord injuries, multiple sclerosis, diabetes, prostate cancer, colon cancer, and uterine cancer. Causes of fecal incontinence include: damage to the anal sphincter muscles, damage to the nerves of the anal sphincter muscles or the rectum, loss of storage capacity in the rectum, diarrhea, or pelvic floor dysfunction. People may feel ashamed or humiliated, and most attempt to hide the problem for as long as possible. Some don't want to leave the house in fear they might have an accident in public; they withdraw from friends and family, and often limit work or education efforts. Incontinence in the elderly is the primary reason for nursing home admissions, an already significant social and economic burden in our aging population. In 2002, IFFGD sponsored a consensus conference entitled, *Advancing the Treatment of Fecal and Urinary Incontinence Through Research: Trial Design, Outcome Measures, and Research Priorities*. IFFGD also collaborated with NIH on the NIH State-of-the-Science Conference on the Prevention of Fecal and Urinary Incontinence in Adults in 2007.

NIDDK recently launched a Bowel Control Awareness Campaign (BCAC) that provides resources for healthcare providers, information about clinical trials, and advice for individuals suffering from bowel control issues. The BCAC is an important step in reaching out to patients, and we encourage continued support for this campaign. Further research on fecal incontinence is critical to improve patient quality of life and implement the research goals of the NCDD.

GASTROESOPHAGEAL REFLUX DISEASE

GERD is a common disorder which results from the back-flow of stomach contents into the esophagus. GERD is often accompanied by chronic heartburn and acid regurgitation, but sometimes the presence of GERD is only revealed when dangerous complications become evident. There are treatment options available, but they are not always effective and may lead to serious side effects. Gastroesophageal reflux (GER) affects as many as one-third of all full term infants born in America each year and even more premature infants. GER results from immature upper gastrointestinal motor development. Up to 8 percent of children and adolescents will have GER or GERD due to lower esophageal sphincter dysfunction and may require long-term treatment.

GASTROPARESIS

Gastroparesis, or delayed gastric emptying, refers to a stomach that empties slowly. Gastroparesis is characterized by symptoms from the delayed emptying of food, namely: bloating, nausea, vomiting, or feeling full after eating only a small amount of food. Gastroparesis can occur as a result of several conditions, and is present in 30 percent to 50 percent of patients with diabetes mellitus. A person with diabetic gastroparesis may have episodes of high and low blood sugar levels due to the unpredictable emptying of food from the stomach, leading to diabetic complications. Other causes of gastroparesis include Parkinson's disease and some medications. In many patients the cause cannot be found and the disorder is termed idiopathic gastroparesis.

CYCLIC VOMITING SYNDROME

CVS is a disorder with recurrent episodes of severe nausea and vomiting interspersed with symptom free periods. The periods of intense, persistent nausea and vomiting, accompanied by abdominal pain, prostration, and lethargy, last hours to days. Previously thought to occur primarily in pediatric populations, it is increasingly understood that this crippling syndrome can occur in many age groups, including adults. CVS patients often go for years without correct diagnosis. CVS leads to significant time lost from school and from work, as well as substantial medical morbidity. The cause of CVS is not known. Research is needed to help identify at-risk individuals and develop more effective treatment strategies.

SUPPORT FOR CRITICAL RESEARCH

IFFGD urges Congress to fund the NIH at level of \$32 billion for fiscal year 2015. Strengthening and preserving our Nation's biomedical research enterprise fosters economic growth and supports innovations that enhance the health and well-being of the Nation. Concurrent with overall NIH funding, IFFGD supports the growth of research activities on FGIMDs to strengthen the medical knowledge base and improve treatment, particularly through the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). Such support would expedite the implementation of recommendations from the NCDD. It is also vital for NIDDK to work with the National Institute of Child Health and Human Development (NICHD) to expand its research on the impact FGIMDs have on pediatric populations. Following years of near level-funding, research has been negatively impacted across all NIH Institutes and Centers. Without additional funding, medical researchers run the risk of losing promising research opportunities that could benefit patients.

We applaud the recent establishment of the National Center for Advancing Translational Sciences (NCATS) at NIH. Initiatives like the Cures Acceleration Network are critical to overhauling the translational research process and overcoming the challenges that plague treatment development. In addition, new efforts like taking the lead on drug repurposing hold the potential to speed new treatment to patients. We ask that you support NCATS and provide adequate resources for the Center in fiscal year 2015.

Thank you for the opportunity to present these views on behalf of the FGIMD community.

[This statement was submitted by Nancy J. Norton, President and Co-Founder, International Foundation for Functional Gastrointestinal Disorders.]

PREPARED STATEMENT OF THE INTERSTATE MINING COMPACT COMMISSION

We are writing in opposition to the fiscal year 2015 Budget Request for the Mine Safety and Health Administration (MSHA), which is part of the U.S. Department of Labor. In particular, we urge the Subcommittee to reject MSHA's proposed defunding of the Assistance to States grant program pursuant to Section 503(a) of the Mine Safety and Health Act of 1977. Until fiscal year 2013, MSHA's budget request for state grants was approximately \$9 million, which approached the statutorily authorized level of \$10 million, but still did not fully consider inflationary and programmatic increases being experienced by the states. In fiscal year 2015, based on a realignment of priorities, MSHA has once again chosen to zero out funding for state assistance grants as it did in fiscal year 2014. We urge the Subcommittee to restore funding to the statutorily authorized level of \$10 million for state grants so that states are able to fully and effectively carry out their responsibilities under Sections 502 and 503 of the Act, including the training of our Nation's miners.

The Interstate Mining Compact Commission is a multi-state governmental organization that represents the natural resource, environmental protection and mine safety and health interests of its 26 member states. The states are represented by their Governors who serve as Commissioners.

IMCC is greatly appreciative of actions by Congress in January of this year as part of the Omnibus Appropriation bill for fiscal year 2014 to reject MSHA's proposed elimination of funding for the state grants program and to restore funding at the fiscal year 2012 level of \$8.4 million. Given that action and the clear message it sent about the importance of state mine safety programs, we had hoped the Administration would respond accordingly and include funding for these programs in its fiscal year 2015 proposed budget. Clearly, this did not happen and as such we appeal to your Subcommittee to once again restore funding for these vital miner health and safety programs.

It should be kept in mind that, whereas MSHA over the years has narrowly interpreted Assistance to States grants as meaning "training grants" only, Section 503 was structured to be much broader in scope and to stand as a separate and distinct part of the overall mine safety and health program. In the Conference Report that accompanied passage of the Federal Coal Mine Health and Safety Act of 1969, the conference committee noted that both the House and Senate bills provided for "Federal assistance to coal-producing States in developing and enforcing effective health and safety laws and regulations applicable to mines in the States and to promote Federal-State coordination and cooperation in improving health and safety conditions in the Nation's coal mines." (H.Conf. Report 91-761). The 1977 Amendments to the Mine Safety and Health Act expanded these assistance grants to both coal and metal/non-metal mines and increased the authorization for annual appropriations to \$10 million. The training of miners was only one part of the obligation envisioned by Congress.

With respect to the training component of our mine safety programs, IMCC's member states are concerned that without full, stable funding of the State Grants Program, the federally required training for miners employed throughout the U.S. will greatly suffer. States have struggled to maintain efficient and effective miner training programs in spite of increased numbers of trainees and the incremental costs associated therewith. The situation has been further complicated by new statutory, regulatory and policy requirements that have grown out of the various reports and recommendations attending the Upper Big Branch investigation. In spite of all this, MSHA has chosen to eliminate funding completely for this critical component of its statutory obligations. In addition to state training programs, these assistance grants also support state mine rescue training programs, mine rescue competitions, EMT training, miner certifications, accident investigations and reporting, review and approval of company safety plans, and, for those states that operate more comprehensive mine safety and health programs (such as PA, WV, VA, OH, IL, AL, KY and OK), program administrative costs such as supplies, staff training, and travel. We can provide a breakdown of these costs at the Committee's request.

In MSHA's budget justification document (at page 70), the agency states that: "Training plays a critical role in preventing deaths, injuries, and illnesses on the job. By providing effective training, miners are able to recognize possible hazards and understand which procedures are safe to follow. MSHA will continue to increase visibility and emphasize on [sic] training, recognizing its critical role in reducing the number of injuries and fatalities in the mining community." We are mystified about how MSHA intends to accomplish these stated objectives without the training and other programs that are provided by the states pursuant to the grants they receive from MSHA—as has been the case since the enactment of the Mine Safety and Health Act in 1969.

By way of an explanation for the drastic cut to state grants, MSHA states on page 72 of its budget justification document: "To meet the demand of the agency's higher priority enforcement activities, MSHA will defund the program and shift the responsibility for training back to mine operators. Mine operators will be required to develop their own programs or contract these services. MSHA is transitioning to an updated training model, and will develop more of its own training curricula, exercises, and materials to assist mine operators with providing a complete training program to their employees. Consistent with existing statutory requirements, mine operators are required to ensure that employees have access to complete training programs."

While this idea of shifting training responsibilities and costs entirely to mine operators may have merit in limited cases, we are uncertain about the ability of the mining industry (especially small operators and contractors) to accommodate these new costs and suspect that any realignment of training responsibilities from the states to the industry will take considerable time and planning. Furthermore, our

experience over the past 35 years has demonstrated that the states are often in the best position to design and offer this training in a way that insures that the goals and objectives of Sections 502 and 503 of the Mine Safety and Health Act are adequately met. There is clear and tangible evidence of training programs offered by mine operators (or contractors on their behalf) falling well below what would be considered a minimum standard for these types of programs. Furthermore, there have never been any suggestions or allegations that the states are not already providing the necessary “training curricula, exercises and materials to assist mine operators with providing a complete training program”. MSHA appears to be playing the “training card” in its budget justification to duplicate the excellent work that has already been undertaken by the states in this area solely to increase funding for MSHA staff.

There have been limited, and not particularly productive, discussions between MSHA and the states about the impacts this proposal will have on state training programs and other components of state mine safety and health programs, including any sort of transition away from how we are currently doing business. To propose such a dramatic shift without first working out the details with the states is inappropriate and a denigration of the role the states have played in protecting our Nation’s miners. Furthermore, to expect such a drastic change to occur within a single fiscal year is unrealistic and will only result in confusion and potential negative impacts to the availability and quality of miner training and the overall health and safety of miners.

MSHA notes in its budget justification document that the State Grants Program trained 132,000 miners in 48 states and the Navajo Nation in fiscal year 2013, a year in which state grants were cut by 66 percent. While MSHA does not admit to what the elimination of this funding will mean for miner training, we believe the consequences could be debilitating. Examples of the direct impacts being reported by just some of the IMCC member states as a result of MSHA’s decision follow. More expanded information from each state is appended to this statement and we request that it be included in the record. The most recent accounting of the number of miners trained by the states (and whose training could be jeopardized by funding cuts) based on fiscal year 2012 reporting for coal and metal/nonmetal is as follows:

- Kentucky: Trained or tested over 25,000 people.
- Louisiana: 1,000 miners trained.
- Alaska: 2,343 miners trained.
- New Mexico: 2,265 miners trained.
- Oklahoma: 5,000 miners trained.
- Pennsylvania: 7,000 miners trained.
- Ohio: 8,443 miners trained (including for mine rescue).
- Colorado: 4,229 miners trained.
- Arkansas: 2,000 miners trained.
- Nevada: 2,700 miners trained.
- North Carolina: 6,000—8,000 miners trained.
- Maryland: 776 miners and contractors trained.
- Arizona: 3,056 miners trained.
- Virginia: 5,455 miners trained.

Interestingly, while MSHA is proposing to eliminate funding for state training grants, it is proposing to increase funding by \$2,800,000 and 18 FTEs for its Educational and Policy Development budget activity. This money will allegedly be used to transition from state grants to a “new training model” which will include new training curricula, materials and online courses, as well as monitoring operator training plans and instructors. From our perspective, this reflects an acknowledgment on MSHA’s part that the transition to a totally industry-lead training initiative will likely be fraught with difficulties. However, heavy-handed Federal oversight is not the solution to an effective training program. We have seen this type of approach fail in the past and assert that the training programs operated by the states have resulted in a higher level of success, as indicated by the significantly reduced rates of injuries and fatalities over the past several years. Congress has clearly understood this dynamic as well, appropriating the necessary moneys needed to preserve and enhance state training programs. It should also be kept in mind that effective training programs operated by the states, especially for small operators, are the first and best method to reduce accidents, injuries and fatalities in mines. On the other hand, enforcement often comes too late to be effective, and by its very nature is not preventative. We are hopeful that Congress will once again recognize these operational realities in fiscal year 2015 and turn back MSHA’s efforts to undercut these valuable programs.

While we can appreciate MSHA’s desire to realign its resources to focus on inspection and enforcement, one of the most effective ways to insure miner health and

safety in the first place is through comprehensive and excellent training. The states have been in the forefront of providing this training for over 35 years and are best positioned to continue that work into the future. Furthermore, the Federal government's relatively modest investment of money in supporting the states to handle this training has paid huge dividends in protecting lives and preventing injuries. The states are also able to provide these services more effectively and at a cost well below what it would cost MSHA to do so.

As you consider our request to reject MSHA's proposed cut and instead to increase MSHA's budget for state assistance grants, please keep in mind that the states play a particularly critical role in providing special assistance to small mine operators (those coal mine operators who employ 50 or fewer miners or 20 or fewer miners in the metal/nonmetal area) in meeting their required training needs. This has been a particular focus in those states where metal/non-metal mining operations predominate. These are often small business operators who cannot afford to offer the comprehensive training that is required under Section 502 of the Mine Safety and Health Act. The states also provide specialized training to the Spanish-speaking communities in the western United States.

The "yo-yo" effect of inconsistent funding for state assistance grants is having a debilitating effect on the way we do business. To run effective, meaningful programs, states need continuous, stable, reliable and sustainable funding from year to year. We greatly appreciate your efforts to make that happen. We also appreciate the opportunity to submit our views on MSHA's fiscal year 2015 budget request. Please contact us for additional information or to answer any questions you may have.

State Reports re Impacts from De-Funding of Assistance to States Grants Program

In preparation for IMCC's presentation of this statement to the House and Senate Appropriations Committees, IMCC asked the states three questions, noted below. Responses from each of the reporting states are indicated.

What do you anticipate the impacts to your state will be from the elimination of grant funding, including the number of miners who may not be trained?

- Kentucky: These cuts will have a devastating effect on our program. Kentucky trains over 20,000 miners yearly. The money we get from MSHA pays our instructors' salaries.
- Louisiana: In Louisiana, the state training is performed through the Louisiana Technical Community College system. If the grant is eliminated, their mine safety training program would be completely eliminated, closing its doors on Sept 30, 2013, and laying off both of its employees. The program trains at least 1,000 miners each year (886 miners from Oct 1, 2012 to present).
- Alaska: Eliminating MSHA training funding potentially impacts each of the 16,400 employees and thousands of owner/operators and contractors working in Alaska's mining industry as of January 2013. Up to 2,600 students are MSHA trained and certified each year by the University of Alaska Mine and Petroleum Training Service ("MAPTS"). MAPTS is the MSHA training grant recipient in Alaska. MAPTS staff have pointed out that a loss of MSHA training grant funds will have a disparate impact on small mines located in more remote areas of Alaska.
- New Mexico: In prior years the State of New Mexico, through New Mexico Institute of Mining and Technology, received \$147,000 from MSHA that was used to train miners in NM to meet the regulatory requirements of 30 CFR Parts 46 and 48 which are mandated training requirements for miners. We train over 2,000 miners in NM yearly. Most of these miners are employed at small business operations in our state that cannot afford trainers at their small operations. In addition we provide Spanish language training to 200–300 miners yearly and are the only service available to Spanish-speaking miners in the State.
- Oklahoma: The Oklahoma Miner Training Institute (OMTI) is funded in part with the state grant. Utilizing the funding provided, OMTI trains 5,000 miners annually in a variety of courses, such as New Miner and Annual Refresher, in accordance with 30 CFR Parts 46 and 48. Without the fully funded support that the state grant provides, the mining community in Oklahoma will be impacted.
- Pennsylvania: Pennsylvania trains approximately 7,000 miners and contractors in the Anthracite, Bituminous and Industrial Minerals mines and facilities of the Commonwealth. This training is provided at no cost to the mining community by in-house staff, Pennsylvania State University and Schuylkill Vo-Tech. We also provide a mine rescue program for small coal and industrial minerals mines to comply with Federal mine rescue requirements and required EMT

training through Indiana University of PA at no cost to mine operators. Although a majority of large operators provide training for their employees to meet Federal requirements, small mine and facility operators and contractors rely on the MSHA grant for their training needs. Pennsylvania also relies on the MSHA grant to fund other aspects of our mine safety program. These include staff training, health and safety conferences, mine rescue contests, safety equipment, mine rescue supplies, and travel related to these functions.

- Ohio: After reviewing our total surface training numbers for the year 2012, it would appear that 1,369 trainees would not have been trained if not for receiving funding from the States Grant program.
- Colorado: The impact of the elimination of the MSHA training grant to the miners of Colorado and our training program will be acute. We trained 5,742 in fiscal year 11 and 4,316 in fiscal year 12. This includes, coal, metal, non-metal and contractors who serve the industry. The reduction would be 2,800—3,700 miners not trained, including many that receive training in Spanish. The reduction would be salaries and operating costs for two trainers. (The program has 5 FTE total).
- Arkansas: While it is difficult for a service provider to estimate the total impact on our state from the elimination of grant funding, we can address how it will impact our ability to provide the mandatory training to the miners and contractors who have utilized our services for years. While the Arkansas MSHA State Training Program has been proactive in trying to maintain the program and continuing to provide effective training to those requesting our service, it has become increasingly difficult to recover the cost for salaries, state match and travel for the sufficient number of staff needed to meet the demand, as well as the costs for maintaining training equipment and supplies. We have already eliminated one part-time position and raised our training fees, but feel confident that if we have to raise them again to generate the revenue needed to sustain the program, it will become a financial hardship on the small mining operations and contractors who are our primary clients. At the current rate, without raising fees, it is likely we would have to eliminate another part-time position, therefore decreasing our ability to provide the mandatory training to our clients requesting the service. Also, grant funds have been used for our staff to attend national and state MSHA conferences and training events. This would have to be completely eliminated. The Arkansas MSHA State Training Program trains an average of 2,000 individual miners and contractors each year. We have been providing new miner, annual refresher, and first aid training.
- North Carolina: If State Grant funding is eliminated, we would be reducing our staff of 6 to a staff of 2 based on our state appropriations and the fact we would not be awarded any additional appropriations. I would estimate there would be 6,000 miners we would not be able to provide training for based on previous number of miners and contractors trained. We average training at around 8,000 miners per year. This would be a devastating burden on the small operators who rely on us to assist them with their safety and health programs. Not only will they have to pay a significant amount of money for future training but the quality of training will certainly be a concern. There are many private instructors who do not provide effective, quality training. The mining industry is experiencing the lowest incident rates ever, lowest amount of accidents, and a record low number of fatalities and we feel quality, effective training plays a major role with accident prevention.
- Maryland: The elimination of the MSHA training grant will be the elimination of the training program in Maryland. Small operators and contractors will have no training. While the national and international companies have their own training programs they still rely on the state to provide training to contractors and often attend statewide forums sponsored by the State Program.
- Virginia: Eliminating the MSHA state training funds would negatively affect the quality of mine safety training in Virginia and the quantity of assistance the DM and the DMM provide to small operators and their work force. In particular, the DM's Small Mine Safety Service (which is dedicated to assisting the small mine operators) would be adversely impacted.

Small operators and contractors would be immediately affected through any reduction in the state's ability to provide mine safety training. Loss of funding would also impact ongoing training opportunities for our training staff, and the development of site-specific training materials, as well as purchase of supplemental training materials, now being offered to mine operators.

To what extent will the mining in your state be able to “develop their own programs or contract these services”? How long do you anticipate this would take?

- Kentucky: The majority of our mines involve small mines and have no trainers. The small mines send their employees to our Office of Mine Safety and Licensing to receive quality training free of charge. These miners will have to pay a private instructor and in turn receive inadequate training and in some cases will receive no training at all. We’ve seen many problems in the past with some private instructors not conducting adequate training and they have been reported to the Federal Mine Safety and Health Review Commission for sanctions.
- Louisiana: In the absence of our state training program, the mining industry would have to return to “fending for themselves” to train its miners, resulting in an increased cost to industry and possibly lower quality of training for individual miners.
- Alaska: The majority of mines in Alaska are small operations with less than 10 employees that do not have the resources or capabilities to develop and maintain their own training and certification systems. It is uncertain how long it may take to develop programs or contract MSHA training services. At this point, there are no MSHA training providers other than MAPTS consistently available for small mines in Alaska.
- Oklahoma: The training OMTI provides serves all of the mining industry, in particular the smaller mining operations. Without the training courses offered, the smaller mine sites are most susceptible to see increased costs and lack of fully trained miners as required in 30 CFR Parts 46 and 48.
- Pennsylvania: Without the MSHA funding, small operators will have to either conduct their own training or use training contractors. Penn State University and Schuylkill Vo-Tech have established a reputation and trust with the operators with a no fee option. If the operators wish to continue this arrangement, a significant cost per student must be absorbed by the operators. The quality of training provided by the PA Bureau of Mine Safety, Pennsylvania State University, Schuylkill Vo-Tech and Indiana University of PA is very high and loss of this program will have a negative impact on miner safety. It will also impact Pennsylvania’s ability to maintain its world class mine safety program and ability to support program functions identified above. One example: Federal law requires all mine rescue teams to attend at least two competitions each year, with the states supporting this requirement by holding and supporting these contests. With state budgets shrinking, the ability to support these contests without Federal funding is in jeopardy.
- Ohio: From past experience, the larger mining companies could deal with developing their own programs and could contract out these services if needed. The smaller companies and contract miners would be the ones who either would be left out, or would struggle with maintaining their training programs. As far as the time it would take for these companies and contractors to assume total responsibility for complying with MSHA’s training law standards, it would take a considerable amount of time.
- Colorado: The reduction in support of mine training particularly affects the medium and small operators who make up 95 percent of the mining operations in Colorado. This severely reduces the affect we can all have on preventing accidents and injuries BEFORE they become a major incident. Unfortunately, this will leave many operators with few resources for safety and health and result in an increase in MSHA enforcement inspection time, citations, and most unfortunately, a likely increase in injury and accident rates in our state.
- Arkansas: Since the Arkansas MSHA State Training Program places emphasis on assisting small mining operations and contractors, we are aware that most of these companies are neither staffed nor equipped to provide effective training; whereas, the State Grant staff has multiple years of combined training experience. Small companies are at a distinct disadvantage in the area of providing their own training.
- North Carolina: Many small operators will not have the resources to develop their own programs adequately. Many of them would not know how to develop lesson plans, outlines, and have the time or resources to prepare a training program. They would have to contract their training out to consultants. Mine safety training was geared to be site-specific and company-specific which is how we prepare for our classes for mining operations. Consultants will use a “canned program” and there are quality control concerns with a canned program. We know of operators who also rely on on-line training and the miners do not like it because there is no interaction or discussion taking place with on-line training. In terms of how long it will take for an operator to implement its own safety and health training program—probably at least a year or longer.

- Maryland: There is no ability for the small operators, many of whom don't even know they need the training until the state advises them, or contractors to provide safety training. Our most frequent calls are from contractors looking to bid work but who have limited safety training and generally do not know where to go to obtain it.
- Virginia: Many larger mining companies already have the infrastructure to meet these obligations and do. The true impact of MSHA's decision to eliminate this program will again, fall on the small operators, who have for years depended on the Department of Mines, Minerals, and Energy (DMME) to assist them in meeting their training obligations required by state and Federal regulations. Most small operators will rely on contractors to provide the required training. As a consequence the quality of training may suffer.
- New Mexico: If the New Mexico grants program is not available to our small businesses in our Part 46 (sand and gravel or aggregate) industries, the quality of annual refresher and new miner training would suffer. I believe the alternative will be that a crusher foreman or pit foreman will be assigned to provide the training. This individual will likely have little training experience and even less interest in providing the training.

What other unanticipated consequences from the elimination of state grant funding might there be, particularly with respect to miner safety and health?

- Kentucky: In our opinion the miners will be the ones to suffer most. They will have to pay for the classes, they will not get adequate training, and the end result will be an increase in mine fatalities.
- Louisiana: It strikes us as particularly unfortunate that MSHA would choose this route of cost savings given that many fatalities are found to have insufficient training as a root cause.
- Alaska: Eliminating training funding is expected to lead to an increase in mining accidents and creates an artificial need for increased enforcement on mine sites. Reduced MSHA-supported training will damage the evolution of safety culture improvements in the mining industry. Focusing solely on enforcement is likely to further deteriorate individual attitudes toward MSHA and voluntary compliance with MSHA requirements.
- New Mexico: The Mine Act of 1977 was very specific in Sections 502 and 503 regarding the requirement to train miners and to fund state programs to meet the requirements of the Act. We are a small organization that uses our funding wisely to provide low cost training services to small business and non-English speaking miners in our state. We believe this to be an efficient use of these funds to educate our miners, thereby providing good paying jobs in a safer environment.
- Pennsylvania: There is no question that cutting the State Grant Program goes against the intent of Congress, but more important it will have a negative impact on the health and safety of our Nation's miners. Every MSHA accident investigation report highlights the need for quality training to eliminate and reduce accidents. Not funding the State Grant Program at the maximum amount (\$10,000,000) is misguided and wrong and will impact our ability to see that all workers go home to their families at the end of each work shift.
- Ohio: For smaller mines and with the contract miners, their safety training would suffer, thus causing a potential increase in mining accidents and serious injuries.
- Colorado: Like other states, we maintain a unique and trusting relationship with our mine operators and contractors through regular contact, assistance (such as safety audits, etc.) and education and training. We can quickly access and update our mining community regarding the wide range of regulatory requirements, technological improvements in mine safety and sharing of mine health and safety resources. The state program is the gold standard for providing effective and innovative mine health and safety training and training mine employees and contractors to effectively train their own employees.
- Arkansas: We believe we will see accidents trend upward. The training provided by the Arkansas MSHA State Training Program has proven to have an impact on reduction in accidents; the statistics reveal that the companies who utilize the State services for their training needs have fewer accidents than the companies who have chosen to go another route to obtain their training. Also, company training might not be comprehensive in certain areas, such as miners' statutory rights, including the right to be provided a safe working environment and the right to refuse to perform unsafe tasks. The State Training program provides comprehensive training that supports accident prevention by focusing on eliminating unsafe practices and conditions that contribute to accidents.

State training reinforces miner knowledge of safe work behavior and encourages safe work practices, as well as increasing their knowledge in identifying an unsafe work environment as detailed in the Code of Federal Regulations. In addition to training, the State Training staff receives constant e-mails and phone calls regarding safety and health issues. Many of the companies and/or individuals the State Grants staff have worked with over the years are not comfortable going directly to Federal MSHA with questions or concerns; whereas, the State has developed a cooperative relationship that has proven mutually beneficial.

- North Carolina: Impacts would include not being available to provide special emphasis projects such as mock drills, mine safety and health law seminars, annual mine safety and health state conferences, explosives safety courses, and not being able to properly prepare training programs geared to site-specific needs of mining operations. Training plan assistance will not be provided. Fatalities, accidents, and incident rates will be on the rise because of ineffective training.
- Maryland: Impacts would be to lessen the awareness and importance of safety in day to day work situations. Small operators often perform multiple tasks and may not take time to think through a situation such as electrical disconnects on conveyors or repair of faulty wiring. In addition, the state program goes beyond MSHA and provides CPR training and warning signs of heat stroke, fatigue and other health related issues. Also, individual contractors may not get other safety training as required at a small operation.
- Virginia: Our most valuable resource, the miner, will be affected the most due to the lack of effective training. Statistics show that, without the proper training, the potential for mining accidents and serious injury does increase significantly. An increase in unsafe acts and conditions, especially at smaller mining operations and with independent contractors, could certainly result in more accidents and injuries to miners and workers.

The increase in unsafe acts and conditions could also increase enforcement action by MSHA and the resulting financial burden could potentially drive many small operators out of business.

- New Mexico: Our number one priority will be to try to continue the training of our states miners using our State funds. This means that we will be unable to fulfill certain functions that we have addressed in the past. These include helping with mine rescue competitions, completing all of our regulatory responsibilities and ensuring interaction with operators on issues such as compliance assistance.

ADDENDUM FROM VIRGINIA DEPARTMENT OF MINES, MINERALS AND ENERGY

Our State (Virginia) supports the statement submitted today by the Interstate Mining Compact Commission, of which we are a member, concerning the fiscal year 2015 proposed budget for the Mine Safety and Health Administration (MSHA) which urges Congress to appropriate \$10 million for State assistance grants pursuant to Section 503 of the Mine Safety and Health Act of 1977.

This addendum was submitted by Bradley C. (Butch) Lambert, Deputy Director, Virginia Department of Mines, Minerals and Energy.

[This statement was submitted by Gregory E. Conrad, Executive Director, Interstate Mining Compact Commission.]

PREPARED STATEMENT OF THE INTERSTITIAL CYSTITIS ASSOCIATION

SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2015

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- \$660,00 for the IC education and Awareness Program at the Centers for Disease Control and Prevention (CDC).
 - \$7.8 billion for CDC.
 - \$32 billion for the National Institutes of Health (NIH) and Proportional Increases Across All Institutes and Centers.
 - Support for NIH Research on IC, including the Multidisciplinary Approach to the Study of Chronic Pelvic Pain (MAPP) Research Network.
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Thank you for the opportunity to present the views of the Interstitial Cystitis Association (ICA) regarding interstitial cystitis (IC) public awareness and research. ICA was founded in 1984 and is the only nonprofit organization dedicated to im-

proving the lives of those affected by IC. The Association provides an important avenue for advocacy, research, and education. Since its founding, ICA has acted as a voice for those living with IC, enabling support groups and empowering patients. ICA advocates for the expansion of the IC knowledge-base and the development of new treatments. ICA also works to educate patients, healthcare providers, and the public at large about IC.

IC is a condition that consists of recurring pelvic pain, pressure, or discomfort in the bladder and pelvic region. It is often associated with urinary frequency and urgency. This condition may also be referred to as painful bladder syndrome (PBS), bladder pain syndrome (BPS), and chronic pelvic pain (CPP). It is estimated that as many as 12 million Americans have IC symptoms. Approximately two-thirds of these patients are women, though this condition does severely impact the lives of as many as 4 million men. IC has been seen in children and many adults with IC report having experienced urinary problems during childhood. However, little is known about IC in children, and information on statistics, diagnostic tools and treatments specific to children with IC are limited.

The exact cause of IC is unknown and there are few treatment options available. There is no diagnostic test for IC and diagnosis is made only after excluding other urinary/bladder conditions. It is not uncommon for patients to experience one or more years delay between the onset of symptoms and a diagnosis of IC. This is exacerbated when healthcare providers are not properly educated about IC.

The effects of IC are pervasive and insidious, damaging work life, psychological well-being, personal relationships, and general health. The impact of IC on quality of life is equally as severe as rheumatoid arthritis and end-stage renal disease. Health-related quality of life in women with IC is worse than in women with endometriosis, vulvodynia, and overactive bladder. IC patients have significantly more sleep dysfunction, and higher rates of depression, anxiety, and sexual dysfunction.

Some studies suggest that certain conditions occur more commonly in people with IC than in the general population. These conditions include allergies, irritable bowel syndrome, endometriosis, vulvodynia, fibromyalgia, and migraine headaches. Chronic fatigue syndrome, pelvic floor dysfunction, and Sjogren's syndrome have also been reported.

IC PUBLIC AWARENESS AND EDUCATION THROUGH CDC

The IC Education and Awareness Program at CDC is critical to improving public and provider awareness of this devastating disease, reducing the time to diagnosis for patients, and disseminating information on pain management and IC treatment options.

The IC program has utilized opportunities with charitable organizations to leverage funds and maximize public outreach. Such outreach includes public service announcements in major markets and the Internet, as well as a billboard campaign along major highways across the country. The IC program has also made information on IC available to patients and the public through videos, booklets, publications, presentations, educational kits, websites, self-management tools, webinars, blogs, and social media communities such as Facebook, YouTube, and Twitter. For healthcare providers, this program has included the development of a continuing medical education module, targeted mailings, and exhibits at national medical conferences.

The CDC IC Education and Awareness Program also provides patient support that empowers patients to self-advocate for their care. Many physicians are hesitant to treat IC patients because of the time it takes to treat the condition and the lack of answers available. Further, IC patients may try numerous potential therapies, including alternative and complementary medicine, before finding an approach that works for them. For this reason, it is especially critical for the IC program to provide patients with information about what they can do to manage this painful condition and lead a normal life.

ICA recommends a specific appropriation of \$660,000 in fiscal year 2015 for the CDC IC Education and Awareness Program. ICA also recommends an appropriation of \$7.8 billion for CDC, as well as continued support for the National Center for Chronic Disease Prevention and Health Promotion which administers the IC program.

IC RESEARCH THROUGH THE NATIONAL INSTITUTES OF HEALTH

The National Institutes of Health (NIH) maintains a robust research portfolio on IC with the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) serving as the primary Institute for IC research. Research currently underway holds great promise to improving our understanding of IC and developing

better treatments and a cure. The NIDDK Multidisciplinary Approach to the Study of Chronic Pelvic Pain (MAPP) Research Network studies the underlying causes of chronic urological pain syndromes. The MAPP Study is now in its second phase and researchers hope to utilize gathered data on patient experiences with IC to identify different phenotypes of the disease. Phenotype information will ultimately allow physicians to prescribe treatments with more specificity. Research on chronic pain that is significant to the community is also supported by the National Institute of Neurological Disorders and Stroke (NINDS) as well as the National Center for Complementary and Alternative Medicine (NCCAM). Additionally, the NIH investigator-initiated research portfolio continues to be an important mechanism for IC researchers to create new avenues for interdisciplinary research.

ICA also supports the National Center for Advancing Translational Sciences (NCATS), including the Cures Acceleration Network (CAN). Initiatives like CAN are critical to overhauling the translational research process and overcoming the research “valley of death” that currently plagues treatment development. In addition, drug repurposing and other efforts led by NCATS hold the potential to speed access to new treatment for patients. ICA encourages support for NCATS and the provision of adequate resources for the Center in fiscal year 2015.

ICA recommends a funding level of \$32 billion for NIH in fiscal year 2015. ICA also recommends continued support the MAPP Study administered by NIDDK.

Thank you for the opportunity to present the views of the interstitial cystitis community.

[This statement was submitted by Lee Claassen, Executive Director, Interstitial Cystitis Association.]

PREPARED STATEMENT OF THE JAMESTOWN S'KLALLAM TRIBE

On behalf of the Jamestown S'Klallam Tribe, I would like to thank you for this opportunity to submit this written testimony on fiscal year 2015 Appropriations for the Department of Health and Human Services. The Federal budget for Tribal health programs and services should reflect the U.S. Government's commitment to honor and uphold its Treaty and Trust obligations to American Indians and Alaska Natives. When Tribal Governments are empowered through Self-Governance with the flexibility and resources to provide quality healthcare to their citizens, these investments hold tremendous promise for not only Tribal communities but for the communities that surround them.

The Jamestown Family Health and Dental Clinics have demonstrated a real return on the Federal investment and reflect the tremendous potential Tribes have to not only reduce healthcare costs but to increase prevention and treatment services for their Tribal citizens.

TRIBAL SPECIFIC HEALTH APPROPRIATION PRIORITIES

- Restore Sequestered Amounts/Exempt Indian Programs from Budget Reductions
- Fully Fund Contract Support Costs—Separate Mandatory Appropriation
- Budget Equity for Tribal Governments/Programs Accessible to Small Tribes
- Medicare/Medicaid Reimbursement
- Provide \$30 Million for Part A Grants for Native Americans in the Older Americans Act—Title VI
- Fund SAMHSA's Behavioral Health Tribal Prevention Grant Program at \$50 million—make sure programs are accessible to small Tribes

NATIONAL HEALTH APPROPRIATION PRIORITIES

- Definition of Indian
- Fully Fund the Implementation of ACA Inclusive of the IHCA
- Self-Governance Promotes Efficiency and the Effective Use of Federal Funds (Title VI of the ISDEAA)

REGIONAL/NATIONAL HEALTH APPROPRIATION PRIORITIES

Our Budget Request endorses the requests of The Northwest Portland Area Indian Health Board, Affiliated Tribes of Northwest Indians, the Indian Health Service Tribal Self-Governance Advisory Committee and the National Congress of American Indians and the National Indian Health Board.

TRIBAL SPECIFIC PRIORITIES

Restore Sequestered Amounts/Exempt Indian Programs from Budget Reductions

Despite the Federal trust obligation and the well documented and profound needs of Indian country, Tribal programs were subjected to sequestration and forced spending reductions. These budgetary reductions were devastating to our community and will drastically impede primary healthcare and disease prevention services for our Tribal citizens for years to come. Tribes should be afforded the same exemption from funding reductions that are in place for programs serving our Nations populations with the highest need, such as, Social Security, Medicaid, Medicare, the Children's Health Insurance Program and the Veteran's Administration.

Fully Fund Contract Support Costs (CSC) as Required by Law

Adequate Contract Support Cost (CSC) funding assures that Tribes, under the authority of their Self-Governance compacts, have the resources necessary to administer and deliver the highest quality healthcare services to their members without sacrificing program services and funding. We urge you to consider turning CSC into a separate mandatory appropriation so that legally enforceable contractual obligations are not being funded at the expense of programmatic needs.

Budget Equity for Tribal Governments/Programs Accessible to Small Tribes

Budget inequity compromises our ability to adequately manage our health programs and services that we are providing on behalf of the Federal Government. When Tribes receive an equitable level of resources, we can address the physical, spiritual and mental well-being of our Tribal communities in a culturally appropriate manner. There are often inconsistencies in how formulas are calculated and funding is distributed for Tribal health programs. In addition, Grant opportunities often contain criteria and processes that give States and other interest groups preferential opportunities for awards. Small Tribes, such as ours, are often further disadvantaged when it comes to securing these opportunities. It is critical that Tribes receive equitable resources and equitable access to funding opportunities that allow Tribes to continue to address Tribally-determined levels of health and wellness for our communities. Grants provided through the Administration for Children and Families (ACF) and the Substance Abuse and Mental Health Services Administration (SAMHSA) are critically important to our Tribe and we urge you to provide both equitable funding and opportunities for all Tribes within the confines of these programs.

Medicare/Medicaid Reimbursement

Federal funding for Medicaid/Medicare expansion is intended to reduce health disparities in our Tribal communities. Historic and persistent underfunding of the Indian healthcare system has limited the ability of Tribes to provide adequate health services that could prevent or reduce chronic health conditions in Native people. As a result, American Indians/Alaska Natives have a significantly worse health status compared to the rest of the Nation.

Because we do not receive full Federal funding to address our unmet healthcare needs, Jamestown has been forced to use innovative approaches in order to provide better healthcare services to our Tribal citizens. Over 50 percent of our healthcare funding is Medicaid and Medicare and we use the revenue that is generated from these programs to provide essential health services to our Tribal citizens and their families. Any changes to the way we receive Medicare and Medicaid funding would negatively impact our ability to provide basic healthcare to our Tribal community and the surrounding non-Indian community. Our innovative approach to providing healthcare services is an effective and efficient use of the Federal investment. It allows us to leverage the Federal dollar to provide better health services to more of our Tribal citizens, reducing future healthcare costs by lessening the need for expensive chronic and emergency care.

\$30 Million—Part A Grants to Native Americans under Title VI of the Older Americans Act

Programs under Title VI of the Older Americans Act are the primary funding vehicle for the provision of nutrition and other ancillary services to our Tribal Elders. Reducing isolation through community and cultural activities and ensuring our Elders receive proper nutrition and healthcare is a priority for our Tribe. Without the capacity to provide support services to our elders, our cultural traditions, and our language is at risk of being lost.

The Jamestown S'Klallam Elders Meal Delivery Program has been around for more than 20 years. The Older Americans Act provides much needed funds to keep this program working for our community. Jamestown has used Federal funds to pre-

pare and deliver well-balanced nutritional meals to our Elders that incorporate traditional foods, such as, elk and fish and use vegetables grown in our community garden. All of our elders are also given fresh fruit. These services are provided to all elders of Native heritage, and their spouses, within our service area.

\$50 Million—Behavioral Health Tribal Prevention Program

American Indians and Alaska Natives have disproportionately higher rates of death related to alcohol and substance abuse and suicide. If funded, the Behavioral Health Tribal Prevention Grant will allow Tribes to provide behavioral health services that address substance abuse and suicide prevention and promote overall mental and emotional health. If funded, this would be the only grant program that is exclusively available for Tribes.

NATIONAL HEALTH PRIORITIES

Definition of Indian

The Administrations current interpretation of “Indian” in the Affordable Care Act (ACA) prevents certain IHS eligible persons from access to certain healthcare and services available to American Indians and Alaska Natives under the law. A technical amendment that uses the Center for Medicare and Medicaid definition of Indian will align the eligibility regulations and create consistency among all the Administrative agencies which will provide full access to healthcare for all American Indians and Alaska Natives.

Fully Fund the Implementation of ACA Inclusive of the IHCA

The permanent reauthorization of the Indian Health Care Improvement Act (IHCA) within the ACA is the most significant advancement in Federal health policy for Tribes in decades. The purpose of the IHCA is to promote healthcare parity for Indian Tribes by addressing deficiencies in health status and resources within the Indian health system. Funding for the IHCA is a top budget priority. Although the IHCA provides the authority and, with it, the opportunity to provide essential healthcare to Tribal citizens, it did not provide the necessary funds to the IHS to carry out these new statutory obligations.

There are twenty three unfunded provisions in the Indian Health Care Improvement Act (IHCA). Many of the provisions that remain unfunded would strengthen the Tribal healthcare workforce, provide greater access to behavioral health and support innovative initiatives for healthcare delivery to Tribal citizens. Funding these provisions is a necessary precursor to increase Tribal capacity, infrastructure and most importantly access to healthcare services. Significant Federal investment is needed to achieve a fully funded Indian Health Service and now is the time to act on opportunities made possible in the newly expanded authorities granted under the Indian Health Care Improvement Act. Given the unique mission of the IHS as a direct healthcare provider fulfilling a Federal trust responsibility, fully funding and implementing the ACA and IHCA will elevate the health status and decrease the health disparities experienced by American Indians and Alaska Natives.

Self-Governance—An Efficient and Effective Use of Federal Funds (Title VI of the ISDEAA)

Self-Governance is the most successful policy in the history of Tribal—Federal relations and it inspires efficient and effective government spending. Through Self-Governance, Tribes are empowered, as sovereign nations, to exercise self-determination and to design facilities, manage programs and funds, and provide services that are responsive to the needs of our communities and Tribal citizens. Tribes participating in Self-Governance have become successful in the business of healthcare and perform several key roles, serving as, governments, employers, healthcare providers and patients.

Self-Governance Tribes have made every attempt to be innovative to operate successful health programs given the budget constraints and cuts Tribal programs have incurred the past two decades. For more than a decade we have made every effort to expand Self-Governance to other programs and our efforts to seek expansion of the program will continue until we achieve our goal. We request that this Committee recognizes the success of Self-Governance and encourage HHS to work with Tribes to make the most efficient and effective use of Federal appropriations to fund Tribal programs.

Conclusion

Thank you for the opportunity to provide this important testimony. We respectfully request that these Budget Priorities be included in the Appropriations for the fiscal year 2015 Tribal Health Programs Budget.

[This statement was submitted by Hon. W. Ron Allen, Tribal Chairman/CEO, Jamestown S'Klallam Tribe.]

PREPARED STATEMENT OF MICHAEL KLURFELD

Members of the subcommittee, my name is Michael Klurfeld, and I am testifying to protect my twin sister, Jessica, and others like her who require active treatment in campus-based or other settings meeting the Federal standards for Intermediate Care Facilities for the Mentally Retarded ("ICF/MR").¹

Jessica has autism, intellectual disability, and a rare genetic disorder called Cornelia de Lange Syndrome. Not long after our thirteenth birthday, Jessica began having severe behavioral challenges, including physical aggression. For lack of an appropriate residential school in New York State, our school district sent her to out-of-State nonpublic residential schools—first in Pennsylvania and then in New Hampshire. Though her education funding ended, she remains at the New Hampshire program awaiting repatriation by the New York State Office for People with Developmental Disabilities to an appropriate adult residential program in New York.

In Jessica's case, an appropriate placement is a campus-based ICF/MR—she is legally entitled to this as a Medicaid recipient. As explained by the Centers for Medicare and Medicaid on the attached page from their website, ICF/MR is a benefit said to be offered by all States as an alternative to home and community-based services ("HCBS") for individuals at the ICF/MR level of care—individuals in need of and receiving "active treatment."² "Active treatment" is the key concept here: defined as "a continuous, aggressive and consistent implementation of a program of specialized and generic training, treatment, and health or related services, directed toward helping the enrollee function with as much self-determination and independence as possible." As CMS points out, "many ICF/MR residents work in the community, with supports, or participate in vocational or other activities outside of the residence, and engage in community interests of their choice." ICF/MR services are provided only in licensed and certified residential facilities, providing quality control to protect the residents and financial controls over the expenditure of public funds—"There are few resources similar to an ICF/MR under any payment source."

Although "States may not limit access to ICF/MR service, or make it subject to waiting lists, as they may for HCBS," in reality access is drastically limited and, as a practical matter, virtually unavailable in many States. The States' failure to provide these mandated services, in violation of the right of Medicaid recipients to choose ICF/MR over community-based waiver services, has been erroneously justified with the notion that deinstitutionalization is required by the Supreme Court's 1999 *Olmstead* decision—a gross misstatement of the holding in this important case. Far from requiring the closing of all institutions, or the denial of legally required ICF/MR services to those like Jessica who qualify for and require them, the Supreme Court in *Olmstead* said that "each disabled person is entitled to treatment in the most integrated setting possible for that person—recognizing on a case-by-case basis, that setting may be an institution" [emphasis added].

Ironically, HHS brandishes *Olmstead* as a tool to force people with Intellectual and Developmental Disabilities (I/DD) to live in what they call "integrated settings," often disregarding both the peoples' needs and choices. In a Kafkaesque fashion, HHS often brings lawsuits against institutions that it funds—beyond belittling the needs and choices of people with I/DD, these egregious lawsuits waste Federal funds because, essentially, HHS is suing itself.

So for the reasons above and for reasons I will explain further, I ask the Senate to adopt the following language regarding HHS appropriations:

No funds appropriated for any Department of Health and Human Services program shall be expended to promote any law or policy that limits the choices of individuals with intellectual and developmental disabilities (or, if an individual has a legal representative, the legal representative), seeking living arrangements they believe are most suitable to their needs and wishes.

¹ In the interest of disclosure, please be aware that I am the New York State Coordinator for VOR, a national organization that advocates for high quality care and human rights for people with intellectual and developmental disabilities. I am submitting this statement solely on my own behalf, and not as a representative of VOR, to share my family's story and my personal views with you.

² As CMS notes, Federal law and regulations continue to use the term "mentally retarded" and therefore CMS uses it in this formal description of these kinds of facilities; CMS otherwise prefers the term "individuals with intellectual disability."

First and foremost, HHS' fallaciously named "Olmstead enforcement" goes against much of what the Supreme Court said in its ruling while ignoring the circumstances of the case. The plaintiffs in Olmstead were two women who "alleged that defendants-petitioners, Georgia healthcare officials, failed to afford them minimally adequate care and freedom from undue restraint, in violation of their rights under the Due Process Clause of the Fourteenth Amendment."

The Supreme Court found that the women's rights had in fact been violated, but not solely because they were in an institutional setting:

We emphasize that nothing in the Americans with Disabilities Act or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings . . . Nor is there any Federal requirement that community-based treatment be imposed on patients who do not desire it."

HHS seems to have largely ignored this language, for if they hadn't, Olmstead enforcement would be entirely different. Olmstead enforcement, properly implemented, would be limited to helping people like the plaintiffs in that case who were institutionalized against their wills without due process. But instead, HHS spends taxpayer money in attempts to shut down the facilities to which my sister and people like her are legally entitled under the law, which they have chosen (as is their right), and which HHS itself funds. Nothing in Olmstead requires—or even authorizes—HHS to deprive Medicaid recipients with I/DD from choosing to receive the "active treatment" to which they are entitled in the "institutional" setting of an ICF/MR, and HHS should not be allowed to appropriate funds in its efforts to deny these recipients their choice.

And that's really the crux of the issue: HHS appropriation of funds in support of deinstitutionalization activities belittles and disregards my sister's choice of living situation. My sister and people like her, whether by their own choice or through their legal guardians (in Jessica's case my mother), are entitled to live in the setting they choose and that best meets their needs. HHS would never try to prohibit a group of non-disabled people from living on a campus together. My sister's disability should not change this.

If HHS is allowed to continue its campaign, it will continue to threaten both my sister's right to the treatment to which she is legally entitled, as well as her access to a living situation which she chooses and which meets her needs. In a world where HHS completes its "Olmstead enforcement," there will be no more campus-based settings, and Jessica will have to live in a group home where she may nominally be "in the community" but not a part of it in any meaningful sense. Because she becomes anxious when in close proximity to others, she would isolate herself in her bedroom and rarely venture out. Because of her aggressive behaviors, any interactions with neighbors or others outside the group home setting would be rare to nonexistent. Her life would be that of Mrs. Rochester from *Jane Eyre*, which is no life at all.

Thank you for your time and consideration in this manner.

The below text comes from CMS' website:

Intermediate Care Facilities for Individuals with Mental Retardation (ICF/MR)

Intermediate Care Facilities for individuals with Mental Retardation (ICF/MR) is an optional Medicaid benefit that enables States to provide comprehensive and individualized healthcare and rehabilitation services to individuals to promote their functional status and independence. Although it is an optional benefit, all States offer it, if only as an alternative to home and community-based services waivers for individuals at the ICF/MR level of care.

IMPORTANT NOTE: Federal law and regulations use the term "intermediate care facilities for the mentally retarded". CMS prefers to use the accepted term "individuals with intellectual disability" (ID) instead of "mental retardation." However, as ICF/MR is the abbreviation currently used in all Federal requirements, that acronym will be used here.

Eligibility for ICF/MR Benefit

ICF/MR is available only for individuals in need of, and receiving, active treatment (AT) services. AT refers to aggressive, consistent implementation of a program of specialized and generic training, treatment and health services. AT does not include services to maintain generally independent clients who are able to function with little supervision and who do not require a continuous program of habilitation services. States may not limit access to ICF/MR service, or make it subject to waiting lists, as they may for HCBS. Therefore in some cases ICF/MR services may be more immediately available than other long term care options. Many individuals

who require this level of service have already established disability status and Medicaid eligibility.

State Variation

Need for ICF/MR is specifically defined by States, all of whom have established ICF/MR level of care criteria. State level of care requirements must provide access to individuals who meet the coverage criteria defined in Federal law and regulation. In addition to level of care for AT, the need for AT must arise from ID or a related condition. The definition of related condition is primarily functional, rather than diagnostic, but the underlying cause must have been manifested before age 22 and be likely to continue indefinitely. States vary in practical application of the concept of related condition. In some States individuals applying for ICF/MR residence may be eligible for Medicaid under higher eligibility limits used for residents of an institution.

Services Included in the ICF/MR Benefit

ICFs/MR provides active treatment (AT), a continuous, aggressive, and consistent implementation of a program of specialized and generic training, treatment, and health or related services, directed toward helping the enrollee function with as much self-determination and independence as possible. ICF/MR is the most comprehensive benefit in Medicaid.

Federal rules provide for a wide scope of required services and facility requirements for administering services. All services including healthcare services and nutrition are part of the AT, which is based on an evaluation and individualized program plan (IPP) by an interdisciplinary team. Facility requirements include staffing, governing body and management, client protections, client behavior and physical environment, which are specified in the survey and certification process.

Day Programs

Many ICF/MR residents work in the community, with supports, or participate in vocational or other activities outside of the residence, and engage in community interests of their choice. These activities are collectively often referred to as day programs. The ICF/MR is responsible for all activities, including day programs, because the concept of AT is that all aspects of support and service to the individual are coordinated towards specific individualized goals in the IPP.

Where ICF/MR Services are Provided

Medicaid coverage of ICF/MR services is available only in a residential facility licensed and certified by the State survey agency as an ICF/MR. Medicaid ICF/MR services are available only when other payment options are unavailable and the individual is eligible for Medicaid. There are few resources similar to an ICF/MR, under any payment source.

PREPARED STATEMENT OF THE KNI PARENT GUARDIAN GROUP

Dear Senate Appropriations Sub-committee, thank you for the opportunity to provide testimony. It is with a heavy heart that I submit outside witness testimony today, respectfully requesting your full consideration of the effects of pervasive Intermediate Care Facility (institutional—ICF/ID) closure activities.

Numerous federally funded agencies under the Department of Health and Human Services (HHS) are pursuing an idealistic agenda that puts the weakest members of our society into harm's way, while ignoring significant deficiencies in the home and community based service system (HCBS).

I am calling on this Sub-committee to PROHIBIT the use of Federal HHS appropriations supporting deinstitutionalization activities which evict without cause, and without regard to individual choice, people with the most profound intellectual and developmental disabilities (I/DD) from HHS-licensed ICF homes.

COMMUNITY DEFICIENCIES

- Stagnant Direct Support Staff wages, high turnover rates, staff rationing, and inadequate professional oversight of scattered homes are affecting quality of care for those served in HCBS waiver systems. The most helpless on the disability spectrum are particularly affected by these systemic deficiencies.
- Diminishing incentive to retain quality staff is reflected in the pervasive, stagnant wage crisis, while re-imbursement rates have not changed significantly for over a decade. As a result, the profoundly disabled often do not get to choose who cares for them, even if they somehow could indicate with whom they would

like to live. This reality flies in the face of idealism—pushing “community for all.”

—There is no adequate system in place which represents persons adjudicated incompetent, who have no or extremely limited self-advocacy skills, particularly to express abusive acts committed against them in poorly supervised community homes with rationed staff and limited professional oversight.

As the Guardian of a profoundly disabled young man, I have navigated and utilized a broad array of community services for over 15 years. My final recourse after exhausting every option, was to place my loved one at the Kansas Neurological Institute (KNI), because no one in the HCBS system was able to handle him.

Since his placement at KNI our grandson has been very well cared for, being restored to a place of stability unparalleled in the community. We have tried without success, to reintegrate him into community as unfortunately, more than a few community providers have refused to serve him.

Facilities like KNI are the safety net for those whom the community is not suitable or has failed to keep safe, yet these havens are under attack nation-wide. A number of HHS funded programs are displacing our most vulnerable without regard to clarifications in the Supreme Court Olmstead ruling, which highlights individual choice, need and safety.

Groups including the ARC, National Council on Disabilities, State DD Councils, Universities for Excellence, and State Protection & Advocacy have ignored mounting evidence of abhorrent community outcomes for the most helpless within the disability spectrum. These federally funded entities appear to collaborate and push the extreme agenda of forced closure of all State “institutions”. This radical agenda fails to recognize community capacity issues and an increasing number of documented tragedies occurring within the community system.

Why are these agencies pushing to close facilities where compassionate staff care for our weakest, forcing our most vulnerable into questionable environments?

How is “justice” served when the most helpless are placed in community settings, suffering neglect and death after a few months time at the hands of poorly trained staff who have little or no professional oversight?

“Is it ever right to handcuff and over-medicate someone with disabilities, just so you can ‘handle’ them?” This question was presented to the National Council on Disabilities in December by a guardian whose brother had been de-institutionalized, and subsequently bounced around to unsuccessful community placements.

HCBS tragedies are happening to such a degree that your colleague, Senator Chris Murphy has called for a nation-wide investigation.

Parents and guardians are speaking out for those who cannot speak for themselves, many of whom had experienced failed community placements, yet these parents are vilified as obstacles to “systems change.”

Do current HCBS deficiencies and tragic outcomes for the weakest reflect sound policy?

There is a compelling need for both community-based and congregate care settings. States need to operate a range of services to meet the diverse requirements of persons with disabilities as clarified within the Supreme Court Olmstead ruling:

OLMSTEAD

“We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any Federal requirement that community-based treatment be imposed on patients who do not desire it.” Id. at 601–602.

A plurality of Justices noted:

“[N]o placement outside the institution may ever be appropriate . . . ‘Some individuals, whether mentally retarded or mentally ill, are not prepared at particular times—perhaps in the short run, perhaps in the long run for the risks and exposure of the less protective environment of community settings’ for these persons, ‘institutional settings are needed and must remain available’” (quoting Amicus Curiae Brief for the American Psychiatric Association, et al).

Justice Kennedy noted in his concurring opinion, “It would be unreasonable, it would be a tragic event, then, were the Americans with Disabilities Act of 1990 (ADA) to be interpreted so that States had some incentive, for fear of litigation to drive those in need of medical care and treatment out of appropriate care and into settings with too little assistance and supervision.” Id. at 610.

The real civil rights issue is the disregard for those who have been forced from safe environments by pervasive deinstitutionalization, without addressing the mounting capacity issues. As a Nation, we have neglected to ensure supports nec-

essary for success, including adequately paid support staff and solid accountability parameters, while pursuing an over-reaching push of “Community for all.”

Until the community Direct Support Staff wage issue is honestly solved, the deficient abuse reporting system remedied, and systemic assurances providing adequate oversight for the most defenseless living in scattered homes across our States, we have no true, successful inclusion for the profoundly disabled who cannot speak or defend themselves.

On behalf of “the least of these,” our most vulnerable, I provide comment today, and ask the Committee to take compassionate actions on their behalf.

[This statement was submitted by Joan Kelley, Legal Guardian; Vice-president, KNI Parent Guardian Group.]

PREPARED STATEMENT OF SUSAN G. KOMEN

On behalf of Susan G. Komen®, I appreciate the opportunity to submit written testimony regarding the need for increased Federal funding for breast cancer early detection programs and cancer research. Specifically, we call on you to increase funding for the National Breast and Cervical Cancer Early Detection Program (NBCCEDP), funded through the Centers for Disease Control and Prevention (CDC), to \$275 million and for the National Institutes of Health (NIH) to \$32 billion in fiscal year 2015, including \$5.26 billion for the National Cancer Institute (NCI).

Komen is the world’s largest grassroots network of breast cancer survivors and advocates fighting to save lives, empower people, ensure quality care for all, and energize science to find the cures. With our network of local Affiliates across the U.S. and the 2.9 million breast cancer survivors we represent, we have long considered ourselves key partners with the Federal Government in the fight against breast cancer. Since 1983, we have invested more than \$2.5 billion for breast cancer research and life-saving community programs across the country.

While I recognize the difficult task in balancing competing budget priorities in the current fiscal climate, the only way to eradicate breast cancer is through a renewed investment and commitment to discovering and delivering the cures and improved access to affordable, quality and timely breast health screening and treatment services.

National Breast and Cervical Cancer Early Detection Program

We call on Congress to increase funding for the National Breast and Cervical Cancer Early Detection Program (NBCCEDP), funded through the Centers for Disease Control and Prevention (CDC), to \$275 million in fiscal year 2015.

NBCCEDP is a State-Federal partnership that provides lifesaving, free or low-cost breast and cervical cancer screenings, diagnostic services, and follow-up services to low-income, uninsured and underinsured women who do not qualify for Medicaid. Since its inception in 1991, NBCCEDP has provided over 11 million screening exams to more than 4.5 million women, detecting more than 62,000 breast cancers, 3,400 cervical cancers and 163,000 premalignant cervical lesions.¹ Despite the critical services this program provides, at current funding levels, NBCCEDP can still only serve less than one-fifth to one-third of those who are projected to be eligible after the implementation of health reform for the program.²

While the Affordable Care Act increases access to mammography coverage for many women, it is estimated that, in 2014, 4.5 million women will remain uninsured and eligible for the program.³ This assumes that all States will implement all the provisions of the ACA and expands Medicaid. For these women, NBCCEDP continues to fill a critical gap in the healthcare delivery system, providing access to annual breast and cervical cancer screenings that can lead to easy detection and effective treatment for breast cancer.⁴ Without NBCCEDP, many uninsured women could be forced to delay or forego screenings, leading to later stage diagnoses, which are deadlier and more costly to treat. In fact, breast cancer can be up to five times more expensive to treat when it has spread to other parts of the body.⁵

¹Centers for Disease Control and Prevention, <http://www.cdc.gov/cancer/nbccedp/about.htm>, accessed 5/21/14.

²Levy AR, Bruen BK, Ku L. Health Care Reform and Women’s Insurance Coverage for Breast and Cervical Cancer Screening. *Prev Chronic Dis* 2012;9:120069.

³Levy AR, Bruen BK, Ku L. Health Care Reform and Women’s Insurance Coverage for Breast and Cervical Cancer Screening. *Prev Chronic Dis* 2012;9:120069.

⁴ACS Cancer Prevention and Early Detection Facts and Figures 2013-<http://www.cancer.org/acs/groups/content/epidemiologysurveillance/documents/document/acspc-037535.pdf>.

⁵Cost of Breast Cancer Treatment in Medicaid- *Med Care*. 2011 Jan;49(1):89-95. doi: 10.1097/MLR.0b013e3181f81c32.

Many women with health insurance still face substantial barriers to obtaining health services, including of lack of health literacy, geographic isolation and limited language proficiency. Among these harder to reach populations, NBCCEDP fills a critical gap by providing outreach and navigation services, which can improve healthcare access and increase breast cancer screening rates.⁶

It is clear that there will still be unmet need; millions of low-income and uninsured women will still lack access to services. We believe the CDC can build on the 20+ year investments made through the NBCCEDP and leverage the extensive capacity and infrastructure the program has built with the clinical care system to increase screening on a population level.

CDC can also work with various healthcare systems (FQHCs, Medicaid, provider networks, etc.), to increase widespread participation in screening by expanding key public health roles such as public education and outreach; provision of screening services and care coordination; quality assurance, surveillance and monitoring; and strategies to enable more organized systems of care.

In 2014, CDC would like to begin transitioning the program by enabling grantees to expand public health roles that can increase population level screening rates, while still being able to provide limited screening services to the most vulnerable.

Increasing current funding levels is critical to ensure that the CDC can raise awareness, provide lifesaving cancer screenings to women, and continue to reach those who will remain vulnerable and without access.

National Institutes of Health

We urge you to increase funding for the National Institutes of Health (NIH) to \$32 billion in fiscal year 2015, including \$5.26 billion for the National Cancer Institute (NCI), in order to restore funding to inflation-adjusted, pre-sequestration levels.

Cancer is an expensive disease—the most costly to our Nation in terms of direct medical costs and lost productivity due to premature deaths and disability—making research which will accelerate cures and improve treatment a sound investment. Federal funding must keep pace with biomedical inflation as we stand on the threshold of life-saving discoveries in the biomedical sciences.

This investment in research will not only protect Americans against disease and illness, but will serve as one of our Nation's primary paths to innovation, global competitiveness, and economic growth. As other nations aggressively invest in research and development, the U.S. is losing ground. We stand to lose the young scientists, high quality jobs, industries and private-sector capital that have made America a global leader.⁷ Studies show each dollar in NIH funding generates more than twice as much in new business activity, and NIH grants and contracts created and supported more than 400,000 jobs across the country in 2013.

Our Nation's investment in biomedical research has helped drive progress against cancer, furthered our understanding of disease mechanisms and spurred the translation of scientific discoveries into new and better ways to prevent, detect, diagnose, and treat cancer. It is important to highlight some of the important advances, which have revolutionized the way in which breast cancer patients are screened, diagnosed and treated. These investments have also positively impacted survival rates beyond 5 years.

It is now established that routine mammographic screening is an accepted standard for the early detection of breast cancer. The results of eight randomized trials, the NIH-ACS Breast Cancer Detection Demonstration Projects, and other research studies showed that mammographic screening can reduce the mortality from breast cancer. In the treatment of breast cancer, lumpectomy followed by local radiation has replaced mastectomy as the preferred surgical approach for treating early-stage breast cancer. The approaches to treatment, by learning critical differences among the types of breast cancer, with chemotherapy and hormonal therapies have allowed patients different options and more personalized treatment plans. Tamoxifen and another SERM, raloxifene, have been approved by the FDA as treatments to reduce the risk of breast cancer in women who have an increased risk of developing the disease.⁸

Finally, several breast cancer susceptibility genes have now been identified, including BRCA1, BRCA2, TP53, and PTEN/MMAC1. Approximately 60 percent of women with an inherited mutation in BRCA1 or BRCA2 will develop breast cancer sometime during their lives, compared with about 12 percent of women in the gen-

⁶Levy AR, Bruen BK, Ku L. Health Care Reform and Women's Insurance Coverage for Breast and Cervical Cancer Screening. *Prev Chronic Dis* 2012;9:120069.

⁷Research!America (www.researchamerica.org).

⁸National Cancer Institute (www.cancer.gov/cancertopics/factsheet/cancer-advances-in-focus/breast).

eral population. Women with inherited BRCA1 or BRCA2 gene mutations also have an increased risk of ovarian cancer.⁹ This knowledge can help patients make more informed decisions about their risks and potential treatment options. We are poised to apply this new knowledge to make significant strides in saving lives.

As a Nation, we are facing a crisis in cancer care. As the population ages, the number of new cancer cases in the United States is projected to increase by as much as 42 percent, 2.3 million new cases annually, by 2025.¹⁰

Despite these staggering statistics, cancer research funding at the NCI as a share of the NIH budget has declined. In the late 1990s, NCI's budget made up nearly 19 percent of the NIH budget. Today, NCI accounts for approximately 16 percent. In real dollars, this decline means that NCI's funding has been reduced by \$680 million below what it would have received in fiscal year 2014 if its share of NIH's total budget had been maintained.¹¹ It is imperative that our Nation's investment in cancer research remains a priority, and that funding for NIH increases.

On behalf of the many Americans who are suffering with cancer, I ask that you consider our requests for increased support for the NBCCEDP and the NIH in fiscal year 2015. Susan G. Komen stands ready to serve as a national resource for Congress and for all Americans on breast health issues.

[This statement was submitted by Judith A. Salerno, MD, MS, President and Chief Executive Officer, Susan G. Komen.]

PREPARED STATEMENT OF THE LENDERS COALITION FOR COMMUNITY HEALTH CENTERS

The Lenders Coalition for Community Health Centers (LCCHC) is pleased to provide the following written testimony related to proposed fiscal year 2015 HRSA funding for federally Qualified Health Centers (FQHCs) funded under Section 330 of the Public Health Services Act. This testimony includes recommendations to assist the Administration and Congress in developing policies that will help meet a near universal goal—expanding community health centers in an affordable and sustainable manner to meet the healthcare needs of millions of families in underserved communities throughout the United States.

LCCHC is a coalition of community development financial institutions (CDFIs) and related entities whose main goal is to advocate for resources and policies that will strengthen health centers' access to capital and CDFIs' ability to finance health center growth. The CDFIs that form the LCCHC are all currently undertaking health center lending. They have made loans totaling more than \$1.4 billion to develop primary care capacity that gives more than 3 million patients access to primary care every year.

The LCCHC has been on record in support of increased—and continued—operational funding support for health centers. Our institutions sent a letter to the President advocating the full operational increase in mandatory funds from the Health Centers Fund in fiscal year 2015, and underscored the need to sustain and grow that investment over the next 5 years to ensure the financial stability of our client FQHCs moving forward.

We note that the President's fiscal year 2015 budget proposes utilizing \$800 million in health center funding for one-time capital grants. We believe that to the extent any new funding for capital projects is included in this year's final appropriation, HHS should encourage awardees to use these scarce dollars to leverage other sources of capital—both grants and loans from the public and private sector—to maximize their impact on health center growth. Given that \$800 million represents less than 10 percent of the estimated \$10 billion of capital funding that will be needed in order to meet the goal of serving 35 million patients in FQHCs by the end of 2018, developing policies that promote the availability of multiple public and private sources of capital will be critical to health centers' successful growth. By incorporating incentives to encourage leveraging into the HHS review process of any potential capital grant funding for those FQHCs that can raise other sources of capital and/or afford to take on some reasonable amount of debt, HHS will be able to support a much larger number of FQHCs around the country.

We also recognize that capital from the Health Centers Fund—even if it is leveraged—is not a complete solution to address the capital needs of FQHCs. We strongly

⁹National Cancer Institute (www.cancer.gov/cancertopics/factsheet/cancer-advances-in-focus/breast).

¹⁰AACR Cancer Progress Report 2013 (http://cancerprogressreport.org/2013/Documents/2013_AACR_CPR_FINAL.pdf).

¹¹One Voice Against Cancer (www.ovaonline.org).

encourage the consideration of robust Federal credit enhancement programs targeting FQHCs expansion, which would leverage much greater levels of private sector financing for FQHCs. Programs such as these are available and have been used to considerable success for a number of vital sectors, including small businesses (SBA), rural and agricultural enterprises (USDA), charter schools (ED) housing and hospitals (HUD).

We wish to be clear that we reject policies encouraging FQHCs to pursue leverage irresponsibly. Over-leverage is a real risk in any sector; where it involves the development of critical health infrastructure and the use of public funds, it simply must be prevented. Indeed, as community lenders, our mission is aligned with our borrowers, and we have a stake in their sustainability and success.

Attached, please find a brief that highlights the benefits of leveraging HHS capital dollars. The arguments in this brief assume that FQHCs work with responsible lenders, develop financially and operationally sustainable expansion projects, and assume a level of debt that supports their expansion without negatively impacting their current operations or financial stability. Based on our collective experience in the FQHC sector itself, as well as across a broad range of other capital needs within low income communities (e.g., affordable housing, healthy food financing, and school financing), we are confident that the Administration and Congress can maintain policies that enable these conditions.

WHY LEVERAGING OF HRSA CAPITAL GRANTS IS ESSENTIAL TO THE FUTURE OF FEDERALLY QUALIFIED HEALTH CENTERS (FQHCs)

HRSA has set, and the health center field has embraced, the goal of expanding health centers to meet the stated goal of serving 35 million patients by the end of 2018 (from approximately 22 million today). Based on an estimate from Capital Link, more than \$10 billion in additional capital will need to flow into FQHC facility development and expansion to meet this target.

If public funding alone will not suffice to meet the FQHC field's collective expansion goal, the only feasible alternative is instead to ensure that limited public funds be deployed strategically to bring private sector capital to bear. Such an approach can stretch scarce Federal resources, attract more lenders into the market, lower borrowing costs, and incentivize FQHCs to develop projects with greater impact on patients than would be possible otherwise.

The Lack of a Clear, Unambiguous Signal that Leverage is Integral to HRSA's Future Plans for FQHCs Causes Inefficiencies in FQHC Financing to Persist

Capital Grant Funding Rounds that Fail to Incentivize Leverage Disrupt the Existing FQHC Pipeline and Distort Project Sizing.—Today, FQHCs often work with CDFIs and other lenders across the country to generate a pipeline with hundreds of viable FQHC expansion projects in varying stages of development. When HRSA announces a capital grant round (or even the possibility of a capital grant round) that holds out the promise of a one-stop, debt-free financing strategy, that pipeline largely freezes, as FQHCs understandably put development plans on hold in the hope of avoiding the need to borrow money at all.

Unfortunately, that hope is often in vain, given the reality that demand far outstrips the funding available, leading to lengthy grant application and review processes and many unfunded projects. Additionally, FQHCs size their projects to the HRSA grant maximum rather than to the size that best serves the healthcare needs of the community and that CDFIs or other responsible lenders will underwrite. The result is delays or cancellation of FQHC expansion projects that could have served hundreds of thousands of patients.

Thoughtful Incentives to Promote Leverage would Enable HRSA to Magnify the Impact of its Capital Grants and Supplement its Own Oversight of FQHCs with Private Sector Underwriting

Leverage is a 'Force Multiplier' for Limited HRSA Capital Grants.—Simply put, a given level of Federal operating and capital funding can yield dramatically increased FQHC expansion if it unlocks access to private sector capital. When FQHCs are required to supplement Federal grant funding with outside capital, they are more likely to develop projects that are scaled to the needs of the community rather than to the size of the grant award, offering the opportunity for greater impact on the community's health.

To offer an instructive experience in another sector, in fiscal year 2014, Congress enacted the Administration's Rental Assistance Demonstration (RAD), providing public housing authorities new flexibilities to leverage their annual public housing operating and capital grants from the Department of Housing and Urban Development (HUD) to rehab or redevelop up to 60,000 units of public housing. Notably,

no ‘new’ money was appropriated—i.e., the operating and capital fund allocations that the local agencies received remained the same (well below their annual operating costs and accumulated capital backlog). To date, applications submitted to HUD under this ‘no cost’ leveraging strategy have proposed to bring to bear in excess of \$6 billion in private and other public sector capital to the rehab and redevelopment of public housing units previously assisted exclusively by Federal funds.

If Congress appropriates capital funding for health centers in fiscal year 2015, HRSA should draw from the experience of the affordable housing field, and other sectors, in the effort to deploy leverage strategically in service of health center capital expansion goals. Health centers have, for the moment, the further good fortune of being ‘ahead of the curve,’ relative to the field’s funding levels and capital needs (the public housing field, for example, embraced policy reforms like RAD only after years of underfunding and a capital backlog in excess of \$27 billion).

Leverage Leads to Superior ‘Front End’ Underwriting and Faster Project Development.—When an FQHC uses debt financing for a project, the project goes through a rigorous review by the lender (or lenders) as part of the underwriting process, creating a higher likelihood for successful development of the project. Scrutiny of the experience and capacity of the project’s development team ensures that the right pieces are in place for construction that is on time and within budget. Furthermore, the lenders’ scrutiny of underlying financials and staffing plans and testing of revenue projections can lead to an FQHC making constructive modifications to its plans. To be clear, this is not a substitute for the conscientious and diligent oversight conducted by HRSA staff on behalf of the taxpayer, but rather a useful supplement to their efforts by project development experts whose livelihood depends on having their loans paid back.

Leverage Builds in ‘Early Warning’ Systems that Prevent FQHC Project Failure.—Experience across capital financing sectors, including affordable housing (e.g., three decades of experience with the Low Income Housing Tax Credit), has demonstrated that private sector oversight of project operations is a useful supplement to the scrutiny of dedicated, competent but often overextended public servants. Lenders, as part of their loan servicing and monitoring, keep a monthly watch on every borrower, enabling them to see financial problems early on, before they have grown more expensive and difficult to fix. When lenders provide financing to FQHCs, they are responsible for ensuring regular loan repayments. Borrowers are required to submit regular financial statements showing cash flow, accounts payables and receivables, and other indicators of financial health. If the borrower misses loan payments or shows other signs of financial distress, a CDFI can work with borrowers to develop solutions that will bring a health center back to financial stability. When necessary, this assistance may involve working with other stakeholders, including foundations, State Medicaid agencies, or HRSA to make sure a community is not deprived of vital primary care capacity.

Leverage Creates Financial, Community and Political Partners in Ensuring Health Center Sustainability.—Critically, the involvement of other stakeholders in FQHC health—from philanthropy to CDFIs to banks and private sector investors—is not limited to the all-hands-on-deck project workouts described above. When FQHCs are required to assemble matching or contributing funds for a project, they seek funding assistance from a range of other public and private sources, including grants and loans. The act of assembling these funds generates community “buy-in” and support for a proposed project, which ultimately contributes to its success by aligning community priorities and resources toward a common end.

Indeed, the broadening of the constituency of stakeholders with ‘skin in the game’ when it comes to both individual FQHCs and the field more broadly, is essential to FQHCs’ long-term sustainability: it creates a bulwark against appropriations risk while simultaneously helping to ensure that FQHCs remain viable and competitive in the rapidly evolving field of primary care provision to low income neighborhoods and populations.

PREPARED STATEMENT OF THE LOCAL INITIATIVES SUPPORT CORPORATION

Chairman Harkin, Ranking Member Moran, and Distinguished Members of the Senate Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies: Thank you for the opportunity to offer written testimony on the Administration’s fiscal year 2015 Budget Request for the Department of Health and Human Services, Administration for Children and Families. The Local Initiatives Support Corporation (LISC) views this hearing as a positive step toward understanding the importance of early childhood development and securing critically needed investments to ensure that all children, especially low-income chil-

dren, are given a strong start and enter kindergarten ready to learn. As you consider ways that Congress can help children get an early start on the pathway to success, we encourage you to recognize the critical role that early childhood facilities play in preparing young children for achievement in school and in life, and urge you to ensure that Federal policies adequately finance the acquisition, construction, and improvement of these spaces.

ABOUT LISC

Established in 1979, the Local Initiatives Support Corporation (LISC) is a national nonprofit with Community Development Financial Institution (CDFI) designation, dedicated to helping community residents transform distressed neighborhoods into healthy places of choice and opportunity—good places to work, do business and raise children. LISC mobilizes corporate, government and philanthropic support to provide local community development organizations with loans, grants and equity investments; local, statewide and national policy support; and technical and management assistance.

LISC has local offices in 30 cities and partners with more than 50 organizations serving rural communities throughout the country. We focus our activities across five strategic community revitalization goals:

- Expanding Investment in Housing and Other Real Estate
- Increasing Family Income and Wealth
- Stimulating Economic Development
- Improving Access to Quality Education, and
- Supporting Healthy Environments and Lifestyles.

For more than three decades, LISC has developed programs and raised investment capital to help local groups revive their neighborhoods. Because we recognize the link between human opportunity and social and economic vitality, we have spent the last 17 years working to bring high quality early care and education settings to low-income neighborhoods where children enter the world at high risk for negative outcomes. Through our signature early childhood program, the Community Investment Collaborative for Kids (CICK), LISC has invested \$48 million in planning and developing 184 new facilities serving 20,000 children in more than 65 low-income urban and rural neighborhoods across the country.

OVERVIEW

Early childhood is a critical development period. Research shows that a complex interplay between genetics and environment profoundly influences how children grow physically, socially, and emotionally. Investments in high quality early childhood programs can help promote healthy development and strong communities. Those active in community revitalization believe without question, that early care and education programs are essential parts of every neighborhood—they prepare young children for success in school and life, support working parents, and improve family well-being.

Regrettably, many families—particularly those who are low-income or in rural areas—lack access to the stable, high-quality early childhood centers that parents need to maintain gainful employment and children need to grow and thrive. Additionally, while there is appropriate focus on the need for high quality curriculum and qualified teachers, the physical environment is an essential feature that is often forgotten.

In this testimony, we highlight the important role that physical environments play in supporting the quality of early learning programs and healthy early childhood development and encourage Congress to address the need for comprehensive early childhood facility policies.

BACKGROUND

Early Childhood is a Critical Development Period

Decades of research has shown that early life experiences are extremely important to the social, emotional, and academic development of children.¹ Positive experiences promote healthy brain development and behavior, while negative experiences undermine development—and, in severe circumstances, permanently impair a child's

¹Jack P. Shonkoff and Deborah A. Phillips, Editors, *From Neurons to Neighborhoods: The Science of Early Childhood Development*, National Research Council Institute of Medicine, National Academy Press, Washington, DC 20000

nervous and immune system, stunting healthy growth.² High quality early care and education is widely regarded as the single most effective intervention to promote healthy development and close the academic achievement gap for low-income children at-risk for poor social and economic outcomes.³ The data are clear: the quality of one's early childhood experiences profoundly influence that person's future life trajectory.

The Quality of Early Childhood Facilities Matters

While many factors contribute to program quality, the physical environment is an essential feature that is often overlooked. The link between the quality of buildings and the quality of programs tends to be only vaguely understood and largely undocumented among child care providers. Despite this inclination, evidence about the connection between space and effectiveness has been found even when physical space is not the focal point of the research undertaken. A study conducted at the School for Young Children (SYC), a distinguished preschool program housed at St. Joseph College in West Hartford, Connecticut, provides a compelling example.⁴

Every State has a minimum adult-child ratio for licensed centers, in large part because attention from nurturing adults is a prime indicator of quality in child care programs. SYC is a highly regarded preschool program with a more than ample staffing ratio; the program is largely viewed as meeting if not exceeding minimum quality standards. Yet, when a research team set out to monitor enrolled children's contact with adults during free play time they found shocking results: Only 3 percent of the children's time was spent engaged in meaningful interactions with a teacher.

While the SYC executive director was digesting the researchers' negative findings in order to develop a workable solution, her organization moved to new accommodations. A routine follow-up test in the new space immediately showed a strikingly higher result. Teacher-child interactions increased to 22 percent. There had been no change in the management, staff, or program, only the physical space. The new space, which Bye had taken pains to design, was considerably roomier and there were bathrooms, telephones, storage space, and other logistical necessities in each classroom. Adults no longer had to leave the room to escort children to the bathroom, retrieve or store supplies, or take a phone call. Fewer distractions and interruptions for adults naturally meant more time for children.

Both children and staff benefited from the new space configuration. The more generous square footage allowed staff to configure each classroom into well-defined areas for different activities. Children were no longer crowded together into inadequate space and distracted by one another, so they ran into conflicts less often, and had better play experiences—making their interactions with adults and other children more constructive. Teachers were able to use their time in a more effective and rewarding way, resulting in higher morale and lower staff turnover for. Overall, the effect of the new space on the content of the program was considerable and measurable—even when not a single change had been made in the program itself.

Space matters: a facility's layout, size, materials and design features can improve program quality and contribute positively to child development while a poorly adapted and overcrowded environment undermines it.⁵ Bathrooms adjacent to classrooms, accessible cubbies, and child-sized sinks, counters, furnishings and fixtures increase children's autonomy and competence while decreasing the demands on teachers. Early learning centers with ample classrooms divided into well-configured activity areas support uninterrupted self-directed play and exploration. The physical configuration of early care and education spaces directly affect adult/child interaction and influence how children grow and learn.

The National Association for the Education of Young Children (NAEYC) acknowledges the importance of a quality environment in the following statement: "The physical environment sets the stage and creates the context for everything that hap-

²National Scientific Council on the Developing Child. "Excessive Stress Disrupts the Architecture of the Developing Brain. Working Paper No. 3" (2005) http://www.developingchild.net/pubs/wp/Stress_Disrupts_Architecture_Developing_Brain.pdf. (Accessed June 17, 2009).

³http://www.readynation.org/uploads/20130919_ReadynationVitalLinksLowResEndnotes.pdf, Schweinhart, L. J., Montie, J., Xiang, Z., Barnett, W. S., Belfield, C. R., & Nores, M. (2005). Lifetime Effects: The High/Scope Perry Preschool Study Through Age 40. Ypsilanti, MI: High/Scope Press. And Reynolds, A. J., Temple, J. A., Robertson, D. L., & Mann, E. A. (2002). Age 21 Cost-Benefit Analysis of the Title I Chicago Child-Parent Centers. Madison, WI: Institute for Research on Poverty. And FPG Child Development Center. (1999). Early Learning, Later Success: The Abecedarian Study. Chapel Hill, NC: University of North Carolina.

⁴Tony Proscio, Carl Sussman & Amy Gillman, Authors, Child Care Facilities: Quality by Design, (2004). <http://www.lisc.org/content/publications/detail/815>.

⁵http://www.lisc.org/docs/publications/2007_nieer_cick_facilities_brief.pdf

pens in any setting—a classroom, a play yard, a multipurpose room. A high-quality environment welcomes children; engages children in a variety of activities; provides space for individual, small-group, and large-group activities; and generally supports the program's philosophy and goals. Ultimately, the physical environment must convey values and messages about who is welcomed, what is important, and what the beliefs are about how children learn.”⁶

What Facilities Experts Know

Although physical spaces play an important role in promoting program quality and healthy development, it is rare to find high quality facilities designed to meet the unique needs of very young children, especially in low-income communities. Early childhood specialists have long maintained that the physical environments where learning takes place—and where young children spend the majority of their waking hours—significantly influence the quality of early care and education programs.

Facilities experts and those proficient in financing the design, acquisition, construction, and improvement of early care and education spaces concur and largely agree that:

- Well-designed facilities enhance child development and program quality;
- An adequate supply of facilities is needed to support rapidly increasing preschool education programs;
- The quality and location of the facilities can encourage enrollment and parent involvement;
- Facilities can help promote a positive workplace in an industry challenged to retain experienced teachers;
- Child care program income, especially in low-income communities, is typically not sufficient to cover the full cost of delivering quality early education services and doesn't allow for the added cost of constructing or improving appropriate facilities; and
- Few centers have the experience or personnel to handle the complexities of real estate development tasks and require specialized technical assistance to address their facilities needs.

Early Childhood Facilities Financing Challenges

Despite what is known about the importance of the spaces where learning takes place, there is no dedicated source of capital to help early care and education programs develop well-designed facilities suitable for our youngest learners. Programs serving low-income communities are highly dependent on public operating revenues that don't cover the cost of purchasing or renovating an appropriate facility. Without a consistent and effective financing system or capital subsidies, providers are left to pursue piecemeal approaches, cobbling together small donations and grants from a variety of sources. This prevents the early childhood field from addressing its physical facility needs and creating the kind of environments that support high quality programs.

Historically, private financial institutions have not made significant infrastructure investments in early care and education—particularly in economically distressed areas. Few mainstream banks, credit unions, and lending institutions are willing to finance early childhood facility projects, which tend to require relatively small, complex loans often characterized by uncertain future funding for repayment through government operating subsidies. The projects generally have little to no equity, and limited collateral value. In addition, private banks typically don't employ staff with specialized knowledge of the child care sector, consequently they are unable to understand the needs of child care or preschool centers and assist program directors lacking experience with real estate development and financing.

Certified Community Development Financial Institutions (CDFI) working in market niches that are underserved by traditional financial entities are among the small number of organizations who have made investments in early childhood physical spaces. They have a proven track record in economically challenged regions and are experienced with providing a unique range of financial products and services that spur private investment in their target markets. Unfortunately, given the limited funding available to CDFIs to carry out their comprehensive mission, demand for early childhood facilities capital far outstrips supply.

RECOMMENDATIONS

As Congress considers ways to help children get an early start on the pathway to success, we urge you to:

⁶<http://www.naeyc.org/store/node/402>

1. Recognize the critical role that early childhood facilities play in preparing young children for achievement in school and in life.

Congress has the power to influence and support State and local early childhood priorities. We believe that conversations about early care and education should always acknowledge the significant impact of early childhood physical settings on early learning.

2. Ensure that Federal policies adequately finance the acquisition, construction, and improvement of early care and education spaces.

Currently, there is no dedicated source of funding for the acquisition, construction, and improvement of early care and education spaces. Additionally, the economic instability of the past 5 years has resulted in very little investment in early childhood physical infrastructure. Capital must be available in order for early care and education providers to create high quality physical spaces that promote early learning. We are encouraged by the national dialogue on the importance of investments in early childhood development, and request that you create the supportive policy, regulatory, and funding environment that is needed to enable the early care and education field to meet its physical capital needs.

CONCLUSION

As investments are made to increase access to preschool and child care, attention must be paid to the physical environment where many young children spend the majority of their waking hours. Without support for facilities, programs will locate in the least expensive and most readily available spaces—makeshift, donated, or surplus space such as basements and storefronts or outdated classrooms for older students that have not been adapted for our youngest children and fall far short of standards to support high quality programs.

We look forward to continuing conversations with you and your staff. Our organization serves on the Executive Committee of the National Children's Facilities Network (NCFN), a coalition of like-minded nonprofit financial and technical assistance intermediaries involved in planning, developing, and financing facilities for low-income child care and early education programs. Both LISC and NCFN would welcome an opportunity to serve as a resource.

Thank you again for your leadership.

[This statement was submitted by Matthew Josephs, Senior Vice President, Policy, and Amy Gillman, Senior Program Director, Community Investment Collaborative For Kids.]

PREPARED STATEMENT OF THE MARCH OF DIMES FOUNDATION

MARCH OF DIMES: FISCAL YEAR 2015 FEDERAL FUNDING PRIORITIES

[Dollars in thousands]

Program	Fiscal year 2015 request
National Institutes of Health (Total)	32,000,000
National Institute of Child Health and Development	1,370,000
National Human Genome Research Institute	536,967
National Institute on Minority Health and Disparities	289,426
Centers for Disease Control and Prevention (Total)	7,800,000
National Center for Birth Defects and Developmental Disabilities	139,000
Birth Defects Research and Surveillance	22,300
Folic Acid Campaign	2,800
Immunizations	720,000
Polio Eradication	146,000
Safe Motherhood Initiative	46,000
Preterm Birth	2,000
National Center for Health Statistics	182,000
Health Resources and Services Administration (Total)	7,480,000
Title V, Maternal and Child Health Block Grant	639,000
SPRANS- Infant Mortality and Preterm Birth	3,000
Heritable Disorders	18,000
Universal Newborn Hearing	18,660
Healthy Start	103,532
Children's Hospitals Graduate Medical Education	300,000

MARCH OF DIMES: FISCAL YEAR 2015 FEDERAL FUNDING PRIORITIES—Continued

[Dollars in thousands]

Program	Fiscal year 2015 request
Agency for Healthcare Research and Quality (Total)	375,000

The three million volunteers and 1,200 staff members of the March of Dimes Foundation appreciate the opportunity to submit Federal funding recommendations for fiscal year 2015. The March of Dimes is a unique partnership of scientists, clinicians, parents, members of the business community and other volunteers affiliated with chapters in every State, the District of Columbia and Puerto Rico. The March of Dimes recommends the following funding levels for programs and initiatives that are essential investments in maternal and child health.

PRETERM BIRTH

Preterm birth is a serious health problem that costs the United States more than \$26 billion annually. Employers, private insurers and individuals bear approximately half of the cost of healthcare for these infants, and another 40 percent is paid by Medicaid. One in nine infants in the U.S. is born preterm. Prematurity is the leading cause of newborn mortality and the second leading cause of infant mortality. Among those who survive, one in five faces health problems that persist for life such as cerebral palsy, intellectual disabilities, chronic lung disease, and deafness. For the past 6 years preterm birth rates have declined, resulting in 176,000 fewer babies being born preterm and saving more than \$9 billion. The March of Dimes believes a key factor behind this continued decline was Congress' passage of the 2006 PREEMIE Act (Public Law 109–450), which brought the first-ever national focus to prematurity prevention and generated a public-private agenda to spur innovative research at the National Institutes of Health (NIH) and Centers for Disease Control and Prevention (CDC) and advanced evidence-based interventions to prevent preterm birth. In 2013 Congress passed the PREEMIE Reauthorization Act (Public Law 113–55), which renews our Nation's commitment to giving every baby a healthy start. The March of Dimes' fiscal year 2015 funding requests regarding preterm birth are based on continuing to enhance public and private investment into understanding the causes of preterm birth and promoting known interventions.

Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)

The March of Dimes recommends at least \$32 billion for the National Institutes of Health and \$1,370 billion for the NICHD in fiscal year 2015. This funding will allow NICHD to sustain its preterm birth-related research through extramural grants, Maternal-Fetal Medicine Units, the Neonatal Research Network and the intramural research program. This funding would also allow for NICHD to continue investments in transdisciplinary research to identify the causes of preterm birth, as recommended in the Director's 2012 Scientific Vision for the next decade, the Institute of Medicine 2006 report on preterm birth, and the 2008 Surgeon General's Conference on the Prevention of Preterm Birth. The March of Dimes fully supports NICHD's pursuit of transdisciplinary science, which facilitates the exchange of scientific ideas and leads to novel approaches to understanding complex health issues and their prevention.

Centers for Disease Control and Prevention—Preterm Birth

The mission of the CDC's National Center for Chronic Disease Prevention and Health Promotion's Safe Motherhood Initiative is to promote optimal reproductive and infant health. The March of Dimes recommends funding of \$46 million for the Safe Motherhood program and re-instatement of the preterm birth sub-line at \$2 million, as reauthorized in the PREEMIE Reauthorization Act, to reflect current preterm birth research within the CDC.

The CDC funds state-based Perinatal Quality Collaboratives, networks of hospitals, healthcare providers, State health departments, consumer groups, and others that advance evidence-based clinical practices and processes. These networks collect data in real time on healthcare practices and outcomes and provide immediate feedback for quality improvement. For example, the New York State Obstetrical and Neonatal Quality Collaborative reduced deliveries without indication from 25 percent in 2010 to 7–8 percent in 2012. Reducing elective deliveries before 39 weeks gestation is a proven way to lower preterm birth and improve infant outcomes.

Health Resources and Services Administration (HRSA)—Preterm Birth

The March of Dimes recommends the Subcommittee specify \$3 million within the Title V Special Projects of Regional and National Significance account be used to support current preterm birth and infant mortality initiatives, as authorized in the PREEMIE Act, and to support the expansion of its initiatives nationwide. The PREEMIE Reauthorization Act renewed preterm birth-related demonstration projects, which are aimed at improving education, treatment and outcomes for babies born preterm. This funding will support HRSA's Collaborative Improvement & Innovation Network (COIIN) to Reduce Infant Mortality, which assists State agencies focusing on a range of interventions proven to reduce preterm birth and improve maternal and child health.

BIRTH DEFECTS

According to the CDC, an estimated 120,000 infants in the U.S. are born with major structural birth defects each year. Birth defects are the leading cause of infant mortality and the causes of more than 70 percent are unknown. Federal investments are sorely needed to support research to discover the causes of all birth defects and for the development of effective interventions to prevent them or reduce their prevalence.

CDC—National Center on Birth Defects and Developmental Disabilities (NCBDDD)

For fiscal year 2015, the March of Dimes recommends funding of \$139 million for NCBDDD. We also request the Subcommittee provide at least \$22.3 million to support birth defects research and surveillance and \$2.8 million to support folic acid education. Birth defects research and surveillance activities have been severely curtailed due to funding reductions which means a slowed pace to research identifying causes of birth defects and decreased ability to track birth defects and connect families to services. Specifically, two Centers for Birth Defects Research and Prevention have been eliminated. Specific expertise from the previously funded Centers in Texas and Utah (medications used during pregnancy, environmental exposures of concern, maternal infections, and birth defects risk among Hispanics) is no longer contributing to the study and 25 percent fewer families are participating in CDC birth defects research. Birth defects surveillance programs funded by NCBDDD have gone from 28 in 2004 to 14 in 2013, with a 40 percent (800,000) reduction in the number of live births monitored by States.

NEWBORN SCREENING

Newborn screening is a vital public health activity designed to identify genetic, metabolic, hormonal and functional disorders in newborns. Screening detects conditions in newborns that, if left untreated, can cause disability, developmental delays, intellectual disabilities, serious illnesses or even death. If diagnosed early, many of these disorders can be managed successfully. The March of Dimes urges the Subcommittee to provide \$18 million for HRSA's heritable disorders program, which plays a critical role in assisting States in the adoption of additional screenings, enhancing provider and consumer education, and ensuring coordinated follow-up care. Also funded by this program is the work of the Advisory Committee on Heritable Disorders in Newborns and Children, which provides States with a Recommended Uniform Screening Panel (RUSP) to ensure that every infant is screened for conditions having a known treatment. The RUSP has helped bring about comprehensive newborn screening in every State. In 2007, only 10 States and DC required infants to be screened for the recommended disorders; today, 42 States and DC require screening of at least 29 of the 31 treatable conditions.

CLOSING

The Foundation's volunteers and staff in every State, the District of Columbia and Puerto Rico look forward to working with Members of this Subcommittee to secure the resources needed to improve the health of the Nation's mothers, infants and children.

PREPARED STATEMENT OF THE MARFAN FOUNDATION

Chairman Harkin and distinguished members of the Subcommittee, thank you for your time and your consideration of the priorities of the heritable connective tissue disorders community as you work to craft the fiscal year 2015 Labor, Health and Human Services Appropriations Bill.

ABOUT MARFAN SYNDROME AND HERITABLE CONNECTIVE TISSUE DISORDERS

Marfan Syndrome

Marfan syndrome is a genetic disorder that affects the body's connective tissue. Connective tissue holds all the body's cells, organs and tissue together. It also plays an important role in helping the body grow and develop properly.

Connective tissue is made up of proteins. The protein that plays a role in Marfan syndrome is called fibrillin-1. Marfan syndrome is caused by a defect (or mutation) in the gene that tells the body how to make fibrillin-1. This mutation results in an increase in a protein called transforming growth factor beta, or TGF- β . The increase in TGF- β causes problems in connective tissues throughout the body, which in turn creates the features and medical problems associated with Marfan syndrome and some related disorders.

Because connective tissue is found throughout the body, Marfan syndrome can affect many different parts of the body, as well. Features of the disorder are most often found in the heart, blood vessels, bones, joints, and eyes. Some Marfan features—for example, aortic enlargement (expansion of the main blood vessel that carries blood away from the heart to the rest of the body)—can be life-threatening. The lungs, skin and nervous system may also be affected. Marfan syndrome does not affect intelligence.

Related Conditions

There are disorders related to Marfan syndrome that can cause people to struggle with some of the same or similar physical problems. Some examples are Loeys-Dietz syndrome, Ehlers-Danlos syndrome, and Familial Thoracic Aortic Aneurysm and Dissection.

Disorders related to Marfan syndrome can also cut lives short, particularly when they go unchecked, and they can deeply affect the quality of life of the individuals and families who must cope with them. Just like people with Marfan syndrome, those affected by related disorders need early and accurate diagnosis to ensure they receive proper care and treatment.

Many of these disorders are genetic conditions that, like Marfan syndrome, cause the aorta (the main blood vessel that carries blood from the heart to the rest of the body) to enlarge, a problem that requires medicine and regular monitoring to determine appropriate treatment. Other features that may overlap with Marfan syndrome include those involving the heart, bones, joints and eyes. Related connective tissue disorders include:

- Loeys-Dietz Syndrome
- Ehlers-Danlos Syndrome
- Familial Thoracic Aortic Aneurysm and Dissection
- Mass Phenotype
- Ectopia Lentis Syndrome
- Beals Syndrome
- Bicuspid Aortic Valve
- Stickler Syndrome
- Shprintzen-Goldberg Syndrome

ABOUT THE FOUNDATION

The Marfan Foundation creates a brighter future for everyone affected by Marfan syndrome and related disorders.

- We pursue the most innovative research and make sure that it receives proper funding.
- We create an informed public and educated patient community to increase early diagnosis and ensure life-saving treatment.
- We provide relentless support to families, caregivers, and healthcare providers.

We will not rest until we've achieved victory—a world in which everyone with Marfan syndrome or a related disorder receives a proper diagnosis, gets the necessary treatment, and lives a long and full life.

ONE FAMILY'S STORY

Hector Roman was 36 years old when he died on June 25, 2012, of an aortic dissection caused by Marfan syndrome. He was never diagnosed with Marfan syndrome—despite being treated by several medical specialists for myriad health issues—and he did not know he was at risk of a sudden early death. He was in pain for days and didn't rush to the hospital because he was frustrated with the lack of help he was getting with his health concerns. He had no idea this delay would be

deadly. After a few days in pain, he went into shock and a friend call 911. He died 3 days later during his third surgery.

Now, his partner, Teresita Mompeller, of Phoenix, AZ, is raising their three boys—Jovan, 5, Joel, 3, and Justus, 2—alone. After Hector died, Teresita learned about Marfan syndrome. Most alarming to her was that affected people have a 50 percent chance of passing it to their offspring. She had her sons checked immediately. Joel and Justus have been diagnosed with Marfan syndrome and already have aortic enlargement. While their condition is the same as their dad; their prognosis is better. The boys can live a normal life span because they have the diagnosis and are being monitored. They can avoid a fatal situation because they know.

Teresita, who has a Facebook page called “Do You Know Marfan?” (and a parallel page in Spanish) recently wrote: “Thanks to the work of The Marfan Foundation, I know that my boys have a greater chance of living a long life. I know first-hand what it is to be a mother with many questions and concerns about a rare disorder that nobody seemed to know anything about. The Marfan Foundation has guided me through all of my concerns. They have given me all the support and information needed to advocate for my children [so they receive] proper treatment. The Foundation has given me and thousands of other people, the peace of mind that they are working hard to better the lives of those affected.”

SEQUESTRATION

We have heard from the medical research community that sequestration and deficit reduction activities have created serious issues for Federal funding opportunities and the career development pipeline. In order to ensure that research into heritable connective tissue disorders can continue to move forward, and, more importantly, to ensure that our country is adequately preparing the next generation of young investigators, we urge you to avert, mitigate, or otherwise eliminate the specter of sequestration. While the Foundation has anecdotal accounts of the harms of sequestration, the Federated American Societies for Experimental Biology has reported:

- In constant dollars (adjusted for inflation), the NIH budget in fiscal year 2013 was \$6 billion (22.4 percent) less than it was in fiscal year 2003.
- The number of competing research project grants (RPGs) awarded by NIH has also fallen sharply since fiscal year 2003. In fiscal year 2013, NIH made 8,283 RPG awards, which is 2,110 (20.3 percent) fewer than in fiscal year 2003.
- Awards for R01-equivalent grants, the primary mechanism for supporting investigator-initiated research, suffered even greater losses. The number awarded fell by 2,528 (34 percent) between fiscal year 2003 and fiscal year 2013.

The pay line for some NIH funding mechanisms has fallen from 18 percent to 10 percent while the average age for a researcher to receive their first NIH-funded grant has climbed to 42. These are strong disincentives to choosing a career as a medical researcher. Our scaling-back is occurring at a time when many foreign countries are investing heavily in their biotechnology sectors. China alone plans to dedicate \$300 million to medical research over the next 5 years; this amount is double the current NIH budget over the same period of time. Scientific breakthroughs will continue, but America may not benefit from the return-on-investment of a robust biotechnology sector. For the purposes of economic and national security, as well as public health, the Foundation asks that you work with your colleagues to eliminate sequestration and recommit to supporting this Nation’s biomedical research enterprise.

CENTERS FOR DISEASE CONTROL AND PREVENTION

People with Marfan syndrome are born with it, but features of the disorder are not always present right away. Some people have a lot of Marfan features at birth or as young children—including serious conditions like aortic enlargement. Others have fewer features when they are young and don’t develop aortic enlargement or other signs of Marfan syndrome until they are adults. Some features of Marfan syndrome, like those affecting the heart and blood vessels, bones or joints, can get worse over time.

This makes it very important for people with Marfan syndrome and related disorders to receive accurate, early diagnosis and treatment. Without it, they can be at risk for potentially life-threatening complications. The earlier some treatments are started, the better the outcomes are likely to be.

Knowing the signs of Marfan syndrome can save lives. Our community of experts estimates that nearly half the people who have Marfan syndrome don’t know it. CDC and NCBDDD have critical programs that can help improve awareness and recognition of warning signs, which can save lives. Some of these programs including CDC’s Million Hearts Campaign and NCBDDD’s newborn screening activities.

Meaningful funding increases will allow CDC and NCBDDD to expand their successful awareness efforts to include additional conditions.

NATIONAL INSTITUTES OF HEALTH

NIH has worked closely with the Foundation to investigate the mechanisms of these conditions. In recent decades, this research has yielded significant scientific breakthroughs that have the potential to improve the lives of affected individuals. In order to ensure that the heritable connective tissue disorders research portfolios can continue to expand and advance, NIH requires meaningful funding increases to invest in emerging and promising activities.

NHLBI

The Marfan Foundation anxiously await the results of this first-ever multicenter clinical trial for our patient population conducted by the National Heart, Lung and Blood Institute's Pediatric Heart Network (PHN). After 4 years of recruitment and 3 years of follow-up evaluations, the results are expected to be released in November 2014 at the American Heart Association Meeting. 604 Marfan syndrome patients (age 6 months to 25 years) are enrolled in the study. Patients are randomized onto either losartan or atenolol (a beta blocker that is the current standard of care for Marfan patients with an enlarged aortic root). The Marfan Foundation thanks both NHLBI and NIAMS for their dedicated support and careful execution of this trial.

NEI

Ectopia lentis, dislocation of the lens, occurs in up to 60 percent of patients with Marfan syndrome. The central positioning of the lens depends on the zonule of Zinn, a fibrous structure which has fibrillin-1 as a major component. NEI-supported investigators are studying the protein interactions of fibrillin-1 in health and disease in the zonule of Zinn to understand the disease mechanisms that cause ectopia lentis. It is hoped that this research will provide therapeutic insights to better treat this complication of Marfan syndrome.

NIAMS

NIAMS continues to support the Consortium for Translational Research in Marfan Syndrome, which is investigating the disease process in MFS. These studies, building on previous advances, are aimed at identifying new biological targets for therapy, as well as predictive biomarkers of vascular and skeletal manifestations, which are the major causes of mortality and morbidity in MFS.

ORDR

The National Center for Advancing Translational Sciences houses ORDR and leads other important activities. In addition to the Rare Disease Clinical Research Consortia, translational treatment development programs hold promise for the heritable connective tissue disorders community.

PREPARED STATEMENT OF MARY A. VITALE, GUARDIAN/SIBLING/ADVOCATE

Dear Committee Members: The opportunity to submit personal testimony to this committee is much appreciated. As 2015 appropriation requests are being considered, this submission of testimony is a request for a review of the misuse of Federal funds by the Health and Human Services (HHS) agencies that promote forced deinstitutionalization of persons with severe and profound intellectual disabilities.

I have been an active guardian for 35 years for my 61 year old brother who has severe intellectual disabilities, behavior challenges, and ongoing medical concerns. He has never been able to walk or talk. He has only partial use of one of his arms. He needs maximum assistance for all his needs. Despite his many disabilities, he is a happy man. His care at his intermediate care facility for individuals with intellectual disabilities (ICF/IID) home is successful, stable, sustainable, consistent, comprehensive, and cost-effective.

HHS agencies, such as State Planning Councils and State Protection and Advocacy Services, are misusing Federal funds to promote the closing of ICF/IID homes like where my brother lives, despite the objections of legal guardians.

The Supreme Court 1999 Olmstead ruling states: "It would be unreasonable, it would be a tragic event, then, were the Americans with Disabilities Act of 1990 (ADA) to be interpreted so that States had some incentive, for fear of litigation to drive those in need of medical care and treatment out of appropriate care and into settings with too little assistance and supervision."

To the great dismay of families, this "tragic event" is exactly what is happening across the United States by the misuse of HHS funding.

Appropriate, cost-effective care for those with the severest disabilities is available in ICF/IID homes, and yet they are aggressively targeted for closure, flagrantly ignoring the educated choice of guardians.

Many community settings have too little assistance and too little supervision to be appropriate for those with severe multiple intellectual and physical impairments. Tragically, the result is an increase in neglect and abuse.

I ask each member of this committee to seriously question HHS about misusing Federal funds to promote forced total deinstitutionalization for persons with intellectual disabilities. Help us keep our beloved family members safe and healthy.

PREPARED STATEMENT OF THE MEALS ON WHEELS ASSOCIATION OF AMERICA

Chairman Harkin and Ranking Member Moran: Thank you for the opportunity to present testimony to your Subcommittee concerning fiscal year 2015 funding for Older Americans Act (OAA) Nutrition Programs administered by the Administration for Community Living/Administration on Aging within the U.S. Department of Health and Human Services. We are sincerely grateful for your longstanding support, as well as your leadership in ensuring that these programs received a restoration of funding in fiscal year 2014 over the devastating fiscal year 2013 sequestration cuts.

Last month, we sent a joint letter with the National Association of Nutrition and Aging Services Program (NANASP) to you, Chairman Mikulski and Ranking Member Shelby urging increased investments in OAA Nutrition Programs, including the Congregate Nutrition Program, Home-Delivered Nutrition Program (commonly referred to as Meals on Wheels), and the Nutrition Services Incentive Program. Specifically, we requested funding these programs at their fiscal year 2010 levels—totaling \$819 million. During the fiscal year 2015 appropriations process, we implore you to give this modest request your utmost consideration due to the significant moral and economic benefits these programs offer.

This week, a new report released by the National Foundation to End Senior Hunger shows that nearly 9.3 million Americans over the age of 60 struggled with hunger in 2012, up from 8.8 million in 2011—and a 28% increase since the start of the recession in 2007. Because OAA funding has not kept pace with needs, the chasm continues to widen. Through OAA Nutrition Programs, we are only able to provide nutritious meals to 2.5 million of them,¹ leaving a staggering gap of nearly 7 million seniors still in need. The infrastructure and network exists to serve more of our seniors in need, but the financial resources fall substantially short. That is why we are asking for a critical boost in funding levels.

Senior hunger is a growing epidemic that has serious implications for our current and future Mandatory spending. Without proper nutrition and the critical social connection that comes along with it, one's health deteriorates and inevitably fails. It is extremely costly not only in personal terms for the individuals who struggle with hunger, but also for our Nation in terms of increased healthcare costs. As such, we hope that you recognize the need to invest in Discretionary programs, like OAA Nutrition Programs, that help prevent and mitigate the effects of chronic diseases, improve quality of life, expedite recovery after an illness or injury, and reduce unnecessary Medicare and Medicaid expenses both today and in the future. These programs are part of the solution to our Nation's fiscal challenges.

For over 40 years, OAA Nutrition Programs in communities large and small, urban and rural have been effectively serving our country's most vulnerable, frail and isolated seniors. What started as a demonstration project has grown into a highly effective community-based, nationwide network of more than 5,000 local programs. While not all programs receive OAA funds, the majority rely, in part, on the Federal dollars authorized under Title III of the Act as a foundation on which to leverage other funding. This enables a very successful public-private partnership to help raise the remaining resources needed to provide daily nutritious meals and social contact to seniors 60 years of age and older who are at significant risk of hunger and losing their ability to remain independent and able to live in their homes.

The evidence demonstrates that these programs are not only saving lives and taxpayer dollars every day, but they are doing precisely what they were designed to do by effectively reaching our Nation's most at-risk seniors.

Data from the 2012 National Survey of OAA Participants shows that the seniors receiving Meals on Wheels and congregate meals are primarily over age 75, impoverished, live alone, are in poor health and functionally impaired. For the majority

¹2011 Older Americans Act State Program Reports. U.S. Department of Health and Human Services, Administration on Aging. March 2013. <http://www.agid.acl.gov/>.

of the individuals served, the meal that they receive provides one half or more of their total food for the day.

Of the seniors receiving Meals on Wheels:

- 60 percent have six to 14 chronic health conditions
- 51 percent take from six to at least 23 medications daily
- 29 percent have three or more limitations in everyday activities, such as bathing, getting dressed and toileting

Of the seniors receiving congregate meals:

- 40 percent have six to 14 chronic health conditions
- 29 percent take from six to at least 23 medications daily
- 50 percent have at least one limitation in everyday activities, such as preparing meals or grocery shopping

Each day, Meals on Wheels programs in Iowa, Kansas and in every State across the Nation are serving far more than just meals to seniors in need. They are delivering a caring and efficient service—nutritious meals, friendly visits, and safety checks—enabling more than 2.5 million seniors to continue to live independently in their own homes and without the worry of hunger and isolation. In short, these programs are a lifeline.

The following comments from individuals served illustrate the degree to which these OAA Nutrition Programs are delivering far more than just a meal.

- “The companionship and fellowship as well as the nutritious meals keep me getting up in the morning, getting dressed and to the site to eat.”
- “My husband needs lots and lots of help . . . If it wasn’t for meals, I wouldn’t be able to continue taking care of him in our home.”
- “If it wasn’t for Meals on Wheels, I would starve.”
- “Once a day a knock at my door means I eat for that day.”
- “I am so grateful for the volunteer drivers . . . sometimes it is the only human contact I have for days.”
- “I had major surgery. I feel these meals are big step toward keeping me from going to a nursing home.”
- “I do not get much social security so at least I have food to eat; this is my only meal; I am 89 and need Meals on Wheels or I can’t stay in my home; the friendly volunteers are the only people I see most days.”^{2,3}

Beyond the real people and lives these programs impact on a daily basis, there is increasing and irrefutable evidence that improving and bolstering funding for OAA Nutrition Programs will substantially reduce healthcare costs—both in the short- and long-term. A recent report from the Center for Effective Government found that for every \$1 invested in Meals on Wheels, up to \$50 could be saved in Medicaid alone.⁴ Brown University conducted a recent study which found that by investing more in Meals on Wheels, more seniors can be kept out of nursing homes. Specifically, the research found that for every additional \$25 a State spends on home-delivered meals each year, per person over 65, the low-care nursing home population—seniors who are nursing home eligible but could remain in their homes with only a little outside support—decreases by a percentage point.⁵ One percentage point can translate to billions of dollars in savings annually.

On top of the social and economic cases for investing in OAA Nutrition Programs, the public overwhelmingly supports them. In fact, an October 2013 survey found that 7 in 10 Americans agree that the government should pay for Meals on Wheels.⁶ The growing problem of senior hunger in America requires the continued public-private partnerships that have been a pivotal foundation; however, the Federal Government must serve as the strongest and most reliable fiscal partner by elevating its support to higher levels that keep pace with a rapidly aging population, increased need and ever-rising costs.

We understand the difficult decisions you and your colleagues are tasked with in fiscal year 2015 and beyond. However, the evidence demonstrates that these programs are not only saving lives and taxpayer dollars every day, but they are effectively reaching our Nation’s most vulnerable seniors and have the capacity to serve

²Lloyd, Jean & Greuling, Holly. The Older Americans Act Nutrition Program Sets a New Table. Aging Today Online. American Society on Aging. March 2014. <http://bit.ly/ONK7eK>.

³Don’t Empty My Plate Campaign: <http://bit.ly/1oUgRQ9> and <http://bit.ly/1jvLSGO>.

⁴Schieder, Jessica & Lester, Patrick. Sequestering Meals on Wheels Could Cost the Nation \$489 Million per year. The Center for Effective Government. April 2013. <http://bit.ly/16jmmRU>.

⁵Thomas, Kali & Mor, Vincent. The Relationship between Older Americans Act Title III State Expenditures and Prevalence of Low-Care Nursing Home Residents. Brown University. December 2012. <http://bit.ly/16wl0B2>.

⁶SSRS, independent research company. Survey among a nationally representative sample of respondents age 18+. October 2013.

more if properly resourced. In short, these proven and effective programs are a part of the solution to our Nation's fiscal challenges and should be looked to as such.

As your Subcommittee crafts and considers the fiscal year 2015 Labor-HHS-Education appropriations bill, we ask that you provide fiscal year 2010 appropriations levels for all three nutrition programs authorized under the OAA—Congregate Nutrition Program, Home-Delivered Nutrition Program, and the Nutrition Services Incentive Program. You have the ability to shorten waiting lists and increase the number of nutritious meals we can serve to seniors today. At the same time you will be investing in a stronger fiscal path for our country by reducing future healthcare costs.

Again, we thank you for the opportunity to present this testimony to you, and for your continued support.

PREPARED STATEMENT OF THE MEDICAL LIBRARY ASSOCIATION AND ASSOCIATION OF
ACADEMIC HEALTH SCIENCES LIBRARIES

SUMMARY OF FISCAL YEAR 2015 RECOMMENDATIONS

- Continue the commitment to the National Library of Medicine (NLM) by supporting the President's budget proposal which requests \$372.85 million, and an additional \$8.2 million from amounts under Section 241 of the Public Health Service Act, for the National Information Center on Health Services Research and Health Care Technology.
- Continue to support the medical library community's role in NLM's outreach, telemedicine, disaster preparedness, health information technology initiatives, and healthcare reform implementation.

INTRODUCTION

The Medical Library Association (MLA) and Association of Academic Health Sciences Libraries (AAHSL) thank the Subcommittee for the opportunity to submit testimony regarding fiscal year 2015 appropriations for the National Library of Medicine (NLM), an agency of the National Institutes of Health (NIH). Working in partnership with the NIH and other Federal agencies, NLM is the key link in the chain that translates biomedical research into practice, making the results of research readily available to all who need it.

NLM Leverages NIH Investments in Biomedical Research

In today's challenging budget environment, we recognize the difficult decisions Congress faces as it seeks to improve our Nation's fiscal stability. We thank the Subcommittee for its long-standing commitment to strengthening NLM's budget. While extramural funding comprises the largest portion of funding for institutes within the NIH, some eighty percent of NLM's budget supports intramural services and programs that sustain the Nation's biomedical research enterprise and more—it builds, sustains, and augments NLM's suite of more than 200 databases which provide information access to health professionals, researchers, educators, and the public. Intramural funding also supports all aspects of library operations and programs, including the acquisition, organization, preservation, and dissemination of the world's biomedical literature, no matter the medium.

In fiscal year 2015 and beyond, it is critical to continue augmenting NLM's baseline budget to support expansion of its information resources, services, and programs which collect, organize, and make readily accessible rapidly expanding biomedical knowledge resources and data. NLM maximizes the return on the investment in research conducted by the NIH and other organizations. The Library makes the results of biomedical information more accessible to researchers, clinicians, business innovators, and the public, enabling such data and information to be used more efficiently and effectively to drive innovation and improve health. NLM is a leader in Big Data and plays a critical role in accelerating nationwide deployment of health information technology, including electronic health records (EHRs), by leading the development, maintenance and dissemination of key standards for health data interchange that are now required of certified EHRs. NLM also contributes to Congressional priorities related to drug safety through its efforts to expand its clinical trial registry and results database (ClinicalTrials.gov) in response to legislative requirements, and to the Nation's ability to prepare for and respond to disasters.

Growing Demand for NLM's Basic Services

NLM delivers more than a trillion bytes of data to millions of users daily that helps researchers advance scientific discovery and accelerate its translation into new therapies; provides health practitioners with information that improves medical care

and lowers its costs; and gives the public access to resources and tools that promote wellness and disease prevention. Every day, medical librarians across the Nation use NLM services to assist clinicians, students, researchers, and the public in accessing information they need to save lives and improve health. Without NLM, our Nation's medical libraries would be unable to provide the quality information services that our Nation's health professionals, educators, researchers and patients increasingly need.

NLM's data repositories and online integrated services such as GenBank, PubMed, and PubMed Central are revolutionizing medicine and ushering in an era of personalized medicine in which care is based on an individual's unique genetic profile. GenBank is the definitive source of gene sequence information. PubMed, with more than 23 million citations to the biomedical literature, is the world's most heavily used source of bibliographic information. Approximately 760,000 new citations were added in fiscal year 2013, and the database provided high quality medical information to about 2.3 million users each day. PubMed Central is NLM's digital archive which provides public access to the full-text versions of more than 3 million biomedical journal articles, including those produced by NIH-funded researchers. On a typical weekday more than one million users download 1.65 million full-text articles, including those submitted in compliance with the NIH Public Access Policy.

As the world's largest and most comprehensive medical library, NLM's traditional print and electronic collections continue to steadily increase each year, standing at more than 21 million items—books, journals, technical reports, manuscripts, microfilms, photographs and images. By selecting, organizing and ensuring permanent access to health sciences information in all formats, NLM ensures the availability of this information for future generations, making it accessible to all Americans, irrespective of geography or ability to pay, and guaranteeing that citizens can make the best, most informed decisions about their healthcare.

Encourage NLM Partnerships

NLM's outreach programs are essential to MLA and AAHSL membership and to the profession. Through the National Network of Libraries of Medicine (NN/LM), with over 6,000 members in communities nationwide, these activities educate medical librarians, health professionals and the general public about NLM's services and train them in the most effective use of these services. The NN/LM promotes educational outreach for public libraries, secondary schools, senior centers and other consumer-based settings, and its emphasis on outreach to underserved populations helps reduce health disparities among large sections of the American public. NLM's "Partners in Information Access" program improves access by local public health officials to information which prevents, identifies and responds to public health threats and ensures every public worker has electronic health information services that protect the public's health.

NLM's MedlinePlus provides consumers with trusted, reliable health information on more than 900 topics in English and Spanish. It has become a top destination for those seeking information on the Internet, attracting more than 1.2 million visitors daily. NLM has continued to make enhancements to MedlinePlus, with selected materials now available in forty other languages. Other products and services that benefit public health and wellness include the NIH MedlinePlus Magazine and NIH MedlinePlus Salud, available in doctors' offices nationwide, and NLM's MedlinePlus Connect—a utility which enables clinical care organizations to implement links from their electronic health records systems to relevant patient education materials in MedlinePlus.

MLA and AAHSL applaud the success of NLM's outreach initiatives, and we look forward to continuing to work with NLM on these programs.

Emergency Preparedness and Response

Through its Disaster Information Management Research Center, NLM collects and organizes disaster-related health information, ensures effective use of libraries and librarians in disaster planning and response, and develops information services to assist responders. NLM responds to specific disasters worldwide with specialized information resources appropriate to the need, including information on bioterrorism, chemical emergencies, fires and wildfires, earthquakes, tornadoes, and pandemic disease outbreaks. MLA and NLM continue to develop the Disaster Information Specialization (DIS) program to build the capacity of librarians and other interested professionals to provide disaster-related health information outreach. Working with libraries and publishers, NLM's Emergency Access Initiative makes available free full-text articles from hundreds of biomedical journals and reference books for use by medical teams responding to disasters. MLA and AAHSL ask the Sub-

committee to support NLM's role in this crucial area which ensures continuous access to health information and use of libraries and librarians when disasters occur.

Health Information Technology and Bioinformatics

For more than 40 years, NLM has supported informatics research, training and the application of advanced computing and informatics to biomedical research and healthcare delivery including telemedicine projects. Many of today's biomedical informatics leaders are graduates of NLM-funded informatics research programs at universities nationwide. A number of the country's exemplary electronic and personal health record systems benefit from findings developed with NLM grant support.

The importance of NLM's work in health information technology continues to grow as the Nation moves toward more interoperable health information technology systems. A leader in supporting the development, maintenance, and dissemination of standard clinical terminologies for free nationwide use (e.g., SNOMED), NLM works closely with the Office of the National Coordinator for Health Information Technology to promote the adoption of interoperable electronic records, and has developed tools to make it easier for EHR developers and users to implement accepted health data standards in their systems.

Organizational Bios

The Medical Library Association (MLA) is a nonprofit, educational organization with 4,000 health sciences information individual and institutional members. Founded in 1898, MLA provides lifelong educational opportunities, supports a knowledge base of health information research, and works with a network of partners to promote the importance of quality information for improved health to the healthcare community and the public.

The Association of Academic Health Sciences Libraries (AAHSL) supports academic health sciences libraries and directors in advancing the patient care, research, education and community service missions of academic health centers through visionary executive leadership and expertise in health information, scholarly communication, and knowledge management.

Thank you again for the opportunity to present our views. We look forward to continuing this dialogue and supporting the Subcommittee's efforts to secure the highest possible funding level for NLM in fiscal year 2015 and the years beyond to support the Library's mission and growing responsibilities. Information about NLM and its programs can be found at <http://www.nlm.nih.gov>.

PREPARED STATEMENT OF THE MESOTHELIOMA APPLIED RESEARCH FOUNDATION

Chairman Harkin, Ranking Member Moran and Members of the Subcommittee, thank you for the opportunity to provide written testimony on behalf of the mesothelioma community. My name is Mary Hesdorffer and I am the Executive Director of the Mesothelioma Applied Research Foundation. I am testifying on behalf of the mesothelioma community composed of patients, physicians, caregivers and family members. I am a Nurse Practitioner with over sixteen years' experience working with mesothelioma patients in the clinical setting. I would like to use this opportunity to emphasize the great need for increased funding for the National Institutes of Health (NIH), including the National Cancer Institute (NCI), both of which play a critical role in improving treatment for mesothelioma.

Mesothelioma is an aggressive cancer known to be caused by exposure to asbestos. Doctors say it is among the most painful of cancers, and the prognosis is poor even with the best available treatment.

The harsh reality for patients with malignant mesothelioma is that it is a terminal illness; the five-year survival rate is five to ten percent, making it one of the most deadly cancers. Left untreated, survival ranges from six to 9 months, and if treated with the sole Food and Drug Administration (FDA) approved therapy, median survival is only 12.3 months.

With only one FDA approved treatment available, mesothelioma patients must take a trial and error approach to treatment, making agonizing decisions each step of the way. Most patients must make the tough decision to go into a clinical trial, use off label treatments, or undergo drastic surgeries knowing they may see no benefit whatsoever. They choose to do this with a powerful hope they can help doctors learn how to treat mesothelioma, possibly live a while longer and prevent future mesothelioma patients from enduring the same difficult experience.

Fortunately, there are brilliant researchers dedicated to mesothelioma. The Mesothelioma Applied Research Foundation has made a significant investment, funding a total of \$8.7 million to support research in hopes of giving researchers the first

seed grant they need to get started. We need the continued partnership with the Federal Government to develop the promising findings into effective treatments.

In research, innovative and personalized therapies from the mapping of the human genome or those that utilize the body's own immune system are becoming a reality for mesothelioma. These developments have the potential to reduce the human toll of mesothelioma, but need continued research funding to bring the advances from the bench to the bedside.

Recent research findings have linked mesothelioma to a germline mutation in the BAP1 gene and a somatic mutation in the NF2 gene. Currently, the research goal of the BAP1 and NF2 genes is for prevention and early detection of mesothelioma. For example, individuals known to be exposed to asbestos who carry this gene can be studied to determine if a cancer signal can be picked up before the development of mesothelioma. The idea is that if you have a germ line mutation, you and your immediate family will be screened for cancers associated with this gene in the hope of picking up an early malignancy. Also, researchers will study ways to turn off this gene, if defective. There is great potential in these findings.

Immunotherapy is another exciting area of research. An immunotherapy is a treatment that uses certain parts of a person's immune system to target cancer, and is one of the most exciting areas in cancer research. Dr. Raffit Hassan at the NCI and his collaborators have shown that mesothelin, a tumor antigen which was discovered at the NCI, is a useful target for tumor-specific therapy of malignant mesothelioma. His group is presently conducting clinical trials of three different agents targeting mesothelin. Namely, SS1P which is an anti-mesothelin immunotoxin, MORAb-009 which is a chimeric anti-mesothelin monoclonal antibody and CRS-207 which is a mesothelin tumor vaccine. They have seen some success, and it has given patients a reason to be optimistic.

It is efforts like these that give mesothelioma patients hope. I am grateful for the Federal Government's investment in mesothelioma research and I want to see it continued and increased. Unless researchers have the funds to continue, these discoveries will not yield improved treatments, patients will run out of options and continue to die from this disease.

Cancer research funding as a share of the NIH budget has declined while the scientific and public health need has gone up. In the late 1990s, NCI's budget made up 18.7 percent of the NIH budget. Today, it is 16.4 percent of the NIH budget. That decline has reduced NCI's funding by \$680 million below what it would have received in fiscal year 2014 if its share of NIH's total budget had been maintained.

The mesothelioma community asks that the Subcommittee recognize the National Institutes of Health (NIH) as a critical national priority by providing at least \$32 billion, including \$5.26 Billion for the National Cancer Institute in funding in the fiscal year 2015 Labor-HHS-Education Appropriations bill. This funding recommendation represents the minimum investment necessary to avoid further loss of promising research and at the same time allows the NIH's budget to keep pace with biomedical inflation.

I look to the Labor, Health and Human Services, Education and Related Agencies Appropriations Subcommittee to provide continued leadership and hope to the people who develop this fatal cancer. Thank you for the opportunity to submit testimony and for funding the National Institutes of Health and the National Cancer Institute at the highest possible level.

About the Mesothelioma Applied Research Foundation:

The Mesothelioma Applied Research Foundation is the nonprofit collaboration of patients and families, physicians, advocates, and researchers dedicated to eradicating the life-ending and vicious effects of mesothelioma. We believe in a cure for mesothelioma. Given the human toll of suffering the disease causes, the compassion and energy of the mesothelioma community, the moral, legal and economic aspects of asbestos, and the benefits of mesothelioma research to cancer research generally, we believe that the resources to accomplish this cure are available and must be mobilized. We seek to marshal and utilize these resources responsibly, as effectively as possible, with financial transparency and by adhering to health policy guidelines that foster ethical clinical and administrative practices, and ethical decisionmaking to:

- Offer hope and support to patients and families by educating them on the disease, helping them to obtain the most up-to-date information on treatment options and to connect with mesothelioma treatment specialists, and providing them assistance, emotional support and community with others;
- Fund the highest quality and most promising mesothelioma research projects from around the world through rigorous peer-review; and

- Raise awareness of mesothelioma, and advocate that the public and private sectors partner in the effort to cure it by directing the resources needed to stop this global tragedy

PREPARED STATEMENT OF THE NATIONAL AHEC ORGANIZATION

The members of the National AHEC Organization (NAO) are pleased to submit this statement for the record recommending \$75 million in fiscal year 2015 for the Area Health Education Center (AHEC) Program authorized under Title VII of the Public Health Service Act and administered through the Health Resources and Services Administration (HRSA) at the Department of Health and Human Services.

The NAO is the professional organization representing AHECs. The AHEC Program is an established and effective national primary care training network built on committed partnerships of 53 medical schools and academic centers. Additionally, 253 AHEC centers within 48 States and tens of thousands of community practitioners are affiliated with the AHEC's national clinical training network.

AHEC is one of the Title VII Health Professions Training programs, originally authorized at the same time as the National Health Service Corps (NHSC) to create a complete mechanism to provide primary care providers for Community Health Centers (CHCs) and other direct providers of healthcare services for underserved areas and populations. The plan envisioned by creators of the legislation was that the CHCs would provide direct service. The NHSC would be the mechanism to fund the education of providers and supply providers for underserved areas through scholarship and loan repayment commitments.

The AHEC program would be the mechanism to recruit providers into primary health careers, diversify the workforce, and develop a passion for service to the underserved in these future providers, i.e. Area Health Education Centers are the workforce development, training and education machine for the Nation's healthcare safety-net programs. The AHEC program is focused on improving the quality, geographic distribution and diversity of the primary care healthcare workforce and eliminating the disparities in our Nation's healthcare system.

AHECs develop and support the community based training of health professions students, particularly in rural and underserved areas. They recruit a diverse and broad range of students into health careers, and provide continuing education, library and other learning resources that improve the quality of community-based healthcare for underserved populations and areas.

The Area Health Education Center program is effective and provides vital services and national infrastructure. Nationwide, over 379,000 students have been introduced to healthcare opportunities, and over 33,000 mostly minority and disadvantaged high school students received more than 20 hours each of healthcare exposure. Over 44,000 health professions students received training at 17,530 community-based sites, and furthermore; over 482,000 health professionals received continuing education through AHECs. AHECs perform these education and training services through collaborative partnerships with Community Health Centers (CHCs) and the National Health Service Corps (NHSC), in addition to Rural Health Clinics (RHCs), Critical Access Hospitals, (CAHs), Tribal clinics and Public Health Departments.

Justification for Recommendations

The AHEC network is an economic engine that fuels the recruitment, training, distribution, and retention of a national health workforce. AHEC stands for JOBS.

- AHECs are critical in the recruitment, training, and retention of the primary care workforce.
- Research has demonstrated that the community-training network is the most effective recruitment tool for the health professions and those who teach remain longer in underserved areas and communities.
- AHECs are in almost every county in the United States.
- With the aging and growing population, the demand for primary care workforce is far outpacing the supply.
- AHECs continue to educate and train current workforce, as well as recruiting and preparing future workforce
- In 2012, AHEC's trained 476,585 Health Professionals in 48 States in 13,842 Health Professions Shortage Areas (HPSAs)—26.4 percent of those trained were physicians (125,818).
- In 2012, the AHEC's introduced nearly 403,000 students to the health careers professions and workforce from grades K–College.

- The AHEC network's outcomes are the backbone of the Nation's community-based health professions training, with a focus on training primary care workforce.
- Continued funding for the AHEC program is necessary as demonstrated by 1) a growing unmet need for primary care doctors in rural areas, and 2) the use of the national network of AHEC programs to carry out administrative priorities.
 1. The National Health Service Corps (NHSC), has been mentioned as a program that addresses the priority of increasing diversity in the health professions workforce in underserved and rural areas and addresses the end of the pipeline. The AHEC program engages in pre-pipeline, pipeline, and post-pipeline activities that works to move individuals through a healthcareers pathway and beyond, with a special focus on primary care doctors.
 2. The national network of the AHEC program has been tasked with:
 - Training 13,000+ providers nationwide in OIF/OEF/OND Veteran's behavioral and mental health, substance abuse, traumatic brain injury and post-traumatic stress, for those not utilizing the VA system
 - Working with the Food and Drug Administration to educate healthcare professionals nationwide on proper opioid prescribing habits to address the epidemic of prescription drug abuse
 - HRSA has encouraged functional linkage between Bureau of Primary Care and Bureau of Health Professions Programs. AHECs have partnerships with over 1,000 Community Health Centers nationally to recruit, train, and retain health professionals who have the cultural and linguistic skills to serve in HRSA designated underserved areas
 - Affordable Care Act activities such as increasing the enrollment of individuals, training community health workers, and educating providers nationwide on health insurance exchanges

[This statement was submitted by Rob Trachtenberg, Executive Director, National AHEC Organization.]

PREPARED STATEMENT OF THE NATIONAL ALLIANCE FOR EYE AND VISION RESEARCH
EXECUTIVE SUMMARY

The National Alliance for Eye and Vision Research (NAEVR) requests fiscal year 2015 NIH funding of \$32 billion, which would fully restore the \$1.7 billion fiscal year 2013 sequester cut partially restored in fiscal year 2014 and enable an inflationary increase—the NIH has lost 22 percent of its purchasing power since fiscal year 2003, in terms of constant dollars—and provide for modest growth. This request improves on the President's proposal to increase NIH funding by only \$200 million over fiscal year 2014 and which also increases the Program Evaluation Transfer to 3 percent, effectively reducing NIH's increase by \$150 million. fiscal year 2015 NIH funding of \$32 billion is an important step toward consistent and sustained funding increases which are necessary to build upon past investment that has created an unprecedented scientific opportunity in biomedical research.

- \$32 billion NIH funding is critical for supporting Research Project Grants, as the number of RPGs awarded in fiscal year 2013 was 20 percent less than in fiscal year 2003. R01s, or investigator-initiated grants, have been affected even more dramatically, as the number awarded fell by 24 percent between fiscal year 2003 and fiscal year 2013.
- NIH-funded basic and clinical research has helped to understand the basis of disease, thereby resulting in innovations in healthcare to save and improve lives. Its research serves an irreplaceable role the private sector could not duplicate.
- As an economic driver, in fiscal year 2011 NIH-funded research supported 432,000 jobs across the United States and generated more than \$62 billion in new economic activity. Every \$1 of NIH funding generates \$2.21 in local economic growth.

NAEVR requests National Eye Institute (NEI) funding at \$730 million, concomitant with \$32 billion NIH funding. The President's budget proposes a minimal NEI increase of \$0.9 million or 0.15 percent, based on its fiscal year 2014 operational net of \$675 million—not its \$682 million appropriation. This is unacceptable since NEI has lost 25 percent of its purchasing power since fiscal year 2003, and the fiscal year 2013 sequester has already resulted in NEI awarding 30 fewer grants—any one of which may have held the promise to save sight and restore vision.

As NEI's Budget Decreases, the Incidence of Eye Disease and Vision Impairment Increases, As Does the Associated Cost, Estimated at \$139 Billion Annually in the United States

Although the fiscal year 2013 sequester cut reduced NEI's budget by \$36 million to \$662 million, \$20 million of that was restored in fiscal year 2014 through an appropriation of \$682 million. In each year, however, NEI's appropriation was reduced even further by \$5.6 million and \$6.9 million to operational nets of \$657 million and \$674 million, respectively, due to the transfer back to the NIH Office of AIDS Research (OAR) for funding of the dissolved NEI-sponsored Ocular Complications of AIDS studies. Although OAR's funding to NEI was not committed into perpetuity, its return to NIH Central effectively reflects a cut in NEI funding and results in a new baseline upon which future funding will be based. For example, the President's fiscal year 2015 budget request bases its 0.15 percent NEI increase on the fiscal year 2014 operational net of \$674 million, which results in just a \$0.9 million increase in NEI funding to \$675 million.

The funding nets described above are well below NEI's highest appropriation—that of \$707 million in fiscal year 2010 (prior to addition of American Recovery and Reinvestment Act (ARRA) funding. Unfortunately, as NEI funding has decreased, the challenges it faces have grown, due to dramatic increases in the incidence and cost of vision impairment and eye disease.

The NEI estimates that more than 38 million Americans age 40 and older experience blindness, low vision, or an age-related eye disease such as age-related macular degeneration (AMD), glaucoma, diabetic retinopathy, or cataracts. This is expected to grow to more than 50 million Americans by year 2020. Much of this is being driven by the aging of the population, for example, the “Silver Tsunami” of the 78 million baby boomers who will turn age 65 this decade and experience the greatest risk for eye disease. Other demographic changes are also contributing to NEI's challenges, for example, African Americans and Hispanics which increasingly account for a larger share of the U.S. population and who experience a disproportionately greater prevalence of eye disease. Vision loss can also be a co-morbid condition of chronic disease, such as diabetes, which is at epidemic levels due to the increased incidence of obesity.

In June 2013, Prevent Blindness America, in conjunction with the National Opinion Research Center at the University of Chicago, released updated estimates of the cost of vision disorders. NORC estimates the annual costs of vision disorders at \$139 billion annually, inclusive of direct and indirect costs. Most importantly, the direct medical costs associated with vision disorders are the fifth highest—only less than heart disease, cancers, emotional disorders, and pulmonary conditions.

NEI's fiscal year 2014 operational net funding of \$674 million, as well as the President's fiscal year 2015 proposed funding of \$675 million, are each less than 0.5 percent of this \$139 billion annual vision disorder cost burden. The U.S. is spending only \$2.10 per-person, per-year for vision research at the NEI, while NORC estimates that the cost of treating low vision and blindness is \$6,690 per-person, per-year.

In 2009, Congress spoke volumes in passing S. Res. 209 and H. Res. 366, which designated 2010–2020 as The Decade of Vision and recognized NEI's 40th anniversary as the lead institute in funding research to save sight and restore vision. With the fiscal year 2015 LHHSS spending bill, Congress can act upon its past resolutions regarding vision and ensure that NEI is adequately funded to meet these challenges.

**\$730 MILLION FISCAL YEAR 2015 FUNDING ENABLES NEI TO PURSUE ITS PRIMARY
“AUDACIOUS GOAL” OF RESTORING VISION**

NEI has lost 25 percent of its purchasing power since fiscal year 2003. The fiscal year 2013 sequester cut resulted in NEI awarding 30 fewer grants, and the President's fiscal year 2015 proposal would result in 23 fewer awards. Any one of those missed funding opportunities could have held the promise to save sight and restore vision-goals that would have seemed unattainable just a few short years ago. The NEI has long been a leader in biomedical research. As NIH Director Francis Collins, M.D., Ph.D. stated in February 2013:

“It's often, it seems to me, that vision research is a couple of steps in front of things that are happening in biomedical research. It's clear that vision research has played a disproportionately large share in scientific breakthroughs.”

Dr. Collins made his comments at NEI's Audacious Goals Development meeting, where more than 200 attendees reflecting every sector of the vision community, including government scientists and regulators from various disciplines, discussed top-

ics built around the ten winning submissions from a pool of nearly 500 entries selected through NEI's Audacious Goals in Vision Research and Blindness Rehabilitation Challenge. This initiative, conducted by NEI with its National Advisory Eye Council (NAEC) and through The America Competes Act, yielded such ideas as restoring light sensitivity to the blind through gene-based therapies and visual prosthetics, pinpoint correction of defective genes, and growing healthy tissue from stem cells for ocular tissue transplants.

In consultation with the NAEC, the NEI converged on its primary Audacious Goal for vision research: To Regenerate Neurons and Neuronal Connections in the Eye and Visual System." As NEI Director Paul Sieving, M.D., Ph.D. stated in February 2014:

"The goals are bold but achievable. They are beyond what medicine currently can do. We are planning for a 10–12–15 year effort to reach these endpoints. Success would transform life for millions of people with eye and vision diseases. It would have major implications for medicine of the future, for vision diseases, and even beyond this, for neurological diseases."

As NEI works to achieve this goal, it will build upon its breakthrough research funded through past Federal investment. For example, NEI has been a leader in determining the genetic basis of disease-the research it has funded has identified more than 500 genes associated with both common and rare eye diseases, which is 7.5 percent of all disease-causing genes discovered to-date. Understanding the genetic basis of the disease and underlying mechanisms will lead to better diagnostics and therapies. Since last year's testimony, NEI has announced that:

- The AMD Gene Consortium, a network of international investigators representing 18 research groups, has discovered seven new regions of the human genome-called loci-that are associated with increased risk of AMD. They also confirmed 12 loci already identified in previous studies. These loci implicate a variety of biological functions, including regulation of the immune system, maintenance of cellular structure, growth and permeability of blood vessels, lipid metabolism, and atherosclerosis. AMD is the leading cause of vision loss overall, as well as the leading cause in individuals age 60-plus.
- The NEI Glaucoma Human Genetics Collaboration (NEIGHBOR) Consortium, which involves clinicians and geneticists at multiple institutions throughout the U.S. who are studying genetic variants associated with Primary Open Angle Glaucoma-the most common form of the disease-has identified the first common genetic risk factors for normal pressure glaucoma. NEIGHBOR, unique because it is the largest Genome-Wide Association Study to-date, will generate new insights into the molecular pathogenesis, effective screening and prevention strategies, and more rational treatment approaches for this disease. Glaucoma is three-to-four times more prevalent in African Americans than non-Hispanic Whites and is the leading cause of blindness in the Latino population.

These are ambitious goals that require increased-not decreased-funding. Our Nation's investment in vision health is an investment in its overall health. NEI's breakthrough research is a cost-effective investment, since it is leading to treatments and therapies that can ultimately delay, save, and prevent health expenditures, especially those associated with the Medicare and Medicaid programs. It can also increase productivity, help individuals to maintain their independence, and generally improve the quality of life, especially since vision loss is associated with increased depression and accelerated mortality.

The very health of the vision research community is also at stake with the decrease in NEI funding. Not only will funding for new investigators be at risk, but also that of seasoned investigators, which threatens the continuity of research and the retention of trained staff, while making institutions more reliant on bridge and philanthropic funding. .

ABOUT NAEVR

NAEVR, which serves as the "Friends of the NEI," is a 501(c)4 non-profit advocacy coalition comprised of 55 professional (ophthalmology and optometry), patient and consumer, and industry organizations involved in eye and vision research. Visit NAEVR's Web site at www.eyersearch.org.

PREPARED STATEMENT OF THE NATIONAL ALLIANCE ON MENTAL ILLNESS

Chairman Harkin and members of the Subcommittee, I am Mary Giliberti, Executive Director of NAMI (the National Alliance on Mental Illness). I am pleased today to offer NAMI's views on the Subcommittee's upcoming fiscal year 2015 bill. The Na-

tional Alliance on Mental Illness (NAMI) is the Nation's largest grassroots advocacy organization representing persons living with serious mental illness and their families. Through our 1,100 affiliates in all 50 States, we support education, outreach, advocacy and research on behalf of persons with serious mental illness such as schizophrenia, manic depressive illness, major depression, severe anxiety disorders and mental health conditions affecting children.

An estimated 11.5 million American adults live with a mental illness, such as schizophrenia, bipolar disorder, and major depression. Based on estimates for 2010, mental disorders accounted for 21.3 percent of all years lived with disability in the United States. Among the top 20 causes of years lived with disability, five were mental disorders: major depressive disorder (8.3 percent of the total), anxiety disorders (5.1 percent), schizophrenia (2.2 percent), bipolar disorder (1.6 percent) and dysthymia (1.5 percent). Suicide is the 10th leading cause of death in the U.S., accounting for the loss of more than 38,000 American lives each year, more than double the number of lives lost to homicide. The social and economic costs associated with these disorders are tremendous. A cautious estimate places the direct and indirect financial costs associated with mental illness in the U.S. at well over \$300 billion annually, and it ranks as the third most costly medical condition in terms of overall healthcare expenditure, behind only heart conditions and traumatic injury.

These costs are not only financial, but also human in terms of lost productivity, broken families and lives lost to suicide. 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 Research Funding

As a member of the Ad Hoc Group for Medical Research Funding, NAMI supports a \$32 billion overall allocation for the National Institutes of Health (NIH). This increase is needed to avoid having our country continue to fall behind China, India and other emerging Nations in terms of our public investment in scientific research. As you know, the President is requesting a \$23 million increase for the National Institute of Mental Health (NIMH) for fiscal year 2015, boosting funding for the agency to \$1.44 billion. NAMI would urge the Subcommittee to fund investments beyond this amount with an overall higher allocation for the entire NIH.

NAMI also supports the President's BRAIN Initiative (Brain Research through Advancing Innovative Neurotechnologies) and the request for a \$40 million boost, up to \$100 million. The BRAIN Initiative is multi-agency collaborative with a number of foundations designed to unleash new technologies and undertake basic mapping of circuits and neurons in the most complex organ in the human body.

Accelerating the Pace of Psychiatric Drug Discovery

In NAMI's view, there is an urgent need for new medications to treat serious mental illness. Existing medications can be helpful, but they often have significant limitations; in some cases requiring weeks to take effect; failing to relieve symptoms in a significant proportion of patients; or, resulting in debilitating side effects. However, developing new medications is a lengthy and expensive process. Many promising compounds fail to prove effective in clinical testing after years of preliminary research. To address this urgent issue, NAMI is encouraging NIMH to accelerate the pace of drug discovery through an 'experimental medicine' approach to evaluate novel interventions for mental illnesses. This "fast-fail" strategy is designed not only to quickly identify candidates that merit more extensive testing, but also to identify targets in the brain for the development of additional candidate compounds. Through small trials focused on proof-of-concept experimental medicine paradigms, we can make progress to demonstrate target engagement, safety, and early signs of efficacy.

Advancing Services and Intervention Research

NAMI enthusiastically supports the NIMH Recovery After an Initial Schizophrenia Episode (RAISE) Project, aimed at preventing the long-term disability associated with schizophrenia by intervening at the earliest stages of illness. The RAISE Early Treatment Program (RAISE ETP) will conclude this year. The RAISE Connection Program has successfully integrated a comprehensive early intervention program for schizophrenia and related disorders into an existing medical care system. This implementation study is now evaluating strategies for reducing duration of untreated psychosis among persons with early-stage psychotic illness. When individuals with schizophrenia and bipolar disorder progress to later stages of their illness, they become more likely to develop—and die prematurely—from medical problems such as heart disease, diabetes, cancer, stroke, and pulmonary disease than members of the general population. NIMH funded research is demonstrating progress advancing the health of people with serious mental illness. NIMH needs to advance

this research to large-scale clinical trials aimed at reducing premature mortality for people living with serious mental illness.

Investing in Early Psychosis Prediction and Prevention (EP3)

As many as 100,000 young Americans experience a first episode of psychosis (FEP) each year. The early phase of psychotic illness is a critical opportunity to alter the downward trajectory and social, academic, and vocational challenges associated with serious mental illness such as schizophrenia. The timing of treatment is critical; short- and long-term outcomes are better when individuals begin treatment close to the onset of psychosis. Unfortunately, the majority of people with mental illness experience significant delays to seeking care—up to 9 years in some cases. Such delays result in periods of increased risk for poor outcomes, especially suicide.

NIMH-funded research has focused on the prodrome, the high-risk period preceding the onset of the first psychotic episode of schizophrenia. Through North American Prodrome Longitudinal Study (NAPLS) and other studies focused on early prediction and prevention of psychosis, NIMH has launched Early Psychosis Prediction and Prevention (EP3) initiative. EP3 is showing promise in detecting risk States for psychotic disorders and reducing the duration of untreated psychosis in adolescents that have experienced FEP.

Advancing Precision Medicine

NAMI supports efforts at NIMH to translate basic research findings on brain function into more person-centered and multifaceted diagnoses and treatments for mental disorders. The Research Domain Criteria (RDoC) is showing promise toward efforts to build a classification system based more on underlying biological and basic behavioral mechanisms than on symptoms, RDoC should begin to give us the precision currently lacking with traditional diagnostic approaches to mental disorders.

Funding for Programs at SAMHSA's Center for Mental Health Services

As noted above, the costs of untreated mental illness to our Nation are enormous—as high as \$300 billion when taking into account lost wages and productivity and other indirect costs. These costs are compounded by the fact that across the Nation States and localities devote enormous resources addressing the human and financial costs untreated mental illness through law enforcement, corrections, homeless shelters and emergency medical services. This phenomenon of “spending money in all the wrong places” is tragic given that we have a vast array of proven evidence-based interventions that we know work—assertive community treatment, supported employment, family psycho-education and supportive housing.

NAMI supports programs at the Center for Mental Health Services (CMHS) at SAMHSA that are focused on replication and expansion of these evidence-based practices that serve children and adults living with serious mental illness. The most important of these programs is the Mental Health Block Grant (MHBG). NAMI is extremely grateful for the increases in funding for the MHBG that this Subcommittee has made in recent years, boosting funding from \$420 million in fiscal year 2010, up to its current level of \$484 million in fiscal year 2014. This increase has been important to helping States fill gaps in services that have occurred as States cut more than \$4 billion from State mental health budgets since the recession began in 2008.

NAMI also supports the 5 percent set aside in the in the MHBG that this Subcommittee enacted in fiscal year 2014 for early intervention in psychosis. As noted above, the NIMH RAISE study validated the most effective approaches for providing coordinated care for adolescents experiencing FEP. Among these is Coordinated Specialty Care (CSC), a collaborative, recovery-oriented approach that emulates the assertive community treatment combining evidence-based services into an effective package. CSC emphasizes shared decisionmaking—which NAMI strongly supports—with the recipient of services taking an active role in determining treatment preferences and recovery goals.

In April, CMHS issued guidance to the States specifying that funding as part of the 5 percent set aside must be used for those who have developed the symptoms of early serious mental illness, not for “preventive intervention for those at high risk of serious mental illness.” NAMI supports this guidance and we recommend that the Subcommittee continue this 5 percent set aside for FEP in fiscal year 2015 and beyond.

NAMI would also recommend the following priorities for CMHS for fiscal year 2015:

—Continuation of the Children’s Mental Health program at \$117 million, and

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

Addressing Early Mortality and Serious Mental Illness, Integrating Primary and Behavioral Health Care

The CMHS Primary Behavioral Health Care Integration (PBHCI) program supports community behavioral health and primary care organizations that partner to provide essential primary care services to adults with serious mental illnesses. Because of this program, more than 33,000 people with serious mental illness and substance use disorders are screened and treated at 100 grantee sites for diabetes, heart disease, and other common and deadly illnesses in an effort to stem the alarming early mortality rate from these health conditions in this population. NAMI urges the Subcommittee to fund the PBHCI for fiscal year 2015 at \$50 million.

Addressing the Needs of Homeless Individuals Living with Serious Mental Illness

On any given night, according to 2013 data, 610,042 people are homeless, and 15 percent of these individuals are defined as long-term or chronically homeless. Years of reliable data and research demonstrate that, for single individuals with serious mental illness who live with complex needs, the most successful intervention for ending and preventing homelessness is linking housing to appropriate support services. Although there is a need for more affordable housing, funding the supportive services is even more difficult. SAMHSA homeless programs fill a gap created by a preference of HUD to fund housing rental assistance and capital needs. HHS must take responsibility to fund the critically important services that are necessary for programs to be effective.

In 2013, SAMHSA was not able to award any new community-based services grants. For the first time, eleven States (AZ, GA, HI, WA, LA, IL, NV, PA, MA, MI and CO) did receive funding to improve statewide alignment of resources but every State could use SAMHSA assistance in their efforts to end homelessness. Over the years, hundreds of government entities and local providers have been unable to move forward with important work due to inadequate funding levels. The current fiscal year 2014 funding level of SAMHSA homeless programs is \$74 million, divided between CMHS and CSAT. NAMI supports an increase for this joint program up to \$100 million, equally divided between CMHS and CSAT.

NAMI also supports funding for the PATH program (Projects for Assistance in Transition from Homelessness) that allocates funds by formula to States to serve homeless people with serious mental illness. Eligible services include outreach, screening and diagnosis, habilitation and rehabilitation, community mental health services, substance abuse treatment, case management, residential supervision, and housing. PATH supported programs reached over 191,839 people in fiscal year 2013. Of these, 65 percent were unsheltered at the time of engagement, 42 percent were not engaged in mental illness treatment and 53 percent had co-occurring substance use disorders. NAMI recommends at least \$75 million for the PATH program for fiscal year 2015 (the authorized amount). In fiscal year 2014, the PATH program is funded at \$65 million.

Conclusion

Chairman Harkin, thank you for the opportunity to share NAMI’s views on the Labor–HHS–Education Subcommittee’s fiscal year 2015 bill. NAMI’s consumer and family membership thanks you for your leadership on these important national priorities.

[This statement was submitted by Mary Giliberti, Executive Director, National Alliance on Mental Illness.]

PREPARED STATEMENT OF THE NATIONAL ALLIANCE TO END SEXUAL VIOLENCE

On behalf of the National Alliance to End Sexual Violence (NAESV) representing 56 state and territorial sexual assault coalitions and more than 1300 local rape crisis centers, I am respectfully requesting fiscal year 2015 Federal funding to support comprehensive rape prevention and education and direct services for victims of sexual violence. Specifically, NAESV is requesting \$50.6 million, \$45 million for the program and \$5.6 million in PHS evaluation tap funds, for the Rape Prevention & Education Program (RPE) in the Centers for Disease Control and Prevention’s (CDC) National Center for Injury Prevention and Control budget. In addition, NAESV is requesting level funding of \$160 million for the Preventive Health and Health Services Block Grant, which includes a \$7 million set-aside for rape preven-

tion services, in CDC's National Center for Chronic Disease Prevention and Health Promotion budget. Together, we must make our communities safer.

One in five women has been the victim of rape or attempted rape. Nearly one in two women has experienced some form of sexual violence and one in five men has experienced a form of sexual violence other than rape in their lifetime. The CDC National Intimate Partner and Sexual Violence Survey study confirmed that the impacts of sexual violence on society are enormous. Over 80 percent of women who were victimized experienced significant short and long-term impacts related to the violence such as Post-Traumatic Stress Disorder (PTSD), injury (42 percent) and missed time at work or school (28 percent). The CDC report also shows that most rape and partner violence is experienced before the age of 24, highlighting the importance of preventing this violence before it occurs.

The 2013 Rape Crisis Center Survey, distributed by NAESV, demonstrated that over 75 percent of these programs lost funding in the last year, causing programs to have to reduce services, lay off staff or even close. Over one third of rape crisis centers reported having a waiting list for services, with victims waiting most often for counseling services and support groups. Three out of four programs cannot meet current requests for community prevention programs. As you begin the fiscal year 2015 appropriations process, please fund the following priorities.

Rape Prevention and Education (RPE).—The National Alliance to End Sexual Violence urges Congress to provide \$45 million for the program and an additional \$5.6 million in PHS evaluation tap funds for RPE program evaluation, with the goal of creating a more extensive evidence base for sexual violence prevention. Funding for RPE through CDC's Injury Center provides formula funding to every State and territory to raise awareness of the problem of sexual assault, support efforts to prevent first-time perpetration and victimization, and bring together diverse partners to develop, implement and evaluate statewide sexual assault prevention plans. The RPE program engages boys and men as partners, supports interdisciplinary research collaborations, fosters cross-cultural approaches to prevention, promotes healthy relationships, and funds the critically important National Sexual Violence Resource Center. High profile cases have increased the demand for prevention and education beyond the current capacity of State sexual assault coalitions and local rape crisis centers. The expansive media attention also points to the need for comprehensive community responses to sexual violence like those funded by RPE. With fiscal year 2013 funding, the program educated more than 1.8 million students, answered 340,000 hotline calls, and conducted over 105,000 trainings nationwide.

Formula Shortfall.—Beginning in fiscal year 2014, a new RPE funding formula is being implemented based on VAWA 2013. While the formula provides a base funding of \$150,000 for all 50 States, Washington, DC and Puerto Rico, and \$50,000 for territories, it reduces the funding provided to large States. In addition, CDC is altering the fiscal year of the program which results in reduced funding stretched over a span of 15 months, further penalizing State coalitions and local rape crisis centers at the same time demand for rape prevention and education is increasing due to high profile cases causing alarm in local communities. Increased funding is required to avoid critical shortfalls.

Program Evaluation.—There is a need to increase the evidence base for sexual violence prevention. However, those efforts should be funded by additional funding—not from program funds to States and local rape crisis centers. Most recently, CDC decided to make "State level evaluation" mandatory despite many States starting local, regional or targeted evaluation efforts. It is the CDC's stated perspective that this would be "less labor intensive." However, this strategy forces everyone down one path, without a recognition of the work and progress that is currently underway in many States, nor of each State's individual goals, projects or bandwidth to accomplish the work. To date, CDC has not demonstrated that they have developed any significant sexual violence specific research and evaluation over the years. Rather, all indicators suggest that they are relying on proxy measures that have been developed for other issues such as alcohol use, which are not suited to measure sexual violence. We support the CDC proposal to use PHS evaluation tap funding for this purpose. We do not want program funds diverted from the communities at a time when demand for prevention and education, as well as services, is increasing at such a rapid rate.

Preventive Health & Health Services Block Grant (PHHSBG).—We are very grateful for the fiscal year 2014 funding of \$160 million enacted by Congress and disappointed with the Administration's efforts to eliminate the program which provides much needed resources to communities. The Public Health Service Act of 2010 authorizes the block grant (CDC, Chronic Disease) and provides a rape set-aside provision which guarantees at least \$7 million for rape services and prevention. Please retain the block grant funding that supports local rape crisis centers providing serv-

ices, statewide training and technical assistance to increase capacity to assist rape victims and prevent future victimization. Maximum funding is requested.

We must have the resources to meet the education and prevention needs in the community. Victims deserve support, our young people deserve to grow up safely, and research tells us that appropriate and early intervention and prevention can mitigate the costs and consequences of sexual violence and prevent that violence from occurring in the first place. The best way to prevent victimization is to prevent first time perpetration. The best way to convict a rapist is to support and advocate for the victim, obtain evidence and provide assistance and training to law enforcement.

Thank you for the opportunity for the National Alliance to End Sexual Violence to present testimony for the record as the Senate Committee on Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies begins the process to prepare the fiscal year 2015 Appropriations Bill. If you need further information, I can be reached at monika@nccasa.org and www.endsexualviolence.org.

[This statement was submitted by Monika Johnson-Hostler, Board President, National Alliance to End Sexual Violence.]

PREPARED STATEMENT OF THE NATIONAL ALOPECIA AREATA FOUNDATION

Chairman Harkin and distinguished members of the Subcommittee, thank you for your time and your consideration of the priorities of the community of individuals affected by alopecia areata as you work to craft the fiscal year 2015 Labor, Health and Human Services Appropriations Bill.

ABOUT ALOPECIA AREATA

Alopecia areata is a prevalent autoimmune skin disease resulting in the loss of hair on the scalp and elsewhere on the body. It usually starts with one or more small, round, smooth patches on the scalp and can progress to total scalp hair loss (alopecia totalis) or complete body hair loss (alopecia universalis).

Alopecia areata affects approximately 2.1 percent of the population, including more than 6.5 million people in the United States alone. The disease disproportionately strikes children and onset often occurs at an early age. This common skin disease is highly unpredictable and cyclical. Hair can grow back in or fall out again at any time, and the disease course is different for each person. In recent years, scientific advancements have been made, but there remains no cure or indicated treatment options.

The true impact of alopecia areata is more easily understood anecdotally than empirically. Affected individuals often experience significant psychological and social challenges in addition to the biological impact of the disease. Depression, anxiety, and suicidal ideation are health issues that can accompany alopecia areata. The knowledge that medical interventions are extremely limited and of minor effectiveness in this area further exacerbates the emotional stresses patients typically experience.

ABOUT THE FOUNDATION

NAAF, headquartered in San Rafael, California, supports research to find a cure or acceptable treatment for alopecia areata, supports those with the disease, and educates the public about alopecia areata. NAAF is governed by a volunteer Board of Directors and a prestigious Scientific Advisory Council. Founded in 1981, NAAF is widely regarded as the largest, most influential, and most representative foundation associated with alopecia areata. NAAF is connected to patients through local support groups and also holds an important, well-attended annual conference that reaches many children and families.

Recently, NAAF initiated the Alopecia Areata Treatment Development Program (TDP) dedicated to advancing research and identifying innovative treatment options. TDP builds on advances in immunological and genetic research and is making use of the Alopecia Areata Clinical Trials Registry which was established in 2000 with funding support from the National Institute of Arthritis and Musculoskeletal and Skin Diseases; NAAF took over responsibility financial and administrative responsibility for the Registry in 2012 and continues to add patients to it. NAAF is engaging scientists in active review of both basic and applied science in a variety of ways, including the November 2012 Alopecia Areata Research Summit featuring presentations from the Food and Drug Administration (FDA) and NIAMS.

DEIDRE'S STORY

It has been 15 years since I first found the bald patch on my head that would completely change the course of my life. As a student at Florida State University during my junior year I found a perfectly round bald patch while blow-drying my very thick long hair—my pride and joy! Little did I know then the significant effect alopecia areata would have on my life.

I followed the typical patient profile for this disease. I started with one patch the size of a 50 cent piece, which later evolved into patches of varying sizes all over my head, and then to total loss of all scalp hair, which progressed to the most severe form of the disease: total loss of all body hair including my scalp, eyebrows, eyelashes, etc. Recently, my hair has inexplicably started to grow back in a very patchy and strange fashion on my head, while most of my body still remains hairless; a perfect example of the completely unpredictable course of this disease, which can cause significant emotional turmoil and distress for the sufferer.

As a professional woman, this disease has had a severe impact on my life. I have to present a confident image to the outside world. Living in constant fear of being discovered as a bald woman, being thought to be sick, bizarre, or worse has always been on the forefront of my mind.

The exorbitant cost for treatments such as cortisone injections, extremely painful with questionable efficacy, has been an issue for me along with the expensive cranial prosthetics. Over the course of the years these have cost me thousands of dollars. If a lawyer like myself has financial difficulty when it comes to paying for treatments and prosthetics (which are not covered by insurance due to lack of CMS coverage benefits for those with Alopecia Areata), can you imagine the plight facing those patients that live on limited or fixed income?

The fact that there is so little known about the causes or possible treatments/cure for this disease only adds to the pain and suffering. This is a disease that alters the way you see yourself and the way the outside world treats you, and also causes significant and often debilitating emotional distress. The fact that there is little that can currently be done adds to that pain and suffering. Patients face a bleak outlook. For me, it has been a constant battle. I have not lived a single moment in the 5,475 days since that I have not looked in the mirror and wanted to scream or cry, not a single day that I haven't thought that I am damaged, abnormal, or ugly because of my hair loss, not a single day that I haven't worried about how a client, colleague, friend, or love-interest might see and judge me. Many will say to me that "it is only hair" or "at least it's not cancer." These comments only frustrate and upset me more. The feelings of being ostracized as an outcast can become deafening, even for a confident, intelligent professional. I shudder to think how others who don't possess my strength of character handle the stresses of this disease.

It is only with additional funding for research that we might hope to improve the lives of the millions in the U.S. living with alopecia areata. Few have even heard of the disease. That fact alone creates additional stresses and difficulties for those of us with the disease, constantly having to explain what is "wrong" with us. Increased research into viable treatment options and a potential cure could significantly impact millions of lives, from small children to adults, facing the constant battle that comes from a total loss of self image and confidence.

I thank you on behalf of myself and of the entire alopecia areata community for consideration of NAAF's requests.

SEQUESTRATION

We have heard from the medical research community that sequestration and deficit reduction activities have created serious issues for Federal funding opportunities and the career development pipeline. In order to ensure that research into alopecia areata, skin, and autoimmune disorders can continue to move forward, and, more importantly, to ensure that our country is adequately preparing the next generation of young investigators, we urge you to avert, mitigate, or otherwise eliminate the specter of sequestration. While the Foundation has anecdotal accounts of the harms of sequestration, the Federated American Societies for Experimental Biology has reported:

- In constant dollars (adjusted for inflation), the NIH budget in fiscal year 2013 was \$6 billion (22.4 percent) less than it was in fiscal year 2003.
- The number of competing research project grants (RPGs) awarded by NIH has also fallen sharply since fiscal year 2003. In fiscal year 2013, NIH made 8,283 RPG awards, which is 2,110 (20.3 percent) fewer than in fiscal year 2003.
- Awards for R01-equivalent grants, the primary mechanism for supporting investigator-initiated research, suffered even greater losses. The number awarded fell by 2,528 (34 percent) between fiscal year 2003 and fiscal year 2013.

The pay line for some NIH funding mechanisms has fallen from 18 percent to 10 percent while the average age for a researcher to receive their first NIH-funded grant has climbed to 42. These are strong disincentives to choosing a career as a medical researcher. Our scaling-back is occurring at a time when many foreign countries are investing heavily in their biotechnology sectors. China alone plans to dedicate \$300 million to medical research over the next 5 years; this amount is double the current NIH budget over the same period of time. Scientific breakthroughs will continue, but America may not benefit from the return-on-investment of a robust biotechnology sector. For the purposes of economic and national security, as well as public health, the Foundation asks that you work with your colleagues to eliminate sequestration and recommit to supporting this Nation's biomedical research enterprise.

CENTERS FOR DISEASE CONTROL AND PREVENTION

CDC and NCCDPHP are well-positioned to improve our understanding of alopecia areata through surveillance and surveys. There are many opportunities in this area due to the fact that alopecia areata is the most easily observable autoimmune disease. Robust epidemiology could yield important information for all autoimmune diseases, not just alopecia areata. CDC requires a meaningful investment in fiscal year 2015 so that it can expand its crucial public health activities beyond winnable battles.

NATIONAL INSTITUTES OF HEALTH

NIH hosts a modest alopecia areata research portfolio, and the Foundation works closely with NIH to advance critical activities. NIH projects, in coordination with the Foundation's TDP, have the potential to identify biomarkers and develop therapeutic targets. In fact, alopecia areata research has a strong value proposition as scientific advancements may have applications for other autoimmune and skin diseases. Please provide NIH with meaningful funding increases to facilitate growth in the alopecia areata research portfolio.

One exciting emerging opportunity is the new Accelerating Medicines Partnership (AMP) that was recently announced by NIH. This effort is outcomes-oriented and based on a public-private-partnership model. Industry, patient organizations, and researchers work together to conduct research with the goals of improving treatments and diagnostic tools. Rheumatoid arthritis is one of the diseases being examined in the first round of study, which should generate opportunities for alopecia areata due to the similarities between the conditions. Please support AMP and encourage NIH to expand activities in this area, particularly when there is research overlap between conditions.

ADDITIONAL ACTIVITIES

FDA nominated alopecia areata as a potential condition for specific review through the Patient-Focused Drug Development Initiative (PFDDI). This is because many of the impacts of alopecia areata have to be reported by patients and cannot be measured biologically. While we appreciate that FDA falls under the guise of the Agriculture Appropriations Subcommittee, we ask that you work with your colleagues on the Appropriations Committee to support this important program. Further, FDA should be encouraged to review all originally-nominated conditions in a timely manner so the PFDDI can continue to move forward.

Thank you for your time and your consideration of the community's requests.

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION FOR GERIATRIC EDUCATION

The National Association for Geriatric Education (NAGE) is pleased to submit this statement for the record recommending \$41.997 million in fiscal year 2015 to support geriatrics programs under the Health Resources and Services Administration (HRSA), Title VII, Section 753 of the Public Health Service Act. NAGE respectfully requests that the Subcommittee return to its approved level for fiscal year 2010, which was also included that year in the Administration's request, but was not included in the final bill. Unfortunately, only \$34 million was funded in the final bill, and that has been cut to under \$34 million in subsequent years.

NAGE is a non-profit membership organization representing Geriatric Education Centers (GECs) and other programs that provide education and training to health professionals in the areas of geriatrics and gerontology. Our mission is to help America's health workforce be better prepared to render age-appropriate care to today's older Americans and those of tomorrow.

NAGE recognizes the Subcommittee faces difficult decisions in a constrained budget environment, a continued commitment to programs supporting the growing need for geriatric education programs that help the Nation's health professions better serve the older and disabled population should remain a top priority. The Nation faces a shortage of geriatric health professionals. Every day in America 10,000 more persons reach the age of 65 years. There simply are not enough geriatricians, gerontological nurse practitioners and the myriad other health professions needed to provide interprofessional care to this burgeoning older population.

Three geriatric health professions programs are financed under Title VII, Section 753 of the Public Health Service Act and are included in the Health Resources and Services Administration (HRSA). Geriatric Education Centers (GECs) and their related programs, the Geriatric Academic Career Awards and the Geriatric Faculty Fellowships, provide much needed interdisciplinary geriatric and gerontology training to a broad range of health professionals who serve our rapidly growing aging population.

GECs train healthcare professional faculty, students, and practitioners in the interprofessional diagnosis, management and prevention of disease, disability, and other health problems of the elderly. This program also provides interprofessional continuing education for healthcare practitioners related to prominent issues in the field of geriatrics, such as Alzheimer's disease, dementia, and advances in palliative care, among others. The GEC program currently funds 45 GECs in 34 States, including statewide and multi-state programs. About half of GECs provide education for areas that are more than 50 percent rural and one-fourth of GECs focuses on training in areas that are 25–49 percent rural. In the 2012–2013 Academic Year, GEC programs provided over 1,650 different continuing education courses to over 94,000 trainees. GEC grantees exceeded the program's performance goal by 58.5 percent.

Geriatrics Training for Physicians, Dentists, and Behavioral/Mental Health Professionals (GTPD) support faculty fellowships that help physicians, dentists, and behavioral and mental health professionals who plan to teach geriatrics in their selected fields. The aim of the program is increase the number of quality, culturally competent geriatric faculty and to retain mid-career faculty in geriatrics. GTPD provided funding for 64 fellows in the academia field of geriatric medicine, dentistry, and psychiatry. The GTPD fellows received clinical training in over 200 different healthcare locations across the Nation. The majority were trained in Veteran's Affairs hospitals, private hospitals and academic centers with nearly half of the sites located in medically underserved communities. Notably, each fellow dedicated at least 25 percent of their time for teaching health students about geriatric-related topics. In Academic Year 2012–2013, it is estimated that over 275 courses, workshops and other activities were delivered by GTPD fellows.

Geriatrics Academic Career Awards (GACAs) provide a financial incentive for junior faculty to pursue an academic career in geriatrics. GACA currently supports 62 newly trained geriatric physicians. Award recipients delivered over 1,110 different health courses, workshops and other types of training activities to over 53,000 trainees across the health profession spectrum. The most common health professions include medical school students, residents in internal medicine and residents in geriatrics.

These successful programs improve the education, supply, distribution, diversity, and quality of healthcare professionals who care for our Nation's growing older adult population, including the underserved and minorities. Thus, we need your continued support for geriatric programs to adequately prepare the next generation of health professionals for the rapidly changing and emerging needs of the growing and aging population.

On behalf of NAGE, thank you for this opportunity to share our requests for support for these important programs. We ask that you thoughtfully consider our request for funding in fiscal year 2015.

[This statement was submitted by Thomas Caprio, MD, MPH, CMD, FACP, University of Rochester, Division of Geriatrics & Aging; Co-Director, Finger Lakes Geriatric Education Center, President, National Association for Geriatric Education.]

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION FOR STATE COMMUNITY SERVICES PROGRAMS

Mr. Chairman and Members of the committee, thank you for the opportunity to submit this testimony on behalf of the National Association for State Community Services Programs (NASCS), a membership association for the administrators of the federally-funded Community Services Block Grant which serves millions of

American families in communities across the country. As the Executive Director of NASCSP, I submit this testimony on behalf of the States in their work to improve the lives of low-income families and strengthen local economies. We are requesting that the Committee approve \$710 million in fiscal year 2015 to adequately fund the CSBG network. This level of funding is the same as the fiscal year 2014 enacted funding for CSBG. We strongly believe that CSBG is a wise strategic investment not only in America's ongoing economic recovery, but in our Nation's long-term economic stability as well. Maintaining funding is necessary not only to continue CSBG's well-documented role in strengthening our economy, but also for the ongoing reforms to the block grant which adapt it to new realities and strengthen it for the next generation. We strongly oppose the reduction in funding for CSBG as proposed by the Administration, and I welcome this opportunity to explain exactly why.

First, however, I'd like to thank Congress for its past support of CSBG. The services provided by this network are crucial to the millions of Americans facing poverty and economic insecurity at a time when the impact of the slow economy is affecting every Congressional District in America. Right now, more than 46 million Americans are living below the Federal poverty level (defined as \$23,050 a year for a family of four). CSBG directly addresses the need to help hard-working Americans who are struggling in the present economy and to prevent people from slipping further into poverty. The strength and productivity of our Nation depends on the economic well-being of all of its citizens, and CSBG is a proven strategy to support millions of low-income Americans on the path to economic security. The CSBG network uses grassroots, innovative strategies to alleviate poverty and provides a significant return on taxpayers' investment. In fiscal year 2012, the CSBG network leveraged \$22.75 for every Federal dollar invested in CSBG.

By acting as a conduit between the Federal administration and local community action agencies (CAA's), States build public-private partnerships, support innovation, and advance best practices to ensure the most effective use of taxpayers' money. Local agencies utilize CSBG funds to leverage additional funds to eliminate poverty through a variety of programs and services. While CAAs across the Nation address similar issues, local needs determine unique approaches to addressing them.

Poverty is a national problem, but can only be effectively addressed at the grassroots level. The CSBG network strives to find local solutions to these community issues by conducting community needs assessments to keep in touch with the needs, challenges, and resources in their community. The community needs assessments enable CAAs to provide the most effective and efficient strategies and services. These efforts fall into nine service categories outlined in the CSBG Act; employment, education, income management, housing, emergency services, nutrition, linkages, self-sufficiency, and health.

National data compiled by NASCSP shows that CSBG serves a broad segment of low-income individuals and families. Data from fiscal year 2012 shows:

- There are 1,045 CAAs across the country, serving 99 percent of U.S. counties;
 - CSBG serves 1 out of every 5 people in America below the poverty line;
 - The majority of clients are female (58 percent), white (59 percent), renters (60 percent) and between the ages of 24–44 years old (24 percent)—the second largest group was children ages 0–5 years old (14 percent);
 - The majority of clients are receiving incomes from employment-related sources (50 percent);
 - Many of the families served (33 percent) were in “severe poverty,” with incomes below 50 percent of the Federal Poverty Guideline.
- The successes of the CSBG network are well documented:
- CSBG served 16 million Americans including 76.9 million families in fiscal year 2012.
 - Over the past 5 years, the CSBG network helped over 630,000 people obtain employment.
 - Over the past 5 years, the CSBG network addressed 21.2 million barriers to employment through helping people to either acquire jobs, obtain employment supports, or to receive job training.
 - Over the past 5 years, the CSBG network expanded 19.8 million community opportunities or resources to stimulate community and economic development.
 - Over the past 5 years, the CSBG network facilitated 18.5 million opportunities for infants, children, youth, parents and other adults through developmental or enrichment programs.

States provide administrative oversight to ensure that eligible entities are meeting State and Federal requirements as well as their locally driven Community Action Plans. This includes monitoring eligible entities, providing training and technical assistance, investing in innovation, and maintaining effective performance

measurement and management systems. Adequate funding is needed to maintain a high level of accountability and performance in the following areas:

Support High Achievement and Innovation

Adequate funding, sufficient to meet national standards and incentives must be provided to States, local agencies, and national partners for high achievement and innovation. CSBG appropriations should include sufficient resources for local agencies, States, and national partners to engage in the work necessary to achieve the goals of the CSBG Act and the Promise of Community Action, which includes addressing the needs of vulnerable people and building strong communities. It should create the opportunity to provide a consistent resource to the people, families and communities that benefit from the activities conducted under the Act. It should also provide funds to extend the work to create and test innovative approaches as well as include and engage an ever wider circle of partners.

Support Coordination of Services

NASCSP believes that a \$710 million funding level for CSBG is essential for continued innovation and stronger coordination. It will also maintain the stature of the CSBG in both State and Federal administrations. Further, adequate funds in the CSBG will create additional opportunities and development for low-income programs and will allow for further coordination with agencies outside our Network that share a similar mission.

Mr. Chairman, I respectfully request the Committee to fund CSBG at the level of \$710 million in fiscal year 2015 to support America's ongoing economic recovery and future economic stability. Maintaining CSBG funding is an investment in both strengthening our economy and in adapting our efforts to new realities for future generations of hard-working Americans. Thank you.

[This statement was submitted by Jenae Conti Bjelland, Executive Director, National Association for State Community Services Programs.]

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF CHAIN DRUG STORES

The National Association of Chain Drug Stores (NACDS) thanks the Members of the Subcommittee on Labor, Health and Human Services, Education and Related Agencies for the opportunity to submit the following statement for the record regarding pharmacy-related provisions contained within the fiscal year 2015 Department of Health and Human Services (HHS) Budget. NACDS and the chain pharmacy industry are committed to partnering with Congress, HHS, patients, and other healthcare providers to improve the quality and affordability of healthcare services.

NACDS represents traditional drug stores and supermarkets and mass merchants with pharmacies. Chains operate more than 40,000 pharmacies, and NACDS' 125 chain member companies include regional chains, with a minimum of four stores, and national companies. Chains employ more than 3.8 million individuals, including 175,000 pharmacists. They fill over 2.7 billion prescriptions yearly, and help patients use medicines correctly and safely, while offering innovative services that improve patient health and healthcare affordability. NACDS members also include more than 800 supplier partners and nearly 40 international members representing 13 countries. For more information, visit www.NACDS.org.

As the face of neighborhood healthcare, community pharmacies and pharmacists provide access to prescription medications and over-the-counter products, as well as cost-effective health services such as immunizations and disease screenings. Through personal interactions with patients, face-to-face consultations and convenient access to preventive care services, local pharmacists are helping to shape the healthcare delivery system of tomorrow—in partnership with doctors, nurses and others.

In recent years, retail community pharmacies have played an increasingly important role in providing patient care, including medication therapy management (MTM) and expanded immunization services. Moreover, policymakers have begun to recognize the vital role that local pharmacists can play in improving medication adherence. The role of appropriate medication use in lowering healthcare costs has been acknowledged by the Congressional Budget Office (CBO). The CBO revised its methodology for scoring proposals related to Medicare Part D and found that for each 1 percent increase in the number of prescriptions filled by beneficiaries there is a corresponding decrease in overall Medicare spending. When projected to the entire population, this translates into a savings of \$1.7 billion in overall healthcare costs, or a savings of \$5.76 for every person in the U.S. for every 1 percent increase in the number of prescriptions filled.

Congress has recognized the importance of pharmacist-provided services such as MTM by including it as a required offering in the Medicare Part D program. The experiences of Part D beneficiaries, as well as public and private studies, have confirmed the effectiveness of pharmacist-provided MTM. A 2013 Centers for Medicare and Medicaid Services (CMS) report found that Part D MTM programs consistently and substantially improved medication adherence and quality of prescribing for evidence-based medications for beneficiaries with congestive heart failure, COPD, and diabetes. The study also found significant reductions in hospital costs, particularly when a comprehensive medication review (CMR) was utilized. This included savings of nearly \$400 to \$525 in overall hospitalization costs for beneficiaries with diabetes and congestive heart failure. The report also found that MTM can lead to reduced costs in the Part D program as well; showing that the best performing plan reduced Part D costs for diabetes patients by an average of \$45 per patient.

How and where MTM services are provided also impact its effectiveness. A study published in the January 2012 edition of *Health Affairs* identified the key role of retail pharmacies in providing MTM services. The study found that a pharmacy-based intervention program increased adherence for patients with diabetes and that the benefits were greater for those who received counseling in a retail, face-to-face setting as opposed to a phone call from a mail-order pharmacist. The study suggested that interventions such as in-person, face-to-face interaction between the retail pharmacist and the patient contributed to improved adherence behavior with a return on investment of 3 to 1.

Since pharmacists have the proven ability to provide services that lead to better clinical outcomes and lower healthcare costs, we urge the implementation of budget proposals that allow all healthcare providers, including retail pharmacists, to practice to their maximum capabilities, working in partnership to provide accessible, high quality care to patients.

NACDS appreciates HHS's proposed goals to reduce healthcare costs and produce a more efficient healthcare system; however, we have concerns with some proposals contained in the fiscal year 2015 HHS Budget. HHS has proposed excluding brand and authorized generic drugs from the calculation of average manufacture price (AMP), thereby calculating Medicaid Federal Upper Limits (FULs) based only on generic drug prices. While the goal of this provision may be to decrease Medicaid costs, we believe it may in fact reduce access to prescription drugs and pharmacy services for Medicaid patients, resulting in increased overall healthcare expenditures.

Given that AMP has never been used as a basis for pharmacy reimbursement, and that AMP-based FULs remain in draft form, we believe the fiscal year 2015 budget provisions changing the calculation of FULs are premature. In fact, based on NACDS' most recent analysis, approximately 35 percent of the draft FULs are below National Average Drug Acquisition Cost (NADAC). This analysis confirms that additional efforts by CMS are necessary to ensure that pharmacies are not reimbursed below their costs using the reimbursement formula created by the Affordable Care Act. We urge CMS to utilize the rulemaking process to implement the Medicaid pharmacy provisions in a manner consistent with Congressional intent, rather than pursuing policies that would further cut pharmacy reimbursement.

The fiscal year 2015 HHS Budget includes a proposal to limit Medicaid reimbursement of durable medical equipment (DME) to the rates paid by Medicare. Implementing a blanket proposal to reduce payment for Medicaid DME has the potential to disrupt access to DME and produce poorer health outcomes. This is particularly true in the case of diabetes testing supplies (DTS). Last year, CMS established a new Medicare single payment of \$10.41 for DTS. This amount drastically decreased Medicare reimbursement by an average of 72 percent for retail pharmacies. The current reimbursement amount barely covers a pharmacy's costs-of-goods plus dispensing and counseling for these products and services. Reducing Medicaid reimbursement for DTS to match the Medicare rate could similarly produce hardships for Medicaid beneficiaries in terms of reducing access to needed supplies and threatening the health of an already fragile population. NACDS urges CMS to refrain from making any changes to Medicaid reimbursement for DTS.

The fiscal year 2015 budget also includes several provisions to increase the utilization of generic drugs. NACDS applauds the inclusion of these important provisions, which would encourage the use of generic medications by Medicare Low Income Subsidy (LIS) beneficiaries, and promote generic competition for biologics. Increasing generic utilization is one of the most effective ways of controlling prescription drug costs, and the generic dispensing rate of retail pharmacies—80 percent—is higher than any other practice setting.

Finally, the fiscal year 2015 HHS Budget includes a number of proposals to cut waste, fraud and abuse in the Medicare and Medicaid programs, including the abil-

ity to suspend coverage and payment for questionable Part D prescriptions. NACDS applauds HHS for working to ensure that such activity does not exist in these Federal programs. However, NACDS urges HHS to move forward in a cautious manner which does not disrupt beneficiary access or jeopardize beneficiary health. This can be done by ensuring that overly-burdensome requirements are not placed on providers to the point that it interferes with the ability to treat and care for patients.

NACDS thanks the Subcommittee for consideration of our comments. We look forward to working with policymakers and stakeholders on these important issues.

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF COMMUNITY HEALTH CENTERS

Introduction

Chairman Harkin, Ranking Member Moran, and Distinguished Members of the Subcommittee: on behalf of health centers across the Nation, we wish to thank you for the opportunity to submit testimony for the committee to review as you craft the fiscal year 2015 Labor-Health and Human Services-Education and Related Agencies Appropriations bill.

Health Centers- General Background

Health Centers are community-owned and operated non-profit entities providing primary medical, dental, and behavioral healthcare as well as pharmacy and a variety of enabling and support services. Today, there are over 1,200 health centers operating at more than 9,000 urban and rural communities nationwide. We are the “healthcare home” for more than 22 million patients in all 50 States and nearly every Congressional district.

By statute and mission, health centers are located in medically underserved areas or serve a medically underserved population. Health centers are directed by patient-majority boards, a model which helps to ensure they are responsive to the needs of each individual community they serve. Health centers offer comprehensive care to all residents of the community who seek their care, regardless of ability to pay or insurance status and offer services on a sliding fee scale. Our unique model of care has enabled us to save the entire health system approximately \$24 billion annually. Health Centers reduce preventable hospitalizations and Emergency Department use, as well as the need for more expensive specialty care. The services provided at health centers save \$1,263 per patient per year compared to expenditures for non-health center users.

In addition to reducing costs, health centers also serve as small businesses and economic drivers in their communities. In 2012, health centers employed 153,000 individuals and in 2009 generated \$20 billion in total economic benefits in poor urban and rural communities.

Fiscal year 2014 Funding Background

In fiscal year 2014, health centers received a total of \$3.7 billion in total Federal funding. This includes \$1.49 billion in discretionary funding provided by the Health Resources and Services Administration (HRSA) and \$2.2 billion in mandatory funding for health centers through the Health Center Fund. We want to thank the members of this Subcommittee for their support of health centers within the Consolidated Appropriations Act of 2014 to ensure health center funding continues to reach communities in need.

Access to a Health Center Reduces Barriers to Primary Care

NACHC’s recently released a report entitled: Access is the Answer finds 62 million Americans lack regular access to primary care and the vast majority of these medically disenfranchised Americans actually have insurance coverage. Many individuals still face barriers such as availability, affordability, and accessibility to primary and preventive care. Even among people who have an insurance card, access may be out of reach because of who they are and where they live. As health reform changes the healthcare landscape, we know that demand for health centers will continue to climb among the uninsured, underinsured and underserved due to the lack of other healthcare providers willing to see our patients.

True “access” means having a regular, reliable source of quality preventive and primary healthcare and simply having an insurance card does not guarantee ready access to primary care. With our unique model of care, Health Centers can help address these primary care demands in a cost effective manner. However, Health Centers cannot continue to deliver results without a sound financial base.

Fiscal year 2015 Funding Request and Health Center Funding Cliff

In fiscal year 2015, Health Centers are respectfully requesting level discretionary funding of \$1.49 billion for the Health Center program. Together with the \$3.6 billion in funding available in fiscal year 2015 through the mandatory Health Center Fund, health centers are requesting a total of \$5.1 billion in total program funding. This funding for the Health Center program, which requires no new appropriation from this Subcommittee, should be fully utilized during fiscal year 2015 to increase access to primary care in medically underserved communities. With access to all available funding for the program in fiscal year 2015, Health Centers could build the capacity to serve up to 11 million new patients, both in new communities and through expanded services and capacity at existing health centers. In addition, existing Health Centers could ensure they are keeping up with current patient demand.

The President's proposed fiscal year 2015 Health Resources and Services Administration (HRSA) budget provides \$1 billion in discretionary funding for the Health Centers program. Together with the \$3.6 billion in fiscal year 2015 mandatory funding available for health centers, under the President's proposal, health centers would receive a net increase of \$960 million in total programmatic funding for fiscal year 2015 equaling total funding of \$4.6 billion. Within this proposal, the President will allocate \$860 million for one-time quality improvement and capital development awards and \$100 million to fund new health center sites.

We strongly oppose the President's proposed \$500 million discretionary funding reduction for health centers as it further reduces the discretionary allocation for the program beyond the levels in place prior to the inception of the Health Center Fund. Health centers simply cannot survive further decreases to their base discretionary funding which undermines the long-term sustainability of the program, and may well threaten access for existing patients.

We do appreciate the President's acknowledgement and recognition of the looming funding crisis for health centers upon the expiration of the Health Center Fund after fiscal year 2015. Under current law the Health Center Fund will end after fiscal year 2015, resulting in as much as a 70 percent reduction in health center grant funding in fiscal year 2016. Averting the health center cliff is critical to ensuring that health centers remain financially viable and able to serve the diverse needs of their communities. However, the President only proposes a temporary (3 year) solution reducing program funding down to fiscal year 2014 levels after a one-time increase in fiscal year 2015. Given the number of communities and individuals in need of access to healthcare, longer-term solutions must encompass both stability and expansion of access to care.

Conclusion

We understand this Subcommittee must make difficult budgetary decisions as you work within the funding limits set for the subcommittee's bill. As the fiscal year 2015 appropriations process moves forward, we urge you to keep in mind that without their local health center, many individuals located in medically underserved communities will seek care in emergency departments and hospitals, often waiting until they are sicker get treatment. This will mean poorer health for these patients and much higher costs to the system. Health centers have continually proven to be a worthwhile investment by delivering high quality, affordable healthcare while generating savings to the entire health system in these communities. We are extremely grateful for your past support and ask for the Subcommittee's continued support for the Health Center program. We look forward to working with you and thank you for your consideration.

[This statement was submitted by Daniel R. Hawkins, Jr., Senior Vice President, Public Policy and Research.]

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF COUNTY AND CITY HEALTH OFFICIALS

The National Association of County and City Health Officials (NACCHO) is the voice of the 2,800 local health departments across the country that work every day to ensure the safety of the water we drink, the food we eat, and the air we breathe. On behalf of local health departments, NACCHO submits the following requests:

Prevention and Public Health Fund

In fiscal year 2015, NACCHO requests \$1 billion for the Prevention and Public Health Fund (PPHF), a dedicated Federal investment in programs that prevent disease at the community level. NACCHO wishes to thank Congress for allocating the

PPHF in fiscal year 2014 and setting specific funding levels to support the prevention of disease and promotion of health in communities across the Nation.

CDC Public Health Emergency Preparedness

NACCHO urges the Subcommittee to provide \$675 million for the Public Health Emergency Preparedness (PHEP) grant program in fiscal year 2015. PHEP protects communities by strengthening local and State public health department capacity to effectively respond to public health emergencies including terrorist threats, infectious disease outbreaks, natural disasters, and biological, chemical, nuclear, and radiological emergencies. These grants have been cut more than 30 percent since fiscal year 2007 with more than 55 percent of local health departments relying solely on Federal funds for emergency preparedness activities. NACCHO urges inclusion of language asking CDC to provide information on how much of the State PHEP grants are being allocated to local health departments and on what basis or formula each State is determining such allocations, including the method through which States reach statutorily-required concurrence with local health departments.

Assistant Secretary for Preparedness and Response

NACCHO urges the Subcommittee to fund the Hospital Preparedness Program (HPP) at \$300 million in fiscal year 2015 and restore some of the \$104 million (35 percent) cut from the program in fiscal year 2014. HPP supports health department preparedness coordinators to organize coalitions of public health and healthcare providers to plan and prepare for public health emergencies, including medical surge following terrorist attacks, mass casualty incidents, an influenza pandemic or other infectious disease outbreak. NACCHO is concerned that the 35 percent cut to HPP in fiscal year 2014 will erode medical system preparedness, making communities across the country more vulnerable. NACCHO urges Congress to request information from Assistant Secretary for Preparedness and Response (ASPR) on how State HPP funding is distributed at the local level, including how much is being allocated to local health departments and on what basis or formula each State making such allocations. This information should be publicly available.

CDC Section 317 Immunization Program

NACCHO urges the Subcommittee to provide \$650 million for the Section 317 Immunization Program in fiscal year 2015. The Section 317 Immunization Program funds 50 States, six large cities and eight territories for vaccine purchase for at-need populations and immunization program operations, including support for implementing immunization billing systems at public health clinics to sustain high levels of vaccine coverage. NACCHO supports directing \$8 million of the funding, as proposed in the President's Budget, to continue projects to facilitate billing by health departments of public and private insurance for covered immunization services.

CDC Chronic Disease Prevention

Partnerships to Improve Community Health (Community Prevention Grants).—NACCHO urges the Subcommittee to provide \$100 million to support continuation of the Partnerships to Improve Community Health program in fiscal year 2015, which supports implementation of evidence-based strategies to address heart attacks, strokes, cancer, diabetes, and other chronic diseases which contribute to the soaring cost of healthcare. Local health departments lead efforts to reduce tobacco use, increase physical activity and expand access to nutrition in order to reduce costly chronic diseases like heart disease and diabetes. NACCHO urges Congress to encourage CDC to conduct a comprehensive national evaluation of the program including recommendations for national qualitative and quantitative standards for quality preventive services and a report of how much of the funding was granted to the local level and to which eligible entities.

Heart Disease and Stroke.—NACCHO urges the Subcommittee to continue to support Heart Disease and Stroke Prevention at \$130 million in fiscal year 2015. In fiscal year 2014, Congress provided a \$76 million increase for heart disease and stroke prevention and urged CDC to ensure that some portion of the increase in funding is sub-granted to the local level. The risk factors of obesity and smoking must be addressed at the community level to combat disease. Local health departments who are experts on community needs and prevention interventions in the area of heart disease and stroke.

Diabetes Prevention and Control.—NACCHO urges the Subcommittee to continue to support Diabetes Prevention at \$150 million in fiscal year 2015. In fiscal year 2014, Congress provided a \$76 million increase for diabetes prevention and urged CDC to ensure that some portion of the increase in funding is sub-granted to the local level. Because evidence-based disease self-management programs are effective

at improving health, greater emphasis must be placed on enhancing the reach of these community level interventions.

CDC Preventive Health and Health Services Block Grant

In fiscal year 2015, NACCHO urges the Subcommittee to continue to support the Preventive Health and Health Services (PHHS) Block Grant at \$160 million. This unique funding gives States the flexibility to address State problems and provide similar support to local communities, while demonstrating the local, State, and national impact of this investment. NACCHO urges Congress to encourage CDC to enhance reporting and accountability for the PHHS Block Grant including providing capacity building to States for core public health capacities that may not be supported through other CDC categorical funding streams. In order to make sure that funding supports the needs of local communities, local health departments should be full partners in developing State plans. CDC should also require States to report the funding allocation used to subgrant funds to local health departments and to encourage they include locals in their statewide planning efforts.

CDC Food Safety

NACCHO urges the Subcommittee to support CDC's Food Safety Program at \$54 million in fiscal year 2015. Local and State health departments are an essential part of the process that ensures that food is safe to eat at home, at community events, in restaurants, and in schools.

As the Subcommittee drafts the fiscal year 2015 Labor-HHS-Education Appropriations bill, NACCHO urges consideration of these recommendations for programs that protect the public's health and safety.

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF STATE DIRECTORS OF
CAREER AND TECHNICAL EDUCATION CONSORTIUM

Dear Chairman Mikulski, Ranking Member Shelby, Chairman Harkin and Ranking Member Moran: On behalf of the National Association of State Directors of Career and Technical Education Consortium (NASDCTEC), I am writing to urge the committee to support Career Technical Education (CTE) through a strong Federal investment in the Carl D. Perkins Career and Technical Education Act (Perkins). The passage of the Consolidated Appropriations Act of 2014 has helped to alleviate most of the harmful sequester cuts which have negatively impacted important Federal investments in CTE programs through this legislation. However, our organization recognizes that there are still difficult decisions to be made regarding individual program funding levels in fiscal year 2015. To that end, NASDCTEC is requesting that the committee restore funding for the Perkins Basic State Grant to at least \$1.264 billion, equivalent to the pre-sequestration level of 2010, and make investing in Perkins a top priority in the fiscal year 2015 Labor, Health and Human Services, and Education appropriations bill.

Perkins is the principal source of Federal support for CTE programs at secondary and postsecondary institutions across the country. This Federal investment is crucial to ensuring that students have the academic, technical and employability skills that are needed for expanding fields like engineering, information technology, advanced manufacturing and healthcare. Perkins-funded CTE programs are working with business and industry partners to help fill positions that are available today, while preparing a qualified workforce for the careers of tomorrow. In a rapidly changing job market, CTE provides students with transferable skills that ensure they are college- and career-ready, while offering retraining opportunities to many adult or dislocated workers.

CTE produces a strong return on the Federal investment and has an unmistakably positive societal and economic impact. Students enrolled in CTE programs are more engaged, perform better academically and graduate at higher rates. CTE supports the development of an educated and highly skilled workforce that provides a direct benefit to employers, while strengthening the economy through increased productivity and innovation.

However, funding for CTE has not been immune to significant budget cuts over the past several years. The Perkins Act basic State grant program still remains approximately \$5 million below pre-sequestration levels. In addition to sequestration, funding for Perkins was reduced by over \$140 million between fiscal year 2010 and fiscal year 2012, dramatically reducing the capacity of CTE programs to offer academically rigorous instruction and career training that is aligned to the needs of business and industry. Dozens of States are currently receiving funding allocations close to the levels they received in 1998. When taking into account inflation over this period, the relative investment in CTE through the Perkins Act has declined

considerably more. This erosion has hurt high schools, CTE centers, community and technical colleges, employers and millions of CTE students nationwide. This pathway of disinvestment in our Nation's CTE system is unsustainable—we cannot cut our way to a 21st century workforce! Instead, Perkins funding must be restored to meet the needs of CTE programs around the country and ensure students are fully prepared for their future academic and career goals.

Thank you for your continued leadership in this difficult fiscal environment and for your thoughtful consideration during the appropriations process. NASDCTEc looks forward to working with the committee in a bipartisan fashion to restore funding for CTE and support the millions of CTE students across the Nation.

[This statement was submitted by Kimberly Green, Executive Director, National Association of State Directors of Career and Technical Education Consortium.]

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF STATE HEAD INJURY ADMINISTRATORS

Dear Chairman Tom Harkin and Ranking Member Jerry Moran: On behalf of the National Association of State Head Injury Administrators (NASHIA), thank you for the opportunity to submit testimony regarding the fiscal year 2015 appropriations for programs authorized by the Traumatic Brain Injury (TBI) Act within the Department of Health and Human Services (HHS). The TBI Act programs are the only programs providing Federal assistance to help States with developing an array of rehabilitation, home and community-based services and other short-term and long-term supports specific to the cognitive and behavioral needs of individuals with TBI and their families. These programs are designed to restore and improve functioning and assist individuals to return to school, engage in employment and to live as independently as possible. To assist States in improving and expanding service delivery, NASHIA recommends the following:

Centers for Disease Control and Prevention (CDC), National Injury Center

The CDC National Injury Center supports State TBI registries, surveillance, data collection and analysis; State and local prevention interventions to address falls related, motor vehicle related, and sports-related injuries, including concussions (mild TBI); as well as educates primary clinicians and other professionals to be able to identify, diagnose and manage TBIs appropriately and effectively.

NASHIA recommends an increase in funding for the CDC TBI Program in the amount of \$10 million to address the expanding population of TBI.

CDC's National Injury Center is the primary Federal agency responsible for translating science into effective programs and policies to prevent and minimize the consequences of TBI when they occur. Through its funded programs and activities, the Injury Center works with national organizations, Federal agencies, State health agencies, and other key groups to develop, implement, and promote effective injury and violence prevention and control practices.

Health Resources and Services Administration (HRSA), Federal TBI Program

NASHIA recommends \$12 million total for the HRSA TBI Federal Program, which is split by HRSA between two programs: HRSA Federal TBI State Grant Program and the HRSA Federal TBI Protection & Advocacy (P&A) Systems Grant Program.

HRSA Federal TBI State Grant Program

Since 1997, HRSA has awarded grants to 48 States, District of Columbia and one Territory, although not concurrently, to develop and improve services and systems to address the short-term and long-term needs. These grants have been time limited and are relatively small. Five years ago, HRSA increased the amount of the award from approximately \$100,000 to \$250,000 to make it more feasible for States to carry out their grant goals and the legislative intent. While this increased amount is more attractive to States, this change reduced the number of grantees to 21—less than half of the States and Territories receive funding. As a result, States that do not have Federal grant funding are finding it increasingly difficult to sustain their previous efforts, let alone expand and improve service delivery, due to other budget constraints within their States. Therefore, NASHIA recommends:

\$8 million in total for the HRSA Federal TBI State Grant Program to increase the number of State grant awards.

Over the course of the grant program, States have developed State plans and implemented initiatives for improving service delivery; information & referral systems; service coordination systems; outreach and screening among unidentified popu-

lations such as children, victims of domestic violence, and veterans; and training programs for direct care workers and other staff. States have conducted public awareness and educational activities that have helped States to leverage and coordinate funding in order to maximize resources within States to the benefit of individuals with TBI.

While NASHIA is well aware that Federal funds are becoming increasingly difficult to obtain, NASHIA is recommending increased funding for the Federal TBI Act programs because:

- The number of Americans who sustain a TBI is increasing, especially among older adults and young children, and among our men and women in uniform as a result of the wars in Iraq and Afghanistan.
- All States have enacted legislation to develop return to play guidelines with regard to sports-related concussions among our youth. Two States have recently expanded their laws to include “return to learn” guidelines to help with the identification of TBI and appropriate accommodations and related educational assistance that may be needed after a mild TBI (concussion) in order to be successful academically. Through these efforts, children and youth are now being identified and screened for potential assistance.
- State budgets have not been able to keep up with the demand for services.

HRSA Federal TBI Protection & Advocacy (P&A) Systems Grant Program

HRSA also administers the Federal TBI P&A Systems Grant Program which is a formula-based program that allows 57 States, Territories, and the Native American Protection and Advocacy Project to assess their State P&A Systems’ responsiveness to TBI issues and provide advocacy support to individuals with TBI and their families. Together, P&As comprise the Nation’s largest provider of legally based advocacy services for people with disabilities. To further the work of the P&As, NASHIA recommends:

\$4 million in total be appropriated to increase the amount of grant awards administered by HRSA Federal TBI P&A Systems Grant Program.

The TBI Act, which was last reauthorized in 2008, is due for reauthorization. TBI stakeholders are working with key Congressional leaders to extend authorization of appropriations for these critical programs. In addition:

NASHIA recommends transferring the HRSA TBI State Grant and P&A programs to the Administration for Community Living to maximize resources to support the array of services and supports needed following a brain injury.

Transferring the TBI State Grant and P&A Grant programs within ACL would:

- Integrate TBI into the HHS long-term services initiatives, which also rely on Aging and Disability Resource Centers (ADRCs) as the entry point into these systems;
- Promote collaboration with the Administration on Aging (AoA) on falls related TBIs among older adults;
- Include TBI in the veterans initiatives between HHS and Department of Veterans Affairs to support Home and Community-Based Services (HCBS) for veterans and returning servicemembers coordinated by the ACL’s Office of Disability and Aging Policy’s Office of Integrated Programs;
- Coordinate and enhance services for individuals with TBI who could benefit from the ACL’s Administration on Intellectual/Developmental Disabilities (AIDD) initiatives to improve education, transition services, employment outcomes and self-advocacy for children and youth; and
- Include TBI in the Office of Disability and Aging Policy’s Office of Integrated Policy initiatives (i.e. Lifespan Respite Care Program, Participant Direction Program, Evidenced-Based Care Transitions, and Transportation Research and Demonstration Program).

In keeping with the Olmstead decision, States are taking advantage of Federal initiatives and opportunities to expand community long-term services options. Unfortunately, most States focus on the traditional populations of I/DD, physical disabilities, aging and mental health and are omitting TBI in their long-term care initiatives. This leaves individuals with TBI with little options, other than nursing facilities or other segregated living programs, for assistance with activities of daily living and residential or housing needs. We believe that aligning the Federal TBI State Grant Program with these other programs will help address these concerns.

About the National Association of State Head Injury Administrators (NASHIA)

NASHIA is a non-profit organization representing and assisting State governmental officials who administer an array of short-term and long-term rehabilitation and community services and supports for individuals with TBI and their families.

Since 1990, NASHIA has held an annual State-of-the-States conference, and has served as a resource to State TBI program managers and others seeking public programs and services. Membership also includes associate members who are professionals, provider agencies, State affiliates of the Brain Injury Association of America (BIAA) or U.S. Brain Injury Alliance, family members and individuals with TBI.

Over the past 30 years, States have initiated efforts to develop capacity for offering information and referral services, service coordination, rehabilitation, in-home support, personal care, counseling, transportation, housing, vocational and other support services for persons with TBI and their families. These services vary in size and scope across the country and even within a State. Twenty-four States have enacted legislation to assess fines or surcharges to traffic related offenses or other criminal offenses and/or assessed additional fees to motor vehicle registration or drivers license to generate funding for TBI programs and services, generally referred to as trust fund programs. About the same number of States have implemented TBI Home and Community-Based Medicaid Waiver Programs with twelve States having the advantage of administering both a trust fund and waiver program. These programs are administered by State public health, Vocational Rehabilitation, mental health, Medicaid, intellectual disabilities, education or social services agencies within the States.

Thank you.

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF STATE LONG-TERM CARE
OMBUDSMAN PROGRAMS

I am pleased to present this testimony on behalf of residents and tenants residing in Iowa's long-term care facilities in collaboration with the National Association of State Long-Term Care Ombudsman Programs (NASOP). This statement and the following funding recommendations for fiscal year 2015 for the Long-Term Care Ombudsman Programs administered through the Administration for Community Living (ACL) is submitted for the record.

- \$5 million authorized under the Elder Justice Act for Long-Term Care Ombudsman Program (LTCOP) services and training to fight elder abuse, neglect, and exploitation;
- \$16.83 million authorized under Title VII of the Older Americans Act for LTCOPs to restore funding back to the fiscal year 2011 level;
- \$20 million for LTCOP services in assisted living facilities; and
- \$1 million authorized under Title II of the Older Americans Act for the National Long-Term Care Ombudsman Resource Center (NORC).

NASOP, formed in 1985 as a non-profit organization, is composed of state long-term care ombudsmen representing their State programs created by the Older Americans Act (OAA). The primary function of the LTCOP in the Federal OAA is to identify, investigate, and resolve complaints that relate to action, inaction or decisions that may adversely affect the health, safety, welfare, and rights of residents of long-term care facilities. Ombudsman representatives work with the consent and at the direction of residents in the resolution of their problems. They visit residents living in nursing homes and residential care homes. Ombudsman representatives ask them about problems or concerns they have and if they need or want our help to resolve these issues. Ombudsman representatives act as their advocates. We strongly believe that our work not only improves the quality of life for millions of long-term care facility residents, but also saves Medicare and Medicaid resources by avoiding unnecessary costs associated with poor quality care.

Nationally, in Federal fiscal year 2012, over 11,000 volunteers, including 8,712 individuals certified to investigate complaints, and 1,180 staff served in 573 local LTCOPs. Ombudsmen investigated and worked to resolve 193,650 complaints made by 126,398 individuals. Ombudsmen were able to resolve or partially resolve 73 percent, or almost three out of every four complaints investigated. In addition, ombudsmen provided information on rights, care and related services 405,589 times.

Iowa's LTCOP is responsible for advocating for 53,287 residents and tenants residing within 844 long-term care facilities. The Iowa Office of State Long-Term Care Ombudsman consists of the State Long-Term Care Ombudsman; 8 Local Long-Term Care Ombudsman; 2 Volunteer Coordinators; numerous volunteers, and an Administrative Assistant. Currently, the Federal funding for our program only fully funds two (2) of the twelve (12) paid positions.

In Federal fiscal year 2013, Iowa's LTCOP received 1,174 complaints by or on behalf of residents and tenants; directly served 3,226 residents and tenants; provided 4,445 hours of advocacy services beyond complaint handling; and provided 5,360 consultations, education sessions, visits, and other activities. Our office advocates

for 53, 287 residents/tenants in 844 facilities and we do this with just a few staff. We are grateful for the staffing that we do have, but feel that our efforts are just a drop in the bucket. According to two national studies from the Institute of Medicine and the Bader Report, the national recommendation for States to follow is 1 long-term care ombudsman for 2,000 beds or people. With the current number of long-term care ombudsman staff in Iowa, our ombudsmen are serving 6,661 beds or people. Iowa would need a total of 27 local long-term care ombudsmen to fully meet this Federal recommendation. This would ensure that all individuals residing in long-term care would have immediate access to an advocate who can represent their interests.

We understand that this Subcommittee faces a strained financial situation, but a continued commitment to Ombudsman programs advocating for the healthcare needs and safety of millions of older adults living in nursing homes and assisted living facilities across the Nation should remain a high priority. Since 1978, the LTCOP has been a core program of the OAA. It is the only program in the OAA that specifically serves residents of nursing homes and assisted living facilities. We all appreciate and value the importance of living in one's own home. The OAA provides critically needed home and community based services that often delay institutionalization. However, some elders can no longer live safely in their own homes and must move at some point in their lives to either an assisted living facility or a nursing home. These residents are usually frail and extremely vulnerable and rely on the advocacy services of the LTCOP.

Demand for our services and advocacy is growing. The number of complex and very troubling cases that long-term care ombudsmen investigate has been steadily increasing. In addition, there continues to be a disturbing increase in the frequency and severity of citations for egregious regulatory violations by long-term care providers. These violations put facility residents in immediate jeopardy of harm. This trend suggests a frightening decline in the quality of long-term care services. Ombudsmen are needed now more than ever in nursing homes, board and care facilities, and in assisted living communities. As well, the demand placed on the program by the need to assist residents who are relocating from long-term care facilities that are downsizing or closing their doors continues to complicate ombudsman programs' daily operations.

Administrators in many long-term care facilities have recognized the value and benefit of having ombudsmen assist with staff training and consultation and this form of outreach has also placed an increasing strain on available advocacy resources. In order to improve advocacy and services available to residents of long-term care facilities, NASOP recommends, and the Iowa Office of the State Long-Term Care Ombudsman supports, several augmentations to appropriations that support the work of LTCOP.

NASOP requests \$5 million to support the work of the LTCOP under the Elder Justice Act. This appropriation would allow States to hire additional staff and leverage that staff to recruit additional volunteers to help support the investigation of complaints of abuse, neglect, and exploitation of residents of nursing home and assisted living facilities.

NASOP request \$16.83 million authorized under Title VII of the Older Americans Act for LTCOPs to restore funding back to the fiscal year 2011 level. Programs in every district and State are suffering from recent cuts. These funds would help in a partial way to restore our reduced ability to visit residents in nursing homes.

NASOP requests \$20 million to support 333 additional Ombudsman salaried staff at an estimated \$60,000 average annual salary/fringe benefits and necessary staff training. The requests adds new ombudsman positions specifically dedicated to providing Ombudsman services to residents of assisted living facilities and other community-based long-term care delivery systems, which currently suffer from a significant lack of personnel resources around the country.

Finally, NASOP wants to acknowledge the importance and value of the National Long-Term Care Ombudsman Resource Center (NORC). The NORC provides valuable and reliable technical assistance, training, and support to State and local LTCOPs.

NASOP requests an appropriation of \$1 million to support the work of the NORC in providing training and technical assistance to State and local LTCOPs. Congress funds the NORC at \$550,000 per year; the very same level of funding it has received since 1993. This request adds \$450,000 to the line item for the NORC, which is such a critical component of the ombudsman program. The NORC plays an integral role in assuring the overall effectiveness of LTCOPs across the country through its training, educational materials, data analysis, and best practices efforts.

Overall, Ombudsmen offer valuable consumer protections to residents and provide a voice for those unable to speak for themselves. Every day in America, 10,000 more

persons reach the age of 65 years. With a rapidly growing older population, LTCOPs can continue to enhance the quality of life, improve the level of care, protect the individual's rights and promote the dignity of Americans across the Nation.

On behalf of residents, tenants and State Long-Term Care Ombudsmen across this Nation, thank you for this opportunity to share these requests for support of this important program that protects the health, safety, welfare, and rights of vulnerable older adults and persons with disabilities. We ask that you thoughtfully consider our detailed request for funding in fiscal year 2015.

[This statement was submitted by Deanna Clingan-Fischer, JD, Iowa State Long-Term Care Ombudsman.]

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF STATES UNITED FOR AGING AND DISABILITIES

Chairman Harkin, Ranking Member Moran: Thank you for the opportunity to submit this testimony. As you work to develop fiscal year 2015 funding priorities, the National Association of States United for Aging and Disabilities (NASUAD) urges you to consider the Administration for Community Living's (ACL) fiscal year 2015 request for \$25 million to address the all-too prevalent problem of elder abuse. This investment would support initial implementation of the Elder Justice Act's (EJA) Adult Protective Services (APS), research, and evaluation activities.

NASUAD represents the 56 officially designated State and territorial agencies on aging and disabilities. Each of our members oversees the implementation of the Older Americans Act (OAA), and many also serve as the operating agency in their State for Medicaid waivers that serve older adults and individuals with disabilities. Together with our members, we work to design, improve, and sustain State systems delivering home and community based services and supports for people who are older or have a disability, and their caregivers.

According to ACL, an estimated 2.1 million older Americans are victims of elder abuse, neglect, or exploitation each year. As the Nation's older population increases, so too does the incidence of elder abuse. While there is no single set of national elder abuse prevalence data, the number of reported cases is on the rise. A 2004 national survey of State APS programs showed a 16 percent increase in the number of elder abuse cases from an identical study conducted in 2000. Additionally, an overwhelming number of cases of abuse, neglect, and exploitation go undetected and untreated each year. Experts estimate that for every case of elder abuse or neglect reported, as many as five cases go unreported.

Despite the clear and growing need, there is no dedicated Federal funding for, or corresponding Federal oversight of, elder abuse prevention services. Absent a national framework, States have been left to address this issue independently from one another, and must rely on multiple funding streams to support their work, ultimately resulting in a fragmented system. Though each State has developed an APS program that responds to reports of elder abuse, neglect, and exploitation, these programs vary greatly from State to State—from the populations they serve, to the reporting mechanisms they use, and the budget structures under which they operate. These discrepancies, which continue to be exacerbated by the absence of Federal APS funding, necessarily impede efforts to compare, evaluate, and improve State approaches to reducing and preventing elder abuse.

To address the systemic inadequacies in our Nation's approach to eradicating elder abuse, neglect, and exploitation, we urge you to support ACL's request of \$25 million in discretionary funding to implement the EJA in fiscal year 2015. This critical funding would be used to develop much-needed program standards and data collection efforts, as well as to support the implementation of a nationwide APS data system; these dollars would also fund research activities, including efforts to translate promising interventions from other violence prevention areas to elder abuse, and evaluations of the effectiveness of these interventions.

NASUAD believes that efforts to improve the response to, awareness of, and intervention in elder abuse, neglect, and exploitation could be more effectively coordinated through the establishment of a national APS program. Accordingly, we urge you to fully fund the Elder Justice Initiative in fiscal year 2015.

Thank you for the opportunity to provide input on this critical issue, and for your leadership. NASUAD looks forward to working with all of you to preserve the dignity, independence, and health of older adults, and to protect those who may no longer be able to protect themselves.

PREPARED STATEMENT OF THE NATIONAL BLOOD CLOT ALLIANCE

The National Blood Clot Alliance (NBCA) is pleased to submit this statement in support of increased appropriations for fiscal year 2015 for the Centers for Disease Control and Prevention's (CDC) Division of Blood Disorders, a component of CDC's National Center on Birth Defects and Developmental Disabilities. NBCA's statement addresses the programs specific to blood clots, known scientifically as Deep Vein Thrombosis (DVT) and Pulmonary Embolism (PE), a major public health problem facing this Nation. Combined, these disorders are known as venous thromboembolism (VTE). Preventing death and disability from VTE is an important public health priority, and the Division is responsible for all CDC activities related to blood clots and other bleeding disorders.

NBCA asks the Subcommittee to restore funding for the Division to its fiscal year 2010 level, \$19.9 million. The fiscal year 2014 funding has dropped precipitously to \$13 million. Of this, support for blood clot prevention has been cut in half, to a mere \$560,000, hardly enough to make a dent in a major public health problem that annually kills more Americans than AIDS, breast cancer and motor vehicle accidents combined. NBCA further requests that the Subcommittee establish a budget line item specific to blood clots and clotting disorders and that \$4 million be appropriated for this line each year for the next 5 years.

Funding this program at the requested level will be a major step in advancing the Surgeon General's 2008 "Call to Action to Prevent Deep Vein Thrombosis (DVT) and Pulmonary Embolism (PE)" and the Nation's "Healthy People 2020 Objectives." The urgency of this request is underscored by the fact that the great majority of blood clots could be prevented. We have the tools to do that, but the resources to deploy them are woefully inadequate.

Blood clots are the leading cause of unnecessary hospital readmissions in the U.S., costing our Nation an estimated \$10 billion dollars in avoidable healthcare expenses annually. According to the American Public Health Association, DVT deaths are the most common preventable cause of hospital death. Researchers at Johns Hopkins University School of Medicine recently reported that as many as 70 percent of healthcare associated VTE could be eliminated with the application of improved prevention protocols. Other targeted population-based prevention tools can be applied to avert disability and death from blood clots due to aging, lengthy travel, immobility, obesity and other risk factors.

The National Blood Clot Alliance

Founded in 2003, NBCA is a patient led non-profit, voluntary health organization dedicated to advancing the prevention, early diagnosis and successful treatment of life-threatening blood clots such as deep vein thrombosis, pulmonary embolism and clot-provoked stroke. We work on behalf of people who have or could be susceptible to blood clots, including, but not limited to, people with clotting disorders, atrial fibrillation, cancer, traumatic injury, and risks related to surgery, lengthy immobility, child birth and birth control. NBCA accomplishes its mission through programs that build public awareness, educate patients and healthcare professionals and promote supportive public and private sector policy. Our content is reviewed by an internationally recognized Medical and Scientific Advisory Board. We invite the Members of the Subcommittee to visit our website at www.stopthecLOT.org to learn more about blood clots and the programs of NBCA.

Who Has Blood Clots and What Are They?

No American is immune from life-threatening blood clots, regardless of age, gender, race, ethnicity or health status. Normal blood clots play an important role in protecting our health because they stop bleeding from a cut or wound. However, blood clots can also form abnormally, causing a heart attack, stroke, or other serious medical problems. Experts estimate that two million Americans suffer such venous and arterial blood clots every year. More than 200,000 Americans die from them annually. An often silent killer, death can be sudden with no forewarning. But in most instances, the damage can be averted or contained. Age, smoking, obesity can all contribute to clotting risk, but so can birth control or pregnancy or cancer. Even prominent athletes in peak physical condition have suffered career-ending, life-threatening clots. It can happen to any of us. In fact, the memories of former U.S. Reps. Walter Capps (D-CA) and Jennifer Dunn (R-WA), who died due to blood clots while serving in Congress, motivated the creation of National Blood Clot Awareness Month in March of 2009.

Physicians estimate that as little as 20 percent of blood clots are actually recognized for what they are. Misdiagnosis and delayed diagnosis are all too common and all too often fatal. The general public is even farther behind, with surveys showing that nearly three quarters of the population has little or no knowledge about blood

clots, their risks, their signs and symptoms and their prevention. The Government must play a greater role in educating the general public, people who are at special risk and health professionals. This is the “low hanging fruit” of public health prevention that has yet to be adequately picked and the return on invest can be tens of thousands of lives saved and billions of dollars in unnecessary healthcare expenses avoided!

The Federal Government Has a Vital Role in Meeting this Acknowledged Public Health Priority

Many Federal agencies play important roles in the effort to reduce death and disability from blood clots and clotting disorders. The National Institutes of Health and the National Science Foundation support the work of basic scientists in their efforts to understand the causes and effects of blood clots and identify improved treatments. The VA also supports research in this field and strives to prevent blood clots in the special population of Americans it serves. The Agency for Healthcare Research and Quality in 2001 was among the first to recognize that blood clot prevention in hospitals was our best opportunity for patient safety improvement. The Partnership for Patients makes made blood clot prevention a key component of improved hospital care. CMS includes surgery-related blood clot prevention as a key measure of hospital quality. DOD has examined how blood clots can be prevented in the military, affecting soldiers who must often live in cramped conditions, suffer dehydration and experience bone fractures and more severe injuries that require surgery.

Each of these agencies plays a special role in the effort to reduce clotting death and injury. However, the CDC, the Nation’s leading prevention agency, is the one best suited to guide and coordinate Federal efforts targeted at populations more broadly. No other agency possesses its unique capabilities in public health outreach, education and promotion. Regrettably the agency best suited for leadership is the one with the fewest resources. NBCA believes it is imperative that Congress act now to provide adequate, sustained funding for this specific activity at CDC—the reduction of death and disability due to blood clots.

The funding request presented at the beginning of this statement will provide CDC with the resources it needs to begin seriously to meet this public health challenge. fiscal year 2014 funding for blood clot programs is only \$560,000, half of what was available in the last fiscal year. The Administration’s proposed fiscal year 2015 budget would make no change to this level. The current funding situation for the Blood Disorders Division has already forced CDC to cut or curtail the few programs it has been able to support. These include two pilot programs to improve community-based VTE surveillance and evaluation; one focused on healthcare provider education; one targeted at women’s health (e.g., blood clots are the leading cause of maternal mortality); and a collaboration with the VA and academia to develop new VTE surveillance tools. Staffing of the Division has also been cut nearly in half, decreasing by 18 FTEs, including essential personnel with specialized laboratory, IT and analytic skills. At a time when this public health problem is growing, we have allowed even the small investment in CDC to address it become further negligible. This is neither thoughtful public policy nor wise economically.

NBCA believes that our citizens deserve better and that Federal support for this acknowledged public health priority should be equal to the task. Tragically, it is not at present. NBCA urges the Subcommittee to take the lead in making the changes needed to provide CDC with the funds it needs to combat this major public health issue—blood clots, clotting disorders and the ensuing disability that consumes far too many lives and dollars in the U.S. unnecessarily.

[This statement was submitted by Joseph C. Isaacs, Chief Executive Officer, National Blood Clot Alliance.]

PREPARED STATEMENT OF THE NATIONAL CENTER FOR LEARNING DISABILITIES

The National Center for Learning Disabilities (NCLD) works to ensure that the Nation’s 60 million children, adolescents and adults with learning disabilities and attention issues have every opportunity to succeed in school, work and life. NCLD asks you to consider our request as you work on the fiscal year 2015 Labor, Health and Human Services, and Education Appropriations bill.

As you begin work on the fiscal year 2015 Labor, Health and Human Services, and Education Appropriations bill, we urge you to support continued funding for special education at the President’s request level of \$11.57 billion for the Individuals with Disabilities Education Act (IDEA) and the President’s \$100 million for Results Driven Accountability Incentive Grants which would provide competitive grants to States to implement promising, evidence-based reforms that would improve service

delivery for children with disabilities while building State and local capacity to improve long-term outcomes for those children

We also urge you to support funding for the National Technical Assistance Center within the Higher Education Opportunity Act (Section 777(a)) at \$2 million to provide useful and comprehensive information to students with disabilities on the choices available to them in higher education and to provide much-needed training, technical assistance, and professional development to institutes of higher education.

IDEA Part B Grants to States & Results Driven Accountability Incentive Grants

Currently, there are over 6.5 million children eligible for special education services under the disability categories of the Individuals with Disabilities Education Act (IDEA). The comprehensive assessment and support services authorized by IDEA help to close the academic achievement gap and ensure a meaningful education for every student. We owe it to all students to provide a quality education that will help them graduate and enter successful careers.

We support the Administration's request that would maintain funding for IDEA, Part B (Grants to States program) at \$11.57 billion, which the Administration estimates would provide \$1,758 per child for an estimated 6.6 million students with disabilities. Additionally we support the President's \$100 million for Results Driven Accountability Incentive Grants, which would provide competitive grants to States to implement promising, evidence-based reforms that would improve service delivery for children with disabilities. We encourage innovation in the realm of service delivery to students receiving special education and believe that these grants have the potential to spark innovative ideas and a renewed focus on improved outcomes for students.

The National Technical Assistance Center

In the HEA reauthorization of 2008, Congress authorized the establishment of National Center for Information and Technical Support for Postsecondary Students with Disabilities. This Center was intended to serve three primary purposes: (1) serve as a resource to parents and students with disabilities on the services available at various IHEs; (2) serve as a technical assistance center to IHEs and provide training to faculty and staff on how to improve services for students with disabilities; and (3) serve as an online database for the collection and dissemination of a variety of disability-related information for students with disabilities who are interested in higher education. Though the Center was authorized, it has never been funded.

How Students with Disabilities are Faring in Higher Education

In recent years, due to the services provided to students with disabilities through the Individuals with Disabilities in Education Act (IDEA) or Section 504 of the Rehabilitation Act, students with learning and attention issues have graduated from high school at higher rates than ever before. In fact, a majority (54 percent) of students with learning disabilities have the goal to attend a 2- or 4-year college.¹ Students with learning disabilities make up the largest population of students with disabilities who attend postsecondary schools, at 69 percent of all students with disabilities in postsecondary programs.²

Unfortunately, students with disabilities are not attending postsecondary education programs at the same rate as students in the general population. In the general education population, within 4 years of graduating high school, 53 percent of students continue on to postsecondary education programs, compared to only 45 percent of youth with disabilities. Even worse, young adults with learning disabilities (LD) attend four-year colleges at half the rate of the general population.³ Students with disabilities would benefit from better outreach, recruitment, and assistance programs to bridge the gap between high school and postsecondary education programs. Comprehensive information on higher education programs and services is needed now more than ever. With more students with disabilities setting goals of attending college but few actually enrolling and completing college programs, it is critical that they have access to the information and support services they need.

¹ Cortiella, Candace and Horowitz, Sheldon H. *The State of Learning Disabilities: Facts, Trends and Emerging Issues*. New York: National Center for Learning Disabilities, 2014.

² Newman, L.A. & Madaus, J. W. (2013). *Reported Accommodations and Supports Provided to Secondary and Postsecondary Students with Disabilities: National Perspective*. Publication forthcoming.

³ Cortiella & Horowitz (2014).

The Lack of Comprehensive Information on Post-Secondary Education Programs

The U.S. Department of Education (ED) has made efforts to improve parent and student access to timely and useful information regarding colleges and universities through the development of the College Navigator. The Department of Education collects data from IHEs through Integrated Postsecondary Education Data System (IPEDS) surveys, including data on enrollment, program completion, graduation rates, faculty and staff, finances, institutional prices, and student financial aid. The data is made available to students and parents via College Navigator—a public website that allows users to perform a search of colleges. The data and information provided through the College Navigator—has the potential to support and improve rates of transition for all young adults from high school into the postsecondary setting. However, this information alone is not enough to ensure a smooth transition for students with disabilities into their postsecondary education programs.

NCLD has conducted its own survey of the information provided by IHEs on College Navigator. College Navigator provides a place for every IHE to provide information on the disability services offered at the institution. We examined the responses that nearly 400 institutions submitted, including private, public, and for profit institutions as well as community colleges. Only 6 of the institutions surveyed listed any information to students and the public regarding disability services.⁴

The Need for a Smoother Transition to Post-Secondary Programs

Research shows that students with disabilities are getting less support in college than in high school, despite wishing they had more assistance. Even though 87 percent of students with disabilities received some type of accommodation or support in high school, that number drops off sharply when students with disabilities enter college, decreasing to only 19 percent of students who receive accommodations or support.⁵ For students with learning disabilities, 17 percent of young adults receive accommodations and supports in postsecondary education compared with 94 percent in high school.⁶ Of the many students who did not receive any help at all, 43 percent felt that it would have been helpful to receive assistance.⁷ We know that self-advocacy is one of the keys to student success, but it is clear that students are not aware of their rights and responsibilities, are not adequately prepared to advocate for themselves, and are not provided adequate transition assistance to be successful in postsecondary education programs.

The Purpose of the National Technical Assistance Center

We recognize that providing useful and comprehensive information to parents and students on the choices available is not an easy task. Therefore, we recommend funding the National Technical Assistance Center, found in the 2008 authorization of HEA, at \$2 million. The Center would serve several key purposes: (1) providing information and resources to students and parents on disability services and programs at IHEs; (2) providing training and technical assistance to IHEs; (3) providing training and professional development to faculty and staff at IHEs; and (4) information collection and dissemination on best practices, documentation requirements, financial aid, services available, policies, and accessible instructional materials.

We urge you to continue your investment in students with disabilities through funding of IDEA and the RDA grants and support funding in fiscal year 2015 for the National Technical Assistance Center. Thank you for your consideration of our request.

[This statement was submitted by Lindsay E. Jones, Esq., Director, Public Policy & Advocacy, National Center for Learning Disabilities.]

PREPARED STATEMENT OF THE NATIONAL CHILDREN'S FACILITIES NETWORK

Chairman Harkin, Ranking Member Moran, and distinguished Members of the Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies: Thank you for the opportunity to offer written testimony on the Administration's fiscal year 2015 Budget Request for the Department of Health

⁴For more information on the survey conducted by NCLD and the IHEs we surveyed to find this data, please contact us.

⁵Newman, L., Wagner, M., Knokey, A.-M., Marder, C., Nagle, K., et al. (2011). The PostHigh School Outcomes of Young Adults With Disabilities up to 8 Years After High School. A Report From the National Longitudinal Transition Study-2 (NLTS2) (NCSE 2011-3005). Menlo Park, CA: SRI International.

⁶Cortiella & Horowitz (2014).

⁷Newman, Wagner, Knokey, Marder, et al. (2011).

and Human Services, Administration for Children and Families. I write on behalf of the National Children's Facilities Network (NCFN) to express support for the funding of Head Start, Early Head Start-Child Care Partnerships and other programs that provide access to high quality early care and education. These initiatives are critical to ensuring that all children, especially low-income children, are given a strong start and the tools necessary to succeed in life. As you make important funding decisions about programs that provide children with the opportunity to obtain an early start on the pathway to success, we encourage you to recognize the critical role that early childhood facilities play in preparing young children for achievement in school and in life, and support Federal policies that adequately finance the acquisition, construction, and improvement of these spaces.

NCFN is a national coalition of nonprofit organizations that provide financing, technical assistance and training on the design, development and financing of early care and education facilities in low-income communities throughout the country. We see the positive impact of high quality early learning on children's lives and on the future economic health and development of neighborhoods. Our coalition also recognizes the importance of the spaces where these programs take place. A growing body of research shows that a well-designed, well-equipped physical environment supports learning and good outcomes for children, while a poorly adapted and overcrowded space undermines it. For example, bathrooms adjacent to classrooms, accessible cubbies, and child-sized sinks, counters, furnishings and fixtures increase children's autonomy and competence while decreasing the demands on teachers.

Infants, toddlers, and young children should be educated and cared for in high quality physical spaces that meet their needs and complement high quality programs. Federal programs focused on improving families' access to high quality early care and education options should include adequate funding for the acquisition, construction, and improvement of facilities.

Thank you for your leadership on these issues. Please consider us as a resource as you advance early childhood policies. If you would like additional information about our work, please contact Karen O'Mansky, Center for Community Self-Help, Chair, National Children's Facilities Network.

PREPARED STATEMENT OF THE NATIONAL CONGRESS OF AMERICAN INDIANS

On behalf of the National Congress of American Indians (NCAI), this testimony addresses programs in the Departments of Education and Labor and the Corporation for Public Broadcasting. NCAI also supports the testimony of the National Indian Child Welfare Association, the American Indian Higher Education Consortium, and the National Indian Education Association. NCAI is the oldest and largest American Indian organization in the United States. Tribal leaders created NCAI in 1944 as a response to termination and assimilation policies that threatened the existence of American Indian and Alaska Native tribes. Since then, NCAI has fought to preserve the treaty rights and sovereign status of tribal governments, while also ensuring that Native people may fully participate in the political system. As the most representative organization of American Indian tribes, NCAI serves the broad interests of tribal governments across the Nation.

Department of Education

Investing in the education of American Indian and Alaska Native students is not only one most of the most important cornerstones of the Federal trust responsibility to tribes, but is also critical strategy for creating jobs and securing the Nation's future prosperity in today's challenging economic climate. Education provides tribal economies with a more highly-skilled workforce while also directly spurring economic development and job creation. The profound value of education for Native Nations extends beyond just economics, however. Education drives personal advancement and wellness, which in turn improves social welfare and empowers communities—elements that are essential to maintaining tribes' cultural vitality and to protecting and advancing tribal sovereignty.

Despite the enormous potential of education for transforming tribal communities, Native education is in a state of emergency. American Indian and Alaska Native students lag far behind their peers on every educational indicator, from academic achievement to high school and college graduation rates. For example, in 2011, only 18 percent of Native fourth graders and 22 percent of Native eighth graders scored proficient or advanced in reading, and only 22 percent of Native fourth graders and

17 percent of Native eighth graders scored proficient or advanced in math.¹ The crisis of Indian education is perhaps most apparent in the Native high school dropout rate, which is not only one of the highest in the country, but is also above 50 percent in many of the States with high Native populations.²

Title I, Part A Local Education Agency Grants—Provide \$25 billion for Title I, Part A.—Title I of the Elementary and Secondary Education Act provides critical financial assistance to local educational agencies and schools with high percentages of children from low-income families that ensure all children meet challenging State academic standards. Currently, there are over 600,000 Native students across the country with nearly 93 percent of those students attending non-Federal institutions, such as traditional public schools in rural and urban locations. A drastic increase in funding to counter annual inflation and sequestration is necessary to meet the needs of Native students and students from low-income families.

Impact Aid—Provide \$2 billion for Impact Aid, Title VIII of the Elementary and Secondary Education Act (ESEA).—Impact Aid provides direct payments to public school districts as reimbursements for the loss of traditional property taxes due to a Federal presence or activity, including the existence of an Indian reservation. With nearly 93 percent of Native students enrolled in public schools, Impact Aid provides essential funding for schools serving Native students. In fiscal year 2014, Impact Aid saw an increase of \$64 million over fiscal year 2013 that restored most of the destructive sequestration cuts tribal communities faced in Indian Country. In order to ensure Native students have access to education, however, Impact Aid must be fully funded at \$2 billion. Furthermore, Impact Aid should be converted to a forward-funded program to eliminate the need for cost transfers and other funding issues at a later date.

Title VII (Indian Education Formula Grants)—Provide \$198 million for Title VII of the ESEA.—This grant funding is designed to supplement the regular school program and assist Native students so they have the opportunity to achieve the same educational standards and attain equity with their non-Native peers. Title VII provides funds to school divisions to support American Indian, Alaska Native, and Native Hawaiian students in meeting State standards. Furthermore, Title VII funds support early-childhood and family programs, academic enrichment programs, curriculum development, professional development, and culturally-related activities. Currently, funding for Title VII only reaches 500,000 Native students leaving over 100,000 without supplementary academic and cultural programs in their schools.

State-Tribal Education Partnership (STEP) Program—Provide \$5 million for the State-Tribal Education Partnership Program.—Congress appropriated roughly \$2 million dollars for the STEP program to five participating tribes in fiscal year 2012 and fiscal year 2013 under the Tribal Education Department appropriations' line that is administered by the Department of Education. In order for this program to continue to succeed and thrive, it must receive its own line of appropriations in fiscal year 2015. Collaboration between tribal education agencies and State educational agencies is crucial to developing the tribal capacity to assume the roles, responsibilities, and accountability of Native education departments and increasing self-governance over Native education.

Alaska Native Education Equity Assistance Program—Provide \$35 million for Title VII, Part C of the ESEA.—This assistance program funds the development of curricula and education programs that address the unique educational needs of Alaska Native students, as well as the development and operation of student enrichment programs in science and mathematics. This funding is crucial to closing the gap between Alaska Native students and their non-Native peers. Other eligible activities include professional development for educators, activities carried out through Even Start programs and Head Start programs, family literacy services, and dropout prevention programs.

Native Hawaiian Education Program—Provide \$35 million for Title VII, Part B of the ESEA.—This program funds the development of curricula and education programs that address the education needs of Native Hawaiian students to help bring equity to this Native population. Where Native Hawaiians once had a very high rate of literacy, today Native Hawaiian educational attainment lags behind the general population.

¹National Indian Education Study 2011, NCES 2012–466. National Center for Education Statistics, Institute of Education Sciences, United States Department of Education.

²School Year 2010–2011 4-Year Regulatory Adjusted Cohort Graduation Rates, Department of Education.

Department of Labor

Fund the Department of Labor's Indian and Native American Program (INAP) at a minimum of \$60.5 million. Fund the Native American Employment and Training Council at \$125,000 from non-INAP resources.—In order to reduce the education and employment disparity between Native people and other groups, a concentrated effort is required that provides tailored and sufficient assistance to enhance education and employment opportunities, to create pathways to careers and skilled employment, and to secure a place for Native people within the Nation's middle class. The Workforce Investment Act (WIA) Section 166 program (INAP) serves the training and employment needs of over 38,000 American Indians and Alaska Natives via a network of 175 grantees through the Comprehensive Service Program (Adult) and Supplemental Youth Service Program (Youth), and the Indian Employment and Training and Related Services Demonstration Act of 1992, Public Law 102-477. Furthermore, the number of American Indians and Alaska Natives served through WIA does not fully capture its impact in Indian Country, as many more are served by grantees that leverage WIA funding, along with other similar federally funded employment and training programs, through PL 102-477.

There has been a trend of decreasing funds for INAP, and a failure to appropriate at the statutory minimum level of \$55 million. These decreases in funding are detrimental and hamper progress in Indian Country's labor situation. According to the Census, the average unemployment rate on reservations dropped more than 3 percentage points since 2000,³ but more still needs to be done as American Indians and Alaska Natives still lag significantly behind. With the average unemployment rate in Indian Country cited up to 17 percent⁴ and an average rate of joblessness of approximately 50 percent,⁵ INAP is vital to helping reverse these trends.

Further, because INAP is the only Federal employment and job training program that serves American Indians and Alaska Natives who reside both on and off reservations, it is imperative that its funding is preserved. For Native citizens living on remote reservations or in Alaska Native villages, it can be difficult to access the State and local workforce systems. In these areas, INAP can be the lone employment and training provider. Since 2003, WIA has been up for reauthorization; and over this 11-year period, WIA has not accounted for the population growth of tribal communities, nor the economic environment that has drastically changed. WIA authorizes the INAP to be funded at "not less than \$55 million," but Section 166 is currently being funded at approximately \$46 million. WIA also authorizes the Native American Employment and Training Council to advise the Secretary on the operation and administration of INAP, but it uses funds that are intended for INAP grantees. Since the current INAP funding is already below \$55 million, the Secretary should use other streams of funding to support its advisory council. Without an increase in funding, not enough tribes are able to benefit from the support and training activities for employment opportunities in Indian Country.

Restore the YouthBuild Program funding to a minimum of \$102.5 million, restore the rural and tribal set-aside in the YouthBuild program, and reinstate a dedicated 10 percent rural and tribal set-aside of at least \$10.25 million.—The YouthBuild program is a workforce development program that provides significant academic and occupational skills training and leadership development to youth ages 16–24, and engages approximately 10,000 youth annually. According to YouthBuild, in 2010, 4,252 youth participated in the program and had a completion rate of 78 percent, and 60 percent of those who completed the program were placed in jobs or further education.⁶ There are a number of tribal YouthBuild programs in several States, and Native Americans make up roughly 4 percent of YouthBuild participants. With the recent reduction in tribal YouthBuild programs, high unemployment rates, serious housing challenges in Indian Country, and the growing Native youth population (42 percent of American Indian/Alaska Native population is under 25 years old),⁷ it is critical that the 10 percent rural and tribal set-aside be restored.

Corporation for Public Broadcasting

In the CPB, NCAI supports an advanced fiscal year 2016 appropriation of \$5 million for American Indian and Alaska Native radio stations. This \$5 million appropriation would come out of the fiscal year 2015 advanced appropriation of \$445 mil-

³U.S. Census Bureau. Census 2000 Summary File 4, 2006–2010, 2009–2011 American Community Survey.

⁴U.S. Census. 2011 American Community Survey.

⁵U.S. Department of Interior. Bureau of Indian Affairs. 2005 American Indian Labor Force Report.

⁶See youthbuild.org/research.

⁷U.S. Census Bureau, 2010 Census, Summary File 1.

lion for the overall CPB budget. This is the same budget amount enacted for fiscal year 2014 and requested for fiscal year 2015.

For more than 30 years, decisions on the amount of Federal support for public broadcasting have been made 2 years ahead of the fiscal year in which the funding is allocated. Since 1976, CPB's 2-year advance appropriation has served as a Congressional strategy to protect public media from any immediate political pressure. Community Service Grants (CSGs) account for approximately 70 percent of CPB's appropriation, which directly funds 1,300 local public television and radio stations including 35 Native radio stations.

In Indian Country, Native radio stations are essential to the tribal communities they serve since they are often the first source of emergency reporting and information. Public broadcasters use datacast technology for homeland security, public alert and warning systems, and public safety purposes. In Oklahoma, KCNP Chickasaw radio provided real time weather reports that saved lives during the 2013 tornado season. In Arizona, KUYI Hopi radio provides "House Calls," a health call-in show that connects listeners with a local doctor on questions about hanta virus, diabetes, HIV, and other local health issues. In Alaska, KNBA covers news from Alaska Native villages about climate change refugees, language revitalization, and other hyper local stories important and relevant to Alaska Native communities. Often, the only place where Native stories and issues are heard is on Native radio stations.

Local public media stations and their employees have experienced significant reductions through cuts to other Federal programs that benefit public media. The elimination of CPB's Digital appropriation and the Public Telecommunications Facilities Program coupled with cuts to programs at the Departments of Education and Agriculture represent a \$57.5 million, or 7.3 percent, funding cut between fiscal year 2010 and fiscal year 2012. These cuts come at a time when stations are struggling to maintain service to their communities in the face of shrinking nonFederal revenues—a \$239 million, or 10.8 percent, drop between fiscal year 2008 and fiscal year 2011.

CPB also funds the essential system-wide station support services provided by Native Public Media, Inc., and content production and satellite programming distribution by Koahnic Broadcast Corporation. Access to these funds allows Native Public Media, Inc., to ensure that Native radio stations stay on the air by maintaining compliance with FCC and other Federal rules and regulations, and by providing the training and support Native broadcasters need. Native public radio stations still exist as one of the primary sources of public information on tribal lands, and represent cornerstones of tribal efforts for information dissemination. Much of Indian Country remains disconnected from vital telecommunications services, radio should not be counted among them. Radio has always existed as a key component of public information and 55 tribal radio stations among this country's 566 federally recognized tribes illustrates the need for these services in Indian Country.

PREPARED STATEMENT OF NATIONAL COUNCIL OF SOCIAL SECURITY MANAGEMENT
ASSOCIATIONS

On behalf of the National Council of Social Security Management Associations (NCSSMA), thank you for the opportunity to submit this testimony regarding the Social Security Administration's (SSA's) fiscal year 2015 Appropriation.

NCSSMA is a membership organization of nearly 3,300 SSA managers and supervisors who provide leadership in over 1,200 community-based field offices and teleservice centers throughout the country. We are the front-line service providers for SSA in communities all over the Nation. Since the founding of our organization over 44 years ago, NCSSMA has considered a stable SSA, which delivers quality and timely community-based service to the American public, our top priority. We also consider it a top priority to be good stewards of the taxpayers' monies and the Social Security programs we administer.

We would like to express our appreciation for the fiscal year 2014 Limitation on Administrative Expenses (LAE) account funding of \$11.697 billion provided to SSA. Increased resources, especially in SSA's field offices and teleservice centers, will have a positive impact on delivering vital services to the American public and in fulfilling the agency's stewardship responsibilities. Since October 2010, SSA field offices had lost almost 4,100 permanent employees prior to the first wave of fiscal year 2014 hiring. The teleservice centers (TSCs) lost 1,159 employees during the same timeframe. For the first time in over 3 years, we are replacing some of these losses. Because of the fiscal year 2014 funding, authority was granted to field offices and teleservice centers to hire 2,350 and 850 permanent employees, respectively. In

addition, 550 permanent hires were approved for Workload Support Units (WSUs) that are expected to ease the burden placed on field offices.

The dramatic growth in SSA workloads, along with the attrition in our offices over the last several years, has highlighted the need to receive necessary resources to maintain service levels vital to the nearly 65 million Social Security beneficiaries and Supplemental Security Income (SSI) recipients. Despite agency strategic planning, expansion of online services, significant productivity gains, and the best efforts of management and employees, SSA still faces many challenges providing the service the American public has earned and deserves.

Over the last several years, SSA has experienced a significant increase in Social Security claims. The additional claims receipts are driven in large part by the initial wave of the nearly 80 million baby boomers who will be filing for Social Security benefits by 2030, an average of 10,000 per day.

- In fiscal year 2013, SSA field offices assisted 43.3 million visitors, received 4.9 million retirement, survivor and Medicare applications, and 2.9 million initial disability claims.
- In fiscal year 2013, SSA completed 2,987,883 initial disability claims. Since fiscal year 2007, initial disability claims receipts have increased by over 25 percent.
- In fiscal year 2013, SSA completed 5,006,855 retirement, survivor, and Medicare claims (5,001,092 in fiscal year 2012)—a record number and over a million more than completed in fiscal year 2007.
- In fiscal year 2013, retirement, survivor, and Medicare claims were 30 percent higher as compared to fiscal year 2007.
- Each day over 155,000 people visit SSA field offices and more than 436,000 call SSA for a variety of services.

We fully support the President's budget request of \$12.024 billion for SSA's LAE account in fiscal year 2015. While this would be a much-appreciated increase of \$327 million over the fiscal year 2014 level of funding, it would only address fixed cost increases. The fiscal year 2015 Budget Request submitted by Acting Commissioner Carolyn Colvin to President Obama for SSA's administrative funding was \$12.6 billion. This level of funding will allow SSA to continue improving and modernizing customer service, enhance program integrity efforts, detect and deter fraud and errors, and continue to address high volumes of work. In November of 2013, NCSSMA co-authored a letter with 29 other organizations, which was submitted to the Office of Management and Budget (OMB) and recommended a funding level consistent with the Acting Commissioner's request for SSA's administrative funding. Specifically the letter stated:

SSA teleservice centers, hearing offices, program service centers, disability determination services (DDS), and field offices are in critical need of adequate resources to address their growing workloads. The recommended fiscal year 2015 budget of no less than \$12.6 billion would allow SSA to cover inflationary increases, resume efforts to reduce hearings and disability backlogs, complete deficit-reducing program integrity work, and replace critical staffing losses in SSA's components, including field offices, teleservice centers, and DDSs.

Adequate funding would also help to minimize the closure of additional field offices. Since fiscal year 2010, SSA consolidated 92 field offices into 46 field offices and closed 521 contact stations. The agency also cancelled plans to open eight new hearing offices and a new teleservice center due to limited resources. In many cases, applicants for benefits or those approaching retirement age who have questions about their eligibility or benefits have been forced to travel greater distances to visit a Social Security field office.

The fiscal year 2014 appropriation for SSA provided \$1.197 billion dedicated to program integrity activities to ensure that disability and other benefits are properly paid. SSA plans to process 2.6 million SSI redeterminations and 510,000 full medical continuing disability reviews (CDRs) in fiscal year 2014. Despite these efforts, the agency continues to have 1.3 million CDRs backlogged due to budgetary shortfalls. The fiscal year 2015 budget request would provide \$1.396 billion dedicated to program integrity. With these funds, the agency would be able to complete 880,000 full medical CDRs and 2.6 million SSI redeterminations. Completing more than 880,000 CDRs would more than double the CDRs completed in 2013, saving billions of taxpayer dollars.

While it is critical SSA focus on cost-effective program integrity work to protect taxpayer dollars, there must be a balance between these efforts, preventing fraud and improper payments before they occur, and service to the American public. One way we can help stop fraud before it starts is through the work of Cooperative Disability Investigation (CDI) units. With the increased fiscal year 2014 funding, SSA will be able to add 7 units to the existing 25. We recognize CDI unit expansion is

not enough and advocate for additional focus on program integrity initiatives including providing in-depth training for identifying and reporting fraud for our front-line employees. Field office employees are the first line of defense against fraud, and must have the training and resources necessary to identify and report questionable activities and claims. Additional training initiatives have begun in fiscal year 2014, but must continue.

SSA is challenged by ever-increasing workloads, very complex programs to administer, and increased program integrity work with diminished staffing and resources. With the current fiscal challenges confronting SSA, we encourage Congress to consider changes to the Social Security and SSI programs that have the potential to increase administrative efficiency and lower operational costs.

It is critical SSA receives adequate, yet flexible funding for the LAE account to respond to requests for assistance from the American public, and to fulfill our stewardship responsibilities. SSA TSCs, hearing offices, program service centers (PSCs), DDS, and the over 1,200 field offices are in grave need of adequate resources to address their growing workloads. Many of SSA's field offices are currently experiencing wait times in excess of 60 minutes. One out of every 8 visitors waits more than 1 hour to receive services, which is 177 percent more than in fiscal year 2012 and 224 percent more than fiscal year 2011. Without adequate funding, SSA will not be able to provide the high-quality customer service Americans deserve and will be unable to process program integrity workloads, which save taxpayer dollars and reduce the Federal budget and deficit.

We realize the fiscal year 2015 funding level requested above is not insignificant, particularly in this difficult Federal budget environment. However, Social Security serves as the largest most vital component of the social safety net of America and is facing unprecedented challenges. The American public expects and deserves SSA's assistance.

On behalf of NCSSMA members nationwide, thank you for the opportunity to submit this written testimony. We respectfully ask that you consider our comments, and would appreciate any assistance you can provide in ensuring the American public receives the critical and necessary service they deserve from the Social Security Administration.

[This statement was submitted by Scott Hale, President, National Council of Social Security Management Associations.]

PREPARED STATEMENT OF THE NATIONAL ENERGY ASSISTANCE DIRECTORS' ASSOCIATION

The members of the National Energy Assistance Directors' Association (NEADA), representing the State directors of the Low Income Home Energy Assistance Program (LIHEAP) would first like to take this opportunity to thank the members of the Subcommittee for considering our funding request for fiscal year 2015 and advance funding for fiscal year 2016.

We would also like to thank the members of the Committee for increasing the funding for fiscal year 2014. These additional funds allowed States to increase grants for low income families to help them pay a portion of their higher home heating costs during this year's bitterly cold winter. The additional funds will also allow States to maintain at least a minimal level of support for cooling programs this summer.

Purchasing Power of LIHEAP Continues to Decline

The increase in program funding in fiscal year 2014, however, was not sufficient to stem the continuing decline in the purchasing power of the average LIHEAP grant. Since fiscal year 2010, the purchasing power of the average grant has declined from 60.2 percent of the cost of home heating to 44.7 percent. In other words, in fiscal year 2010, the average grant could purchase approximately 72 days of home heating, whereas in fiscal year 2014, the average grant could only purchase 54 days of home heating.

The program's purchasing power is declining for two reasons:

—First and foremost is the decline in the program's appropriation. Between fiscal year 2010 and fiscal year 2013, LIHEAP's annual appropriation declined from \$5.1 billion to \$3.25 billion. As a result, during this time States were forced to reduce the average grant from \$520 to \$398 and the number of households served from 8.1 million to 6.7 million. The increase in funding in fiscal year 2014 to \$3.4 billion allowed States to increase the average grant by \$21 to \$419, still almost \$100 less than the average grant awarded in fiscal year 2010.

—Second, average home heating costs increased from \$796 during the winter heating season of 2011—12 (fiscal year 2012) to \$936 during this recent winter heating season. During this period, the average increase for those using natural gas went from \$567 to \$663; for electricity, from \$840 to \$934; for heating oil, from \$1,735 to \$2,243; and for propane, from \$1,563 to \$2,269.

LIHEAP is the primary source of heating and cooling assistance for some of the poorest families in the United States. In fiscal year 2014, the number of households receiving heating assistance is expected to remain at about 6.7 million households, or about 19 percent of those eligible to receive assistance. In addition, the program is expected to reach about 600,000 households for cooling assistance, the same level that received assistance in fiscal year 2013.

President's Budget Would Severely Reduce the Number of Households Served

The President's fiscal year 2015 Budget request for LIHEAP would result in even greater cuts to the program's effectiveness by reducing the amount available for program grants to \$2.7 billion. In order to maintain the program's purchasing power, States would have no choice but to reduce the number of households served from about 6.7 million to 5.3 million, or about 15 percent of eligible households.

Fiscal year 2015 Funding Request and fiscal year 2016 Advanced Funding Request

For fiscal year 2015 we are requesting that the Subcommittee restore funding for LIHEAP to the authorized level of \$5.1 billion. The additional funds would allow States to increase the number of households served to 8.1 million, raise the average grant to at least 50 percent of the cost of home heating, and expand the number of households served by home cooling.

In addition, we are concerned that States will be hampered in their ability to administer their programs efficiently due to the lack of advanced funding. The lack of a final program appropriation prior to the beginning of the fiscal year creates significant administrative problems for States in setting their program eligibility guidelines. To address this concern, we are requesting advance appropriations of \$5.1 billion for fiscal year 2016.

What Is the Impact of Declining Federal Funds?

Surveys of families receiving Federal assistance have been consistent over the years. Poor families struggle to pay their home energy bills. When they fall behind, they risk shut-off of energy services or they are not able to afford the purchase of delivered fuels. In fiscal year 2011, NEADA conducted a survey of approximately 1,800 households that received LIHEAP benefits. The results show that LIHEAP households are among the most vulnerable in the country:

- 40 percent had someone age 60 or older.
 - 72 percent had a family member with a serious medical condition.
 - 26 percent used medical equipment that requires electricity.
 - 37 percent went without medical or dental care.
 - 34 percent did not fill a prescription or took less than their full dose of prescribed medication.
 - 19 percent became sick because the home was too cold.
 - 85 percent of people with a medical condition were seniors.
- Many LIHEAP recipients were unable to pay their energy bills:
- 49 percent skipped paying or paid less than their entire home energy bill.
 - 37 percent received a notice or threat to disconnect or discontinue their electricity or home heating fuel.
 - 11 percent had their electric or natural gas service shut off in the past year due to nonpayment.
 - 24 percent were unable to use their main source of heat in the past year because their fuel was shut off, they could not pay for fuel delivery, or their heating system was broken and they could not afford to fix it.
 - 17 percent were unable to use their air conditioner in the past year because their electricity was shut off or their air conditioner was broken and they could not afford to fix it.

LIHEAP's impact in many cases goes beyond providing bill payment assistance by playing a crucial role in maintaining family stability. It enables elderly citizens to live independently and ensures that young children have safe, warm homes to live in. Although the circumstances that lead each client to seek LIHEAP assistance are different, LIHEAP links these stories by enabling people to cope with difficult circumstances with dignity.

The Need for LIHEAP

Households reported enormous challenges despite the fact that they received LIHEAP assistance. However, they reported that LIHEAP was extremely important.

About 64 percent reported that they would have kept their home at unsafe or unhealthy temperatures and/or had their electricity or home heating fuel discontinued if it had not been for LIHEAP. Almost 98 percent said that LIHEAP was very or somewhat important in helping them to meet their needs. In addition, 53 percent of those who did not have their electricity or home heating fuel discontinued said that they would have if it had not been for LIHEAP.

The members of NEADA recognize the difficult budget decisions that you face as you consider funding levels for LIHEAP for fiscal year 2015 and advance funding for fiscal year 2016. We appreciate your interest and continued support for LIHEAP. Please feel free to call upon us if we can provide you with additional information.

[This statement was submitted by Mark Wolfe, Executive Director, National Energy Assistance Directors' Association.]

PREPARED STATEMENT OF THE NATIONAL FAMILY PLANNING & REPRODUCTIVE
HEALTH ASSOCIATION

Summary: Requesting \$337 million in funding for fiscal year 2015 for the national family planning program (Title X of the Public Health Service Act).

My name is Clare Coleman; I'm the President & CEO of the National Family Planning & Reproductive Health Association (NFPRHA), a membership organization representing the Nation's safety-net family planning providers—nurse practitioners, nurses, physicians, administrators and other key healthcare professionals. Many of NFPRHA's members receive Federal funding from Medicaid and through Title X of the Federal Public Health Service Act, the only federally funded, dedicated, family planning program for the low income and uninsured. These critical components of the Nation's public health safety net are essential resources for those providing access to high-quality services in communities across the country. As the Committees work on the fiscal year 2015 appropriations bill, NFPRHA respectfully requests that you make a significant investment in Title X by including \$337 million to restore the capacity of the program to serve those in need.

NFPRHA was disappointed to see the president's fiscal year 2015 proposal only included \$286.5 million for Title X. As more individuals gain access to healthcare coverage through the Affordable Care Act, the publicly funded family planning network will continue to play an essential role in our Nation's service delivery framework, setting the standard for and providing high-quality care to all patients—the insured, uninsured, under-insured as well as patients seeking confidential services. If the Massachusetts health reform experience were to prove representative of what could be expected by nationwide health reform, there will be a strong increase in demand for services within the already-strained safety net. At present, six in ten women describe family planning centers as their usual source of medical care. According to a report by the Centers for Disease Control and Prevention (CDC), as health reform in Massachusetts expanded coverage for most people living in the State, Title X family planning health centers continued to have high volumes of patients, both insured and uninsured, and remained providers of choice for many.

The failure of States to expand Medicaid eligibility for all adults up to 138 percent of the Federal poverty level (an income of \$16,105 a year for an individual in 2014)—along with new barriers to coverage being sought by some expansion States, such as premiums and other cost-sharing requirements—compounds the demand being placed on the Title X safety net. Currently, 25 States have not expanded their Medicaid eligibility under the ACA. Twenty-one of these States have Medicaid eligibility equal to or less than 75 percent of FPL (an income of \$8,753 a year); 14 have eligibility at or below 50 percent (an income of \$5,835 a year). Five States have eligibility set at less than 25 percent of FPL—that means individuals making more than \$2,918 are too “rich” for Medicaid.

Similar to other publicly funded health programs, Title X has unfortunately suffered budget cuts despite rising patient need. Between fiscal year 2010-fiscal year 2013, the Title X family planning program was cut \$39.2 million (–12.3 percent). As a result, the total number of Title X users shrunk from 5.22 million users to 4.76 million during this time period, with no indication that patients went elsewhere for care. Congress made incremental progress in fiscal year 2014, funding Title X at \$286.5 million, a restoration of \$8.2 million over the fiscal year 2013 post-sequester level. As appropriators grapple with how best to distribute limited Federal resources, NFPRHA encourages the Committees continue to prioritize investments in programs, including Title X, that are proven to save critical taxpayer dollars. Every \$1 invested in publicly funded family planning services saves \$5.68 in Medicaid costs associated with unplanned births. Additionally, services provided in Title X-

supported centers alone yielded \$5.3 billion of the \$10.5 billion in total savings for publicly funded family planning in 2010.

Lastly, Title X supports critical infrastructure and technology necessary for modern service delivery that are not reimbursable under Medicaid and commercial insurance. Resources for electronic health record implementation for safety-net providers—just as for others in the safety net—are necessary to help achieve the ACA goal of having a nationwide health information technology infrastructure and more coordinated models of care. Increased Title X funding is essential to help address the gap caused by the oversight in Federal planning that led to most family planning health providers' ineligibility for the electronic health records (EHR) incentives available under the HITECH Act.

For these reasons, NFPRHA urges the Committees to make a significant investment in the Nation's safety-net family planning health services and requests funding for Title X at \$337 million in fiscal year 2015.

[This statement was submitted by Clare Coleman, President & CEO, National Family Planning & Reproductive Health Association.]

PREPARED STATEMENT OF THE NATIONAL HEAD START ASSOCIATION

Chairman Harkin, Ranking Member Moran, and Members of the Subcommittee, thank you for allowing the National Head Start Association (NHSA) to submit testimony on behalf of funding for Head Start and Early Head Start in fiscal year 2015. For almost 50 years, Head Start centers have been creating opportunities for at-risk children and families to achieve success in life by providing critical early education, health, nutrition, parent engagement and family support services. NHSA respectfully urges the Subcommittee to continue its enduring bipartisan support by allocating \$8,868,389,000 for Head Start and Early Head Start in fiscal year 2015, in line with the President's Budget.

Head Start and Early Head Start directors remain appreciative of your leadership in ensuring that the fiscal year 2014 Omnibus Appropriations legislation not only restored the damaging cuts from sequestration, but also prioritized high quality by including additional funds to retain qualified staff and cope with the increased costs of program operation. We also sincerely appreciate the new investment in one of our most underserved populations—low-income infants and toddlers.

Within the total amount of funding for fiscal year 2015, we urge the Subcommittee to continue and build on these investments. In particular, we propose a \$150 million increase to support workforce quality improvements and to help offset the continued rise in energy, transportation, and other fixed costs related to operating a Head Start program. It is well known that one of the hallmarks of excellence in any early learning program is the caliber of its teachers. Head Start teachers are required to possess Bachelor's degrees in early learning or related fields, which enables the program to have one of the best-trained workforces in the country. However, the average salary for these degreed teachers is \$30,086—lower than what many schools pay teachers, and much lower than salaries for many other jobs with comparable education requirements.

Examples of programs losing their best staff to higher paying schools or other providers are plentiful across the country. In New York, one Head Start social/emotional education mentor-coach reported seeing several "gifted teachers, assistants and aides leave our classrooms after short stays due to the pressure to provide for their own families." Many of the staff who choose to stay with Head Start struggle to make ends meet—such as the Oregon teachers who have depended on a local food bank to help feed their own children. Others depend on other income supports. Focusing increased investment toward workforce quality improvements will help enable programs to hold on to dedicated teachers, and provide a solid foundation for the good of our students and families.

Supporting a High-Quality Birth-to-Five Pipeline:

NHSA also urges the Subcommittee to support the continued development of a birth-to-five pipeline of services through expanded access to Early Head Start, which today is only able to serve a scant 4 percent of eligible infants and toddlers. Continued early brain research tells us that with the achievement gap present as early as 18 months, these first 2 years of life represent a critical window in development. Early Head Start centers are among the highest quality environments for children of this age. We propose that the Subcommittee continue to fund the new Early Head Start-Child Care Partnerships at \$500 million. These funds should, as in fiscal year 2014, support the straight expansion of Early Head Start as well as partnerships

with Child Care providers, ensuring programs designed by and solely based on the needs of individual communities.

We are aware of many underserved areas with few options for partnerships—these communities should be given as much flexibility as possible to increase access to high-quality care. For example, Audubon Area Community Services, Inc. in Kentucky serves a 16 county area. However, even though there are an estimated 17,911 children in their service area that are eligible for Early Head Start, they are only funded to serve 301 Early Head Start slots. In two of those 16 counties, there are 600 eligible children but no licensed child care facilities with which possibly to partner. In yet a third county, there is licensed child care but none of it for infants and toddlers. With flexibility to invest in expansion, they could find a way to serve those areas.

Further, NHSA also urges the Subcommittee to allocate \$100 million to fund the expansion of the Birth-to-Five pilot programs that the Office of Head Start (OHS) began last year in Detroit, Baltimore, Jersey City, Washington, DC, and Mississippi's Sunflower County as part of the first Designation Renewal System (DRS) recompetition. The grants are meant to encourage applicants to develop comprehensive, flexible, seamless Birth-to-Five programs which incorporate both Head Start and Early Head Start funding. We hope the Subcommittee will recognize the value of this approach and support expansion of these models outside of DRS. In particular, we suggest that the Administration utilize a portion of the funds to create a process that enables current grantees that hold both types of grants to streamline the administrative burden and combine these two grants into one.

These Birth-to-Five expansion funds should also be used to assist Head Start grantees to add Early Head Start slots and convert existing Head Start slots for 3–4 year olds to Early Head Start slots; both actions support the goal of providing an Early Head Start slot to complement each Head Start slot. Across the country, as States and localities both expand and contract services for infants, toddlers, and preschoolers, Head Start programs have the necessary skills to adapt their services to fit the changing needs of their community. But as resources shift, additional funding to help transition to new or different types of slots would be a welcome support.

For instance, many States have increased their investment in serving 4-year-olds in a variety of settings through their mixed delivery system, including through organizations who receive Head Start grants. Head Start grantees are able to tap into this funding stream to support and expand their current services to 4-year-olds—however many of those communities are now under-investing in low-income infants and toddlers. If that same Head Start grantee were able to apply for funds to help transition some of its Head Start slots to Early Head Start slots, the community would then be served by a more comprehensive birth-to-five pipeline—meeting a significant need for the working parents of very young children.

Ongoing Quality Improvements:

Robust funding for Head Start and Early Head Start will ensure that key quality improvement initiatives are able to continue at the Office of Head Start. In particular, we are keen for the Office of Head Start to finalize an update to our rigorous performance standards as mandated in the 2007 Head Start Reauthorization Act. Serious and meaningful efforts are underway to ensure that the standards are modernized to reflect the needs of today's children, families, teachers, staff, and communities—while allowing for innovation and local adaptability. These standards are the heart of Head Start's model, and critical to future success.

Further, we are hopeful that the Office of Head Start is able to continue its improvements to the Head Start Monitoring System—the oversight mechanism that ensures Head Start and Early Head Start grantees are meeting all of their high standards. We are pleased that the Office has instituted new initiatives that aim to work with programs to prevent issues before they occur. We are also appreciative that they are enabling iterative feedback and data collection to better target assistance and intervention where programs require it most. These are welcome changes, and we are hopeful that the Office of Head Start is afforded the resources to continue these improvements.

One of the best-known provisions of the 2007 Head Start Act requires Head Start grantees designated as low-performing to compete for the continuation of their grant. Different from the Head Start grant termination process, this additional accountability measure, the Designation Renewal System (DRS) which is now in its third cycle, has been an enormous undertaking for the Office of Head Start and requires adequate resources to fully staff and execute.

We support the Administration's request for \$25 million to assist with grantee transition costs in the event that a grant turns over, though NHSA remains con-

cerned that the Office of Head Start's timetable for executing these competitions is unintentionally poorly timed. Currently, Head Start grantees are notified in January of their recompetition status, but the results of those competitions are not determined until late in the summer. With a school year beginning shortly thereafter, any new grantee taking over for a low-quality incumbent faces a steep climb to recruit teachers, enroll children, and find any necessary facilities and other resources to start up their program. This is an avoidable strain on communities.

Considering the opportunity that DRS provides to improve program quality, we must ensure that the process is done right. We hope the Subcommittee considers additional assistance to the Office of Head Start to ensure that these competitions are run effectively and efficiently, and that the process is accurately capturing programs that are of low quality.

Head Start is a High Yield Investment:

To take a step back, NHSA believes that the budget caps now in place limit the opportunities to make effective investments in our future. President Obama proposed an additional \$800 million to support Head Start and Early Head Start expansion. We support the President's focus on the need to reach the large population of underserved, at-risk infants, toddlers, and preschoolers, but understand that appropriations that exceed the fiscal year 15 budget caps are unlikely.

Certainly, we respect the idea that our debt cannot be left for the very children we serve. We do hope that deficit reduction can still be achieved in a way that does not squander our highest-yield investments. Studies show that for every one dollar invested in a Head Start child, society earns at least \$7 back through increased earnings, employment, and family stability;¹ as well as decreased welfare dependency,² healthcare costs,³ crime costs,⁴ grade retention,⁵ and special education.⁶ These are the very results taxpayers demand.

Again, the Head Start community understands the pressure the Subcommittee faces and is grateful for the commitment shown by Congress and the President to keep early learning, and Head Start in particular, as a priority. We urge the Subcommittee to build on the investments made in Head Start and Early Head Start, to increase access, to improve accountability, and ensure the prosperity of our next generation. Thank you for your time and consideration.

[This statement was submitted by Yasmina Vinci, Executive Director, National Head Start Association.]

PREPARED STATEMENT OF THE NATIONAL INDIAN CHILD WELFARE ASSOCIATION

The National Indian Child Welfare Association (NICWA) is a national American Indian/Alaska Native (AI/AN) nonprofit organization. NICWA has over 35 years of experience providing leadership in the development of public policy that supports tribal self-determination in child welfare and children's mental health systems.

Child Welfare Overview

Tribes have an important relationship with their children and families: they are experts in the needs of AI/AN children, best suited to effectively serve those needs,

¹Ludwig, J. and Phillips, D. (2007). The Benefits and Costs of Head Start. Social Policy Report. 21 (3): 4; Deming, D. (2009). Early childhood intervention and life-cycle skill development: Evidence from Head Start. American Economic Journal: Applied Economics, 1(3): 111-134; Meier, J. (2003, June 20). Interim Report. Kindergarten Readiness Study: Head Start Success. Preschool Service Department, San Bernardino County, California; Deming, D. (2009, July). Early childhood intervention and life-cycle skill development: Evidence from Head Start, p. 112.

²Meier, J. (2003, June 20). Kindergarten Readiness Study: Head Start Success. Interim Report. Preschool Services Department of San Bernardino County.

³Frisvold, D. (2006, February). Head Start participation and childhood obesity. Vanderbilt University Working Paper No. 06-WG01; Currie, J. and Thomas, D. (1995, June). Does Head Start Make a Difference? The American Economic Review, 85 (3): 360; Anderson, K.H., Foster, J.E., & Frisvold, D.E. (2009). Investing in health: The long-term impact of Head Start on smoking. Economic Inquiry, 48 (3), 587-602.

⁴Reuters. (2009, March). Cost of locking up Americans too high: Pew study; Garces, E., Thomas, D. and Currie, J. (2002, September). Longer-term effects of Head Start. American Economic Review, 92 (4): 999-1012.

⁵Barnett, W. (2002, September 13). The Battle Over Head Start: What the Research Shows.; Garces, E., Thomas, D. and Currie, J. (2002, September). Longer-Term Effects of Head Start. American Economic Review, 92 (4): 999-1012.

⁶NHSA Public Policy and Research Department analysis of data from a Montgomery County Public Schools evaluation. See Zhao, H. & Modarresi, S. (2010, April). Evaluating lasting effects of full-day prekindergarten program on school readiness, academic performance, and special education services. Office of Shared Accountability, Montgomery County Public Schools.

and most able to improve child welfare outcomes for these children (NICWA & Pew Charitable Trust, 2007). In addition, statistics show that AI/AN children face elevated rates of child abuse and neglect (Dept. of Health and Human Services, 2012). The key to successful tribal child welfare is a budget that avoids unnecessary restraint on tribal decisionmaking and accounts for the elevated need. For this reason we make the following recommendations:

—For programs administered by the Department of Health and Human Services, Administration for Children and Families: Promoting Safe and Stable Families (\$75 million discretionary; \$345 million mandatory), Child Welfare Services (\$280 million), Child Abuse Discretionary Activities (\$35 million), Community Based Child Abuse Prevention Program (\$60 million), and Demonstration to Address Over-Utilization of Psychotropic Medications for Children in Foster Care (\$250 million).

Children's Mental Health Overview

To understand the mental health needs of AI/AN children, policymakers must consider the legacy of trauma that has been visited upon this population and left them with unresolved historical trauma (Yellow Horse Brave Heart and DeBruyn, 1998). Inadequate funding, uncoordinated health systems, cultural incompetence, and a shortage of mental health professionals are barriers to the development of successful mental health systems of care in AI/AN communities (Novins & Bess, 2011). Key to children's mental health programs in tribal communities is a budget that supports and strengthens a system of tribally driven children's mental health prevention, intervention, and treatment. For this reason we make the following recommendations:

—For programs administered by the Department of Health and Human Services, Substance Abuse Mental Health Services Administration: Programs of Regional and National Significance, Children and Family Programs (\$6.5 million), Children's Mental Health Services Program, Children's Mental Health Initiative (\$117 million), Tribal Behavioral Health Grants (\$40 million), GLS Youth Suicide Prevention Program (\$35.5 million), and AI/AN Suicide Prevention (\$2.94 million).

CHILD WELFARE PRIORITY RECOMMENDATIONS

Child Welfare Services Program recommendation: Restore funding to at least \$280 million, to increase funding for tribal programs while still providing for an increase in state funding.

This program provides funds to promote program flexibility and fill gaps in child welfare programming. Tribes receive an allocation based on a population-based formula identified within the regulations. This tribal allocation is then deducted from the state's allocation. Studies show that culturally competent programs, resources, and case management result in better outcomes for AI/AN children and families involved in the child welfare system (Red Horse, Martinez & Day, 2001). The funding of the Child Welfare Service Program is flexible enough for tribes to tailor their child welfare services to fit their communities' needs and culture.

Without adequate funding AI/AN children and families in tribal communities cannot receive the care they need and remain at risk of further harm and trauma. Of the 566 federally recognized tribes 180 depend on this funding. The median tribal grant is about \$13,300 an insufficient amount to support all the gaps in tribal services this program can fill. Because of the way the formula for tribal grants has been created, it is essential to increase the entire appropriation of this program to \$280 million to increase tribal amounts.

Promoting Safe and Stable Families recommendation: Increase discretionary funding to \$75 million to allow more tribes, who are currently ineligible, access to these funds. As recommended by the President's Budget fully fund the \$345 million in mandatory funding cut due to sequestration.

PROMOTING SAFE AND STABLE FAMILIES (SOCIAL SECURITY ACT TITLE IV-B, SUBPART 2)

	Fiscal year 2012 enacted	Fiscal year 2013 * enacted	Fiscal year 2014 enacted	Fiscal year 2015 president budget	Fiscal year 2015 recommended	Authorization
Mandatory	\$345,000,000	\$327,405,500	\$320,160,000	\$345,000,000	\$345,000,000	\$345,000,000
Discretionary	63,065,000	59,671,500	59,765,000	59,765,000	75,000,000	200,000,000
Total	408,065,000	387,077,000	379,925,000	404,765,000	420,000,000	545,000,000
Tribal Mandatory	9,149,000	8,459,200	9,604,800	10,350,000	14,100,000	3% set aside

PROMOTING SAFE AND STABLE FAMILIES (SOCIAL SECURITY ACT TITLE IV-B, SUBPART 2)—
Continued

	Fiscal year 2012 enacted	Fiscal year 2013 * enacted	Fiscal year 2014 enacted	Fiscal year 2015 president budget	Fiscal year 2015 recommended	Authorization
Tribal Discretionary	1,892,000	1,790,000	1,792,950	1,792,950	2,250,000	of total
Tribal Total	11,041,000	~10,249,200	~11,397,750	12,142,950	16,350,000	appropriation

* Reflects sequestration effects.

This program is designed to provide funds to operate a coordinated program of family preservation, family support, reunification, and adoption services. Promoting Safe and Stable Families is authorized with both a mandatory capped entitlement (\$345 million) as well as a discretionary appropriation (\$200 million). Tribes are eligible for funds based on a 3 percent set-aside of the total appropriation. All tribes whose plan receives approval are eligible for a portion equal to that tribe's relative share of children compared with all tribal entities with approved plans. Tribes who would qualify for less than 10 thousand dollars under the formula are not eligible to receive funding.

Tribal child welfare programs work tirelessly to strengthen families and provide services that keep children safely in their homes. This program is an integral part of these efforts. It supports parenting classes, home-visiting services, respite care for caregivers of children, and other services that safely preserve families.

One hundred and thirty tribes and tribal consortia depend on this funding. Yet because of the funding levels, many tribes are ineligible for these formula grant dollars as their portion of the tribal set-aside is less than \$10,000. Increasing this program's discretionary funding to \$75 million and fully funding the \$345 million in mandatory funding would help dozens of new tribes access this funding and hundreds of families obtain tribal child welfare services.

CHILD WELFARE OTHER RECOMMENDATIONS

Child Abuse Discretionary Activities, including Innovative Evidence-Based Community Prevention Programs recommendation: Increase appropriations to \$35 million to account for tribes' recent eligibility for these funds while holding state and other grantees harmless.

The Community Based Child Abuse Prevention Program recommendation: Increase funding to \$60 million, so that more tribes can have access to these scarce child abuse prevention dollars.

Demonstration to Address Over-Utilization of Psychotropic Medications for Children in Foster Care (Presidents fiscal year 2015 Initiative) recommendation: Fund this initiative at the proposed \$250 million and ensure a tribal set-aside of 3 percent so that tribal communities can also participate in this important initiative to ensure children receive holistic mental healthcare.

DEPARTMENT OF HEALTH AND HUMAN SERVICES RECOMMENDATIONS SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION

CHILDREN'S MENTAL HEALTH PRIORITY RECOMMENDATIONS

Programs of Regional and National Significance: Children and Family Programs (Circles of Care) recommendation: Fund Circles of Care Program at \$6.5 million as recommended by the President to ensure current communities can continue their important work and new tribal communities can have access to this program.

The Children and Family Programs line item represents funds allocated to the Circles of Care Program. The Circles of Care program is the cornerstone of children's mental health programming in tribal communities. The Circles of Care program is the only SAMHSA grant program that is focused specifically on AI/AN children's mental health needs. It is also the only SAMHSA program that allows tribes and tribal organizations to apply without competing for funding with other governmental entities such as States, counties, or cities. There are currently seven communities receiving Circles of Care funding.

The American Psychiatric Association has found that AI/AN children and youth face a "disproportionate burden" of mental health issues while simultaneously facing more barriers to quality mental healthcare (2010). Circles of Care provides communities with funding to plan and build culturally competent services and design integrated supports that meet the specific needs of their youth with behavioral health challenges. It is essential to the well-being of AI/AN children. It is imperative that

funding that matches the President's Budget request of \$6.5 million be reserved in this line item for the Circles of Care program. This will ensure that more tribal communities can access this grant and improve their children's mental healthcare systems.

Children's Mental Health Services Program: Children's Mental Health Initiative (Systems of Care) recommendation: Maintain funding at \$117 million to continue support of Tribal children's mental health systems change efforts.

The various Systems of Care grants funded under this line item support a community's efforts to plan and implement strategic approaches to mental health services and supports that are family driven; youth guided; strength based; culturally and linguistically competent; and meet the intellectual, emotional, cultural, and social needs of children and youth.

The American Psychiatric Association (APA; 2010) has recognized family, culture, and traditional health practices as important protective factors for AI/ANs struggling with mental health challenges. The Systems of Care program, which foster those protective factors described by the APA, has been both well-received and particularly effective in tribal communities. Currently, 17 tribal communities are funded under the Children's Mental Health Initiative line item.

The well-being of AI/AN children is dependent on the ability of more tribes to access these funds and create real systems change. Thus, funding must be maintained at \$117 million as recommended by the President's Budget. This will ensure the current Systems of Care grantees can continue, and a new robust cohort of grantees can begin this important work.

CHILDREN'S MENTAL HEALTH RECOMMENDATIONS

Tribal Behavioral Health Grants recommendation: Implement President's Budget fiscal year 2013 recommendation to fund this new initiative at \$40 million so that additional tribal communities can receive resources for children's mental health and substance abuse.

The GLS State/Tribal Youth Suicide Prevention and Early Intervention Program recommendation: Keep funding at the fiscal year 2014 appropriated level of \$35.5 million to ensure that current grantees can complete their projects, and a similar sized cohort of annual grantees will have access to this program.

AI/AN Suicide Prevention program recommendation: Fund at the President's Budget recommended amount of \$2.94 million, to ensure that the epidemic of AI/AN suicide receives the attention it warrants.

If you have any questions about this testimony please contact NICWA Government Affairs Associate Addie Smith at addie@nicwa.org.

PREPARED STATEMENT OF THE NATIONAL INDIAN EDUCATION ASSOCIATION

The National Indian Education Association (NIEA) was incorporated in 1970 and is the most representative Native education organization in the United States. NIEA's mission is to advance comprehensive and equal educational opportunities for American Indian, Alaska Native, and Native Hawaiian students. NIEA supports tribal sovereignty over education as well as strengthening traditional Native cultures and values that enable Native learners to become contributing members of their communities. As the most inclusive Native education organization, NIEA membership consists of tribal leaders, educators, students, researchers, and education stakeholders from all 50 States. From communities in Hawaii, to tribal reservations across the continental U.S., to villages in Alaska and urban communities in major cities, NIEA has the most reach of any Native education organization in the country.

Tribes and Native communities have a tremendous stake in an improved education system, because an improved system equates to better services for Native people and students. As tribes work to increase their footprint in education, there must be support for that increased participation. The Federal Government must uphold its trust relationship with tribes. Established through treaties, Federal law, and U.S. Supreme Court decisions, this relationship includes a fiduciary obligation to provide parity in access and equal resources to all American Indian and Alaska Native students, regardless of where they attend school. National fiscal and policy concerns should not be addressed by decreasing funds and investment to Native students or the programs that serve them. Rather, Native education, including those programs and services under the Departments of Education (ED) and Health and Human Services (HHS), is one of the most effective and efficient investments the Federal Government can make.

As tribes and Native communities work with Congress for parity in access to increase their role and responsibility in administering education, Federal support for tribal governments and Native education institutions has continued to shrink as a percentage of the Federal budget. Historical funding trends illustrate that the Federal Government is abandoning its trust responsibility by decreasing Federal funds to Native-serving programs by more than half in the last 30 years. Sequestration only exacerbated those shortfalls.

While fiscal year 2014 funding increases over sequestration levels were welcome, several Native-serving programs remained flat with 2013 sequestration levels, such as Elementary and Secondary Education Act Title VII funding. These levels continue to be insufficient for effectively and equally serving Native students. Partly as a result of this insufficient funding, Native students continue to lag behind their non-Native peers. Graduation rates often hover around 50 percent in many States, which can lead to increased substance abuse, criminal acts, and extended periods of unemployment. If the 25,000 Native students who dropped out of the Class of 2010 had graduated, an additional \$295 million would likely have been added to total annual earnings, supplementing local and regional economies.

To provide tribes and Native communities the educational institutions that supplement economic growth, the Federal Government should fund Native education programs at the levels requested below as they detail the minimum appropriations needed to maintain a system that is already struggling and underfunded. The following funding requests illustrate continuing need for Native programs but do not comprise the full list of budget requests, which can be found in the fiscal year 2015 NIEA Budget Document. Further, NIEA supports the budget requests of the National Congress of American Indians and American Indian Higher Education Consortium.

State-Tribal Education Partnership (STEP) Program (ED)

—Provide \$5 million. An increase of \$3 million.

Congress appropriated roughly \$2 million dollars for the STEP program to five participating tribes under the Tribal Education Department appropriations. In order for this program to successfully achieve the original intent of the appropriation, it must receive its own line and authorization of appropriations in fiscal year 2015. Collaboration between tribal education agencies and State education agencies is crucial to developing the tribal capacity to assume the roles, responsibilities, and accountability of tribal education departments that increase self-governance in Native education.

Impact Aid (ED)

—Provide \$2 billion for Impact Aid, under ESEA Title VIII. An increase of \$711 million.

Impact Aid provides direct payments to public school districts as reimbursement for the loss of traditional property taxes due to a Federal presence or activity, including the existence of an Indian reservation. With nearly 93 percent of Native students enrolled in public schools, Native students were disproportionately affected by the devastating reductions implemented under sequestration. Additional funds are required to cover previous Impact Aid shortfalls.

Title VII (Indian Education Formula Grants in ED)

—Provide \$198 million under ESEA Title VII, Part A. An increase of \$74 million.

This grant funding is designed to supplement the regular school program and assist Native students so they have the opportunity to achieve the same educational standards as their non-Native peers. Title VII funding, which was maintained at 2013 sequestration levels in fiscal year 2014, only reaches 500,000 Native students leaving over 100,000 without supplementary academic and cultural programs in their schools. As Native students continually lag behind their non-Native peers in educational achievement, increased funding is necessary to address this substantial gap.

Native Hawaiian Education Program (ED)

—Provide \$35 million under ESEA Title VII, Part B. An increase of \$3 million.

The Native Hawaiian Education program empowers innovative culturally-appropriate programs to enhance the quality of education for Native Hawaiians. When establishing the Native Hawaiian Education Program, Congress acknowledged the trust relationship between the Native Hawaiian people and the United States. These programs strengthen Native Hawaiian culture and improve educational attainment, both of which are correlated with positive economic outcomes.

Alaska Native Education Equity Assistance Program (ED)

—Provide \$35 million under ESEA Title VII, Part C. An increase of \$5 million. This assistance program funds the development of curricula and education programs that address the unique educational needs of Alaska Native students as well as the development and operation of student enrichment programs in science and mathematics. Other eligible activities include professional development for educators, activities carried out through Even Start and Head Start programs, family literacy services, and dropout prevention programs.

Vocational Rehabilitation Services Projects for American Indians with Disabilities (ED)

—Provide \$67 million to Vocational Rehabilitation Services Projects. Create a line item of \$5 million for providing outreach to tribal recipients.

According to the Centers for Disease Control and Prevention, approximately 30 percent of Native adults have a disability—the highest rate of any other population in the Nation. Of those, 51 percent reported having fair or poor health. A number of issues contribute to this troubling reality, including high incidences of diabetes, heart disease, and preventable accidents. As a result, tribes have an extraordinary need to support their disabled citizens in improving their health, attaining experiential learning courses, and becoming self-sufficient. Tribes have limited access to funding for vocational rehabilitation and job training as compared to States and \$67 million would begin to put tribes on par to support their disabled citizens.

Native Languages Preservation (Esther Martinez Program Grants in HHS)

—Provide \$12 million for Native language preservation with \$5 million designated to fund the Esther Martinez Native Language Programs. An increase of \$3 million.

Native language grant programs are essential to revitalizing Native languages and cultures, many of which are at risk of disappearing in the upcoming decades. In addition to protecting Native languages, these immersion programs promote higher academic success for participating students in comparison to their Native peers who do not participate. The Federal budget should include \$12 million for Native language preservation activities which would include \$5 million designated to support Esther Martinez Native Language Programs' immersion initiatives.

Thank you for your consideration of this testimony. For more information or to attain NIEA's complete budget document with all fiscal year 2015 requests for the Departments of Education and Health and Human Services, please contact Ahniwake Rose, NIEA Executive Director, at arose@niea.org.

PREPARED STATEMENT OF THE NATIONAL KIDNEY FOUNDATION

The National Kidney Foundation (NKF) is pleased to submit testimony for the written record in support of the Centers for Disease Control and Prevention Chronic Kidney Disease Program, the National Institute of Diabetes and Digestive and Kidney Disease, and the Health Resources and Services Administration Division of Transplantation. NKF is America's largest and oldest health organization dedicated to the awareness, prevention and treatment of kidney disease for hundreds of thousands of healthcare professionals, millions of patients and their families, and tens of millions of people at risk. In addition, we have provided universally recognized evidence-based clinical practice guidelines for all stages of chronic kidney disease (CKD) since 1997 through the NKF Kidney Disease Outcomes Quality Initiative (NKF KDOQI).

We respectfully request fiscal year 2015 funding of \$2.1 million for the CDC Chronic Kidney Disease Program, \$2.066 billion for NIDDK, and \$24 million for the HRSA Division of Transplantation.

In 2011, almost 616,000 Americans had End Stage Renal Disease (ESRD), including more than 430,000 dialysis patients and nearly 186,000 kidney transplant recipients, with members of many minority populations disproportionately affected. Complicating the cost and human toll is the fact that it is a disease multiplier, with patients very likely to be diagnosed with diabetes, cardiovascular disease, or hypertension (40 percent of ESRD patients had a diagnosis of diabetes and two-thirds have diabetes or hypertension). ESRD is the only disease-specific coverage under Medicare regardless of age or other disability. In 2011, ESRD was present in 1.4 percent of Medicare beneficiaries but responsible for more than 7 percent of Medicare expenditures. (1)

NKF recently announced an initiative to help address awareness of CKD by increasing communication between practitioners and patients. There is a misconception

tion that once someone is diagnosed with CKD, there must be a referral to a nephrologist. However, there are not enough nephrologists to care for the 15 percent of the U.S. population with chronic kidney disease. NKF's CKD Primary Care Initiative will disseminate CKD guidelines to primary care physicians through education programs, symposia and practical implementation tools so they can provide this care to the growing numbers of Americans with CKD. Our initiative will help build on CDC's program, outlined below.

CDC Chronic Kidney Disease Program

To address the social and economic impact of kidney disease, NKF worked with Congress to initiate a Chronic Kidney Disease Program at CDC in fiscal year 2006. Prior to this, no national public health program focusing on early detection and treatment existed. Cost-effective treatments exist to potentially slow progression of kidney disease and prevent its complications, but only if individuals are diagnosed before the latter stages of CKD.

The CDC program is designed to identify members of populations at high risk for CKD, develop community-based approaches for improving detection and control, and educate health professionals about best practices for early detection and treatment. The National Kidney Foundation respectfully urges the Committee to maintain \$2.1 million in line-item funding for the Chronic Kidney Disease Program for fiscal year 2015. Continued support will benefit kidney patients and Americans who are at risk for kidney disease, advance the objectives of Healthy People 2020 and the National Strategy for Quality Improvement in Health Care, and fulfill the mandate created by Sec. 152 of the Medicare Improvement for Patients and Providers Act.

It is estimated that CKD affects 26 million adult Americans (2) and 73 million more are at risk. Furthermore, a task force of the American Heart Association noted that decreased kidney function has consistently been found to be an independent risk factor for cardiovascular disease (CVD) outcomes and all-cause mortality and that the increased risk is present with even mild reduction in kidney function. (3) Therefore addressing CKD is a way to achieve one of the priorities in the National Strategy for Quality Improvement in Health Care: Promoting the Most Effective Prevention and Treatment of the Leading Causes of Mortality, Starting with Cardiovascular Disease.

CKD is often asymptomatic, especially in the early stages and therefore goes undetected without laboratory testing. Some people remain undiagnosed until they have reached CKD Stage 5 and must begin dialysis immediately. However, early identification and treatment can slow the progression of kidney disease, delay complications, and prevent or delay kidney failure. Accordingly, Healthy People 2020 Objective CKD—2 is to “increase the proportion of persons with chronic kidney disease (CKD) who know they have impaired renal function.”

Screening and early detection provides the opportunity for interventions to foster awareness, foster adherence to medications and control risk factors. Additional data collection is required to precisely define the incremental benefits of early detection on kidney failure, cardiovascular events, hospitalization and mortality. Increasing the proportion of persons with CKD who know they are affected requires expanded public and professional education programs and screening initiatives targeted at populations who are at high risk. As a result of consistent congressional support, the National Center for Chronic Disease Prevention and Health Promotion at CDC has instituted a series of projects that could assist in attaining the Healthy People 2020 objective. However, this forward momentum will be stifled and CDC's investment in CKD to date jeopardized if line-item funding is not continued.

As noted in CDC's Preventing Chronic Disease: April 2006, Chronic Kidney Disease meets the criteria to be considered a public health issue: (1) the condition places a large burden on society; (2) the burden is distributed unfairly among the overall population; (3) evidence exists that preventive strategies that target economic, political, and environmental factors could reduce the burden; and (4) evidence shows such preventive strategies are not yet in place.

The Chronic Kidney Disease program has consisted of three projects to promote kidney health by identifying and controlling risk factors, raising awareness, and promoting early diagnosis and improved outcomes and quality of life for those living with CKD. These projects include (1) demonstrating approaches for identifying individuals at high risk for CKD through State-based screening; (2) conducting an economic analysis on the economic burden of CKD and the cost-effectiveness of interventions; and (3) establishing a surveillance system for CKD by analyzing and interpreting information to assist in prevention and health promotion efforts for kidney disease. The surveillance project includes a CDC website program containing information on risk factors, early diagnosis, and strategies to improve outcomes.

Undetected Chronic Kidney Disease can lead to costly and debilitating irreversible kidney failure. However, cost-effective interventions are available if patients are identified in the early stages of CKD. With the continued support of Congress, NKF is confident a feasible detection, surveillance and treatment program can be established to slow, and possibly prevent, the progression of kidney disease.

NIDDK

NKF joins multiple other kidney patient and professional organizations to request \$2.066 billion for NIDDK in fiscal year 2015. Medicare spends \$77 billion annually to care for patients with kidney disease, including nearly \$35 billion for individuals with ESRD, yet NIH funding for kidney disease research is only about \$600 million annually or less than \$25 per patient for the 26 million adults with CKD. In March 2014, NKF hosted a Kidney Patient Summit that included participation from our advocates and those of five other kidney patient organizations. Increased Federal support for kidney disease research was one of the requests the advocates presented in meetings with their congressional delegations.

We were honored to have NIDDK Director Dr. Griffin Rodgers address the Kidney Summit where we learned of exciting opportunities in CKD research. America's scientists are at the cusp of many potential breakthroughs in improving our understanding of CKD and providing new therapies to delay and treat various kidney diseases. With the unique status of ESRD in the Medicare program, it can be argued that breakthroughs in CKD have the potential to provide cost savings to the Federal Government like that of no other chronic disease. We urge Congress to continue its strong bipartisan support for NIH in fiscal year 2015 and to fund NIDDK at this requested level that is widely supported by the kidney community.

HRSA Organ Transplantation

NKF also urges the Committee to support the President's Budget Request of \$24 million for organ donation and transplantation programs run by the Health Resources and Services Administration's (HRSA) Division of Transplantation (DoT). This represents an increase of less than \$500,000 over the fiscal year 2014 level and would restore funding to the fiscal year 2012 level.

The national organ transplant wait list contains more than 122,000 listings, including 100,000 people waiting for a kidney. Transplantation remains the treatment of choice for most patients with kidney failure yet few of them will be given an opportunity to receive a new kidney, especially if they do not have a potential living kidney donor. Kidney recipients often have an improved quality of life (and are more likely to stay in or return to the work force) and transplantation is tremendously cost effective. Medicare spends about \$25,000 per year on a kidney recipient after the year of transplant, compared to more than \$80,000 annually on a dialysis patient (these figures reflect all Medicare expenses and are not limited to kidney related care).

The HRSA program supports the Organ Procurement and Transplantation Network (OPTN) which allocates donor organs to individuals on wait lists. Additional activities supported by DoT include initiatives to increase the number of donor organs; a grant program to assist living donors with out-of-pocket expenses that are not reimbursed by insurance, a health benefit program, or any other State or Federal program; State donor registry initiatives to enroll potential donors; and, activities to build upon achievements of HRSA's Breakthrough Collaboratives of a decade ago.

Thank you for your consideration of our requests for fiscal year 2015.

(1) 2013 U.S. Renal Data System Annual Report.

(2) Josef Coresh, et al. "Prevalence of Chronic Kidney Disease in the United States," *JAMA*, November 7, 2007.

(3) Mark J. Sarnak, et al. Kidney Disease as a Risk Factor for the Development of Cardiovascular Disease: A Statement from the American Heart Association Councils on Kidney in Cardiovascular Disease, High Blood Pressure Research, Clinical Cardiology, and Epidemiology and Prevention. *Circulation* 2003; 108: 2154–69.

PREPARED STATEMENT OF THE NATIONAL LEAGUE FOR NURSING

The National League for Nursing (NLN) is the premiere organization dedicated to promoting excellence in nursing education to build a strong and diverse nursing workforce to advance the Nation's health. With leaders in nursing education and nurse faculty across all types of nursing programs in the United States—doctorate, master's, baccalaureate, associate degree, diploma, and licensed practical—the NLN has more than 1,200 nursing school and healthcare agency members, 40,000 individual members, and 24 regional constituent leagues.

The NLN urges the subcommittee to fund the following HRSA nursing programs:

- The Title VIII Nursing Workforce Development Programs at \$251 million in fiscal year 2015; and
- The Title III Nurse-Managed Health Clinics at \$20 million in fiscal year 2015.

Nursing Education Is a Jobs Program

According to the Bureau of Labor Statistics (BLS), the registered nurse (RN) workforce will grow by 19.4 percent from 2012 to 2022, outpacing the 11 percent average for most occupations. BLS projects that this growth will result in 1,052,600 job openings in the economy, representing one of the largest numeric job increases for all occupations. BLS calculates the openings from an increase of 526,800 new RN jobs due to technological advancements fueling growth in treatments, preventive care being emphasized more, expanding demand from new health reform enrollments, and accelerating demand from the two million Baby Boomers aging into Medicare every year. A particularly disconcerting element of the probable RN job openings is a loss of nursing expertise owing to the replacement need of some 525,700 jobs vacated by RNs expected to leave the profession and/or retire from the labor force by 2022.

The March 7, 2014, BLS Employment Situation Summary—February 2014 likewise reinforces the strength of the nursing workforce in creating job growth. While the Nation's overall unemployment rate was little changed at 6.7 percent for February 2014, the employment in healthcare increased with the addition of 10,000 jobs at ambulatory healthcare services, hospitals, and nursing and residential care facilities, amounting to an unemployment rate of only 4.0 percent in the industry.

BLS notes that the healthcare sector is a critically important industrial complex for the Nation. It is at the center of the economic recovery with the number of jobs climbing steadily. Growing even when the recession began in December 2007, healthcare jobs are up nationwide. Almost five million workers are in hospital settings, which often are the largest employer in a State. Healthcare has been a stimulus program generating employment and income, and nursing is the predominant occupation in the healthcare industry with more than 4.031 million active, licensed RNs in the United States in 2014.

The Nursing Workforce Development Programs provide training for entry-level and advanced degree nurses to improve the access to, and quality of, healthcare in underserved areas. The Title VIII nursing education programs are fundamental to the infrastructure delivering quality, cost-effective healthcare. The NLN applauds the subcommittee's bipartisan efforts to recognize that a strong nursing workforce is essential to a health policy that provides high-value care for every dollar invested in capacity building for a 21st century nurse workforce.

The current Federal funding falls short of the healthcare inequities facing our Nation. Absent consistent support, slight boosts to Title VIII will not fulfill the expectation of generating quality health outcomes, nor will episodic increases in funding fill the gap generated by a 15-year nurse and nurse faculty shortage felt throughout the U.S. health system.

The Nurse Pipeline and Education Capacity

Although the recession resulted in some stability in the short-term for the nurse workforce, policy makers must not lose sight of the long-term growing demand for nurses in their districts and States. The NLN's findings from its Annual Survey of Schools of Nursing—Academic Year 2011–2012 cast a wide net on all types of nursing programs, from diploma through doctoral, to determine rates of application, enrollment, and graduation. This data can be found at <http://www.nln.org/researchgrants/slides/index.htm>. Key findings include:

- Demand for spots in nursing education programs historically outstripped supply. In 2012, 43 and 37 percent of master's and doctoral nursing programs, respectively, rejected qualified applicants. More dramatically, 72 percent of programs offering practical nursing (PN) degrees and 84 percent offering associate's degrees in [registered] nursing programs (ADN) were forced to turn away qualified candidates, as did almost two-thirds (64 percent) of baccalaureate in science of [registered] nursing (BSN) programs. The aggregate rate across all basic RN programs was 28 percent of qualified applications not accepted in the Fall 2012.
- Expansion of nursing education programs impeded by shortage of faculty. Deans and directors of schools providing programs that did not accept all eligible applicants were asked to identify the primary obstacle to expanding their program's capacity. Since 2010, the percentage of those directing ADN and PN programs that cited a shortage of clinical sites as the primary impediment to expansion has steadily increased. For PN programs in particular, the percentage jumped

to 51 percent in 2012. By contrast, graduate programs consistently cite a lack of faculty as the primary obstacle to expansion. A strong correlation exists between the shortage of nurse faculty and the inability of nursing programs to keep pace with the demand for new nurse faculty and new RNs. Increasing the productivity of education programs is a high priority in most States, but faculty recruitment is a glaring problem. Without faculty to educate our future nurses, the shortage cannot be resolved.

- Age of associate degree students rises. A substantial increase in the percentage of ADN students who were over 30 years old occurred, rising in 2012 to 50 percent of the student nursing enrollments. Because ADN students comprise two-thirds of all pre-licensure RN enrollees, this uptick in enrollments among older students could reignite concerns over an aging nursing workforce and the potential for future labor shortages.

Equally Pressing Is Lack of Diversity

Our Nation is enriched by cultural diversity—37 percent of our population identify as racial and ethnic minorities. Yet ethnic, cultural, and gender diversity eludes the nursing student and nurse educator populations. A survey of nurse educators conducted by the NLN and the Carnegie Foundation's Preparation for the Professions Program found that only 7 percent of nurse educators were minorities compared with 16 percent of all U.S. faculty. The lack of faculty diversity limits nursing schools' ability to deliver culturally appropriate health professions education. In addition, the NLN survey for the 2011–2012 academic year reported that:

- African-American enrollment drops. The percentage of racial-ethnic minority students enrolled in pre-licensure RN programs has declined steadily over the past 2 years—ultimately dropping from a high of 29 percent in 2009 to 24 percent in 2011 and up to 26 percent in 2012. The majority of that decline stems from a steep reduction in the percentage of African-American students enrolled in associate degree nursing programs, which dropped by almost 5 percent to 9 percent. BSN programs saw a small, but not significant drop, in African-American enrollment, down from 13 to 12 percent. Inversely, diploma programs saw a sharp rise in African-American enrollments to 30 percent, but because they represent just 4 percent of all basic RN programs, the impact is not great.
- Hispanic representation, while still lagging, inches upward. Hispanics remain dramatically underrepresented among nursing students. Representing a mere 6 percent of associate degree and baccalaureate nursing students, Hispanics were enrolled in basic nursing programs at less than half the rate at which they were enrolled in undergraduate programs overall. However, the percentage of Hispanics enrolled in post-licensure programs has nearly doubled at every level.
- Men's enrollment at historic high. While significantly less than the proportion in the U.S. population, at 15 percent, men enrolled in basic RN programs (i.e., 13 percent BSN, 16 percent diploma, and 16 percent ADN) remained at the historic high reached at the start of the recession. Approximately 11 percent of PN students, RN-to BSN students, master's, and doctoral students were male in 2012.

Besides representing an untapped talent pool to remedy the nursing shortage, ethnic, cultural, and gender-diverse minorities in nursing are essential to developing a healthcare system that understands and addresses the needs of our rapidly diversifying population. Workforce diversity is needed where research indicates that factors such as societal biases and stereotyping, communication barriers, limited cultural sensitivity and competence, and system and organizational determinants contribute to healthcare inequities.

Title VIII Federal Funding Reality

Today's undersupply of appropriately prepared nurses and nurse faculty, as well as the projected loss of experienced nurses over the next decade, does not bode well for our Nation. The Title VIII Nursing Workforce Development Programs are a comprehensive system of capacity-building strategies that provide students and schools of nursing with grants to strengthen education programs, including faculty recruitment and retention efforts, facility and equipment acquisition, clinical lab enhancements, and loans, scholarships, and services that enable students to overcome obstacles to completing their nursing education programs. A few examples of HRSA's Title VIII data below provide perspective on current Federal investments.

Nurse Faculty Loan Program (NFLP)—BLS projects a need of 35 percent more faculty members to meet the expected increase in demand. In addition, with 10,200 current faculty members expected to retire, 34,200 new nursing instructors will be needed by 2022. NFLP supports the establishment and operation of a loan fund at participating schools of nursing to assist nurses in completing their graduate edu-

cation to become qualified nurse faculty. Ongoing NFLP support for faculty production is critical to building the pipeline that assures the full capacity of the Nation's future nursing workforce. Targeting a portion of those funds for minority faculty preparation is fundamental to achieving that goal. In fiscal year 2012, NFLP grantees exceeded the program's performance target by 49.6 percent in providing loans to 2,259 students pursuing faculty preparation. About one out of every four students receiving the NFLP loans were considered underrepresented minorities.

Comprehensive Geriatric Education Program (CGEP)—CGEP provides support to educate individuals in providing geriatric care for the elderly. This goal is accomplished through curriculum development and dissemination, continuing education, and traineeships for individuals preparing for advanced nursing education degrees. In fiscal year 2012, CGEP grantees awarded traineeships to 74 students—the majority of whom (81 percent) were pursuing a Master's Degree in Nursing.

Nurse Education, Practice, Quality, and Retention Grants (NEPQR)—NEPQR addresses the critical nursing shortage via projects to expand the nursing pipeline, promote career mobility, provide continuing education, and support retention. Grants to support recruiting and retaining nursing assistants and personal and home care aides in occupational shortage and/or high demand areas trained 4,624 students during fiscal year 2012. NEPQR also supported expanding the size of BSN programs and supported nurse-managed health clinics.

Nurse-Managed Health Clinics (NMHC)

NMHCs are a nurse-practice arrangement, managed by advanced practice registered nurses, that provides primary care or wellness services. NMHCs are associated with a school, college, university, or department of nursing, federally qualified health center, or independent nonprofit health or social services agency.

NMHCs deliver comprehensive primary healthcare services, disease prevention, and health promotion in medically underserved areas for vulnerable and specialized populations (e.g., veterans and/or families of active military). The complexity of care for these patients presents significant financial barriers, heavily affecting the sustainability of these clinics. While providing access points in areas where primary care providers are in short supply, expansion of NMHCs also increases the number of structured clinical teaching sites available to train nurses and other primary care providers. In fiscal year 2012, more than 1,600 health professions students were trained in NMHCs, where the majority of NMHCs and associated training sites were primarily located in medically underserved communities (97 percent) and served as a primary care setting for their local community (65 percent). Appropriating \$20 million in fiscal year 2015 to NMHCs would increase access to primary care for thousands of underserved people.

The NLN can state with authority that the deepening health inequities, inflated costs, and poor quality of healthcare outcomes in this country will not be reversed until the concurrent shortages of nurses and qualified nurse educators are addressed. Your support will help ensure that nurses exist in the future who are prepared and qualified to take care of you, your family, and all those who will need our care. Without national efforts of some magnitude to match the healthcare reality facing our Nation today, an under resourced nurse education and its adverse effect in healthcare generally will be difficult to avoid.

The NLN urges the subcommittee to maintain the Title VIII Nursing Workforce Development Programs by funding them at a level of \$251 million in fiscal year 2015. We also recommend that the Title III Nurse-Managed Health Clinics be funded at \$20 million in fiscal year 2015.

[This statement was submitted by Beverly Malone, PhD, RN, FAAN, Chief Executive Officer, National League for Nursing.]

PREPARED STATEMENT OF THE NATIONAL MPS SOCIETY

The National MPS Society supports research to find cures for Mucopolysaccharidoses (MPS) and related diseases, and provides hope and support for affected individuals and their families through research, advocacy, and awareness of these devastating disorders. The Society submits this testimony to request insertion of language in the fiscal year 2015 Appropriations to direct the National Institutes of Health (NIH) to fund MPS research.

MPS diseases are rare genetic diseases that affect both children and adults. They cause progressive damage to cells in the body, resulting in severe disability and early death. There are currently few treatments and no cures. There are 11 types of MPS but only 4 FDA approved enzyme replacement therapy treatments to slow disease progression. The damage from MPS results in severe problems, including

profound intellectual disabilities, heart disease, vision loss, speech and hearing impairment, short stature, stiff joints, and pain, among others. MPS diseases are devastating for children and families, largely due to the progressive nature of the diseases. Babies are often born looking perfectly healthy. It is only later, as cell damage becomes worse, that parents receive the heartbreaking diagnosis. All MPS diseases are terminal with most affected individuals not surviving beyond teenage years.

The National MPS Society is requesting the insertion of language specific to MPS and related diseases into the fiscal year 2015 Appropriations Bill. This language will help focus NIH research efforts related to MPS and related diseases. After several years of decreased funding, the NIH budget for MPS research increased between 2010 through 2013 but saw a significant decline in 2014 due to sequestration.

Researchers focused on MPS diseases get almost all of their funding from the NIH. There is very little private funding for MPS and related diseases research. Although there are very few therapies for MPS diseases, the ones that are available are the result of NIH-funded research. Prominent researchers in the field believe that continued research holds the promise of effective treatments and cures for MPS diseases, including stem cell therapies, gene therapies, and small molecule therapies. Researchers are beginning to build momentum in their work on MPS diseases. Increased funding for MPS and related diseases research will ensure that this momentum translates into progress toward new treatments and a cure. Reduced funding stalls progress and prevents these critical gains.

On behalf of the children and families impacted by MPS diseases, the National MPS Society respectfully requests the insertion of the following language into the fiscal year 2015 Appropriations Bill.

Mucopolysaccharidoses: The Committee encourages the NINDS and NIDDK to expand research efforts in the development of effective treatments for MPS diseases. The Committee commends the National Institute of Neurological Disorders and Stroke (NINDS) and the Office of Rare Diseases Research (ORDR) and National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) for sponsoring scientific conferences like the Gordon Research Conference (April 2013) focusing on basic science of lysosomal biology and function but with strong emphasis on pathogenic mechanisms of lysosomal disease. The Committee further acknowledges and applauds the National Institutes of Health ORDR, NINDS and NIDDK for their work related to the Rare Diseases Clinical Research Network (RDCRN) over the next 5 years to fund research consortia including lysosomal diseases: mucopolysaccharidosis (MPS), and MPS bone disease, helping to create additional opportunities for small research communities, such as the Lysosomal Disease Network, to address some of these clinical research needs.

Mucopolysaccharidoses (MPS) are a group of genetic, progressive diseases that are caused by the absence or malfunctioning of certain enzymes needed to break down molecules called glycosaminoglycans—long chains of sugar carbohydrates in each of our cells. When mutations occur in the genes for the enzymes involved in the normal turnover of Mucopolysaccharidoses, excess amounts of them are stored in the body, causing progressive damage to a number of different organs and tissues, and, in most cases, early death. There are no current cures for MPS, although stem cell transplants and enzyme replacement therapy show potential for reducing symptom severity. Treatment for the skeletal abnormalities remains a challenge due to the difficulty of introducing replacement enzymes or transplanted cells into skeletal tissues. Although the greatest benefit is likely to be discovered through MPS research supported by other NIH components, ongoing research at the NIAMS in other areas of skeletal research may help to inform the science base and potentially improve the quality of life of patients with the disease.

Action taken or to be taken: The Committee encourages NINDS, ORDR and NIDDK to continue supporting scientific conferences in the Mucopolysaccharidoses and other Lysosomal Disease research community, such as the Lysosomal Disease Network's Annual WORLD Symposium. This international conference gives researchers an opportunity to share findings in basic, translational and clinical research and to establish collaborations that could enable multicenter studies in natural history and other areas of clinical research. In addition, this Symposium promotes interaction among interested lay participants and medical and scientific experts, in addition to representatives from pharmaceutical industry, involved in lysosomal diseases.

The intent of the report language is to focus and encourage the National Institutes of Health's efforts with respect to the direction of Mucopolysaccharidoses and other Lysosomal Disease related research. The language included annually in the LHHS report has consistently addressed some of the most pressing, scientific needs in this complex area of biomedical research. The outcome has been, and one would

hope continue to be, the Institutes examination of the issues raised by the Committee so that it can make meaningful efforts to enhance NIH activity on these important Mucopolysaccharidoses and Lysosomal Disease research issues.

PREPARED STATEMENT OF THE NATIONAL MULTIPLE SCLEROSIS SOCIETY

Mr. Chairman and Members of the Subcommittee, thank you for this opportunity to provide testimony regarding funding of critically important Federal programs that impact those affected by multiple sclerosis. We urge the Subcommittee to provide the following in fiscal year 2015: \$2.5 million for the Lifespan Respite Care Program; at least \$32 billion for the National Institutes of Health (NIH); robust support for Medicare and Medicaid; and \$12.6 billion for the Social Security Administration (SSA).

Multiple sclerosis (MS) is an unpredictable, often disabling disease of the central nervous system that interrupts the flow of information within the brain, and between the brain and body. Symptoms range from numbness and tingling to blindness and paralysis. The progress, severity, and specific symptoms of MS in any one person cannot yet be predicted. Most people with MS are diagnosed between the ages of 20 and 50, with at least two to three times more women than men being diagnosed with the disease.

The National MS Society sees itself as a partner to the Government in many critical areas. As we advocate for NIH research, we do so as an organization that in 2013, funded approximately \$48 million in MS research through funds generated through the Society's fundraising efforts. And as we advocate for Lifespan Respite funding, we do so as an organization that works to provide some level of respite relief for caregivers. So while we're here to advocate for Federal funding, we do it as an organization that commits tens of millions of dollars each year to similar or complementary efforts as those being funded by the Federal Government.

Lifespan Respite Care Program

Up to one quarter of individuals living with MS require long-term care services at some point during the course of the disease. Often, a family member steps into the role of primary caregiver. According to a 2011 AARP report, 61.6 million family caregivers provided care at some point during 2009 and the value of their uncompensated services was approximately \$450 billion per year. Family caregivers allow the person living with MS to remain home for as long as possible and avoid premature admission to costlier institutional facilities.

Family caregiving, while essential, can be draining and stressful. A 2012 National Alliance for Caregiving (NAC) survey of individuals providing care to people living with MS shows that on average, caregivers spend 24 hours a week providing care. Sixty 4 percent of caregivers were emotionally drained, 32 percent suffered from depression and 22 percent have lost a job due to caregiving responsibilities.

The Lifespan Respite Care Program, enacted in 2006 under President Bush, provides competitive grants to States to establish or enhance statewide lifespan respite programs that better coordinate and increase access to quality respite care. Respite offers professional short-term help to give caregivers a break from the stress of providing care and has been shown to provide family caregivers with the relief necessary to maintain their own health and bolster family stability. Perhaps the most critical aspect of the program for people living with MS is that Lifespan Respite serves families regardless of special need or age—literally across the lifespan. Much existing respite care has age eligibility requirements and since MS is typically diagnosed between the ages of 20 and 50, Lifespan Respite programs are often the only open door to needed respite services.

For these reasons, the National MS Society asks that Congress provide \$2.5 million for the Lifespan Respite Care Program in fiscal year 2015.

National Institutes of Health

As mentioned previously, the National MS Society invested \$48 million to MS research in 2013 and sees the NIH as an invaluable partner to stop MS in its tracks, restore function and end MS forever. Approximately \$115 million of fiscal year 2013 was directed to MS-related research and over the years, NIH research projects have helped make significant progress in understanding MS. NIH scientists were among the first to report the value of MRI in detecting early signs of MS and have enhanced knowledge about how the immune system works and its role in the development of MS lesions.

Twenty years ago, there were no MS therapies or medications—now there are ten. The NIH provided the basic research necessary so that these therapies could be developed. Despite this progress, there are still no treatments approved for people liv-

ing with progressive MS. Only with continued investment will the innovation momentum continue, allowing us to find successful treatments for those with progressive MS and a cure for all.

The NIH also directly supports jobs in all 50 States and 17 of the 30 fastest growing occupations in the U.S. are related to medical research or healthcare. More than 83 percent of the NIH's funding is awarded through almost 50,000 competitive grants to more than 325,000 researchers at over 3,000 universities, medical schools, and other research institutions in every State.

For these reasons, the Society urges Congress to provide at least \$32 billion for the NIH in fiscal year 2015.

Centers for Medicare & Medicaid Services

Medicare: It is estimated that over 20 percent of the MS population relies on Medicare as its primary insurer. The majority of these individuals are under the age of 65 and receive the Medicare benefit as a result of their disability. Of particular importance to the MS community are: having appropriate reimbursement levels for Medicare physicians, maintaining access to diagnostics and durable medical equipment, protecting access to needed speech, physical and occupational therapy services, and discouraging overly burdensome cost-sharing for prescription drugs.

Medicaid: Medicaid provides comprehensive health coverage to over eight million persons living with disabilities, plus six million persons with disabilities who rely on Medicaid to fill Medicare's gaps. The latest statistics (which are pre-recession) show that about 5–10 percent of people with MS have Medicaid coverage. The most recently available data (2007) reveals that the average annual direct and indirect (e.g. lost wages) cost for someone with MS in the U.S. is approximately \$69,000. After years of paying to manage their disease, some people with MS have spent the vast majority of their earnings and savings, making their financial situation so dire that Medicaid becomes their only option for health coverage.

The National MS Society urges Congress to maintain funding for Medicaid and reject proposals to cap or block grant the program. Any of these proposals would merely shift costs to States, forcing States to shoulder a seemingly insurmountable financial burden or cut services on which our most vulnerable rely. The Society also urges Congress to protect and promote access to home- and community-based care in line with the 1999 U.S. Supreme Court decision *Olmstead*.

Social Security Administration

Because of the unpredictable nature and sometimes serious impairment caused by the disease, SSA recognizes MS as a chronic illness or "impairment" that can cause disability severe enough to prevent an individual from working. During such periods, people living with MS are entitled to and rely on Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI) benefits to survive. The National MS Society urges Congress to provide \$12.3 billion for the SSA's administrative budget so that it can continue efforts to reduce hearings and disability backlogs, pay monthly benefits in a timely manner, and determine post-entitlement issues in a timely manner.

Conclusion

The National MS Society thanks the Committee for the opportunity to provide written testimony and our recommendations for fiscal year 2015 appropriations. The agencies and programs we have discussed are of vital importance to people living with MS and we look forward to continuing to working with the Committee to help move us closer to a world free of MS. Please don't hesitate to contact me with any questions.

[This statement was submitted by Ted Thompson, Vice President, Federal Government Relations.]

PREPARED STATEMENT OF THE NATIONAL NURSING CENTERS CONSORTIUM

On behalf of the National Nursing Centers Consortium (NNCC), I would like to thank the members of this subcommittee for the opportunity to submit testimony regarding the importance of appropriating funds to support nurse-managed health clinics. Specifically, NNCC and its members request an appropriation of \$20 million to support grants to nurse-managed health clinics through the Nurse Managed Health Clinic grant program under the Health Resources and Services Administration's Bureau of Primary Health Care in the Department of Health and Human Services.

NNCC is a 501(c)(3) member association of nonprofit, nurse-managed health clinics, sometimes called nurse-managed health centers or NMHCs. Section 254(c)–1a(a)(2) of the Public Health Services Act defines “nurse-managed health clinic” as “a nurse practice arrangement, managed by advanced practice nurses, that provides primary care or wellness services to underserved or vulnerable populations and that is associated with a school, college, university or department of nursing, federally qualified health center (FQHC), or independent nonprofit health or social services agency.” Currently, there are approximately 250 NMHCs in operation throughout the United States. Section 254(c)–1a also mandates the creation of a Nurse Managed Health Clinic grant program and authorizes \$50 million in grant funding.¹ The NMHC grant program was established to provide these clinics with a stable source of Federal funding that would place them on footing similar to other safety-net providers. However, to date, funding for the grant program has not been appropriated.

The Value of NMHCs and the Need for NMHC Grant Funding

NMHCs Expand Primary Care Workforce Capacity.—The Nation is facing a primary care crisis that is about to get worse. According to the Association of American Medical Colleges (AAMC), by 2025 there will be a dearth of 130,600 physicians, which includes a shortage of 65,800 primary care physicians.² AAMC data also shows that American medical schools are not graduating enough doctors to meet this need.³ The Congressional Budget Office estimates the Medicaid expansion called for by the ACA will lead to 11 million new enrollees.⁴ As these new enrollees establish primary care homes, the burden on the primary care workforce is likely to increase dramatically. Data from Massachusetts shows just how bad the problem could get. A study conducted 2 years after expanding its public coverage found that only 52 percent of internists in Massachusetts were accepting new patients and one-third of family physicians were no longer accepting new patients.⁵

NMHCs are primarily managed by nurse practitioners, which make up the fastest growing segment of primary care providers in the country. According to the Health Resources and Services Agency, the number of primary care NPs is expected to grow by 30 percent, from 55,400 in 2010 to 72,100 by 2020.⁶ Because of these growing numbers, policymakers across the country are calling for nurse practitioners and NMHCs to assume a greater role in primary care. For example, in its report, “The Future of Nursing, Leading Change, Advancing Health,” the Institute of Medicine (IOM) states, “advanced practice registered nurses should be called upon to fulfill and expand their potential as primary care providers across practice settings based on their education and competency.”⁷ When discussing the role of NMHCs, the IOM report says, “Nurse-managed health clinics offer opportunities to expand access; provide quality, evidence-based care; and improve outcomes for individuals who may not otherwise receive needed care.”⁸

Along with the IOM, the National Governor’s Association (NGA) and the National Institute for Health Care Reform (NIHCR) both released reports identifying the greater use of nurse practitioners as a means of alleviating the pressure on the primary care workforce and presenting NP scope of practice law and payment policy reform as important to ensuring comprehensive access to primary care. Most recently, in a 2013 study published in Health Affairs, the RAND Corporation projected

¹Public Health Services Act, 42 USC § 254(c)–1a(e) (2014).

²American Association of Medical Colleges (AAMC). (June 2010). The impact of healthcare reform on the future supply and demand for physicians updated projections through 2025. Retrieved from https://www.aamc.org/download/158076/data/updated_projections_through_2025.pdf.

³Dill, M. & Salsberg, E., AAMC Center for Workforce Studies. (Nov. 2008). The complexities of physician supply and demand. Retrieved from <https://members.aamc.org/eweb/upload/The%20Complexities%20of%20Physician%20Supply.pdf>.

⁴Congressional Budget Office (CBO). (July 2012). Estimates for the insurance coverage provisions of the affordable care act updated for the recent supreme court decision. Retrieved from <http://www.cbo.gov/sites/default/files/cbofiles/attachments/43472-07-24-2012-CoverageEstimates.pdf>.

⁵Massachusetts Medical Society. (2008). Physician workforce study: Executive summary. Retrieved from www.massmed.org/workforce.

⁶Health Resources and Servs. Admin., Dept. of Health and Human Services. (November 2013). Projecting the supply and demand for primary care practitioners through 2020. Retrieved from <http://bhpr.hrsa.gov/healthworkforce/supplydemand/usworkforce/primarycare/projectingprimarycare.pdf>.

⁷Institute of Medicine (IOM). The future of nursing: Leading change, advancing health. p. 1–

2. Washington, D.C.: National Academies Press.

⁸Institute of Medicine (IOM). The future of nursing: Leading change, advancing health. p. c–4. Washington, D.C.: National Academies Press.

that greater use of the nurse-managed health centers model could address the increased demand for primary care.⁹

As safety-net providers, NMHCs offer high quality primary care to medically underserved patients regardless of the patient's ability to pay. However, NMHCs are struggling financially and often lack access to FQHC money available to other safety net providers. Thus, the NMHC grant program was created, providing NMHCs with alternative Federal funding to ensure their continued ability to meet the needs of their patients and communities. Because they already serve a high percentage of Medicaid patients, the clinics are positioned to not only absorb demand from the newly ensured but also fill gaps in care resulting from the fragmented application of Medicaid expansion.

To lessen the primary care crisis and ensure the underserved can take full advantage of the care NMHCs offer, NNCC requests that the Subcommittee appropriate funding to the NMHC grant program. Evidence suggests that funding NMHCs will not only expand access but also lower the cost of care. In addition to lower labor costs, research shows that NMHCs decrease costs by reducing unnecessary emergency room visits and hospitalizations.¹⁰

NMHCs Help Educate the Health Professionals of Tomorrow.—FQHC funding is often unavailable to NMHCs, because many are affiliated with academic schools of nursing. Academically-affiliated NMHCs operate under the jurisdiction of a university, so most cannot meet FQHC governance requirements without breaking their academic connection and giving up their clinical programs. Ironically, it is these academic affiliations that make the NMHC model especially responsive to primary care shortages, since they contribute to workforce development. NMHCs naturally serve as community-based clinical training sites for a diverse group of health profession students including those training to be registered nurses and advance practice nurses (mostly nurse practitioners) as well as medical, pharmacy, dental, social work, public health, and other students. In post-clinical focus groups, students report being “overwhelmingly satisfied” with their experience in NMHC clinical rotations, crediting, in part, the community-based experience absent from other clinical rotations.¹¹ The Future of Nursing report also praised NMHC clinical programs for their interprofessional education, which relates to both job satisfaction and a flexible workforce.¹²

In 2012, the NNCC conducted a survey of its members to measure their contribution to health professions education. Twenty-eight NMHCs in a mix of urban, rural, and suburban communities reported providing educational opportunities for nearly 1,500 students.¹³ The average number of students educated by the NMHC grant funded clinics was 80, while the clinics participating in the 2012 survey reported educating an average of 55 students. These results demonstrate that (1) NMHCs advance workforce development and (2) increased funding enhances the ability of NMHCs to offer educational opportunities.

Despite the benefits of NMHC clinical programs, NMHC leaders are often forced to abandon this important piece of the NMHC model to qualify for FQHC funding. By providing an alternative source of funding for NMHCs, the Nurse-Managed Health Clinic grant program helps to preserve the contribution of NMHCs to workforce development. Given the country's growing need for nurses, NNCC respectfully requests that the subcommittee members appropriate funding to support clinical programs and place NMHCs on a similar footing with other safety-net providers through the NMHC grant program.

In October of 2010, HRSA released \$14.8 million in Prevention and Public Health Fund dollars to fund ten NMHC grants. In addition to serving over 27,000 patients and recording more than 72,000 encounters, the NMHC grantees have provided interdisciplinary clinical training to over 800 health profession students annually.¹⁴

Request.—The 10 NMHC grants distributed in 2010 will expire this year if Congress does not move to appropriate funding to the program. NNCC respectfully requests an appropriation of \$20 million in fiscal year 2015 for the Nurse-Managed Health Clinic Grant Program, as authorized under Title III of the Public Health Service Act.

⁹Auerbach, D. I. (Nov. 2013). Nurse-Managed Health Centers and Patient-Centered Medical Homes Could Mitigate Expected Primary Care Physician Shortage. *Health Affairs*, 32 (11), 1933–41.

¹⁰Coddington, J. A. & Sands, L. P. (2008). Cost of healthcare and quality outcomes of patients at nurse-managed clinics. *Nurs. Econ*, 26(2), 75-83.

¹¹Institute for Nursing Centers. (2009). Feedback from student focus groups.

¹²Institute of Medicine (IOM). The future of nursing: Leading change, advancing health. p. c-4. Washington, D.C.: National Academies Press.

¹³NNCC. (2012). NNCC Membership Survey.

¹⁴National Nursing Centers Consortium (NNCC). (2011). Survey of NMHCs.

[This statement was submitted by Tine Hansen-Turton, CEO, National Nursing Centers Consortium.]

PREPARED STATEMENT OF THE NATIONAL RESPITE COALITION

Mr. Chairman, I am Jill Kagan, Chair of the National Respite Coalition (NRC), a network of respite providers, family caregivers, national, State and local agencies and organizations who support respite. Thirty State respite coalitions are also affiliated with the NRC. This statement is presented on behalf of these organizations. The NRC also facilitates the Lifespan Respite Task Force, a coalition of over 100 national, State and local groups who support the Lifespan Respite Program and its continued funding. We are requesting that the Subcommittee include \$2.5 million for the Lifespan Respite Care Program administered by ACL/AoA in the fiscal year 2015 Labor, HHS, and Education Appropriations bill or designate this amount from the Prevention and Public Health Fund as recommended in the President's fiscal year 2015 budget. This amount is only modestly above the current fiscal year 2014 level of \$2.3. This will enable:

- State replication of best practices in Lifespan Respite to allow family caregivers, regardless of the care recipient's age or disability, to have access to affordable respite, and to be able to continue to play the significant role in long-term care that they are fulfilling today, saving Medicaid billions;
- Improvement in the quality of respite services currently available;
- Expansion of respite capacity to serve more families by building new and enhancing current respite options, including recruitment and training of respite workers and volunteers; and
- Greater consumer direction by providing family caregivers with training and information on how to find, use and pay for respite services.

WHO NEEDS RESPITE?

A 2012 national survey from the Pew Research Center found that four in ten adults in the U.S. are caring for an adult or child with significant health issues, up from 30 percent in 2010 (Fox, S, et al, 2013). The estimated economic value of the unpaid contributions of family caregivers caring for someone over the age of 18 is approximately \$450 billion. This amount is more than total Medicaid spending, including both Federal and State contributions for healthcare and long-term services and supports. If parents caring for children with special needs are also considered, another \$50 to \$100 billion would be added to the economic value of family caregiving (AARP Public Policy Institute, 2011).

Family caregiving is not just an aging issue, but also a lifespan one. While the aging population is growing rapidly, the majority of family caregivers are caring for someone under age 75 (56 percent); 28 percent of family caregivers care for someone between the ages of 50–75, and 28 percent care for someone under age 50 (National Alliance for Caregiving (NAC) and AARP, 2009). Many family caregivers are in the sandwich generation—46 percent of women who are caregivers of an aging family member and 40 percent of men also have children under the age of 18 at home (Aumann, K, and Galinsky, E, 2008). And 6.7 million children are in the primary custody of an aging grandparent or other relative.

Families of the wounded warriors, military personnel who returned from Iraq and Afghanistan with traumatic brain injuries and other serious chronic and debilitating conditions, don't have full access to respite. Even with enactment of the VA Family Caregiver Support Program which serves only veterans since 9/11, the need for respite will remain high for all veterans and their family caregivers. Caregivers whose veterans have PTSD are about half as likely as other caregivers to receive respite (11 percent vs. 20 percent) (NAC, November 2010). Sixty-eight percent of veterans' caregivers reported their situation as highly stressful compared to 31 percent of caregivers nationally, and three times as many say there is a high degree of physical strain (40 percent vs. 14 percent) (NAC, 2010). Veterans' caregivers specifically asked for up-to-date lists of respite providers in their communities and help to find services, the very thing Lifespan Respite is charged to provide (NAC, 2010).

National, State and local surveys have shown respite to be the most frequently requested service of the Nation's family caregivers (The Arc, 2011; National Family Caregivers Association, 2011). Other than financial assistance for caregiving through direct vouchers payments or tax credits, respite is the number one national policy related to service delivery that family caregivers prefer (NAC and AARP, 2009). Yet respite is unused, in short supply, inaccessible, or unaffordable to a majority of the Nation's family caregivers. The NAC 2009 survey found that despite the fact that among the most frequently reported unmet needs of family caregivers

were “finding time for myself” (32 percent), “managing emotional and physical stress” (34 percent), and “balancing work and family responsibilities” (27 percent), nearly 90 percent of family caregivers across the lifespan are not receiving respite services at all.

An estimated 80 percent of all long-term care in the U.S. is provided at home. This percentage will only rise in the coming decades with greater life expectancies of individuals with disabling and chronic conditions living with their aging parents or other caregivers, the aging of the baby boom generation, and the decline in the percentage of the frail elderly who are entering nursing homes.

RESPIRE BARRIERS AND THE EFFECT ON FAMILY CAREGIVERS

Barriers to accessing respite include reluctance to ask for help, fragmented and narrowly targeted services, cost, and the lack of information about respite or 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. Lifespan Respite is designed to help States eliminate these barriers through improved coordination and capacity building.

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. In a 2009 survey of family caregivers, a majority (51 percent) who are caring for someone over age 18 have medium or high levels of burden of care, measured by the number of activities of daily living with which they provide assistance, and 31 percent were identified as “highly stressed” (NAC and AARP, 2009). Parents of children with special healthcare needs report poorer general health, more physical health problems, worse sleep, and increased depressive symptoms compared to parents of typically developing (TD) children (McBean, A and Schlosnagle, L, 2013).

A family caregiver’s declining health status is a risk factor for care recipient institutionalization. When caregivers lack effective coping styles or are depressed, care recipients may be at risk for falling, developing preventable secondary health conditions or limitations in functional abilities. The risk of abuse from caregivers among care recipients with significant needs increases when caregivers themselves are depressed or in poor health (American Psychological Association, nd).

Supports that would ease family caregiver stress, most importantly respite, are too often out of reach or completely unavailable. Restrictive eligibility criteria also preclude many families from receiving services or continuing to receive services for which they once were eligible. Children with disabilities will age out of the system when they turn 21 and they will lose many of the services, such as respite. A survey of nearly 5000 caregivers of individuals with intellectual and developmental disabilities (I/DD) conducted by The Arc found: the vast majority of caregivers report that they are suffering from physical fatigue (88 percent), emotional stress (81 percent) and emotional upset or guilt (81 percent) some or most of the time; 1 out of 5 families (20 percent) report that someone in the family had to quit their job to stay home and support the needs of their family member; and more than 75 percent of family caregivers caring for adult children with developmental disabilities could not find respite services (The Arc, 2011). Respite may not exist at all in some States for individuals with Alzheimer’s, those under age 60 with conditions such as ALS, MS, spinal cord or traumatic brain injuries, or children with serious emotional conditions.

RESPIRE BENEFITS FAMILIES AND IS COST SAVING

Respite has been shown to be an effective way to reduce stress and 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 study of parents of children with autism spectrum disorders found that respite care was associated with reduced stress and improved marital quality (Harper, Amber, et al, 2013). A U.S. Department of Health and Human Services report prepared by the Urban Institute found that 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). In a survey of caregivers of individuals with Multiple Sclerosis (MS), two-thirds said that respite would help keep their loved one at home. When the care recipient with MS also has cognitive impairment, the percentage of those saying respite would be helpful to avoid or delay nursing home placement jumps to 75 percent (NAC, 2012).

The budgetary benefits that accrue because of respite are just as compelling. Delaying a nursing home placement for just one individual with Alzheimer’s or other

chronic condition for several months can save Medicaid and other government programs thousands of dollars. Researchers at the University of Pennsylvania studied the records of over 28,000 children with autism ages 5 to 21 who were enrolled in Medicaid in 2004. They concluded that for every \$1,000 States spent on respite services in the previous 60 days, there was an 8 percent drop in the odds of hospitalization (Mandell, David S., et al, 2012). In the private sector, U.S. businesses lose from \$17.1 billion to \$33.6 billion per year in lost productivity of family caregivers (MetLife Mature Market Institute, 2006). Higher absenteeism alone among working caregivers costs the U.S. economy an estimated \$25.2 billion in lost productivity per year (Witters, D., 2011). Respite for working family caregivers could help improve job performance and employers could potentially save billions.

LIFESPAN RESPITE CARE PROGRAM WILL HELP

The Federal Lifespan Respite program is administered by the Administration for Community Living (ACL), Administration on Aging (AoA), U.S. Department of Health and Human Services (HHS). ACL/AoA provides competitive grants to eligible State agencies in concert with Aging and Disability Resource Centers (ADRCs) working in collaboration with State respite coalitions or respite organizations. Congress appropriated \$2.5 million each year from fiscal year 2009—fiscal year 2012 and a slightly lower amount due to sequestration in fiscal year 2013 and fiscal year 2014. Since 2009, 32 States and the District of Columbia each received three-year \$200,000 start-up Lifespan Respite Grants. Nine States and DC received one-time \$150,000 expansion grants to focus on direct services, especially for those who are unserved. In the last 2 years, many of the States received 17-month Integration and Sustainability grants to continue their important work.

The purpose of the law is to expand and enhance respite services, improve coordination, and improve respite access and quality. States are required to establish State and local coordinated Lifespan Respite care systems to serve families regardless of age or special need, provide new planned and emergency respite services, train and recruit respite workers and volunteers and assist caregivers in gaining access to services. 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.

Lifespan Respite, defined as a coordinated system of community-based respite services, helps States use limited resources across age and disability groups more effectively. Provider pools can be recruited, trained and shared, administrative burdens reduced by coordinating resources, and savings used to fund new respite services for families who do not qualify for any Federal or State program.

HOW IS LIFESPAN RESPITE PROGRAM MAKING A DIFFERENCE?

With limited funds, Lifespan Respite grantees are engaged in innovative activities such as:

- In TN and RI, the Lifespan Respite program is building respite capacity by expanding volunteer networks of providers by recruiting University students or Senior Corps volunteers or expanding the national TimeBanks model for establishing voluntary family cooperative respite strategies.
- In Texas, the Lifespan Respite program has established a statewide Respite Coordination Center, and an online database.
- In SC, the State respite coalition and the Lifespan Respite program are partnering in new ways with the untapped faith community to provide respite, especially in rural areas.
- The North Carolina Lifespan Respite Program has challenged each of its 100 counties to improve respite service delivery locally, and has partnered with the Money Follows the Person program to develop family caregiver peer-to-peer support and respite.
- In NH, new providers have been recruited and trained through partnerships with the NH National Alliance on Mental Illness, New Hampshire Family Voices, and the College of Direct Support with funding from the Department of Labor to expand the pool of respite providers to work with teens and older individuals with mental health conditions or other groups where respite is in short supply.
- The AZ Lifespan Respite program housed in Division of Aging and Adult Services has partnered with their State's Children with Special Health Care Needs Program to provide respite vouchers to families in need across the age and disability spectrum.

—The OK Lifespan Respite program partnered with their State's Federal Transit Administration's Section 5310 transportation authority to release a van no longer needed to develop mobile respite to serve isolated rural areas of the State.

Across the board, States are building respite registries and "no wrong door systems" in collaboration with State respite coalitions and ADRCs to help family caregivers access respite and funding sources. OK, AL, NV, TN and others are using Lifespan Respite grants to expand or implement participant-directed respite through voucher systems so that family caregivers have greater control over the type and quality of the respite they select. State grantees secure commitments from partnering State agencies to share information and coordinate resources to build a seamless Lifespan Respite system for accessing respite.

Funding must be maintained to help sustain these innovative State efforts. The goal of Lifespan Respite System is to coordinate respite services and funding, maximize existing resources and leverage new dollars in both the public and private sectors to build respite capacity and serve the unserved, but States need more time and fiscal support to do so. Maintaining funding for the program in fiscal year 2015 could allow several new States to start Lifespan Respite Programs and help assist at least a few of the remaining grantees to complete the work that they have started. As it is, given the limited funding for fiscal year 2014, only 1–2 new States and 5–8 of the current grantees are expected to be funded. States are working successfully with ARCH to develop comprehensive sustainability plans, but without Federal support, many of the grantees will be cut off before they have had a chance to have a lasting impact.

No other Federal program mandates respite as its sole focus, helps ensure respite quality or choice, and allows funds for respite start-up, training or coordination to address accessibility and affordability issues for families. With tens of millions of families affected, caregiving is a public health issue requiring an immediate proven preventive response, such as respite. We urge you to include at least \$2.5 million in the fiscal year 2015 Labor, HHS, and Education appropriations bill or designate this amount in the Prevention and Public Health Fund. This will allow Lifespan Respite Programs to be replicated and sustained. Families, with access to respite, will be able to maintain their own health and well-being and continue to play the significant role that they are fulfilling today.

[This statement was submitted by Jill Kagan, Chair, National Respite Coalition.]

PREPARED STATEMENT OF THE NATIONAL RURAL HEALTH ASSOCIATION

The National Rural Health Association (NRHA) is pleased to provide the Labor, Health and Human Services, Education and Related Agencies Appropriations Subcommittee with a statement for the record on fiscal year 2015 funding levels for programs with a significant impact on the health of rural Americans.

NRHA is a national nonprofit membership organization with a diverse collection of 21,000 individuals and organizations who share a common interest in rural health. The Association's mission is to improve the health of rural Americans and to provide leadership on rural health issues through advocacy, communications, education and research.

NRHA is advocating support for a group of rural health program that assist rural communities in maintaining and building a strong healthcare delivery system into the future. Most importantly, these programs help increase the capacity of the rural healthcare delivery system and true safety net providers. Rural Americans, on average, are poorer, sicker and older than their urban counterparts. Programs in the rural health safety net increase access to healthcare, help communities create new health programs for those in need and train the future health professionals that will care for the 62 million rural Americans. With modest investments, these programs evaluate, study and implement quality improvement programs and health information technology systems.

Important rural health programs supported by NRHA are outlined below.

Rural Health Outreach and Network Grants provide capital investment for planning and launching innovative projects in rural communities that later become self-sufficient. These grants are unique in the Federal system as they allow the community to build a program around their needs. These grants award funding to develop needed formal, integrated networks of providers that deliver primary and acute services. The grants have led to projects including information technology networks, oral screenings, and preventative care. Due to the community nature of the grants and a focus on self-sustainability after the terms of the grant have run out—85 per-

cent of the Outreach Grantees continue to deliver services 5 full years after Federal funding ended. Request: \$62.7 million.

Rural Health Research and Policy Grants form the Federal infrastructure for rural health policy. Without these funds, rural America has no coordinated voice in the Department of Health and Human Services (HHS). In addition to the expertise provided to agencies such as the Centers for Medicare and Medicaid Services, this line item also funds rural health research centers across the country. Additionally, we urge the Subcommittee to include in report language instructions to the Office of Rural Health Policy to direct additional funding to the State rural health associations. Request: \$10.3 million.

State Offices of Rural Health are the State counterparts to the Federal rural health research and policy efforts, and form the State infrastructure for rural health policy. They assist States in strengthening rural healthcare delivery systems by maintaining a focal point for rural health within each State and by linking small rural communities with State and Federal resources to develop long term solutions to rural health problems. Without these funds, States would have diminished capacity to administer many of the critical rural health programs. The State offices play a key role in assisting rural health clinics, community health centers, and small, rural hospitals assess community healthcare needs. This program creates a State focus for rural health interests, brings technical assistance to rural areas, and helps frontier communities tap State and national resources available for healthcare and economic development. In partnership with other State agencies, the State rural health offices have been essential in addressing the unique needs of rural communities. Request: \$11.1 million.

Rural Hospital Flexibility Grants fund quality improvement and emergency medical service projects for Critical Access Hospitals (CAHs) across the country. The BBA created this essential program to improve access to essential healthcare services by CAHs, rural hospital networks and rural emergency medical services. These grants allow statewide coordination and provide expertise to CAHs for quality improvement or information technology activities. Also funded in this line is the Small Hospital Improvement Program (SHIP), which provides grants to more than 1,500 small rural hospitals (50 beds or less) across the country to help improve their business operations, focus on quality improvement and to ensure compliance provisions related to health information privacy. Request: \$47.7 million.

Rural and Community Access to Emergency Devices assist communities in purchasing emergency devices and training potential first responders in their use. Defibrillators double a victim's chance of survival after sudden cardiac arrest, which an estimated 163,221 Americans experience every year. This program trains lay rescuers and first responders in their use and places them in public areas where sudden cardiac arrest is likely to occur. Request: \$3.7 million.

The Office for the Advancement of Telehealth supports distance-provided clinical services and is designed to reduce the isolation of rural providers, foster integrated delivery systems through network development and test a range of telehealth applications. Long-term, telehealth promises to improve the health of millions of Americans, provide constant education to isolated rural providers and save money through reduced office visits and hospital care. The OAT leads, coordinates and promotes the use of telehealth technologies by fostering partnerships between Federal agencies, States and private sector groups to create telehealth projects. These approaches are still new and unfolding and continued investment in the infrastructure and development is needed. Request: \$15.3 million.

National Health Service Corps (NHSC) plays a critical role in providing primary healthcare services to rural underserved populations by placing healthcare providers in our Nation's most underserved communities. Investment in our healthcare workforce is absolutely vital to support the newly insured population resulting from health reform and the long-term underserved in isolated rural communities. Programs like the NHSC help maximize the capacity of our health system to care for patients. The demand for primary care providers far exceeds the supply, and the needs of our rural communities continue to grow. The NRHA supports the President's request to ensure that the NHSC has access to the dedicated funding through the CHC Fund.

Frontier Community Health Integration Demonstration Program (F-CHIP) funds development and testing of new models for the delivery of healthcare services in frontier areas through improving access and integration of the delivery of healthcare to Medicare beneficiaries.

Frontier Extended Stay Clinic (FESC) a geographically isolated medical clinic designed to provide primary, emergency, and extended-stay care 24 hours per day when hospital services are not readily available. The Federal Office of Rural Health

Policy (ORHP) has provided funding for infrastructure development to four clinics in Alaska.

Title VII Health Professions Training Programs (with a significant rural focus):

- Area Health Education and Centers (AHECs) financially support and encourage those training to become healthcare professionals to practice in rural areas. Without this experience and support while in medical school, far fewer professionals would make the commitment to rural areas and facilities including Community Health Centers, Rural Health Clinics and rural hospitals. The AHEC Programs and Centers play a critical national role in addressing healthcare workforce shortages, particularly those in primary care through an established infrastructure. The program grantees support the recruitment and retention of physicians, students, faculty and other primary care providers in rural and medically underserved areas by providing local, community-based, interdisciplinary primary care training. Educating and training rural healthcare providers ensures a sound future in the delivery of rural healthcare. It has been estimated that nearly half of AHECs would shut down without Federal funding. Request: \$75 million.
- Rural Physician Pipeline Grants will help medical colleges develop special rural training programs and recruit students from rural communities, who are more likely to return to their home regions to practice. This “grow-your-own” approach is one of the best and most cost-effective ways to ensure a robust rural workforce into the future. Request: \$4.4 million.
- Geriatric Programs train health professionals in geriatrics, including funding for Geriatric Education Centers (GEC). There are currently 47 GECs nationwide that ensure access to appropriate and quality healthcare for seniors. Rural America has a disproportionate share of the elderly and could see a shortage of health providers without this program. Request: \$36.7 million.

The National Rural Health Association appreciates the opportunity to provide our recommendations to the Subcommittee. These programs are critical to the rural health delivery system and help maintain access to high quality care in rural communities. We greatly appreciate the support of the Subcommittee and look forward to working with Members of the Subcommittee to continue making these important investments in rural health.

PREPARED STATEMENT OF THE NATIONAL SAFETY COUNCIL

Chairman Harkin, Ranking Member Moran, and Members of the subcommittee, thank you for the opportunity to submit testimony regarding the National Safety Council's workplace safety appropriations priorities. My name is Jim Johnson, and I am Vice President of Workplace Safety Initiatives at the National Safety Council. We are a 100 year-old Congressionally chartered nonprofit safety organization dedicated to saving lives by preventing injuries and deaths at work, in homes and communities, and on the roads through leadership, research, education, and advocacy. Our more than 14,000 member companies represent over 8 million employees at more than 51,000 worksites. Today I am seeking support for \$565.01 million for the Occupational Safety and Health Administration (OSHA) and \$332.86 million for the National Institute for Occupational Safety and Health (NIOSH), two organizations whose work is vitally important to the mission of safety.

Occupational Safety and Health Administration

The National Safety Council believes that an effective and efficient OSHA is important for the safety of American workers and workplaces. NSC supports stable funding for OSHA that adequately funds all the agency's key functions, including compliance assistance and support to companies striving for safety excellence, the timely promulgation of regulations to protect America's workers, enforcement actions against companies that fail to comply with OSHA standards, and whistle blower protection for workers.

The Council supports the top line funding level of \$565.01 million for the agency included in the President's fiscal year 2015 budget request, and we strongly encourage the committee to fund the agency at a minimum of this funding level. While the Council is pleased that OSHA rulemaking and enforcement efforts in fiscal year 2014 have been restored to pre-sequester funding levels, we continue to have strong concerns about funding constraints placed on the agency's Federal compliance assistance efforts, which are presently funded at \$69.4 million, more than 9 percent less than fiscal year 2012 enacted levels.

Of special concern to the Council is the impact that reduced compliance assistance funding has had on the agency's Voluntary Protection Programs (VPP). We encour-

age the committee to include report language recommending that VPP receive no less than \$3 million in fiscal year 2015.

VPP were created by OSHA in 1982 as a way of recognizing those employers who successfully implement effective safety and health management systems and maintain injury and illness rates below the national average for their industries. Under VPP, company stakeholders establish a relationship with OSHA based on a cooperative partnership. Because of this, approval into VPP is as much a proactive effort as it is recognition of hard work and effort put in by employers and employees to achieve exceptional records in occupational safety and health.

The pursuit of VPP status has helped many safety professionals encourage their employers' leadership to improve safety management systems by complying with the program's criteria. Organizations with VPP status represent business leaders who have implemented strong safety management systems and demonstrated a commitment to continuous improvement. VPP sites have a Days Away Restricted or Transferred (DART) case rate of 52 percent below the industry average. The majority of VPP sites have less than 100 employees.

However, despite the success of this program, recent budget constraints have required the agency to slow the growth in the number of new cooperative program participants. Following sequestration in fiscal year 2013, OSHA only reapproved sites that could be visited through local travel. As it stands, OSHA is not scheduling new VPP site approvals until a region's backlog of re-approvals of existing VPP facilities is eliminated. Minimum funding at a level of at least \$3 million will ensure that OSHA has the resources necessary to address the backlog of re-approvals of existing VPP facilities and to begin to approve new VPP sites.

National Institute for Occupational Safety and Health

Funding NIOSH at the fiscal year 2014 program level of \$332.86 million at a minimum, and preserving the fiscal year 2014 level of \$24 million for the Institute's Agriculture, Forestry and Fishing (AgFF) Sector Program and \$27.5 million for the Education and Research Centers (ERCs), is essential to ensuring that NIOSH can fulfill its mission of saving lives and preventing injuries.

Finally, I would like to focus on the important role that NIOSH programs play in reducing workplace injuries and fatalities. NIOSH's primary responsibility is to conduct research and make recommendations for the prevention of work-related injuries and illnesses. NIOSH works to ensure the health and safety of the American workforce through research, education and training. It is not a regulatory agency, and can only issue recommendations for health and safety standards. The Council is disheartened to see the President's budget request again target the Institute's Agriculture, Forestry and Fishing (AgFF) Sector Program and Education and Research Centers (ERCs) by eliminating their budget.

NIOSH established the AgFF program in 1990 in response to evidence that agricultural workers were suffering higher rates of injury and illness than other U.S. workers. The agriculture, forestry, and fishing, industry fatality rate is more than 8 times that of the all-industry average. Yearly, almost 18,000 workers in this sector are injured seriously enough to require time away from work.¹ Daily, an average of over 330 workers in this sector sustain injuries serious enough to require medical consultation, and nearly 2 workers die from an injury suffered at work.² Today, the initiative includes nine regional centers and one national center to address children's farm safety. These centers conduct vital research leading to evidence-based standards that save lives. The AgFF Program is the only substantive Federal effort to meet the obligation to ensure safe conditions for workers in this sector, and it is effective.

NIOSH supports education and research in occupational health through academic degree programs and research opportunities, primarily through 18 university-based ERCs located at leading universities around the country serving all 50 States. The mission of the ERCs is to reduce work-related injuries and illnesses in the U.S. by performing prevention research and by educating, through degree programs and continuing education, high-quality professionals who implement programs to improve occupational health and safety and minimize the dangers faced by workers across the country. The ERCs provide programs in a unique group of disciplines that benefit employers of all sizes and industries in every part of the country. Currently, the ERCs are responsible for supplying a good portion of the country's OSH graduates who will go on to fill professional roles. With an aging occupational safety and

¹U.S. Bureau of Labor Statistics, U.S. Department of Labor. (2013). Table 2. numbers of nonfatal occupational injuries and illnesses by case type and ownership, selected industries, 2012. Retrieved February 12, 2014, from <http://www.bls.gov/news.release/osh.t02.htm>.

²National Safety Council. (2013). Injury Facts®, 2013 Edition.

health workforce, and a shortage of qualified OSH professionals, ERCs are essential to educating the next generation of professionals.

Thank you again for the opportunity to submit testimony for the record.

PREPARED STATEMENT OF THE NATIONAL TECHNICAL INSTITUTE FOR THE DEAF AND
ROCHESTER INSTITUTE OF TECHNOLOGY

Mr. Chairman and Members of the Committee: I am pleased to present the fiscal year 2015 budget request for the National Technical Institute for the Deaf (NTID), one of nine colleges of the Rochester Institute of Technology (RIT), in Rochester, N.Y. Created by Congress by Public Law 89-36 in 1965, we provide university technical and professional education for students who are deaf and hard of hearing, leading to successful careers in high-demand fields for a sub-population of individuals historically facing high rates of unemployment and under-employment. We also provide baccalaureate and graduate-level education for hearing students in professions serving deaf and hard-of-hearing individuals. NTID students live, study and socialize with more than 17,000 hearing students on the RIT campus.

Budget Request

On behalf of NTID, for fiscal year 2015 I would like to request \$66,291,000 in Operations. NTID has worked hard to manage its resources carefully and responsibly and as such is not requesting an increase in support in 2015. Over the past 2 years we have reduced our workforce by 12 percent (70 positions) and limited our equipment expenditures. We also reduced our non-personnel expenditures by over 30 percent in such areas as building and equipment maintenance, instructional supplies, freelance interpreting, professional travel and student employment. NTID has also postponed requests for construction funding for critical and long overdue renovations to a 33-year old building currently housing three times the number of staff for which it was intended. In terms of non-Federal revenues, from fiscal year 2006 to fiscal year 2014, student tuition and fees increased by 63 percent to offset the rising costs of providing a state-of-the-art college education. Likewise, from fiscal year 2006 to fiscal year 2013, NTID raised almost \$20 million in support from individuals and organizations.

Our fiscal year 2015 request to continue fiscal year 2014 funding of \$66,291,000 in Operations would allow us to maintain a balanced budget and avoid harmful reductions. Without this funding, we would have to impose additional limitations in the areas of equipment purchasing, interpreting and captioning, scholarship support, building maintenance, and, most importantly, in personnel and enrollment. These are not the consequences a successful Federal investment should face.

Enrollment

Truly a national program, NTID has enrolled students from all 50 States. In Fall 2013 (fiscal year 2014), we attracted 1,432, the sixth straight year of more than 1,400 students. For fiscal year 2015, NTID hopes to maintain this high enrollment, if our operational resources allow us to do so. Our enrollment history over the last 8 years is shown below:

NTID ENROLLMENTS: FISCAL YEAR 2007—FISCAL YEAR 2014

Fiscal Year	Deaf/Hard-of-Hearing Students				Hearing Students			Grand Total
	Undergrad	Grad RIT	MSSE	Sub-Total	Interpreting Program	MSSE	Sub-Total	
2014	1,195	42	18	1,255	147	30	177	1,432
2013	1,269	37	25	1,331	167	31	198	1,529
2012	1,281	42	31	1,354	160	33	193	1,547
2011	1,263	40	29	1,332	147	42	189	1,521
2010	1,237	38	32	1,307	138	29	167	1,474
2009	1,212	48	24	1,284	135	31	166	1,450
2008	1,103	51	31	1,185	130	28	158	1,343
2007	1,017	47	31	1,095	130	25	155	1,250

MSSE: Master of Science in Secondary Education of Deaf/Hard of Hearing Students

Grad RIT: other graduate programs at RIT

NTID Academic Programs

NTID offers high quality, career-focused associate degree programs preparing students for specific well-paying technical careers. NTID also is expanding the number of its transfer associate degree programs to better serve the higher achieving segment of our student population seeking bachelor's and master's degrees. These transfer programs provide seamless transition to baccalaureate studies in the other colleges of RIT. In support of those deaf and hard-of-hearing students enrolled in the other RIT colleges, NTID provides a range of access services (including sign language interpreting, real-time speech-to-text captioning, and notetaking) as well as tutoring services. One of NTID's greatest strengths is our outstanding track record of assisting high-potential students to gain admission to, and graduate from, the other colleges of RIT at rates comparable to their hearing peers.

A cooperative education (co-op) component is an integral part of academic programming at NTID and prepares students for success in the job market. A co-op gives students the opportunity to experience a real-life job situation and focus their career choice. Students develop technical skills and enhance vital personal skills such as teamwork and communication, which will make them better candidates for full-time employment after graduation. Almost 300 students last year participated in 10-week co-op experiences that augment their academic studies, refine their social skills, and prepare them for the competitive working world.

Student Accomplishments

For our graduates, over the past 5 years, an average of 91 percent have found jobs commensurate with their education level. Of our fiscal year 2012 graduates (the most recent class for which numbers are available), 93 percent were employed 1 year later, with 65 percent employed in business and industry, 24 percent in education/non-profits, and 11 percent in government.

Graduation from NTID has a demonstrably positive effect on students' earnings over a lifetime, and results in a notable reduction in dependence on Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI). In fiscal year 2012, NTID, the Social Security Administration, and Cornell University examined earnings and Federal program participation data for approximately 16,000 deaf and hard-of-hearing individuals who applied to NTID over our entire history. The studies show that NTID graduates over their lifetimes are employed at a much higher rate, earn substantially more (therefore paying significantly more in taxes), and participate at a much lower rate in SSI and SSDI than students who withdrew from NTID.

Using SSA data, at age 50, 78 percent of NTID deaf and hard-of-hearing graduates with bachelor degrees and 73 percent with associate degrees report earnings, compared to 58 percent of NTID deaf and hard-of-hearing students who withdrew from NTID. Equally important is the demonstrated impact of an NTID education on graduates' earnings. At age 50, \$58,000 is the median salary for NTID deaf and hard-of-hearing graduates with bachelor degrees and \$41,000 for those with associate degrees, compared to \$34,000 for deaf and hard-of-hearing students who withdrew from NTID. Higher earnings, of course, yield higher tax revenues.

An NTID education also translates into reduced dependency on Federal transfer programs, such as SSI and SSDI. At age 40, less than 2 percent of NTID deaf and hard-of-hearing associate and bachelor degree graduates participated in the SSI program compared to 8 percent of deaf and hard-of-hearing students who withdrew from NTID. Similarly, at age 50, only 18 percent of NTID deaf and hard-of-hearing bachelor degree graduates and 28 percent of associate degree graduates participated in the SSDI program, compared to 35 percent of deaf and hard-of-hearing students who withdrew from NTID.

Access Services

NTID provides an access services system to meet the needs of a large number of deaf and hard-of-hearing students enrolled in baccalaureate and graduate degree programs in RIT's other colleges as well as students enrolled in NTID programs who take courses in the other colleges of RIT. Access services also are provided for events and activities throughout the RIT community. Access services include sign language interpreting, real-time captioning, classroom notetaking services, captioned classroom video materials, and Assistive Listening Services.

As enrollments have steadily increased, so has the demand for access services. In fiscal year 2013, 145,003 hours of interpreting were provided—an increase of 27 percent compared to fiscal year 2008. In fiscal year 2013, 18,263 hours of real-time captioning were provided to students—a 9 percent increase over fiscal year 2008. The increase in demand is partly a result of the increase in the number of students enrolled in baccalaureate programs at RIT and the number of students with cochlear

implants. In fiscal year 2014, there were 526 deaf and hard-of-hearing students enrolled in baccalaureate programs at RIT, a 19 percent increase compared to fiscal year 2008, and 360 students with cochlear implants, a 47 percent increase over fiscal year 2008.

Summary

It is extremely important that our fiscal year 2015 funding request be granted in order that we might continue our mission to prepare deaf and hard-of-hearing people to excel in the workplace. NTID has shown through hard data that our graduates have higher salaries, pay more taxes, and depend less on Federal SSI/SSDI payments than their counterparts who do not attend NTID. Our employment rate is 91 percent over the past 5 years—even more remarkable given the state of the economy. Demand for an NTID education is higher than ever. Therefore, I ask that you please consider funding our fiscal year 2015 request of \$66,291,000 for Operations.

We are hopeful that the members of the Committee will agree that NTID, with its long history of successful stewardship of Federal funds and outstanding educational record of service with people who are deaf and hard of hearing, remains deserving of your support and confidence. Likewise, we will continue to demonstrate to Congress and the American people that NTID is a proven economic investment in the future of young deaf and hard-of-hearing citizens. Quite simply, NTID is a Federal program that works.

[This statement was submitted by Dr. Gerard J. Buckley, President, National Technical Institute for the Deaf, and Vice President and Dean, Rochester Institute of Technology.]

PREPARED STATEMENT OF THE NATIONAL VIOLENCE PREVENTION NETWORK

Thank you for this opportunity to submit testimony in support of increased funding for the National Violent Death Reporting System (NVDRS), which is administered by the National Center for Injury Prevention and Control at the Centers for Disease Control and Prevention (CDC). The National Violence Prevention Network, a broad and diverse alliance of health and welfare, suicide and violence prevention, and law enforcement advocates supports increasing the fiscal year 2015 funding level to \$25 million to allow for nationwide expansion of the NVDRS program. fiscal year 2014 NVDRS funding is \$11.2 million.

BACKGROUND

Each year, about 55,000 Americans die violent deaths. In addition, an average of 105 people (22 of which are military veterans) take their own lives each day.

The NVDRS program makes better use of data that are already being collected by health, law enforcement, and social service agencies. The NVDRS program, in fact, does not require the collection of any new data. Instead it links together information that, when kept in separate compartments, is much less valuable as a tool to characterize and monitor violent deaths. With a clearer picture of why violent deaths occurs, law enforcement, public health officials and others can work together more effectively to identify those at risk and target effective preventive services.

Currently, NVDRS funding levels only allow the program to operate in 18 States, including Alaska, Colorado, Georgia, Kentucky, Maryland, Massachusetts, Michigan, New Jersey, New Mexico, North Carolina, Ohio, Oklahoma, Oregon, Rhode Island, South Carolina, Utah, Virginia, and Wisconsin. Several other States have expressed an interest in joining once new funding becomes available. While NVDRS is beginning to strengthen violence and suicide prevention efforts in the 18 participating States, non-participating States continue to miss out on the benefits of this important public health surveillance program.

NVDRS IN ACTION

Child abuse and other violence involving children and adolescents remains a problem in America, and it is only through a comprehensive understanding of its root causes that these needless deaths can be prevented. Studies suggest that between 3.3 and 10 million children witness some form of domestic violence annually. Additionally, 1,560 children died as a result of abuse or neglect in 2010.

Children are most vulnerable and most dependent on their caregivers during infancy and early childhood. Sadly, NVDRS data has shown that young children are at the greatest risk of homicide in their own homes. Combined NVDRS data from Alaska, Maryland, Massachusetts, New Jersey, Oregon, South Carolina, and Vir-

ginia determined that African American children aged 4 years old and under are more than four times as likely to be victims of homicide than Caucasian children, and that homicides of children aged four and under are most often committed by a parent or caregiver in the home. The data also shows that household items, or “weapons of opportunity,” were most commonly used, suggesting that poor stress responses may be factors in these deaths. Knowing the demographics and methods of child abusers can lead to more effective, targeted prevention programs.

Intimate partner violence (IPV) is another issue where NVDRS is proving its value. While IPV has declined along with other trends in crime over the past decade, thousands of Americans still fall victim to it every year. Intimate partner homicides accounted for 30 percent of the murders of women and 5 percent of the murders of men in 2006, according to the Bureau of Justice Statistics.

Despite being in its early stages in several States, NVDRS is already providing critical information that is helping law enforcement and health and human service officials allocate resources and develop programs in ways that target those most at risk for intimate partner violence. For example, NVDRS data shows that while occurrences are rare, most murder-suicide victims are current or former intimate partners of the suspect, and a substantial number of victims were the suspect’s offspring. In addition, NVDRS data indicate that women are about seven times more likely than men to be killed by a spouse, ex-spouse, lover, or former lover, and most of these incidents occurred in the women’s homes.

NVDRS & VA SUICIDES

Although it is preventable, every year more than 38,000 Americans die by suicide and another one million Americans attempt it, costing more than \$36 billion in lost wages and work productivity. In the United States today, there is no comprehensive national system to track suicides. However, because NVDRS includes information on all violent deaths—including deaths by suicide—information from the system can be used to develop effective suicide prevention plans at the community, State, and national levels.

The central collection of this data can be of tremendous value for organizations such as the Department of Veterans Affairs that are working to improve their surveillance of suicides. For instance, CDC determined from national NVDRS data that veterans comprised 20 percent of all suicide victims. The types of data collected by NVDRS including gender, blood alcohol content, mental health issues and physical health issues can help prevention programs better identify and treat at-risk individuals.

FEDERAL ROLE NEEDED

At an estimated annual cost of \$25 million for full implementation, NVDRS is a relatively low-cost program that yields high-quality results. While State-specific information provides enormous value to local public health and law enforcement officials, data from all 50 States, the U.S. territories and the District of Columbia must be obtained to complete the national picture. Aggregating this additional data will allow us to analyze national trends and also more quickly and accurately determine what factors can lead to violent death so that we can devise and disseminate strategies to address those factors.

STRENGTHENING AND EXPANDING NVDRS IN FISCAL YEAR 2014

The 2014 Consolidated Appropriations Act recognized the public health utility of NVDRS in preventing violent deaths and increased NVDRS funding by roughly \$8 million to facilitate continued expansion of the NVDRS program. With this new funding, NVDRS will expand to roughly two-thirds of the country. The time is now to complete the nation-wide expansion of NVDRS by providing an appropriation of \$25 million in fiscal year 2015.

We thank you for the opportunity to submit this statement for the record. The investment in NVDRS has already begun to pay off, as the 18 participating States are adopting effective violence prevention programs. We believe that national implementation of NVDRS is a wise public health investment that will assist State and national efforts to prevent deaths from domestic violence, veteran suicide, teen suicide, gang violence and other violence that affects communities around the country. We look forward to working with you secure an fiscal year 2015 NVDRS appropriation of \$25 million.

PREPARED STATEMENT OF THE NATIVE HAWAIIAN EDUCATION COUNCIL

Aloha Chairman Harkin and members of the Senate Committee on Appropriations, Labor, HHS, and Education Subcommittee: Mahalo, thank you, for allowing us an opportunity to submit this request for appropriations.

We are seeking continued funding at pre-sequestration levels for the Native Hawaiian Education Program (NHEP) that targets the Native Hawaiian student population. The NHEP is an important part of fulfilling the trust relationship between the U.S. and Native Hawaiians, and it helps to improve the educational status of Native Hawaiians. It is an important element in the Native community's effort to control its education programs and policies and to achieve educational parity. NHEP aims to close the education achievement gap between Native Hawaiians and the general population, and also functions to fulfill the trust relationship between the United States and Native Hawaiians, the indigenous people of a once sovereign nation. During the time of their own sovereignty in the kingdom of Hawai'i, Native Hawaiians had a higher rate of literacy than citizens of the United States. The educational achievement gap has occurred during the intervening years since the loss of Native Hawaiian sovereignty, so that today Native Hawaiians are among the most disadvantaged groups in the State.

The NHEP Works

NHEP has been effective over the years in meeting the goals of the program. For example, NHEA has been instrumental in preserving and protecting the Native Hawaiian language through funding projects that are designed to address the use of the Native Hawaiian language in instruction, one of the priorities named in the NHEA. The number of speakers nearly doubled in 18 years from 8,872 speakers in 1990 to 16,864 in 2008 (Source: OHA Data Book 2011 Tables 4.19 and 4.44).

The NHEP has funded programs that incorporate culture and indigenous teaching practices in the classroom that leads to better outcomes for Native Hawaiian students. An example is the improvement in the graduation rates for Native Hawaiians and math and reading scores. Graduation rates for Native Hawaiians between 2002 and 2010 rose from 70 percent to 72.2 percent (Sources: Kamehameha Schools' Native Hawaiian Education Assessment Update 2009, Fig. 9 and HI DOE 2005–06 to 2009–10).

Similarly, math and reading scores have risen for Native Hawaiians. The percent of Native Hawaiians scoring "Proficient or Above" from 2007 to 2012 rose from 27 percent to 49 percent in math and from 41 percent to 62 percent in reading (Source: Hawaii DOE Longitudinal Data System).

School attendance rates in schools with student populations that are over 50 percent Native Hawaiian have increased from 90.1 percent in the 2000–01 school year to 91.3 percent in the 2011–12 school year (Source: Kamehameha Schools' draft Ka Huaka'i update, p. 58).

The Need Still Exists

In spite of the gains that Native Hawaiians have made educationally, the need for innovative programs to assist Native Hawaiians to improve their academic performance still exists, since Native Hawaiians have not yet attained parity with the rest of the students in the State.

Timely high school graduation rates for students in the State rose from 77 percent to 79.6 percent in the same time period that it rose from 70 percent to 72.2 percent for Native Hawaiians (Sources: Kamehameha Schools' Native Hawaiian Education Assessment Update 2009, Fig. 9 and HI DOE 2005–06 to 2009–10).

Native Hawaiians still lag behind the rest of the State in academic performance; however the gap between the Native Hawaiians and others is decreasing. From 2007 to 2012 the increase in the percentage of Native Hawaiians scoring "Proficient or Above" in math rose 22 percentage points, while the increase for the State during the same time period was 21 percentage points. The increase for Native Hawaiians in reading was even more dramatic during that time period, increasing 21 percentage points compared to the State increase of only 11 percentage points. Unfortunately those gains were not enough to bring Native Hawaiians to parity. In 2012 Native Hawaiians were still 10 points behind the State in the percentage scoring "Proficient or Above" in math and nine points behind in the percentage scoring "Proficient or Above" in reading.

Percent Scoring Proficient or Above

		2007	2012	Change
Native Hawaiians	Math	27%	49%	22

Percent Scoring Proficient or Above—Continued

		2007	2012	Change
State Totals	Math	38	59	21
	Difference	-11	-10	
Native Hawaiians	Reading	41	62	21
State Totals	Reading	60	71	11
	Difference	-19	-9	

Source: Hawaii DOE Longitudinal Data System.

In the area of Native Hawaiian language immersion, although the gains have been tremendous, the nearly 17,000 speakers in 2008 only represents 6 percent of the approximately 290,000 Native Hawaiians in Hawai'i (2010 U.S. Census).

Appropriations Request

The pre-sequestration appropriations level for the NHEP was \$34 million. Sequestration reduced the amount by \$2 million to \$32 million, which is the amount entered into the President's budget. For such a small program as the NHEP, the \$2 million reduction makes a significant negative impact on the program. We would like to continue to make gains in the educational achievement of Native Hawaiians, and request the pre-sequestration level of \$34 million so that we don't lose the momentum of improvement.

NHEP funds programs to help improve the educational attainment of Native Hawaiians in ways that are linguistically and culturally aligned to the needs of our Native students and communities in Hawai'i. Improving education, particularly for the most depressed groups, eventually leads to cost savings over time through decreased incarceration, poor health, and public assistance. (Barnett, W. S., & Ackerman, D. J. 2006. Costs, benefits, and the long-term effects of early care and education programs: Cautions and recommendations for community developers. *Journal of the Community Development Society*, 37(2), 86–100.) Academic achievement is also correlated with positive economic outcomes. (Belfield, C. 2008, June. The economic investments of early education in Hawaii. Issue Brief. Flushing, NY: Queen's College, City University of New York.)

Please help us sustain the NHEP to its pre-sequestration level in order to continue the educational gains that have taken this program years to accomplish.

PREPARED STATEMENT OF THE NEPHCURE FOUNDATION

SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2015

- \$32 billion for the National Institutes of Health (NIH)
- Provide a corresponding increase to the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)
- Expansion of the FSGS/NS Research Portfolio at NIDDK, the Office of Rare Diseases Research (ORDR) and the National Institute on Minority Health and Health Disparities (NIMHD) by funding more research proposals for Primary Glomerular Disease

Thank you for the opportunity to present the views of the NephCure Foundation regarding research on idiopathic focal segmental glomerulosclerosis (FSGS) and primary nephrotic syndrome (NS). NephCure is the only non-profit organization exclusively devoted to fighting FSGS and the NS disease group. Driven by a panel of respected medical experts and a dedicated band of patients and families, NephCure works tirelessly to support kidney disease research and awareness.

NS is a collection of signs and symptoms caused by diseases that attack the kidney's filtering system. These diseases include FSGS, Minimal Change Disease and Membranous Nephropathy. When affected, the kidney filters leak protein from the blood into the urine and often cause kidney failure, which requires dialysis or kidney transplantation. According to a Harvard University report, 73,000 people in the United States have lost their kidneys as a result of FSGS. Unfortunately, the causes of FSGS and other filter diseases are poorly understood.

FSGS is the second leading cause of NS and is especially difficult to treat. There is no known cure for FSGS and current treatments are difficult for patients to endure. These treatments include the use of steroids and other dangerous substances which lower the immune system and contribute to severe bacterial infections, high

blood pressure and other problems in patients, particularly child patients. In addition, children with NS often experience growth retardation and heart disease. Finally, NS that is caused by FSGS, MCD or MN is idiopathic and can often reoccur, even after a kidney transplant.

FSGS disproportionately affects minority populations and is five times more prevalent in the African American community. In a groundbreaking study funded by NIH, researchers found that FSGS is associated with two APOL1 gene variants. These variants developed as an evolutionary response to African sleeping sickness and are common in the African American patient population with FSGS/NS.

FSGS has a large social impact in the United States. FSGS leads to end-stage renal disease (ESRD) which is one of the most costly chronic diseases to manage. In 2008, the Medicare program alone spent \$26.8 billion, 7.9 percent of its entire budget, on ESRD. In 2005, FSGS accounted for 12 percent of ESRD cases in the U.S., at an annual cost of \$3 billion. It is estimated that there are currently approximately 20,000 Americans living with ESRD due to FSGS.

Research on FSGS could achieve tremendous savings in Federal healthcare costs and reduce health status disparities. For this reason, and on behalf of the thousands of families that are significantly affected by this disease, we encourage support for expanding the research portfolio on FSGS/NS at the NIH.

Encourage FSGS/NS Research at NIH

There is no known cause or cure for FSGS and scientists tell us that much more research needs to be done on the basic science behind FSGS/NS. More research could lead to fewer patients undergoing ESRD and tremendous savings in healthcare costs in the United States.

With collaboration from other Institutes and Centers, ORDR established the Rare Disease Clinical Research Network. This network provided an opportunity for the NephCure Foundation, the University of Michigan, and other university research health centers to come together to form the Nephrotic Syndrome Study Network (NEPTUNE). NEPTUNE is developing a database of NS patients who are interested in participating in clinical trials which would alleviate the problem faced by many rare disease groups of not having access to enough patients for research. NephCure urges the subcommittee to continue its support for RDCRN and NEPTUNE, which has tremendous potential to facilitate advancements in NS and FSGS research.

The NephCure Foundation is also grateful to NIDDK for issuing program announcements (PA) that serve to initiate grant proposals on primary glomerular disease. Two PAs that have recently been issued utilize the R01 and UM1 mechanisms to award funding for primary glomerular disease research. NephCure recommends the subcommittee encourage NIDDK to continue to issue primary glomerular disease PAs.

Due to the disproportionate burden of FSGS on minority populations, it is appropriate for NIMHD to develop an interest in this research. NephCure asks the subcommittee to encourage ORDR, NIDDK and NIMHD to collaborate on research that studies the incidence and cause of this disease among minority populations. NephCure also asks the Subcommittee to urge NIDDK and the NIMHD to undertake culturally appropriate efforts aimed at educating minority populations about primary glomerular disease.

Thank you for the opportunity to present the views of the FSGS/NS community. Please contact the NephCure Foundation if additional information is required.

[This statement was submitted by Irving Smokler, PH.D., President and Founder, NephCure Foundation.]

PREPARED STATEMENT OF THE NEUROFIBROMATOSIS NETWORK

Thank you for the opportunity to submit testimony to the Subcommittee on the importance of continued funding at the National Institutes of Health (NIH) for research on Neurofibromatosis (NF), a genetic disorder closely linked to many common diseases widespread among the American population. We respectfully request that you include the following report language on NF research at the National Institutes of Health within your fiscal year 2015 Labor, Health and Human Services, Education Appropriations bill.

Neurofibromatosis [NF]—The Committee supports efforts to increase funding and resources for NF research and treatment at multiple NIH Institutes, including NCI, NINDS, NIDCD, NHLBI, NICHD and NEI. Children and adults with NF are at significant risk for the development of many forms of cancer; the Committee encourages NCI to increase its NF research portfolio in fundamental basic science, translational research and clinical trials focused on NF. The Committee also encour-

ages the NCI to support NF centers, NF clinical trials consortia, NF preclinical mouse models consortia and NF-associated tumor sequencing efforts. Because NF causes brain and nerve tumors and is associated with cognitive and behavioral problems, the Committee urges NINDS to continue to aggressively fund fundamental basic science research on NF relevant to nerve damage and repair, learning disabilities and attention deficit disorders. Since NF2 accounts for approximately 5 percent of genetic forms of deafness, the Committee encourages NIDCD to expand its investment in NF2 basic and clinical research.

On behalf of the Neurofibromatosis (NF) Network, a national organization of NF advocacy groups, I speak on behalf of the 100,000 Americans who suffer from NF as well as approximately 175 million Americans who suffer from diseases and conditions linked to NF such as cancer, brain tumors, heart disease, memory loss, and learning disabilities. Thanks in large measure to this Subcommittee's strong support, scientists have made enormous progress since the discovery of the NF1 gene in 1990 resulting in clinical trials now being undertaken at NIH with broad implications for the general population.

NF is a genetic disorder involving the uncontrolled growth of tumors along the nervous system which can result in terrible disfigurement, deformity, deafness, pain, blindness, brain tumors, cancer, and even death. In addition, approximately one-half of children with NF suffer from learning disabilities. NF is the most common neurological disorder caused by a single gene and is more common than Muscular Dystrophy and Cystic Fibrosis combined. There are three types of NF: NF1, which is more common, NF2, which initially involves tumors causing deafness and balance problems, and Schwannomatosis, the hallmark of which is severe pain. While not all NF patients suffer from the most severe symptoms, all NF patients and their families live with the uncertainty of not knowing whether they will be seriously affected because NF is a highly variable and progressive disease.

Researchers have determined that NF is closely linked to heart disease, learning disabilities, memory loss, cancer, brain tumors, and other disorders including deafness, blindness and orthopedic disorders, primarily because NF regulates important pathways common to these disorders such as the RAS, cAMP and PAK pathways. Research on NF therefore stands to benefit millions of Americans:

Learning Disabilities/Behavioral and Brain Function

Learning disabilities affect one-half of people with NF1. They range from mild to severe, and can impact the quality of life for those with NF1. In recent years, research has revealed common threads between NF1 learning disabilities, autism and other related disabilities. New drug interventions for learning disabilities are being developed and will be beneficial to military dependants, as well as the general population. Research being done in this area includes a clinical trial of the statin drug Lovastatin, as well as other categories of drugs.

Bone Repair

At least a quarter of children with NF1 have abnormal bone growth in any part of the skeleton. In the legs, the long bones are weak, prone to fracture and unable to heal properly; this can require amputation at a young age. Adults with NF1 also have low bone mineral density, placing them at risk of skeletal weakness and injury. Research currently being done to understand bone biology and repair will pave the way for new strategies to enhancing bone health and facilitating repair.

Pain Management

Severe pain is a central feature of Schwannomatosis, and significantly impacts quality of life. Understanding what causes pain, and how it could be treated, has been a fast-moving area of NF research over the past few years. Pain management is a challenging area of research and new approaches are highly sought after.

Nerve Regeneration

NF often requires surgical removal of nerve tumors, which can lead to nerve paralysis and loss of function. Understanding the changes that occur in a nerve after surgery, and how it might be regenerated and functionally restored, will have significant quality of life value for affected individuals. Light-based therapy is being tested to dissect nerves in surgery of tumor removal. If successful it could have applications for treating nerve damage and scarring after injury, thereby aiding repair and functional restoration.

Wound Healing, Inflammation and Blood Vessel Growth

Wound healing requires new blood vessel growth and tissue inflammation. Mast cells, important players in NF1 tumor growth, are critical mediators of inflammation, and they must be quelled and regulated in order to facilitate healing. Re-

searchers have gained deep knowledge on how mast cells promote tumor growth, and this research has led to ongoing clinical trials to block this signaling, resulting in slower tumor growth. As researchers learn more about blocking mast cell signals in NF, this research can be translated to the management of mast cells in wound healing.

New Cancer Treatments

NF can cause a variety of tumors to grow, which includes tumors in the brain, spinal cord and nerves. NF affects the RAS pathway which is implicated in 70 percent of all human cancers. Some of these tumor types are benign and some are malignant, hard to treat and often fatal. One of these tumor types is malignant peripheral nerve sheath tumor (MPNST), a very aggressive, hard to treat and often fatal cancer. MPNSTs are fast growing, and because the cells change as the tumor grows, they often become resistant to individual drugs. Clinical trials are underway to identify a drug treatment that can be widely used in MPNSTs and other hard-to-treat tumors.

The enormous promise of NF research, and its potential to benefit over 175 million Americans who suffer from diseases and conditions linked to NF, has gained increased recognition from Congress and the NIH. This is evidenced by the fact that numerous institutes are currently supporting NF research, and NIH's total NF research portfolio has increased from \$3 million in fiscal year 1990 to an estimated \$18 million in fiscal year 2014. Given the potential offered by NF research for progress against a range of diseases, we are hopeful that the NIH will continue to build on the successes of this program by funding this promising research and thereby continuing the enormous return on the taxpayers' investment.

We appreciate the Subcommittee's strong support for NF research and will continue to work with you to ensure that opportunities for major advances in NF research are aggressively pursued. Thank you.

PREPARED STATEMENT OF THE NEW ENGLAND EDUCATIONAL OPPORTUNITY ASSOCIATION

On behalf of the low-income, first-generation students and students with disabilities served by the Federal TRIO Programs ("TRIO") across Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, and Vermont, the New England Educational Opportunity Association ("NEOA") respectfully requests that the Senate Subcommittee on Labor, Health and Human Services, and Education boost TRIO funding by \$52 million in fiscal year 2015.

A \$52 million funding increase would allow for a total funding level of \$890 million in fiscal year 2015 which, in turn, would allow TRIO's Student Support Services program to expand its reach by 10 percent and grow to serve 20,000 additional low-income, first-generation students at colleges and universities across the Nation during the 2015–2016 academic year. This funding level would also allow current TRIO programs to sustain the high-quality access and success services provided to 750,000 students across the Nation as well as allow for the expansion of these services to include 23,000 more who stand in need. Such growth is critical as TRIO programs have lost more than 120,000 students over the last decade. While we are tremendously grateful for the work of this Subcommittee to restore 95 percent of the funds lost to sequestration in fiscal year 2014, we would be remiss if we did not request additional funding so that we may continue to recoup from earlier losses. If the success of TRIO in New England serves as any indicator, it becomes clear that greater investment in TRIO is critical to boosting educational attainment nationally.

More than 42,000 students ranging from middle school through graduate study participate in TRIO programs across New England. Throughout the region, stories of student success abound, with strong statistics to support them. For instance, both the Talent Search and Upward Bound programs in Rhode Island can boast of 99 percent high school graduation rates. Moreover, 86 percent of Rhode Island's Talent Search students go directly onto college as do 90 percent of the Upward Bound students.

In New Hampshire, a longitudinal study of Student Support Services ("SSS") participants at the University of New Hampshire demonstrated that, compared to eligible non-participants, SSS students exhibited higher graduation rates, greater improvement in grades, and lower academic suspension rates. Meanwhile, during fiscal year 2010, Plymouth State University had a 92 percent retention rate among non-graduating SSS participants. The SSS program at the University of Bridgeport in Connecticut can demonstrate similar success. During the 2013–2014 Academic Year,

58 percent of SSS participants made the Dean's List and/or the President's List as a result of their GPAs.

In recent years, the Educational Opportunity Center (EOC) in Vermont aided 63 percent of its clients—which include out-of-work adults and military veterans—in enrolling in postsecondary education programs for the first time; a similar percentage (61 percent) of postsecondary “stop-outs” re-enrolled in postsecondary education programs. Similarly, the EOC program in Maine helped more than 900 adult learners enroll in college and assisted nearly 2,000 adults in developing career and educational plans.

Massachusetts also produces stellar results through its TRIO programs. Many notable examples are found at the University of Massachusetts-Boston. For instance, the institution's Veterans Upward Bound (VUB) program found that 81.5 percent of VUB participants who enrolled in postsecondary education programs persisted through to a second year of academic study. Meanwhile, 48 percent of students who participated in their Ronald E. McNair Postbaccalaureate Achievement program earned doctoral degrees within 10 years of receipt of their bachelor's degree.

This is just a sampling of the success sparked by the supportive services provided by TRIO. We hope that you will strongly consider these examples when determining funding levels for our program in fiscal year 2015.

Thank you for your consideration of this request.

[This statement was submitted by Karen Keim, President, New England Educational Opportunity Association.]

PREPARED STATEMENT OF THE NEW HAMPSHIRE COMMUNITY LOAN FUND

Chairman Harkin, Ranking Member Moran, and distinguished Members of the Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies: Helping child-care centers finance improvements to their facilities has been a key poverty-fighting strategy of the New Hampshire Community Loan Fund for the last two decades. We see first-hand what the experts are able to prove: that quality early learning provides a critical foundation for social and economic success.

The Community Loan Fund wishes to endorse the testimony of the National Children's Facilities Network and the network's call for adequate Federal funding for the acquisition, construction, and improvement of child-care facilities. Over the last 7 years, New Hampshire's child-care centers have grown increasingly averse to the risks associated with investing in capital improvements. The recession heightened the typical executive director's financial anxiety and that anxiety persists. Now would be the perfect time for Federal action that would increase their confidence and encourage investments in their facilities.

Please let me know if you would like additional information from us.

[This statement was submitted by Richard A. Minard, Jr., Vice President, New Hampshire Community Loan Fund.]

PREPARED STATEMENT OF THE NURSING COMMUNITY

The Nursing Community is a forum comprised of 60 national professional nursing associations that builds consensus and advocates on a wide spectrum of healthcare and nursing issues surrounding practice, education, and research. These organizations are committed to promoting America's health through the advancement of the nursing profession. Collectively, the Nursing Community represents nearly one million Registered Nurses (RNs), Advanced Practice Registered Nurses (APRNs—including certified nurse-midwives, nurse practitioners, clinical nurse specialists, and certified registered nurse anesthetists), nurse executives, nursing students, faculty, and researchers.

For fiscal year 2015, our organizations respectfully request \$251 million for the Health Resources and Services Administration's (HRSA) Nursing Workforce Development programs (authorized under Title VIII of the Public Health Service Act [42 U.S.C. 296 et seq.]), \$150 million for the National Institute of Nursing Research (NINR) within the National Institutes of Health (NIH), and \$20 million in authorized funding for the Nurse-Managed Health Clinics (Title III of the Public Health Service Act). These investments will help ensure that our Nation's population receives the highest-quality nursing services possible.

Demand for Nurses Continues to Grow

According to the Bureau of Labor Statistics' (BLS) Employment Projections for 2012–2022, the expected number of practicing nurses will grow from 2.71 million in 2012 to 3.24 million in 2022, an increase of 526,800, or 19.4 percent. The number of job openings due to demand for registered nursing services and replacements in the workforce brings the total of RNs needed to 1.053 million by 2022. In addition, nurse practitioners are one of the fastest growing occupations according to the BLS projections, noting there will be a 33.7 percent increase in nurse practitioners between 2012–2022.

Two primary factors contribute to this overwhelming demand. First, America's nursing workforce is aging. A 2013 HRSA report, *The U.S. Nursing Workforce: Trends in Supply and Education*, indicates that over the next 10 to 15 years, the nearly one million RNs over age 50 (comprising approximately one-third of the current workforce), will reach retirement age. Secondly, America's Baby Boomer population is aging. This population will require a vast influx of nursing services, particularly in areas of primary care and chronic illness management. A significant investment must be made in the education of new nurses to provide the Nation with the nursing services it demands.

Addressing the Demand: Title VIII Nursing Workforce Development Programs

For 50 years, the Nursing Workforce Development programs, authorized under Title VIII of the Public Health Service Act, have helped to build the supply and distribution of qualified nurses to meet our Nation's healthcare needs. The Title VIII programs bolster nursing education at all levels, from entry-level preparation through graduate study, and provide support for institutions that educate nurses for practice in rural and medically underserved communities. Today, the Title VIII programs are essential to ensure the demand for nursing care is met. Between fiscal year 2005 and 2012 alone, these programs supported over 450,000 nurses and nursing students, as well as numerous academic nursing institutions and healthcare facilities.

The American Association of Colleges of Nursing's (AACN) Title VIII Student Recipient Survey gathers information about Title VIII dollars and their impact on nursing students. The 2013–2014 survey, which included responses from over 800 students, indicated that the Title VIII programs played a critical role in funding these students' nursing education. The survey showed that 78 percent of the students receiving Title VIII funding are attending school full-time. By supporting full-time students, the Title VIII programs are helping to ensure that students enter the workforce without delay.

The Title VIII programs also address the need for more nurse faculty. Data from AACN's 2013–2014 enrollment and graduations survey show that nursing schools were forced to turn away 78,089 qualified applications from entry-level baccalaureate and graduate nursing programs in 2013, and faculty vacancy was a primary reason. The Title VIII Nurse Faculty Loan Program aids in increasing nursing school enrollment capacity by supporting students pursuing graduate education, provided they serve as faculty for 4 years after graduation.

—*The Nursing Community respectfully requests \$251 million for the Nursing Workforce Development programs in fiscal year 2015.*

National Institute of Nursing Research: Foundation for Evidence-Based Care

As one of the 27 Institutes and Centers at the NIH, the NINR funds research that lays the groundwork for evidence-based nursing practice. Nurse scientists at NINR examine ways to improve care models to deliver safe, high-quality, and cost-effective health services to the Nation. Our country must look toward the prevention aspect of healthcare as the vehicle for saving our system from further financial burden, and the work of NINR embraces this endeavor through research related to care management of patients during illness and recovery, reduction of risks for disease and disability, promotion of healthy lifestyles, enhancement of quality of life for those with chronic illness, and care for individuals at the end of life.

Moreover, NINR helps to provide needed faculty to support the education of future generations of nurses. Training programs at NINR develop future nurse researchers, many of whom also serve as faculty in our Nation's nursing schools.

—*The Nursing Community respectfully requests \$150 million for the NINR in fiscal year 2015.*

Nurse-Managed Health Clinics: Expanding Access to Care

NMHCs are healthcare delivery sites managed by APRNs and are staffed by an interdisciplinary health provider team which may include physicians, social workers, public health nurses, and therapists. These clinics are often associated with a

school, college, university, department of nursing, federally qualified health center, or independent nonprofit healthcare agency. NMHCs serve as critical access points to keep patients out of the emergency room, saving the healthcare system millions of dollars annually.

NMHCs provide care to patients in medically underserved regions of the country, including rural communities, Native American reservations, senior citizen centers, elementary schools, and urban housing developments. The populations within these communities are the most vulnerable to chronic illnesses that create heavy financial burdens on patients and the healthcare system. NMHCs aim to reduce the prevalence of disease and create healthier communities by providing primary care services and educating patients on health promotion practices. Furthermore, NMHCs serve as clinical education training sites for nursing students and other health professionals. This is crucial given that a lack of training sites is commonly identified as a barrier to nursing school enrollment.

—*The Nursing Community respectfully requests \$20 million for the Nurse-Managed Health Clinics authorized under Title III of the Public Health Service Act in fiscal year 2015.*

Without a workforce of well-educated nurses providing evidence-based care to those who need it most, including our growing aging population, the healthcare system is not sustainable. The Nursing Community's request of \$251 million for the Title VIII Nursing Workforce Development programs, \$150 million for the National Institute of Nursing Research, and \$20 million for Nurse-Managed Health Clinics in fiscal year 2015 will help ensure continued access to quality care provided by America's nursing workforce.

MEMBERS OF THE NURSING COMMUNITY SUBMITTING THIS TESTIMONY

Academy of Medical-Surgical Nurses	Association of Women's Health, Obstetric and Neonatal Nurses
American Academy of Ambulatory Care Nursing	Commissioned Officers Association of the U.S. Public Health Service
American Academy of Nursing	Dermatology Nurses' Association
American Assembly for Men in Nursing	Developmental Disabilities Nurses Association
American Association of Colleges of Nursing	Emergency Nurses Association
American Association of Critical-Care Nurses	Gerontological Advanced Practice Nurses Association
American Association of Heart Failure Nurses	Hospice and Palliative Nurses Association
American Association of Neuroscience Nurses	Infusion Nurses Society
American Association of Nurse Anesthetists	International Society of Psychiatric Nursing
American Association of Nurse Assessment Coordination	National American Arab Nurses Association
American Association of Nurse Practitioners	National Association of Clinical Nurse Specialists
American College of Nurse-Midwives	National Association of Hispanic Nurses
American Nurses Association	National Association of Pediatric Nurse Practitioners
American Organization of Nurse Executives	National Association of School Nurses
American Pediatric Surgical Nurses Association	National Black Nurses Association
American Psychiatric Nurses Association	National Forum of State Nursing Workforce Centers
American Rehabilitation Nurses	National Nursing Centers Consortium
American Society for Pain Management Nursing	National Organization for Associate Degree Nursing
American Society of PeriAnesthesia Nurses	National Organization of Nurse Practitioner Faculties
Association of Community Health Nursing Educators	Nurses Organization of Veterans Affairs
Association of Nurses in AIDS Care	Oncology Nursing Society
Association of periOperative Registered Nurses	Preventive Cardiovascular Nurses Association
Association of Public Health Nurses	Society of Urologic Nurses and Associates

PREPARED STATEMENT OF THE OLDER AMERICANS ACT

Mr. Chairman, Ranking Member, and distinguished Members of the Subcommittee, Oral Health America (OHA), a leading organization dedicated to changing lives by connecting communities with resources to increase access to care, education, and advocacy for all Americans, especially those most vulnerable; is requesting fiscal year 2015 funding for all programs administered under the Older Americans Act (OAA) be restored to fiscal year 2012 levels. Of particular interest to OHA is to ensure Title III–D, Disease Prevention and Health Promotion, is restored to at least \$21,000,000 because of the cost-effectiveness that health education, prevention and promotion programs provide to the system.

The OAA provides Federal programs that serve to meet the needs of millions of older Americans. We understand the United States continues to operate amid a challenging budgetary environment. However, OHA believes that proper Federal investment in the OAA is critical to keep pace with the rate of inflation and to meet the needs of this ever-growing segment of the population through the multitude of services the OAA provides. Simply stated, proper investment in OAA saves taxpayer dollars. This is especially evident when it comes to health services. Health services the emphasize prevention and promotion will help to reduce disease, leading to the improvement of the overall health and well-being of America's older adults and resulting in the reduction of premature and costly medical interventions. OHA strongly contends that one's health and overall well-being begins with proper oral health.

Background

The population of the United States is aging at an unprecedented rate. Older adults make up one of the fastest growing segments of the American population. In 2009, 39.6 million seniors were U.S. residents. This aging cohort is expected to reach 72.1 million by 2030—an increase of 82 percent.¹

The oral health of older Americans is in a state of decay. The reasons for this are complex. Limited access to dental insurance, affordable dental services, community water fluoridation, and programs that support oral health prevention and education for older Americans are significant factors that contribute to the unmet dental needs and edentulism among older adults, particularly those most vulnerable. While improvements in oral health across the lifespan have been observed in the last half century, long term concern may be warranted for the 10,000 Americans retiring daily, as it is estimated that only 9.8 percent of this “silver tsunami”—baby boomers turning age 65—will have access to dental insurance benefits.²

Dental Health and Disparities.—Older adults experience an increased risk for oral conditions such as edentulism, oral cancer, and periodontal disease. The reasons for this vary but are often related to age-associated physiologic changes, underlying chronic diseases, race, gender, and the use of various medications. These oral conditions disproportionately affect persons with low income, racial and ethnic minorities, and those who have limited or no access to dental insurance. Older adults with physical and intellectual disabilities and those persons who are homebound or institutionalized are also at greater risk for poor oral health.³

As examples of these disparities, older African American adults are 1.88 times more likely than their white counterparts to have periodontitis;⁴ low-income older adults suffer more than twice the rate of gum disease than their more affluent peers (17.49 verses 8.62 respectively); and Americans who live in poverty are 61 percent more likely to have lost all of their teeth when compared to those in higher socioeconomic groups.

Edentulism and Overall Health.—Despite these existing conditions, recent dental public health trends demonstrate that as the population at large ages, older Americans are increasingly retaining their natural teeth.⁵ Today, many older adults benefit from healthy aging associated with the retention of their natural teeth, improve-

¹Administration on Aging. (2013). Aging Statistics. Retrieved from http://www.aoa.gov/Aging_Statistics/.

²Consumer Survey, National Association of Dental Plans. 2012.

³U.S. Department of Health and Human Services. (2000). Oral Health in America: A Report of the Surgeon General. Retrieved from <http://silkh.nih.gov/public/hck1ocv.@www.surgeon.fullrpt.pdf>.

⁴Borrel, L.N., Burt, B.A., & Taylor, G.W. (2005, October). Prevalence and Trends in Periodontitis in the USA: from the NHANES III to the NHANES, 1988 to 2000. *Journal of Dental Research*, 84(10). Retrieved from <http://jdr.sagepub.com/content/84/10/924.abstract>.

⁵Dolan, T. A., Atchison, K., & Huynh, T. N. (2005). Access to Dental Care Among Older Adults in the United States. *Journal of Dental Education*, 69(9), 961–974. Retrieved from <http://www.jdentaled.org/content/69/9/961.long>.

ments in their ability to chew, and the ability to enjoy a variety of food choices not previously experienced by earlier generations of their peers.

Oral health data reveals that many older adults experience adverse oral health associated with chronic and systemic health conditions. For example, associations between periodontitis and diabetes have emerged in recent years, as well as oral conditions such as xerostomia associated with the use of prescription drugs.^{6,7} Xerostomia, commonly known as dry mouth, contributes to the inception and progression of dental caries (cavities). For older Americans, the occurrence or recurrence of dental caries coupled with an inability to access treatment may lead to significant pain and suffering along with other detrimental health effects.

Oral Care Provider Issues.—Although a growing number of older Americans need oral healthcare, the current workforce is challenged to meet the needs of older adults. The current dental workforce is aging, and many dental professionals will retire within the next decade.² A lack of geriatric specialty programs complicates this problem, and few practitioners are choosing geriatrics as their field of choice.

While these trends are favorable, adverse oral health consequences are emerging. Due to reasons stated in this report, together with increased demand for services, lack of access to dental benefits through Medicare, increased morbidity and mobility among older adults, and reduced income associated with aging and retirement, many older Americans are unable to access oral healthcare services. As a result, many older adults who have retained their natural teeth are now experiencing dental problems.

Older Adults' Oral Health in State of Decay

OHA released State of Decay on October 8, 2013, which is a State-by-State analysis of oral healthcare delivery and public health factors impacting the oral health of older adults. The report revealed more than half of the country received a “fair” or “poor” assessment when it comes to minimal standards affecting dental care access for older adults. The top findings of the report were:

- Persistent lack of oral health coverage across much of the Nation. Forty-two percent of States (21 States) provide either no dental benefits or provide only emergency coverage through adult Medicaid Dental Benefits. Nearly 70 percent of older Americans lack dental insurance, and in the context of a rapidly aging Nation, this percentage will only likely increase.
- Strained dental health work force. Thirty-one States (62 percent) have high rates of Dental Health Provider Shortage Areas (HPSAs), meeting only 40 percent or less of dental provider needs.
- Tooth loss remains a signal of suboptimal oral health. Eight States had strikingly high rates of edentulism, with West Virginia notably having an adult population that is 33.8 percent edentate.
- Deficiencies in preventive programs. Thirteen States (26 percent) have upwards of 60 percent of their residents living in communities without water fluoridation (CWF), despite recognition for 68 years that this public health measure markedly reduces dental caries. Hawaii (89.2 percent) and New Jersey (86.5 percent) represent the highest rates of citizens unprotected by fluoridation, an unnecessary public peril.

Moreover, poor oral health has substantial financial implications. For example, in 2010 alone, between \$867 million and \$2.1 billion was spent on emergency dental procedures. When compared to care delivered in a dentist's office, hospital treatments are nearly ten times more expensive than the routine care that could have prevented the emergency. This places a costly yet avoidable burden on both the individual and the health institutions that must then bear the expense.

In sum, oral health and access to preventive care significantly impact overall health and expenditure, yet are difficult to maintain—particularly for older adults—in the Nation's present context of support systems and healthcare.

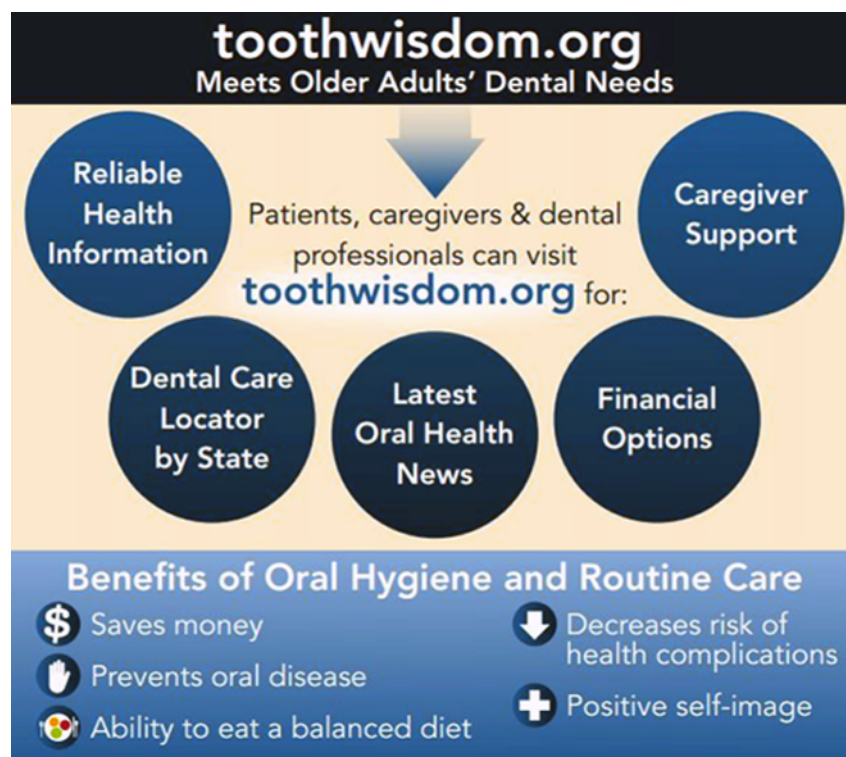
How OHA Empowers Older Adults to Meet their Oral Health Needs

Oral Health America's Wisdom Tooth Project® aims to change the lives of older adults especially vulnerable to oral disease. Its goal is to educate Americans about the oral health needs of older adults, connect older adults to local resources, and to advocate for policies that will improve the oral health of older adults. The Wis-

⁶Ira B. Lamster, DDS, MMSc, Evanthia Lalla, DDS, MS, Wenche S. Borgnakke, DDS, PhD and George W. Taylor, DMD, DrPH. (2008). Journal of the American Dental Association.

⁷Fox, Philip C. (2008). Xerostomia: Recognition and Management. Retrieved from: http://www.colgateprofessional.com.hk/LeadershipHK/ProfessionalEducation/Articles/Resources/profed_art_access-supplement-2008-xerostomia.pdf.

dom Tooth Project achieves these goals through five strategies: publications, our web portal, regional symposia, communications, and demonstration projects.



In addition to the State of Decay report referenced above, a vital component of the Wisdom Tooth Project is Toothwisdom.org, which is a first-of-its-kind website created to connect older adults and their caregivers to local care and education around the oral health issues they face, the importance of continuing prevention as we age, and the overall impact of oral health on overall health.

Importance of OAA Reauthorization to Oral Health of Older Adults

Recognizing this current State of oral health among older adults, Oral Health America welcomes the bipartisan-supported Older Americans Act reauthorization in the U.S. Senate, S.1562. The Senate's bill includes—for the first time—a small provision that allows the Aging Network to use funds they receive for disease prevention and health promotion activities to conduct oral health screenings. Preventive dental care that can be provided through oral health screenings can head off more expensive dental work and help prevent severe diseases. Unfortunately, dentists see older adults everyday living with infection and pain that could be easily avoided with proper care that these screenings could provide. Although the oral health screenings provision would not require new or additional funding under Title III—D, Disease Prevention and Health Promotion Services, restoring funding to fiscal year 2012 levels would greatly assist the Aging Network to conduct the screenings. More succinctly, the Senate's bill recognizes the importance of oral health and its role in disease prevention. We view this as a step toward improving the oral—and overall—health of older adults and call for the bill's passage.

RECOMMENDATION

It is evident the United States' healthcare system is woefully unprepared to meet the oral health challenges of a burgeoning population of older adults with special needs, chronic disease complications, and a growing inability to access and pay for dental services. However, the benefits of proper oral hygiene and routine care for

older adults to our Nation's healthcare system and economy are also quite clear. Through OHA's Wisdom Tooth Project, OHA aspires to change the lives of older adults especially vulnerable to oral disease. OHA views proper funding of the Older Americans Act as a crucial Federal investment vehicle to advance health promotion and disease prevention. Therefore, OHA recommends the Subcommittee to restore fiscal year 2015 funding for all OAA program to fiscal year 2012 levels, and moreover, to ensure Title III–D, Disease Prevention and Health Promotion, is restored to at least \$21,000,000 because of the cost-effectiveness that health education, prevention and promotion programs provide to the system.

Thank you for the opportunity to present and submit our written testimony before the Subcommittee.

[This statement was submitted by Beth Truett, CEO/President, Oral Health America.]

PREPARED STATEMENT OF THE OVARIAN CANCER NATIONAL ALLIANCE

The Ovarian Cancer National Alliance (the Alliance) greatly appreciates the opportunity to submit testimony for the record regarding our fiscal year 2015 funding recommendations. The fiscal year 2015 programmatic funding levels we are advocating for will help advance the awareness, detection and treatment of ovarian cancer, the deadliest of gynecologic cancers. Specifically, the Alliance respectfully requests Congress provide \$7.5 million for the Centers for Disease Control and Prevention's (CDC) Ovarian Cancer program, which funds critical public health research of ovarian cancer. CDC also leads a public gynecologic cancer (ovarian, uterine, cervical, vaginal, vulvar) awareness initiative, authorized by Johanna's Law, that plays an integral role in women's cancer education, detection and prevention. As such, the Alliance respectfully requests Congress appropriate \$5.5 million for Johanna's Law implementation. Furthermore, to advance and leverage the important ovarian cancer research funded through the National Cancer Institute (NCI) at the National Institutes of Health (NIH), the Alliance respectfully requests Congress allocate \$5.26 billion to NCI, as a portion of \$32 billion appropriated to NIH in fiscal year 2015.

For 17 years, the Alliance has worked to increase awareness of ovarian cancer and advocate on behalf of women with ovarian cancer. As an umbrella organization of 58 State and regional Partner Member organizations, the Alliance unites the efforts of survivors, caretakers and healthcare professionals to bring national attention to ovarian cancer. The Alliance advocates at a national level for greater investment in Federal research to support the development of an early detection test, improved healthcare practices and life-saving treatment protocols. The Alliance also educates healthcare professionals about—and raises public awareness of—risk factors for and symptoms of ovarian cancer.

Ovarian cancer is a highly deadly disease. According to the American Cancer Society, in 2013, an estimated 22,240 women were diagnosed with ovarian cancer and 14,030 women lost their lives to this terrible disease. A quarter of women diagnosed with ovarian cancer will die within 1 year of diagnosis and over half of women do not survive 5 years after diagnosis. Unfortunately, these rates have not changed in nearly 40 years. These grim statistics arise from the fact that there is no early detection test for ovarian cancer; tragically, most cases of ovarian cancer are diagnosed after the disease has already begun to spread and are more difficult to effectively treat. However, if ovarian cancer is caught in the early stages, nearly ninety percent of women survive. As such, it is critical that women and healthcare providers be aware of the signs and symptoms of ovarian cancer and that valid and reliable early detection tests be developed.

Few treatments for ovarian cancer have been approved by the Food and Drug Administration (FDA). Many FDA approved drugs are platinum-based therapies, to which cancers readily become resistant if multiple rounds of chemotherapy are needed. Nearly 80 percent of ovarian cancer patients will have a recurrence of disease, underscoring the great need for new and better treatments for ovarian cancer. For these reasons, we respectfully urge you and your colleagues to support ovarian cancer research, education and awareness efforts.

CDC DIVISION OF CANCER PREVENTION AND CONTROL—OVARIAN CANCER

The Ovarian Cancer Line (also known as the Ovarian Cancer Control Initiative) funds public health research of ovarian cancer to better identify women most at risk for developing ovarian cancer, and design risk-reduction and prevention-focused interventions. In fiscal year 2014, CDC's ovarian cancer program received \$4.75 mil-

lion to achieve its mission. Some of the projects being supported by those funds include: the development of a Continuing Medical Education curriculum on hereditary breast and ovarian cancer that educates physicians about how to identify, screen and manage high-risk patients; the investigation of ways to improve follow-up care for ovarian cancer patients given that so many experience disease recurrence; and the examination of risk factors, treatment disparities and other factors influencing survival rates to identify ways to improve patient outcomes with existing tools and treatments.

With an allocation of \$7.5 million in fiscal year 2015, the CDC will be able to continue this important work, and expand a pilot initiative that promotes educating women and providers about the BRCA mutations, identifies women at high risk for developing breast/ovarian cancer and ensures appropriate referral of these at risk women for genetic counseling or testing. This pilot program is currently operational in three States, but with increased funding, similar programs can be established in additional States and communication among women and their providers about genomic risk and testing can be further encouraged.

Given the shared risk between ovarian and breast cancers for individuals with BRCA mutations, it is imperative that we integrate ovarian cancer risk assessment, education and genetic testing into other CDC cancer-related programs, such as the EARLY Act and the National Breast and Cervical Cancer Early Detection Programs. Combining breast and ovarian cancer programs in this manner will leverage scarce resources, better coordinate efforts between existing Federal programs, create economies of scale and efficiencies with respect to CDC education and awareness programs and advance complementary efforts to reduce ovarian cancer related deaths.

CDC DIVISION OF CANCER PREVENTION AND CONTROL—JOHANNA'S LAW

Johanna's Law funds a CDC-led gynecologic cancer awareness campaign, Inside Knowledge, which educates women and healthcare providers about the signs and symptoms of gynecologic cancers. In fiscal year 2014, CDC received \$4.85 million for Johanna's Law activities, which include supporting the ongoing creation and dissemination of awareness campaign materials in English and Spanish, and a series of print, radio and television PSAs featuring survivor stories. In 2012, the campaign achieved one billion views of its PSAs across media types.

With \$5.5 million in fiscal year 2015, CDC will be able to continue to raise awareness of the signs and symptoms of ovarian and other gynecologic cancers, undertake a targeted outreach of its messages to high risk women and expand its partnerships with external patient advocacy, health professional and other stakeholder organizations to leverage scarce resources and amplify their messages. Collaboration with these organizations, such as the Alliance, would magnify the CDC's efforts to raise awareness and help ensure that women, particularly those known to be at a higher risk, seek the healthcare they need to identify and treat gynecologic cancers early.

NCI AT NIH

NCI and the NIH fund the majority of ovarian cancer research in the United States and the world. On average, each year, NCI and NIH fund more than \$140 million in peer-reviewed research grants to researchers at universities and small businesses across the United States. These studies are generating insights into the origins of ovarian cancer and disease progression that may lead to the development of early detection tests and better treatments for ovarian cancer. For example, NIH and NCI investments in basic research led to the understanding of a class of enzymes called PARPs implicated in ovarian cancer. Pharmaceutical companies have built upon these insights to develop PARP inhibitors, a class of drugs holding great promise for ovarian cancer patients.

In addition to the basic research underlying future cures, NCI supports clinical research necessary for translating those ideas into treatments. NCI funding provides critical support to the ovarian cancer Specialized Programs of Research Excellence (SPORE), which facilitate collaborative research studies on the early detection and treatment of ovarian cancer. The Roswell Park Cancer Institute and University of Pittsburgh Cancer Institute Ovarian Cancer SPORE is working on reducing morbidity and mortality of ovarian cancer through groundbreaking translational research aimed at risk stratification, treatment, and prevention of relapse. Currently, a phase I clinical trial is being conducting on vaccines that induce anti-tumor immunity and several other clinical trials are in development. NCI's clinical trials enterprise plays an essential role in testing the safety and effectiveness of potential treatments for ovarian cancer. Robust NCI funding is critical to the continued excellence of the SPOREs.

Furthermore, NCI recently launched the National Clinical Trials Network (NCTN), which consolidates and streamlines existing cooperative clinical trial groups. One of these new groups, the NRG Oncology Clinical Trial network, includes the Gynecologic Oncology Group (GOG), whose trials have been responsible for several advances in ovarian cancer research. Specifically, a GOG trial found that chemotherapy followed by maintenance use of Avastin increased progression free survival time of advanced ovarian cancer patients, when compared to chemotherapy alone. By funding important trials such as this, GOG (and now NRG) fills a clinical research gap left open by pharmaceutical companies that do not often research maintenance therapies. Due to the NCTN's critical importance in clinical trial design and implementation, robust NCI funding is necessary to accomplish these and other important tasks.

Robust investment in NCI of \$5.26 billion, out of a total \$32 billion for NIH in fiscal year 2015, is critical to ensuring the next generation of discoveries that will improve the health and well-being of women with—and at-risk for—ovarian cancer, as well as all Americans.

* * *

The Alliance maintains a long-standing commitment to working with Congress and other stakeholders to improve the survival rates for women with ovarian cancer through increased research, education and awareness. On behalf of our community of patients, caregivers and survivors, we thank you for your consideration of our fiscal year 2015 requests and urge you to support the aforementioned Federal programs so vital to conquering this horrible disease.

PREPARED STATEMENT OF PARENTS OF DEAD CHILDREN

Can you please address a serious health epidemic that is affecting families everywhere? There is a medical epidemic that no one in Congress seems to want to address. That is heroin addiction and proper ways to treat it. The government is spending way too much money in the wrong places and the money should go for helpful and intensive treatment, including a significant amount of time addressing mental health treatment—again, something no one wants to talk about. Addicts do not choose to be addicts, which seems to be the way the vast majority of Americans like to think about it. There are mental health issues that go untreated and lead to self-medication. Methadone Clinics are a huge failure and have little to no oversight and certainly have no statistics that provide meaningful data as to their success or failure. The money poured into those places could be better utilized. Also, more oversight of in patient treatment centers is desperately needed—these are money making ventures and they say they treat for co-occurring disorders (such as bi-polar), it is a joke. If a patient meets one on one with a psychiatrist for half an hour every 2 weeks, how does that help?

Read this article: [The Problem with Methadone Clinics: They Are For-Profit Businesses](#)

Sine Nomine, Yahoo Contributor Network

Mar 30, 2007

Today, many Americans go to a methadone clinic. Some do it for legitimate reasons, others do it just to get a high. The problem with these methadone clinics are that they are for-profit organizations. Many people do not realize that the methadone clinic is a business. Businesses are open to make money. Here in lies the biggest problem facing people who do go to these clinics. The nurses, the counselors, and the doctors that are there to help patients are actually there to keep patients coming back. Why would they want someone to quit coming to the clinic? If everyone decided to quit using methadone then they would be out of a job. I know many people who get up every morning and make it to the methadone clinic. Some of these people have tried to quit and they always go back. Most don't even last 2 days without their methadone. These people have ended up trading one addiction for another. That is what methadone is, a legal addiction. People can go there everyday and get a legal high.

Besides that, regulations for methadone clinics are practically non existent. You can fail a drug test there and not have to worry about it. All that will happen to you is that they will make you come there everyday to get your methadone. You won't be allowed to take any home with you. What is even worse is they do not care if you fail a drug test just as long as your back there the next day to get your next dose. The government needs to step in and make some serious regulations on this business.

As it stands, right now you can go to the methadone clinic for as long as you need to. There is no turning you away just as long as you can pay for your dose and to make that easier they will even let you charge a day if you don't have the money. People go to the methadone clinic for years even decades because they are addicted to the methadone. Their bodies won't let them quit. They start suffering withdraw symptoms within the first 48 hours. So back to the methadone clinic they go. No one will help you detox if they know you are on methadone. You have to go to a specialized institution to detox off methadone.

The government can step in and ban the sell of prescription drugs, ban the use of marijuana, they even tell you where you can and can't smoke today. But what are they doing for the growing methadone problem? Very little. More and more people are dying every day because of methadone. But let me be clear it is not just the methadone that is killing them. These people are mixing methadone with other drugs such as Xanax, Valium, Percocet, OxyContin, etc. The drug tests done at these methadone clinics show up these other drugs. Yet nothing is done about the fact that these people are abusing other drugs that interact with methadone causing a lethal combination. The government should step in and implement a system for checking this so called business. A system that would allow them to check the drug screens of each individual. Those individuals that cannot pass three drug screens should be eliminated from the program. The government should also make it mandatory to drug test each individual at least twice a week. I also believe that a set time limit for methadone maintenance should be implemented. Every two weeks the patient should be made to come down a minimum of two milligrams of methadone. This means that a patient starting out at 50 mg will be completely off the methadone in a little under a year. By implementing this system the government would decrease the patients who abuse methadone and would help those who need the methadone without making them methadone addicts.

Gina Haggerty, mother of a dead son who just wanted help and was not going to a methadone clinic because he said they were a joke. The deadline for submitting this testimony, May 23rd, would have been his 25th birthday.

PREPARED STATEMENT OF THE PARKINSON'S ACTION NETWORK

Dear Chairman Harkin and Ranking Member Moran: The Parkinson's Action Network (PAN) appreciates the opportunity to comment on the fiscal year 2015 appropriations for the U.S. Department of Health and Human Services. Our comments will focus on the importance of Federal investment in biomedical research at the National Institutes of Health (NIH) and the National Institute of Neurological Disorders and Stroke (NINDS), which recently adopted a series of priority research recommendations for Parkinson's disease. PAN supports at least \$32 billion in funding for the NIH and an increase for NINDS to support the research recommendations set forth by the NINDS planning strategy to bring us closer to better treatments and a cure for Parkinson's disease.

PAN is the unified voice of the Parkinson's community advocating for better treatments and a cure. In partnership with other Parkinson's organizations and our powerful grassroots network, we educate the public and government leaders on better policies for research and improved quality of life for the estimated 500,000 to 1.5 million Americans living with Parkinson's, for whom there is no treatment available that slows, reverses, or prevents progression.

As the second most common neurodegenerative condition after Alzheimer's disease, Parkinson's disease is projected to grow substantially over the next few decades as the size of the elderly population grows and will have a direct impact on the healthcare system and economy. A study published in *Movement Disorders* estimated that the economic burden of Parkinson's disease is at least \$14.4 billion a year in the United States, and the prevalence of Parkinson's will more than double by the year 2040.¹ In addition, the study calculated an additional \$6.3 billion in indirect costs such as missed work or loss of a job for the patient or family member who is helping with care, long-distance travel to see a neurologist or movement disorder specialist, as well as costs for home modifications, adult day care, and personal care aides.

A second study also published in *Movement Disorders* projected that if Parkinson's progression were slowed by 50 percent, there would be a 35 percent reduction in excess costs, representing a dramatic reduction in cost of care spread over a

¹ "The Current and Projected Economic Burden of Parkinson's Disease in the United States," *Movement Disorders*, Vol. 28, No. 3, 2013.

longer expected survival.² Both studies highlight the enormous economic implications of this devastating disease, and make it abundantly clear that increased research funding is a wise investment on the front end to help significantly lower or eliminate costs on the back end.

NIH has the unique role of being at the forefront of medical discovery in the United States. NIH supports research in all fifty States, with more than 80 percent of the funding going to universities, research institutions, and small businesses, which create thousands of jobs and grow local economies. In 2012, this amounted to over 402,000 jobs nationwide and \$57.8 billion in economic activity. Perhaps even more important than their economic contributions is the practical impact NIH grants have in identifying and developing a better understanding of and treatments for countless complex diseases and disorders.

There is currently a concerted effort at NIH to better target areas of unmet medical need, including Parkinson's research. In January 2014, NINDS approved a list of 31 priority research recommendations specific to Parkinson's that highlight areas in which NINDS and the broader field should direct its resources to achieve the greatest impact in addressing treatments and the underlying causes of the disease. These recommendations were the result of an intensive planning process that brought together clinicians, researchers, and the patient community to determine the areas of greatest need to reframe how we approach the disease. We applaud NINDS for their leadership in this effort, which represents an unparalleled opportunity to coordinate critical initiatives to help unlock the mysteries of Parkinson's—but its success is dependent upon strengthening funding at NIH and NINDS to ensure that sufficient capacity and resources are available.

Unfortunately, due to ongoing fiscal constraints, including sequestration, the NIH research budget has not kept pace with inflation or the growing needs of an aging population and the overall public health. Sequestration alone cut over \$1.55 billion from NIH in fiscal year 2013, which is roughly equivalent to the entire budget for NINDS. NIH, the largest funder of Parkinson's research in the world, was also forced to reduce its Parkinson's-related research from a high of \$154 million in fiscal year 2012 to \$135 million in fiscal year 2013, a 12 percent decrease. Across the country, many institutions have felt the burden of these cuts, receiving smaller grants or no grants at all. As NIH continues to find high-priority areas to fund in order to advance Parkinson's research, we should be increasing support and not applying cuts that could possibly delay years of progress toward a cure for Parkinson's and other diseases.

Despite some greater certainty in the current appropriations cycle because of the budget agreement passed in December 2013, there is still grave concern over the implications for medical research long-term. Dr. Francis Collins, director of NIH, has even noted that “without sustained investment, many high-priority efforts would move at a substantially slower pace, and years of effectively flat funding for biomedical research have left scientists facing the lowest chances in history of having their research funded by NIH.”³ Because of this trend, there is also the fear that the next generation of scientists will leave the United States or be reluctant to enter the field of neurological research at all because of the uncertainty in financial support they see and feel here at home. Innovation and new possibilities for medical research are at our fingertips, and we must be sure that we have the resources in place to fully recognize and cultivate their potential.

We recognize that due to spending caps put into place by the 2013 budget agreement, the President's fiscal year 2015 budget proposal only requests a modest increase for NIH and many other important programs. But, we also understand that the final decision on how these funds should be allocated within those caps is the responsibility of Congress—and we look to you for your leadership and support. PAN urges the Subcommittee to prioritize biomedical research funding by supporting at least \$32 billion for the NIH overall and increasing funding for NINDS to advance critical priorities designed to fundamentally change our understanding of Parkinson's disease. We look forward to working with the Subcommittee as the fiscal year 2015 appropriations process moves forward.

²“An Economic Model of Parkinson's Disease: Implications for Slowing Progression in the United States,” *Movement Disorders*, Vol. 28, No. 3, 2013.

³“Investing in the Nation's Health,” Dr. Francis Collins. *The Washington Post*. Opinions. December 24, 2013.

PREPARED STATEMENT OF THE PEW CHILDREN'S DENTAL CAMPAIGN

On behalf of the Pew Children's Dental Campaign, thank you for the opportunity to submit testimony regarding appropriations for fiscal year 2015. We appreciate the subcommittee's recognition of oral health as a key aspect of overall health and its continued support of programs that expand access to preventive and restorative services through the Health Resources and Services Administration (HRSA) and the Centers for Disease Control and Prevention (CDC).

The Pew Children's Dental Campaign works at the State and national levels to ensure that more children receive dental care and benefit from evidence-based policies, such as community water fluoridation, dental sealant programs, and expansion of the dental workforce. Since it was established in 2008, our initiative has produced numerous reports evaluating access to care across the 50 States and the District of Columbia, and while we have made significant progress in advancing reforms nationally and in the States, there is still much to be done on this important issue.

Tooth decay affects nearly 60 percent of the Nation's children, and, unsurprisingly, its consequences are concentrated disproportionately among low-income children.¹ Dental disease is the most common chronic disease among children in the U.S.—five times more prevalent than asthma, and in a single year, U.S. students may miss as many as 51 million hours of school due to dental health problems.² It causes pain, hampers school performance, and if left untreated can lead to tooth loss and abscesses that spread infection to the blood and brain.³

Lack of access to preventive services and oral healthcare also imposes a huge cost on States. In 2011, preventable dental conditions were the primary reason for 857,712 emergency room (ER) visits in the U.S.⁴ In 2010, Florida spent more than \$88 million on more than 115,000 hospital ER visits for dental problems and in 2007, 60,000 dental visits to ERs cost the State of Georgia more than \$23 million.^{5,6} Dental problems can also impact the workforce, causing an estimated 164 million hours of lost work time each year, and can inhibit a person's ability to find a job.⁷ Additionally, a 2008 study of the armed forces found that 52 percent of new recruits were found to be Class 3 in "dental readiness," meaning they had oral health problems that needed urgent attention and would delay overseas deployment.⁸

Given the enormous impact of oral health on overall health and the associated social and economic consequences, we respectfully request that the subcommittee consider the following appropriations requests for programs that aim to expand access to care and preventive services for those most in need.

Focusing on prevention

With support from the CDC Division of Oral Health, States can better promote oral health and efficiently administer scarce resources, monitor oral health status and problems, and conduct and evaluate prevention programs through cooperative agreements. This funding is critical to a State's ability to prevent problems before they occur, rather than treating them when they are painful and expensive. The cooperative agreement program also supports State community water fluoridation programs and school-based dental sealant programs, and while funding for this program has been authorized for all 50 States, the Division is currently only able to support 21 States: Colorado, Connecticut, Georgia, Hawaii, Idaho, Iowa, Kansas, Louisiana, Maryland, Michigan, Minnesota, Mississippi, New Hampshire, New York, North Dakota, Rhode Island, South Carolina, Vermont, Virginia, West Virginia, and Wisconsin.

Research shows that community water fluoridation offers one of the greatest returns on investment of any preventive healthcare strategy. For most cities, every

¹U.S. Department of Health and Human Services, Oral Health in America: A Report of the Surgeon General, DHHS, Rockville, MD, 2000.

²Ibid.

³Ibid.

⁴HCUPnet, Healthcare Cost and Utilization Project, "Information on ED visits from the HCUP Nationwide Emergency Department Sample (NEDS)," Agency for Healthcare Research and Quality, Rockville, MD. <http://hcupnet.ahrq.gov/>

⁵"315 Patients a Day Seek Dental Treatment in Florida's Hospital Emergency Rooms," a news release by the Florida Public Health Institute, (December 15, 2011).

⁶Andy Miller, "Fight over Georgia dental rules flares again," Georgia Health News, September 7, 2011, <http://www.georgiahealthnews.com/2011/09/fight-dental-rules-flares/>.

⁷U.S. Department of Health and Human Services, Oral Health in America: A Report of the Surgeon General, DHHS, Rockville, MD, 2000.

⁸T. M. Leiendecker, G. C. Martin et al., "2008 DOD Recruit Oral Health Survey: A Report on Clinical Findings and Treatment Need," Tri-Service Center for Oral Health Studies (2008), 1.

\$1 invested in water fluoridation saves \$38 in dental treatment costs.⁹ CDC estimates that fluoridated water saves more than \$4.6 billion annually in dental costs in the United States,¹⁰ and even more could be saved by expanding coverage to some of the 70 million people who still do not have it.¹¹ Dental sealants are also cost-effective; school-based programs can efficiently prevent 60 percent of decay in the permanent teeth most likely to become decayed during childhood.¹² We recommend a funding level sufficient to enable all States and the District of Columbia to receive the critical CDC prevention funds, starting with an increase for the coming fiscal year to begin moving toward full funding.

Funding request for fiscal year 2015: \$19 million for the CDC Division of Oral Health to expand cooperative agreements to additional States

Addressing the dental access crisis

Pew's 2013 brief, *In Search of Dental Care*, found that roughly 45 million Americans live in dental professional shortage areas, regions that have a scarcity of dentists relative to the population.¹³ Additionally, in 2011, more than 14 million children enrolled in Medicaid did not receive any dental service, in part due to the low numbers of dentist participation in the Medicaid program.¹⁴ The supply of dentists nationally is also likely to shrink in the coming years. The American Dental Association projects that despite the addition of new dental schools and possible increase in graduates, between 2010 and 2030 the ratio of dentists to Americans will continue to fall due to high numbers of dentists approaching retirement age.¹⁵

Many States are expanding scope of practice laws to enable a variety of dental care providers to expand access to care to the underserved, such as dental therapists in Minnesota and Alaska tribal lands, public health hygienists in Kentucky, Maryland, and New Hampshire, and community dental health coordinators in Arizona, California, Montana, New Mexico, Oklahoma, and Wisconsin. A Federal demonstration grant program authorized in 2010 but currently unfunded would provide training institutions, community health centers, public hospitals, and other organizations with funding to train these types of providers, all in accordance with State scope of practice laws, and evaluate their impact on access to care.¹⁶ Also eligible for funding through this demonstration are programs such as one in California that uses telehealth services to bring care to patients in Head Start centers and nursing homes¹⁷ and ER diversion programs that link public hospitals to federally qualified health centers.¹⁸

Pilot efforts to assess how new dental providers can increase access to care are being developed in Oregon, Michigan, Connecticut and Hawaii, and Maine, Kansas, New Mexico, Ohio, and Washington are among the States considering legislation to

⁹Centers for Disease Control and Prevention, "Cost Savings of Community Water Fluoridation," Fact Sheet, Accessed March 27, 2014: <http://www.cdc.gov/fluoridation/factsheets/cost.htm>

¹⁰Centers for Disease Control and Prevention, "Preventing Dental Caries with Community Programs," Fact Sheet, Accessed March 27, 2014: http://www.cdc.gov/oralhealth/publications/factsheets/dental_caries.htm

¹¹Centers for Disease Control and Prevention, "2012 Water Fluoridation Statistics," Data and Statistics, Accessed March 27, 2014: <http://www.cdc.gov/fluoridation/statistics/2012stats.htm>

¹²Truman, B. I., Gooch, B. F., Sulemana, I., Gift, H. C., Horowitz, A. M., Evans, C. A., et al. (2002). Reviews of evidence on interventions to prevent dental caries, oral and pharyngeal cancers, and sports-related craniofacial injuries. *American Journal of Preventive Medicine*, 23(1 Suppl.), 21–54.

¹³The Pew Charitable Trusts, "In Search of Dental Care," June 2013, http://www.pewstates.org/uploadedFiles/PCS_Assets/2013/In_search_of_dental_care.pdf

¹⁴This figure counts children ages 1 to 18 eligible for the Early and Periodic Screening, Diagnostic and Treatment Benefit. See U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services, Annual EPSDT Participation Report, Form CMS-416 (National) fiscal year: 2011, April 1, 2013. Analysis by The Pew Charitable Trusts; U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services, Early and Periodic Screening, Detection and Treatment Web page (accessed May 24, 2013), <http://www.medicare.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Early-Periodic-Screening-Diagnosis-and-Treatment.html>.

¹⁵American Dental Association, Health Policy Resources Center, 2011 American Dental Association Workforce Model: 2009–2030 (Chicago: American Dental Association, 2011), 11.

¹⁶Patient Protection and Affordable Care Act of 2010, Public Law No. 111–148, sec. 5304, 124 Stat. 119, 621–622 (2010).

¹⁷Virtual Dental Home Demonstration Project, Arthur A. Dugoni School of Dentistry, University of the Pacific: [http://www.dental.pacific.edu/Community_Involvement/Pacific_Center_for_Special_Care—\(PCSC\)/Innovations_Center/Virtual_Dental_Home_Demonstration_Project.html](http://www.dental.pacific.edu/Community_Involvement/Pacific_Center_for_Special_Care—(PCSC)/Innovations_Center/Virtual_Dental_Home_Demonstration_Project.html)

¹⁸Centers for Medicare and Medicaid Services, "Emergency Room Diversion Grant Program," 2008–2011, <http://www.medicare.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Grant-Programs/ER-Diversion-Grants.html>.

authorize dental therapists. These providers and programs can increase access at a lower cost to States, and numerous studies have reaffirmed the quality of the services being provided.¹⁹ These evaluations would not only benefit those States that have authorized alternative providers, but would also provide information to inform policies in the many other States that are struggling to find answers to the challenge of expanding access to the underserved.

HRSA funding request for fiscal year 2015:

- Removal of the current funding block on existing funding for the Alternative Dental Health Care Provider Demonstration Grants, Section 340G–1 of the Public Health Service Act, and an appropriation of \$10 million to initiate the program
- \$32 million for Title VII program grants to expand and educate the dental workforce

By making targeted Federal investments in effective policy approaches, the subcommittee can enable States to sustain programs that prevent the pain, missed school hours and long-term health and economic consequences of untreated dental disease. A handful of States are leading the way, but all States can and must do more to ensure access to dental care for those who need it most. Thank you for your consideration of this testimony.

[This statement was submitted by Shelly Gehshan, Director, Pew Children's Dental Campaign.]

PREPARED STATEMENT OF THE PHYSICIAN ASSISTANT EDUCATION ASSOCIATION

On behalf of the 187 accredited physician assistant (PA) education programs in the United States, the Physician Assistant Education Association (PAEA) is pleased to submit these comments on the fiscal year 2015 appropriations for PA education programs that are authorized through Title VII of the Public Health Service Act. PAEA supports funding of at least \$280 million in fiscal year 2015 for the health professions education programs authorized under Title VII of the Public Health Service Act and administered through the Health Resources and Services Administration (HRSA). We also request \$12 million of that funding support PA programs operating across the country. This is the only designated source of Federal funding for PA education and is crucial to the U.S. PA education system's ability to meet the demand for education and to continue to produce highly skilled physician assistants ready to enter the healthcare workforce in an average of 26 months. The way that PAs are educated in America—the caliber of our institutions and the expertise of our educators—is the gold-standard throughout the world and that distinction must be maintained in this period of unprecedented patient need and rapid growth within the PA profession.

Need for Increased Federal Funding

The unmet need for primary care services in the United States is well documented, and only expected to grow as Baby Boomers age and the Affordable Care Act is fully implemented. The very parameters of access and healthcare quality are rapidly evolving. Yet the one constant in our healthcare system remains the need for qualified healthcare providers in numbers sufficient to meet demand, and primary care has been clearly identified as the critical entry point into the healthcare system where that access must be guaranteed. The PA profession was created specifically to address a shortage of primary care physicians almost fifty years ago, and today's PAs stand ready to help address the challenges our Nation faces in primary care. The effectiveness of physician assistants is well-documented by studies showing better patient access, especially for Medicaid patients, high patient satisfaction, more frequent patient education, and healthcare outcomes similar to physicians. Importantly, PAs could play an even larger role in high-quality, cost-effective care if offered appropriate financial support and through innovations in the PA education system.

Like physicians, the PA profession also faces a shortage of graduates that will hinder its ability to help fully address the primary care issue in the United States. Without new solutions, at the current output of approximately 7000 graduates from PA programs per year, these shortages will persist, particularly in the rural and underserved communities where care is needed the most. Title VII is the only funding

¹⁹ David A. Nash et al., A Review of the Global Literature on Dental Therapists, April 2012, W.K. Kellogg Foundation, <http://www.wkcf.org/knowledge-center/resources/2012/04/nash-dental-therapist-literaturereview.aspx>.

source that provides direct support for PA programs and plays a crucial role in developing and supporting the education system's ability to produce the next generation of these advanced practice clinicians.

Background on the Profession

Since the 1960s, PAs have consistently demonstrated they are effective partners in healthcare, readily adaptable to the needs of an ever-changing delivery system. Physician assistants are licensed health professionals with advanced education in general medicine that practice medicine as members of the healthcare team. They provide a broad range of medical and therapeutic services to diverse populations in rural and urban settings, including prescriptive authority in all 50 States, the District of Columbia, and Guam. PAs practice medicine to the extent allowed by law and within the physician's scope of practice and their combination of medical training, advanced education, and hands-on experience allows PAs to practice with significant autonomy, and in rural and other medically underserved areas where they are often the only full-time medical provider. The profession is well established, yet nimble enough to embrace new models of care, adopt innovative approaches to training and education, and adapt to health system challenges. The PA practice model is, by design, a team-based approach to patient-centered care where the PA works in tandem with a physician and other health professionals. This PA practice approach to quality care is uniquely aligned with the patient-centered, collaborative, interprofessional and outcomes-based care models transforming the U.S. healthcare system.

PA Education: The Pipeline for Physician Assistants

There are currently 187 accredited PA education programs in the United States—a 23 percent increase over the past 5 years; together these programs graduate over 7,000 PA students each year. PAs are educated as generalists in medicine and that training gives them the flexibility to practice in more than 60 medical and surgical specialties. More than one third of PA program graduates are working in a primary care specialty.

The average PA education program is 26 months in length and includes one didactic year in the classroom, and another year devoted to clinical rotations. Most curricula include 340 hours of basic sciences and nearly 2,000 hours of clinical training, second only to physicians in time spent in clinical study.

As of today, approximately 65 new PA programs are in the pipeline at various stages of development and moving toward accredited status. The growth rate in the applicant pool is even more pronounced. Since its inception in 2001 through the most recent application cycle, the Centralized Application Service (CASPA) used by most programs grew from 4,669 applicants to over 20,000. As of March 2014, there were 19,968 applicants to PA education programs, a 36 percent increase in CASPA applicants over the past 5 years alone.

The PA profession is expected to continue to grow as a result of the projected shortages of physicians and other healthcare professionals, the growing demand for care driven by an aging population, and the continuing strong PA applicant pool. Accordingly, The Bureau of Labor Statistics projects a 39 percent increase in the number of PA jobs between 2008 and 2018. With its relatively short initial training time and the flexibility of generalist-trained PAs, the PA profession is well-positioned to help fill projected shortages in the numbers of healthcare professionals—if appropriate resources are available to support the education system behind them.

AREAS OF ACUTE NEED

Faculty Shortages

Faculty development is one of the profession's critical needs and educators are an often overlooked element to developing an adequate primary care workforce. Nearly half of PA program faculty are 50 years or older and the PA teaching profession faces large numbers of retirements in the next 10–15 years. An interest in education must be developed early in the educational process to ensure a continuous stream of educators, and to do so, we must alleviate the significant loan burdens that prevent many physician assistants from entering academia. In order to attract the most highly qualified faculty, PA education programs must have the resources to help clinicians transition into education, including curriculum development, teaching methods, and laboratory instruction. Most educators come from clinical practice and these non-clinical professional skills are essential to a successful transition from clinical practice to a classroom setting. Without Federal support, we will face an impending shortage of educators who are prepared for and committed to the critical teaching role that will ensure the next generation of skilled practitioners.

Clinical Site Shortages

Outside of the classroom, PA education faces additional challenges in meeting demand. A lack of clinical sites for PA education is hampering PA programs' ability to produce PAs at the pace needed to meet the demand for primary care in the U.S. This shortage is caused by two main factors: a shortage of medical professionals willing to teach students as they are cycling through their clinical rotations (preceptors), and a lack of sites with the physical space to teach.

This phenomenon is experienced throughout the health professions, and is particularly acute in primary care. It has created unintentional competition for clinical sites and preceptors within and among PAs, physicians and advance practice nurses. Federal funding can help incentivize practicing clinicians to both offer their time as preceptors, and volunteer their clinical operations as training grounds for PAs and other health professionals to train together and directly interact with patients as a team. PAEA believes that interprofessional clinical training and practice are necessary for optimum patient care and will be a defining model of healthcare in the U.S. in the 21st century. We can only make that a reality if we begin to build a sufficient network of health professionals who are willing to teach the next generation of primary care professionals—that approach will benefit PAs as well as the future physicians, nurses and other clinicians that comprise the full primary care team.

Enhancing Diversity

Workforce diversity, and practice in underserved areas are key priorities identified by HRSA and are consistent with those of PAEA. It is increasingly important for patient care quality that the health workforce better represents America's changing demographics, as well as addresses the issues of disparities in healthcare. PA programs have been committed to attracting students from underrepresented minority groups and disadvantaged backgrounds into the profession, including veterans who have served our country and desire to transition to civilian health professions. Studies have found that health professionals from underserved areas are three to five times more likely to return to underserved areas to provide care, and PA programs are looking for unique ways to recruit diverse individuals into the profession, and sustain them as leaders in the education field. If we can provide resources to schools that are particularly poised to improve their diversity recruitment efforts and replicate or create best practices including transition programs for our veterans, we can begin to address this systemic need.

In order to leverage the efforts of PA programs through Title VII funding to increase workforce diversity in the PA profession, PAEA also supports the restoration of funding for the Health Careers Opportunity Program (HCOP), and increased funding for the Scholarships for Disadvantaged Students and National Health Service Corps. Historically, access to higher education has been constrained for individuals from disadvantaged backgrounds. These programs help to provide a clear path for students who might not otherwise consider a physician assistant career.

Title VII Funding

Title VII funding fills a critical need for curriculum development, faculty development, clinical site expansion and diversification of the primary care workforce—areas that if appropriately supported can help ensure the PA profession realizes its full promise in the U.S. healthcare system. These funds enhance clinical training and education, assist PA programs with recruiting applicants from minority and disadvantaged backgrounds, and enable innovative programs that focus on educating a culturally competent workforce. Title VII funding increases the likelihood that PA students will practice in medically underserved communities with health professional shortages. The absence of this funding would result in the loss of care to patients with the most urgent need for access to care.

Title VII support for PA programs was strengthened in 2010 when Congress enacted a 15 percent allocation in the Appropriations process specifically for PA programs working to address the health provider shortage. This funding has enhanced capabilities to train a growing PA workforce, creatively expand care to the underserved, and develop a more diverse PA workforce:

- One Texas program has used its PA training grant to support the program at a distant site in an underserved area. This grant provides assistance to the program for recruiting, educating, and training PA students in the largely Hispanic South Texas and mid-Texas/Mexico border areas and supports new faculty development.
- A Utah program has used its PA training grant to promote interprofessional teams. The grant allowed the program to optimize its relationship with three service-learning partners, develop new partnerships with three service-learning

sites, and create a model geriatric curriculum that includes didactic and clinical education.

- An Alabama program used its PA training grant to update and expand the current health behavior educational curriculum and HIV/STD training. They were also able to include PA students from other programs who were interested in rural, primary care medicine for a four-week comprehensive educational program in HIV disease diagnosis and management.

Recommendations on fiscal year 2015 Funding

The Physician Assistant Education Association requests the Appropriations Committee's support in funding for Title VII health professions programs at a minimum of \$280 million for fiscal year 2015. This level of funding is crucial to support the Nation's ability to produce and maintain highly skilled primary care practitioners, particularly those from diverse backgrounds and the military who will practice in medically underserved areas and serve vulnerable populations. We also ask for the continuation of the 15 percent allocation for PA education programs in the Primary Care cluster as mandated in the Affordable Care Act. The Accreditation Review Commission on Education for the Physician Assistant estimates that an additional 75 programs will be added by 2018. Therefore, we request an increase in funding to \$12 million which will allow sufficient funding for the expanding number of PA programs expected to begin enrolling students during the next four to 5 years.

We thank the members of the subcommittee for their support of the health professions and look forward to your continued commitment to finding solutions to the Nation's health workforce shortage. We appreciate the opportunity to present the Physician Assistant Education Association's fiscal year 2015 funding recommendation.

[This statement was submitted by Anthony Miller, M.Ed., PA-C Chief Policy and Research Officer.]

PREPARED STATEMENT OF THE POPULATION ASSOCIATION OF AMERICA AND ASSOCIATION OF POPULATION CENTERS

Introduction

Thank you, Mr. Chairman Harkin, Ranking Member Moran, and other distinguished members of the Subcommittee, for this opportunity to express support for the National Institutes of Health (NIH), National Center for Health Statistics (NCHS), and Bureau of Labor Statistics (BLS). These agencies are important to the members of the Population Association of America (PAA) and Association of Population Centers (APC) because they provide direct and indirect support to population scientists and the field of population, or demographic, research overall. In fiscal year 2015, we urge the Subcommittee to adopt the following funding recommendations: NIH, \$32 billion, consistent with the level recommended by the Ad Hoc Group for Medical Research; NCHS, \$182 million, consistent with the Administration's request; and BLS, \$610 million, consistent with the Administration's request, at a minimum.

The PAA and APC are two affiliated organizations that together represent over 3,000 social and behavioral scientists and almost 40 population research centers nationwide that conduct research on the implications of population change. Our members, which include demographers, economists, sociologists, and statisticians, conduct scientific research, analyze changing demographic and socio-economic trends, develop policy recommendations, and train undergraduate and graduate students. Their research expertise covers a wide range of issues, including adolescent health and development, aging, health disparities, immigration and migration, marriage and divorce, education, social networks, housing, retirement, and labor.

National Institutes of Health

Demography is the study of populations and how or why they change. A key component of the NIH mission is to support biomedical, social, and behavioral research that will improve the health of our population. The health of our population is fundamentally intertwined with the demography of our population. Recognizing the connection between health and demography, NIH supports extramural population research programs primarily through the National Institute on Aging (NIA) and the National Institute of Child Health and Human Development (NICHD).

National Institute on Aging

To inform the implications of our rapidly aging population, policymakers need objective, reliable data about the antecedents and impact of changing social, demographic, economic, health and well-being characteristics of the older population. The

NIA Division of Behavioral and Social Research (BSR) is the primary source of Federal support for basic research on these topics.

In addition to supporting an impressive research portfolio that includes the prestigious Centers on the Demography and Economics of Aging, the NIA BSR Division also supports several large surveys that produce accessible data. These surveys include the National Health and Aging Trends Study (NHATS), which has enrolled 8,000 Medicare beneficiaries with the goal of studying late-life disability trends and dynamics. The study also includes a supplement to examine informal caregivers and their impact on the utilization of long-term care by people with chronic disabilities. Another NIA survey, the Health and Retirement Study (HRS), provides unique information about economic transitions in work, income, and wealth, allowing scientists to study how the domains of family, economic resources, and health interact. The HRS has collected data every 2 years since 1992, including most recently, biomarkers, from a representative sample of more than 26,000 Americans over the age of 50. These data are accessible to researchers worldwide and have informed numerous scientific findings. For example, in 2013, researchers using the HRS published a study in the *New England Journal of Medicine*, concluding that the cost of providing dementia care is comparable to, if not greater than, those for heart disease and cancer.

Eunice Kennedy Shriver National Institute of Child Health and Human Development

Since 1968, NICHD has supported research on population processes and change. This research is housed in the Institute's Population Dynamics Branch, which supports research and training in demography, reproductive health, and population health and funds major national studies that track the health and well-being of children and their families from childhood through adulthood. These studies include *Fragile Families* and *Child Well-Being*, the first scientific study to track the health and development of children born to unmarried parents, and the *National Longitudinal Study of Adolescent Health* (Add Health), tracing the effects of childhood and adolescent exposures on later health.

One of the most important population research programs that the NICHD supports is the Population Dynamics Centers Research Infrastructure Program. This program promotes innovation, supports interdisciplinary research, translates scientific findings into practice, and develops the next generation of population scientists. In addition, the centers provide incentives to reduce the costs and increase the efficiency of research by streamlining and consolidating research infrastructure. The population research centers generate and facilitate significant scientific research findings as well. For example, in March 2014, researchers at Johns Hopkins University published findings in *JAMA*, concluding that opening or expanding casinos on California tribal lands reduces poverty and the obesity rate of children by almost 3 percent.

National Center for Health Statistics

The National Center for Health Statistics (NCHS) is the Nation's principal statistical agency. Most notably, NCHS funds and manages the National Vital Statistics System (NVSS), which contracts with the States to collect birth and death certificate information, and funds a number of complex large surveys, such as *National Survey of Family Growth* and *National Health Interview Survey*, which are an invaluable resource for population scientists. The Subcommittee's support of NCHS in recent years has enabled it to make significant progress toward modernizing the NVSS and expediting the release of these data to the user community. Yet, much work is still needed to fully modernize the NVSS and to support necessary expansions to the agency's core surveys so that these data can effectively assess Americans' health.

Bureau of Labor Statistics

The Bureau of Labor Statistics (BLS) produces essential economic information for public and private decisionmaking. Its data are used extensively by population scientists who study and evaluate labor and related economic policies and programs. Given the importance and unique nature of BLS data, we urge the Subcommittee to support the Administration's request, \$610 million, at a minimum, but to consider increasing its funding to \$631 million. This additional funding is necessary to restore the agency's purchasing power back to fiscal year 2010 levels and specifically to restore recent program cuts.

Thank you for considering the importance of these agencies under your jurisdiction that benefit the population sciences.

[This statement was submitted by Mary Jo Hoeksema, Director, Government Affairs Population Association of America/Association of Population Centers.]

PREPARED STATEMENT OF PREVENT BLINDNESS

FUNDING REQUEST OVERVIEW

Prevent Blindness appreciates the opportunity to submit written testimony for the record regarding fiscal year 2015 funding for vision and eye health related programs. As the Nation's leading non-profit, voluntary health organization dedicated to preventing blindness and preserving sight, Prevent Blindness maintains a long-standing commitment to working with policymakers at all levels of government, organizations and individuals in the eye care and vision loss community, and other interested stakeholders to develop, advance, and implement policies and programs that prevent blindness and preserve sight. Prevent Blindness respectfully requests that the Subcommittee provide the following allocations in fiscal year 2015 to help promote eye health and prevent eye disease and vision loss:

- Provide at least \$1,000,000 to strengthen the Vision Health Initiative (visual screening education) at the Centers for Disease Control and Prevention (CDC).
- Provide at least \$3,319,000 to continue the Glaucoma Project at the CDC.
- Support the Maternal and Child Health Bureau's (MCHB) National Center for Children's Vision and Eye Health.
- Provide at least \$639 million in to sustain programs under the Maternal and Child Health (MCH) Block Grant.
- Provide at least \$730 million to the National Eye Institute (NEI).

INTRODUCTION AND OVERVIEW

Vision-related conditions affect people across the lifespan. Good vision is an integral component to health and well-being, affects virtually all activities of daily living, and impacts individuals physically, emotionally, socially, and financially. Loss of vision can have a devastating impact on individuals and their families. An estimated 80 million Americans have a potentially blinding eye disease, three million have low vision, more than one million are legally blind, and 200,000 are more severely visually blind. Vision impairment in children is a common condition that affects five to 10 percent of preschool age children, and is a leading cause of impaired health in childhood. Recent research showed that the economic burden of vision loss and eye disorders is \$139 billion each year, \$47.4 billion of which is Federal spending. Alarming, while half of all blindness can be prevented through education, early detection, and treatment, the NEI reports that "the number of Americans with age-related eye disease and the vision impairment that results is expected to double within the next three decades."¹

To curtail the increasing incidence of vision loss in America, and its accompanying economic burden, Prevent Blindness advocates sustained and meaningful Federal funding for programs that promote eye health and prevent eye disease, vision loss, and blindness; needed services and increased access to vision screening; and vision and eye disease research. In a time of significant fiscal constraints, we recognize the challenges facing the Subcommittee and urge you to consider the ramifications of decreased investment in vision and eye health. Vision loss is often preventable, but without continued efforts to better understand eye conditions, and their treatment, through research, to develop the public health systems and infrastructure to disseminate and implement good science and prevention strategies, and to protect children's vision, millions of Americans face the loss of independence, loss of health, and the loss of their livelihoods, all because of the loss of their vision.

VISION AND EYE HEALTH AT THE CDC: HELPING TO SAVE SIGHT AND SAVE MONEY

The CDC serves a critical role in promoting vision and eye health. Since 2003, the CDC and Prevent Blindness have collaborated with other partners to create a more effective public health approach to vision loss prevention and eye health promotion. The CDC works to promote eye health and prevent vision loss; improve the health and lives of people living with vision loss by preventing complications, disabilities, and burden; reduce vision and eye health related disparities; and integrate vision health with other public health strategies. However, severely constrained financial resources have limited the CDC's ability to take the work of the Vision Health Initiative (VHI) to the next level.

Prevent Blindness requests at least \$1,000,000 in fiscal year 2015 to strengthen vision and eye health efforts of the CDC. This funding level would allow the VHI to increase vision impairment and eye disease surveillance efforts, apply previous

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

CDC vision and eye health research findings to develop effective prevention and early detection interventions, and begin to incorporate vision and eye health promotion activities into State and national public health chronic disease initiatives, with an initial focus on early detection of diabetic retinopathy

Improving Access to Eye Care for those at High Risk for Glaucoma

An estimated 2.2 million people are affected by glaucoma. A disease of the aging eye, risk for glaucoma increases with age, especially among black, Hispanic/Latinos, and Asians. Once vision is lost to glaucoma, it cannot be restored, but with early diagnosis and appropriate treatment, it is possible to slow disease progression and save the remaining sight. Detection and management of glaucoma are challenged by difficulties in reaching high-risk populations and by the lack of simple, cost-effective screening plans.

Prevent Blindness requests at least \$3,319,000 in fiscal year 2015 to continue the work of the Glaucoma Project to improve glaucoma screening, referral, and treatment. The program is intended to reach those populations experiencing the greatest disparity in access to glaucoma care through an integrated collaboration among private and public organizations.

INVESTING IN THE VISION OF OUR NATION'S MOST VALUABLE RESOURCE—CHILDREN

While the risk of eye disease increases after the age of 40, eye and vision problems in children are of equal concern. The visual system in children younger than 8 years old is in a critical developmental stage. Unidentified and untreated vision problems can lead to permanent and irreversible visual loss and/or cause problems socially, academically, and developmentally in this critical time of a child's life. Currently, only one in three children receive eye care services before the age of six.[1] Requirements for preventive eye care/vision screenings prior to or during the school years vary broadly from State to State. Many States have no standards and those with standards present with little consistency regarding type, frequency, and referral or follow-up requirement protocol.[i] Inclusion of vision screenings with a comprehensive approach to follow up treatment and an integrated approach to data collection as a part of the required health component for grant recipients will help to change disparities in vision and eye health for our Nation's children.

In 2009, the MCHB established the National Center for Children's Vision and Eye Health (the Center), a national vision health collaborative effort aimed at developing the public health infrastructure necessary to promote eye health and ensure access to a continuum of eye care for young children.

The Center is guided by an Advisory Committee comprised of the Nation's leaders in children's vision and public health to implement national guidelines for quality improvement strategies, vision screening and developing a continuum of children's vision and eye health. With this support the Center, will continue to: (1) provide national leadership in dissemination of best practices, infrastructure development, professional education, and national vision screening guidelines that ensure a continuum of vision and eye healthcare for children; (2) advance State-based performance improvement systems, screening guidelines, and mechanisms for uniform data collection and reporting; and (3) provide technical assistance to States in the implementation of strategies for vision screening, establishing quality improvement measures, and improving mechanisms for surveillance.

Prevent Blindness also requests at least \$639 million in fiscal year 2015 to sustain programs under the MCH Block Grant. The MCH Block Grant enables States to expand critical healthcare services to millions of pregnant women, infants and children, including those with special healthcare needs. In addition to direct services, the MCH Block Grant supports vital programs, preventive and systems building services needed to promote optimal health—including the National Center for Children's Vision and Eye Health.

ADVANCE AND EXPAND VISION RESEARCH OPPORTUNITIES

Prevent Blindness calls upon the Subcommittee to provide \$730 million for the NEI to enable the agency to pursue its primary "audacious goal" of restoring vision by bolstering its efforts to identify the underlying causes of eye disease and vision loss, improve early detection and diagnosis of eye disease and vision loss, and advance prevention and treatment efforts. Research is critical to ensure that new treatments and interventions are developed to help reduce and eliminate vision problems and potentially blinding eye diseases facing consumers across the country. By providing additional funding for the NEI at the NIH, essential efforts to identify the underlying causes of eye disease and vision loss, improve early detection and

diagnosis of eye disease and vision loss, and advance prevention, treatment efforts and health information dissemination will be bolstered.

CONCLUSION

On behalf of Prevent Blindness, our Board of Directors, and the millions of people at risk for vision loss and eye disease, we thank you for the opportunity to submit written testimony regarding fiscal year 2015 funding for the CDC's vision and eye health efforts, the MCHB's National Center for Children's Vision and Eye Health, and the NEI. Please know that Prevent Blindness stands ready to work with the Subcommittee and other Members of Congress to advance policies that will prevent blindness and preserve sight. Please feel free to contact us at any time; we are happy to be a resource to Subcommittee members and your staff. We very much appreciate the Subcommittee's attention to—and consideration of—our requests.

[This statement was submitted by Hugh Parry, President & CEO, Prevent Blindness.]

PREPARED STATEMENT OF THE PROSTATITIS FOUNDATION

Some young men have prostatitis before they even reach twenty years of age, many older men have had symptoms for many years. You do not hear about it as much as prostate cancer because men do not discuss such issues with their friends, families and acquaintances. Many couples assume there may be a stigma to having the annoying condition. Even many urologists tell them there is no cure and they will just have to live with it.

Prostatitis is a family affair as it presents itself as a disabling pain accompanied by sexual dysfunction and infertility issues. It usually causes a hesitant urination and an inability to empty the bladder. Patients are sometimes unable to work and sometimes even become suicidal.

Prostatitis is a huge financial drain as it tends to imitate prostate cancer symptoms. The tests and procedures needed to rule out prostate cancer are very expensive and often unnecessary but needed to reassure the patient and his family. Prostatitis has been mentioned in historical literature from previous times and generations ago.

The NIH has worked to find a cause and cure for (CP/CPPS) chronic prostatitis/chronic pelvic pain syndrome for nearly twenty years. In the latest research group called the MAPP Research Network they have included other specialties than urologists to help find a clue to prostatitis which affects 10 percent of men all over the world. It is critical to fully fund those research efforts of the NIH and keep the CDC involved.

[This statement was submitted by Mike Hennenfent, President, Prostatitis Foundation.]

PREPARED STATEMENT OF THE PULMONARY HYPERTENSION ASSOCIATION

Chairman Harkin and distinguished members of the Subcommittee, thank you for your time and your consideration of the priorities of the pulmonary hypertension community as you work to craft the fiscal year 2015 Labor, Health and Human Services Appropriations Bill.

ABOUT PULMONARY HYPERTENSION

Pulmonary hypertension (PH) is a disabling and often fatal condition simply described as high blood pressure in the lungs. It affects people of all ages, races and ethnic backgrounds. Although anyone can get PH, there are risk factors that make some people more susceptible.

Treatment and prognosis vary depending on the type of PH. In one type, pulmonary arterial hypertension (PAH), the arteries in the lungs become too narrow to handle the amount of blood that must be pumped through the lungs. This causes several things to happen: a backup of blood in the veins returning blood to the heart; an increase in the pressure that the right side of your heart has to pump against to push blood through your lungs; and a strain on the right side of your heart due to the increased work that it has to do. If this increased pressure is not treated, the right side of your heart can become overworked, become very weak and may possibly fail. Because the blood has difficulty getting through the lungs to pick up oxygen, your blood oxygen level may be lower than normal. This can put a strain

not only on your heart, but also decrease the amount of oxygen getting to your brain.

There is currently no cure for PAH. Twelve treatment options are available to help patients manage their disease and feel better day to day but even with treatment, life expectancy with PAH is limited.

ABOUT THE ASSOCIATION

From simple beginnings—four women who met around a kitchen table in Florida in 1990—the Pulmonary Hypertension Association has evolved into a community of well over 10,000 pulmonary hypertension patients, caregivers, family members and medical professionals.

As we have grown, we have stayed true to our roots and the vision and ingenuity of our founders: We continue to work every day to end the isolation that PH patients face, and find a cure for pulmonary hypertension.

Research

PHA provides grants to promising researchers in the field of pulmonary hypertension. The program fosters new leaders in the field by supporting their interest in PH research and providing them with opportunities to work with mentors and learn new skills. Researchers supported by PHA are looking for new methods for early detection, new treatments to prevent the onset of PH and ultimately a cure for this terrible illness. To date, PHA has leveraged more than \$13 million in PH research funding through partnerships with the NIH and others.

Early Diagnosis Campaign

It takes too long for pulmonary hypertension to be diagnosed. The median survival rate without treatment is approximately 2.8 years, making the need to obtain a rapid and accurate diagnosis urgent. Unfortunately, the median duration from symptom onset to a confirmed diagnosis by right heart catheterization is 1.1 years. We are reaching patients too late in the process. Almost three-fourths of patients have advanced PH by the time they are diagnosed, leading more costly treatments and poorer outcomes. For the most advanced cases of PH, a lung or heart-lung transplant may be the only treatment option. The goal of PHA's Early Diagnosis Campaign is to discover the disease sooner in the early stages. This will allow the start of a treatment regimen that can slow the progression of PH and secure a better life for the patient.

Center Accreditation

The Pulmonary Hypertension Association's Scientific Leadership Council, 28 global leaders in the field of pulmonary hypertension, have spearheaded the PHA-Accredited PH Care Centers (PHCC) initiative. The goal of this initiative is to establish a program for accreditation of centers with special expertise in pulmonary hypertension (PH), particularly pulmonary arterial hypertension (PAH), to raise the overall quality of care and outcomes in patients with this life-threatening disease.

ONE PATIENT'S STORY

In 2011, at the age of 29, GS12 Human Terrain Analyst Jessica (Puglisi) Armstrong began experiencing shortness of breath and dizziness. She was in Afghanistan at the time. Jessica was first diagnosed with dehydration. Then, as is the case with many PH patients, she was told she had asthma and was given an inhaler. Two months later, she fainted for no apparent reason. An echocardiogram revealed blood clots in her lungs and Jessica was medically evacuated to Germany and then to the U.S. Six months after her first symptoms, she was finally given a complete work up and diagnosed with pulmonary hypertension.

Jessica, she had a unique form of PH due to blood clots that can be mitigated with a pulmonary thromboendarterectomy (PTE)—a complex surgery that involves opening the chest cavity and stopping circulation for up to twenty minutes. She describes the surgery, which she underwent at the University of California San Diego, as “more painful than I could ever imagine.” She notes that UCSD's PTE program did not begin until 1990 and even now, despite being recognized as the global leaders on this procedure, has only completed about 3,000 surgeries. The procedure that saved Jessica's was developed in her lifetime.

Jessica was terminated from Army employment and spent \$60,000 out of pocket on medical expenses which she has not been able to recoup. She was forced to begin a civilian job just two weeks after her PTE in order to retain health insurance. Despite this, Jessica is, in many ways, one of the lucky ones. I am glad to report that she is now doing well and serving an integral role at PHA as the coordinator of our Early Diagnosis Campaign.

Over the past decade, treatment options, and the survival rate, for pulmonary hypertension patients have improved significantly. However, courageous patients of every age lose their battle with PH each day. There is still a long way to go on the road to a cure and biomedical research holds the promise of a better tomorrow.

SEQUESTRATION

We have heard from the medical research community that sequestration and deficit reduction activities have created serious issues for Federal funding opportunities and the career development pipeline. In order to ensure that the pulmonary hypertension research portfolio can continue to grow, and, more importantly, to ensure that our country is adequately preparing the next generation of young investigators, we urge you to avert, mitigate, or otherwise eliminate the specter of sequestration. The Association has anecdotal accounts of the harms of sequestration and the Federated American Societies for Experimental Biology has reported:

- In constant dollars (adjusted for inflation), the NIH budget in fiscal year 2013 was \$6 billion (22.4 percent) less than it was in fiscal year 2003.

- The number of competing research project grants (RPGs) awarded by NIH has also fallen sharply since fiscal year 2003. In fiscal year 2013, NIH made 8,283 RPG awards, which is 2,110 (20.3 percent) fewer than in fiscal year 2003.

- Awards for R01-equivalent grants, the primary mechanism for supporting investigator-initiated research, suffered even greater losses. The number awarded fell by 2,528 (34 percent) between fiscal year 2003 and fiscal year 2013.

The pay line for some NIH funding mechanisms has fallen from 18 percent to 10 percent while the average age for a researcher to receive their first NIH-funded grant has climbed to 42. These are strong disincentives to choosing a career as a medical researcher. Our scaling-back is occurring at a time when many foreign countries are investing heavily in their biotechnology sectors. China alone plans to dedicate \$300 million to medical research over the next 5 years; this amount is double the current NIH budget over the same period of time. Scientific breakthroughs will continue, but America may not benefit from the return-on-investment of a robust biotechnology sector. For the purposes of economic and national security, as well as public health, the Association asks that you work with your colleagues to eliminate sequestration and recommit to supporting this Nation's biomedical research enterprise.

HEALTH RESOURCES AND SERVICES ADMINISTRATION

Due to the serious and life-threatening nature of PH, it is common for patients to face drastic health interventions, including heart-lung transplantation. Federal organ transplantation activities are coordinated through HRSA. To ensure HRSA can expand its important mission and continue to make improvements in donor lists and donor-matching please provide HRSA with a meaningful funding increase in fiscal year 2015.

CENTERS FOR DISEASE CONTROL AND PREVENTION

As a result of Federal investment in medical research, there are now twelve FDA-approved treatments for PH. The effectiveness of these therapies though is dependent on how early a patient can receive an accurate diagnosis and begin treatment. Unfortunately, two-thirds of patients are not diagnosed until PH has reached a late stage. In addition to mitigating the impact of many treatments, late diagnosis puts PH patients in a position to face interventions like heart-lung transplantation and even death. CDC and NCCDPHP have the resources to compliment PHA's own Sometimes its PH Early Diagnosis Campaign. Improving public awareness and recognition of PH will not only save lives, it can save the Federal healthcare system money. Please provide CDC with meaningful funding increases so the agency can expand its focus beyond winnable battles into increasingly important and cost-effective areas.

NATIONAL INSTITUTES OF HEALTH

NIH hosts a sizable PH research portfolio. Further, NIH and PHA have a strong track record of working together to advance our scientific understanding of PH. The twelve FDA-approved treatments, more than nearly every other rare disease, are evidence of the return-on-investment from these activities. Please provide NIH with meaningful increases to facilitate expansion of the PH research portfolio so we can continue to improve diagnosis and treatment.

NCATS

The Office of Rare Diseases Research (ORDR), located within NCATS, supports and coordinates rare disease research and provides information on rare diseases to patients, their families, healthcare providers, researchers and the public. In collaboration with other NIH institutes, ORDR funds rare diseases research primarily through the Rare Diseases Clinical Research Network (RDCRN), which supports clinical studies, investigator training, pilot projects, and access to information on rare diseases. The most recent funding opportunity announcement, which was widely broadcast and open to all rare diseases, including PAH, was issued in the fall of 2013 and awards are expected to be made in the summer of 2014.

NHLBI

The NHLBI-funded Centers for Advanced Diagnostics and Experimental Therapeutics in Lung Diseases Stage II program, which will begin in fiscal year 2014, will provide a mechanism to accelerate the development of therapies for lung diseases, including pulmonary fibrosis and pulmonary arterial hypertension.

ADDITIONAL ACTIVITIES

S. 1453

Senator Robert Casey (D-PA) has introduced the Pulmonary Hypertension Research and Diagnosis Act (S.1453). This budget neutral legislation has a bipartisan companion in the House due to its emphasis on lowering healthcare costs by promoting efficiencies within the Federal Government. S. 1453 seeks to establish an HHS-wide Committee tasked with preparing a report on how to leverage limited resources to improve early diagnosis of PH. Please consider cosponsoring S. 1453 and working with your colleagues to advance this important legislation.

S. 2115

PHA has written to Senators Richard Durbin (D-IL) and Barbara Mikulski (D-MD) to thank them for their leadership on the American Cures Act (S. 2115). We hope this legislation is an indication that policymakers have committed themselves to supporting innovative proposals to bolster and advance our Nation's biomedical research enterprise.

PREPARED STATEMENT OF RESEARCH!AMERICA

Research!America, the Nation's largest public education and advocacy alliance committed to advancing medical research and development, appreciates your stewardship over such a critical subset of our Nation's discretionary funding priorities. As the subcommittee begins the process of prioritizing fiscal year 2015 funding, we urge you to consider the following thoughts on Federal agencies entrusted with sustaining our Nation's sophisticated public health infrastructure, partnering with the private sector to accelerate medical progress, and optimizing healthcare outcomes.

The National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC), and the Agency for Healthcare Research and Quality (AHRQ) play pivotal roles in combating disabling and deadly health conditions. Moreover, the funding, or lack of it, allocated to these agencies will bear on our Nation's ability to compete in key export markets within the global economy, foster business development that grows and maintains jobs across the country, meet our solemn obligations to wounded warriors and support troops on the ground, combat deadly medical errors, and protect our Nation against pandemics and emerging health threats. The stakes truly are that high.

NIH as a driver of innovation

In fiscal year 2015, we urge you to provide at least \$32 billion in NIH funding to drive us beyond the stagnation that squanders opportunities to advance science and strengthen our Nation. Research funded by the NIH at universities, academic medical centers, independent research institutions and small businesses across the country lays the foundation for new product development by the private sector. Since much of the research NIH supports is at the non-commercial stages of the research pipeline, NIH funding does not compete with, but rather sets the stage for, critical private sector investment and development. These two complementary funding streams lead to business development, job growth and beneficial medical advances. Taxpayer-funded research through the NIH has helped our Nation make remarkable progress against such insidious health threats as childhood cancer, HIV-AIDS and heart disease.

The secrets of diabetes, Alzheimer's, Parkinson's, myriad cancers and many other diseases can and will be unlocked by science. The question is not if, but when . . . unless we dismiss the significance of such progress and continue to allow research resources to stagnate. And our Nation's best weapon against spiraling healthcare costs is research. Ignoring growing healthcare costs is a ticket to disaster. Alzheimer's disease alone is projected to cost the Federal Government over \$1 trillion during the next 20 years. Ultimately, we must prevent and cure disease in order to tackle the costs associated with it.

CDC as a first responder

In fiscal year 2015, we urge you to provide a funding level that continues the growth in CDC budget authority that was initiated in fiscal year 2014. The CDC engages in research that stems deadly and costly pandemics, bolsters our Nation's defenses against bioterrorism, and helps prevent the onset of debilitating and expensive diseases. The CDC is the Nation's first responder to lethal viruses and infections, including life-threatening and costly drug-resistant infections that pose a particular threat to children and young adults, as well as investigating tragic phenomena like cancer clusters. Due to cuts in recent years, the CDC is functioning with one hand tied behind its back, even as health challenges like the obesity epidemic, autism epidemic and infectious disease outbreaks capture headlines and ruin lives. It is always more efficient and cost effective to be in front of an outbreak or biological attack than to take reactionary measures.

AHRQ translates medical innovation into the right care at the right time

In fiscal year 2015, we urge you to provide at least \$375 million in funding for AHRQ. Research supported by AHRQ identifies inefficiencies in healthcare delivery that inflate the cost of public and private insurance. AHRQ-supported research also combats medical errors and improves the quality of care to help reduce the length and intensity of disability and disease. It helps patients and physicians make informed treatment decisions that improve outcomes and reduce costly "false starts" in the provision of healthcare services.

Just one of many success stories is AHRQ's issuance of new standards of care and practices related to central line-associated bloodstream infections. The implementation of the guidelines resulted in a reduction of up to two-thirds of cases during early rollout studies. With an annual estimated 80,000 cases, up to 28,000 deaths and an average cost per patient of \$45,000, this has the potential to save \$2.3 billion annually in healthcare costs. Given the enormity of the challenge of inefficiency in healthcare delivery, AHRQ is severely underpowered.

The threat of sequestration's return

The Ryan-Murray Bipartisan Budget Act provided America with 2 years of partial relief from sequestration after across the board budget cuts dramatically impacted medical research in March 2013. Unfortunately, sequestration will go back into full effect in 2016 unless Congress takes action, and it will be in effect for 2 years longer than originally established under the 2011 Budget Control Act. The return of sequestration's budget cuts to discretionary spending, including that for NIH, CDC and AHRQ, poses potentially devastating setbacks to medical research. Short-changing medical research is not a solution to the Federal deficit or debt. On the contrary, neglecting medical research undercuts strategies to fight chronic disease and the multipronged Federal costs that arise from it, while squandering opportunities to increase private sector and Federal revenues through new medical innovations.

Research!America appreciates the difficult task facing the subcommittee as it seeks to simultaneously confront the budget deficit, strengthen the U.S. and promote the well-being of Americans. There are few Federal investments that confer as many benefits as medical research—new cures, new businesses, new jobs, new solutions to healthcare cost inflation, and new fuel to drive U.S. leadership in a global economy shaped by the ability of countries to continuously innovate. We firmly believe that investing in NIH, CDC and AHRQ is a means of advancing all three of these fundamental goals. Thank you for your leadership and consideration; we know that your task is extraordinarily difficult, and that our Nation is fortunate to have such pragmatic, committed and gifted leaders at the helm.

PREPARED STATEMENT OF THE RESEARCH WORKING GROUP

Chairman Harkin, Ranking Member Moran, and members of the Committee, thank you for the opportunity to provide testimony on the National Institutes of Health (NIH) budget overall and for AIDS research in fiscal year 2015. Tomorrow's scientific and medical breakthroughs depend on your vision, leadership, and com-

mitment to robust NIH funding this year. To this end, the Research Working Group (RWG) urges this Committee to support a funding target of \$36 billion in fiscal year 2015 to maintain the United States' position as the world leader in medical research and innovation.

Investments in health research via the NIH have paid enormous dividends in the health and wellbeing of people in the U.S. and around the world. NIH-funded HIV and AIDS research has supported innovative basic science for better drug therapies, evidence-based behavioral and biomedical prevention interventions, and vaccines that have saved and improved the lives of millions, and holds great promise for significantly reducing HIV infection rates and providing more effective treatments for those living with HIV/AIDS in the coming decade.

Despite these advances, the number of new HIV/AIDS cases continues to rise in the U.S. and around the world. There are 1.1 million HIV-infected people in the U.S., the highest number in the epidemic's more than 30 year history; additionally over 50,000 Americans become newly infected every year. In 2012, 35.3 million were infected with HIV/AIDS worldwide, 1.6 million died from the disease and 2.3 million people were newly infected. With proper funding, we can capitalize on the ongoing scientific progress in therapeutics and prevention science, vaccines, and finding a cure for HIV, as well as addressing the comorbidity such as viral hepatitis and tuberculosis that affect patients living with HIV.

Major advances over the last few years in HIV prevention technologies—with HIV vaccines, medical male circumcision, antiretroviral treatment as prevention, and pre-exposure prophylaxis using antiretrovirals (PrEP) —demonstrate that adequately resourced NIH programs can transform our lives. Because HIV disease entails many common co-morbidities, HIV research funding is spread across the Institutes and Centers—and HIV research discoveries have had broad benefits for many other conditions including: aging, cancer, immunosuppression and auto-immune disorders, heart disease, stroke, Alzheimer's disease, osteoporosis, viral hepatitis, and influenza, among others. Federal support for AIDS research has led to new treatments for other diseases, including cancer, heart disease, Alzheimer's, hepatitis, osteoporosis, and a wide range of autoimmune disorders.

Over the years, the NIH has sponsored the evaluation of a host of vaccine candidates, some of which are advancing to efficacy trials. The successful iPrEx and HPTN 052 trials have shown the potential of antiretroviral drugs to prevent HIV infection. Moreover, increased funding will support the future testing of new vaccines, microbicides and therapeutics in the pipeline via the newly restructured, cross-cutting NIAID clinical trials network that translates NIH-funded scientific innovation into critical quality-of-life gains.

It is also essential to note that NIH-funded HIV pathogenesis and clinical research has contributed substantially to our understanding of potential curative approaches. The NIAID clinical trial networks comprise one of the largest groups of clinical research sites in the world and have been instrumental to the progress made in response to the HIV epidemic domestically and globally. These networks are now taking on the challenges of tuberculosis and hepatitis C and have dramatically expanded the opportunities to test new drugs and other critically needed interventions to advance knowledge in these leading infectious disease killers.

Increased funding for the NIH in fiscal year 2015 makes good bipartisan economic sense, especially in shaky fiscal times. Robust funding for the NIH overall will enable research universities to pursue scientific opportunity, advance public health, and create jobs and economic growth. In every State across the country, the NIH supports research at hospitals, universities, private enterprises, and medical schools. This includes the creation of jobs that will be essential to future discovery. Sustained investment is also essential to train the next generation of scientists and prepare them to make tomorrow's HIV discoveries. NIH funding puts 350,000 scientists to work at research institutions across the country. According to the NIH, each of its research grants creates or sustains six to eight jobs, and NIH-supported research grants and technology transfers have resulted in the creation of thousands of new, independent private-sector companies. Strong, sustained NIH funding is a critical national priority that will foster better health and economic revitalization.

Since 2003, funding for the NIH has failed to keep up with our existing research needs—damaging the success rate of approved grants and leaving very little money to fund promising new research. The real value of the increases prior to 2003 has precipitously declined because of the relatively higher inflation rate for the cost of research and development activities undertaken by the NIH. According to the Biomedical Research and Development Price Index, which calculates how much the NIH budget must change each year to maintain purchasing power, between fiscal year 2003 and fiscal year 2014, the cost of NIH activities increased by 38.1 percent. By comparison, the overall NIH budget increased by 10.8 percent, over fiscal year

2003. So in real terms, the NIH has already sustained budget decreases of close to 30 percent over the past decade due to inflation alone! As such, flat funding or cuts to the NIH will have the clear and devastating effects of undermining our Nation's leadership in health research and our scientists' ability to take advantage of the expanding opportunities to advance healthcare. The race to find better treatments and a cure for cancer, heart disease, AIDS, and other diseases, and for controlling global epidemics like AIDS, tuberculosis, and malaria, all depend on a robust long-term investment strategy for health research at NIH.

In conclusion, the RWG calls on Congress to continue the bipartisan Federal commitment towards combating HIV as well as other chronic and life-threatening illnesses by increasing funding for the NIH to \$36 billion in fiscal year 2015. A meaningful commitment to stemming the epidemic and securing the well being of people with HIV cannot be met without prioritizing the research investment at the NIH that will lead to tomorrow's lifesaving vaccines, treatments, and cures. Thank you for the opportunity to provide these written comments.

PREPARED STATEMENT OF THE ROTARY INTERNATIONAL

Chairman Harkin, members of the Subcommittee, Rotary International appreciates this opportunity to submit testimony in support of the polio eradication activities of the U. S. Centers for Disease Control and Prevention (CDC). The Global Polio Eradication Initiative (GPEI) is an unprecedented model of cooperation among national governments, civil society and UN agencies working together to reach the most vulnerable children through the safe, cost-effective public health intervention of polio immunization. We appeal to this Subcommittee for continued leadership to ensure we seize the opportunity to conquer polio once and for all. Rotary International strongly supports the President's 2015 request of \$161 million for the polio eradication activities of the CDC to enable full implementation of the polio eradication strategies and innovations outlined in the Polio Eradication and Endgame Strategic Plan (2013–2018).

PROGRESS IN THE GLOBAL PROGRAM TO ERADICATE POLIO

Significant strides were made in 2013 toward stopping transmission of polio. Thanks to this committee's leadership in appropriating funds for the polio eradication activities of the CDC:

- India was certified polio free in February 2014, following 3 years with no cases of polio. The entire Southeast Asia region was certified polio free on 27 March 2014.
- Eradication efforts have led to more than a 99 percent decrease in cases since the launch of the GPEI in 1988.
- The number of polio cases in the endemic countries was 40 percent lower in 2013 than in 2012 (160 vs. 217). Afghanistan and Nigeria each had less than half the number of cases in 2013 that they had in 2012.
- Pakistan is now considered to be the only country in the world with uncontrolled transmission of wild polio and as of 20 March, accounts for more than 75 percent of polio cases in 2014.
- Outbreaks in the Horn of Africa and Syria accounted for roughly 60 percent of all cases in 2013. These outbreaks underscore the risk to polio-free countries until the wild poliovirus has been eradicated in the remaining places where it persists.
- Incidence of type 3 polio is at historically low levels. There have been no cases of type 3 polio since November 2012.
- Lack of access to children in insecure areas continues to hamper progress. In Pakistan alone, more than 50 health workers and security personnel assigned to protect them have been killed in targeted attacks since November of 2012. Insecurity/inability to access large populations is now a key factor in all endemic transmission zones and is also a factor in outbreak areas (Syria, Horn of Africa).

The Polio Eradication and Endgame Strategic Plan (2013–2018) launched in 2013 lays out the strategies for the certification of the eradication of wild poliovirus by 2018 at a total global cost of US\$5.5 billion. This new plan builds on the lessons learned from the successful eradication of polio to date and the substantial advances in technology in 2012. The timely availability of funds remains essential to the achievement of a polio free world. The United States has been the leading public sector donor to the Global Polio Eradication Initiative. Members of U.S. Rotary clubs appreciate the United States' generous support and recognize increased funding provided by Congress in fiscal year 2014 to ensure the GPEI can fully implement the

plan. Rotarians are committed to continuing their own fundraising for the program until the world is certified polio free. Rotarians will also continue to advocate support from the public and other governments, both polio free and polio affected, to support the successful execution of the Strategic Plan. The ongoing support of donor countries, like the United States, is essential to assure the necessary human and financial resources are made available to polio-endemic and at risk countries to certify the world polio free by the end of 2018.

THE ROLE OF ROTARY INTERNATIONAL

Rotary International, a global association of more than 34,000 Rotary clubs in more than 170 countries with a membership of over 1.2 million business and professional leaders (more than 345,000 of which are in the U.S.), has been committed to battling polio since 1985. Rotary International has contributed more than US\$1.2 billion toward a polio free world—representing the largest contribution by an international service organization to a public health initiative ever. Rotary also leads the United States Coalition for the Eradication of Polio, a group of committed child health advocates that includes the March of Dimes Foundation, the American Academy of Pediatrics, the Task Force for Global Health, the United Nations Foundation, and the U.S. Fund for UNICEF. These organizations join us in thanking you for your support of the GPEI.

THE ROLE OF THE U.S. CENTERS FOR DISEASE CONTROL AND PREVENTION

Rotary commends CDC for its leadership in the global polio eradication effort, and greatly appreciates the Subcommittee's increased support of CDC's polio eradication activities to support full implementation of the Strategic Plan. The United States is the leader among donor nations in the drive to eradicate this crippling disease. CDC is using the increased Congressional support provided in fiscal year 2014 to:

- Build capacity in Nigeria. Increased investment in Nigeria will serve to establish and broaden environmental surveillance; strengthen traditional AFP surveillance, scale up the National Stop Transmission of Polio Program (N-STOP) in Kano and other high risk polio States to ensure broad coverage at the Local Government Authority Level, trapping poliovirus in its remaining reservoirs in Northern Nigeria.
- Build capacity in Pakistan. Increased investment in Pakistan will focus on training and placing local personnel to strengthen the program in areas where access is possible.
- Provide essential technical assistance in Afghanistan. The investment in Afghanistan will support two staff members in country.
- Laboratory Surveillance: Investment with CDC's Polio Global Reference Lab will allow the recruitment of additional staff, training for country and regional labs, essential IPV research, and expansion of environmental surveillance capabilities in the field. CDC provides technical and programmatic assistance to the global polio laboratory network through the Polio Laboratory in CDC's Division of Viral Diseases. CDC's labs provide critical diagnostic services and genomic sequencing of polioviruses to help guide disease control efforts. CDC will continue to serve as the global reference laboratory, while expanding environmental surveillance in countries to serve as a "safety measure" to detect any polioviruses circulating in areas without cases.
- Vaccine Purchase: CDC funds are being used to purchase oral polio vaccine to immunize children against polio.
- Vaccine Operations & Social Mobilization. CDC, through its cooperative agreement with WHO, provides funding for immunization activities in high risk and polio infected countries. CDC funding is essential to supporting the supplemental immunization activities that both stop existing outbreaks and prevent new outbreaks. CDC collaborates closely with UNICEF and provides critical support on analysis and use of campaign results to identify and address reasons why children are missed and address vaccine hesitancy concerns.
- Immunization Systems Strengthening. Investment in this area will allow CDC to provide scientific assistance across a range of topics related to the introduction of IPV to focus countries, other GAVI-eligible countries, and to non-eligible countries.

Continued funding will allow CDC to fully capitalize on the resources of the Emergency Operation Center to provide direct support and build capacity to continue intense supplementary immunization activities in the remaining polio-affected countries, continue leadership on data management to drive evidence-based decisionmaking, and continue to implement strategies to increase effective management

and accountability. These funds will also help maintain essential certification standard surveillance.

BENEFITS OF POLIO ERADICATION

Since 1988, over 10 million people who would otherwise have been paralyzed are walking because they have been immunized against polio. Tens of thousands of public health workers have been trained to manage massive immunization programs and investigate cases of acute flaccid paralysis. Cold chain, transport and communications systems for immunization have been strengthened. The global network of 145 laboratories and trained personnel established by the GPEI also tracks measles, rubella, yellow fever, meningitis, and other deadly infectious diseases and will do so long after polio is eradicated.

A study published in the November 2010 issue of the journal *Vaccine* estimates that the GPEI could provide net benefits of at least \$40–50 billion. Polio eradication is a cost-effective public health investment with permanent benefits. On the other hand, as many as 200,000 children could be paralyzed annually in the next 10 years if the world fails to capitalize on the more than \$10 billion already invested in eradication. Success will ensure that the significant investment made by the U.S., Rotary International, and many other countries and entities, is protected in perpetuity.

PREPARED STATEMENT OF THE RYAN WHITE MEDICAL PROVIDERS COALITION

My name is Dr. James Raper, and I serve as the Director of the 1917 HIV/AIDS Outpatient Clinic at the University of Alabama at Birmingham. I am writing to submit testimony on behalf of the Ryan White Medical Providers Coalition (RWMPC), which I co-chaired from 2010–2013. I remain a member of the RWMPC Steering Committee. Thank you for the opportunity to describe the lifesaving HIV/AIDS care and treatment provided by Ryan White Part C funded programs, including those provided at my own clinic.

RWMPC is a national coalition of medical providers and administrators who work in clinics supported by the Ryan White HIV/AIDS Program funded by the HIV/AIDS Bureau (HAB) at the Health Services and Resources Administration (HRSA). I thank the Subcommittee for its support of Ryan White Part C Programs in fiscal year 2014. And while I am grateful for this support, and understand that times are tough, I request \$225.1 million, or a \$24 million increase for Ryan White Part C programs in fiscal year 2015. While I know that this is a lot of funding, it is in fact well below the estimated need, and Ryan White providers would spend those dollars identifying, engaging and treating persons living with HIV/AIDS—an infectious disease that can be effectively prevented and treated in a way that saves both lives and money.

The 1917 Clinic is a dedicated, not-for-profit outpatient HIV/AIDS medical and dental clinic established in 1988 at the University of Alabama at Birmingham. Ryan White Part C funding provides critical assistance in helping the clinic meet the needs of our patients. Today, 35 percent of the 1917 Clinic's patients are uninsured and would be at risk for losing access to lifesaving services without Ryan White Program funding.

The 1917 Clinic provides comprehensive outpatient HIV primary care services to residents of Jefferson, Walker, Winston, Cullman, Blount, St. Clair, and Shelby counties. Although our service area technically includes only these seven counties, we serve people with HIV/AIDS throughout Alabama and its neighboring States. In February 2013, the 1917 Clinic absorbed 800+ new patients from the previously Ryan White Part C funded Cooper Green Hospital's St. Georges' Clinic, which closed on January 31, 2013. The 1917 Clinic is now providing care to 2,950 adult patients—this represents approximately 24 percent of the 12,404 known adults living with HIV/AIDS in Alabama.

The clinic offers a range of primary care and social services critical to successful HIV treatment, including primary medical and oral healthcare; on-site case management; mental health and substance abuse treatment services; onsite access to clinical trials; medication adherence; spiritual, risk reduction, and nutrition counseling; infusion therapy; coordination of hospital discharge planning; and home healthcare/hospice referral. To avoid emergency room visits, the 1917 Clinic provides 'sick call' services five days a week. Subspecialty care is available at the University's Kirklin Clinic—which is located just two blocks from the 1917 Clinic.

In addition to critical funding that Ryan White Part C provides through direct Federal grants for comprehensive medical care clinics like the 1917 Clinic, most Part C clinics, including the 1917 Clinic, also receive support from other Parts of the Ryan White Program that help support access to medication; additional medical

care, such as dental services; and key support services, such as case management and transportation, which are essential components of the highly effective Ryan White HIV care model that result in excellent outcomes for our patients.

Ryan White Part C Programs Support Comprehensive, Expert and Effective HIV Care

Part C of the Ryan White Program funds comprehensive, expert and effective HIV care and treatment—services that are directly responsible for the dramatic decrease in AIDS-related mortality and morbidity over the last decade. The Ryan White Program has supported the development of expert HIV care and treatment programs that have become patient-centered medical homes for individuals living with this serious, chronic condition. In 2011, a ground-breaking clinical trial—named the scientific breakthrough of the year by Science magazine—found that HIV treatment not only saves the lives of people with HIV, but also reduces HIV transmission by more than 96 percent—proving that HIV treatment is also HIV prevention.

The comprehensive, expert HIV care model that is supported by the Ryan White Program has been highly successful at achieving positive clinical outcomes with a complex patient population.¹ In a convenience sample of eight Ryan White-funded Part C programs ranging from the rural South to the Bronx, retention in care rates ranged from 87 to 97 percent. In estimates from the Centers for Disease Control and Prevention (CDC), only 37 percent of all people with HIV are in regular care nationally.² Once in care, patients served at Ryan White-funded clinics do well—with 75 to 90 percent having undetectable levels of the virus in their blood. This is much higher than the estimate from the CDC that just 25 percent of all people living with HIV in the U.S. are virally suppressed.

Investing in Ryan White Part C Programs Saves Both Lives and Money

Early and reliable access to HIV care and treatment both helps patients with HIV live relatively healthy and productive lives and is more cost effective. One study from the 1917 Clinic at the University of Alabama at Birmingham found that patients treated at the later stages of HIV disease required 2.6 times more healthcare dollars than those receiving earlier treatment meeting Federal HIV treatment guidelines. On average it costs \$3,501 per person per year to provide the comprehensive outpatient care and treatment available at Part C funded programs. The comprehensive services provided often include lab work, STD/TB/Hepatitis screening, ob/gyn care, dental care, mental health and substance abuse treatment, and case management.

Current Challenges—Future Promise

However, this effective and comprehensive HIV care model is not completely supported by Medicaid or most private insurance. While many Ryan White Program clients have some form of insurance coverage, without the Ryan White Program, they would risk falling out of care. Barriers include poor reimbursement rates; benefits designed for healthier populations that fail to cover critical services, such as care coordination; and inadequate coverage for other important services, such as extended medical visits, mental health and substance use treatment. Full implementation of the Affordable Care Act plus continuation of the Ryan White Program will dramatically improve health access and outcomes for many more people living with HIV disease.

Fully Funding and Maintaining Ryan White Part C Programs Is Essential

Because of both the inadequacy of insurance coverage for people with complex conditions like HIV and the fact that some individuals will remain uncovered, even with Affordable Care Act implementation (particularly in the non-Medicaid expansion States), fully funding and maintaining the Ryan White Program is essential to providing comprehensive, expert and effective HIV care nationwide.

And while RMWPC is concerned about the proposal to consolidate Ryan White Part D funding into Part C, it welcomes the \$4 million increase for Part C programs proposed in the President's fiscal year 2015 budget. RWMPC's specific concerns include:

—Part D funding supports effective HIV care and treatment services for vulnerable populations, including women and adolescents. With adolescents accounting for 39 percent of new HIV infections in the U.S., it is critical to target re-

¹ See Improvement in the Health of HIV-Infected Persons in Care: Reducing Disparities at <http://cid.oxfordjournals.org/content/early/2012/08/24/cid.cis654.full.pdf+html>.

² See CDC's HIV in the United States: The Stages of Care <http://www.cdc.gov/nchhstp/newsroom/docs/2012/Stages-of-CareFactSheet-508.pdf>.

sources to support comprehensive services that effectively engage and retain young people in HIV care and treatment.

—In some communities, Part D-funded programs are the main providers of HIV care and treatment. It is critical to ensure that implementation of any budget proposal does not leave any community without adequate access to effective and comprehensive HIV care and treatment. Also, for Ryan White medical clinics that currently receive only Part D funding, it could prove difficult to successfully compete for Part C funding if there currently exists a Part C program serving that community. Loss of the aforementioned Part D program would reduce the community's access to HIV care and treatment.

—It is unclear how the proposed consolidation would be implemented. At this time it is unclear what the consolidation process would entail and how it would practically impact grantees and access to HIV care and treatment in communities. Since most Ryan White medical clinics receive funding from multiple parts of the Ryan White Program, reduction of funding to one part can have damaging and unintended consequences to the overall services provided by Ryan White medical clinics, especially now, at a time when providers are working to expand access to HIV care and treatment.

At this critical time in the HIV/AIDS epidemic, when research has confirmed that early access to HIV care and treatment not only saves lives but prevents new infections by reducing the risk of transmission to near zero for patients who are virally suppressed, it is essential to maintain overall funding levels for the Ryan White Program. While the ACA provides important new healthcare coverage options for many patients, most health insurers fail to support the comprehensive care and treatment necessary for many patients to manage HIV infection. Exorbitant cost sharing, benefit gaps and limited State uptake of the Medicaid expansion necessitate a vital and ongoing role for the Ryan White Program. Increasing access to and successful engagement in effective, comprehensive HIV care and treatment is the only way to lead the Nation to an AIDS-free generation and reduce the devastating costs of—including lives lost to—HIV infection.

Conclusion

Thank you very much for your consideration of RWMPC's fiscal year 2015 request of \$225.1 million for Ryan White Part C programs, a \$24 million increase over fiscal year 2014.

[This statement was submitted by James L. Raper, PhD, CRNP, JD, FAANP, FAAN; Director, 1917 HIV/AIDS Outpatient Clinic; Professor of Medicine & Nursing.]

PREPARED STATEMENT OF THE SAFE STATES ALLIANCE

Safe States Alliance, the national membership association dedicated to strengthening the practice of injury and violence prevention, appreciates the opportunity to provide testimony in support of the Centers for Disease Control and Prevention (CDC). Safe States Alliance requests that the CDC's National Center for Injury Prevention and Control (Injury Center) receive \$205.5M in fiscal year 15—an additional \$29.7M for the Core Violence and Injury Prevention Program (VIPP), including resources to meaningfully address the epidemic of prescription drug misuse, abuse and overdose; and an additional \$13.7M for the National Violent Death Reporting System (NVDRS). Safe States Alliances also supports continued funding of the CDC's Preventive Health and Health Services (PHHS) Block Grant at \$180 million.

BACKGROUND

In 1985, the Institute of Medicine (IOM) first called attention to the lack of recognition and funding for injury and violence prevention (IVP) as a public health issue in the United States.¹ Although some progress has been made in subsequent years, injuries and violence continue to have a significant impact on the health of Americans and the healthcare system, as more people ages 1–44 die from injuries than from any other cause, including cancer, HIV, or the flu.²

Injuries and violence are serious public health problems. Areas include:

¹ National Research Council. *Injury in America: A Continuing Public Health Problem*. Washington, DC: The National Academies Press, 1985.

² Centers for Disease Control and Prevention, National Center for Injury Prevention and Control. Web-based Injury Statistics Query and Reporting System (WISQARS) [online] (2007) [accessed 2013 Feb 15]. Available from URL: <http://www.cdc.gov/injury/wisqars>.

Assault & Homicide	Fire & Burns
Bullying	Motor Vehicle Safety
Child Maltreatment	Pedestrian & Bicycle Safety
Child Passenger Safety	Poisoning & Prescription Drug Overdose
Disaster Response	Sexual Assault & Rape
Domestic & Intimate Partner Violence	Suicide
Drowning	Traumatic Brain Injury
Elder Abuse	Youth Violence
Falls	

In fact, more than 29 million people are treated in emergency departments each year, two million are hospitalized, and approximately 180,000 people die—one person every three minutes. Every 45 minutes, one of those preventable deaths is a child.² In a single year, injuries and violence will ultimately cost \$406 billion in medical costs and lost productivity.³ Yet to date, there is no national program to support State public health IVP programs.

At the Federal level, the CDC Injury Center serves as the focal point for the public health approach to IVP. The CDC Injury Center only receives approximately 2 percent of the CDC/Agency for Toxic Substances and Disease Registry budget to address the significant burden of injuries and violence nationwide. In fiscal year 2013, the total Injury Center budget was only \$138.9 million.

CORE VIOLENCE AND INJURY PREVENTION PROGRAM (VIPP) AND NEW PRESCRIPTION DRUG OVERDOSE PREVENTION EXPANDED COMPONENT

Given its limited budget, the CDC Injury Center currently provides small capacity building grants of approximately \$250,000 to only 20 State health departments (SHDs) through the Core Violence and Injury Prevention Program (VIPP). The Core VIPP is comprised of multiple components including: Basic Prevention (20 States); Regional Network Leaders (5 States); Surveillance Quality Improvement (4 States); Older Adult Falls Prevention (3 States); and Motor Vehicle/Child Injury Prevention (4 States). The President's 2015 Budget Request includes an increase of approximately \$15.6M to expand the number of funded Core VIPP programs (\$5.6M) and to allow for the development of a new expanded component for States to address the epidemic of prescription drug misuse, abuse and overdose (\$10 million).

Opioid pain relievers are now involved in more overdose deaths than cocaine and heroin combined. The abuse of prescription opioid pain relievers costs up to \$72 billion annually. The CDC Injury Center provides leadership in enhancing drug overdose surveillance, identifying and evaluating effective program and policy interventions for preventing overdoses, improving clinical practice to reduce prescription drug diversion and abuse, and equipping and empowering States with the information and resources they need to reverse the epidemic. Core VIPP States would be funded to advance promising surveillance and prevention strategies and would complement other Federal agencies, such as SAMHSA's work on screening, treatment and community prevention activities. State health departments are well positioned to coordinate the necessary multi-sector responses to reverse the epidemic through the regulation of healthcare professionals, prescription drug monitoring programs, and other major levers for preventing prescription drug abuse.

Ohio's Core Violence and Injury Prevention Program (VIPP) provides statewide leadership and funding for community-based efforts to address prescription drug abuse and overdose through the PHHS Block Grant from CDC. The OH VIPP coordinates the development and implementation of statewide prevention strategies, conducts surveillance, supports the Governor's Cabinet Opiate Action Team Prescriber Education Work Group including the development of opioid prescribing guidelines, and provides support and technical assistance to expand naloxone distribution programs. Examples of locally PHHS Block Grant funded strategies include: expanding access to naloxone distribution programs; facilitating healthcare system changes such as implementation of opioid prescribing guidelines and other pain management strategies; obtaining commitment of prescribers to use the Ohio prescription drug monitoring program; and expanding access to sustainable drug disposal options.

With overall program funding of \$29.7M, the CDC Injury Center could support injury and violence prevention programs in ALL States and territories, much as it does for other key public health issues including chronic and infectious diseases, as

³Centers for Disease Control and Prevention, National Center for Injury Prevention and Control. Web-based Injury Statistics Query and Reporting System (WISQARS) [online] (2007) [accessed 2013 Feb 15]. Available from URL: <http://www.cdc.gov/injury/wisqars>

well as make significant strides in reversing the prescription drug overdose epidemic.

NATIONAL VIOLENT DEATH REPORTING SYSTEM (NVDRS)

NVDRS is a state-based surveillance system that uses information from a variety of States and local agencies and sources—medical examiners, coroners, police, crime labs and death certificates—to form a more complete picture of the circumstances that surround violent deaths. State and local violence prevention practitioners use these data to guide their prevention programs, policies and practices including: identifying common circumstances associated with violent deaths of a specific type (e.g. gang violence) or a specific area (e.g. a cluster of suicides); assisting groups in selecting and targeting violence prevention efforts; supporting evaluations of violence prevention activities; and improving the public's access to in-depth information on violent deaths. CDC Injury Center currently funds 18 States to implement NVDRS and received an approximately \$7.9M increase in fiscal year 2014 to expand number of participating States up to 30–35 States.

The Oregon Older Adult Suicide Prevention Advisory Work Group and the Oregon Department of Human Services used NVDRS data to inform efforts to develop and focus suicide prevention programs for older adults. Almost 50 percent of men ages 65 and older who died by suicide were reported to have a depressed mood before death, but only a small proportion were receiving treatment, suggesting screening and treatment for depression might have saved lives. As a result, Oregon developed primary care recommendations in 2006 to better integrate with mental health services so that suicidal behavior and ideation are diagnosed and older adults received appropriate treatment. These recommendations were implemented as part of Oregon's "Healthy Aging" efforts. The recommendations include the objectives of increasing the confidence and competence of primary care providers and other clinicians to identify, assess and treat older adult suicide behavior and depression. The suicide rates among males ages 65 and older in Oregon decreased approximately 8 percent from 2007 to 2010.

Safe States Alliance supports the investment of an additional \$13.7 million to expand NVDRS to all States and territories.

PREVENTIVE HEALTH AND HEALTH SERVICES (PHHS) BLOCK GRANT

For more than 30 years, the PHHS Block Grant has remained an essential source of Federal agencies to support State solutions to State health problems. The PHHS Block Grant allows each State to respond to its own distinct health priorities and need. In fiscal year 2011, more than 20 percent of the Prevent Block Grant was used by States to support IVP and emergency medical services. According to a 2011 survey conducted by Safe States Alliance, 29 States reported receiving an average of \$329,000 from the Prevent Block Grant for IVP efforts.⁴ The Prevent Block Grant is a critical source of funding for SHD IVP programs representing 9.4 percent of total State funding in 2011. Safe States Alliance supports continued funding of the PHHS Block Grant at the \$180 million level.

Preventable injuries exact a heavy burden on Americans through premature deaths and disabilities, pain and suffering, medical and rehabilitation costs, disruption of quality of life for families, and disruption of productivity for employers. Strengthening investments in public health IVP programs is a critical step to keep Americans safe and productive for the 21st century. Safe States Alliance would like to thank the Committee for consideration of this testimony.

[This statement was submitted by Amber Williams, Executive Director, Safe States Alliance.]

PREPARED STATEMENT OF THE SCLERODERMA FOUNDATION

Chairman Harkin and distinguished members of the Subcommittee, thank you for your time and your consideration of the scleroderma community's priorities while working to craft the fiscal year 2015 Labor, Health and Human Services Appropriations Bill.

ABOUT SCLERODERMA

Scleroderma, or systemic sclerosis, is a chronic connective tissue disease generally classified as one of the autoimmune rheumatic diseases.

⁴State of the States: 2011 Report. Atlanta, GA: Safe States Alliance; 2013.

The word “scleroderma” comes from two Greek words: “sclero” meaning hard, and “derma” meaning skin. Hardening of the skin is one of the most visible manifestations of the disease. The disease has been called “progressive systemic sclerosis,” but the use of that term has been discouraged since it has been found that scleroderma is not necessarily progressive. The disease varies from patient-to-patient.

It is estimated that about 300,000 Americans have scleroderma. About one third of those people have the systemic form of scleroderma. Since scleroderma presents with symptoms similar to other autoimmune diseases, diagnosis is difficult. There may be many misdiagnosed or undiagnosed cases.

Localized scleroderma is more common in children, whereas systemic scleroderma is more common in adults. Overall, female patients outnumber male patients at a ratio of 4-to-1. Factors other than gender, such as race and ethnic background, may influence the risk of getting scleroderma, the age of onset, and the pattern or severity of internal organ involvement. The reasons for this are still unknown. Although scleroderma is not directly inherited, some scientists feel there is a slight predisposition to it in families with a history of rheumatic or autoimmune diseases. While, scleroderma can develop in every age group from infants to the elderly, its onset is most frequent between the ages of 25 to 55.

Currently, there is no cure for scleroderma. Treatments are based on a patient’s particular symptoms. For instance, heartburn can be controlled by medications called proton pump inhibitors or medicine to improve the motion of the bowel. Some treatments are directed at decreasing the activity of the immune system. Due to the fact that there is so much variation from one person to another, there is great variation in the treatments prescribed.

Any chronic disease can be serious. The symptoms of scleroderma vary greatly for each person, and the effects of scleroderma can range from mild to life threatening. The seriousness will depend on which organ systems of the body are affected, and the extent to which they are affected. A mild case can become more serious if not properly treated. Prompt and proper diagnosis and treatment by qualified physicians may minimize the symptoms of scleroderma and lessen the chance for irreversible damage.

ABOUT THE FOUNDATION

The non-profit Scleroderma Foundation is the national organization for people with scleroderma and their families and friends. It was formed January 1, 1998, by a merger between the West Coast-based United Scleroderma Foundation and the East Coast-based Scleroderma Federation. The national office is headquartered in Danvers, Massachusetts. The Foundation has a three-fold mission of support, education, and research.

Support

The Scleroderma Foundation offers the following tools and resources in support of people living with scleroderma and their families:

- A nationwide network of 24 chapters and more than 150 support groups
- A toll-free helpline providing information and referrals to callers
- Educational materials, including a quarterly magazine called “Scleroderma Voice”
- Offer a variety of brochures, booklets and newsletters, along with our informative website

Additionally, the Foundation hosts an annual National Patient Education Conference. The conference offers various educational and networking opportunities for people living with scleroderma, their caregivers, family members and friends. Workshops, panel discussions and other educational sessions are led by the leading scleroderma researchers and healthcare professionals.

Education

As part of our education mission, we not only perform all the functions mentioned above, we also work with our Medical Advisory Board of internationally known scleroderma experts to provide patient education programs as well as education for physician/healthcare professionals.

Research

The Scleroderma Foundation budgets at least \$1 million a year for research funding, its single largest budgeted expense. The Scleroderma Foundation takes its fiduciary responsibility to donors very seriously, especially with regard to our research grant program.

In the case of research funds, the Foundation’s Peer Research Review Committee, composed of medical experts on scleroderma from around the world, helps determine

which proposals will be funded by reading, analyzing and ranking all proposals received. It follows a peer review system based on that of the National Institutes of Health.

ONE FAMILY'S STORY

Cheyenne Cogswell is an 8-year old third-grader living in the poverty-stricken town of Falmouth, Kentucky. Cheyenne was diagnosed at age six with a severe case of systemic scleroderma. The disease has caused kidney failure and significant damage to her digestive system, making it difficult for the body to receive the proper nutrition needed for a growing child. She has undergone several life-saving operations and numerous hospitalizations. Her skin and other internal organs, such as the heart and lungs, are also affected. Cheyenne's treatment first consisted of hospitalization and intense chemotherapy. She continues with daily chemotherapy injections, now given by her mother, to help suppress her immune system and slow the progression of the disease. Cheyenne is being raised by a single mother who has faced extreme consequences from the financial burden created by scleroderma, losing her job in the economic downturn, as well as the family's home. Doctors doubted if Cheyenne would survive beyond her seventh birthday, but she continues to beat the odds. Chronic diseases like scleroderma are unpredictable in their course, and the family—together with their close circle of friends—continues to fight and hope for the best. Their road is uncertain and illustrates why funding for NIH and its research programs are vital to so many people whose lives are impacted by chronic illness such as scleroderma.

SEQUESTRATION

We have heard from the medical research community that sequestration and deficit reduction activities have created serious issues for Federal funding opportunities and the career development pipeline. In order to ensure that the scleroderma research portfolio can continue to grow, and, more importantly, to ensure that our country is adequately preparing the next generation of young investigators, we urge you to avert, mitigate, or otherwise eliminate the specter of sequestration. While the Foundation has anecdotal accounts of the harms of sequestration, the Federated American Societies for Experimental Biology has reported:

- In constant dollars (adjusted for inflation), the NIH budget in fiscal year 2013 was \$6 billion (22.4 percent) less than it was in fiscal year 2003.
- The number of competing research project grants (RPGs) awarded by NIH has also fallen sharply since fiscal year 2003. In fiscal year 2013, NIH made 8,283 RPG awards, which is 2,110 (20.3 percent) fewer than in fiscal year 2003.
- Awards for R01-equivalent grants, the primary mechanism for supporting investigator-initiated research, suffered even greater losses. The number awarded fell by 2,528 (34 percent) between fiscal year 2003 and fiscal year 2013.

The pay line for some NIH funding mechanisms has fallen from 18 percent to 10 percent while the average age for a researcher to receive their first NIH-funded grant has climbed to 42. These are strong disincentives to choosing a career as a medical researcher. Our scaling-back is occurring at a time when many foreign countries are investing heavily in their biotechnology sectors. China alone plans to dedicate \$300 million to medical research over the next 5 years; this amount is double the current NIH budget over the same period of time. Scientific breakthroughs will continue, but America may not benefit from the return-on-investment of a robust biotechnology sector. For the purposes of economic and national security, as well as public health, the Foundation asks that you work with your colleagues to eliminate sequestration and recommit to supporting this Nation's biomedical research enterprise.

CENTERS FOR DISEASE CONTROL AND PREVENTION

Early recognition and an accurate diagnosis of scleroderma can improve health outcomes and save lives. CDC in general and the NCCDPHP specifically have programs to improve public awareness of scleroderma and other rare, life-threatening conditions. Unfortunately, budgetary challenges at CDC have pushed the agency to focus resources on combating a narrow set of "winnable battles." Please increase funding for CDC and NCCDPHP so that the agency can invest in additional, critical education and awareness activities that have the potential to improve health and save lives.

NATIONAL INSTITUTES OF HEALTH

NIH has worked with the Foundation to lead the effort to enhance our scientific understanding of the mechanisms of scleroderma with the shared-goal of improving diagnosis and treatment, and ultimately finding a cure. Since scleroderma impacts multiple organ systems, NIAMS, NHLBI, and NIDDK all play crucial roles in basic, translational, and clinical research efforts. Further, emerging NIH initiatives like the Cures Acceleration Network and the Accelerating Medicines Partnership are creating meaningful opportunities to advance scleroderma research. Please provide NIH with a significant funding increase to the scleroderma research portfolio can continue to expand and facilitate key breakthroughs.

—NHLBI, is leading Scleroderma Lung Study II, is comparing the effectiveness of two drugs in treating pulmonary fibrosis in scleroderma.

—NIAMS, is leading efforts to discover whether three gene expression signatures in skin can serve as accurate biomarkers predicting scleroderma, and investigations into progression and response to treatment to clarify the complex interactions of T cells and interleukin-31 (IL-31) in producing inflammation and fibrosis, or scarring in scleroderma.

ADDITIONAL MEDICAL RESEARCH ACTIVITIES

In recent years, scleroderma has been listed as a condition eligible for study through the Department of Defense (DOD) Peer-Reviewed Medical Research Program (PRMRP). Since fiscal year 2005, the opportunity for scleroderma researchers to compete for funding through this mechanism led to over \$10 million in scleroderma research funding as well as the initiation of meaningful research projects. Research on the underlying mechanisms of scleroderma is showing relevance to all fibrosis, which occurs at higher rates among individuals who served in the military and our veterans. Further, military service-associated environmental triggers, particularly silica, solvent, and radiation exposure, are believed to be potential triggers for scleroderma in individuals that are genetically predisposed to it.

Despite the connection between military service and scleroderma, the condition was left off the PRMRP's eligible conditions list in fiscal year 2014. While we appreciate that the Defense Appropriations Subcommittee and the Senate play important roles in crafting the annual eligible conditions list, the scleroderma community urges you to weigh in with your colleagues on the Appropriations Committee to actively work to see that scleroderma is re-listed as a condition eligible for study through the PRMRP within the Committee Report accompanying the fiscal year 2015 Defense Appropriations Bill.

Thank you again for your time and your consideration of the scleroderma community's requests.

PREPARED STATEMENT OF THE SENIOR SERVICE AMERICA, INC.

This statement concerns the Administration's proposed fiscal year 2015 appropriations of \$380 million for the Department of Health and Human Services—Administration for Community Living's Senior Community Service Employment Program. We urge that funding for this program be increased to \$600 million, returning the program to its funding levels prior to the Great Recession (adjusted for inflation). This investment would provide jobs and training for more than 30,000 additional unemployed older Americans than the Administration's proposal. We also urge that the Congress refer to the authorizing committee any proposals to revise the mission of the program or transfer the program from the Department of Labor.

The Senior Community Service Employment Program (SCSEP) is the only Federal program targeted to provide jobs and training to low-income older adults 55 and older. According to GAO Report GAO-11-92, SCSEP is one of only three Federal workforce development programs that do not overlap with any other program. Launched in 1968, SCSEP is authorized by Title V of the Older Americans Act and is currently administered by the Department of Labor Employment and Training Administration. In the year ending June 30, 2013, SCSEP provided jobs and training for 67,551 economically disadvantaged older adults, who in turn provided over 37.2 million hours of staffing to 30,000 local private and private nonprofit agencies serving the community. The value of these community service hours was \$825 million, based on hourly-wage estimates from the Independent Sector.

The Administration's fiscal year 2015 budget proposes to cut funding for SCSEP to \$380 million, \$52 million less than \$432 million in total grants awarded by the USDOL for fiscal year 2014. Senior Service America estimates that this cut would

result in 8,600 fewer jobs and training nationwide for low income older adults and 4.4 million fewer staff hours in local agencies (whose value exceeds \$97 million).

The following facts strongly support increasing the appropriations for SCSEP in fiscal year 2015:

Low-income older workers, most of whom are long-term unemployed, continue to suffer extremely high rates of joblessness.—As the following table shows, since 2000 the jobless rate of low-income older workers (55 years and older with annual family incomes less than \$20k) has been 2.5 to 3 times higher than the rate among all older workers:

Year	Unemployment rate for low income older workers (%)	Unemployment rate of All 55+ (%)
2000	6.6	2.6
2001	7.6	3.0
2002	9.7	3.8
2003	11.1	4.0
2004	10.6	3.7
2005	10.1	3.4
2006	9.9	3.0
2007	10.0	3.1
2008	11.8	3.8
2009	18.8	6.6
2010	19.9	7.0
2011	19.5	6.5
2012	18.4	6.0
2013	17.0	5.8

Source: Low-income (<\$20,000) age 55+ jobless rate tabulations from Current Population Survey, by the Center for Labor Market Studies, Northeastern University, for Senior Service America, Inc., January 2014.

SCSEP is a unique employment and training program of the Federal Government.—Cited in the previously mentioned 2011 GAO report as one of only three Federal workforce programs “that do not overlap with other programs.” It also assists a harder-to-serve segment of the older adult workforce: 88 percent of participants were at or below the poverty level; 60 percent were at least 60 years old; nearly two-thirds were women; and over half of the participants were from a racial/ethnic minority (PY2012).

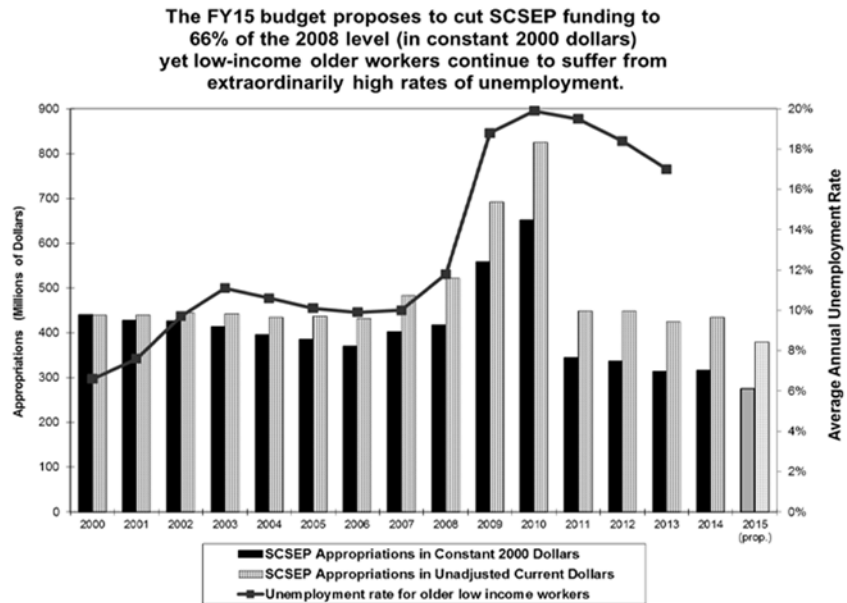
SCSEP grantees succeed in carrying out the Congressional intent for the program.—According to an independent national evaluation conducted by Mathematica Policy Research (MPR) and Social Policy Research Associates (SPR) in 2012 for the U.S. Department of Labor, “SCSEP projects are largely successful in recruiting and enrolling older workers with serious barriers to employment, providing participants with community service assignments at host agencies, and [annually] placing nearly half of program exiters who are available for work into unsubsidized jobs.”

Programs under the Workforce Investment Act (WIA) continue to underserve older workers.—Several GAO reports have cited that WIA performance measures may create disincentives for serving older workers seeking part-time work. As a result, a disproportionately small percentage of those served by American Job Centers are older workers. The 2012 MPR/SPR evaluation of SCSEP stated that “SCSEP projects find it difficult to draw on the resources of American Job Centers to support participants in finding jobs.”

The value of work performed by SCSEP participants in their community service assignments is nearly double the total amount appropriated for SCSEP.—In PY2012, SCSEP participants worked over 37 million hours at minimum wage in over 30,000 host agencies (nonprofit, faith-based, and public), including more than 10 million hours serving other older persons through Meals on Wheels, area agencies on aging, and other organizations. Using the Independent Sector’s estimated hourly value of volunteer work, the estimated value of this community service was nearly \$825 million.

The fiscal year 2015 budget proposes to cut SCSEP funding to 66 percent of the 2008 level (in constant 2000 dollars), yet low-income older workers continue to suffer from extraordinarily high rates of unemployment.—The following graph shows the unemployment rate among low-income older workers since 2000 (described in the previous table on page 2) in contrast to the history of SCSEP funding, in both cur-

rent dollars and constant 2000 dollars. In 2008, the average annual unemployment rate for low-income older adults 55 and over was 11.8 percent and SCSEP funding was \$521.6 million (unadjusted) or \$417.2 million (in constant 2000 dollars). In unadjusted dollars, the proposed fiscal year 2015 budget for SCSEP of \$380 million represents 73 percent of the 2008 funding for SCSEP, but the fiscal year 2015 budget would cut SCSEP to only 66 percent of the 2008 funding in constant dollars—yet the average annual unemployment rate for the SCSEP-eligible population is about 17 percent in 2013 compared to less than 12 percent in 2008.



Sources: Low-income (<\$20,000) age 55+ jobless rate tabulations from Current Population Survey, by the Center for Labor Market Studies at Northeastern University, for Senior Service America, Inc. (SSAI). Calculations of inflation-adjusted constant dollars by B. Harootyan, SSAI. Constant dollar estimate for 2015 is based on a projected annual inflation rate of 1.5 percent. (SSAI, March 2014)

The following table shows the history of SCSEP funding since 2000:

Fiscal Year	Final appropriations in current dollars (millions)	Real value of annual appropriations in constant dollars (base year: 2000)
2000	440.2	440.2
2001	440.2	428.0
2002	445.1	426.1
2003	442.3	413.9
2004	434.0	395.7
2005	436.7	385.0
2006	432.3	369.3
2007	483.6	401.6
2008	521.6	417.2
2009	691.9	558.4
2010	825.4	651.8
2011	449.1	343.8
2012	448.3	336.2
2013	424.8	313.9
2014	434.4	318.6
2015 (proposed)	380.0	274.6 (est)

Note: Estimation Procedure for 2015 Constant Dollar Value (base year = 2000):
 Estimated Cumulative Inflation Index (CII) for 2015 is based on projected annual inflation rate of 1.5 percent. OMB proposed SCSEP appropriation for fiscal year 2015 = \$380m, fiscal year 2015 \$380m = \$278.7m in 2014 constant dollars. The CII through 2014 = $\$380/\$278.7 = 1.3635$. Estimated CII for 2015 (based on 1.5 percent inflation rate) = $1.3635 + (1.3635 \times 0.015) = 1.3840$, fiscal year 2015 proposed \$380m appropriation = $\$380m/1.3840 = \$274.57m$ in constant dollars (base year 2000).

The proposed fiscal year 2015 would have a damaging impact on local communities.—As the following table shows, cuts in SCSEP funding would harm small and large States:

	Total fiscal year 2014 funding awarded by USDOL (\$)	Estimated funding in fiscal year 2015 (\$)	Cut in funding in fiscal year 2015 (\$)	Cut in number of SCSEP participants	Cut in total hours of community service	Value of lost hours of community service (\$)
All States and Territories	432,285,000	380,000,000	-52,285,000	-8,630	-4,381,900	97,000,000
Alabama	8,011,355	7,042,000	-969,000	-160	-87,800	-1,900,000
Illinois	16,502,969	14,507,000	-1,996,000	-330	-161,000	-3,600,000
Iowa	5,430,241	4,773,000	-657,000	-110	-57,900	-1,300,000
Kansas	4,210,174	3,701,000	-509,000	-80	-43,900	-1,000,000
Maryland	5,832,216	5,127,000	-705,000	-120	-62,200	-1,400,000
Mississippi	5,232,771	4,600,000	-633,000	-100	-53,000	-1,200,000
Tennessee	8,660,178	7,613,000	-1,047,000	-170	-93,000	-2,100,000
Washington	6,489,633	5,705,000	-785,000	-130	-54,900	-1,200,000

In summary, our economy continues to leave millions of low-income older Americans behind. These older workers help expand the capacity of local agencies to meet the basic needs of their communities. In an independent national survey of 10,000 of these agencies, 75 percent reported that SCSEP significantly or somewhat increased their ability to provide services. SCSEP is a unique program that achieves a wide range of outcomes and produces multiple returns on investment. Throughout the Nation, older Americans and communities need and depend on the Senior Community Service Employment Program.

[This statement was submitted by Anthony R. Sarmiento, Executive Director, Senior Service America, Inc.]

PREPARED STATEMENT OF THE SLEEP RESEARCH SOCIETY

Chairman Tom Harkin, Ranking Member Jerry Moran, and distinguished members of the Subcommittee, as you begin to craft the fiscal year 2015 Labor-HHS-Education appropriations bill, the Sleep Research Society (SRS) is pleased to submit this statement for the record asking you to provide \$32 billion for NIH, including a proportional increase for the National Heart, Lung, and Blood Institute (NHLBI), \$1 million in funding for sleep disorders awareness and surveillance at the Centers for Disease Control and Prevention (CDC), full support for the National Center on Sleep Disorders Research (NCSDR), and implementation of the 2011 NIH Sleep Disorders Research Plan. These actions will ensure increased awareness of the importance of sleep and circadian rhythms and further the advancements being made by sleep researchers to better understand the relationship between sleep and health.

SLEEP RESEARCH SOCIETY

SRS was established in 1961 by a group of scientists who shared a common goal to foster scientific investigations on all aspects of sleep and sleep disorders. Since that time, SRS has grown into a professional society comprising over 1,100 researchers nationwide. From promising trainees to accomplished senior level investigators, sleep research has expanded into areas such as psychology, neuroanatomy, pharmacology, cardiology, immunology, metabolism, genomics, and healthy living. SRS recognizes the importance of educating the public about the connection between sleep and health outcomes. We promote training and education in sleep research, public awareness, and evidence-based policy, in addition to hosting forums for the exchange of scientific knowledge pertaining to sleep and circadian rhythms.

According to an Institute of Medicine's report entitled, "Sleep Disorder and Sleep Deprivation: An Unmet Public Health Problem" (2006), chronic sleep and circadian disturbances and disorders are a very real and relevant issue in today's society as they affect 50–70 million Americans across all demographic groups. Sleep deprivation is a major safety issue, particular in reference to drowsy driving, where it is a factor in 20 percent of motor vehicle injuries. The widespread effect of sleep disorders on every age group poses a public health risk, extending from the ability to learn to maintain a healthy lifestyle. Furthermore, it is important to recognize that sleep disorders and circadian disturbances are often an indicator of, or a precursor to other major diseases and disorders including; obesity, diabetes, hypertension, cardiovascular disease, stroke, depression, bipolar disorder, and substance abuse. Another increasingly detrimental condition affecting 15 percent of the population is sleep-disordered breathing, including obstructive sleep apnea. Sleep apnea results in excessive daytime somnolence, poor performance, increased frequency of road traffic accidents, and arterial hypertension. Studies show that 85 percent of 725 troops returning home from Afghanistan and Iraq had a sleep disorder and the most common was obstructive sleep apnea (51 percent). If left untreated, obstructive sleep apnea has significant negative impacts on health, including early mortality.

NATIONAL INSTITUTES OF HEALTH

Due to the fact that sleep is a multi-disciplinary issue, many institutes and centers at NIH, utilize a portion of their funding to support sleep and circadian research. The majority of sleep research is coordinated by NHLBI, particularly the National Center on Sleep Disorders Research. An appropriation of \$32 billion for NIH, and \$3 billion for NHLBI, is needed to facilitate the continued growth and advancement in the sleep and circadian research portfolio.

The reason NCSDR is housed at NHLBI is due to the important link between sleep disorders and cardiovascular health. NCSDR supports research, health education, and research training related to sleep-disordered breathing and the fundamental function of sleep and circadian rhythms. Furthermore, NCSDR coordinates

sleep research across NIH and with other Federal agencies and outside organizations.

NCSDR's coordinating role between institutes is made possible through adequate funding. These research activities also have far reaching effects, beginning with training grants targeted towards undergraduate students and career development opportunities attracting top talent in doctoral programs. Sequestration has the potential to disrupt the research training pipeline by reducing the amount of K, T, and F series awards for new investigators. It could also disrupt the career development pipeline designed to train future investigators who are pursuing research in sleep disorders and circadian rhythms. It is important to fund NIH at \$32 billion and NHLBI at \$3 billion in fiscal year 2015 so that we can continue these advancements in sleep and circadian research.

DEPARTMENT OF VETERANS AFFAIRS & DEPARTMENT OF DEFENSE RESEARCH ACTIVITIES

It is also important to recognize that by increasing the Federal commitment to sleep and circadian research, we can improve the health of those brave Americans who have served in uniform and are suffering from sleep disorders. Both obstructive sleep apnea and insomnia have a high prevalence among active-duty U.S. Armed Forces and among Veterans. Post-traumatic stress disorder and/or depression are highly prevalent in returning Iraq and Afghanistan combat Veterans. Sleep disturbance is a prominent symptom in these disorders. Traumatic brain injury is increasingly common in modern combat, and sleep disruption in the aftermath of TBI may have negative effects on long-term recovery of normal brain function.

The Department of Veterans Affairs (VA) and the Department of Defense have shown a commitment to collaborating with NIH on sleep research related to Post-Traumatic Stress Disorder (PTSD), Traumatic Brain Injury (TBI), and Gulf War Illness (GWI). This is highlighted in the fiscal year 2014 president's budget request detailing research initiatives in PTSD and TBI. The "Longitudinal Health Study of Gulf War Era Veterans" is one of the largest scientific research studies on chronic diseases and multi-symptom illnesses, including Gulf War Illness. Researchers found that prazosin, an inexpensive drug already used by millions of Americans for hypertension and prostate problems, improves sleep and reduces nightmares for veterans with PTSD. They continue to pursue activities such as the difference between female and male veterans with PTSD and possible intervention strategies to help veterans with TBI return to daily activities. One study described in the Veteran's Health Administration report State of VA Research 2012, found that 96 percent of veterans with chronic multi-symptom illnesses experienced sleep disordered breathing. By using continuous positive airway pressure (CPAP) these veterans reported reductions in pain and fatigue and improvements in cognitive function.

Sleep disruption, especially insomnia, is a contributing risk factor to the onset and severity of major mental health problems such as depression, bipolar disorder, substance abuse, PTSD, TBI, and suicide among the veteran population. It is important to continue supporting the sleep research endeavors of the VA through robust funding for the Medical and Prosthetic Research Program at \$589 million.

CENTERS FOR DISEASE CONTROL AND PREVENTION

CDC gathers important data on sleep disorders through their surveillance efforts under the Chronic Disease Prevention and Health Promotion program. Most notably, CDC hosts a National Sleep Awareness Roundtable (NSART) by promoting the importance of sleep through the production of State fact sheets, updating the CDC website, and disseminating information on sleep related topics. CDC also promotes awareness of sleep disorders and the dangers associated with sleep deprivation for the benefit of millions of Americans. Currently population-based data on the prevalence of circadian disruption and its relationship to disease risk is relatively limited. Please fund CDC at \$7.8 billion including an allocation of \$1 million solely for sleep awareness and surveillance activities within the Chronic Disease Prevention and Health Promotion program and within NSART, so that progress can continue in the areas of sleep disorders and disturbances, sleep awareness, and education to the public community.

NIH SLEEP DISORDERS RESEARCH PLAN

NCSDR published the NIH Sleep Disorders Research Plan in November of 2011 highlighting the implementation of pertinent sleep research goals to enable further advancements in the realm of sleep and circadian rhythm disorders. A Joint Task Force between the two leading organizations representing the sleep medicine and research community, Sleep Research Society (SRS) and American Academy of Sleep

Medicine (AASM), has identified research opportunities that will have the highest impact on health within the plan.

The Plan recommends implementation of the following sleep research goals which will help us understand the function of sleep and inform individuals on healthier lifestyle choices:

- Advance the understanding of sleep and circadian functions and of basic sleep and circadian mechanisms, in both the brain and the body, across the lifespan.
- Identify genetic, pathophysiological, environmental, cultural, lifestyle factors, and sex and gender differences contributing to the risk of sleep and circadian disorders and disturbances, and their role in the development and pathogenesis of co-morbid diseases and disability.
- Improve prevention, diagnosis, and treatment of sleep and circadian disorders, chronic sleep deficiency, and circadian disruption, and evaluate the resulting impact on human health.
- Enhance the translation and dissemination of sleep and circadian research findings and concepts to improve healthcare, inform public policy, and increase community awareness to enhance human health.
- Enable sleep and circadian research training to inform science in cross-cutting domains, accelerate the pace of discovery, and the translation of enhanced therapies from bench to bedside to community.

Research activities and stakeholders addressed by the plan benefit from the encompassing range of NIH research, training, and outreach programs. Over the past 2 years, steps have been taken to implement portions of this research plan, but additional work needs to be done. SRS encourages you to recommend that this research plan continue to be implemented during fiscal year 2015.

Thank you for the opportunity to submit the views of the sleep research community. Please do not hesitate to contact us should you have any questions or require additional information.

[This statement was submitted by Dr. Janet Mullington, Ph.D., President, Sleep Research Society.]

PREPARED STATEMENT OF THE SOCIETY FOR HEALTHCARE EPIDEMIOLOGY OF AMERICA AND THE ASSOCIATION FOR PROFESSIONALS IN INFECTION CONTROL AND EPIDEMIOLOGY

The Society for Healthcare Epidemiology of America (SHEA) and the Association for Professionals in Infection Control and Epidemiology (APIC) thank you for this opportunity to submit testimony on Federal efforts to detect dangerous infectious diseases, protect the American public from preventable healthcare-associated infections (HAIs) and address the rapidly growing threat of antibiotic resistance (AR). We ask that you support the following programs: First, under the Centers for Disease Control and Prevention National Center for Emerging and Zoonotic Infectious Diseases: \$250 million for Core Infectious Diseases including \$30 million for the new Detect and Protect Against Antibiotic Resistance (AR) Initiative, \$32 million for the National Healthcare Safety Network (NHSN), and \$30 million for the Advanced Molecular Detection (AMD) Initiative. Additionally, we request \$34 million for HAI research activity conducted by the Agency for Healthcare Research and Quality (AHRQ) and \$4.58 billion for the National Institutes of Health/National Institute of Allergy and Infectious Diseases (NIAID).

HAIs are among the leading causes of preventable death in the United States. In hospitals alone, CDC estimates that one in 25 patients has an HAI, totaling approximately 722,000 infections in 2011. According to the CDC, every day, more than 200 Americans with HAIs will die during their hospital stay. Further, AR is one of the most critical public health and patient safety threats facing us today, causing an estimated two million illnesses and approximately 23,000 deaths annually. It is estimated that as much as half of antibiotic prescribing in hospitals is not necessary. Antibiotics, created to save lives, are now contributing to patient's deaths by promoting the emergence of highly resistant bacteria and leading to deadly adverse events.

Centers for Disease Control and Prevention (CDC)

We urge you to support the CDC Coalition's request for \$7.8 billion in fiscal year 2015 for the CDC's "core programs." We are concerned that the President's fiscal year 2015 budget proposal would reduce the CDC's budget authority by \$243 million when compared with fiscal year 2014. This total is, in fact, lower than 2003 levels. We urge Congress to prioritize funding for the activities and programs supported

by CDC that are essential to protect the health of the American people and reduce healthcare costs.

We especially want to highlight our support for the \$30 million in the President's budget for the Detect and Protect Against Antibiotic Resistance (AR) Initiative. This initiative will establish a robust network of five regional labs that will detect the deadliest AR threats and protect patients and communities through the rapid identification of outbreaks, saving lives and reducing healthcare costs. It will prioritize healthcare prevention collaboratives focused on improving antibiotic use and preventing deadly infections caused by *Clostridium difficile* (C. diff), carbapenem-resistant Enterobacteriaceae (CRE), *Pseudomonas*, and methicillin-resistant *Staphylococcus aureus* (MRSA). Most importantly, the initiative will invest in direct action by implementing proven evidence-based interventions that reduce the emergence and spread of AR pathogens and improve antibiotic use. It is critical that Congress prioritize this rapidly growing threat to public health and patient safety in our Nation and around the world. Moreover, we strongly support CDC's focus on the implementation of antimicrobial stewardship programs in all healthcare settings.

We urge you to support the \$32 million in the President's budget for the CDC's National Healthcare Safety Network (NHSN). The President's request represents a \$14 million increase over the fiscal year 2014 enacted level for the NHSN to extend HAI prevention efforts to more than 3,000 ambulatory surgery centers and other non-hospital settings. This will enable CDC to conduct applied research on interventions for infection prevention and continue to provide data for national HAI elimination and targeted HAI prevention intervention. This funding level will also allow for the extension and implementation of the NHSN Antimicrobial Use and Resistance Components to enable rapid detection of highly resistant pathogens and track antibiotic use in healthcare settings.

The NHSN serves as the foundation for the development of innovative, evidence-based HAI prevention strategies through high-quality monitoring of HAI prevalence as well as antibiotic usage in the US. It is a critical tool used by healthcare facilities to monitor and prevent HAIs. The NHSN provides medical facilities, states, regions, and the Nation with data collection and reporting capabilities needed to comply with state and Federal public reporting mandates, including the Centers for Medicare & Medicaid Services' Value-Based Purchasing Program. Consistent, scientifically sound and validated data are necessary to be reported at the state and Federal levels to ensure that accurate data are available to evaluate progress related to the HHS National Action Plan to Prevent HAIs as well as to support transparency to the public, allowing for fair comparisons between facilities.

By August 2013, over 12,400 healthcare facilities, including nearly all U.S. hospitals, participated in NHSN for quality improvement. The number of acute care hospitals reporting multi-drug resistant organisms (such as C.diff and MRSA) through NHSN more than doubled to 4,000 in fiscal year 2013. Since 2008, the cumulative impact of CDC data systems, guidelines and programs has contributed to significant reductions of HAIs in healthcare settings, including a 44 percent reduction in central line-associated bloodstream infections, a 31 percent reduction in healthcare-associated invasive MRSA infections, and a 20 percent reduction in surgical site infections.

We strongly support the CDC Prevention Epicenters Program. Funded through the NHSN, this program is a collaboration between CDC and academic medical centers that conduct innovative infection control and prevention research to address important scientific questions regarding the prevention of HAIs, antibiotic resistance and other adverse healthcare events. The Epicenters Program has provided a unique forum in which academic leaders in healthcare epidemiology can partner directly with each other and with CDC subject matter experts. The resultant emphasis on multicenter collaborative research projects, through which investigators work together as a group, allows for research that in many cases, would not have been possible for a single academic center. Going forward, the Prevention Epicenters will continue to address gaps and pilot innovative ways to prevent HAIs and antimicrobial resistance.

We urge your continued support of the President's \$30 million request for the Advanced Molecular Detection (AMD) Initiative in bioinformatics and genomics, which allows CDC to more quickly determine where emerging diseases come from, whether microbes are resistant, and how microbes are moving through a population. This Initiative is critical because it strengthens CDC's epidemiologic and laboratory expertise to effectively guide public health action.

We strongly support the critical work conducted through the Emerging Infections Program (EIP), which engages a network of state health departments and their academic medical center partners to help answer important questions about emerging

HAI threats, advanced infection tracking methods and antibiotic resistance in the U.S.

Agency for Healthcare Research and Quality

We request your support of the proposed investment of \$34 million for AHRQ's HAI research activity, the level of enacted support in fiscal year 2014. Building on the successes of fiscal year 2013 and 2014, these funds will support a portfolio of grant- and contract-funded projects seeking to advance our knowledge about effective approaches to reducing HAIs while promoting the implementation of proven methods for preventing HAIs. These grants (\$13.9 million) and contracts (\$20.1 million) will investigate methods of controlling HAIs in diverse healthcare settings and will address the major types of HAIs. In addition, contracts funded by the HAI budget will accelerate the nationwide implementation of the Comprehensive Unit-based Safety Program (CUSP). To date, widespread adoption of this evidence-based checklist of safety practices to over 1,000 intensive care units has reduced the incidence of central line-associated bloodstream infections (CLABSIs) by 41 percent. Our organizations are pleased to participate in the On the CUSP: Stop CAUTI initiative, which aims to reduce mean rates of CAUTI in U.S. hospitals by 25 percent by working with state organizations and hospitals across the country to implement the CUSP and catheter-associated urinary tract infection (CAUTI) reduction practices in hospital units. In spite of notable progress, there remains work to be done toward the goal of HAI elimination.

National Institutes of Health (NIH)/National Institute of Allergy and Infectious Diseases (NIAID)

Within NIH, we believe that the National Institute of Allergy and Infectious Diseases (NIAID) should be funded at least at the \$4.58 billion requested by the Administration in the fiscal year 2014 budget request. Nearly flat-funding NIAID limits investment in new research and serves as a disincentive for young people to pursue infectious disease research careers so critical to the discovery of new therapies, new diagnostic approaches, and new preventive strategies.

In 2013, the NIAID began funding a new clinical trials network focused on antibiotic-resistant bacterial infections. With sufficient funding, the new research network/infrastructure will conduct studies to address antibiotic resistance as well as begin to answer questions that will help fill the nearly empty antibiotic research and development pipeline. Severe economic disincentives have caused a mass exodus of private companies from the antibiotics market, making federally funded research in this area more critical than ever. We applaud NIAID's initiative in launching the new network. We recommend increased investment in this area.

We thank you for the opportunity to submit testimony and greatly appreciate your leadership in the effort to eliminate preventable HAIs and combat antibiotic resistance.

Please forward questions to:

Melanie Young, Policy & Strategic Initiatives Director, SHEA, myoung@shea-online.org and Lisa Tomlinson, Senior Director, Government Affairs, APIC, ltomlinson@apic.org.

PREPARED STATEMENT OF THE SOCIETY FOR NEUROSCIENCE

Mr. Chairman and members of the Subcommittee, my name is Carol Ann Mason, Ph.D. I am a professor of pathology and cell biology, neuroscience, and ophthalmic science at Columbia University. I study the development of visual pathways in mammalian brains, with a focus on how neurons in the eye are encoded to project to the correct side of the brain, setting up the circuit for binocular vision. This statement is in support of increased funding for NIH for fiscal year 2015.

I am pleased to submit this testimony in my capacity as president of the Society for Neuroscience (SfN). On behalf of the nearly 40,000 members of SfN, thank you for your past support of neuroscience research at NIH. SfN's mission is to advance the understanding of the brain and nervous system; provide professional development activities, information and educational resources; promote public information and general education; and inform legislators and other policymakers.

The Society stands with others in the research community in requesting at least \$32 billion for NIH for fiscal year 2015. Sequestration is taking an enormous toll on biomedical research, coming on top of recent years when funding has failed to keep pace with the cost of research—let alone the scientific opportunities that are available. SfN urges Congress to reverse the current course and find ways to invest more in biomedical research. Let's work to put biomedical research on a trajectory

of sustained growth that recognizes its promise and opportunity as a tool for economic growth and, more importantly, for advancing the health of Americans.

Neuroscience: An Investment in Our Future

Even in the face of the difficult funding situation, the last several years have been a tremendously exciting and productive time for neuroscience discoveries. Major research advances on brain development, imaging, genomics, circuits, computational neuroscience, neural engineering, and many other disciplines are leading to new tools, new knowledge, and greater understanding that were unimaginable even a few years ago. Sustained investment to fuel and speed these discoveries is essential to American health and economic well-being for many reasons.

First, major investment in basic and translational neuroscience is not only fueling an enduring and vital scientific endeavor; it is the essential foundation for understanding and treating diseases that strike nearly 1 billion people worldwide. All told, there are more than 1,000 debilitating neurological and psychiatric diseases that strike over 100 million Americans each year, producing inestimable hardship for millions of America families and costing the U.S., in a conservative estimate, at least \$760 billion a year, with expenses in the trillions looming for conditions such as Alzheimer's disease. Advances made possible by publicly-funded basic research will help better understand and treat traumatic brain injury, Alzheimer's, Parkinson's disease, Down syndrome, schizophrenia, epilepsy, and post-traumatic stress disorder, to name just a few. With so much promising research, now, more than ever, it is time to fan the flames of research in order to ensure lifesaving breakthroughs continue.

Additionally, NIH funding is an investment in America's current economic strength. Funding for research supports quality jobs and increases economic activity. NIH supports approximately 400,000 jobs and \$58 billion in economic output nationwide. Eighty-five percent of the NIH budget fund extramural research in communities located in every State.

Finally, without robust, sustained investment, America's status as the preeminent leader in biomedical research is at risk. Other countries are investing heavily in biomedical research to take advantage of new possibilities. Even with the growing philanthropic support, private sector cannot be expected to close the gap. The lag time between discovery and profitability means that the pharmaceutical, biotechnology, and medical device industries need federally-funded basic (also known as fundamental) research to develop products and treatments. The foundation that basic research provides is at risk if federally-funded research declines.

The BRAIN Initiative

SfN appreciates that both Congress and the administration recognize brain science as one of the great scientific challenges of our time. The Brain Research through Application of Innovative Neurotechnologies (BRAIN) Initiative—announced by the President last April—will enable NIH and other Federal agencies to develop tools and plans that will help accelerate fundamental discoveries and improve the health and quality of life for millions of Americans. An eminent group of neuroscientists with diverse research interests is helping to formulate a scientifically-driven direction for the initiative, and SfN thanks public leaders for their interest and early support for a truly transformative scientific grand challenge that would need major financial emphasis in future years.

The overarching goal of the BRAIN Initiative is to map the circuits of the brain and the activity within those circuits to understand our unique cognitive and behavioral capabilities. The Initiative has a strong focus on developing technologies which has the potential to benefit all of neuroscience and even non-neuroscience research. BRAIN, like other major brain-related initiatives around the world, demonstrates the global interest in tackling the mysteries of the brain. But BRAIN—as with all the neuroscience research that takes place with Federal support—can only be successful if it is part of a broad neuroscience commitment across Congress and the Administration. Such an investment will also help ensure the U.S. remains a global leader, as other nations and regions are now rapidly ramping up their investments in neuroscience research.

Cross-Disciplinary Neuroscience and the Promise of Brain Circuits

NIH-funded basic research continues to be essential for discoveries that will inspire scientific and medical progress for generations. Past NIH-supported projects have helped neuroscientists make tremendous strides in diagnosing and treating neurological and psychiatric disorders.

A prime example of the importance of funding research at levels from the most basic to translational is the current focus on understanding brain circuits. Circuits in the brain underlie every thought, emotion, and action we take. Current knowl-

edge about the intricate patterns connecting brain cells is extremely limited. Identifying these patterns is essential to understand healthy brain function and dysfunction in injury or disease. Research suggests that some brain disorders, like autism and schizophrenia, may result from errors in neural circuit development. Elucidating brain circuit structure and function is an enormously challenging endeavor; the brain consists of billions of cells, and each cell contacts thousands of others. These cells communicate with precisely-timed signals, which then activate a multitude of biochemical pathways that influence every process in the cell. However, scientists are beginning to map the functions of brain circuits with previously unheard-of specificity using cutting-edge technologies, and learning how these circuits produce behaviors.

The following examples are just a few of the many basic research success stories in the science of brain circuitry emerging now thanks to interdisciplinary research funded by a strong historic investment in NIH and other research agencies.

Optogenetics

Optogenetics is a technique which uses light to activate specific populations of neurons with millisecond precision. It is difficult to overstate how revolutionary optogenetics is for neuroscience research. With optogenetics, flashes of light are used to activate neurons that have been genetically modified to contain a light-sensing protein. This precise control over specific populations of neurons at specific times was impossible until a confluence of basic research in marine biology, genetic engineering, cellular biology, and fiber optic technology facilitated its development; together these developments created an approach that enables the proteins to be used as “on switches” for cells. Introduced a decade ago, optogenetics is now used by hundreds of labs; it is one of the many neurotechnologies that today is transforming the field’s ability to understand brain function, and is being used to study brain circuits in both normal function and disease, including Parkinson’s disease, as described below. The development of this technology also perfectly demonstrates the often serendipitous nature of scientific discovery and the need to fund both research on all levels, from basic to translational to clinical.

Understanding the Development of Vision

My own area of research is the development of the circuits underlying vision. For binocular vision to function, the brain must receive information from both eyes. Nerve fibers from each retina grow to the ‘optic chiasm,’ at the midline of the bottom of the brain. Here, nerve fibers from each eye cross to the other side of the brain. Other axons, however, are repelled at the midline and project to the same side of the brain. These connections underlie binocular vision which enables animals, including humans, to calculate how far objects lie in the distance. One area of my research focuses on this question and the molecular mechanisms that prompt some growing nerve fibers to “stop in their tracks” and reroute to the same side. These two groups of cells in the eye, each taking different routes, are endowed with distinct genes that direct their time of birth and their growth to the regions where they make their synaptic connections. Understanding their genetic “signatures” and growth helps us to learn how to encourage stem cells to be integrated into the diseased eye and injured nerve fibers to regrow in the correct circuits. We also investigate how the retinal pigment epithelium (RPE) surrounding the eye, directs retinal development. Perturbations in the RPE occur in albinism and in juvenile forms of macular degeneration, the latter leading to blindness, and our gene identification efforts are important for gene therapy at early stages of the disease. Moreover, understanding how tracts are laid down is essential for unraveling the basis of defects in fiber pathways and synapse formation in neurodevelopmental disorders such as autism. This research is made possible with support primarily from NIH, especially the National Eye Institute and with a team of innovative and collaborative scientists and trainees in my lab and in our community, and provides a foundation for future discovery and new understanding about diseases of the eye and other neurodevelopmental conditions.

Deep Brain Stimulation

Deep brain stimulation (DBS) is a tool that emerged as a result of advances in health research. DBS involves a surgical procedure in which a neurostimulator device—similar to a heart pacemaker—is implanted to deliver electrical stimulation to targeted areas in the brain. While both DBS and optogenetics have emerged as instrumental methods to influence circuits, DBS has also been developed into a revolutionary therapy for the treatment of neurological disease. The electrical pulses delivered through the electrodes can transiently disrupt abnormal activity that occurs in localized circuits of diseased brains, such as in Parkinson’s patients.

DBS has created a new way to approach the treatment of Parkinson's disease. Many patients experience pronounced relief from symptoms that include tremor, stiffness, slowed movement, and walking problems. Moreover, DBS can allow patients to reduce the dosage of their medication, providing relief from debilitating motor side-effects. Additionally, advances in materials science to create more flexible electrodes and in imaging research to produce higher resolution images of the brain will improve the precision and outcome of this intervention.

At this time, how and why DBS works is unknown. Insight into its mechanism of action came from optogenetic studies in rodents of the brain circuits that control movement. By systematically manipulating precise areas of the circuit affected by this disease, scientists were able to implicate the connection between two areas of the brain as the most effective target for DBS. These studies will also inform the design of other interventions in Parkinson's, and establish a model for study of basic brain circuitry to inform DBS treatment.

DBS has also had success in treating both intractable depression and epilepsy, and has the potential to improve therapies for a whole host of brain diseases and disorders—as long as the correct target is identified. Because stimulating adjacent regions in the brain can have vastly different effects, researchers are attempting to better understand the complex brain circuits that control our normal functions (e.g., movement, emotion) and how they can go wrong (e.g., addiction). They also are tweaking the physical devices used, as well as the frequency and strength of the electrical pulses delivered. As we understand more about language of the brain through the research made possible by NIH funding, new applications of DBS will be possible.

The Future of American Science

As the subcommittee considers this year's funding levels, please consider that significant advancements in the biomedical sciences often come from young investigators. As a director of the PhD training program of a leading neuroscience department, I see firsthand that the current funding environment is taking a toll on the energy and resilience of these young people and their career choice. America's scientific enterprise—and its global leadership—has been built over generations. Without sustained, consistent investment, we will quickly lose that leadership. Dramatic swings in funding have stifling and irreversible impacts on progress; a closed laboratory can't simply open again when funding is restored. The culture of entrepreneurship and curiosity-driven research could be hindered for decades.

We live at a time of extraordinary opportunity in neuroscience. A myriad of questions once impossible to consider are now within reach because of new technologies, an ever-expanding knowledge base, and a willingness to embrace many disciplines. To take advantage of the opportunities in neuroscience we need an NIH appropriation that allows for sustained, reliable growth. That, in turn, will lead to improved health for the American public and will help maintain American leadership in science worldwide. Thank you for this opportunity to testify.

[This statement was submitted by Carol Ann Mason, Ph.D., President, Society for Neuroscience.]

PREPARED STATEMENT OF THE SOCIETY FOR PUBLIC HEALTH EDUCATION

I am pleased to submit this testimony on behalf of The Society for Public Health Education (SOPHE), a 501 (c)(3) professional organization founded in 1950 to provide global leadership to the profession of health education and health promotion. SOPHE's 4,000 national and chapter members work in universities, medical/healthcare settings, businesses, voluntary health agencies, international organizations, and all branches of Federal/State/local government. Members include behavioral scientists, faculty, practitioners, and students engaged in disease prevention and health promotion in both the public and private sectors. The Society contributes to the health of all people and the elimination of health disparities through advances in health education theory and research; excellence in professional preparation and practice; and advocacy for public policies conducive to health. SOPHE is the only independent professional organization devoted exclusively to health education and health promotion. SOPHE's two scientific peer-reviewed journals, electronic newsletters, listservs, websites, new Center for Online Education (CORE), as well as its national conference help ensure that vital public health activities and programs in various regions are expeditiously disseminated. There are currently 20 SOPHE chapters covering more than 30 States and regions across the country.

SOPHE's vision of a healthy world through health education compels us to advocate for increased resources targeted at the most pressing public health issues. For

the fiscal year 2015 funding cycle, SOPHE encourages the Labor, Health and Human Services, Education and Related Agencies (Labor-HHS) Subcommittee to increase funding for public health programs that focus on preventing chronic disease and other illnesses in adults as well as youth, and eliminating health disparities. In particular, SOPHE requests the following fiscal year 2015 funding levels for Labor-HHS programs:

- \$7.8 billion for the U.S. Centers for Disease Control and Prevention (CDC)
- \$1.1 billion for the CDC National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP)
- \$25 million for CDC's National Chronic Disease Prevention and Health Promotion's Division of Population Health School Health Program
- \$1 billion for the Prevention and Public Health Fund
- \$80 million for Community Prevention Grants
- \$50 million for Racial and Ethnic Approaches to Community Health

The discipline of health education and health promotion, which is some 100 years old, uses sound science to plan, implement, and evaluate interventions that enable individuals, groups, and communities to achieve personal, environmental and population health. Beyond supporting individual behavior change, health education focuses on policy, systems, and environmental changes to support a healthy lifestyle. There is a robust, scientific evidence-base documenting not only that health education specialists and their various health education interventions work, but that they are also cost-effective. These principles serve as the basis for our support for the programs outlined below and can help ensure our Nation's resources are targeted for the best return on investment. Our profession is the first to recruit and train community health workers in terms of cost-effective program interventions.

SOPHE is requesting a fiscal year 2015 funding level \$7.8 billion for CDC in order to prevent chronic diseases and other illnesses, promote health, prevent injury and disability, and ensure preparedness against health threats. Unfortunately, President Obama's fiscal year 2015 budget request of \$6.6 billion for CDC represents a decrease of some \$243 million when compared with fiscal year 2014. CDC is at the forefront of U.S. efforts to monitor health, detect and investigate health problems, conduct research to enhance prevention, develop sound public health policies, and foster safe and healthful environments. More than 80 percent of all CDC funds go back to States to address State and local health issues. Measured investments now in community-led, evidence-based innovative programs will help to increase our Nation's productivity and performance in the global market; help ensure military readiness; decrease costly deaths due to infant low birth weight and adult onset of cancer, cardiovascular disease, diabetes, and HIV/AIDS, and; increase pediatric and adult immunization rates. Moreover, cuts to CDC's budget are not sustainable and will reduce the ability to investigate and respond to public health emergencies as well as foodborne and infectious disease outbreaks.

Preventing Chronic Disease

The data are clear: chronic diseases are the Nation's leading causes of morbidity and mortality and account for 75 percent of every dollar spent on healthcare in the U.S. Collectively, they account for 70 percent of all deaths nationwide. Healthcare accounts for 18 percent of GDP, and it is expected to account for 19.6 percent by 2021. Yet evidence shows that investing just \$1 in preventing chronic disease will yield a \$5 return on investment.

SOPHE requests an appropriation of \$1.1 billion for the CDC's National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP). For example, heart conditions cost the Nation more than \$107 billion annually in healthcare costs, and nearly \$95 billion in lost economic productivity. Studies show that spending as little as \$10 per person on proven preventive interventions could save the country over \$16 billion in just 5 years. The public overwhelmingly supports increased funding for disease prevention and health promotion programs.

Among the many vital programs in CDC's NCCDPHP, SOPHE is requesting a fiscal year 2015 funding level of \$25 million to the CDC Division of Population Health's School Health Branch (SHB). The increase in funding will allow the SHB to create a coordinated, national response to school health and chronic disease, which will maximize program effectiveness and accelerate health improvements. School health activities supported through the SHB include: supporting healthier nutrition environments in schools; providing comprehensive school physical activity programs and multi-component physical education policies; and improving capacity to manage chronic conditions. Almost 80 percent of young people do not eat the recommended five servings of fruits and vegetables each day. Daily participation in high school physical education classes dropped from 42 percent in 1991 to 32 per-

cent in 2001. Health and fitness are linked to improved academic achievement and grades, cognitive ability, and behavior as well as reduced truancy.

Since fiscal year 2012, funding for CDC's school health activities to prevent chronic diseases has essentially been level funded at \$14.9 million. DPH provides a basic level of funding for school health activities in all 50 States (about \$75,000 per State). This small amount of funding allows States to only conduct a minimum of school-based health activities. The School Health Branch also provides an enhanced level of funding on a competitive basis to a smaller number of States. Increasing resources for the SHB will enable all 50 States and DC to engage in enhanced school health activities that improve the school nutrition environment and increase the quality and quantity of physical education and physical activity opportunities. States would also be strongly encouraged to fund a school health position at the State education agency to coordinate efforts with the State health department. CDC's Coordinated School Health Programs are cost-effective in improving children's health, their behavior, and their academic success. This funding builds bridges between State education and public health departments to coordinate health education, nutritious meals, physical education, mental health counseling, health services, healthy school environments, and parent and community involvement. The 2013 IOM report *Educating the Student Body: Taking Physical Activity and Physical Education to School*, stated that the school environment is key in encouraging and providing opportunities for children and adolescents to be active. The lack of physically fit and health-literate graduates has become a national security issue—being overweight or obese has become the leading medical reason why applicants fail to qualify for military service.

An Avenue to Future Health Savings

SOPHE is requesting a fiscal year 2015 funding level of \$1 billion for the Prevention and Public Health Fund. We applaud Congress for appropriating the Fund for the first time, as was intended by the law since the Fund's inception, in the fiscal year 2014 omnibus bill. We strongly encourage Congress to continue to appropriate the Fund at this level in fiscal year 2015 to sustain essential core public health infrastructure, the workforce, and our capacity to improve health in our communities. This fund provides the agility for innovation and meeting the needs of communities at the State and local levels.

Specifically, the Prevention Fund helps States tackle the leading causes of death and root causes of costly, preventable chronic disease; detect and respond rapidly to health security threats; and prevent accidents and injuries. With this investment, the Fund helps States and the Nation as a whole focus on fighting disease and illness before they happen. The evidence is overwhelming: investing in prevention saves lives and money. A 2011 Urban Institute study concluded that it is in the Nation's best interest from both a health and economic standpoint to maintain funding for evidence-based, public health programs that save lives and bring down costs; a July 2011 study published in the journal *Health Affairs* found that increased spending by local public health departments can save lives currently lost to preventable illnesses; and a follow up to that study in 2013 found that low-income communities experience the largest health and economic gains with respect to increases in local public health spending. In addition, lower death rates and healthcare costs were seen especially in communities that allocated their public health funding across a broader mix of preventive services.

SOPHE supports the new Community Prevention Grant program that will be funded at \$80 million to help communities build multi-sector partnerships to strengthen multisector partnerships aimed at better health. Although SOPHE is disappointed that the Community Transformation Grant (CTG) program was discontinued in the fiscal year 2014 omnibus, we look forward to a new stream of funding that will support communities to implement evidence-based chronic disease prevention strategies. SOPHE has met with key stakeholders in both Congress and the Administration and looks forward to realizing the vision of forthcoming funding opportunity announcements.

As part of the Prevention Fund, SOPHE strongly supports the increase in funding CDC's Racial and Ethnic Approaches to Community Health Across the U.S. (REACH U.S.) program, which addresses health risk behaviors in both children and adults. Chronic diseases account for the largest health gap among populations and increase health disparities among racial and ethnic minority groups. As the U.S. population becomes increasingly diverse, the Nation's health status will be heavily influenced by the morbidity of racial and ethnic minority communities. With additional funding from the Prevention and Public Health Fund, the REACH program will address strategies in the areas of tobacco-free living, active living and healthy eating, clinical and other preventive services, social and emotional wellness, and

healthy and safe physical environments—with a primary focus on African-American/Black, Hispanic/Latino, Asian, Native Hawaiian/Pacific Islander, and American Indian/Alaskan Native populations. These culturally sensitive, population specific programs, often led by health education specialists in tandem with community health workers, are aimed at disease risk reduction and preventing costly hospital re-admission rates.

Thank you for this opportunity to present our views to the Subcommittee. We understand there will be difficult choices to make in this fiscal environment, and join you in seriously evaluating how our Nation's scarce resources can provide maximum return on investment. Public health funding gets the job done at the State and local levels and only represents 1.5 percent of Federal budget; lack of full funding would only be "penny wise and pound foolish".

SOPHE shares the Subcommittee's goals to support the Nation's efforts to thrive and grow through sound investments in labor, education and health. This can only be accomplished with a healthy population contributing to a skilled, healthy and productive workforce. We look forward to working with you to prevent chronic illness, improve the quality of lives, and save billions of dollars in healthcare spending.

[This statement was submitted by M. Elaine Auld, MPH, MCHES, Chief Executive Officer, Society for Public Health Education.]

PREPARED STATEMENT OF THE SOCIETY FOR PUBLIC HEALTH EDUCATION

The Society for Public Health Education (SOPHE) is a 501 (c)(3) professional organization founded in 1950 to provide global leadership to the profession of health education and health promotion. SOPHE contributes to the health of all people and the elimination of health disparities through advances in health education theory and research; excellence in professional preparation and practice; and advocacy for public policies conducive to health. SOPHE is the only independent professional organization devoted exclusively to health education and health promotion. SOPHE's two scientific peer-reviewed journals, electronic newsletters, listservs, websites, new Center for Online Education (CORE), as well as its national conference help ensure that vital public health activities and programs in various regions are expeditiously disseminated. Members include behavioral scientists, faculty, practitioners, and students engaged in disease prevention and health promotion in both the public and private sectors. Collectively, SOPHE's 4,000 national and chapter members work in universities, medical/healthcare settings, businesses, voluntary health agencies, international organizations, and all branches of Federal/State/local government. There are currently 20 SOPHE chapters covering more than 30 States and regions across the country.

SOPHE's vision of a healthy world through health education compels us to advocate for increased resources targeted at the most pressing public health issues. For the fiscal year 2015 funding cycle, SOPHE encourages the Labor, Health and Human Services, Education and Related Agencies (Labor-HHS) Subcommittee to increase funding for public health programs that focus on preventing chronic disease and other illnesses in adults as well as youth, and eliminating health disparities. In particular, SOPHE requests the following fiscal year 2015 funding levels for Labor-HHS programs:

- \$7.8 billion for the Centers for Disease Control and Prevention (CDC)
- \$1 billion for the Prevention and Public Health Fund
- \$50 million for Racial and Ethnic Approaches to Community Health
- \$80 million for Community Prevention Grants
- \$25 million for CDC's Division of Population Health School Health Program

The discipline of health education and health promotion, which is some 100 years old, uses sound science to plan, implement, and evaluate interventions that enable individuals, groups, and communities to achieve personal, environmental and population health. There is a robust, scientific evidence-base documenting not only that various health education interventions work but that they are also cost-effective. These principles serve as the basis for our support for the programs outlined below and can help ensure our Nation's resources are targeted for the best return on investment.

Preventing Chronic Disease

The data are clear: chronic diseases are the Nation's leading causes of morbidity and mortality and account for 75 percent of every dollar spent on healthcare in the U.S. Collectively, they account for 70 percent of all deaths nationwide. Healthcare now accounts for 18 percent of GDP, and it's expected to account for 19.6 percent

by 2021. Yet evidence shows that investing just \$1 in preventing disease will yield a \$5 return on investment.

SOPHE is requesting a fiscal year 2015 funding level \$7.8 billion for CDC in order to prevent chronic diseases and other illnesses, promote health, prevent injury and disability, and ensure preparedness against health threats. Unfortunately President Obama's fiscal year 2015 budget request of \$6.6 billion for CDC represents a nearly \$243 million reduction when compared with fiscal year 2014. CDC is at the forefront of U.S. efforts to monitor health, detect and investigate health problems, conduct research to enhance prevention, develop sound public health policies, and foster safe and healthful environments. More than 80 percent of all CDC funds go back to States to address State and local health issues. Studies show that spending as little as \$10 per person on proven preventive interventions could save the country over \$16 billion in just 5 years. The public overwhelmingly supports increased funding for disease prevention and health promotion programs. Small investments now in community-led, innovative programs will help to increase our Nation's productivity and performance in the global market; help ensure military readiness; decrease rates of infant mortality, deaths due to cancer, cardiovascular disease, diabetes, and HIV/AIDS, and; increase immunization rates. Cuts to CDC's budget are not sustainable and will reduce the ability to investigate and respond to public health emergencies as well as foodborne and infectious disease outbreaks.

SOPHE is requesting a fiscal year 2015 funding level of \$1 billion for the Prevention and Public Health Fund. We applaud Congress for appropriating the Fund for the first time, as was intended by the law since the Fund's inception, in the fiscal year 2014 omnibus bill. We strongly encourage Congress to continue to appropriate the Fund at this level in fiscal year 2015 to sustain essential core public health infrastructure, the workforce, and our capacity to improve health in our communities. The Prevention Fund helps States tackle the leading causes of death and root causes of costly, preventable chronic disease; detect and respond rapidly to health security threats; and prevent accidents and injuries. With this investment, the Fund helps States and the Nation as a whole focus on fighting disease and illness before they happen. The evidence is overwhelming: investing in prevention saves lives and money. A 2011 Urban Institute study concluded that it is in the Nation's best interest from both a health and economic standpoint to maintain funding for evidence-based, public health programs that save lives and bring down costs; a July 2011 study published in the journal *Health Affairs* found that increased spending by local public health departments can save lives currently lost to preventable illnesses; and a follow up to that study in 2013 found that low-income communities experience the largest health and economic gains with respect to increases in local public health spending. In addition, lower death rates and healthcare costs were seen especially in communities that allocated their public health funding across a broader mix of preventive services.

SOPHE strongly supports the increase in funding CDC's Racial and Ethnic Approaches to Community Health Across the U.S. (REACH U.S.) program, which addresses health risk behaviors in both children and adults. Chronic diseases account for the largest health gap among populations and increase health disparities among racial and ethnic minority groups. As the U.S. population becomes increasingly diverse, the Nation's health status will be heavily influenced by the morbidity of racial and ethnic minority communities. With additional funding from the Prevention and Public Health Fund, the REACH program will address strategies in the areas of tobacco-free living, active living and healthy eating, clinical and other preventive services, social and emotional wellness, and healthy and safe physical environments—with a primary focus on African-American/Black, Hispanic/Latino, Asian, Native Hawaiian/Pacific Islander, and American Indian/Alaskan Native populations.

SOPHE supports the new Community Prevention Grant program that will be funded at \$80 million to help communities build multi-sector partnerships around better health. While SOPHE is disappointed that the Community Transformation Grant (CTG) program was discontinued in the fiscal year 2014 omnibus, we look forward to a new stream of funding that will support communities to implement evidence-based chronic disease prevention strategies. SOPHE looks forward to working with the Administration on forthcoming funding opportunity announcements.

SOPHE is requesting a fiscal year 2015 funding level of \$25 million to CDC's Division of Population Health's School Health Branch (SHB). The increase in funding will allow the SHB to create a coordinated, national response to school health and chronic disease, maximizing program effectiveness, and accelerating health improvements. School health activities supported through the SHB include: supporting healthier nutrition environments in schools; providing comprehensive school physical activity programs and multi-component physical education policies; and improving capacity to manage chronic conditions. Almost 80 percent of young people do not

eat the recommended five servings of fruits and vegetables each day. Daily participation in high school physical education classes dropped from 42 percent in 1991 to 32 percent in 2001. Health and fitness are linked to improved academic achievement and grades, cognitive ability, and behavior as well as reduced truancy.

Since fiscal year 2012, funding for CDC's school health activities to prevent chronic diseases has essentially been level funded at \$14.9 million. DPH provides a basic level of funding for school health activities in all 50 States (about \$75,000 per State). This small amount of funding allows States to only conduct a minimum of school-based health activities. The School Health Branch also provides an enhanced level of funding on a competitive basis to a smaller number of States. Increasing resources for the SHB will enable all 50 States and DC to engage in enhanced school health activities that improve the school nutrition environment and increase the quality and quantity of physical education and physical activity opportunities. States would also be strongly encouraged to fund a school health position at the State education agency to coordinate efforts with the State health department. CDC's Coordinated School Health Programs have been shown to be cost-effective in improving children's health, their behavior, and their academic success. This funding builds bridges between State education and public health departments to coordinate health education, nutritious meals, physical education, mental health counseling, health services, healthy school environments, and parent and community involvement.

Thank you for this opportunity to present our views to the Subcommittee. We understand there will be tough choices to make in this fiscal environment. However, public health funding only makes up 1.5 percent of Federal budget, and yields a much a greater return on investment. We look forward to working with you to prevent chronic illness, improve the quality of lives, and save billions of dollars in healthcare spending.

[This statement was submitted by Elaine Auld, Chief Executive Officer, Society for Public Health Education.]

PREPARED STATEMENT OF THE SOCIETY FOR WOMEN'S HEALTH RESEARCH

The Society for Women's Health Research (SWHR) is pleased to have the opportunity to submit the following testimony urging renewed investment in scientific and medical research within the Department of Health and Human Services (HHS). For almost 25 years, our organization has been considered the thought leader in research on biological differences in disease and is dedicated to transforming women's health through science, advocacy, and education. We believe that a robust Federal research agenda that is inclusive of women's health research is critical for the U.S. to meet the needs and expectations of its citizens. We request that for fiscal year 2015, Congress fund the following agencies and programs at the following levels:

- Agency for Healthcare and Research Quality-\$471 million
- Centers for Disease Control and Prevention-\$6.904 billion
- Health Resources Services Administration-\$6.113 billion
- National Institutes of Health-\$32 billion
- Substance Abuse and Mental Health Services Administration-\$3.6 billion
- Office of Research on Women's Health at NIH-\$42 million
- HHS Office of Women's Health-\$35 million

SWHR remains concerned with the ramifications of the Budget Control Act and sequestration. Funding levels for Department of Health and Human Services (HHS), were significantly cut and those agencies that fall underneath the umbrella of HHS; The Agency for Healthcare Research and Quality (AHRQ), Centers for Disease Control and Prevention (CDC), Health Resources Services Administration (HRSA), National Institutes of Health (NIH), Substance Abuse and Mental Health Services Administration (SAMHSA), all play vital roles in improving and protecting the health of Americans but are forced to do more with less funding. Continued cuts to public health agencies decrease public health emergency preparedness and response capabilities, reducing funding for States to monitor air quality and offer mental health services, and increasing the risk for infectious disease outbreaks. These are essential public health services that save lives and protect our health. Currently, healthcare spending is the largest driver of the Federal deficit. By 2021, estimates indicate that this spending will account for nearly one-fifth of the U.S. economy. Proper and sustained Congressional investment in medical and scientific research can ultimately save valuable healthcare dollars that are wasted on inappropriate and ineffective treatment. We realize that the current budgetary environment limits the amount of monies available for a substantial increase; however, the benefit from every dollar invested in medical research outweighs the cost many times over and

is, perhaps, the single most cost effective strategy in reducing our Federal deficit. Past investments in medical research have allowed scientists to begin unraveling the biologic and genetic underpinning of disease. This research has shown that biological sex impacts every organ of the body, and plays an important role in disease susceptibility, prevalence, time of onset and severity. Sex differences are evident in all major disease categories, including cancer, obesity, and heart disease. These differences are also evident in drug absorption, distribution, metabolism and elimination. The medical community has now begun to tailor treatments to meet the needs of individual patients, taking the first step towards truly personalized medicine.

National Institutes of Health-NIH serves as the America's premier medical research agency and is the largest source of funding for biomedical and behavioral research in the world. Many of the medical advances in recent decades are direct results from investments in the agency. Unfortunately, years of flat-funding, without controlling for rising inflation, has meant that NIH's overall budget has decreased by 10 percent between 2004 and 2014, and its purchasing power has decreased by 22 percent. This number does not just impact NIH's campus in Maryland. Approximately 85 percent of NIH funding is spent in communities across the country, creating jobs at more than 3,000 universities, medical schools, teaching hospitals, and research institutions. In 2013, NIH funded 750 fewer grants than in 2012 and grant funding fell to an all-time low of 20 percent. A shrinking number of available grants put scientists out of work. With limited opportunities for research funding, scientists have little choice than to pursue opportunities outside of academic research in the U.S., resulting in the loss of skilled bench scientists and researchers to Asia, the European Union and the United Kingdom, who continue to heavily invest in research. Unfortunately, the Administration's request of a 0.7 percent increase doesn't make much headway in reversing the \$1.5 billion cut the agency sustained under sequestration in fiscal year 2013, nor does it keep up with biomedical inflation rate, projected by the HHS's Biomedical Research and Development Price Index, to be 2.2 percent. Once that inflation rate is taken into account, the Administration's budget request results in another cut to the Agency. SWHR recommends that Congress set, at a minimum, a budget of \$32 billion for NIH for fiscal year 2015. Further we recommend that Congress expand NIH's mandate on the inclusion of women in basic research to include women in all phases of basic, clinical and medical research. Current practice only mandates sufficient female subjects only in Phase III research, and researchers often miss out on the chance to look for variability by sex in the early phases of research, safety and effectiveness is determined.

Federal offices of women's health-The offices of women's health within the Federal health agencies do critical work, both individually and in collaboration with other offices and Federal agencies, to ensure that women receive the appropriate care and treatments in a variety of different areas. Under HHS, the agencies currently with offices, advisors or coordinators for women's health or women's health research include the AHRQ, CDC, FDA, HRSA, Indian Health Service (INS), and SAMHSA. These offices do important work, both individually and in collaboration with other offices and Federal agencies to ensure that women receive the appropriate care and treatments in a variety of different areas. In a time of limited budgetary dollars, Congress should invest in these offices that promote working in collaboration with other agencies, which shares much needed expertise while avoiding unnecessary duplication. SWHR recommends that these offices be sufficiently funded to ensure that these programs can continue to provide much needed services to women and their families in fiscal year 2015.

Office of Research on Women's Health—ORWH is the focal point for coordinating women's health and sex differences research at NIH, and supports innovative interdisciplinary initiatives that focus on women's health and sex differences research. ORWH promotes opportunities for and support of recruitment, retention, re-entry and advancement of women in biomedical careers. The Building Interdisciplinary Research Careers in Women's Health (BIRCWH) is an innovative, trans-NIH career development program that pairs junior faculty with senior investigators in a mentored environment. Approximately 500 scholars, the majority of them female, have been trained at 39 centers and have produced approximately 5,000 publications. ORWH's administrative supplements for research on sex and gender differences, a trans-NIH initiative to broaden the field of sex and gender differences research, adds new dimensions to on-going studies. The specialized centers of research on sex and gender factors affecting women's health (SCOR) are designed to integrate basic and clinical approaches to sex and gender research across scientific disciplines and has resulted in over 650 articles, reviews, abstracts, book chapters and other publications. To allow ORWH's programs and research grants to continue make their impact on the research community, Congress must direct that NIH con-

tinue its support of ORWH and provide it with a \$1 million dollar budget increase, bringing its fiscal year 2015 total to \$42 million.

Health and Human Services' Office of Women's Health-The HHS OWH is the government's champion and focal point for women's health issues. It works to address inequities in research, healthcare services, and public education gaps, which have historically placed the health of women at risk. Without OWH's actions, the task of translating research into practice would be only more difficult and delayed. Considering the impact of women's health programs from OWH on the public, we urge Congress to provide an increase of \$1 million for this office, a total of \$35.7 million for fiscal year 2015.

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

[This statement was submitted by Leslie Ritter, Director of Government Affairs, Society for Women's Health Research.]

PREPARED STATEMENT OF THE SQUAXIN ISLAND TRIBE

On behalf of the Tribal Leadership and members of the Squaxin Island Tribe, I am honored to submit our recommendation to this Subcommittee for appropriations to address the un-funded needs of American Indian and Alaska Native Treatment (AI/AN) Centers. The alarming statistics of increased alcohol and substance abuse use in the AI/AN communities speaks volumes to the need for improved and additional facilities to provide treatment and recovery opportunities to our citizens, our youths, our future leaders and the next seven generations. Although SAMHSA has limited discretionary funding and even less resources for residential care facilities, the Indian Health Service cannot keep pace with the growing need for these treatment centers. The only funding opportunity available in SAMHSA is the Treatment for Pregnant and Postpartum Women. In 2015, we respectfully request the Subcommittee:

- \$10 million—Expand access to residential care facility appropriations to include Treatment Centers and increase the annual appropriations to supplement inadequate funding for these centers from the Indian Health Service of which the NWITC will receive \$1.5 million;
- \$50 million—SAMHSA's Behavioral Health Tribal Prevention Grant Program; and,
- \$15 million—SAMHSA for Behavioral Health

The Squaxin Island Tribe has been operating the Northwest Indian Treatment Center (NWITC) since 1994. Ingenious in creativity, the center offers a wide variety of cultural activities and traditional/religious ceremonies, making it a natural place to heal—body, mind and soul. Fittingly, the center was given the spiritual name "D3WXbi Palil" meaning "Returning from the Dark, Deep Waters to the Light." NWITC is a residential chemical dependency treatment facility designed to serve American Indians from Tribes located in Oregon, Washington and Idaho who have chronic relapse patterns related to unresolved grief and trauma. NWITC is unique in its integration of Tribal cultural values into a therapeutic environment for co-occurring substance abuse and mental health disorders. It is a 28 bed, 30–60 day residential facility.

Welcomed and hailed by Tribal Leaders who felt the urgent need for such a facility, NWITC is centrally located in Grays Harbor County between Olympia and Aberdeen, on 2.5 acres in the small rural town of Elma, Washington. NWITC accepts patients that are referred through outpatient treatment programs, parole and probation services, hospitals, assessment centers and child and family service centers. Medical care is provided through local Indian Health Service clinics and other medical service providers. NWITC has responded with an overwhelming success rate of nearly 65 percent.

Since the original Congressional set-aside in 1993, NWITC has not received an adequate increase in the base Indian Health Service budget. It is critical to increase the NWITC's annual base in order to sustain the current services to the Tribes of the Northwest. An increase of \$1.5 million would restore lost purchasing power and meet the need to add mental health and psychiatric components to the treatment program. This increase would allow NWITC to continue its effective treatment of Native Americans.

In 2011, the NWITC served 225 patients from 28 Tribes and added intensive case management and crisis support to alumni in order to continue to promote positive outcomes for clients. Despite funding challenges, NWITC has continued to develop

and deliver innovative, culturally appropriate services to meet increasingly complex demands.

The Treatment Center's traditional foods and medicines program is supported through a partnership with the Northwest Indian College and is funded through grants from the Washington Health Foundation, the National Institute of Food and Agriculture, The Potlatch Fund and several Tribes. Weekly hands-on classes focus on traditional foods and medicines, including methods for growing, harvesting, processing, and preparation. Twice a month, Tribal elders, storytellers, and cultural specialists speak as part of the program. A monthly family class allows patients to share what they are learning with their loved ones. Patients gain hands-on experience by working in three on-site teaching gardens. This program serves as a model for other Tribal communities.

\$50 million—SAMHSA Behavioral Health Tribal Prevention Grant Program

The Behavioral Health Tribal Prevention Grant will support behavioral health services that promote overall mental and emotional health, specifically substance abuse prevention and suicide prevention services. If funded, the grant program would be the only source for Federal substance abuse and suicide prevention funding exclusively available to Tribes.

\$15 million—SAMHSA for Behavioral Health

This SAMHSA grant program has been authorized to award grants to Indian health programs to provide prevention or treatment of drug use or alcohol abuse, promotion of mental health, or treatment services for mental illness. To date, these funds have never been appropriated. An appropriation of \$15 million would provide support to Indian health programs to meet the critical substance abuse and mental health needs of our citizens.

Self-Governance—An Efficient and Effective Use of Federal Funds (Title VI of the ISDEAA)

Self-Governance is the most successful policy in the history of Tribal—Federal relations and it inspires efficient and effective government spending. Through Self-Governance, Tribes are empowered, as sovereign nations, to exercise self-determination and to design facilities, manage programs and funds, and provide services that are responsive to the needs of our communities and Tribal citizens. Tribes participating in Self-Governance have become successful in the business of healthcare and perform several key roles, serving as, governments, employers, healthcare providers and patients.

Self-Governance Tribes have made every attempt to be innovative to operate successful health programs given the budget constraints and cuts Tribal programs have incurred the past two decades. For more than a decade we have made every effort to expand Self-Governance to other programs and our efforts to seek expansion of the program will continue until we achieve our goal. We request that this Committee recognizes the success of Self-Governance and encourage HHS to work with Tribes to make the most efficient and effective use of Federal appropriations to fund Tribal programs.

Thank you for this opportunity to submit written testimony.

[This statement was submitted by Dave Lopeman, Chairman, Squaxin Island Tribe.]

PREPARED STATEMENT OF THE TREATMENT ADVOCACY CENTER

The Treatment Advocacy Center is grateful for the opportunity to submit this testimony in support of the Department of Health and Human Services' Assisted Outpatient Treatment (AOT) Grant Program (AOT Grant Program) for Individuals with Serious Mental Illness. The Treatment Advocacy Center supports full funding of the AOT Grant Program at \$15,000,000 for each of the fiscal years 2015 through 2018.

The Treatment Advocacy Center (Organization) is a national nonprofit organization dedicated to eliminating barriers to the timely and effective treatment of severe mental illness. The Organization promotes laws, policies and practices for the delivery of psychiatric care and supports the development of innovative treatments for and research into the causes of severe and persistent psychiatric illnesses, such as schizophrenia and bipolar disorder. The Treatment Advocacy Center is funded by a host of individual donors, foundations and grants and does not accept funding from companies or entities involved in the sale, marketing, or distribution of pharmaceutical products.

In far too many communities across the country, individuals whose severe mental illness impairs their ability to seek and voluntarily comply with treatment become caught up in a revolving door of hospitalization, incarceration, homelessness and repeated victimization. This small segment of the total population of individuals with a severe mental illness consumes a disproportionate percentage of their communities' limited mental health resources, without a concurrent benefit. AOT is a life-line that can break this cycle, allowing this otherwise highly vulnerable population to survive and thrive safely in the community. AOT achieves this by providing medically prescribed mental health treatment under court order.

Unfortunately, local communities are sometimes unable to realize AOT's benefits due to the initial start-up costs of moving away from their current flawed approach to one that effectively utilizes AOT. The AOT Grant Program will help to address this concern by providing communities with resources they can leverage to implement these proven programs. Studies show that AOT benefits not only those who receive court-ordered treatment, but also, "those who will be served in a more efficient public behavioral healthcare system . . . with greater capacity that produces better outcomes for a broader population in need."¹ For example, an analysis of New York's Kendra's Law found that, "In the long run . . . overall service capacity was increased, and the focus on enhanced services for AOT participants appears to have led to greater access to enhanced services for both voluntary and involuntary recipients"²

AOT is a Proven Means of Assisting Those Most in Need

AOT is proven to help address the revolving door that traps far too many individuals with severe mental illness. In 2012, the Department of Justice deemed AOT to be an effective, evidence-based program for reducing crime and violence.³

AOT Reduces Hospitalization

Researchers in 2009 conducted an independent evaluation of New York's court-ordered outpatient treatment law (Kendra's Law) and documented a striking decline in the rate of hospitalization among participants. During a 6-month study period, AOT recipients were hospitalized at less than half the rate they were hospitalized in the 6 months prior to receiving AOT. Among those admitted, hospital stays were shorter: average length of hospitalization dropped from 18 days prior to AOT to 11 days during the first 6 months of AOT and 10 days for the seventh through twelfth months of AOT.⁴

A randomized controlled study in North Carolina (Duke Study) in 1999 demonstrated that intensive routine outpatient services alone, without a court order, did not reduce hospital admission. However, when the same level of services (at least three outpatient visits per month, with a median of 7.5 visits per month) were combined with long-term AOT (6 months or more), hospital admissions were reduced 57 percent, and length of hospital stay was reduced by 20 days compared to individuals receiving the services alone. The results were even more dramatic for the subset of individuals with schizophrenia and other psychotic disorders—long-term AOT reduced hospital admissions by 72 percent and length of hospital stay by 28 days compared with services alone. The participants in the North Carolina study were from both urban and rural communities and "generally did not view themselves as mentally ill or in need of treatment."⁵

A Washington State study of 115 patients found that AOT decreased hospitalization by 30 percent over 2 years. The savings in hospital costs for these 115 patients alone was \$1.3 million.⁶ In an AOT program in Florida, AOT reduced hospital days

¹Swanson, Jeffrey W., Van Dorn, Richard A., Swartz, Marvin S., Robbins, Pamela Clark, Steadman, Henry J., McGuire, Thomas G., and John Monahan. 2013. "The Cost of Assisted Outpatient Treatment: Can It Save States Money?" *American Journal of Psychiatry* 170:1423–1432.

²Swanson, Jeffrey W., Van Dorn, Richard A., Swartz, Marvin S., Cisló, Andrew M., Wilder, Christine M., Moser, Lorna L., Gilbert, Allison R., and Thomas McGuire. 2010. "Robbing Peter to Pay Paul: Did New York State's Outpatient Commitment Program.

Crowd Out Voluntary Service Recipients?" *Psychiatric Services* 61: 1–10.

³Assisted Outpatient Treatment. Department of Justice Office of Justice Programs. Retrieved from <http://www.crimesolutions.gov/ProgramDetails.aspx?ID=228>.

⁴Swartz, Marvin S., Swanson, Jeffrey W., Steadman, Henry J., Robbins, Pamela Clark, and John Monahan. 2009. New York State Assisted Outpatient Treatment Program Evaluation. Duke University School of Medicine.

⁵Swartz, Marvin S., Swanson, Jeffrey W., Wagner, H. Ryan, Burns, Barbara J., Hiday, Virginia A., and Randy Borum. "Can Involuntary Outpatient Commitment Reduce Hospital Recidivism?: Findings from a Randomized Trial With Severely Mentally Ill Individuals." *American Journal of Psychiatry* 156: 1968–1975.

⁶Zanni, Guido and Paul F. Stavis. 2007. "The Effectiveness and Ethical Justification of Psychiatric Outpatient Commitment." *American Journal of Bioethics* 7: 31–41.

from 64 to 37 days per patient over 18 months, a 43 percent decrease. The savings in hospital costs averaged \$14,463 per patient.⁷

AOT Reduces Arrests and Incarceration

A study of Kendra's Law published in 2010 concluded that the "odds of arrest in any given month for participants who were currently receiving AOT were nearly two-thirds lower" than those not receiving AOT.⁸ According to a 2005 New York State Office of Mental Health report on Kendra's Law, arrests for AOT participants were reduced by 83 percent, from 30 percent prior to the onset of a court order to only 5 percent after participating in the program.⁹

A Florida report found AOT reduced days spent in jail among participants from 16.1 to 4.5 days, a 72 percent reduction.¹⁰ Similarly, the Duke Study found that, for individuals who had a history of multiple hospital admissions combined with arrests and/or violence in the prior year, long-term AOT reduced the risk of arrest by 74 percent. The arrest rate for participants in long-term AOT was 12 percent, compared with 47 percent for those who had services without a court order.¹¹

AOT Reduces Violence, Crime, and Victimization.

The New York State Office of Mental Health report also found that Kendra's Law resulted in dramatic reductions in harmful behaviors for AOT. Among AOT recipients at 6 months of assisted outpatient treatment compared to a similar period of time prior to the court order: 55 percent fewer recipients engaged in suicide attempts or physical harm to self; 47 percent fewer physically harmed others; 46 percent fewer damaged or destroyed property; and 43 percent fewer threatened physical harm to others. Overall, the average decrease in harmful behaviors was 44 percent.¹²

A 2010 study by Columbia University's Mailman School of Public Health reached equally striking findings about the impact of Kendra's Law on the incidence of violent criminal behavior. When AOT recipients in New York City and a control group of other mentally ill outpatients were tracked and compared, the AOT patients—despite having more violent histories—were found four times less likely to perpetrate serious violence after undergoing treatment.¹³

The Duke Study found that long-term AOT combined with intensive routine outpatient services was significantly more effective in reducing violence and improving outcomes for severely mentally ill individuals than the same level of outpatient care without a court order. Among a group of individuals characterized as "seriously violent," 63.3 percent of those not in long-term AOT repeated violent acts, while only 37.5 percent of those in long-term AOT did so. Long-term AOT combined with routine outpatient services reduced the predicted probability of violence by 50 percent.¹⁴

The Duke Study further demonstrated that individuals with severe psychiatric illnesses who were not on AOT "were almost twice as likely to be victimized as were outpatient commitment subjects." 24 percent of those on AOT were victimized, compared with 42 percent of those not on AOT.¹⁵

⁷ Esposito, Rosanna, Westhead, Valerie, and Jim Berko. 2008. "Florida's Outpatient Commitment Law: Effective but Underused" (letter). *Psychiatric Services* 59: 328.

⁸ Gilbert, Allison R., Moser, Lorna L., Van Dorn, Richard A., Swanson, Jeffrey W., Wilder, Christine M., Robbins, Pamela Clark, Keator, Karli J., Steadman, Henry J., and Marvin S. Swartz. 2010. "Reductions in Arrest Under Assisted Outpatient Treatment in New York." *Psychiatric Services* 61: 996–999.

⁹ New York State Office of Mental Health. 2005. *Kendra's Law: Final Report on the Status of Assisted Outpatient Treatment*.

¹⁰ Esposito, Rosanna, Westhead, Valerie, and Jim Berko. 2008. "Florida's Outpatient Commitment Law: Effective but Underused" (letter). *Psychiatric Services* 59: 328.

¹¹ Swanson, Jeffrey W., Borum, Randy, Swartz, Marvin S., Hiday, Virginia A., Wagner, H. Ryan, and Barbara J. Burns. 2001a. "Can Involuntary Outpatient Commitment Reduce Arrests Among Persons with Severe Mental Illness?" *Criminal Justice and Behavior* 28: 156–189.

¹² New York State Office of Mental Health. 2005. *Kendra's Law: Final Report on the Status of Assisted Outpatient Treatment*.

¹³ Phelan, Jo C., Sinkewicz, Marilyn, Castille, Dorothy, Huz, Steven, and Bruce G. Link. 2010. "Effectiveness and Outcome of Assisted Outpatient Treatment in New York State." *Psychiatric Services* 61: 137–143.

¹⁴ Swanson, Jeffrey W., Swartz, Marvin S., Borum, Randy, Hiday, Virginia A., Wagner, H. Ryan, and Barbara J. Burns. 2001. "Involuntary Outpatient Commitment and Reduction of Violent Behaviour in Persons with Severe Mental Illness." *British Journal of Psychiatry* 176: 224–231.

¹⁵ Hiday, Virginia A., Swartz, Marvin S., Swanson, Jeffrey W., Borum, Randy, and H. Ryan Wagner. 2002. "Impact of Outpatient Commitment on Victimization of People with Severe Mental Illness." *American Journal of Psychiatry* 159: 1403–1411.

AOT Improves Treatment Compliance

AOT has also been shown to be effective in increasing treatment compliance. In New York, AOT led to a 51 percent increase in recipients' exhibition of good service engagement, and more than doubled the exhibition of "good" adherence to medication.¹⁶

In North Carolina, only 30 percent of AOT patients refused medication during a 6-month period, compared to 66 percent of patients not under AOT.¹⁷ In Ohio, AOT increased attendance to outpatient psychiatric appointments from 5.7 to 13.0 per year; it also increased attendance at day treatment sessions from 23 to 60 per year.¹⁸

AOT also promotes long-term voluntary treatment compliance. In Arizona, "71 percent [of AOT patients] . . . voluntarily maintained treatment contacts 6 months after their orders expired" compared with "almost no patients" who were not court-ordered to outpatient treatment.¹⁹ In Iowa, "it appears as though outpatient commitment promotes treatment compliance in about 80 percent of patients while they are on outpatient commitment. After commitment is terminated, about three-quarters of that group remained in treatment on a voluntary basis."²⁰

The New York Independent Evaluation also yielded interesting findings on the likelihood of voluntary compliance after AOT is allowed to expire. For individuals who received AOT for periods of 6 months or less, the researchers found that post-AOT sustainability of improvements in medication adherence depended on whether intensive outpatient services were continued on a voluntary basis. Those who continued with intensive services maintained their substantial increase in medication adherence relative to the pre-AOT period (from 37 to 45 percent); those who discontinued such assistance dropped back to near the pre-AOT levels (33 percent). Patients who received AOT for more than 6 months, however, experienced increased medication adherence whether or not intensive services were continued. The medication adherence rate was higher for those who continued intensive services than for those who did not (50 percent vs. 43 percent), but both groups maintained substantial improvements from the pre-AOT rate (37 percent).²¹

The Treatment Advocacy Center reemphasizes its support for full funding of the AOT Grant Program at \$15,000,000 for each of the fiscal years 2015 through 2018. Should you have any questions, please feel free to contact John Snook, Deputy Executive Director, Treatment Advocacy Center at (703) 294-6006 or snookj@treatmentadvocacycenter.org.

PREPARED STATEMENT OF THE TREVOR PROJECT

Dear Chairman Harkin and Senator Moran: The Trevor Project appreciates the opportunity to submit a statement on the critical and timely issue of funding for children's suicide prevention and mental health initiatives. We encourage you to support our Nation's most vulnerable youth by funding these vital programs:

(Dollars in millions)

Program	Fiscal year 2014 enacted	President's proposed fiscal year 2015 budget	Fiscal year 2015 trevor project recommendation
SAMHSA—Suicide Prevention Programs	51	40.1	61
HHS/ACF—Runaway and Homeless Youth Act Fund- ing	114.1	114	152.5
NIMH—Suicide Prevention Research			40

¹⁶ New York State Office of Mental Health. 2005. *Kendra's Law: Final Report on the Status of Assisted Outpatient Treatment*.

¹⁷ Hiday, Virginia A. and Teresa L. Scheid-Cook. 1987. "The North Carolina Experience with Outpatient Commitment: A Critical Appraisal." *International Journal of Law and Psychiatry* 10: 215–232.

¹⁸ Munetz, Mark R., Grande, Thomas, Kleist, Jeffrey, and Gregory A. Peterson. 1996. "The Effectiveness of Outpatient Civil Commitment." *Psychiatric Services* 47: 1251–1253.

¹⁹ Van Putten, Robert A., Santiago, Jose M., and Michael R. Berren. 1988. "Involuntary Outpatient Commitment in Arizona: A Retrospective Study." *Hospital and Community Psychiatry* 39: 953–958.

²⁰ Rohland, Barbara M. 1998. *The Role of Outpatient Commitment in the Management of Persons with Schizophrenia*. Iowa City: Iowa Consortium for Mental Health, Services, Training, and Research.

²¹ Swartz, Marvin S., Swanson, Jeffrey W., Steadman, Henry J., Robbins, Pamela Clark, and John Monahan. 2009. *New York State Assisted Outpatient Treatment Program Evaluation*. Duke University School of Medicine.

[Dollars in millions]

Program	Fiscal year 2014 enacted	President's proposed fiscal year 2015 budget	Fiscal year 2015 trevor project recommendation
CDC—National Violent Death Reporting System	11.3	23.5	25
SAMHSA Project AWARE	55	55	60

The Trevor Project is the leading national organization providing crisis intervention and suicide prevention services to lesbian, gay, bisexual, transgender and questioning (LGBTQ) young people under 24. Among young people ages 10 to 24, suicide is the second leading cause of death.¹ According to the National Survey of Children's Health, up to 20 percent of young people have a diagnosable mental illness, but only 60 percent of those in need of mental healthcare receive the treatment they require.² In fact, half of all individuals with mental illness experience onset of the disorder by age 14, but do not seek treatment, on average, until the age of 24.³ For youth, the consequences of untreated mental illness vary and include increased suicide risk, school failure, involvement in the criminal justice system, unemployment, substance abuse, and homelessness. Among stigmatized populations such as LGBTQ young people, these negative outcomes can be exacerbated by prejudice, fear, and hate experienced in homes, schools, and communities.

Suicidality is closely associated with mental illness; more than 90 percent of those who die by suicide have a diagnosable mental disorder.⁴ Therefore suicide prevention is an essential component of a comprehensive mental health system.

We thank the Committee for your ongoing support for suicide prevention and mental health initiatives, and we hope that this letter will identify the critical programs that exist to protect our most vulnerable youth.

The Trevor Project recommends the following fiscal year 2015 appropriations to improve access to effective mental healthcare and reduce suicide risk for young people:

GARRETT LEE SMITH MEMORIAL ACT SUICIDE PREVENTION PROGRAMS (SAMHSA)

The Garrett Lee Smith Memorial Act provides the largest dedicated source of Federal funding for youth suicide prevention efforts, which are a life-saving and effective means to address the daunting issue of youth suicide. We can help avoid tragedy by appropriately funding programs that focus on extreme harming behaviors and mental illness in young people. To date, Garrett Lee Smith funding has supported suicide prevention programs in 49 States, 48 tribes, and 138 colleges. Fully appropriating these programs would ensure that the Suicide Prevention Resource Center continues to provide technical assistance to organizations nationwide; and it would allow for the expansion of State, tribal, and campus grants. Also encompassed within our funding recommendations for these programs is the National Strategy for Suicide Prevention, which works towards a unified approach to suicide prevention through collaboration between public and private sectors; and the National Suicide Prevention Lifeline, which answers more than 94,000 calls a month, including calls from veterans, active duty members and their families, as well as the general public.

¹Centers for Disease Control and Prevention, National Center for Injury Prevention and Control, Web-based Injury Statistics Query and Reporting System (WISQARS), available at <http://www.cdc.gov/ncipc/wisqars> (last visited Mar. 14, 2013).

²2007 National Survey of Children's Health, Data Resource Center for Child & Adolescent Health, Child and Adolescent Health Measurement Initiative, <http://www.nschdata.org> (last visited May 2009).

³Ronald C. Kessler et al., Lifetime Prevalence and Age-of-Onset Distributions of DSM-IV Disorders in the National Co-morbidity Survey Replication (NCSR), 62 GENERAL PSYCHIATRY 593 (2005); and Philip S. Wang et al., Failure and Delay in Initial Treatment Contact After First Onset of Mental Disorders in the National Co-morbidity Survey Replication (NCS-R), 62 GENERAL PSYCHIATRY 603 (2005).

⁴Suicide in the U.S.: Statistics and Prevention, National Institute of Mental Health, available at <http://www.nimh.nih.gov/health/publications/suicide-in-the-us-statistics-and-prevention/index.shtml#Moscicki-Epi> (last visited Mar. 14, 2013).

RUNAWAY AND HOMELESS YOUTH ACT (HEALTH AND HUMAN SERVICES)

An estimated 40 percent of all homeless youth are LGBTQ-identified, often because they are thrown out of their homes or face family rejection.⁵ Nearly 2/3 of these young people are likely to attempt suicide at least once.⁶

HUDs last Point in Time Count counted over 46,000 homeless youth, but less than 5,000 beds. Less than 10 percent of our homeless youth are receiving services, but funding for the RHYA has not significantly increased since 2008, despite a growing population desperately in need of the services provided by this Act. In order to meet the Administration's goal of ending youth homelessness by 2020, funding for runaway and homeless youth services needs to significantly increase. Through the RHYA, Congress ensures funding for community outreach programs, transitional housing and support services, and counseling and reunification guidance for families to be reconnected. Congress should appropriate \$152.5 million to help keep our vulnerable youth safe and healthy as part of a nationwide commitment to ending youth homelessness by 2020.

SUICIDE PREVENTION RESEARCH (NIMH)

There is a strong correlation between research funding and morbidity rates associated with diseases and disorders. Between 2009 and 2012, \$165 million has been spent on suicide prevention research, and yet in the last decade, suicide rates have increased by 31 percent. Conversely, over 5 billion dollars has been spent on heart disease research, and rates in the past decade have decreased by 16 percent.

We encourage you to include an additional \$40 million for the National Institute of Mental Health to conduct suicide prevention and brain research, a recommendation that reflects current legislation in the Senate and House (S. 2305/H.R. 7045), the Suicide Prevention Research INnovaTion Act (the SPRINT Act). The SPRINT Act aims to reduce the risk of self-harm, suicide, and interpersonal violence, especially in rural communities with a shortage of mental health services.

PROJECT AWARE—(SAMHSA)

The President's Now is the Time plan is an important step forward to effectively address school safety and youth mental health. These programs must be adequately funded in order to fulfill the promise of making our schools and communities safe for all young people. Through piloting Mental Health First Aid training with \$20 million, Project AWARE would support innovative, State-based strategies for improving mental health training and responsiveness to mental health emergencies; and would be particularly effective in rural communities, where community mental health services are less frequently available. Additionally, through \$40 million in State grants, Project AWARE would put more trained teachers and mental health professionals on the ground; help school districts make sure students get the referrals they need; and would underscore the importance of prevention by offering students mental health services for trauma or anxiety, conflict resolution programs, and other school-based violence prevention strategies.

NATIONAL VIOLENT DEATH REPORTING SYSTEM (NVRDS) (CDC)

The NVDRS serves as a clearinghouse for the details and circumstances surrounding suicides completed in the jurisdictions in which it operates. This valuable information informs suicide prevention and crisis intervention efforts, but it is currently only collected in 18 States. Proposals to expand this system have received broad bipartisan support, and the NVDRS expansion was included in the Mental Health Awareness and Improvement Act (S. 689), which passed nearly unanimously in the Senate as an amendment to S. 649. Fully funding the NVRDS with \$25 million would allow nationwide collection of this data to further public health research on suicide prevention.

Conclusion

We thank the Committee for taking the time to fully assess our Nation's mental healthcare system, and we appreciate the opportunity to provide a written statement. We strongly support efforts to increase access to suicide prevention and men-

⁵Durso, L. E. & Gates, G. J. (2012). Serving our youth: Findings from a national survey of service providers working with lesbian, gay, bisexual, and transgender youth who are homeless or at risk of becoming homeless. Los Angeles, CA: The Williams Institute with True Colors Fund and The Palette Fund.

⁶Van Leeuwen, J. M., Boyle, S., Salomonsen-Sautel, S., Baker, D. N., Garcia, J. T., Hoffman, A. & Hopfer, C. J. (2006). Lesbian, gay, bisexual homeless youth: An eight-city public health perspective. *Child Welfare* 85(2), 151–170.

tal healthcare for young people, and we urge the Committee to fully fund these critical programs.

[This statement was submitted by Abbe Land, Executive Director & CEO, Trevor Project.]

PREPARED STATEMENT OF THE TRI-COUNCIL FOR NURSING

The Tri-Council for Nursing, comprising the American Association of Colleges of Nursing (AACN), the American Nurses Association, the American Organization of Nurse Executives, and the National League for Nursing, respectfully requests \$251 million for the Nursing Workforce Development programs authorized under Title VIII of the Public Health Service Act (42 U.S.C. 296 et seq.) and administered by the Health Resources and Services Administration in fiscal year 2015.

The Tri-Council is a long-standing nursing alliance focused on leadership and excellence in the nursing profession. The members of these respective organizations are acutely aware of the demand for nursing services due to a growing aging population, an increased focus on preventative care, and skyrocketing rates of individuals with multiple chronic conditions. In fact, according to the U.S. Bureau of Labor Statistics (BLS) Employment Projections for 2012–2022, the profession of registered nurses (RN) will grow by 19 percent for the 10-year timeframe between 2012 and 2022. The number of job openings due to both the increasing demand for nursing services and the large number of retiring RNs, brings the total of RNs needed to 1.053 million by 2022. A 2013 HRSA report, *The U.S. Nursing Workforce: Trends in Supply and Education*, indicates that over the next 10 to 15 years, the nearly one million RNs over age 50 (comprising approximately one-third of the current workforce), will reach retirement age.

Moreover, the acute nurse faculty shortage is one significant reason why schools of nursing across the country turn away tens of thousands of qualified applications each year. The demand for nurses and the faculty who educate them is a serious impediment to improving the Nation's healthcare needs. Nurses continue to be the largest group of healthcare providers whose services are directly linked to quality and cost-effectiveness. The Tri-Council is grateful to the Subcommittee for your past commitment to Title VIII funding and respectfully asks that you continue to make the long-term investment that will build the nursing workforce necessary to deliver the quality, affordable care envisioned in health reform.

A Proven Solution: Nursing Workforce Development Programs

The Nursing Workforce Development programs, authorized under Title VIII of the Public Health Service Act, have helped build the supply and distribution of qualified nurses to meet our Nation's healthcare needs since 1964. Over these past 50 years, the original programs, newly added, and expanded programs have addressed all aspects of supporting the workforce—education, practice, retention, and recruitment. They have bolstered nursing education at all levels—from entry-level preparation through graduate study—and have provided support for institutions that educate nurses who practice in rural and medically underserved communities. A description of the Title VIII programs and their impact are included below.

Advanced Nursing Education (ANE) Programs (Sec. 811) fund a number of grant activities—including several traineeships—that aim to increase the size and quality of the advanced nursing workforce. Supporting the preparation of RNs in master's and doctoral nursing programs, the ANE grants help prepare our Nation's nurse practitioners, clinical nurse specialists, nurse midwives, nurse anesthetists, nurse educators, nurse administrators, nurses in executive practice, public health nurses, and other nursing specialists requiring advanced nursing education. In fiscal year 2012, these grants supported the education of 15,986 students. Under the ANE program are two critical traineeship programs that are particularly relevant as the demand for primary and acute care services rise.

Advanced Education Nursing (AEN) Traineeships assist graduate nursing students by providing full or partial reimbursement for the costs of tuition, books, program fees, and reasonable living expenses. Funding for the AEN Traineeships supports the education of future nurse practitioners, clinical nurse specialists, nurse midwives, nurse anesthetists, nurse educators, nurse administrators, public health nurses, and other nurse specialists requiring advanced education.

Nurse Anesthetist Traineeships (NAT) support the education of students in nurse anesthetist programs. In some States, certified registered nurse anesthetists are the sole anesthesia providers in almost 100 percent of rural hospitals.

In fiscal year 2012, the AEN Traineeship and the NAT supported 5,545 nursing students.

Nursing Workforce Diversity (NWD) Grants (Sec. 821) prepare students from disadvantaged backgrounds to become nurses, producing a more diverse nursing workforce. This outcome will help meet the increasing need for culturally aligned, quality healthcare for the Nation's rapidly diversifying population and help close the gap in health disparities. This program awards grants and contract opportunities to schools of nursing for a variety of clinical training facilities to address nursing educational needs, not only for disadvantaged students, but also for racial and ethnic minorities underrepresented in the nursing profession. In fiscal year 2012, the program supported 12,077 students.

Nurse Education, Practice, Quality and Retention (NEPQR) Grants (Sec. 831) help schools of nursing, academic health centers, nurse-managed health clinics, as well as State and local governments strengthen nursing education programs, thereby increasing the size and quality of the nursing workforce. The purposes of the NEPQR grants are broad and flexible, allowing the program to address emerging needs in nursing workforce development. For example, projects have been funded to develop and disseminate collaborative practice models that incorporate the full range of healthcare workers in team-based care are of certain interest. NEPQR supports infrastructure development to enhance the coordination and capacity building of inter-professional practice and education among health professions across the United States, and particularly in medically underserved areas.

For other interests, a number of grant activities have been funded to support several legislative purposes such as expanding the size of academic programs that are able to confer a baccalaureate degree of science in nursing (BSN); recruiting and educating individuals as qualified personal and home care aides in occupational shortage and/or high demand areas; training qualified nursing assistants and home health aides to meet the growing healthcare needs of the aging population; and/or supporting nurse-managed health clinics that serve as primary care access points in areas where primary care providers are in short supply.

NURSE Corps (formerly known as the Nursing Education Loan Repayment and Scholarship Program) (Sec. 846) provides monies to students by paying up to 85 percent of a student's loan in return for at least 3 years of service in a designated health shortage area or in an accredited school of nursing. The NURSE Corps Loan Repayment Program (LRP) is a financial incentive program under which individual RNs and advanced practice registered nurses enter into a contractual agreement with the Federal Government to work full-time in a healthcare facility with a critical shortage of nurses, in return for repayment of qualifying nursing educational loans. In fiscal year 2013, the Nursing Education Loan Repayment Program supported 1,446 nurses working in these facilities. However, given the current climate, the HRSA 2015 Congressional Budget Justification anticipates that they will only be able to support 1,296 in fiscal year 2014.

Nurse Faculty Loan Program (NFLP) (Sec. 846 A) increases the number of qualified nurse faculty by creating a student loan fund within individual schools of nursing. Students 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 4-year period. In fiscal year 2012, these grants supported the education of 2,259 future nurse educators.

Comprehensive Geriatric Education Program (CGEP) Grants (Sec. 855) provide support to nursing students specializing in care for the elderly. These grants may be used to educate RNs who will provide direct care to older Americans, develop and disseminate geriatric curriculum, prepare faculty members, and provide continuing education. They may also fund traineeships for individuals who are preparing for advanced education nursing degrees in geriatric nursing, long-term care, geropsychiatric nursing or other nursing areas that specialize in the care of the elderly population. In fiscal year 2012, there were 11,600 trainees supported by these grants.

Our Nation is faced with a growing healthcare crisis that must be addressed on many fronts. Nurses are an important part of the solution to the crisis of cost, burden of disease, and access to quality care. To meet this challenge, funding of proven Federal programs such as Title VIII will help ease the demand for RNs. The Tri-Council respectfully requests your support for \$251 million for the Title VIII Nursing Workforce Development Programs in fiscal year 2015. If our organizations can be of assistance, please contact AACN's Director of Government Affairs and Health Policy, Dr. Suzanne Miyamoto, at Smiyamoto@aacn.nche.edu.

Sincerely,

Eileen Breslin, PhD, RN, FAAN, President, Geraldine “Polly” Bednash, PhD, RN, FAAN, Chief Executive Officer, American Association of Colleges of Nursing; Linda Knodel, MHA, MSN, RN, NE-BC CPHQ, FACHE, President, Pamela A. Thompson, MS, RN, CENP, FAAN, Chief Executive Officer and Sr. Vice President, American Organization of Nurse Executives; Karen Daley, PhD, MPH, RN, FAAN, President, Marla J. Weston, PhD, RN, FAAN, Chief Executive Officer, American Nurses Association, Marsha Howell Adams, PhD, RN, CNE, ANEF, President, Beverly Malone, PhD, RN, FAAN, Chief Executive Officer, National League for Nursing.

PREPARED STATEMENT OF THE TRUST FOR AMERICA’S HEALTH

Trust for America’s Health (TFAH), a nonprofit, nonpartisan organization dedicated to saving lives by working to make disease prevention a national priority, is pleased for this opportunity to provide written testimony on the State of public health funding. As this subcommittee works to develop a fiscal year 2015 Labor, Health & Human Services, Education and Related Agencies (LHHS) appropriations bill, I urge you to ensure adequate funding for public health prevention and preparedness programs at the Centers for Disease Control and Prevention (CDC) and other public health agencies.

After several years of cuts, Congress included a significant increase to CDC in the fiscal year 2014 Consolidated Appropriations Act, and we thank you for recognizing the importance of public health. Eighty-five percent of the CDC’s annual budget flows to your States and districts in the form of grants and contracts to State and local public health departments, and community partners, to conduct critical public health and prevention activities that every American relies on, such as protecting us from infectious disease by combating healthcare-associated infections, delivering immunizations, ensuring preparedness, and conducting nonstop surveillance.

The CDC and its grantees across the country are working to help give Americans the information they need to adopt the healthy lifestyles that will reduce the chronic disease burden on our healthcare system. In 2012, we spent roughly 75 percent of our Nation’s annual \$2.8 trillion healthcare bill on treating preventable chronic diseases. Long-term healthcare spending at these levels is unsustainable for our economy and our Federal budget.

There is a growing evidence base that demonstrates that the majority of chronic disease is preventable by addressing common risk factors. We have begun to see signs of success, with childhood obesity rates declining in cities and States that were among the first to adopt a comprehensive approach to obesity prevention. We must bring that knowledge to scale, so that Americans across the country have the opportunity to lead healthier lives. We were pleased that last year Congress made important new investments in community prevention that will help continue our efforts to transform our healthcare system to one that values prevention and wellness, and we urge the Committee to build on those investments in the fiscal year 2015 bill.

The recently released Robert Wood Johnson Foundation 2014 County Health Rankings serve as another sobering reminder that an American’s zip code is a strong predictor of whether or not they have the opportunity to lead a healthy life. Meeting these twin challenges of protecting the American people from natural and man-made threats and preventing disease can only occur with continued support for CDC.

Centers for Disease Control and Prevention (CDC)

From fiscal year 2010 to 2013, the CDC saw its budget authority cut by 18 percent. We were pleased that the fiscal year 2014 Omnibus Appropriations measure provided CDC with an increase of more than \$550 million, including \$373 million from the Prevention and Public Health Fund, resulting in a nearly \$175 million increase for chronic disease programs. For perspective, however, that increase simply brought CDC funding back to fiscal year 2013 levels. Scarce resources means CDC will be forced to make extremely difficult, sometimes life and death choices. We urge the Committee to maintain adequate CDC funding levels in fiscal year 2015.

The Prevention and Public Health Fund (PPHF)

TFAH was pleased to see Congress exercise its authority to allocate the Prevention and Public Health Fund in fiscal year 2014, and we urge this committee to do so again in the fiscal year 2015 appropriations bill. To date, the Fund had made investments in every State to support State and local efforts to transform and revitalize communities, build epidemiology and laboratory capacity to track and respond to disease outbreaks, address healthcare associated infections, train the Nation’s

public health and health workforce, prevent the spread of HIV, expand access to vaccines, reduce tobacco use, and help control the obesity epidemic.

National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP)

Our Nation's doctors and hospitals are our trusted front line when illness appears, but we must continue to engage not only health systems but sectors such as education, housing, business and planning to transform communities to make the healthy choice the easy choice and prevent illness in the first place. The Chronic Disease Center has made progress in moving away from the traditional categorical approach to funding disease prevention and toward more coordinated, cross-cutting strategies. While we were disappointed at the premature termination of the Community Transformation Grants program, TFAH appreciates the new investments in community prevention made in fiscal year 2014. We hope the Committee restores funding for the Chronic Disease Center to fiscal year 2010 levels (\$1.167 billion), building upon fiscal year 2014 investments in diabetes, heart disease and stroke, the Partnerships to Improve Community Health initiative, the Racial and Ethnic Approaches to Community Health program and the Preventive Health and Health Services Block Grant program. For the block grant, TFAH calls upon the Committee to promote its use to modernize our public health system by supporting health department accreditation and other efforts to ensure the Nation's health departments can deliver foundational public health capabilities to all Americans.

National Center for Environmental Health (NCEH)

Critical programs conducted at the CDC National Center for Environmental Health support our chronic disease prevention and public health preparedness efforts. Yet it remains one of the most critically underfunded parts of CDC. We recommend that you fund NCEH at fiscal year 2010 levels (\$181.004 million) in fiscal year 2015 to continue to rebuild the lead control program, grow our National Environmental Public Health Tracking Network, and pursue other priorities.

Public Health Emergency Preparedness Grants

The Public Health Emergency Preparedness (PHEP) Grants, administered by CDC, is the only Federal program that supports the work of health departments to prepare for all types of disasters, including bioterror attacks, natural disasters, and infectious disease outbreaks. The grants fund nearly 4,000 State and local public health staff positions, and support 15 core capabilities including public health laboratory testing, surveillance and epidemiology, community resilience, countermeasures and mitigation, and more. These funds are used for everyday preparedness activities, such as monitoring public health threats, and have been integral in expanding to respond to full-scale disasters such as Hurricane Sandy, the fungal meningitis outbreak, and the West Nile Virus outbreak in Texas. TFAH recommends \$670 million for the Public Health Emergency Preparedness Cooperative Agreements in fiscal year 2015 to help States and localities restore some of the core capabilities lost due to significant cuts to the program.

Hospital Preparedness Program

The Hospital Preparedness Program (HPP), administered by the Assistant Secretary for Preparedness and Response (ASPR), provides funding and technical assistance to prepare the health system to respond to and recover from a disaster. The program, which began in response to 9/11, has evolved from one focused on equipment and supplies held by individual hospitals in response to a terrorist event, to a system-wide, all-hazards approach. The new HPP is building the capacity of healthcare coalitions—regional collaborations between healthcare organizations, providers, emergency managers, public sector agencies, and other private partners—to meet the disaster healthcare needs of communities. Through the coalition planning process, facilities are learning to leverage resources, such as developing interoperable communications systems, tracking beds, and writing contracts to share assets.

HPP helped a prepared healthcare system save lives during recent events, including the Boston Marathon bombings and tornadoes in Kentucky and Joplin, MO. HPP appropriations have decreased from \$426 million in fiscal year 10 to \$255 million in fiscal year 2014, including a one third cut in the fiscal year 2014 omnibus. TFAH recommends \$300 million for fiscal year 2015 for HPP, an incremental step to rebuild the program. The significant reduction in fiscal year 14 will likely result in fewer staff, fewer coalitions and less of the Nation prepared for disasters.

Combatting Prescription Drug Abuse

Prescription drug abuse is a growing public health crisis. Overdose deaths involving prescription painkillers have quadrupled since 1999 and now outnumber deaths from all illicit drugs, including heroin and cocaine, combined. This is a multi-faceted

problem, and the CDC, SAMHSA, NIH and a range of other agencies have a role to play in finding a solution. TFAH recommends a \$15.6 million increase to the CDC Injury Center's Injury Prevention Activities line to enable the CDC to work with additional States with a high burden of prescription drug abuse to help address the main drivers of the epidemic of prescription drug overdoses, and also urge you to provide the funding to ensure that patients with prescription drug addiction have access to the treatment they need to turn their lives around.

Conclusion

Investing in disease prevention is the most effective, common-sense way to improve health and address our long-term deficit. Hundreds of billions of dollars are spent each year to pay for healthcare services once patients develop an acute illness, injury, or chronic disease. A sustained investment in public health and prevention is essential to reduce high rates of disease and improve health in the United States.

[This statement was submitted by Jeffrey Levi, Executive Director, Trust for America's Health.]

PREPARED STATEMENT OF REBECCA UNDERWOOD, PARENT/GUARDIAN/ADVOCATE

Thank you for this opportunity to provide outside witness testimony for the record to the Senate Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies. I strongly object to the use of United States Department of Health and Human Services (DHHS) appropriations to develop coercive and subversive methods of deinstitutionalization resulting in the eviction of the most vulnerable individuals with intellectual/developmental disabilities from DHHS Medicaid licensed and funded facilities including intermediate care facilities for individuals with intellectual disabilities (ICFs/IID). I submit this testimony as a request that Congress prohibit Federal funds be allocated to Federal programs which are currently using their public funds to achieve dangerous public policies of forced deinstitutionalization, resulting in the eviction of eligible individuals with severe, profound and extreme intellectual and developmental disabilities (I/DD) from their HHS-licensed and funded homes, without regard to individual choice.

I am the mother and co-guardian of an adult son, aged 34 who, as the result of brain and pulmonary hemorrhaging occurring during a premature birth, functions at the level of a 4–12 week old infant with chronic and complex medical issues. After providing his 24/7 care in our home for several years, we accepted the reality that our son would benefit from the extended care available in a highly specialized intermediate care facility for individuals with intellectual disabilities. Our son has benefitted tremendously from the highly specialized medical services provided in this setting as evidenced by his continued survival beyond any one's expectations.

Our parenting decisions, our son's continued residence in his current DHHS funded facility and receipt of the services uniquely suited to meet his extensive and complex physical and medical needs, which have proven beneficial for his survival, are under attack. A number of DHHS funded programs are targeting forced displacement of our most fragile constituency without regard to individual choice, need and safety.

Examples of how government dollars, through DHHS appropriations, are being misused in a cruel and absurd method by DHHS funded programs and policies to affect the downsizing and closure of DHSS licensed and funded facilities include:

—*Administration on Intellectual and Developmental Disabilities (AIDD)* administers programs and grants created under Public Law 106–402, Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act). The DD Act was last reauthorized in 2000. Authorizations for DD Act appropriations expired in 2007; however Congress continues to fund these programs. DD Act programs, including Protection and Advocacy (P&A) and DD Councils, operate in every State. AIDD, now under the umbrella of the Administration for Community Living within DHHS, administers the DD Act programs. In 2011 AIDD's (f/k/a ADD) proposed recommendations included "[d]evelop and implement plans to close public and private institutions". There have been no hearings or recourse for families to address concerns as to the way in which programs, including AIDD, use/misuse Federal funds. DHHS has been unresponsive to complaints from families of persons with severe, profound and extreme forms of developmental disabilities about AIDD policies. DHHS has turned a blind eye to the tragic, but predictable, results for many individuals when they are forced from their specialized, Medicaid certified and funded congregate care settings. Independent oversight of Federal AIDD and DD Act programs is desperately needed. How long will Congress and society continue to ignore the increasing rate of

tragic outcomes due to a misguided ideological agenda of forced deinstitutionalization of our most vulnerable citizens from their safe environments?

—*National Council on Disability (NCD)* is an independent Federal agency funded through DHHS appropriations. In October 2012 the NCD released a 110 page policy document and an accompanying 201 page “tool-kit” to assist opponents of congregate care to accomplish the closure of Medicaid-certified specialized homes of 4 or more beds in which individuals with severe and profound cognitive and other developmental disabilities receive supports and services. Families and guardians of these affected individuals are universally opposed to such closures and are united in their opposition to NCD’s misuse of their authority as an independent Federal agency and their Federal funding. NCD has been called upon by these families to reject their stance on forced deinstitutionalization. The NCD has thus far ignored, and failed to respond to, the request of these most important stakeholders. Despite extensive documentation of widespread abuse in community settings, along with a nationwide crisis of understaffed, underpaid, and poorly trained direct care workers resulting in tragic outcomes, the NCD continues pressing forward with their position that ALL individuals with intellectual/developmental disabilities, even those who experience profound and complex medical, physical and/or behavioral challenges, be forced from their safe homes if that safe home is 4 or more beds. As an “independent Federal agency charged with advising the President, Congress, and other Federal agencies regarding policies, programs, practices and procedures that affect people with disabilities” NCD should not be taking any position which tramples on the rights of a portion of the disability community.

—*DHHS Incentive grants (increase in FMAP funds) to encourage States to move away from providing institutional care.*

—Money Follows the Person is a Federal “reward” for cash strapped States to move away from providing institutional care. Money Follows the Person (MFP) grants provide increased FMAP (Federal Medical Assistance Percentage) funds to States as a reward for each institutionalized person in the target population who transitions to an eligible non-institutional setting. Money Follows the Person grants (\$4 Billion) have been acknowledged to disproportionately target individuals with developmental disabilities for transition.¹ MFP has also been acknowledged as a way for States to transition individuals “out the back door” of institutions while “closing the front door” to new admissions in an effort to close facilities.

—Balancing Incentive Program (BIP) is another Federal incentive in the amount of \$3 billion to cash strapped States to divert eligible individuals from institutional settings, disregarding choice and need.

Combined total of \$7 Billion in Federal funds through these Incentive grants, in addition to States’ regular Federal Medical Assistance Percentage (FMAP), to encourage States to abandon institutional settings. Federal funds should not be utilized to favor one service setting over another, particularly as clarified in the Supreme Court’s *Olmstead* ruling: “We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any Federal requirement that community-based treatment be imposed on patients who do not desire it.” *Olmstead*, 119 S. Ct. 2176, 2187 (1999) (majority).

It will be a travesty if the Federal Government is successful in pigeon-holing disability policy into a one-size-fits-all, eliminating choice, while continuing to ignore Supreme Court clarifications within *Olmstead* regarding the care of those with the most severe forms of developmental disabilities. We need an increasing array of viable options for services and supports for our most vulnerable, not less.

How long will Congress and society continue to ignore the increasing rate of tragic outcomes (abuse, neglect, unnecessary & preventable deaths) of a misguided ideological agenda of forced deinstitutionalization of our most vulnerable citizens from their safe environments?

In conclusion I call upon Congress to prohibit the Department of Health and Human Services’ use of appropriations for deinstitutionalization activities that result in the eviction of eligible individuals with intellectual and other developmental disabilities from DHHS licensed and funded facilities.

¹Audra T. Wenzlow and Debra J. Lipson, “Transitioning Medicaid Enrollees from Institutions to the Community: Number of People Eligible and Number of Transitions Targeted Under MFP”, Reports from the Field, Number 1, January 2009, Mathematica Policy Research, pg 6, <http://www.mathematica-mpr.com/publications/PDFs/health/MFPfieldrpt1.pdf> (accessed 20 March 2014).

PREPARED STATEMENT OF THE UNITED NEGRO COLLEGE FUND

Introduction

I am Dr. Beverly Daniel Tatum, President of Spelman College in Atlanta, Georgia. Founded in 1881, Spelman College is a global leader in the education of women of African descent and a Historically Black College. Since 2008 Spelman College has averaged a 6-year graduation rate of 77 percent—one of the highest of the 105 Historically Black Colleges and Universities and substantially above the national average of 59 percent.

Spelman College is one of the 37 private Historically Black Colleges and Universities (HBCUs) that are members of the United Negro College Fund (UNCF), which I am representing. UNCF is the Nation's largest higher education organization serving students of color, perhaps best known by the iconic motto—"A mind is a terrible thing to waste®."

In its 70-year history, UNCF has raised more than \$4 billion in scholarship aid to help more than 400,000 students of color attend HBCUs and 900 other colleges and universities across the country to obtain the education they need to excel in the 21st century economy. UNCF's largest scholarship is the Gates Millennium Scholarship offered to high-achieving, low-income African American, American Indian/Alaska Native, Asian Pacific Islander and Hispanic American students. UNCF has awarded \$179 million in Gates Millennium Scholarships to help 3,200 students from the States the Labor-Health and Human Services Education Subcommittee represents earn college degrees.

HBCU Value Proposition

UNCF's core mission, however, remains its partnership with the Nation's 37 private HBCUs. The money raised by UNCF has become even more important today as HBCUs have suffered from a "perfect storm" of Federal disinvestments since 2011. Limitations on Pell Grant eligibility requirements, sequestration cuts to the Title III HBCU Program and Parent PLUS Loan reductions have resulted in a loss of more than \$250 million in Federal support. Despite these challenges, HBCUs provide enormous value for students and the Nation. HBCUs represent approximately 4 percent of all 4-year colleges and universities; enroll 9 percent of all African American college students; confer 16 percent of bachelor's degrees awarded to African Americans; and generate 27 percent of the STEM bachelor's degrees awarded to African Americans. Moreover, HBCUs accomplish this while serving students with greater need: more than 70 percent of students who attend HBCUs are low-income students who depend on Federal Pell Grants for their education, a substantially greater share than the 43 percent of students at all other 4-year colleges and universities. At the same time, total cost of attendance at HBCUs is 30 percent lower, on average, than other 4-year institutions.

Fiscal year 2014 Appropriations

I would like to thank the Subcommittee and, in particular, Chairman Harkin and Ranking Member Moran for playing leadership roles in restoring some of the vital Federal resources to HBCUs and the students we serve in the fiscal year 2014 budget. UNCF appreciates you providing a maximum Pell award of \$5,730, restoring sequestration cuts to other student aid programs, and restoring two-thirds of the sequestration cuts to the Title III HBCU Program.

Fiscal year 2015 Appropriations Priorities

Looking to fiscal year 2015, a national strategy to produce more college graduates, boost our economy and enhance global competitiveness must include greater investment in HBCUs. On behalf of the UNCF institutions and all HBCUs, I urge the Subcommittee to support our highest priority programs listed below:

- I urge you to appropriate \$267 million in discretionary dollars and \$85 million in mandatory dollars for the Title III, Part B—Strengthening Historically Black Colleges and Universities Program. These are formula funds awarded to HBCUs for operational support and essential academic services. Let me note that during the 2007–2012 grant cycle, Spelman College received and expended more than \$11 million in Title III funding. Spelman has enhanced its campus infrastructure to include upgrades in technology to facilities, classrooms, labs and centers. Title III assisted with the establishment of the SpelBots (Spelman's Robotic Team) a winning robotics initiative. Additional examples of the achievements that critical Title III funding has supported at Spelman are included as an attachment to my testimony. Please reinvest in this program and restore the \$43 million cut from the program since fiscal year 2010.
- The HBCU Capital Financing Program finances low-risk Federal loans to help HBCUs, especially private institutions, improve facilities, infrastructure and

technology. Investing in capital projects not only enhances the educational environment for students but also reinvigorates our communities and provides much needed jobs. I urge you to increase the appropriation for loan subsidies to \$25 million, which would leverage \$390 million in annual loans to meet the infrastructure needs of our institutions.

- Without Pell Grants, most HBCU students could not pay for the college education that is essential in today's economy. I urge you to fund a \$5,830 maximum Pell award to help our students persist and complete college. In addition, I encourage you to reinstate "summer" Pell Grants so students can earn their college degrees faster and at a lower cost.
- UNCF also strongly supports the President's fiscal year 2015 request of \$75 Million for College Success Grants for Minority-Serving Institutions. These competitive grants would help Minority-Serving Institutions launch new innovations and best practices to improve student outcomes. I urge you to fully fund this important initiative.
- I urge you to approve the proposed College Opportunity and Graduation Bonuses, which would reward institutions that enroll and graduate large numbers of low-income students. UNCF recommends that this proposal be amended to take into consideration both the numbers and percentages of low-income students graduating from institutions, given that some HBCUs have smaller enrollments.
- Finally, I urge you to restore the Health Professions Training for Diversity programs to fiscal year 2012 levels and ask that you expand the National Institute on Minority Health and Health Disparities to \$283 million to improve diversity in the workforce and research funding for minority populations.

Chairman Harkin and Ranking Member Moran and members of this Subcommittee—you have the power to increase Federal resources for operating support, student assistance, best practices and innovations so that HBCUs can thrive in years to come. Or, you can adhere to the status quo and allow our institutions to merely survive.

UNCF does not accept the status quo. We are accelerating our fundraising efforts, investing in capacity building at our member institutions, building new partnerships and leveraging our resources to enhance educational opportunities for minority students. In fact, UNCF has updated its motto to recognize education is an investment in better futures for everyone. We believe that, "A mind is a terrible thing to waste, but a wonderful thing to invest in." Please help us invest in our youth, in our HBCUs, and most importantly, in our country so that millions more low-income, minority students can graduate from college and lead our country to heights we have yet to imagine. Thank you for the opportunity to submit written testimony.

[This statement was submitted by Dr. Beverly Daniel Tatum, President, Spelman College.]

Attachments:

- HBCU Coalition fiscal year 2015 Appropriations Priorities
- Spelman College Title III Accomplishments

ATTACHMENTS

HISTORICALLY BLACK COLLEGES AND UNIVERSITIES

\$267 Million Discretionary/\$85 Million Mandatory for Strengthening Historically Black Colleges and Universities Program—Title III, Part B, supports critical investments in HBCUs such as student academic services, infrastructure and teacher education programs needed to enhance educational opportunities for our students. This critical investment helps HBCUs to continue delivering services to our Nation's neediest students. The HBCU Coalition respectfully requests \$267 million discretionary funding, which would restore this program to its fiscal year 2010 level, and \$85 million mandatory funding for fiscal year 2015.

\$61 Million for Strengthening Historically Black Graduate Institutions Program—This program provides financial assistance to Historically Black Graduate Institutions to establish or strengthen physical buildings and supports graduate students with scholarships and fellowships. This aid allows the next generation of scientists, mathematicians and graduate students to complete professional degrees in under-represented fields of study. The HBCU Coalition requests \$61 million funding, which would restore this program to its fiscal year 2010 funding level.

\$11 Million Discretionary/\$15 Million Mandatory for Strengthening Predominantly Black Institutions—This program provides Predominantly Black Institutions

with funds to develop and implement programs to educate more low-income, African American college and secondary students. The HBCU Coalition requests \$11 million discretionary and \$15 million mandatory funding, which would restore this program to its fiscal year 2010 funding level.

\$25 Million for the HBCU Capital Financing Program and Remove the Loan Guarantee Cap—The HBCU Capital Financing program provides low-cost capital to finance physical improvements on HBCU campuses by guaranteeing and administering loans. In fiscal year 2013 and fiscal year 2014, demand is expected to exceed \$800 million. We urge Congress to increase loan subsidies by \$5.5 million to \$25 million. This increase would support \$86 million in new loans to approximately 2–8 additional institutions for a total annual loan volume of \$390 million. At a minimum, we recommend restoring the loan subsidy to its pre-sequester level of \$20.5 million. We support the appropriations language recommended by the Education Department to remove the \$1.1 billion loan guarantee statutory cap.

\$5,830 for the Pell Grant Maximum Award and Reinstate “Summer” Pell Grants—Pell Grants provide low- to moderate- income students with the financial assistance to go to and through college. The HBCU Coalition requests funding for the maximum Pell award at its authorized fiscal year 2015 level (currently estimated by OMB to be \$5,830). In addition, we request reinstatement of the “summer” Pell Grant to allow students to accelerate their paths to graduation and lower their overall college costs.

\$75 Million for College Success Grants for Minority-Serving Institutions—The President’s fiscal year 2015 budget proposes to initiate new College Success Grants for Minority-Serving Institutions (MSIs) to assist MSIs in developing sustainable strategies to reduce costs and improve student outcomes. Funded activities could include partnering with school districts and schools to provide college recruitment, awareness, and preparation activities; establishing high-quality dual-enrollment programs that allow students to earn college credit while still in high school; providing comprehensive student support services; and reducing the need for remedial education. The HBCU Coalition supports the President’s request of \$75 million for this program.

\$647 Million for a College Opportunity and Graduation Bonus Program—President Obama’s fiscal year 2015 budget proposes a College Opportunity and Graduation Bonus program that will reward colleges that successfully enroll and graduate a significant number of low- and moderate-income students on time. Grants would fund key investments and best practices such as providing need-based financial aid, enhancing academic and student supports and other innovative strategies to improve low-income student outcomes. The HBCU Coalition supports the President’s request but also encourages Congress to modify the proposal to recognize institutions that enroll and graduate significant numbers or percentages of Pell-eligible students, accounting for the many HBCUs that have small enrollments.

\$50 Million for a National Five Fifths Agenda for America Initiative—To support the Administration’s My Brother’s Keeper initiative, the HBCU Coalition proposes \$50 million for a new program called the Five Fifths Agenda for America to expand educational outcomes for African American males. The objective of this program is to demonstrate how colleges and universities, especially HBCUs, and K–12 schools can forge partnerships to help African-American males prepare for, get to and through college by implementing research-based best practices.

\$250 Million Authorization for a HBCU Innovation Fund—To support the Administration’s efforts to drive change in higher education policies and practices that improves college access, affordability, completion and quality, the HBCU Coalition proposes that additional financial resources be provided to HBCUs through an Innovation initiative under the Higher Education Act. An Innovation Fund would incentivize HBCUs to address performance goals in certain categories, such as student retention and completion, STEM, use of technology and new educational delivery methods that can speed time to degree and lower costs. All public and private HBCUs, or consortia of these HBCUs, other institutions and nonprofit organizations, would be eligible to receive planning and implementation grants.

SPELMAN COLLEGE

HIGHLIGHTS: TITLE III, PART B, SEC. 323—STRENGTHENING HISTORICALLY BLACK COLLEGES AND UNIVERSITIES PROGRAM

Spelman College is the oldest historically black college for women. Located in Atlanta, Georgia, Spelman was founded in 1881 as the Atlanta Baptist Female Seminary. The College maintains a student population of approximately 2,000 from 45

U.S. States and 13 countries, and since 2008 has had an average 6-year graduation rate of 77 percent.

Title III—Strengthening Historically Black Colleges and Universities funding plays a critical role in obtaining resources that provide students and faculty with unparalleled opportunities for educational enrichment and advancement. In the 2007–2012 grant cycle, Spelman College expended more than \$11 million in Title III funds. Those resources were expended on a number of projects with wide-ranging effects on student life, faculty engagement, and facility improvement.

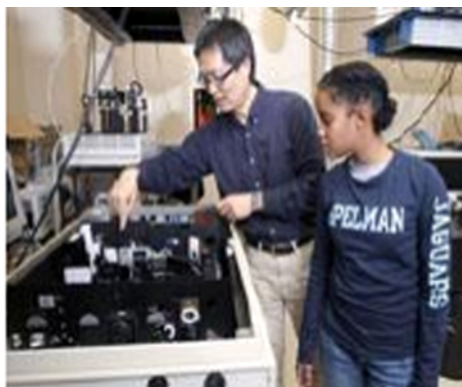


- Title III funding supports and enhances institutional efforts in four critical areas: Academic Quality, Student Services Outcomes, Institutional Management and Fiscal Stability. Our advancements in these key areas are reflected in key indicators related to enrollment, retention, graduation and fiscal stability.
- Title III funding undergirds 100 percent of the Foundational Priorities of the College's Strategic Plan, enhancing academic rigor in new student orientation, freshman-year and sophomore-year experiences.
- The College's retention rate is 90 percent. The average 5-year (2007–2011) second-year retention rate is 87 percent. Title III funds continue to assist the institution with providing supportive programs that ensure Spelman's first and second year students successfully progress to junior status.
- The College's 6-year graduation rate has ranged from a high of 83 percent to a low of 73 percent. The average 6-year (2001–2006) cohort rate is 77 percent.
- Forty-nine Global STEM students have conducted STEM research abroad since 2011.
- 48 labs and 22 classrooms upgraded with state-of-the-art technology.
- Between 2008–2012, Spelman had 722 students who were admitted to and attended graduate or professional degree programs in disciplines in which African Americans are underrepresented.

Select Examples of Title III Activities that Support our Success

- A campus classroom was transformed into a data analysis hub, with 16 new workstations installed. More than 90 percent of students reported that their interest in and skills related to data analysis improved as a result of their work in this facility.
- The College implemented DegreeWorks, an online auditing and advising system that aids students in proactively creating and fulfilling their individual academic plans and assists faculty advisors in providing effective support.
- Spelman's Education Studies Program enlarged its interdisciplinary course offerings through the addition of a new course entitled "History and Philosophy of African American Education."
- Creation and implementation of the Student Success Center, which provides a centralized location for student support services.
- Spelman's Department of Computer and Information Science (CIS) achieved international recognition for the accomplishments of its graduates and for its award-winning robotics initiative. The SpelBots participated in the NSF Education Technology Senate showcase in November 2009.

These accomplishments serve as evidence of the important role that resources from the Strengthening Historically Black Colleges and Universities program play at Spelman and on HBCU campuses across the Nation.



PREPARED STATEMENT OF THE UNITED TRIBES TECHNICAL COLLEGE

For 45 years, United Tribes Technical College (UTTC) has provided postsecondary career and technical education, job training and family services to some of the most impoverished, high risk Indian students from throughout the Nation. We are governed by the five tribes located wholly or in part in North Dakota. We are not part of the North Dakota State college system and do not have a tax base or State-appropriated funds on which to rely. We have consistently had excellent retention and placement rates and are a fully accredited institution. Section 117 Carl Perkins Act funds represent a significant portion of our operating budget and provides for our core instructional programs. The request of the UTTC Board for fiscal year 2015 is:

- \$10 million for base funding authorized under Section 117 of the Carl Perkins Act for the Tribally Controlled Postsecondary Career and Technical Institutions program (20 U.S.C. Section 2327). This is \$2.3 million above the fiscal year 2014 level and the fiscal year 2013 post-sequestration level. These funds are awarded competitively and distributed via formula. We are seeking a change to the formula which is not so reliant on Indian Student Count in order to avoid dramatic swings in annual awards.
- Forward Funding. We ask that the Section 117 Perkins funds, like the other funds under the Carl Perkins Career and Technical Education Act, be put on a forward funded basis.
- \$30 million as requested by the American Indian Higher Education Consortium for Title III-A (Section 316) of the Higher Education Act, \$5 million above the fiscal year 2014 level.
- Maintain Pell Grants at the \$5,830 maximum award level.

We are disappointed that the fiscal year 2014 Appropriations Act did not restore the fiscal year 2013 Section 117 sequestration even though funding for the overall Perkins Act was restored. Perhaps Section 117 was overlooked as a source of job training as it is in the Higher Education portion of the budget. We all realize the urgent need to better prepare a workforce to meet industry and other emerging needs. We are part of that undertaking, but need more resources to come closer to our potential.

We don't know if Congress will reauthorize the Carl Perkins Act this session, but point out that the Administration's Blueprint for Perkins reauthorization specifically states support for the Tribally Controlled Postsecondary Career and Technical Education program and includes some national recommendations that UTTC is already implementing including:

- Training that is industry certified and provision of postsecondary certificates and degrees.
- Alignment with labor market needs—the ramifications of the North Dakota Bakken oil boom are seen throughout the State. We saw the need for more certified welders in relation to the oil boom and so expanded our certified welding program for these good-paying, in-demand jobs. Similarly, our online medical transcription program was designed to meet the growing need for certified med-

ical support staff. Other courses reflect new emphasis on energy auditing and GIS Technology.

—Articulation agreements between UTTC and junior and senior high schools.

—A broad range of services for our students to help ensure their success.

Additional Information about UTTC. We have:

—Renewed unrestricted accreditation from the North Central Association of Colleges and Schools for July 2011 through 2021, with authority to offer all of our full programs on-line. We have 26 Associate, 20 Certificate and three Bachelor degree programs.

—Services including a Child Development Center, family literacy program, wellness center, area transportation, K–8 elementary school, tutoring, counseling and housing.

—A semester retention rate of 85 percent and a graduate placement rate of 77 percent. Over 45 percent of our graduates move on to 4-year or advanced degree institutions.

—Students from 75–88 tribes; 85 percent of our undergraduate students receive Pell Grants.

—An unduplicated count of undergraduate degree-seeking students and continuing education students of 1391.

—A critical role in the regional economy. Our presence brings at least \$34 million annually to the economy of the Bismarck region. A 2005 study showed a projected return on Federal investment of 20–1.

—We have recently opened a distance learning center in Rapid City, SD, where there are some 16,000 American Indians in the area. We are also working toward the establishment of an American Indian Specialized Health Care Training Clinic.

Section 117 Perkins Base Funding. Funds are needed to: 1) maintain 100-year-old education buildings and 50-year-old housing stock for students; 2) upgrade technology capabilities; 3) provide adequate salaries for faculty and staff who are in the bottom quartile of salary for comparable positions elsewhere; and 4) fund program and curriculum improvements.

Perkins funds are central to the viability of our core postsecondary education programs. Very little of the other funds we receive may be used for core career and technical educational programs; they are competitive, often one-time targeted supplemental funds. Our Perkins funding provides a base level of support while allowing the college to compete for desperately needed discretionary funds.

Forward Funding. We ask that the Appropriations Committees provide one-time funding for Section 117 Perkins to put it on a forward funded basis. We do not know why it is not already forward funded, given that the rest of the Perkins is forward funded. A number of years ago Section 117 was moved to the Higher Education portion of the budget even though it is authorized through the Perkins Act. Perhaps that has something to do with it, although we point out that many education programs are forward funded. Forward funding provides for vital education programs before the start of each school year, which is critically important when appropriations are delayed and the Government is funded via Continuing Resolutions.

Title III-A (Section 316) Strengthening Institutions. Among the Title III-A statutorily allowable uses is facility construction and maintenance. We are constantly in need of additional student housing, including family housing. With the completion of a Science, Math and Technology building on our South Campus on land acquired with a private grant, we urgently need housing for up to 150 students, many of whom have families.

While we have constructed three housing facilities using a variety of sources in the past 20 years, approximately 50 percent of students are housed in the 100-year-old buildings of what was Fort Abraham Lincoln, as well as housing that was donated by the Federal Government along with the land and Fort buildings in 1973. These buildings require major rehabilitation. New buildings are actually cheaper than rehabilitating the old buildings that now house students.

Pell Grants. We support maintaining the Pell Grant maximum to at least a level of \$5,830. This resource makes all the difference in whether most of our students can attend college.

Government Accountability Office (GAO) Report. As you know, in March 2011 the GAO issued two reports regarding Federal programs which may have similar or overlapping services or objectives (GAO–11–318SP of March 1 and GAO–11–474R of March 18). Funding from the Bureau of Indian Education (BIE) and the Perkins Act for Tribally Controlled Postsecondary Career and Technical Institutions were among the programs listed in the supplemental report of March 18, 2011. The GAO did not recommend defunding these or other programs; in some cases consolidation

or better coordination of programs was recommended to save administrative costs. We are not in disagreement about possible consolidation or coordination of the administration of these funding sources so long as funds are not reduced.

Perkins funds supplement, but do not duplicate, our BIE funds. It takes both sources of funding to frugally maintain the institution. Even these combined sources do not provide the resources necessary to operate and maintain the college and we actively seek alternative funding to assist with curricula, deferred maintenance, and scholarship assistance. The need for postsecondary career and technical education in Indian Country is so great and the funding so small, that there is little chance for duplicative funding. There are only two institutions targeting American Indian/Alaska Native career and technical education at the postsecondary level—UTTC and Navajo Technical University. Combined, these institutions received less than \$15 million in fiscal year 2014 Federal operational funds (\$7.7 million from Perkins; \$7 million from BIE), a very modest amount for two campus-based institutions which offer a wide and expanding array of training opportunities.

UTTC offers services catered to the needs of our students, many of whom are first generation college attendees and many of whom come to us needing remedial education and services. Although BIE and Section 117 Perkins funds do not pay for remedial education, we make this investment through other sources to ensure our students succeed at the postsecondary level.

Thank you for your consideration of our requests.

[This statement was submitted by David M. Gipp, Chancellor, United Tribes Technical College.]

PREPARED STATEMENT OF THE UNIVERSITY OF KANSAS MEDICAL CENTER

Mr. Chairman and Members of the Subcommittee; thank you for the opportunity to submit this statement regarding fiscal year 2015 funding for the National Institutes of Health's Institutional Development Award or "IDeA" Program. The IDeA program is funded by NIH's National Institute of General Medical Sciences (NIGMS), and was authorized by the 1993 NIH Revitalization Act (Public Law 103-43). I submit this testimony on behalf of the Coalition of EPSCoR/IDeA States,¹ the Kansas IDeA program, and the University of Kansas Medical Center. The Coalition of EPSCoR/IDeA States respectfully requests that the Subcommittee provide \$310 million for the IDeA program in fiscal year 2015.

I would first like to provide some basic information about the IDeA program. The IDeA program increases our Nation's biomedical research capability by improving research in States that have historically been less successful in obtaining biomedical research funds. Twenty-three States and Puerto Rico are eligible. The program funds only merit-based, peer-reviewed research that meets NIH's biomedical research objectives. While IDeA was authorized by the 1993 NIH Revitalization Act (Public Law 103-43), sizable increases in funding only began in fiscal year 2000. The IDeA program then grew rapidly, due in large part to the thoughtful actions of this Subcommittee. This initial funding permitted the launch of two program elements: the COBRE and BRIN/INBRE programs.

The first was the COBRE program or "Centers of Biomedical Research Excellence," which are research clusters targeting specific biomedical research problems. The second IDeA program was BRIN or "Biomedical Research Infrastructure Networks," which targeted key areas such as bioinformatics and genomics, and facilitated the development of cooperative networks between research-intensive universities and primarily undergraduate colleges. The BRIN grants underwent competitive renewals in 2004 and were funded under the new name of "IDeA Networks of Biomedical Research Excellence," or INBRE.

The COBRE program is designed to increase the pool of well-trained investigators in the IDeA States by expanding research facilities, equipping laboratories with the latest research equipment, providing mentoring for promising candidates, and developing research faculty through support of a targeted multi-disciplinary center, led by an established, senior investigator with expertise in the research focus area of the center.

¹ Alabama, Alaska, Arkansas, Delaware, Guam, Hawaii, Idaho, Iowa, Kansas, Kentucky, Louisiana, Maine, Mississippi, Missouri, Montana, Nebraska, Nevada, New Hampshire, New Mexico, North Dakota, Oklahoma, Puerto Rico, Rhode Island, South Carolina, South Dakota, Tennessee, Utah, Vermont, Virgin Islands, West Virginia, and Wyoming

The INBRE program is designed to increase the pipeline of outstanding students and enhances the quality of science faculty in the IDeA States by research-intensive networking with undergraduate institutions. The INBRE program supports research infrastructure and mentoring of young investigators, and prepares students for graduate and professional schools as well as careers in the biomedical sciences at participating institutions. As you can see, these two programs play complementary roles in developing research capability and human capital in biomedical fields in the IDeA States.

Impact of the IDeA Program on Kansas

Since the year 2000, Kansas has received more than \$190 million in awards from the IDeA program. Those IDeA investments have enabled our investigators to secure National Institutes of Health grants and more than double the amount of funding coming into Kansas. The IDeA program has resulted in funding of 570 biomedical research grants, supported 71 core biomedical research core facilities, and has resulted in 1,152 new research related jobs.

The Kansas INBRE (K-INBRE) program consists of three research-intensive universities and seven primarily undergraduate universities. Over its 13-year history, the K-INBRE has provided significant benefits to the State of Kansas, including training a skilled workforce and helping to drive scientific commercialization potential. Over \$45.1 million from the NIH, numerous Kansas Universities, as well as philanthropies and industry support to the K-INBRE has benefitted Kansas Universities by significantly aiding Kansas's faculty to increase NIH funding from \$50.3M (2000) to \$82.8M (2013). The K-INBRE has significantly improved in the dissemination of knowledge throughout Kansas via videoconferencing, symposia and increased intra- and inter-State collaborations.

The K-INBRE has been successful in establishing the first bioinformatics facility in Kansas (three campus cores) and been instrumental in preparing for new advances in increased medical informatics and translational research. The K-INBRE has also assisted with building the Kansas biomedical science industry by facilitating industry collaborations. This is critical, as the growth of the Kansas bioscience sector is climbing at more than twice the national rate.

Finally, the K-INBRE has contributed to building a skilled workforce for Kansas by assisting with the building of the biomedical workforce in Kansas by supporting research training for over 800 undergraduates, numerous post-docs and new faculty investigators. Importantly, the K-INBRE has helped broaden student research participation of under-represented groups (rural and ethnic). In 2013 alone, approximately 160 graduate and undergraduate students throughout the State of Kansas were supported by K-INBRE funds. More importantly, these funds have broadened research participation by under-represented rural and ethnic groups, and NIH-level research infrastructure has been initiated in seven of ten campuses within the K-INBRE network.

Overall, the implementation of the K-INBRE program facilitates the generation of new strengths in Cell and Developmental Biology in the State of Kansas, and ultimately contributes importantly to the development of new tools and strategies for improving human health.

Kansas researchers are currently involved in six active COBRE awards. Three of these COBREs are located at University of Kansas Medical Center in Kansas City. The Molecular Regulation of Cell Development and Differentiation COBRE has established a thriving multidisciplinary research group focused on the molecular regulation of cell development. This COBRE has been highly successful in helping young faculty obtain NIH funding. The purpose of the Nuclear Receptors in Liver Health and Disease COBRE has been to establish a recognized center to study liver function in health and disease. This COBRE has also been very successful at aiding young faculty in obtaining NIH funding. Importantly, it has also created a valuable "liver bank" from many strains of inbred mice. The objective of the Novel Approaches for Control of Microbial Pathogens COBRE is to promote and enhance the research capabilities of tenure track junior faculty members of participating institutions in the State of Kansas with an emphasis on inhibiting microbial pathogens. This COBRE has been critical in enabling Kansas faculty to obtain \$52 million in NIH funding and has established a highly utilized flow cytometry core facility at the University of Kansas Medical Center.

The remaining three COBRE programs reside in Lawrence, Kansas at the University of Kansas. The Center of Biomedical Research Excellence in Protein Structure and Function conducts important basic research in health-related protein structure and function. By better understanding the structure, function, and interaction of proteins present in human cells, researchers are gaining a deeper understanding of how proteins carry out critical functions within cells. This COBRE has helped 13

faculty establish independent NIH funding and two faculty supported by this COBRE have gone on to receive national recognition for their research.

The Center for Molecular Analysis of Disease Pathways (CMADP) COBRE brings together junior and senior faculty from the physical, biological, and pharmaceutical sciences at the University of Kansas and other academic institutions in Kansas to conduct multidisciplinary research to develop and implement cutting-edge technologies for elucidating the genetic, chemical, and physical mechanisms of biological processes involved in disease. This COBRE has established a much needed Genome Sequence Core that provides state of the art sequencing capabilities for researchers in Kansas.

Finally, the Center for Cancer Experimental Therapeutics (CCET) COBRE brings together researchers from the University of Kansas Lawrence campus, Kansas State University and the University of Kansas Medical Center. The Center combines the resources and faculty of Kansas' institutions to create the infrastructure needed to pursue cancer-related research and experimentation at the interface between chemistry and biology. This is the oldest of the COBRE programs in Kansas and the CCET works to identify novel bioactive compounds that will be useful basic biomedical research tools and potential therapeutic agents. Scientists from the participating schools fight cancer through research projects focusing on specific types of cancer and the discovery of new anti-cancer drugs and therapies. This COBRE has established two important research cores associated with medicinal chemistry and high throughput screening, two key services that are important for drug discovery. The CCET was also instrumental in establishing a National Cancer Institute Designated Cancer Center at the University of Kansas Medical Center in 2012.

Conclusion

Despite these successes, our task is far from complete. Funding disparities between the States remain and may have a detrimental impact on our national self-interest. Together, the 23 States and Puerto Rico that comprise the IDeA community secured just 5 percent of the total NIH budget in fiscal year 2011. With over 22 percent of the Nation's population living in the EPSCoR/IDeA States, this figure clearly indicates the critical need for further research development and the importance of a strong IDeA program. In fiscal year 1999, the year before COBRE grants were initiated, the 23 IDeA States and Puerto Rico received a total of \$596 million from NIH. In fiscal year 2013 total NIH funding to the IDeA community has risen to \$1.5 billion. This is evidence that the program is working and that the IDeA States are moving in the right direction. To put the value of the IDeA investment into perspective, the overall fiscal year 2014 IDeA budget, \$273.325 million, for 23 States and Puerto Rico, pales in comparison to the \$606.8 million in NIH funding that one institution in one single non-IDeA State received in fiscal year 2012. In fiscal year 2012, the top seven States with NIH funding received over a \$1 billion each, and California alone received over \$3.5 billion.

We request that this committee recommend the program to be funded in fiscal year 2015 at \$310 million. As you know, the EPSCoR/IDeA Coalition has maintained that IDeA program should constitute at least 1 percent of the total NIH budget. This level of funding would restore and continue funding for COBRE and INBRE, provide funding for the IDeA Program Infrastructure for Clinical and Translational Research (IDeA-CTR) program, and provide co-funding which would allow researchers and institutions to merge with the overall national biomedical research community.

On behalf of the University of Kansas Medical Center, I express gratitude to this Subcommittee for the efforts it has made over the years to provide increased funding for IDeA, in particular this committee's work to ensure the successful inclusion of a \$50 million increase for the program in fiscal year 2012. I hope that you will continue to invest in this biomedical research program, which is so important to almost half of the States in the Union. Every region of the country has talent and expertise to contribute to our Nation's biomedical research efforts—and every region of the country must participate if we are to increase our Nation's biomedical research capacity substantially. On behalf of the EPSCoR/IDeA Coalition, the University of Kansas Medical Center and our partner institutions across Kansas, I thank the Subcommittee for the opportunity to submit this testimony.

[This statement was submitted by Douglas Wright, Ph.D., Professor and Vice Chair Principal Investigator, Kansas INBRE, Department of Anatomy and Cell Biology, University of Kansas Medical Center.]

PREPARED STATEMENT OF THE UNIVERSITY OF NORTH DAKOTA AND NORTH DAKOTA
STATE UNIVERSITY

On behalf of the University of North Dakota and North Dakota State University, thank you for the opportunity to submit our written testimony regarding the fiscal year 2015 funding for the National Institutes of Health (NIH) Institutional Development Award (IDeA) program. We respectfully request your support of no less than \$310.0 million for this critically important program. We further request that the Subcommittee gives serious consideration to legislative language which would direct that future NIH budgets include funding for the IDeA program that reaches no less than 1 percent of the total NIH budget. IDeA was authorized by the 1993 NIH Revitalization Act (Public Law 103-43) and funds only merit-based, peer reviewed research that meets NIH research objectives in the 23 IDeA States and Puerto Rico.

The States eligible for IDeA funding are defined as "all States/commonwealths with a success rate for obtaining NIH grant awards of less than 20 percent over the period of 2001-2005 or received less than an average of \$120 million per year during that time period." Currently this includes 23 States and Puerto Rico—nearly half of the States. Funding from this critical capacity-building program has been a key part of the growth in research capacity and impact at the two North Dakota research universities in recent years.

Funding for the IDeA program in fiscal year 2014 was \$273.325 million. The total budget for NIH in fiscal year 2014 was \$30.2 billion; thus in fiscal year 2014, the IDeA program—funding competitively awarded biomedical research in nearly half the Nation—comprised only 0.89 percent of the entire NIH budget. The IDeA program exists because the 23 eligible States overall receive less than 20 percent of NIH's extramural funding. The President's proposed fiscal year 2015 budget request of \$30.4 billion represents only a 0.7 percent increase to the NIH, and the proposed increase of \$31 million for the entire National Institute for General Medical Sciences, which houses the IDeA program is even less, only 0.3 percent. The President's proposed fiscal year 2015 budget request does not include a recommended increase for the IDeA program. The IDeA program is designed to aid small, rural States; it is small in the overall scheme of things at NIH, but huge for the States that compete for these funds. Our requested funding level of \$310.0 million represents only 1 percent of the President's total fiscal year 2015 budget request for NIH.

Our State, North Dakota, has benefited immensely from the competitive funding available through the IDeA program in the form of COBRE (Center for Biomedical Research Excellence) and INBRE (IDeA Networks of Biomedical Research Excellence) grants.

At the University of North Dakota, we have been awarded funding for three phases of a COBRE grant supporting research on neurodegenerative diseases. North Dakota has one of the largest populations of the extremely old in the Nation (second only to Rhode Island in the percentage of its citizens over 85 years of age), and high rates of neurodegenerative diseases such as Alzheimer's, Parkinson's, and multiple sclerosis. As an example of the impact of this funding and the research capacity it has built, externally funded research at the University of North Dakota's School of Medicine and Health Sciences has grown substantially. Prior to COBRE funding, in fiscal year 2002, the SMHS received about \$12.0 million in external funding; by fiscal year 2013, this had increased to \$27.1 million, an increase of 126 percent. In 2010, when UND developed a new strategic plan for research, neuroscience was identified as an existing strength on which to build further.

Thus, the neurobiology COBRE grant is achieving its intended purpose of expanding our research capacity and our ability to compete for Federal funding. That research is directed at problems of direct interest not only to our citizenry, but also to the rest of the United States.

The University of North Dakota has also received an additional COBRE grant on the topic of epigenetics. Epigenetics is the study of how environmental factors influence the expression of our genes; in many cases these changes in gene expression can then be inherited by the next generation. This \$12.0 million grant was awarded early in fiscal year 2014, and will serve to carry out research on environmental factors that affect disease resistance while developing critical research capacity in the State.

At North Dakota State University, the Center for Protease Research, a COBRE supported center, provides fundamental information on how proteases, key biological players, impact several diseases, including cancer, arthritis, autoimmune diseases, diabetes, and asthma. These studies have the potential to provide novel therapeutics that can treat these deadly and debilitating diseases. The multidisciplinary program has established two central Core Facilities in biology and synthesis that have had

a significant impact on research programs in the university and throughout North Dakota. The \$24.0 million Center has initiated several outreach activities such as workshops for North Dakota University System faculty and students and a summer research program for undergraduates.

The Center for Visual and Cognitive Neuroscience established in 2004 at North Dakota State University is devoted to increasing our understanding of the ways that information is perceived and processed by the brain. Center investigators are involved in the study of visual and cognitive processing. Core laboratory infrastructure has been developed allowing faculty and students to fruitfully explore the relationships between the nervous system and the behavior that it governs.

Another critically important IDeA program is INBRE, which provides funding to build the biomedical workforce through activities ranging from outreach to elementary school children to creating opportunities for undergraduates to engage in research. This program has provided support for undergraduate students at 2- and 4-year colleges in North Dakota to participate in research during the summer at their home institutions. This program includes two tribal colleges and serves between 70 and 100 students each year. Another program at the University of North Dakota serves about 60 undergraduates per year and applications routinely exceed the number of slots that are available. These programs are critical for keeping students in the pipeline for the STEM (science, technology, engineering, and math) workforce. Studies have repeatedly shown that engaging undergraduates in original research is a powerful tool for retaining students in college so that they graduate in a timely way.

A major emphasis has been on outreach programs to Native American students, the minority group that is most under-represented in the fields of science, engineering, and math. Between 25 and 35 Native American students in grades 7–12 participate each year in a program that uses traditional Native American tools to teach science. As many as 40 students from tribal colleges are funded each year to visit UND and learn about opportunities to transfer to the university and complete their 4-year degrees. INBRE provides support for transfer students from tribal colleges through the Pathway program, a 6-week summer program that prepares participants for advanced coursework in science. Pathway students can also receive tuition waivers from the university. INBRE funding is also provided to support the American Indian Health Research Forum on the UND campus each year; this forum attracts attendees from across the Nation.

North Dakota, with an estimated 2013 population of 723,393, is the smallest of all the IDeA States. Yet, our School of Medicine and Health Sciences graduates a disproportionately large number of primary care physicians who practice in rural areas, and 20 percent of all Native American physicians in the U.S. are graduates of the University of North Dakota. The School recently was recognized by the American Academy of Family Physicians for having the largest percentage of its graduates enter the field of family medicine of all medical schools in the United States. The medical school clearly is making important contributions to healthcare for underserved populations. Like all medical schools, it must have a healthy research program underpinning its training of physicians, and funding from the IDeA program is critical to the health of that program and to building research capacity for the future.

The IDeA States produce STEM graduates at the same per capita rate as States with larger populations and larger research portfolios. The students from IDeA States need and deserve the same exposure to research as students in larger States. If fiscal year 2015 funding levels for the IDeA program are not at least maintained at the current level, and preferably increased to \$310.0 million, North Dakota and other small, mostly rural States, will receive a major setback in their efforts to increase their capacity to undertake biomedical research and to train the next generation of scientists who are critical for the health of our Nation and our economy.

The IDeA program is absolutely critical not only for North Dakota's two research universities, but also for the biomedical research capacity and capability of research institutions nationwide. We sincerely appreciate the Subcommittee's ongoing support of the IDeA program and request that you give full consideration to our recommendations and fiscal year 2015 request of no less than \$310.0 million for the National Institutes of Health IDeA program. We further request that the Subcommittee considers legislative language directing that future NIH budgets include funding for the IDeA program that reaches no less than 1 percent of the total NIH budget.

PREPARED STATEMENT OF US HEREDITARY ANGIOEDEMA ASSOCIATION
SUMMARY OF FISCAL YEAR 2015 RECOMMENDATIONS

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- \$32 Billion for the National Institutes of Health (NIH) at an increase of \$1 billion over fiscal year 2014.
 - Continued focus on Hereditary Angioedema Research and Education at NIH
 - Funding to create and support the Centers for Disease Control and Prevention's (CDC) to Increase Awareness Efforts for Hereditary Angioedema at CDC
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Thank you for the opportunity to present the views of the US Hereditary Angioedema Association (US HAEA) regarding the importance of Hereditary Angioedema (HAE) public awareness activities and research.

The US HAEA is a non-profit patient advocacy organization founded in 1999 to help those suffering with HAE and their families to live healthy lives. The Association's goals were, and remain, to provide patient support, advance HAE research and find a cure. The US HAEA provides patient services that include referrals to HAE knowledgeable healthcare providers, disease information and peer-to-peer support. US HAEA also provides research funding to scientific investigators to increase the HAE knowledge base and maintains an HAE patient registry to support groundbreaking research efforts. Additionally, US HAEA provides disease information materials and hosts forums to educate patients and their families, healthcare providers, and the general public on HAE.

HAE is a rare and potentially life-threatening inherited disease with symptoms of severe, recurring, debilitating attacks of edema (swelling). HAE patients have a defect in the gene that controls a blood protein called C1-inhibitor, so it is also more specifically referred to as C1-inhibitor deficiency. This genetic defect results in production of either inadequate or nonfunctioning C1-inhibitor protein. Because the defective C1-inhibitor does not adequately perform its regulatory function, a biochemical imbalance can occur and produce an unwanted peptide—called bradykinin—that induces the capillaries to release fluids into surrounding tissues, thereby causing swelling.

People with HAE experience attacks of severe swelling that affect various body parts including the hands, feet, face, airway (throat) and intestinal wall. Swelling of the throat is the most life-threatening aspect of HAE, because the airway can close and cause death by suffocation. Studies reveal that more than 50 percent of patients will experience at least one throat attack in their lifetime.

HAE swelling is disfiguring, extremely painful and debilitating. Attacks of abdominal swelling involve severe and excruciating pain, vomiting, and diarrhea. Because abdominal attacks mimic a surgical emergency, approximately one third of patients with undiagnosed HAE undergo unnecessary surgery. Untreated, an average HAE attack lasts between 24 and 72 hours, but some attacks may last longer and be accompanied by prolonged fatigue.

The majority of HAE patients experience their first attack during childhood or adolescence. Most attacks occur spontaneously with no apparent reason, but anxiety, stress, minor trauma, medical, surgical, and dental procedures, and illnesses such as colds and flu have been cited as common triggers. ACE Inhibitors (a blood pressure control medication) and estrogen-derived medications (birth control pills and hormone replacement drugs) have also been shown to exacerbate HAE attacks.

HAE's genetic defect can be passed on in families. A child has a 50 percent chance of inheriting the disease from a parent with HAE. However, the absence of family history does not rule out the HAE diagnosis; scientists report that as many as 25 percent of HAE cases today result from patients who had a spontaneous mutation of the C1-inhibitor gene at conception. These patients can also pass the defective gene to their offspring. Worldwide, it is estimated that this condition affects between 1 in 10,000 and 1 in 30,000 people.

PUBLIC AWARENESS AT THE CENTERS FOR DISEASE CONTROL AND PREVENTION

HAE patients often suffer for many years and may be subject to unnecessary medical procedures and surgery prior to receiving an accurate diagnosis. Raising awareness about HAE among healthcare providers and the general public will help reduce delays in diagnosis and limit the amount of time that patients must spend without treatment for a condition that could, at any moment, end their lives.

Once diagnosed, many individuals are able to piece together a family history of mysterious deaths and episodes of swelling that previously had no name. In some families, over many years, this condition has come to be accepted as something that must simply be endured. Increased public awareness is crucial so that these pa-

tients understand that HAE often requires emergency treatment and disabling attacks no longer need to be passively accepted. While HAE cannot yet be cured, intelligent use of available treatments can help patients lead a productive life.

In order to prevent deaths, eliminate unnecessary surgeries, and improve patients' quality of life, it is critical that CDC pursue programs to educate the public and medical professionals about HAE in fiscal year 2015.

RESEARCH THROUGH THE NATIONAL INSTITUTES OF HEALTH

In years past, HAE research was conducted at the National Institutes of Health (NIH) through the National Institute of Allergy and Infectious Diseases, the National Institute of Neurological Disorders and Stroke, the National Heart Lung and Blood Institute, the National Institute of Child Health and Human Development, National Center for Research Resources, and the National Institute on Diabetes and Digestive and Kidney Diseases. However, NIH has not engaged in HAE-specific research since 2009, and there is no longer any Federal research as it relates to HAE.

As it may provide greater opportunities for HAE research, we applaud the recent establishment of the National Center for Advancing Translational Sciences (NCATS) at NIH. Housing translational research activities at a single Center at NIH will allow these programs to achieve new levels of success. Initiatives like the Cures Acceleration Network are critical to overhauling the translational research process and overcoming the challenges that plague treatment development. In addition, new efforts like taking the lead on drug repurposing have the potential to speed access to new treatments, particularly to patients who struggle with rare or neglected diseases. As a rare disease community, HAE patients may also benefit from the Therapeutics for Rare and Neglected Diseases (TRND) program, housed at NCATS, as well coordination with the Office of Rare Diseases Research (ORDR). We ask that you support NCATS and provide adequate resources for the Center in fiscal year 2014.

In order to reinvigorate HAE research at NIH, it is vital that NIH receive increased support in fiscal year 2015. US HAEA recommends an overall funding level of \$32 billion for NIH in fiscal year 2015 and the inclusion of recommendations emphasizing the importance of HAE research to learn more about this rare disease and new pathways for appropriate treatment.

Thank you for the opportunity to present the views of the HAE community.

[This statement was submitted by Janet Long, Executive Vice President, US Hereditary Angioedema Association.]

PREPARED STATEMENT OF VOR

I. Introduction

VOR is a national organization that advocates for high quality care and human rights for all people with intellectual and developmental disabilities (I/DD). VOR calls on the U.S. Senate to prohibit the use of U.S. Department of Health and Human Services' (HHS) appropriations in support of deinstitutionalization activities which evict eligible individuals with I/DD from their HHS-licensed and funded Medicaid homes, in violation of Federal law.

Deinstitutionalization activities, including advocacy, lobbying, class action lawsuits, and other tactics by some HHS-funded agencies (discussed below) resulting in the downsizing and closure of HHS-licensed homes are a cruel and absurd use of Federal funding. These closures often lead to human tragedy. Medicaid-licensed facility homes, including Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs/IID) and other specialized nursing facilities, are uniquely suited to meet the residents' profound support, healthcare and behavioral needs. Tragedies are widespread and predictable when fragile citizens are removed from specialized care. The legally-protected rights of families and legal guardians to serve as primary decision-makers are routinely ignored.

II. Using HHS Funds to Eliminate HHS-Supported Homes: The Administration on Intellectual and Developmental Disabilities (AIDD) and its State-based Developmental Disabilities Assistance and Bill of Rights Act (DD Act) Programs

It has been 14 years since Congress last reauthorized the DD Act. Authorizations for DD Act appropriations expired in 2007; however, Congress continues to fund these programs. DD Act programs, including Protection & Advocacy (P&A), DD Councils, and University Programs, operate in every State. AIDD, within HHS, administers the DD Act programs.

Independent oversight of Federal AIDD and DD Act programs is nearly non-existent.¹ DD Act programs are using their public funds to achieve dangerous deinstitutionalization, evicting vulnerable people with I/DD from Medicaid-certified homes, disregarding individual choice and the legal right to appropriate services, as required by the Americans With Disabilities Act (ADA) (as interpreted by the Olmstead decision) and Medicaid law, both discussed below.

The DD Act programs' own authorizing statute supports residential choice and recognizes that individuals and their families are in the best position to make care decisions:

"Individuals with developmental disabilities and their families are the primary decisionmakers regarding the services and supports such individuals and their families receive, including regarding choosing where the individuals live from available options, and play decisionmaking roles in policies and programs that affect the lives of such individuals and their families." DD Act, 42 U.S.C. 15001(c)(3)(2000); see also, H. Rep. 103-442 (March 21, 1994) ("[T]he goals expressed in this Act to promote the greatest possible integration and independence for some individuals with developmental disabilities may not be read as a Federal policy supporting the closure of residential institutions").

Yet, AIDD persists in its support for DD Act programs' deinstitutionalization activities and even proposed a recommendation to "[d]evelop and implement plans to close public and private institutions," and "[k]eep people with disabilities out of congregate institutions," in collaboration with DOJ and The Arc (2011). Hundreds of families and others objected; the recommendation has not yet been finalized. Likewise, the national organizations for the three DD Act programs have referred to families who select HHS-licensed homes (ICFs/IID) as "clueless" and "unaware,"² a view not shared by the Supreme Court (see, *Heller v. Doe*, 509 U.S. 312, 329 (1993)) ("... close relatives and guardians, both of whom likely have intimate knowledge of a mentally retarded person's abilities and experiences, have valuable insights which should be considered during the involuntary commitment process.").

With AIDD directive, State-level DD Act program deinstitutionalization activities continue, exacting great harm on the very people Congress entrusted these HHS-entities to protect. Since 1996, more than fifteen (15) P&A class action lawsuits for closure (not relating to conditions of care) and other deinstitutionalization tactics have been pursued over the objection of residents and their families. The P&A class action lawsuits are a particularly egregious use of Federal funds; they equate HHS suing itself because the targets of these HHS-funded lawsuits are HHS/Medicaid-licensed ICFs/IID.

AIDD and its State-based programs persist in their ideological devotion to community placement despite reports of 1,200 "unnatural and unknown" deaths in New York, a risk of mortality in community settings of up to 88 percent in California, more than 100 deaths in Connecticut, 53 deaths in Illinois, 114 deaths in the District of Columbia, plus many more reports of abuse, neglect and death across the majority of all States (see e.g., *Widespread Abuse, Neglect and Death in Small Settings Serving People with Intellectual Disabilities* (VOR, 2014)).

III. Using HHS Funds to Eliminate HHS-Supported Homes: National Council on Disability

The National Council on Disability (NCD) is an HHS-funded, independent Federal agency that advises the President, Congress, and other Federal agencies on issues affecting people with disabilities.

On October 23, 2012, NCD released a 300-page policy paper and related toolkit calling for the closure of residential homes for people with I/DD, arbitrarily targeting residential homes for four or more people. NCD spent nearly \$150,000 in Federal funds to prepare and publish "Deinstitutionalization: Unfinished Business," calling on the broader advocacy community to engage in advocacy efforts and lawsuits to evict people with I/DD from their homes. NCD did not consult with the individuals who could be evicted from their homes, nor their families and legal guardians. Instead, NCD accuses these caring families and guardians of violating their family members' civil rights for choosing a care setting of four or more people. NCD has since received more than 350 letters from families opposing forced deinstitutionalization.

¹See, VOR Federal Comments Urging Objective Performance—Not More Self-Reporting—of DD Act Programs (January 25, 2012) (vor.net/images/VORCommentDDActEvaluationJan2012.pdf).

²June 14, 2010 and July 30, 2007 letters to Congress referring to families as "unaware" and "clueless," respectively.

Like AAID, NCD cites the landmark Supreme Court decision of *Olmstead v L.C.* (1999) as justification for its position to close HHS homes. Like many organizations that support deinstitutionalization, AAID and NCD misread and misapply the *Olmstead* decision's requirements. The Supreme Court is clear in its holding that the ADA requires individual choice before community placement can be imposed and recognizes the need for specialized care:

"We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any Federal requirement that community-based treatment be imposed on patients who do not desire it." *Olmstead*, 119 S. Ct. 2176, 2187 (1999) (majority).

"As already observed [by the majority], the ADA is not reasonably read to impel States to phase out institutions, placing patients in need of close care at risk ...Each disabled person is entitled to treatment in the most integrated setting possible for that person—recognizing on a case-by-case basis, that setting may be an institution[quoting VOR's Amici Curiae brief]." *Id.* at 2189 (plurality).

Likewise, Medicaid law and regulation requires that ICF/IID residents be "[g]iven the choice of either institutional or home and community-based services." 42 C.F.R. § 441.302(d)(2); see also, 42 U.S.C. § 1396n(c)(2)(C) and 42 C.F.R. § 441.303.

NCD's support for deinstitutionalization is contrary to Federal law and reckless. ICFs/IID have an array of services not often available elsewhere (e.g., on-site medical care, dental care, other specialties, and involvement in their broader communities). As discussed above, tragedies are predictable when residents are separated from life-sustaining supports.

IV. Solution and Conclusion

HHS-funded agencies should not be allowed to advance an ideological agenda in support of evicting eligible people from HHS-licensed homes, contrary to the DD Act, Medicaid law, and the ADA/*Olmstead*. Such actions are a cruel and absurd use of Federal funding that is exacting great harm on our nation's most vulnerable citizens, and contrary to societal values which respect individual and family decision-making.

Please support language to prohibit the use of HHS appropriations in support of deinstitutionalization activities which evict eligible individuals with I/DD from HHS-licensed and funded homes. No Federal agency should define "choice" so narrowly and illegally as to disenfranchise the most vulnerable segment of our disabled population.

PREPARED STATEMENT OF THE WORKFORCE DATA QUALITY CAMPAIGN

Workforce Data Quality Campaign (WDQC)—a nonprofit initiative that advocates for inclusive, aligned and market-relevant data systems—urges Congress to support programs that provide crucial data needed to ensure that our Nation is educating its students and workers to succeed in the 21st century economy.

Federal investments in State data systems, labor market information and statistical programs have real impacts for:

- Students and workers trying to figure out which colleges and training programs are best at helping people land a job, continue their studies or advance in the labor market.
- Policymakers who need to know whether education and workforce programs are preparing people for good jobs.
- Business leaders wondering whether education and training programs are preparing enough prospective employees to meet their companies' needs.
- Educators who want to know the long-term education and employment outcomes of their graduates, so they can continually improve their courses and curricula.

Despite their profound impact on education and workforce development, a number of data-related programs and services have faced stagnant or declining funding in recent years. As Congress deliberates on fiscal year 2015 appropriations, we recommend halting this downward trend and increasing funding for the following programs.

State longitudinal data system grants.—The State Longitudinal Data System grants provided by the Department of Education (ED) and the Workforce Data Quality Initiative grants from Department of Labor (DOL) have propelled the successful development, implementation and expansion of longitudinal data systems. Continued Federal support will incentivize the State interagency cooperation nec-

essary to build and utilize systems that can hold education and workforce programs accountable for their results. Funding for these grants has been decreasing over the past several years, gradually eroding this important source of support for State data systems. The last grant competition was in fiscal year 2012. Additional funding is important to help more States improve their data infrastructure and conduct a new grant competition that focuses States on using data to improve policy and practice, as well as incorporating longitudinal data from postsecondary and workforce programs into their systems to allow more analysis of varied education and career pathways.

Recommendation.—Double the fiscal year 2014 funding level, as requested by the President's Budget, to support about 20 grants and national activities designed to promote data coordination, quality, and use. Include report language directing ED and DOL to collaborate on providing technical assistance to grantees to ensure inclusive and aligned data systems.

Workforce Information Grants/Electronic Tools. DOL awards grants to help States conduct research on local and regional labor markets, including shifts in industrial and occupational demand and its impact on the skills needed by the workforce. This information is critical to align education and training programs with employer needs, and help the workforce system guide students and workers to programs that will prepare them for high-demand occupations. Funding for these grants—including in the Workforce Information/Electronic Tools/System Building line item in the State Unemployment Insurance and Employment Service Operations Account—has not increased for over a decade, even as demand for labor market information has grown. This line item also funds important national data activities, including the dissemination of information on different types of credentials and O*NET, which collects and disseminates information about occupations including associated skills, knowledge and abilities. O*NET is used as the foundation for variety of tools to help workers explore careers, such as a new Skills to Work tool from Texas that helps veterans translate their military experience into skills appropriate for civilian resumes and match their skills to job openings.

Recommendation.—Increase funding by \$10 million to support an \$8 million increase in grants to States and a \$2 million increase for O*NET.

National Center for Education Statistics. This office at ED provides a number of important services, including labor market-relevant data products and tools on secondary and postsecondary enrollments, completions and credential attainment.

Recommendation.—Increase funding to match fiscal year 2012 (pre-sequester) levels.

Bureau of Labor Statistics. This DOL agency produces an array of important data, including employment and unemployment of individuals, jobs and earnings by industry and occupation, job openings and labor turnover, mass layoffs and occupational projections. As the Nation continues to face high unemployment, this data is vital to help align human capital policies with the needs of employers.

Recommendation.—Increase funding by \$23 million to support the following efforts.

- Restore Current Employment Survey funding to 2010 levels (+\$7 million) to provide resources to enhance data quality and reduce employer response burden by encouraging businesses to voluntarily provide information through electronic data interchange. This survey is used by local leaders to provide a near real-time summary of employment conditions and to rapidly spot key trends in major industries.
- Expand Current Population Survey supplements (+\$4 million), which monitor labor market changes that can help State and local leaders understand the education and training needs in their communities.
- Develop new cost-effective approaches for Occupational Employment Statistics and the National Compensation Survey (+\$2 million) that allow data users to see occupational trends over time by locality.
- Increase funding for cooperative agreements with States (+\$10 million) to enable State partners to produce a variety of labor market information that is critical for workers, educators and employers. Funding for these agreements has not risen in over a decade.

SUMMARY OF RECOMMENDED INCREASES

[Dollars in thousands]

Department of Labor	2014 Enacted	2015 Recommendation	Increase
Workforce Data Quality Initiative	6,000	6,463	463
Workforce Information/E-Tools/System Building	60,153	70,153	10,000
Bureau of Labor Statistics	592,212	615,212	23,000
Total Increase			33,463
Department of Education—Institute of Education Sciences			
Statewide Longitudinal Data Systems	34,539	70,000	35,461
Statistics	103,060	108,748	5,688
Total Increase			41,149

Thank you for the opportunity to comment.

[This statement was submitted by Rachel Zinn, Director, Workforce Data Quality Campaign.]