

**DEPARTMENTS OF LABOR, HEALTH AND  
HUMAN SERVICES, AND EDUCATION, AND  
RELATED AGENCIES APPROPRIATIONS FOR  
FISCAL YEAR 2017**

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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 AMERICA'S PUBLIC TELEVISION STATIONS AND THE  
PUBLIC BROADCASTING SERVICE

On behalf of America's 171 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 2019, \$50 million for the Public Television Interconnection System in fiscal year 2017 and \$25.7 million for the Ready To Learn program at the Department of Education in fiscal year 2017.

CORPORATION FOR PUBLIC BROADCASTING: \$445 MILLION (FISCAL YEAR 2019), 2-YEAR  
ADVANCE FUNDED

Local stations and PBS are committed to serving the public good in education, public safety, civic leadership, 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 bipartisan Hart Research Associates/American Viewpoint poll, nearly 70 percent of American voters, including majorities of Republicans, Independents, and Democrats, support Federal funding for public broadcasting. Additionally, 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 successful public-private partnership of locally owned and controlled, trusted, community servants.

*Education*

Local public television stations are America's largest classroom, meeting their communities' lifelong learning needs by providing the highest quality educational content and resources on multiple media platforms and in-person. Public television's exceptional content is available to nearly every household in America and 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 more than 1.8 million K-12 educators and users and 39,000 homeschoolers access more than 118,000 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. Overall, PBS LearningMedia helps teach 40 million students every day. Public television stations also operate virtual high schools that bring high-quality instruction in specialized fields to remote areas.

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 lower the drop-out rate in their communities. In partnership with others engaged in this work, American Graduate has helped raise the national high school graduation rate to 81 percent—an all-time high. In addition, by operating the most comprehensive non-profit GED programs in the country, public television stations have helped hundreds of thousands of individuals get their high-school equivalency certificate. Public television stations have also made it a top priority to help retrain the American workforce, including veterans, by providing digital learning opportunities for those looking for training, licensing, and more.

#### *Partners in Public Safety*

Public broadcasting stations throughout the country are leading innovators and irreplaceable partners to local public safety officers. In partnership with FEMA, the public television interconnection system provides the necessary redundant path for the Warning Alert and Response Network that enables cell subscribers to receive geo-targeted text messages in the event of an emergency—reaching citizens wherever they are. This digital infrastructure and public television's spectrum also enable stations to provide State and local officials with critical community emergency alert, public safety, first responder and homeland security services and information during emergencies through a process known as datacasting. Datacasting uses broadcast spectrum to send encrypted data and video to first responders with no bandwidth constraints. In partnership with local public television stations and local law enforcement agencies, the U.S. Department of Homeland Security recently conducted two pilots in Houston and Chicago demonstrating the efficacy of this technology for expanding emergency communications capabilities. Stations are increasingly partnering with their local emergency responders to customize and utilize public television's infrastructure for public safety in a variety of critical ways, with many serving as their States' Emergency Alert Service (EAS) hub for weather and AMBER alerts.

#### *Providing Civic Leadership*

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 often serve as the State-level "C-SPAN" by airing State government proceedings. Local stations also provide more public affairs programming, local history, arts and culture, candidate debates, specialized agricultural news, and citizenship information of all kinds than anyone else.

#### *Public Broadcasting is a Smart Investment*

All of this public service is made possible by the Federal funding to CPB that amounts to about \$1.35 per year, per American. This Federal investment sustains the public service missions of public television, which are distinct from the mission of commercial broadcasting and will not be funded by private sources, as the Government Accountability Office concluded in a 2007 study commissioned by the Congress. The need for Federal investment is particularly acute in small-town and rural America, whose lack of population density, shortage of corporate and philanthropic involvement, and challenging topography make the economics of local television and public service especially challenging. As a result, public broadcasters can be the only local broadcaster serving rural communities—and only with the help of the Federal investment. For all stations, Federal funding is the "lifeblood" of public broadcasting, providing indispensable seed money to stations to build additional support from State legislatures, foundations, corporations, and "viewers like you."

Thus, for every dollar in Federal funding, local stations raise six dollars in non-Federal funding, creating a strong public-private partnership and supporting approximately 20,000 jobs 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 accompanying educational materials—all of which contribute to extraordinary levels of public trust. For the thirteenth consecutive year, the American people have ranked PBS as one of the most trusted national institutions.

Local 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 the seed money for fundraising efforts at every station,

no matter its size. Advance funding also benefits the partnership between States and stations since many States operate on 2-year budget cycles. Finally, the 2-year advance funding mechanism gives stations and producers, both local and national, the critical lead time needed to raise the additional funds necessary to sustain effective partnerships with local community organizations and engage them around high-quality programs. Producers like Ken Burns spend years developing programs like *The Civil War*, *Cancer: The Emperor of All Maladies* and future programs on the history of the Vietnam War and the history of country music. It would be impossible to produce this in depth programming and the curriculum-aligned educational materials that accompanies it without the 2-year advance funding.

PUBLIC TELEVISION INTERCONNECTION SYSTEM: \$50 MILLION

The public television interconnection system is the infrastructure that connects PBS and national, regional and independent producers to every local public television station around the country. The interconnection system is essential to bringing public television's educational, cultural and civic programming to every American household, no matter how rural or remote. Without interconnection, there is no Nation-wide public media service. The interconnection system is also critical for public safety, providing key redundancy for the communication of presidential alerts and warnings, and ensuring that cellular customers can receive geo-targeted emergency alerts and warnings.

Congress recognized the need for interconnection when it created CPB and authorized it to "assist in the establishment and development of one or more interconnection systems" in the Public Broadcasting Act of 1967. As technology has advanced, public television has worked to make the interconnection system more efficient and cost-effective. Congress has always provided Federal funding for periodic improvements of the interconnection system including year-one funds in the fiscal year 2016 Omnibus. The previous two rounds of interconnection funding were provided by Congress in fiscal 1991–1993 and fiscal year 2004–2007.

*The Next Interconnection System*

Current interconnection satellite leases, support contracts, and existing financing expire on September 30, 2016. CPB and the public television system are committed to ensuring that the next interconnection system efficiently supports our universal service and public service commitments, while taking advantage of technological advances. PBS operates the interconnection system and is collaborating with CPB to design and implement a system that encompasses maximum efficiencies and supports emerging applications and expanded station collaboration.

Public television is very appreciative that Congress provided the funding necessary for the first year of this multi-year project in fiscal year 2016. For fiscal year 2017 \$50 million in interconnection funding is necessary to continue the essential work that is now underway. It is critical that Congress continue to provide interconnection funding in fiscal year 2017 to avoid any interruption of service to the millions of Americans served by PBS and over 350 noncommercial educational stations across the country.

READY TO LEARN: \$25.7 MILLION (DEPARTMENT OF EDUCATION)

The Ready To Learn (RTL) competitive grant program, recently reauthorized in the Every Student Succeeds Act, 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. 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.

*Results*

RTL is rigorously tested and evaluated to assess its impact on children's learning and to ensure that the program continues to offer children the tools they need to succeed in school. 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; use of RTL content has been associated with a 29 percent improvement in reading ability in children grades K–2; and parents who used RTL math resources in the home became considerably more involved in supporting their children's learning outcomes. In combination, RTL games, activities and videos provide early learners with the critical math and literacy skills needed to succeed in school.

*An Excellent Investment*

In addition to being research-based and teacher tested, RTL also provides excellent value for our Federal dollars. In the last 5-year grant round, public broadcasting leveraged an additional \$50 million in non-Federal funding to augment the \$73 million investment by the Department of Education for content production. RTL exemplifies how the public-private partnership that is public broadcasting can change lives for the better.

## 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 CPB’s federally appropriated Community Service Grants to public television stations are an irreplaceable source of revenue for public broadcasting, and a 2012 study conducted by an independent third party for CPB at Congress’s request came to the same conclusion. 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 2019 for the 2-year advance of the Corporation for Public Broadcasting, \$50 million in fiscal year 2017 for the Public Television Interconnection System and \$25.7 million in fiscal year 2017 for the Ready To Learn Program.

## PREPARED STATEMENT OF THE CORPORATION FOR PUBLIC BROADCASTING

Chairman Blunt, Ranking Member Murray, 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 2019, \$50 million in fiscal year 2017 for the replacement of the public broadcasting interconnection system, and \$25.74 million for Ready To Learn at the Department of Education.

Nearly 50 years after passage of the Public Broadcasting Act, this uniquely American public-private partnership is keeping its promise—to provide high-quality trusted content that educates, inspires, informs and enriches. Through the nearly 1,500 locally owned and operated public radio and television stations across the country, public media reaches nearly 99 percent of the American people—with an overwhelming majority of them consuming public media throughout the year.

Every day more people, businesses, organizations and foundations are committing their time and resources to support the work of public media. President Ronald Reagan said, “government should provide the spark and the private sector should do the rest.” The Federal appropriation remains the critical investment that ensures your constituents have access to public media for free and commercial free. America’s local public media stations utilize the “spark” of the Federal investment—approximately 10 to 15 percent of a stations’ budget—and raise the rest from non-Federal resources.

Private donations and existing funding sources can and do help defray costs for the much-honored programs of public television and radio. In fact, non-Federal funding represents five of every six dollars invested annually in public broadcasting. However, the Federal investment is indispensable to sustaining the operations of public broadcasting stations, capitalizing on the benefits of an integrated system, and fostering the public service mission they pursue: community-based accountability and a universal service to which the Public Broadcasting Act aspires. Over the years, congressionally mandated studies have concluded that there is no alternative to Federal funding when it comes to safeguarding the public media service that Americans know and love.

Our trusted, noncommercial services are 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. For these smaller stations serving rural, minority and other underserved communities, the Federal dollars provide much more than just a spark, in some cases CPB’s investment 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 educational content available to all children, including those who cannot afford pre-

school. Further, parents, caregivers and teachers repeatedly value public media content as the “most trusted.”

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. More than 20 years ago, Congress recognized the reach and potential of public media to help disadvantaged children become better prepared to enter school. Last year, Congress reaffirmed this belief in the Every Student Succeeds Act by reauthorizing Ready To Learn. For the next 5 years, public media will continue to provide coordinated and connected STEM and literacy learning experiences for children across multiple platforms, including TV, Internet, mobile, and in multiple settings, including in classrooms, summer and after-school programs, and at home.

While innovation on multiple platforms is important, television is still the primary tool to reach low-income and rural families. More than 80 studies have proven that Ready To Learn content builds and improves early literacy skills for high-need children, ages two to eight. Continued funding will allow public media to carry-on this critical work.

Public media is also differentiated from commercial media through content that matters and engagement that counts. An example of this is CPB’s “American Graduate” initiative, which puts faces behind the statistic of one million young people failing to graduate from high school every year. Our stations told the stories, and communities throughout the country responded. Over the past 5 years more than 120 public media stations located in at-risk communities in 49 States have worked with nearly 1,600 national and community-based partners to bring together diverse stakeholders and community organizations all working toward a national graduation rate of 90 percent by 2020. I am pleased to report that as a result of our and others combined efforts, in 2015, the high school graduation rate rose to 82 percent for the first time in our Nation’s history. However, much work remains and many stories remain untold.

Public media is utilizing today’s technology to provide content of value to millions of Americans. CPB strategically focuses its investments through the lens of what we refer to as the “Three D’s” —Digital, Diversity and Dialogue. This refers to support for innovation over multiple platforms; content that is for, by and about Americans of all backgrounds; and services that foster engagement between the American people and the public service media organizations that serve them.

Public media tells stories that are worth telling, worth watching and worth listening to. The Public Broadcasting Act ensures diversity in programming by requiring CPB to fund independent and minority producers. CPB fulfills this mission, 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. Moreover, 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.

What further distinguishes the power of public media is that our mission directs us to serve every American—not only on-air or online, but face to face in our communities. More than 70 percent of CPB’s appropriation goes directly to local stations who work closely with their communities to best serve local interests and concerns. This allows public media to work in partnership with people of diverse backgrounds, ensuring that we are listening to and reflecting the changing story of America.

Facing the reality that many communities are losing local news coverage because of cutbacks in commercial journalism outlets, CPB is helping stations support the production of more local news content. Since 2009, CPB has invested more than \$27 million to launch 22 local and regional newsroom collaborative operations. These partnerships connect 105 public media stations in 37 States, providing the basis for a vibrant multimedia network of high-quality journalism.

In the coming years, public media has an opportunity to help fill the widening substantive news gap left by weak local newspapers. CPB’s goal is to support and encourage public media organizations and producers to operate as a true news network—one that routinely works together to strengthen both the signature national programs and the local/regional news, reaching more of the American people more often on more platforms with more compelling journalism.

The work of public media goes well beyond broadcast. Public television and radio stations are increasingly effective partners with State and local public safety, law enforcement and first responder organizations—connecting these agencies with one another, with the public, and with vital data-casting capabilities in times of crisis.

Further, CPB is supporting stations, both financially and by defining best practices, so they can create more public-private partnerships, bringing more services and benefits to their communities. One example of this local public-private partnership is CPB's Veterans Coming Home initiative. Stations and their partners are communicating veterans' stories through award winning reporting, documentaries, and online content; convening local events such as town hall meetings that connect veterans with resources; and collaborating with local veterans' organizations to identify services available to them.

Ever since the FCC set aside a block of spectrum exclusively for non-commercial educational use in 1953, public media has been efficiently utilizing this spectrum as a vehicle to serve families all across America. The FCC's upcoming spectrum incentive auction and subsequent repacking process present a unique set of challenges for public media.

Unlike commercial broadcast stations, where auction decisions will be made at the corporate level, public television stations are locally owned and operated, so each station will directly incur the costs of the auction and repacking process. Not all of these costs will be covered by auction proceeds, nor is it certain that the \$1.75 billion that Congress has set aside for repacking will be sufficient. Indeed, many stations that do not participate in the auction will still have to spend time and resources on the mandatory repacking process.

Finally, it must be understood that CPB will not receive any auction proceeds. Further, public broadcasting license holders that participate in the auction are not required to invest their proceeds in a public media service. The auction brings an air of uncertainty to public television service both in terms of future signal coverage and financial impact. The continued Federal investment will help safeguard this valued service for all Americans.

#### INTERCONNECTION

Interconnection is the backbone of the public broadcasting system, delivering content every day from public media producers to the locally owned and operated public television and radio stations in communities throughout the country. Without it, there is no nationwide public media service. Congress recognized the need for an interconnection system in 1967 when it passed the Public Broadcasting Act. It has always funded the interconnection system, and has provided a separate appropriation for interconnection since fiscal year 1991.

As we near the expiration of our current interconnection system for both television and radio, CPB must plan for the next generation of interconnection. Technology and distribution systems have greatly evolved since Congress established its practice of funding interconnection. Today, an expansive range of technologies, including satellite, cloud and terrestrial broadband, is widely available to create the most cost effective and efficient means to distribute content to public broadcasting stations. We are grateful for Congress's \$40 million initial investment in the public broadcasting interconnection system in fiscal year 2016 and would appreciate your continued support for this essential infrastructure.

#### CONCLUSION

Public media's treasure trove of content and services is available to all Americans for about \$1.35 per American per year. As a result of the Federal investment, public media stations are able to connect to people's lives in impactful ways—ensuring every child is ready to learn, every person has access to lifelong learning; every veteran can connect to resources and support; and every citizen has access to fact-based local, national and global journalism. We make the arts accessible to all Americans and provide emergency alert services for first responders. CPB ensures that 95 cents of every dollar it receives 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.

CPB's fiscal year 2019 request of \$445 million and fiscal year 2017 requests of \$50 and \$25.74 million for interconnection and Ready To Learn, respectively, balance 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 attention to education, innovation, and collaboration.

Public media has been inspiring and enriching our lives for nearly half a century, and Congress' support of our request will allow stations to continue providing high-quality trusted content that educates, informs, and strengthens our civil society. Mr. Chairman and members of the subcommittee, this is only part of the story of America's public media system. Public media is truly a national treasure. I thank you

for allowing me to submit this testimony and appreciate your consideration of our request for funding.

[This statement was submitted by Patricia de Stacy Harrison, President and CEO, Corporation for Public Broadcasting.]

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PREPARED STATEMENT OF THE NATIONAL PUBLIC RADIO

Dear Chairman Blunt, Senator Murray and Members of the Subcommittee: Thank you for this opportunity to urge the Subcommittee's support for an annual Federal investment of \$445 million to public broadcasting through the Corporation for Public Broadcasting, (CPB) for fiscal year 2019. Public radio joins with our public television partners in urging the Subcommittee's support for \$50 million in fiscal year 2017 for the second year of a multi-year request to upgrade interconnection for the public broadcasting system. With your support, and these essential funds, every American will continue to have free access to the best in public service journalism, music, news, educational, entertainment and cultural programming.

I offer this testimony on behalf of the public radio system, a uniquely American public service, non-for-profit media enterprise that includes NPR, our more than 950 independently owned local member stations, other producers and distributors of public radio programming including American Public Media (APM), Public Radio International (PRI), the Public Radio Exchange (PRX), and many stations, both large and small, rural and urban, that create and distribute content through the Public Radio Satellite System (PRSS).

The annual demonstration of support by Congress to CPB helps to sustain and enhance a system that is wholly representative of its users in our country. While just a tiny fraction (0.01 percent) of the entire Federal budget goes to CPB, you help support one of America's most successful community-centric programs. With the money provided by Congress, local stations are able to raise \$6 for every Federal grant dollar they are awarded. This Federal financial investment permits local stations to invest more deeply in their own local news and cultural programming and participate in CPB-backed regional news collaborations with stations across the country. This in turn enables our stations to provide the American public with an enduring and daily return on investment that is heard, seen, read, and experienced in public radio broadcasts, apps, podcasts, and on online.

With support from CPB's community service grants, each of the hundreds of independently operated public radio stations is responsible for curating and creating the mix of programs that best addresses the needs of their local community. Local stations and their programming choices are as diverse as the people who live in the communities they serve. Some have all-news formats. Others have all-music formats and still other blend news, talk, commentary and music into their program offerings. Close to thirty percent of our stations' daily programming is locally generated. Every year the Federal Government invests roughly \$90 million dollars in the operation of America's local public radio stations. And these stations provide service to all of America's communities.

Each public radio station operates autonomously, but they are all interconnected through a single satellite service that allows Americans to receive free and universal access to a wide array of content and services from local, national and international reporters and producers. The Public Radio Satellite System reaches 95 percent of the U.S. population, making a community's local station the single most reliable source for public safety information in an emergency or natural disaster situation. PRSS fulfills an important mission by providing a common, shared platform for secure, reliable, cost-effective and efficient distribution of all public radio content including news, music, cultural, educational and entertainment programming to almost 1,600 stations across the country that serve an increasingly diverse population. As part of that mission, the PRSS provides satellite transmission services to distribute programming that reaches under-served audiences and rural areas.

With the combined strength of public radio's role as a trusted media and information resource and the interconnected of the PRSS serving as an essential public-safety asset, U.S. consumers are urging the mobile phone industry to install and activate FM chips in all cellphones and smart phones. During every hurricane, tornado, flood, earthquake, blizzard and wildfire, local public radio stations play an essential role in conveying information about response efforts, local relief supplies, evacuation orders, emergency routes and where to find food, shelter and fuel, as well as on-the-ground, and at-the-scene reporting to help affected communities understand and respond. Now is the time for major cell carriers and manufacturers to activate FM chips in their mobile devices.

Our overarching goal is to ensure that we are serving our audience wherever they are, and however they are finding us, with exceptional journalism, balancing the needs of our traditional broadcast listeners with those whose connection to public radio's work is through our many digital platforms. With more than 1,400 journalists in nearly 200 newsrooms across America, public radio is already an essential part of people's lives. The opportunity now is to share expertise between our journalists to make our local, regional and national stories even better. Collaborative reporting helps local stories spread national and give national stories unique local perspective by leveraging the ideas, the money and the system that are already in place. For example, the CPB supported New England News Collaborative (NENC) will produce multimedia coverage focusing on the region's energy usage, climate, transportation infrastructure, and its people and immigration issues. This robust partnership will produce dynamic reporting projects for on-air broadcast, digital and web presentations, and a series of public Town Hall-style meetings designed to discuss and debate the issues facing New England and its residents.

Public radio's culture of innovation is evident in the system's commitment to the news collaborations. The base of public radio's efforts to improve news collaboration are strengthened by NPR One, the audio app that connects listeners to a stream of public radio news, stories and podcasts curated for the listener. A service that is not provided anywhere else- making news and information accessible for all citizens via mobile device. News of the listener's community is seamlessly woven into the listening experience, informing, engaging, inspiring and surprising. This creates access for an individual to be informed and up to date at all times, whether they have a transistor radio available or not.

Stations continue to adapt their coverage to meet their community's needs. In Missouri Chairman Blunt, St. Louis Public Radio is making their mission in news to help the people of the region understand this moment in history, appreciate their culture, recognize their strengths, while meeting challenges and embracing opportunities. The Ferguson Project is a locally produced focused effort to illuminate and explain the events that have happened and the wide-ranging conversation that is going on for the citizens of Missouri. In addition, St. Louis on the Air creates a unique local space where guests and listeners can share ideas and opinions. Whether exploring issues and challenges confronting the region, discussing the latest innovations in science and technology, taking a closer look at history or talking with authors, artists and musicians, St. Louis on the Air brings the stories of St. Louis and the people who live, work and create in the region. Also, We live Here explores the issues of race, class and power that led to the emotional eruption in the wake of Michael Brown's shooting death in Ferguson by providing an in-depth exploration of how systematic racism impacts people and the well-being of the region.

In Central Washington, Northwest Public Radio and Spanish-language public radio station KDNA established a bilingual news reporting team. The new initiative pairs the talents of the two stations to bridge the cultural and linguistic gaps between communities by combining their reporting and digital services teams and tackling the issues of their respective communities, bilingually. Northwest Public Radio also provides a forum for Listener Stories to be shared; how the public service is incorporated into their routines, the benefits they gain, and the gifts of Public Radio they hope to leave behind to future generations. Also, Ask the Governor is a locally run program where Governor Jay Inslee takes questions about State Government and hears ideas from the community about how Washington can improve. The public service show has been opening up dialogue between Washington citizens and government since 1993.

Federal funding for public broadcasting is a small investment that pays big dividends. And when it comes to music, public radio plays a unique and critically important role. We have created a value partnership that connects music and those who devote their lives to it from artists, performers and composers to audiences. Our local stations play a significant role in music discovery, preservation, education, diversification and local music economies. And this role is enabled by CPB's community service grants to local public radio stations.

Nationally, more than 400 public radio stations have full-time music formats and an additional 747 play music as part of their programming lineups. Local public radio stations air more than 5.6 million hours of music per year, the majority of which is local programming. In addition to prerecorded music, member stations host more than 10,000 in-studio and community-based performances.

With music platforms changing so dramatically in the last 10 years, public radio provides a home for genres that are economically unsustainable in the commercial market, including classical, jazz, folk, opera and traditional regional music such as bluegrass and zydeco. In fact, over 90 percent of all broadcast classical music in America is available only on public radio, and the same is quickly becoming true



for jazz. Our stations help support and preserve cultural institutions, including local bands, symphony orchestras, philharmonic societies, theater groups, and historical venues. Public radio's role in music is not possible without a diverse revenue base, including CPB's financial support to local stations.

Mr. Chairman and Senator Murray, NPR and the public radio system are committed to being America's public radio where rationale, fact-based, accurate and civil reporting and conversation are our top priorities. We have no political agenda and we do not take sides. Public radio plays an important, significant and growing role in news, journalism, talk and music/cultural programming across all age groups. Our stations are essential to, and part of, the communities they serve.

Through news, talk, music and cultural programming, public radio stations are reaching out to audiences wherever they are with the content their audience wants. We're embracing America's changing demographics and using digital media and news collaborations 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.

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

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#### PREPARED STATEMENT OF THE RAILROAD RETIREMENT BOARD

Mr. Chairman and Members of the Committee: We are pleased to present the following information to support the Railroad Retirement Board's (RRB) fiscal year 2017 budget request of \$122,499,000 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 (RRA) and Railroad Unemployment Insurance (RUIA) Acts. The RRB also has administrative responsibilities under the Social Security Act for certain benefit payments and Medicare coverage for railroad workers and special economic recovery payments and extended unemployment benefits under a variety of public laws.

During fiscal year 2015, the RRB paid \$12.2 billion, net of recoveries, in retirement/survivor benefits to about 558,000 beneficiaries. We also paid \$85.1 million in net unemployment/sickness insurance benefits to about 25,000 claimants. Temporary extended unemployment benefits paid were \$8,625 million. In addition, the RRB paid benefits on behalf of the Social Security Administration amounting to \$1.5 billion to about 111,000 beneficiaries.

#### PROPOSED FUNDING FOR AGENCY ADMINISTRATION

The RRB faces major challenges in its mission to pay benefits and serve as responsible stewards for our Customer's Trust funds and agency resources. Those areas of challenge include agency staffing, information technology, and program integrity. The President's proposed budget would provide \$122,499,000 for agency operations. This level of funding includes \$6.1 million toward a multi-year plan to re-engineer legacy mainframe applications while maintaining 850 full-time equivalents (FTEs). Historically, however, the enacted level of funding awarded to the RRB, has not been sufficient to implement significant improvements and initiatives in our most challenging areas. The remainder of this testimony will focus on these areas with a few additional topics in conclusion.

#### AGENCY STAFFING

The RRB's dedicated and experienced workforce is the foundation for our tradition of excellence in customer service and satisfaction. Eighty-percent of our administrative expense is for labor. Like many Federal agencies, however, the RRB has a number of employees at or near retirement age. About 55 percent of our employees have 20 or more years of service, and over 40 percent of our current workforce will be eligible for retirement by fiscal year 2017. Based on trend analysis of our position index, hiring plans, and full-time equivalent (FTE) reporting of attritions and accessions from 2010 through 2016, the RRB has attrited half of its agency.

Almost half of our staff has been replaced. The agency has been able to utilize the re-employment of retirees under the Civil Service and FERS to temporarily re-hire under Section 1122(a) of Public Law 111-84 and assist in areas that have knowledge gaps due to attrition. The implementation of Learning Management System (LMS), an Internet-based software package that provides comprehensive

functionality for training administration, documentation, tracking, reporting and delivery of e-learning education and training programs supports the agency's efforts for continued excellence in our workforce. Although 850 is the FTE level the RRB can maintain for fiscal year 2017 President's Budget in order to leverage funds to support information technology (IT) and program integrity initiatives, the agency would be at-risk if such strategy was used for fiscal year 2018 and out-years as our attrition rate is expected to take a significant downturn from 7 separations/retirements per month to 4 separations/retirements per month now that half of our workforce over 6 years is replaced. At a minimum, the agency needs to be able to restore FTE funding to 860 starting with fiscal year 2018, and maintain an 885 FTE level in the out-years to address our most vital costs, which is sustaining our workforce.

#### INFORMATION TECHNOLOGY IMPROVEMENTS

The President and the Office of Management and Budget (OMB) have challenged agencies to create a 21st Century Government. Although we are not a CFO Act agency, we are classified as a significant entity for Federal Government audit and reporting purposes. The RRB has chosen to be progressive in implementing initiatives and improvements. In fiscal year 2017, \$6.1 million in IT requested funding is targeted toward system modernization to re-engineer mainframe applications that build on prior year investments. Fiscal year 2016 enacted funding provided no such investments. As a result, the agency is taking risk in the current year of \$2 million in support of the agency's critical need to migrate over 14 million lines of common business-oriented language (COBOL) code that support more than 4,200 custom programs included in 200 major application systems. We awarded a contract in fiscal year 2015 to implement the conversion, subject to funds availability. We have taken risk in our fiscal year 2016 Operating Plan to leverage funds of \$2 million towards this legacy benefit system modernization contract. We took this risk because in addition to mitigating cybersecurity risks of operating legacy systems, enhancing data analytics capabilities towards stronger program integrity measures, and creating 26 FTE savings that can be accrued from change in business processes, a large number of the agency's technology employees are at or nearing retirement age. As the years go by, the skills required to enhance and maintain legacy benefit systems, especially developers with COBOL skills, will be hard to find. By re-engineering the applications, we mitigate the inherent risks of an aging workforce of which 40 percent can retire today, some taking with them the institutional knowledge of over 40 years. Given that technology advances rapidly, it is essential that we have the ability to modernize business applications.

Fiscal year 2017 funding of \$6.1 million for legacy benefit system modernization, if received, will re-engineer critical legacy mainframe applications to sustain agency operations and enable a future ready RRB workforce equipped with modern tools and technologies to do their jobs in the most efficient and effective manner that leads to sustained customer satisfaction in the railroad community. The RRB would be able to revolutionize the current applications development environment to make it flexible to accommodate change and embrace new technologies. Each year that enacted funding does not equal the agency's request for system modernization, contract work will have to stop as we enter fiscal year 2017 and jeopardizes the success of the on-going project.

#### PROGRAM INTEGRITY

Fiscal year 2017 President's Budget also provides approximately \$4.3 million in mandatory no-year funding for the RRB's program integrity activities. In light of recent fraud events that have impacted the agency, the RRB must increase staff disability oversight, improve existing program integrity functions, and implement initiatives to target groups of annuitants most likely to commit medical and/or earnings fraud. The proposed \$4.3 million was determined based on a review of current operations as well as disability recommendations from the Government Accountability Office and the RRB's Office of the Inspector General. The RRB takes its program integrity initiatives very serious and increased its standards significantly.

These new standards come at a cost greater than what the agency continually absorbs from enacted funds provided. In the current fiscal year, the agency has experienced increased costs of at least \$2.5 million in the area of medical examinations, training and staffing. As long as we continue to absorb program integrity cost increases in our baseline budget without receiving mandatory funding, the RRB risks having to halt system modernization efforts and perform fragmented staffing efforts of workforce after fiscal year 2017.

The proposed funding is for staffing costs and contractual costs. Augmented staff includes four people dedicated to quality assurance and seven people dedicated to

program evaluation through such activities as oversight of fraud prevention initiatives, special studies, and the development and implementation of enhanced procedures critical to program integrity. An additional six employees will support enhanced emphasis on initial eligibility and continuing entitlement to benefits. A Chief Medical Officer will be hired to provide assistance and guidance to agency staff in the adjudication of disability claims, work with our medical contractors and develop processes to ensure disability examiners have updated training. Contractor costs include on-going annual fraud training for employees at all levels of the organization and confirming medical exams for all initial disability applications.

The RRB has proven to be a good investment for program integrity over the years. Our program integrity efforts save the Trust Fund from which railroad benefits are paid an estimated \$4.49 for each \$1 spent on program integrity activities.

#### LEGISLATIVE PROPOSALS

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.

Our budget request includes two additional legislative proposals. The first is to amend the RRA and the RUIA to include a felony charge for individuals committing fraud against the agency. The second is to amend the Social Security Act to provide access for the RRB to the National Directory of New Hires (NDNH). Access to NDNH supports the RRB's integrity efforts to prevent improper payments.

#### FINANCIAL STATUS OF THE TRUST FUNDS

*Railroad Retirement Accounts.*—The RRB continues to coordinate its activities with the National Railroad Retirement Investment Trust (Trust), which was established by the Railroad Retirement and Survivors' Improvement Act of 2001 (RRSIA) to manage and invest railroad retirement assets. Pursuant to the RRSIA, the RRB has transferred a total of \$21.276 billion to the Trust. All of these transfers were made in fiscal years 2002 through 2004. The Trust has invested the transferred funds, and the results of these investments are reported to the RRB and posted periodically on the RRB's website. The net asset value of Trust-managed assets on September 30, 2015, was approximately \$24.5 billion, a decrease of almost \$1.6 billion from the previous year. Through February 2016, the Trust had transferred approximately \$18.3 billion to the Railroad Retirement Board for payment of railroad retirement benefits.

The RRB's latest report required by the Railroad Retirement Act of 1974 and Railroad Retirement Solvency Act of 1983 was released in September 2015. The overall conclusion is, barring a sudden, unanticipated, large decrease in railroad employment or substantial investment losses, the railroad retirement system will experience no cash flow problems during the next 32 years. The report recommended no change in the rate of tax imposed on employers and employees. The tax adjustment mechanism will automatically increase or decrease tax rates in response to changes in fund balance. Only under the most pessimistic employment assumption does the tax rate mechanism not avoid cash flow problems.

*Railroad Unemployment Insurance Account.*—The RRB's latest annual report required by Section 7105 of the Technical and Miscellaneous Revenue Act of 1988 was issued in June 2015. The report indicated that even as maximum daily benefit rates rose approximately 39 percent (from \$70 to \$97) from 2014 to 2025, experience-based contribution rates are expected to keep the unemployment insurance system solvent.

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 Walter A. Barrows, Labor Member and Steven J. Anthony, 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 2017 would provide \$10,499,000 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 2017, 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 2017, 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 six broad areas of potential audit coverage: Financial Accountability; Railroad Retirement Act and Railroad Unemployment Insurance Act Benefit Program Operations; RRB Contracts and Contracting Activities; Railroad Medicare Program Operations; Security, Privacy, and Information Management; and Improper Payments Act of 2010 Oversight.

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); audit of the RRB's compliance with the Improper Payments Elimination and Recovery Act of 2010; review of IG Requirements for Government Charge Card Abuse and Prevention Act of 2012; assessments required under the Digital Accountability and Transparency Act of 2014; and semi-annual reporting in accordance with the Inspector General Act of 1978, as amended.

During fiscal year 2017, OA will complete the audit of the RRB's fiscal year 2016 financial statements and begin its audit of the agency's fiscal year 2017 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.

The portion of OA resources dedicated to conducting mandated audits continues to increase substantially. In fiscal year 2015, approximately 50 percent of direct audit time was spent completing mandated audits. While mandated work results in important audit findings and increased agency oversight, it also limits other audits that can be undertaken without an increase in resources.

OA currently reports on seven major challenges facing the RRB. Additional resources will make it possible for OA to provide additional oversight to these programs that represent billions in taxpayer dollars.

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 utilizes a strategic planning process to focus on areas affecting program performance, the efficiency and effectiveness of agency operations, and areas of potential waste, fraud and abuse. OA also considers staff availability, current trends in management, and 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 2015

Civil Judgments	Indictments/Informations	Convictions	Recoveries/Receivables
27	49	43	<sup>1</sup> \$203,692,184

<sup>1</sup>This total amount of financial accomplishments reflect fraud amounts related to programs administered exclusively by the RRB and fraud amounts from other Federal Programs such as Medicare or Social Security, which were included in the disposition resulting from the investigation.

OI anticipates an ongoing caseload of about 350 investigations in fiscal year 2017. During fiscal year 2015, OI opened 186 new cases and closed 212. At present, OI has cases open in 48 States, the District of Columbia, and Canada with estimated fraud losses of over \$596 million. Disability and Medicare 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 related to a large number of individuals in New York. To date, this investigation has resulted in 33 individuals pleading guilty or being convicted in Federal court. All individuals prosecuted in connection with this case have been sentenced. This investigation is continuing, and there is the potential for more charges in this case. OI agents will likely have to spend a considerable amount of time traveling to New York for continuing investigations. Based on this investigation, the OI has initiated several other large scale disability investigations that could result in significant charges being filed.

The OI continues to work joint cases with other Offices of Inspector General and Federal law enforcement agencies that have responsibility for healthcare fraud matters. Medicare fraud investigations currently represent approximately 18 percent of OI's total caseload and more than \$378 million in fraud losses. OI's collaborative joint investigative efforts ensure that RRB beneficiaries are protected from sham medical practitioners, and that the Railroad Medicare program's interests are safeguarded from fraudulent schemes.

During fiscal year 2017, OI will continue to coordinate its efforts with agency program managers to address vulnerabilities in benefit programs that allow fraudulent activity to occur and will recommend changes to ensure program integrity. OI plans to continue proactive projects to identify fraud matters that are not detected through the agency's program policing mechanisms.

Findings will be conveyed to agency management through OIG systemic implication reports to alert officials of operational weaknesses that may result in fraud against RRB programs. OI will also continue to work with RRB program managers to ensure appropriate and timely referral of all fraud matters to the OIG.

#### CONCLUSION

In fiscal year 2017, 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 fami-

lies. 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 GENERAL DENTISTRY

Dear Chairman Blunt and Ranking Member Murray: On behalf of the Academy of General Dentistry (AGD) and its 39,000 national membership, I am writing to respectfully request the inclusion of the following report language in the Labor-HHS appropriations bill for fiscal year 2017. Our requests focus on the critical issue of oral health literacy and the importance of maintaining a well-trained and robust oral health workforce.

Oral disease left untreated can result in pain, disfigurement, loss of school and work days, nutritional deficiencies, expensive emergency department use for preventable dental conditions, and even death. Despite these grim outcomes, studies show that regardless of insurance status and income, many individuals forgo preventive and needed dental services because the relationship between good oral health and overall health is not well understood.

The AGD feels strongly that the importance of prevention in the form of oral health literacy is often overlooked—especially by the Federal agencies—much to the detriment of our Nation’s oral health needs. Our goal with the enclosed language is to push agencies that play an important role, like HRSA, to step up on this issue and make oral health literacy a top public health priority.

Therefore, we recommend that you consider the following language to be included in the Committee Report at the appropriate point with respect to either Training in Oral Health Care and/or Rural Health:

The Committee encourages HRSA to work with the States to develop and facilitate public education programs that promote preventive oral health treatments and habits via increased oral health literacy in rural and underserved areas. The Committee believes that prevention-centered programs represent a cost effective way to address oral health access. The Committee also encourages the Office of Rural Health Policy to support these programs. Further, the Committee encourages HRSA to include innovative public education programs as eligible for funding as part of the State Oral Health Workforce Improvement Program.

We also ask that the Committee continue its investment in our Nation’s oral health by fully funding HRSA’s Title VII Primary Care Dental Training Cluster and Related Oral Health Programs, and to again include a \$10 million set-aside for general dentistry residencies and a \$10 million set-aside for pediatric dentistry residencies within the funds provided. Title VII grantees play a key role in diversifying the dental workforce and providing outreach and services to underserved and vulnerable populations, resulting in better oral health for many Americans.

Relatedly, we ask that the Committee request \$875,000 for section 748 authority for the Dental Faculty Loan Repayment Program and include language directing HRSA to issue a new grant cycle for fiscal year 2017 from the funding provided. Please see below for our suggested language pertaining to these Title VII requests:

*Title VII—Dental Workforce*

Sec. 748. Within the funds provided, the Committee intends no less than \$10,000,000 for General Dentistry Programs and no less than \$10,000,000 for Pediatric Dentistry programs. The Committee provides \$875,000 for section 748 authority for the Dental Faculty Loan Repayment Program. The Health Resources and Services Administration (HRSA) is directed to publish a new funding opportunity and then award grants in fiscal year 2017 from the funding provided.

The AGD thanks you and the Committee for your consideration and encourages you to contact Daniel J. Buksa, JD, Associate Executive Director, Public Affairs, by email at [daniel.buksa@agd.org](mailto:daniel.buksa@agd.org) should you have any questions concerning our report language requests.

Thank you again for your ongoing support of and commitment to improving oral health for all Americans.

Sincerely,

[This statement was submitted by W. Mark Donald, DMD, MAGD, President, Academy of General Dentistry.]

## PREPARED STATEMENT OF THE ACADEMY OF NUTRITION AND DIETETICS

We are pleased to submit this testimony to the Members of this Subcommittee on the urgency of continuing to support the Ryan White Program through the Ap-

propriations process and increasing funding for the domestic HIV/AIDS portfolio in fiscal year 2017. This support and funding will be decisive for achieving the goals of the National HIV/AIDS Strategy (NHAS) 2020, the AIDS Free Generation and halting the devastating effects of the HIV Treatment Cascade.

The Academy of Nutrition and Dietetics (the “Academy”) is part of a nationwide coalition, the Food is Medicine Coalition, of over 80 food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PWH) and other chronic illnesses. The Academy, with 76,000 members throughout the Nation, is the world’s largest organization of food and nutrition professionals, committed to improving the Nation’s health through healthy and safe food choices. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

#### *Why Food and Nutrition Services (FNS) Matter for PWH*

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient’s overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PWH at any stage of their illness. For those who are most mobile, there are congregate meals, walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective core medical service in the Ryan White Program. These services play a critical role in ensuring that PWH enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

#### *FNS as a Care Completion Service Unique to Ryan White*

Social and economic interventions, most often in the form of care completion service like food and nutrition services, are fundamental to making healthcare work for PWH. Support services for PWH are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life’s emergencies are held at bay, PWH are poised to remain connected to care and treatment.

#### *Access to FNS and the Triple Aim*

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PWH.

#### BETTER HEALTH OUTCOMES

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines.<sup>1</sup> Studies show both

<sup>1</sup>Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at [https://www.health.ny.gov/diseases/aids/ending\\_the\\_epidemic/docs/key\\_resources/housing\\_and\\_supportive\\_services/chain\\_factsheet3.pdf](https://www.health.ny.gov/diseases/aids/ending_the_epidemic/docs/key_resources/housing_and_supportive_services/chain_factsheet3.pdf).



the health benefits of access to MNT and/or nutrition counseling for people with HIV infections<sup>2</sup> and the resulting decreases in their healthcare costs. Compare these outcomes to PWH who are food insecure, who have:

- Lower CD4 counts & lower likelihoods of having undetectable viral loads<sup>3</sup>
- More ER visits<sup>4</sup> & increased morbidity and mortality<sup>5</sup>
- More missed primary care appointments & reduced use of antiretroviral therapy.<sup>6</sup>

#### LOWER HEALTHCARE COSTS

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PWH. A recent study comparing participants in a medically-tailored FNS program vs. a control group within a local managed care organization found that average monthly healthcare costs for PWH fell 80 percent in first 3 months after receiving FNS.<sup>7</sup> If hospitalized, nourished clients' costs were 30 percent lower, their hospital length of stay was cut by 37 percent and they were 20 percent more likely to be able to be discharged to their homes rather than a more expensive institution.<sup>8</sup> Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

#### IMPROVED PATIENT SATISFACTION

Studies show nutrition counseling improves quality of life.<sup>9</sup> Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

#### *FNS and the National HIV/AIDS Strategy (NHAS)*

Access to FNS for PWH is fundamental to fulfilling the goals of the NHAS.

—NHAS Goal: Reducing new HIV infections: PWH who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96 percent of the time,<sup>10</sup> thus, FNS is key to prevention.<sup>11</sup>

—NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV: PWH who receive effective FNS are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines.<sup>12</sup>

<sup>2</sup>Academy of Nutrition and Dietetics (formerly American Dietetic Association). HIV/AIDS Nutrition Evidence Analysis Project at [http://www.adaevidencelibrary.com/conclusion.cfm?conclusion\\_statement\\_id=250707](http://www.adaevidencelibrary.com/conclusion.cfm?conclusion_statement_id=250707) Accessed 29 July 2012.

<sup>3</sup>Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011); Singe AW, Weiser SD, McCoy, SI. Does Food Insecurity Undermine Adherence to Antiretroviral Therapy? A Systematic Review. *AIDS Behav* (2015) 19:1510–1526.

<sup>4</sup>Ibid.

<sup>5</sup>Anema A, Chan K, Yip B, Weiser S, Montaner JSG, Hogg RS. Impact of food insecurity on survival among HIV-positive injection drug users receiving antiretroviral therapy in a Canadian cohort. 141st APHA Annual Meeting, Nov. 2–6, 2013. Boston, MA. Abstract #: 290277.

<sup>6</sup>Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).

<sup>7</sup>Gurvey J, Rand K, Daugherty S, Dinger C, Schmeling J, Laverty N. Examining Health Care Costs Among MANNA Clients and a Comparison Group. *J Prim Care Community Health*. (2013) 4:311–317.

<sup>8</sup>Ibid.

<sup>9</sup>Rabeneck L, Palmer A, Knowles JB, Seidehamel RJ, Harris CL, Merkel KL, Risser JMH, Akrabawi SS. A randomized controlled trial evaluating nutrition counseling with or without oral supplementation in malnourished HIV-infected patients. *J Am Diet Assoc*. (1998) 98: 434–438; Schwenk A, Steuck H, Kremer G. Oral supplements as adjunctive treatment to nutritional counseling in malnourished HIV-infected patients: randomized controlled trial. *Clinical Nutrition* (1999) 18(6): 371–374.

<sup>10</sup>M. S. Cohen et al., Prevention of HIV-1 Infection with Early Antiretroviral Therapy. *N. Engl. J. Med.* (2011) 365, 493–505. HPTN 052.

<sup>11</sup>Palar K, Laraia B, Tsai A, Weiser SD Food insecurity is associated with sexually transmitted infections and HIV serostatus among low income adults in the National Health and Nutrition Examination Survey (NHANES) (1999–2010). Presented at the American Public Health Association 141st Annual Meeting, Boston, MA, November 5, 2013.

<sup>12</sup>Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014.

- NHAS Goal: Reducing HIV-related disparities and health inequities: By providing FNS to PWH who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities.<sup>13</sup>
- NHAS Goal: Achieving a more coordinated national response to the HIV epidemic: There remains a tremendous variation by State in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White HIV Program all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including Ryan White and the ACA.

#### CONCLUSION

We are deeply aware of the difficult decisions that face the members of the Subcommittee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PWH live healthy and productive lives, produces better overall health outcomes and reduces healthcare costs.

Along with our colleagues, we appreciate the opportunity to offer this testimony regarding the fiscal year 2017 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Respectfully submitted.

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

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#### 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 strengthening the Federal investment in biomedical, behavioral, social, and population-based research conducted and supported by the National Institutes of Health (NIH).

The Ad Hoc Group is deeply grateful to the Subcommittee for its long-standing and bipartisan leadership in support of NIH, as demonstrated most recently by the \$2 billion increase provided in the fiscal year 2016 omnibus spending bill. We believe that science and innovation are essential if we are to continue to meet current and emerging health challenges, improve our Nation's health, and sustain our leadership in medical research.

If this Nation is to continue to accelerate the development of life-changing cures, pioneering treatments, and innovative prevention strategies, it is essential to sustain predictable increases in the NIH budget.

The Ad Hoc Group recommends that Congress appropriates at least \$34.5 billion through the Labor-HHS-Education spending bill for fiscal year 2017. This \$2.4 billion increase represents 5 percent real growth above the projected rate of biomedical inflation, and will help ensure that NIH-funded research can continue to improve our Nation's health and enhance our competitiveness in today's global information and innovation-based economy.

We share the bipartisan enthusiasm in Congress for the potential that NIH-supported research holds in improving the health and well-being of all Americans. We look forward to working with appropriators to secure an increase of 5 percent real growth in fiscal year 2017 for NIH as the next step to ensuring stability in the Nation's research capacity over the long term. We also stand ready to work with authorizers on unique mechanisms to take full advantage of the exceptional scientific opportunities now available and to meet current and emerging health challenges.

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<sup>13</sup>Weiser SD, Frongillo EA, Ragland K, Hogg RS, Riley ED, Bangsberg DR. Food insecurity is associated with incomplete HIV RNA suppression among homeless and marginally housed HIV-infected individuals in San Francisco. *J Gen Intern Med.* (2009) 24(1):14–20.

*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 translate this knowledge into the next generation of diagnostics, therapeutics, and other clinical innovations. Nearly 84 percent of the NIH's budget is competitively awarded through more than 55,000 research and training grants to more than 300,000 researchers at over 2,500 universities and research institutions located in every State.

The Federal Government has an essential and 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 basic research necessary to yield new innovations and technologies of the future.

NIH has supported biomedical research to enhance health, lengthen life, and reduce illness and disability for more than 100 years. The following are a few of the many examples of how NIH research has contributed to improvements in the Nation's health.

- The death rate for all cancers combined has been declining since the early 1990s for adults and since the 1970s for children. Overall cancer death rates have dropped by about 1.5 percent per year, or nearly 15 percent in total from 2003—2012. Research in cancer immunotherapy has led to the development of several new methods of treating cancer by restoring or enhancing the immune system's ability to fight the disease. As researchers develop new approaches to overcoming tumor avoidance of immune destruction and new methods for identifying antigens on tumor cells that can be targeted most effectively, immunotherapy is becoming an integral part of precision medicine.
- Deaths from heart disease fell 67.5 percent from 1969 to 2013, through research advances supported in large part by NIH. The Framingham Heart Study and other NIH-supported research have identified risk factors for heart disease, such as cholesterol, smoking, and high blood pressure. This work has led to new strategies for preventing heart disease.
- Since 1950, the stroke mortality rate has decreased by 79 percent, due in part to NIH-funded research on treatments and prevention.
- Despite the increasing prevalence of diabetes in the U.S., from 1969 to 2013 the death rate for adults with diabetes declined by 16.5 percent. Between 1990 and 2010, the rates of major diabetes complications dropped dramatically, particularly for heart attacks, which declined by 68 percent, and stroke, which declined by 53 percent. These improvements are due largely to clinical trials supported by NIH. NIH's Diabetes Prevention Program has shown that lifestyle changes, such as diet and physical activity, can lower the risk of developing type 2 diabetes by 58 percent in adults at high risk for the disease.
- Thanks to an unprecedented collaborative effort between NIH and industry, today treatments can suppress HIV to undetectable levels, and a 20-year-old HIV-positive adult living in the United States who receives these treatments is expected to live into his or her early 70s, nearly as long as someone without HIV. Since the mid-1990s, HIV testing and prevention strategies based on NIH research have resulted in a more than 90 percent decrease in the number of children perinatally infected with HIV in the United States.
- In 1960, 26 of every 1,000 babies born in the United States died before their first birthday. By 2013, that rate had fallen to under 6 per 1,000 babies, thanks in large part to NIH research on reducing preterm births, neonatal mortality, and other complications.
- The haemophilus influenza type B (Hib) vaccine has reduced the cases of Hib, once the leading cause of bacterial meningitis in children, by more than 99 percent.
- NIH-supported researchers partnered with a pharmaceutical company to produce a naloxone nasal spray, the first easy-to-use, non-injectable version of a life-saving treatment for opioid or heroin overdoses. NIH-supported researchers collaborated with the pharmaceutical industry to develop the drug buprenorphine, the first drug for opioid addiction that could be prescribed in a doctor's office instead of requiring daily visits to a clinic.
- As a result of NIH efforts, nearly all infants born in U.S. hospitals in 2010 were screened for hearing loss, allowing them to get hearing aids or cochlear implants during their developmental years when they will be most helpful. Studies have shown that screening and implantation before the age of 18 months allows more than 80 percent of children with hearing loss to join mainstream classes with their normal-hearing peers.

- Deep brain stimulation is used to help relieve symptoms of Parkinson’s disease and Obsessive Compulsive Disorder, thanks in part to NIH-funded research, and is currently being tested in other neuropsychiatric conditions, such as treatment-resistant depression and dementia.
- In the mid-1970s, burns that covered even 25 percent of the body were almost always fatal. Today, people with burns covering 90 percent of their bodies can survive. NIH-funded research on wound cleaning, skin replacement, infection control, and other topics has greatly improved the chances of surviving catastrophic burns and traumatic injuries.

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 necessary to bring the promise of this knowledge to fruition requires a sustained investment in NIH.

#### *Sustaining Scientific Momentum Requires Sustained Funding*

Despite the increase in fiscal year 2016, 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. Sustained predictable increases in NIH funding are needed if we are to continue to take full advantage of these opportunities to accelerate the development of pioneering treatments and innovative prevention strategies.

One long-lasting potential impact of the past decade is on the next generation of scientists, who have seen training funds slashed and the possibility of sustaining a career in research diminished. The continued success of the biomedical research enterprise relies heavily on the imagination and dedication of a diverse and talented scientific workforce. Of particular concern is the challenge of maintaining a cadre of clinician-scientists to facilitate translation of basic research to human medicine. NIH supports many innovative training programs and funding mechanisms that foster scientific creativity and exploration. Additional funding is needed if we are to strengthen our Nation’s research capacity, ensure a biomedical research workforce that reflects the racial and gender diversity of our citizenry, and inspire a passion for science in current and future generations of researchers.

#### *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 sequestration cuts, 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. This shift in funding is creating an innovation deficit in the U.S. and 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 continue 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 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 and generated more than \$62 billion in new economic activity.

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 \$34.5 billion in fiscal year 2017 as the next step toward a multi-year increase in our Nation's investment in medical research.

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PREPARED STATEMENT OF THE ADULT CONGENITAL HEART ASSOCIATION

On behalf of the Adult Congenital Heart Association (ACHA), I am pleased to submit testimony in support of funding for the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention's (CDC) National Center on Birth Defects and Developmental Disabilities (NCBDDD). We urge you to include \$34.5 billion for NIH and \$10 million for congenital heart disease at NCBDDD in the Labor-Health and Human Services-Education appropriations bill for fiscal year 2017.

Founded in 1998 by a group of adult congenital heart defect survivors and their families, the ACHA and its Board of Directors continues to consist primarily of those living with heart defects. ACHA is dedicated to promoting excellence in adult congenital heart disease (ACHD). Our mission is to improve and extend the lives of the millions born with heart defects through education, advocacy and the promotion of research.

The success of childhood cardiac intervention has created a new and growing patient population of those living with CHDs into adulthood. Thanks to the increase in survival, of the over 2 million people alive today with CHD, more than half are adults, increasing at an estimated rate of 5 percent each year. Few congenital heart survivors are aware of their high risk of additional problems as they age, facing high rates of neuro-cognitive deficits, heart failure, rhythm disorders, stroke, and sudden cardiac death. Many survivors require multiple operations throughout their lifetime. Fifty percent of all congenital heart survivors have complex problems for which lifelong care from an adult congenital heart specialist, who has training is more specialized than a general cardiologist, is required. Yet less than 10 percent of adult congenital heart patients receive this cardiac care. Delays in care can result in premature death and disability. In adults, this often occurs during prime wage-earning years.

NATIONAL INSTITUTES OF HEALTH

The National Heart Lung and Blood Institute (NHLBI) is the research home for congenital heart disease. The research undertaken there is one of the primary reasons children born with CHDs are living into adulthood. We believe that the one critical challenge for adults with CHD is the matter of continued expert care across the lifespan. Continued research into better quality of care for those with CHDs—whether it be better surgical techniques or a better understanding of what those with CHDs face as they age—is a critical area for NHLBI to address.

To advance research on CHDs, NHLBI should prioritize the following research areas:

- Advancing Translational Research*: Ensuring that basic science is translated into clinical practice is essential. While there have been great strides in ensuring that babies born with CHD are identified and repaired, we know that there are lifelong implications for those with CHDs that require continued follow-up and treatment. As the proportion of adults with CHD grows larger than the pediatric population, NHLBI must look at this area as an opportunity for advancing translational research. It is an area of great need.
- Development of Workforce and Resources*: No where do we see a greater need than in the area of workforce, specifically for experts in CHD. We are working with others to ensure that those with CHDs have access to the best care, but the continued need for additional partners remains. Ensuring that researchers and clinicians have the training and resources available to address areas of need is essential. Focusing on ensuring access to science and care will certainly further the needs of this important population as well as the broader heart health community.

## NATIONAL CENTER ON BIRTH DEFECTS AND DEVELOPMENTAL DISABILITIES

Despite its prevalence and significance, there are gaps in research and standards of care for CHD patients. Previous Congressional support for the congenital heart disease activities at the NCBDDD has yielded an increased understanding of the public health burden of this condition, but additional resources are required to continue and expand these efforts. Continued Federal investment is necessary to provide rigorous epidemiological and longitudinal public health surveillance and research on infants, children, adolescents, and adults to better understand congenital heart disease across the lifespan, improve outcomes, and reduce costs.

Increasing congenital heart disease funding at the CDC to \$10.0 million in fiscal year 2017 would allow for improved awareness of CHDs and understanding of prevalence, healthcare utilization, and short and long-term physical and psychosocial outcomes, achieved by building upon the pilot congenital heart adolescent and adult surveillance program, incorporating public health research, developing a longitudinal cohort, and completing a survivorship study. This funding would allow NCBDDD to develop a report on adult congenital heart disease surveillance efforts, including an estimated number of individuals in the U.S. living with a CHD, epidemiology of CHDs across the life span, age-specific prevalence and factors associated with those patients “lost to care” who may have dropped out of appropriate specialty care. Having this information is critical to meeting the needs of adults with CHDs.

## PREPARED STATEMENT OF THE AGRICULTURE WORKFORCE COALITION

## Statement on Behalf of

American Farm Bureau Federation | AmericanHort

Florida Fruit &amp; Vegetable Association

National Council of Agricultural Employers

National Council of Farmer Cooperatives | U.S. Apple Association

United Fresh Produce Association | USA Farmers | Western Growers

Chairman Blunt, Ranking Member Murray, and members of the subcommittee, thank you for your continued leadership and support for U.S. agriculture. The above signed steering committee members of the Agriculture Workforce Coalition appreciate this opportunity to submit our views regarding the fiscal year 2017 Labor, Health and Human Services, and Education, and Related Agencies appropriations bill, and respectfully requests this statement be made part of the official hearing record.

The labor situation in agriculture has been a concern for many years, but is moving towards a breaking point. Today, large segments of American agriculture face a critical lack of workers, a shortage that makes our farms and ranches less competitive with food from abroad and that threatens the abundant, safe and affordable domestic food supply American consumers enjoy today.

Repeated evidence over the past decades has shown that there are some jobs in agriculture that Americans simply do not want to do. Although many of these jobs offer wages competitive with similar, non-agricultural occupations, they are physically demanding, conducted outdoors in all seasons and weather, and are often seasonal or transitory. It is for this reason that farmers have grown to rely on foreign workers to perform this work.

The overarching challenge to workforce stability in agriculture is the widely acknowledged lack of authorized work status by a large number of agricultural workers despite the prevalence of documentation presented by workers to the contrary. The only option for farmers and ranchers to legally find the workers they need is the H-2A temporary work visa program, a program that has not worked for many agricultural employers.

The H-2A program’s basic framework is overly restrictive and difficult to maneuver. Furthermore, the H-2A program is only accessible for producers with seasonal needs; excluding the year-round needs of many producers such as dairy, livestock, mushrooms, and other crops. In recent years the program has become even more bureaucratic, burdensome and costly to use. But, each year, more and more farms have to turn to the H-2A program for legal foreign labor to meet their workforce needs.

The demand on the program is increasing as producers have nowhere else to turn; yet the administrative weight of the program cannot keep up. H-2A employment has doubled in the past 4 years and will double again in the next 2 years or less.

Even at current levels, capacity and infrastructure issues at the Departments of State, Homeland Security and Labor are leading to greater processing delays than ever before. This means bureaucratic red tape and delays in the program result in workers showing up at the farm well after the date they were needed to be there, and millions of dollars in agricultural production is lost in the interim.

To improve the function of the H-2A program, we seek the following as part of the fiscal year 2017 Labor, Health and Human Services, and Education, and Related Agencies appropriations bill:

*Farm Labor Survey Wage Categories*

*Agency:* Department of Labor

*Program:* Farm Labor Survey

*Justification:* Allows for more detailed data collection and normalizes the data with Occupational Employment Statistics categories used by the Department of Labor.

*Language Type:* Bill

*Proposal:* No such sums shall be provided for the determination pursuant to 20 CFR 655.120 unless the Secretary determines the weighted average annual rate for field workers separately from livestock workers and equipment operators and provides a rate for field workers and a separate rate for livestock workers and equipment operators.

*Advertising*

*Agency:* DOL Employment and Training Administration

*Program:* H-2A Program

*Justification:* The H-2A program's basic framework is overly restrictive and difficult to maneuver. The traditional newspaper advertising requirement is another example of sheer inefficiencies. In this modern day farmers should not be required to place costly job postings in newspapers, but rather use the already existing DOL State Workforce Agency's online tools.

*Language Type:* Bill

*Proposal:* No such sums shall be used to implement or enforce 20 CFR 655.121, as long as the employer is using the Department of Labor State Workforce Agency's online system for advertising methods.

*Staggered Entry*

*Agency:* Department of Labor—Office of Foreign Labor Certification

*Program:* H-2A Program

*Justification:* This modification was recommended by the Government Accounting Office in a September 2012 report, which stated that to reduce the burden on agricultural employers and improve customer service, the Secretary of Labor should permit the use of a single application with staggered dates-of-need for employers who need workers to arrive at different points of a harvest season.

*Language Type:* Bill

*Proposal:* No such funds may be used to implement 20 CFR 655 unless provisions are made to allow for staggered entry dates for workers defined in 8 USC 1101(a)(15)(H)(ii)(A). (NOTE: Staggered entry for seafood was included under H-2B in the fiscal year 2016 omnibus: Division H, Title 1, Sec. 111, page 358)

*Limitations on NFJP*

*Agency:* Department of Labor

*Program:* Migrant and Seasonal Farmworker Programs under Section 167 of the Workforce Innovation and Opportunity Act

*Account:* 016-0174-0-1-504-0011

*POTUS Budget:* Page 787

*Justification:* At a time of increased labor shortages in the agricultural sector, the Federal Government should not continue spending money to exacerbate this problem, but should instead be directing these funds in a manner that will enhance skills needed for agricultural work.

*Language Type:* Bill

*Proposal:* No such funds may be used for training purposes under Section 167 of the Workforce Innovation and Opportunity Act unless the training is dedicated to skills improvement for workforce development in all aspects of agricultural operations.

*Corresponding Employment*

*Agency:* Department of Labor Office of Foreign Labor Certification

*Program:* H-2A Program

*Justification:* From 1987 until 2010, DOL interpreted the term corresponding employment to mean that a U.S. worker who performed all the duties in the occupation defined in the job order was in corresponding employment with H-2A workers and had to be provided the same wages and benefits as the H-2A worker. In 2010, DOL changed the wording of the regulation to state that any U.S. worker who performed any activity in the job order was in corresponding employment. The adverse consequence is that an H-2A worker may perform highly skilled work most of the time but occasionally performs very basic unskilled work. If the H-2A worker performs any unskilled work, then the 2010 rule sweeps the entire U.S. workforce incapable of performing the skilled work defined in the job order into corresponding employment, forcing the employer to pay unskilled workers the same as highly skilled workers.

*Language Type:* Bill

*Proposal:* No such funds shall be used to implement the definition of corresponding employment (20 CFR 655.103) unless it is implemented consistent with the final 1987 regulation (29 CFR §501.0, 52 Fed.Reg. page 20524) to read that “the employment of workers who are not H-2A workers by an employer who has an approved H-2A application for Temporary Employment Certification in the occupation described in the job order performed by H-2A workers and for the time period set forth in the approved job order.”

#### *Commuter Housing*

For operations along the southern border, workers commute daily from their homes in Mexico. Required housing that is provided to these workers goes unused and is therefore an unnecessary cost imposed on employers.

*Agency:* DHS U.S. Citizenship & Immigration Services and DOL Wage and Hour Division

*Program:* H-2A Program

*Proposal:* 8 USC 1188(c)(4) is amended as follows: the housing requirement for H-2A workers is waived when the job site is within 50 miles of the border and the worker’s place of residence is within normal commuting distance.

We remain steadfast in our pursuit of broader immigration reform that meets both the short- and long-term workforce requirements of all of agriculture—both those producers with seasonal labor needs, and those with year-round needs. Yet we recognize such reforms may not come to fruition in the near term.

Left with no other alternative, we seek your support for the inclusion of these modest adjustments as you prepare fiscal year 2017 appropriations legislation.

Thank you again, and members of the Subcommittee, for the opportunity to share our views.

[This statement was submitted by Lisa Van Doren, Vice President & Chief of Staff, Government Affairs, National Council of Farmer Cooperatives.]

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

Dear Chairman Blunt 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 2017 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 2017 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 Ryan White Part D, the program funded solely to provide family-centered primary medical care and support services for women, infants, children, and youth with HIV/AIDS has successfully identified, linked, and retained these vulnerable populations in much needed care and treatment, resulting in optimum health outcomes. We thank the Subcommittee for its continuous support of Ryan White Part D Programs, providing \$75,008,000 million to the program in fiscal year 2016, restoring dedicated funding eliminated in the President’s fiscal year 2016 budget proposal. 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 again restore its dedicated funding eliminated in the President's fiscal year 2017 budget proposal and increase Ryan White Part D funding by \$9.9 million in fiscal year 2017.

*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 and today are known as Ryan White Part D and have served approximately 200,000 women, infants, children, youth and family members. 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. The family-centered primary medical and supportive services provided by Part D are uniquely tailored to address the needs of women, including HIV positive pregnant women, HIV exposed infants, children and youth. Part D programs are the only perinatal clinical service available to serve HIV-positive pregnant women and HIV exposed infants, 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 life-line for women, infants, children and youth living with HIV/AIDS. The Part D programs continue to be 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 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 5 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 more than 2,000 newborn infections annually more than a decade ago to an estimated 174 in 2014 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 8,500 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 aged 13–24 accounted for more than 1 in 5 new HIV diagnoses in the U.S. in 2014. Most new HIV infections in youth (about 55 percent) occur in young Black gay and bisexual males. Of the new HIV infections among youth, 80 percent are among young women of color. Ryan White Part D programs are the entry point into medical care for many of these HIV positive youth and lead 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 (ACA), along 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 thus increasing the existing gaps in the HIV Care Continuum. Moreover, major program changes that are this controversial should be left to Congress and should not be done through the appropriations process.

*Conclusion*

While we recognize the need to reduce administrative burdens associated with the overall operational aspects of Ryan White programs, the elimination of dedicated funding for Ryan White Part D in fiscal year 2017 and the proposed Part C/D consolidation would undoubtedly destabilize existing models of care created to address the unique needs of women, infants, children, and youth living with HIV/AIDS and jeopardizes the success of retaining these most vulnerable populations in life-saving HIV/AIDS care and treatment ensuring achieved and maintained viral load suppression. If we believe that one day we will realize an "AIDS-free generation," then surely we know how essential it is to maintain the Ryan White Program and all of its Parts.

AIDS Alliance for Women, Infants, Children, Youth & Families urges the Committee to again reject the President's fiscal year 2017 budget proposal to eliminate dedicated funding for Ryan White Part D and move the funding to Part C, and respectfully request that the Committee include language in the appropriations bill attesting to such. 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 provided to them for the last two decades.

On behalf to the women, infants, children, and youth living with HIV/AIDS and the Ryan White Part D funded programs across the country that serve them we sincerely thank you for all that you do to ensure that these populations receive the much needed primary care, treatment and supportive services needed to sustain their lives.

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

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PREPARED STATEMENT OF THE AIDS INSTITUTE

Dear Chairman Blunt 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 domestic HIV/AIDS and hepatitis programs as part of the fiscal year 2017 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.

CDC VIRAL HEPATITIS PREVENTION

Before detailing our HIV/AIDS requests, we would like to highlight the critical importance of increasing funding for viral hepatitis at the Centers for Disease Control and Prevention (CDC). The CDC estimates that between 2010 and 2013, the U.S. saw an increase in new hepatitis infections of more than 150 percent. With

55,000 new infections every year, and nearly 5.3 million people living with hepatitis B (HBV) or hepatitis C (HCV) in the U.S., increased investments in hepatitis are needed now more than ever before. Similar to the factors that resulted in the 2015 HIV and HCV outbreak in Scott County, Indiana, new hepatitis infections are largely driven by increases in the use of heroin and other opiates. Additionally, HBV and HCV are the leading causes of liver cancer, which is now one of the most lethal and fastest growing cancers in the United States. The CDC estimates that deaths attributed to HCV now surpass the number of deaths associated with all 59 other notifiable infectious disease combined.

We are thankful for the small increase the CDC's Division of Viral Hepatitis (DVH) received in fiscal year 2016, but it is nowhere near the estimated \$170 million needed for DVH to reduce new hepatitis infections in the U.S. We have the tools to prevent this growing epidemic and to eliminate hepatitis in the U.S., but only with increased funding for DVH to provide the level of testing, education, and surveillance needed.

#### HIV/AIDS

HIV/AIDS remains one of the world's worst health pandemics. A record 1.2 million people in the U.S. are living with HIV, and there are still 50,000 new infections each year. Persons of minority races and ethnicities are disproportionately affected. The rate of new infections in the African American community is eight times that of whites. HIV/AIDS disproportionately affects low income people; nearly 90 percent of Ryan White Program clients have a household income of less than 250 percent of the Federal Poverty Level.

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

With the advent of antiretroviral medicines, HIV has turned from a near certain death sentence to a treatable chronic disease if people have access to consistent and affordable healthcare and medications. Through prevention, care and treatment, and research we now have the ability to actually end AIDS. HIV treatment not only saves the lives of people with HIV, but also reduces HIV transmission by more than 96 percent. Therefore, 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.

Diagnosing, treating, and achieving viral suppression for all individuals living with HIV are key elements to achieving the goals of the updated National HIV/AIDS Strategy, and to one day reaching an AIDS-free generation.

#### THE RYAN WHITE HIV/AIDS PROGRAM

The Ryan White HIV/AIDS Program, acting at the payer of last resort, provides medications, medical care, and essential coverage completion services to approximately 512,000 low-income, uninsured, and underinsured individuals with HIV/AIDS in the U.S. 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 39 percent of people living with HIV in the U.S. are retained in HIV care, 36 percent have been prescribed antiretroviral treatment, and 30 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 262,000 people. While ADAPs continue to provide medications to Ryan White clients to keep them healthy, an increased amount of ADAP funding is being used to help low-income enrollees afford insurance premiums, deductibles, and high cost-sharing related to the cost of their HIV medications. 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. With this increased demand for medications comes a corresponding increase in medical care and support services provided by all other parts of the program.

With the Affordable Care Act (ACA), there are expanded opportunities for healthcare coverage for some Ryan White clients. While the ACA will result in some cost shifting for medications and primary care, it will never be a substitute for the Ryan White Program. Nearly three-quarters of all Ryan White Program clients

today have some sort of insurance coverage; over half have coverage through Medicaid and Medicare. However, public and private insurance programs do not always provide the comprehensive array of services required to meet the needs of individuals living with HIV/AIDS. Services critical to managing HIV include case management; mental health and substance use services; adult dental services; and transportation, legal, and nutritional support services. Because not all States are choosing to expand Medicaid, benefits differ from State to State, and for many individuals living with HIV/AIDS, the Ryan White Program is the only source of care and treatment. This approach of coordinated, comprehensive, and culturally competent care leads to better health outcomes. In fact, over 81 percent of those in the Ryan White Program are virally suppressed, an increase of over 17 percent since 2010. Therefore, the Ryan White Program must continue and 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 mother-to-child transmission and providing medical care and family-centered support that helps ensure these vulnerable populations remain in care and adhere to their medications. While changes to the Ryan White Program might be needed in the future, it should not be done through the appropriations process and must include community input.

Additionally, we support the President's request to increase by \$9 million the Part F Special Projects of National Significance in order to increase HCV testing, and care and treatment for people living with HIV who are co-infected with HCV. About one in four people living with HIV is co-infected with HCV.

#### CDC HIV PREVENTION

We have made significant progress in the fight against HIV/AIDS in the United States over the last 30 years. Due to past investments, we have averted thousands of new infections and lowered new infection rates among heterosexuals, people who inject drugs, and African Americans. However, some communities continue to experience increases in new infections, including gay, bisexual, and other men who have sex with men (MSM), particularly young black and Latino MSM. In fact, MSM accounted for 70 percent of all new HIV infections in 2014, and black MSM have experienced a 22 percent increase in infections since 2005. Averting all 50,000 new infections each year would result in approximately \$20 billion in lifetime treatment 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. With over 156,000 people living with HIV in the U.S. who are unaware of their infection, the CDC is also focused on increased HIV testing programs. Testing people early allows them to be diagnosed and referred to care and treatment earlier, which is critical to bettering individual health outcomes and preventing new infections. We are also in support of the Administration's proposal that would allow health departments to spend a limited portion of their prevention funding on pre-exposure prophylaxis (PrEP) and related services. PrEP has been proven to reduce the chances of HIV infection by up to 92 percent in people, and are particularly effective for those who are at high risk.

The CDC estimates that one in four new HIV infections are among young people between the age of 13 and 24; most of whom are young gay men. We must do a better job of educating the youth, including gay youth, about HIV. Increasing funding to the HIV Division of Adolescent and School Health (DASH) would help build schools' capacity to implement quality sexual health education, support student access to healthcare, and enable safe and supportive environments.

#### SYRINGE SERVICES PROGRAMS

In the fiscal year 2016 omnibus appropriations bill, Congress revised the restrictions on the use of Federal funds for syringe service programs (SSPs). Federal funding can now be used for SSPs in jurisdictions that are experiencing or are at risk for significant increases in HIV or hepatitis infections due to injection drug use. Federal funding cannot support the purchase of actual syringes. We urge the Subcommittee to maintain the current appropriations language that allows access to syringe services in those jurisdictions that meet the criteria.

## HIV/AIDS RESEARCH AT THE NATIONAL INSTITUTES OF HEALTH

While we have made great strides, there is still a long way to go for AIDS research. NIH (National Institutes of Health) has supported innovative basic science for better drug therapies, behavioral and biomedical prevention interventions, and has saved the lives of millions around the world. However, continued research is necessary to learn more about the disease and to develop new treatments and prevention tools. NIH has proved the efficacy of pre-exposure prophylaxis (PrEP), the effectiveness of treatment as prevention, and the first partially effective AIDS vaccine. We look forward to an eventual cure. AIDS research has also contributed to the development of effective treatments for other diseases, including cancer and Alzheimer's disease.

## HIV RESEARCH NETWORK AT THE AGENCY FOR HEALTHCARE RESEARCH AND QUALITY

We ask the Subcommittee to restore funding to the HIV Research Network (HIVRN) at the Agency for Healthcare Research and Quality (AHRQ). This \$1.6 million program funds clinical research that measures the quality and cost-effectiveness of HIV/AIDS care in the U.S. Additionally, HRSA relies on this data for monitoring the status of clients served by the Ryan White Program. We urge the Subcommittee to restore AHRQ funding for the HIVRN.

## MINORITY AIDS INITIATIVE

As racial and ethnic minorities in the U.S. are disproportionately impacted by HIV/AIDS, it is critical that this Subcommittee continue to support the Minority AIDS Initiative (MAI). The resources for MAI supplement, rather than replace, other Federal funding for HIV/AIDS, and encourage capacity building, innovation, collaboration, and integration of best practices to fully address the needs of some of the most vulnerable populations for HIV infection.

Again, we thank you for your continued support of these programs. We have made great progress, but we are still far from achieving zero new HIV infections, an AIDS-free generation, and eradicating viral hepatitis. We now have the tools, but we need continued leadership and the necessary resources to realize our goals. Thank you.

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

## PREPARED STATEMENT OF THE ALLIANCE FOR AGING RESEARCH

Chairman Blunt, Ranking Member Murray, and members of the subcommittee, for 30 years the nonprofit Alliance for Aging Research, has advocated for policies that will accelerate the pace of scientific discoveries and their application to improve the universal experience of aging and health. We support increased Federal funding of aging research by the National Institutes of Health (NIH), through the National Institute on Aging (NIA) and other NIH institutes and centers. The Alliance for Aging Research appreciates the opportunity to submit testimony highlighting the important role the NIH plays in facilitating medical research activities related to aging and the need for sustained Federal investment to advance scientific discoveries to keep aging Americans healthier longer. When considering the rapid aging of America and the resources the Federal Government devotes to Medicare and other healthcare services for age-related diseases, we find it prudent to increase appropriated spending on aging research. Considering the unique funding challenges facing the NIA, and the range of promising scientific opportunities in the field of aging research, the Alliance for Aging Research recommends an additional \$500 million in the fiscal year 2017 NIH budget to support biomedical, behavioral, and social sciences aging research efforts at the NIH and a minimum increase of \$400 million in Alzheimer's disease and related dementias research. To ensure that overall research progress at the NIH continues, the Alliance for Aging Research endorses the Ad Hoc Group for Medical Research recommendation that the NIH be funded at \$34.5 billion in fiscal year 2017. We further urge the committee to include report language requesting that the U.S. Secretary of Health and Human Services establish an Interagency Geroscience Research Coordination Committee (IGRCC) comprised of representatives from the NIH, FDA and other designated agencies to identify and direct grants for new geroscience research; and, to provide \$1 million to administer the activities of the IGRCC and \$5 million in grant-making authority to advance aging research priorities.

The NIA leads the national scientific effort to understand the nature of aging and to extend the healthy, active years of life. Congress established the NIA in 1974 with the mission of conducting and supporting genetic, biological, clinical, behavioral, social, and economic research related to the aging process, diseases and conditions associated with aging, and needs of older Americans; developing research and clinician-scientists for research and aging; and disseminate information about aging and advances in research with the scientific community, healthcare providers, and the public. These following projects highlight some of the important work directed by the NIA:

- The Biology of Aging Program is a trans-NIH initiative, coordinating with the Nathan Shock Centers of Excellence, to support translational research at the individual and community level. Under this umbrella, the Interventions Testing Program seeks to identify compounds that extend median and/or maximal life span in both mammal and non-mammalian organisms.
- The Behavioral and Social Research Program conducts longitudinal studies focusing on trends in late-life disability and on the influences of behavioral, psychological, and social factors in mid-life on age-related variations in health and well-being. Major programs include initiatives to stimulate research on mid-life adults informing efforts to optimize health and well-being, prevent illness and disability in later years, and potentially reverse the negative impact of early life adversity on later life health.
- The Geriatrics and Clinical Gerontology Program is studying how early life factors influence health and diseases as people age. The program also plans and administers clinical trials for age-related conditions and is conducting an ongoing initiative to identify behavioral interventions with a high potential impact to improve health outcomes for individuals with three or more chronic conditions.
- The Neuroscience Program seeks to expand knowledge on the aging nervous system to allow improvement in the quality of life of older people. The program supports a national network of Alzheimer's disease centers to translate research advances into improved diagnosis and care of Alzheimer's disease patients.
- The Accelerating Medicines Partnership (AMP) is a collaboration between the NIH and 10 pharmaceutical company partners to identify and characterize biomarkers and targets of intervention for Alzheimer's disease, type 2 diabetes, and autoimmune disorders, rheumatoid arthritis, and systemic lupus erythematosus.
- The Healthy Aging in Neighborhood of Diversity across the Life Span (HANDLS) is a 20-year project within the NIA Intramural Research Program to examine the influences of race and socioeconomic status on the development of age-related health disparities in Baltimore.
- The NIA has partnered with Patient-Centered Outcomes Research Institute (PCORI) on an intervention study testing individually tailored strategies for falls prevention in older adults.

The NIA's mission becomes ever more urgent as the American population ages. Older Americans now make up the fastest growing segment of the population. According to the U.S. Census Bureau, the number of Americans aged 65 and older is expected to double between 2010 and 2050 to 88.5 million; the number of Americans aged 85 and older is expected to triple in the same time period. The impact this will have on the U.S. healthcare system is profound. As the American population ages, the number of Americans living with chronic diseases skyrockets.

The influx of Americans living with the chronic diseases of aging threatens to overwhelm the U.S. healthcare system. According to the Centers for Medicare & Medicaid Services, in 2011 approximately 23 percent of beneficiaries had four to five chronic diseases associated with aging. This increase of people living with multiple chronic disease is a large contributing factor to the Congressional Budget Office projecting total spending on healthcare to increase by 25 percent of the U.S. GDP by 2025. Streamlining delivery and eliminating unneeded care will not sufficiently contain the costs of caring for the chronic diseases of geriatric populations. To effectively solve this problem, we must increase Federal resources to understand the biology of aging. Research to better understanding the aging process and its underlying relationship to chronic disease could help Americans live longer and more productive lives while greatly alleviating much of the burden to the healthcare system. Scientists studying aging are in general agreement that there is a strong likelihood the pace of aging can be slowed. Closing the gap between the promises of basic research into aging and the clinical application of this research will require considerable focus and investment.

An increase in funding for aging research is urgently needed to enable scientists to capitalize on the field's recent exciting discoveries. The Alliance for Aging Re-

search, has led the Healthspan Campaign—an awareness campaign to educate the public and policymakers about the need to focus and adequately fund basic research into the underlying processes of aging—that if targeted can extend a person’s healthy years of life. In addition to increased resources, we believe that the field could benefit from the creation of a trans-agency coordinating committee that could improve the quality and pace of research that advances the understanding of aging, its impact on age-related diseases, and the development of interventions to extend human healthspan. Throughout the first half of 2012 the Alliance and its Healthspan Campaign partners met with the leadership of the NIA, the National Institute of Neurological Diseases and Stroke (NINDS), the National Institute of Arthritis Musculoskeletal and Skin Diseases (NIAMS), the National Institute of Diabetes Digestive and Kidney Diseases (NIDDK), the National Heart Lung and Blood Institute (NHLBI), and the National Cancer Institute (NCI). These meetings led to the establishment of the Trans-NIH GeroScience Interest Group (GSIG), a group seeking to discover common risks and mechanisms behind age-related diseases and conditions. Twenty-one of the 27 institutes and centers at the NIH are now working on the GSIG. The regular meetings, quarterly seminars, and the recommendations from the “Advances in Geroscience: Impact on Healthspan and Chronic Disease Summit” have identified multiple opportunities for collaboration. Funding these research opportunities can reduce the burden of a “Silver Tsunami” of age-associated chronic diseases. We urge the committee to include report language requesting that the U.S. Secretary of Health and Human Services establish an Interagency Geroscience Research Coordination Committee (IGRCC) comprised of representatives from the NIH, FDA and other designated agencies to identify and direct grants for new geroscience research; and, to provide \$1 million to administer the activities of the IGRCC and \$5 million in grant-making authority to advance aging research priorities.

NIA leads the Federal effort on researching Alzheimer’s disease, receiving roughly 70 percent of NIH Alzheimer’s disease research funding. As many as five million Americans aged 65 years and older are living with Alzheimer’s disease, with 13.2 million anticipated by 2050. The national cost of caring for individuals with Alzheimer’s disease is estimated at \$100 billion annually. To address the problem, the NIA has a comprehensive research agenda to understand the disease, spanning from basic neuroscience through translational research and clinical applications. The NIA supports treatment trials that aim to slow the disease or alleviate its symptoms, such as last year’s discovery that the anti-depressant citalopram may be a safer and more effective treatments for disruptive agitation in Alzheimer’s disease than currently used treatments.

The exponential increase in computer processing power has strengthened the NIA’s efforts to study Alzheimer’s disease. These new technologies allow researchers to generate and analyze enormous data sets with the aim of identifying risk and protective genes for Alzheimer’s disease. This has led to the Alzheimer’s disease Sequencing Project (ADSP), a collaborative effort between the NIA and the National Human Genome Research Institute working to identify genomic variants contributing to the development and protecting against the development of Alzheimer’s disease. The NIA is also using the Accelerating Medicines Partnership (AMP) to incorporate an expanded set of biomarkers into three ongoing trials designed to delay or prevent Alzheimer’s disease and determine their usefulness in tracking disease progression and treatment responsiveness. These trials will be ongoing from 2017 to 2020. AMP also supports large-scale systems biology analyses using data from 2,500 brains at different stages of Alzheimer’s disease to build predictive models of the disease. All of the data from this initiative is shared with the public.

However, despite the NIH’s exciting work on Alzheimer’s disease, the current level of funding the NIH receives is insufficient to meet the National Plan to Address Alzheimer’s disease’s goal of developing effective treatment modalities to treat or cure Alzheimer’s disease by 2025. To meet this goal, we support an increase of at least \$ 400 million for Alzheimer’s disease and related dementia research. This would put the NIH-wide dementia research budget at \$1.34 billion in fiscal year 2017. Furthermore, the NIA’s current budget does not reflect the tremendous responsibility it has to meet the health research needs of America’s aging population. When adjusting for inflation, the NIA’s budget has decreased more than 20 percent since 2003. An increase of \$500 million will allow the NIH to capitalize on the potential transformational gains in aging research. Few, if any, investments have a greater potential return on investment for public health. The Alliance for Aging Research recommends that overall NIH funding be increased to \$34.5 billion in fiscal year 2017. We also support a minimum \$500 million increase over fiscal year 2016 enacted levels for aging research across the NIH that will accelerate progress toward preventing, treating, and slowing the progression, or even possibly curing con-

ditions related to aging. We would also be remiss not to acknowledge the Subcommittee's significant increase for the NIH and Alzheimer's disease and related dementia research in fiscal year 2016. We truly appreciate your prioritization of the critical work conducted at the NIH and ask for your ongoing support.

Mr. Chairman, thank you for the opportunity to present testimony and elucidate on the challenges posed by the aging population. Our organization will gladly provide additional information and answer questions upon request.

[This statement was submitted by Cynthia Bens, Vice President Public, Alliance for Aging Research.]

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#### PREPARED STATEMENT OF THE ALLIANCE OF INFORMATION AND REFERRAL SYSTEMS

Chairman Blunt, Ranking Member Murray: On behalf of the Alliance of Information and Referral Systems (AIRS), we thank you for the opportunity to offer testimony in support of the Department of Health and Human Services' proposed increase of \$10 million for the Older Americans Act Title III(B) Home and Community-Based Supportive Services program within the Administration for Community Living, as well as testimony against the Department of Health and Human Services' proposed cuts to the Low-Income Home Energy Assistance Program and Community Services Block Grant program within the Administration for Children and Families.

AIRS, with more than 1,000 members from across the United States and Canada, is the organization which brings people and services together. More specifically, we are the lead national agency which developed the professional standards that are a part of thousands of quality Information and Referral (I&R) programs operated under the Older Americans Act. AIRS members answer more than 28 million calls per year for help about community, social and health services.

#### OLDER AMERICANS ACT TITLE III(B) HOME AND COMMUNITY-BASED SUPPORTIVE SERVICES

I&R services provided under Title III(B) of the Older Americans Act are critical to providing older adults in need with assistance in every community in this Nation. I&R organizations have databases of programs and services and disseminate information through a variety of channels to individuals and communities. Older adults in need of critical services such as food, shelter, work and job training, and mental health support often do not know where to turn for support. I&R services provide answers.

Title III(B) also provides important supportive services such as home healthcare, transportation, and adult day care, programs to which AIRS members refer older adults. These programs are all in need of increased funding. The Administration has proposed an increase of \$10 million for Title III(B) for fiscal year 2017. Title III(B) has been level-funded for years and has not had funding restored from sequestration cuts in fiscal year 2013. This increase would not fully restore funding, but it would help immensely to serve the growing need for these programs as our population ages.

#### LOW-INCOME HOME ENERGY ASSISTANCE PROGRAM

AIRS is very concerned about the Administration's proposed cut to the Low-Income Home Energy Assistance Program (LIHEAP). This 12 percent cut would reduce funding for LIHEAP by \$390 million.

One AIRS member stated that in her county's elderly services program, two-thirds of her clients either have low enough incomes or have enough medical expenses to qualify for LIHEAP. When they receive shut-off notices, they call her I&R service for assistance; the I&R service refers the clients to one of a few possible resources for help. However, those resources do not have enough funding, so these older adults go without heating for days. In the winter, their pipes may break due to lack of heat, and it can take several days to start repairs. Meanwhile, these vulnerable adults have no heat or water.

This is only one local example; these issues happen nationally. Another AIRS member said that during the 4th quarter of 2015, 40 percent of the requests his agency received for heating or electric assistance were recorded as an unmet request, primarily because there were insufficient resources to assist households to pay arrearages. During the 3rd quarter, the unmet need requests neared 80 percent. Reducing funding for this important program would be a huge mistake and could harm many vulnerable populations, including frail older adults.



## COMMUNITY SERVICES BLOCK GRANT

AIRS is also very concerned about the Administration's proposed cut to the Community Services Block Grant (CSBG). This cut would reduce funding for CSBG by \$41 million.

Many I&R providers refer callers to the services provided under the CSBG, such as employment, education, housing assistance, nutrition, energy, emergency services, health, and substance abuse. These programs serve people of all ages. Reducing funding for this program would mean that many important services could be cut.

We thank you for your past and future support, and hope to continue to work with you through the appropriations process.

[This statement was submitted by Robert McKown, President, Board of Directors and Charlene Hipes, Chief Operating Officer, Alliance of Information and Referral Systems.]

## PREPARED STATEMENT OF THE ALPHA-1 FOUNDATION

On behalf of the Alpha-1 Foundation, I am pleased to submit testimony in support of funding for the National Institutes of Health (NIH). We urge you to include \$34.5 billion for NIH in the Labor-Health and Human Services-Education appropriations bill for fiscal year 2017.

The Alpha-1 Foundation is committed to finding a cure for Alpha-1 Antitrypsin Deficiency (Alpha-1) and to improving the lives of people affected by Alpha-1 worldwide. This condition is inherited and may result in serious lung disease, like COPD, and/or liver disease. Like many other inherited conditions, those with Alpha-1 must have two defective genes to cause disease. In the case of Alpha-1 this results in lower than normal levels of protective protein in the blood and lungs.

Prioritizing research related to Alpha-1, specifically, Alpha-1 associated Chronic Obstructive Pulmonary Disease (COPD) at the National Heart Lung and Blood Institute (NHLBI) in fiscal year 2017 is essential to tackling the broader issue of not just rare diseases, but also public health issues related to COPD. In fiscal year 2016, the NHLBI convened an interagency meeting on Federal COPD planning. Unfortunately we have yet to see any peer-reviewed publications following this meeting. I hope that you will include language in the accompanying report that urges NHLBI to move forward on efforts to address the rising burden of COPD in the U.S.

Specifically, we know that Alpha 1 Antitrypsin Deficiency (Alpha 1) is a major genetic risk factor for developing COPD. Therefore we at the Alpha-1 Foundation believe that a treatment algorithm for Alpha-1 related disease along with a coordinated public-private collaborative approach will not only increase the knowledge that can improve the diagnosis of Alpha 1, but make for a more clear understanding of COPD. We urge you to encourage the NHLBI to convene a group of expert stakeholders and other Federal agencies to take the first steps in developing such a treatment algorithm.

In short, we are committed to ensuring that Alphas have a community of support, places to go for answers, and in furthering research for therapies and ultimately, cures. Prioritizing research at the NHLBI, specifically ensuring that this treatment algorithm related to Alpha-1 associated COPD is created, will go a long way in furthering these goals.

## PREPARED STATEMENT OF THE ALZHEIMER'S FOUNDATION OF AMERICA

As President and CEO of the Alzheimer's Foundation of America (AFA), a national nonprofit organization that unites more than 2,400 member organizations nationwide with the goal of providing optimal care and services to individuals confronting dementia, and to their caregivers and families I, Charles J. Fuschillo, Jr., urges the Senate Appropriations Committee to commit:

- An additional \$1 billion for Alzheimer's disease research at the National Institutes of Health (NIH); and
- An additional \$40 million to fund caregiver supports and services provided by programs administered by the Administration for Community Living (ACL)

*National Institutes of Health (NIH):*

AFA wants to commend the Committee for approving an historic increase in funding for Alzheimer's disease research at the National Institutes of Health (NIH) in fiscal year 2016. The \$350 million in additional resources will help ensure promising research gets funded and that we move ever closer to the goal of finding a cure or

disease-modifying treatment by 2025 as articulated in the National Plan to Address Alzheimer's Disease.

AFA hopes Congressional appropriators will continue to build upon this progress and make combatting Alzheimer's disease a national priority. To this end, AFA urges the Committee to provide an additional \$1 billion for Alzheimer's disease in fiscal year 2017. Leading Alzheimer's disease scientists have called for \$2 billion in annual research funding to keep us on track to achieve the 2025 goal. With just eight short years until the deadline, we can no longer wait. We need to ensure there is proper investment in promising research today that will get us to a cure tomorrow. An increase of \$1 billion in fiscal year 2017 would put research funding close to that \$2 billion dollar target.

AFA also urges the Committee to include \$34.5 billion in total funding for NIH, as recommended by the Ad Hoc Group for Medical Research. 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.

*Administration on Community Living (ACL) Programs:*

AFA would like to highlight the following programs within the ACL that are critical to individuals living with dementia and their caregivers. As incidences of Alzheimer's disease increase, the importance of these programs to family caregivers is vital in meeting the challenges of caring for a loved one living with dementia.

- 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 \$150.5 million cannot possibly keep up with the need for care as our population ages. AFA urges that \$161 million be appropriated in fiscal year 2017 to support this important program.
- Lifespan Respite Care Program (LRCP): AFA urges the Committee to commit \$9 million, a \$4 million increase to LRCP in fiscal year 2017. 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.
- The Alzheimer's Disease Supportive Services Program (ADSSP) provides competitive grants to States to expand dementia-capable home and community-based long-term services and supports. It was funded at \$4.8 million in fiscal year 2016. AFA is calling for an increase of \$2.5 million to bring the ADSSP up to \$7.3 million in fiscal year 2017.
- Alzheimer's Disease Initiative (ADI): AFA supports a budget request of \$16.5 million—a \$6 million increase for this program—in fiscal year 2017 that provides grants for services such as supporting 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 \$6.7 million, a \$2.5 million increase, for the Alzheimer's Disease Communications Campaign.

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](mailto:esokol@alzfdn.org) if you have any questions or require further information.

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PREPARED STATEMENT OF THE AMERICA FORWARD COALITION

Dear Chairman Blunt and Ranking Member Murray: As you prepare the fiscal year 2017 Appropriations bill, the America Forward Coalition urges you to include funding for the programs identified below that spur innovation, reward results, and catalyze cross-sector partnerships to propel America forward.

The America Forward Coalition is a network of more than 70 social innovation organizations that champion innovative, effective, and efficient solutions to our country's most pressing social problems. Our Coalition members are achieving measurable outcomes in more than 14,500 communities nationwide, touching the lives of 8 million Americans each year, and driving progress in education, workforce development, early learning, poverty alleviation, public health, pay for success, social innovation, national service, and criminal justice reform. Since 2007, America For-

ward's community of innovators has played a leading role in driving the national dialogue on social innovation and advocating for lasting policy change.

We are eager to work with you to advance the policies outlined in this letter and urge you to include and prioritize the following programs in the Labor, Health and Human Services, Education and Related Agencies Appropriations bill for fiscal year 2017.

*Corporation for National and Community Service*

—\$1.47 billion for the Corporation for National and Community Service to support high-impact, cost-effective service opportunities in communities that continue to fuel the expansion of innovative programs in a variety of fields.

—\$70 million for the Social Innovation Fund to test promising new approaches to major social challenges and to expand evidence-based programs that demonstrate measureable outcomes. This includes the allowable use of up to 20 percent of funds for Pay for Success projects.

The America Forward Coalition respectfully requests that the above programs be included at the identified levels in your fiscal year 2017 Appropriations bill. We recognize the many difficult choices the Committee faces and thank you for the Committee's ongoing support for social innovation policies. We look forward to working with you to advance these important issues in the months ahead.

Sincerely,

Members of the America Forward Coalition

AMERICA FORWARD COALITION

Acelero Learning/Shine	Enterprise Community	Peace First
Early Learning	Partners	Peer Health Exchange
Alternative Staffing	Eye to Eye	Public Allies
Alliance	Family Independence	Reading Partners
America's Promise	Initiative (FII)	REDF
Alliance	First Place for Youth	Roca
ANet	Generation Citizen	Root Cause
AppleTree Institute for	Genesys Works	Save the Children
Education Innovation	Global Citizen Year	Say Yes to Education
AVANCE, Inc.	GreenLight Fund	ServiceNation
Bard Early Colleges	iMentor	Single Stop
BELL	Institute for Child Success	Social Enterprise Alliance
Beyond 12	Invest in Outcomes	Social Finance US
Blue Engine	Jumpstart for Young	Teach For America
Bottom Line	Children, Inc.	The Children's Aid Society
BUILD	KIPP	The Corps Network
Child Mind Institute	LIFT	The Mission Continues
Citizen Schools	LISC	Third Sector Capital
City Year, Inc.	Match Education	Partners, Inc.
College Advising Corps	National Center for	Turnaround for Children
College Forward	Learning Disabilities	Twin Cities RISE!
College Possible	(NCLD)	uAspire
College Summit	New Classrooms	Waterford Institute
Compass Working Capital	Innovation Partners	Year Up
Connecticut Center for	New Leaders	YouthBuild USA
Social Innovation, Inc.	New Sector Alliance	Youth Villages, Inc.
Corporation for Supportive	New Teacher Center	10,000 Degrees
Housing (CSH)	Opportunity Nation	

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ward's community of innovators has played a leading role in driving the national dialogue on social innovation and advocating for lasting policy change.

We are eager to work with you to advance the policies outlined in this letter and urge you to include and prioritize the following programs in the Labor, Health and Human Services, Education and Related Agencies Appropriations bill for fiscal year 2017.

*Department of Education*

- \$1.16 billion for 21st Century Community Learning Centers, which is the same amount provided in fiscal year 2016, to support effective extended learning and enrichment opportunities that are connected to content covered during the school day through effective community-school partnerships.
- \$350 million for the Charter Schools Program to support high-quality charter schools that break the mold of the status quo and create new solutions to meet critical needs.
- \$180 million for the Education, Innovation, and Research (EIR) to increase the number of high-quality applications to build evidence of effectiveness and to demonstrate the feasibility of scaling effective interventions, including support for ARPA-ED, to spur the development of educational technology necessary to personalize learning.
- \$100 million for First in the World to encourage innovation in higher education necessary to tackle and improve college completion rates, increase the productivity of higher education, build evidence of what works, and scale up proven strategies.
- \$9.6 billion for Head Start to increase the number of children attending Head Start for a full school day and a full school year.
- \$15 million for the InformED initiative at the Institute of Education Sciences to support efforts that will collect, analyze, and release data and evaluation studies, for internal users and the public, to answer pressing education questions.
- \$13.6 billion for IDEA to serve students with disabilities.
- \$350 million for Preschool Development Grants to support significant national investments necessary to ensure that all young people have access to a high quality education and the opportunity to succeed.
- \$30 million for the School Leader Recruitment and Support Program to seed models of promising principal preparation programs, scale preparation programs with results, and support effective professional development for school leaders in the field. \$100 million for the Supporting Effective Educator Development (SEED) Grant Program to recruit and develop teachers, principals, or other school leaders.
- \$190 million for the Striving Readers Comprehensive Literacy Grant program to advance literacy skills for students from birth through grade 12.
- \$1.6 billion for Student Support and Academic Enrichment Grants to support locally designed efforts to provide students with well-rounded educational experiences, safe and healthy learning environments, and personalized instruction, including through the effective use of technology.

*General Provision—Department of Education*

- Continued authority for Performance Partnership Pilots to award up to 10 new pilots that allow States, tribes and localities to blend certain discretionary funding in order to improve education, employment and other key outcomes for vulnerable youth.

The America Forward Coalition respectfully requests that the above programs be included at the identified levels in your fiscal year 2017 Appropriations bill. We recognize the many difficult choices the Committee faces and thank you for the Committee's ongoing support for social innovation policies. We look forward to working with you to advance these important issues in the months ahead.

Sincerely,

Members of the America Forward Coalition

AMERICA FORWARD COALITION

Acelero Learning/Shine	ANet	Beyond 12
Early Learning	AppleTree Institute for	Blue Engine
Alternative Staffing	Education Innovation	Bottom Line
Alliance	AVANCE, Inc.	BUILD
America's Promise	Bard Early Colleges	Child Mind Institute
Alliance	BELL	Citizen Schools

City Year, Inc.	Invest in Outcomes	Root Cause
College Advising Corps	Jumpstart for Young Children, Inc.	Save the Children
College Forward	KIPP	Say Yes to Education
College Possible	LIFT	ServiceNation
College Summit	LISC	Single Stop
Compass Working Capital	Match Education	Social Enterprise Alliance
Connecticut Center for Social Innovation, Inc.	National Center for Learning Disabilities (NCLD)	Social Finance US
Corporation for Supportive Housing (CSH)	New Classrooms	Teach For America
Enterprise Community Partners	Innovation Partners	The Children's Aid Society
Eye to Eye	New Leaders	The Corps Network
Family Independence Initiative (FII)	New Sector Alliance	The Mission Continues
First Place for Youth	New Teacher Center	Third Sector Capital Partners, Inc.
Generation Citizen	Opportunity Nation	Turnaround for Children
Genesys Works	Peace First	Twin Cities RISE!
Global Citizen Year	Peer Health Exchange	uAspire
GreenLight Fund	Public Allies	Waterford Institute
iMentor	Reading Partners	Year Up
Institute for Child Success	REDF	YouthBuild USA
	Roca	Youth Villages, Inc.
		10,000 Degrees

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PREPARED STATEMENT OF THE AMERICA FORWARD COALITION

Dear Chairman Blunt and Ranking Member Murray: As you prepare the fiscal year 2017 Appropriations bill, the America Forward Coalition urges you to include funding for the programs identified below that spur innovation, reward results, and catalyze cross-sector partnerships to propel America forward.

The America Forward Coalition is a network of more than 70 social innovation organizations that champion innovative, effective, and efficient solutions to our country's most pressing social problems. Our Coalition members are achieving measurable outcomes in more than 14,500 communities nationwide, touching the lives of 8 million Americans each year, and driving progress in education, workforce development, early learning, poverty alleviation, public health, pay for success, social innovation, national service, and criminal justice reform. Since 2007, America Forward's community of innovators has played a leading role in driving the national dialogue on social innovation and advocating for lasting policy change.

We are eager to work with you to advance the policies outlined in this letter and urge you to include and prioritize the following programs in the Labor, Health and Human Services, Education and Related Agencies Appropriations bill for fiscal year 2017.

*Department of Labor*

- \$1.33 billion for major formula funds under the Workforce Innovation and Opportunity Act (WIOA), including the adult, youth, and dislocated worker funding streams and \$3.2 million for WIOA technical assistance to provide resources to support State implementation of WIOA.
- \$500 million for the creation of a Workforce Data Science and Innovation Fund to address the quality of workforce related data in order to improve training programs and consumer choice.
- \$2 billion for an Apprenticeship Training Fund to be funded over 5 years in an effort to double the number of registered apprenticeships by helping more employers provide high-quality on-the-job training through apprenticeship and to support States and localities with resources to assist employers in creating and expanding apprenticeships.
- \$102.5 million for YouthBuild grants that are used to engage low-income 16–24 year olds in a comprehensive full-time education, job training, and community service program in which students earn their GED or HSD while learning job skills by building affordable green housing under skilled supervision, or through providing health or technology services in their communities.

*General Provision—Department of Labor*

- Continued authority for Performance Partnership Pilots to award up to 10 new pilots that allow States, tribes and localities to blend certain discretionary fund-

ing in order to improve education, employment and other key outcomes for vulnerable youth.

The America Forward Coalition respectfully requests that the above programs be included at the identified levels in your fiscal year 2017 Appropriations bill. We recognize the many difficult choices the Committee faces and thank you for the Committee's ongoing support for social innovation policies. We look forward to working with you to advance these important issues in the months ahead.

Sincerely,

Members of the America Forward Coalition

AMERICA FORWARD COALITION

Acelero Learning/Shine	Enterprise Community	Peace First
Early Learning	Partners	Peer Health Exchange
Alternative Staffing	Eye to Eye	Public Allies
Alliance	Family Independence	Reading Partners
America's Promise	Initiative (FII)	REDF
Alliance	First Place for Youth	Roca
ANet	Generation Citizen	Root Cause
AppleTree Institute for	Genesys Works	Save the Children
Education Innovation	Global Citizen Year	Say Yes to Education
AVANCE, Inc.	GreenLight Fund	ServiceNation
Bard Early Colleges	iMentor	Single Stop
BELL	Institute for Child Success	Social Enterprise Alliance
Beyond 12	Invest in Outcomes	Social Finance US
Blue Engine	Jumpstart for Young	Teach For America
Bottom Line	Children, Inc.	The Children's Aid Society
BUILD	KIPP	The Corps Network
Child Mind Institute	LIFT	The Mission Continues
Citizen Schools	LISC	Third Sector Capital
City Year, Inc.	Match Education	Partners, Inc.
College Advising Corps	National Center for	Turnaround for Children
College Forward	Learning Disabilities	Twin Cities RISE!
College Possible	(NCLD)	uAspire
College Summit	New Classrooms	Waterford Institute
Compass Working Capital	Innovation Partners	Year Up
Connecticut Center for	New Leaders	YouthBuild USA
Social Innovation, Inc.	New Sector Alliance	Youth Villages, Inc.
Corporation for Supportive	New Teacher Center	10,000 Degrees
Housing (CSH)	Opportunity Nation	

PREPARED STATEMENT OF THE AMERICAN ACADEMY OF FAMILY PHYSICIANS

The American Academy of Family Physicians (AAFP), which represents 120,900 family physicians and medical students across the country, submits this written statement for the record to urge the House Appropriations Committee to invest appropriately in our Nation's primary care physician workforce in fiscal year 2017.

In order to ensure high-quality, cost-effective healthcare for patients of all ages, the AAFP recommends that the Committee restore the discretionary budget authority for the Health Resources and Services Administration (HRSA) to the fiscal year 2010 level of \$7.48 billion and provide \$364 million in budget authority for the Agency for Healthcare Research and Quality (AHRQ).

Within those agency budgets, we specifically highlight the need to provide the following appropriations for programs which are particularly important to family physicians and their patients:

- \$59 million for Health Professions Primary Care Training and Enhancement authorized under Title VII, Section 747 of the Public Health Service Act ;
- An additional \$70 million for the National Health Service Corps for a total program level of \$380 million at least \$20 million of which should be discretionary funding; and
- \$364 million for the AHRQ to support research vital to primary care practice.

*HRSA—Title VII Primary Care Training & Enhancement*

The Primary Care Training & Enhancement (PCTE) program administered by the Health Resources and Services Administration (HRSA) and authorized by Title VII, § 747 of the Public Health Service Act of 1963 is important to support the education and training of family physicians. The PCTE strengthens medical education for phy-

sicians to improve the quantity, quality, distribution, and diversity of the primary care workforce. Without additional funding, there will be no new grant competitions for four more years. For that reason, we urge the Committee to increase the appropriation by \$20 million from the fiscal year 2016 level to \$59 million in fiscal year 2017.

An *Annals of Family Medicine* [<http://www.annfammed.org/content/13/2/107.full>] study projects that the rising number of primary care office visits for the expanding, aging, and increasingly insured population will require an additional 33,000 practicing primary care physicians by 2035. Another study in the same journal [<http://www.annfammed.org/content/10/2/163>] noted meeting the increased demand for primary care physicians would require a major investment in training. The article explicitly called for the expansion of Title VII, Section 747 to improve access to primary care. But we already face family physician shortages. A National Association of Community Health Centers report found that more than two-thirds of centers are actively recruiting for at least one family physician. [[http://www.nachc.com/client/NACHC\\_Workforce\\_Report\\_2016.pdf](http://www.nachc.com/client/NACHC_Workforce_Report_2016.pdf)].

The Federal Advisory Committee on Training in Primary Care Medicine and Dentistry noted in a report released early in 2015 [<http://www.hrsa.gov/advisorycommittees/bhpradvisory/actpcmd/Reports/eleventhreport.pdf>] that the funds “available through Title VII, Part C, sections 747 and 748 have decreased significantly over the past 10 years, and are currently inadequate to support the system changes.” The advisory committee recommended restoring funding to inflation-adjusted fiscal year 2003 levels plus an additional \$25 million per year over the next 5 years beginning in fiscal year 2017 to permit annual competitive grant cycles for primary care training grants.

For decades, these grants to medical schools and residency programs have helped increase the number of physicians who select primary care specialties and who go on to work in underserved areas. A 2014 study of the effect of a PCTE grant addressing faculty development needs found that targeted Federal funding can bring about changes that contribute to an up-to-date, responsive primary care workforce. [<http://www.jgme.org/doi/full/10.4300/JGME-D-14-00329.1>].

#### *National Health Service Corps*

Since in 1972, the National Health Service Corps (NHSC), also administered by HRSA, has offered financial assistance to recruit and retain healthcare providers to meet the workforce needs of communities across the Nation designated as health professional shortage areas. The AAFP is committed to supporting the objectives of the NHSC in assisting communities in need of additional primary care physicians, and we support the Administration’s budget request for the NHSC of \$20 million in discretionary appropriations for fiscal year 2017.

The Government Accountability Office (GAO-01-1042T) described the NHSC as “one safety-net program that directly places primary care physicians and other health professionals in these medically needy areas.” As the only medical society devoted solely to primary care, the AAFP recognizes the importance of the NHSC to the reducing geographic disparities in healthcare access.

Not only does the NHSC program of placing physicians and medical professionals in health professional shortage areas to meet the needs of patients in rural and medically underserved areas, it also provides scholarships as incentives for medical students to enter primary care and to provide healthcare to underserved Americans. By addressing medical school debt burdens, NHSC scholarships ensure wider access to medical education opportunities by providing financial support for tuition and other education expenses, and a monthly living stipend for medical students committed to providing primary care in underserved communities of greatest need.

More than 40,000 providers have served in the NHSC since its inception. In fiscal year 2015, the National Health Service Corps (NHSC) had a field strength of 9,683 primary care and other clinicians. However, the need for primary care continues to exceed the available investment. The AAFP recommends that the Congress provide at least the program level of \$380 million for the NHSC in fiscal year 2017.

#### *Agency for Healthcare Research and Quality—Primary Care Research?*

The Agency for Healthcare Research and Quality (AHRQ) is the sole Federal agency charged with producing research to support clinical decisionmaking, reduce costs, advance patient safety, decrease medical errors and improve healthcare quality and access. AHRQ provides the critical evidence reviews needed to answer questions on the common acute, chronic, and co-morbid conditions that family physicians encounter in their practices on a daily basis.

Without AHRQ research, too little is known about appropriate care for real patients in primary care practices. More attention and research need to be directed

to patients with more than one mental or physical health condition. In 2000, for example, an estimated 60 million Americans had multiple chronic conditions. By 2020, that population is expected to grow to an estimated 81 million. Care for people with chronic conditions is expected to consume 80 percent of the resources of publicly funded health insurance programs by 2020. Treatment of patients with multiple chronic conditions already accounts for 51 percent of total health expenditures.

Unfortunately, fiscal year 2016 cuts harmed AHRQ's efforts to research the care of those with multiple chronic conditions. The agency's research initiative aimed at optimizing care for patients with multiple chronic conditions halted this year due to lack of funds. Restoring AHRQ's funding to fiscal year 2015 levels will support research to provide primary care physicians the tools they need for evidence-based practice.

The AAFP urges the Committee provide no less than \$364 million in appropriated funds for AHRQ to support research vital to primary care.

#### PREPARED STATEMENT OF THE AMERICAN ACADEMY OF PAs

On behalf of more than 108,500 nationally-certified PAs (physician assistants), the American Academy of PAs (AAPA) is pleased to submit comments on the fiscal year 2017 appropriations for the Departments of Labor, Health and Human Services, and Education and related agencies. AAPA respectfully requests the Subcommittee to approve funding of \$280 million for the Title VII health professions education program administered by the Health Resources and Services Administration (HRSA) and provide \$12 million of the funding allocated to the Primary Care Training and Enhancement program (PCTE) for PA education programs. Additionally, AAPA supports continued funding for the National Health Service Corps (NHSC), community health centers (CHCs), and activities within the Substance Abuse and Mental Health Services Administration (SAMHSA) which use PAs to increase access to treatment for mental illnesses and substance use disorders.

#### *PA Education and Practice*

PAs receive a broad education over approximately 27 months which consists of two parts. The didactic phase includes coursework in anatomy, physiology, biochemistry, pharmacology, physical diagnosis, behavioral sciences, and medical ethics. This is followed by the clinical phase, which includes rotations in medical and surgical disciplines such as family medicine, internal medicine, general surgery, pediatrics, obstetrics and gynecology, emergency medicine, and psychiatry. Due to these demanding rotation requirements, PA students will have completed at least 2,000 hours of supervised clinical practice in various settings and locations by graduation.

There are currently 210 accredited PA educational programs in the U.S., all of which are located within schools of medicine or health sciences, universities, teaching hospitals, and the Armed Services. The majority of these programs award a master's degree. PAs must pass the Physician Assistant National Certifying Examination and be licensed by a State in order to practice. The PA profession is the only medical profession that requires a practitioner to periodically take and pass a high-stakes comprehensive exam to remain certified, which PAs must do every 10 years. To maintain their certification, PAs must also complete 100 hours of continuing medical education (CME) every 2 years.

PAs practice and prescribe medication in all 50 States, the District of Columbia, and all U.S. territories with the exception of Puerto Rico. They manage the full scope of patient care, often handling patients with multiple comorbidities. In their normal course of work, PAs conduct physical exams, order and interpret tests, diagnose and treat illnesses, assist in surgery, and counsel on preventative healthcare. The rigorous education and clinical training of PAs enables them to be fully qualified and equipped to care for patients in every medical and surgical specialty and setting.

#### *PAs and Title VII Funding*

Title VII of the Public Health Service (PHS) Act is the only continuing Federal funding available to PA educational programs. As a result, AAPA supports increased funding for Title VII, particularly for PA education grants funded through PCTE. These grants have proven successful in training new PAs; for instance, the Physician Assistant Training in Primary Care program supported the education of 4,390 PA students in the 2014–2015 school year (up from 4,071 in 2013–2014). Of those students, 29 percent were minorities and/or from disadvantaged backgrounds, and 13 percent were from rural areas. Fifty-eight percent of the institutions which were



awarded grants through this program were focused on primary care, and the majority of them were in rural or medically underserved areas.

Likewise, the Expansion of Physician Assistant Training (EPAT) program under PCTE assisted 429 students during the 2014–2015 school year (equal to 2013–2014), with 48 percent of these students receiving training in a medically-underserved area. EPAT funds support PA students in covering the cost of tuition, fees, and training and fellowships for up to 2 years. 130 students supported by these grants graduated in 2015—of these, 36 percent intended to practice in a medically underserved area, 22 percent wished to practice in a rural community, and 73 percent planned to work in primary care. These statistics clearly show that both programs have lived up to their intended purposes: encouraging students from under-represented groups to attend PA school and increasing PA practice in rural and medically underserved areas.

Title VII has been instrumental in allowing increased numbers of PA students to pursue their education. However, this funding has also helped PA programs expand opportunities for clinical rotations in rural and medically underserved areas. This expansion benefits PA students, but just as important, it benefits local residents who would otherwise have limited access to healthcare providers. It is common for new PAs to remain in the area in which they completed their education, and a review of PA graduates from 1990–2009 showed that PAs who graduated from programs supported by Title VII were 47 percent more likely to work in rural health clinics than graduates of other programs. Continued funding for PA educational programs under Title VII is a win-win scenario for underserved communities and the Nation’s healthcare workforce.

#### *PAs in Primary Care*

Currently, 30 percent of practicing PAs work in primary care settings, and PAs are one of three primary care providers along with physicians and nurse practitioners (NPs) who may participate in NHSC. There are now more than 9,200 clinicians participating in NHSC’s loan repayment and scholarship programs—12 percent of which are PAs. In light of the demand for providers in the rural and medically underserved areas which are covered by NHSC, as well as the ongoing primary care provider shortage, continued funding is needed to ensure this important program can reach patients who lack access to care and help grow the next generation of healthcare providers in places where they are needed most.

PAs also provide medical care in community health centers (CHCs), and in some cases, serve as CHC medical directors. CHCs offer cost-effective healthcare throughout the country and serve as medical homes for millions of patients who live in medically underserved areas. CHCs provide a wide variety of healthcare services through team-based care, providing high quality care to CHC patients and significantly reducing their medical expenses by focusing on primary care services. AAPA supports continued funding for both NHSC and CHCs.

#### *PAs in Mental Health and Addiction Medicine*

PAs typically work on the “front lines” of healthcare and they often treat patients who are experiencing mental illnesses or addiction, even when they do not specialize in these areas. AAPA is pleased HRSA acknowledged the role of PAs in the mental healthcare and addiction medicine spaces in its fiscal year 2017 budget request by including them in the definition of “behavioral health workforce.” We support efforts in the budget request to further integrate primary care and behavioral healthcare by encouraging the use of screenings, referrals, and warm handoffs to specialists in the same facility or via telemedicine services, all of which have been shown to improve patient outcomes and mitigate gaps in coverage caused by too few providers.

Additionally, we are pleased both Congress and the Administration are focused on addressing the shortage of treatment options for individuals who are struggling with opioid addiction. AAPA supports funding for programs intended to allow additional healthcare providers—including PAs—to prescribe buprenorphine as a part of medication-assisted treatment (MAT). The Administration has proposed in its budget a demonstration program to gauge the feasibility of making this change, even though the majority of these providers, including PAs, can already prescribe this drug for pain management purposes. Instead, we believe it is necessary for Congress to pass a statutory fix to the Drug Addiction Treatment Act of 2000 (DATA 2000) which would remove the Federal ban on PAs prescribing buprenorphine for MAT. A demonstration project is an unnecessary step that only slows down bringing in more providers to assist with this crisis.

## SUMMARY

AAPA recognizes the fiscal challenges facing the country, and we understand tough choices must be made in allocating scarce Federal dollars to our Nation's varied priorities. Yet, HRSA has estimated there could be a shortage of more than 20,000 physicians by 2020. The PA profession continues to experience record growth—the profession grew 36.4 percent between 2009 and 2014—with historically high numbers of PAs currently practicing in the U.S. We believe better utilization of PAs—particularly in rural and medically underserved areas—is an important way to mitigate these projections and ensure all Americans have access to high quality healthcare. As such, AAPA urges continued Federal support for programs which support PAs and PA students.

We appreciate the opportunity to present our views during the fiscal year 2017 appropriations process, and we welcome the opportunity to serve as a resource to the Subcommittee. If you have any questions, please do not hesitate to have your staff contact Sandy Harding, AAPA Senior Director of Federal Advocacy, at sharding@aapa.org.

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 PREPARED STATEMENT OF THE AMERICAN ACADEMY OF PEDIATRICS

The American Academy of Pediatrics (AAP), a non-profit professional organization of 64,000 primary care pediatricians, pediatric medical subspecialists, and pediatric surgical specialists dedicated to the health, safety, and well-being of infants, children, adolescents, and young adults, appreciates the opportunity to submit this statement for the record in support of strong Federal investments in children's health in fiscal year 2017 and beyond. AAP urges all Members of Congress to put children first when considering short and long-term Federal spending decisions.

As pediatricians, 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. As such, we urge you to pass strong policies that invest in children in the earliest days of life. We implore you to take meaningful strides to address chronic poverty and its impacts on the health and well-being of American families.

AAP supports robust funding of the Department of Health and Human Services (HHS) and its individual agencies which all combine to support important programs that ensure the health and safety of children. Federal funding through these agencies supports critical programs that address pressing public health challenges including: efforts to prevent infant mortality and birth defects; healthy child development; antimicrobial resistance and infectious diseases; emergency medical services for children; mental health and substance abuse prevention; tobacco prevention and cessation; unintentional injury and violence prevention; child maltreatment prevention; childhood obesity; environmental and chemical exposures; poison control; teen pregnancy prevention and family planning; health promotion in schools; and medical research and innovation. In addition, we would like to highlight our support for investments in the following crucial child health programs:

*National Center for Birth Defects and Developmental Disabilities (CDC)*

The National Center for Birth Defects and Developmental Disabilities (NCBDDD) 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, and promoting health and well-being among people of all ages with disabilities. 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 2017 REQUEST: \$135.610 MILLION;  
 FISCAL YEAR 2016 LEVEL: \$135.610 MILLION

*Emergency Medical Services for Children (HRSA)*

Established by Congress in 1984 and last reauthorized in 2015, 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 that state of the art emergency medical care for the ill and injured child or adolescent pediatric services are well integrated into an EMS system backed by optimal resources; and the entire spectrum of emergency services is provided to children and adolescents no matter where they live, attend school, or travel. Gaps in providing quality care to children in emergencies continue to persist throughout the country. The EMSC program helps to address these gaps by promoting the quality of care provided in the pre-hospital and hospital setting, reducing pediatric mortalities due to serious injury, and supporting rigorous multi-site clinical trials through the Pediatric Emergency Care Applied Research Network (PECARN).

FISCAL YEAR 2017 REQUEST: \$21.213 MILLION;  
FISCAL YEAR 2016 LEVEL: \$20.162 MILLION

*National Vaccine Injury Compensation Program (HRSA)*

The National Vaccine Injury Compensation Program (NVICP) was established in 1988 to ensure an adequate supply of vaccines, stabilize vaccine costs, and establish and maintain an accessible and efficient forum for individuals found to be injured by certain vaccines. NVICP is an alternative to the traditional tort system for resolving vaccine injury claims and provides compensation to individuals found to have been injured by certain vaccines. Over the past 5 years, NVICP has seen a 71.6 percent rise in the number of petitions filed, due in large part to the flu vaccine. In fact, more than 60 percent of all petitions filed are now adult claims for alleged injuries from the flu vaccine. Though the number of petitions has risen, the number of staff has not. This additional funding can be used to hire more staff in order to expedite the processing of claims, thereby reducing the administrative backlog.

FISCAL YEAR 2017 REQUEST: \$9.2 MILLION;  
FISCAL YEAR 2016 LEVEL: \$7.5 MILLION

*Lead Poisoning Prevention Program (CDC)*

There is no safe level of lead exposure, and lead damage can be permanent and irreversible, leading to increased likelihood for behavior problems, attention deficit and reading disabilities, and failure to graduate high school, in addition to experiencing a host of other impairments to their developing cardiovascular, immune, and endocrine systems. Today, over 500,000 children are exposed to unacceptably high levels of lead, and prevention efforts are critical to protect children from its harmful effects. The crisis in Flint, MI is a tragic inflection point in the ongoing issue of vulnerable communities facing lead exposure as one of many forms of adversity, with lifelong health effects. Prevention efforts like those at CDC are critical to addressing this problem.

FISCAL YEAR 2017 REQUEST: \$35 MILLION;  
FISCAL YEAR 2016 LEVEL: \$17 MILLION

*Global Immunizations (CDC)*

The U.S. Government has played a leading role in expanding access to immunizations around the world. Since 1988, a coordinated global immunization campaign has reduced the number of polio cases by more than 99 percent, saving more than 13 million children from paralysis and bringing the disease close to eradication. Investments in polio have also trained health workers and strengthened the surveillance systems, laboratory networks and biocontainment capabilities that helped to arrest the spread of Ebola in countries such as Nigeria and Uganda. Global mortality attributed to measles, one of the top five diseases killing children, declined by 79 percent between 2000 and 2014 thanks to expanded immunization, saving an estimated 17.1 million lives. Despite this progress, the world is failing to meet most of its immunization goals, due in large part to weak healthcare systems and challenges presented by migration, rapid urbanization, conflict and natural disasters. The U.S. Government has a timely opportunity to foster interagency coordination for efficiency and impact and reprioritize global immunization targets, as outlined in the Global Vaccine Action Plan, through its updates of the U.S. National Vaccine Plan and the Centers for Disease Control and Prevention's (CDC's) Global Immunization Strategic Framework. The CDC should also maintain its support for country-level polio transition plans that are led by national governments and involve a broad range of stakeholders, which will be critical to ensuring continued benefits from past investments in the their routine immunization systems.

FISCAL YEAR 2017 REQUEST: \$224 MILLION;  
FISCAL YEAR 2016 LEVEL: \$219 MILLION

*Title X Family Planning Program (Office of Population Affairs)*

Title X remains the sole source of dedicated Federal funding for family planning services for underserved populations. In fact, 91 percent of clients had incomes at or below 250 percent of the Federal poverty level. Through Title X health centers, nearly five million women and men access life-saving healthcare such as birth control, cancer screenings, and testing for sexually transmitted infections. In addition, Title X family planning centers help to avert an estimated one million unintended pregnancies.

FISCAL YEAR 2017 REQUEST: \$327 MILLION;  
FISCAL YEAR 2016 LEVEL: \$286 MILLION

*Children's Hospital Graduate Medical Education (HRSA)*

The Children's Hospital Graduate Medicaid Education (CHGME) program 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. Continued funding is essential to maintaining the gains that have been achieved under CHGME in strengthening the pediatric workforce pipeline. While much has been achieved, much remains to be done, as serious shortages in many pediatric specialties persist. Since Congress created the program in 1999 to address the gap in Federal support for pediatric training, CHGME has increased the number of pediatric providers, addressed critical shortages in pediatric specialty care and improved children's access to care. Today, nearly half (49 percent) of all pediatric residents are trained by CHGME recipient hospitals. Overall, 51 percent of pediatric specialists are trained at CHGME hospitals, and in many specialties, such as pediatric surgery or critical care medicine, over 65 percent of physicians are trained at these children's hospitals.

FISCAL YEAR 2017 REQUEST: \$300 MILLION;  
FISCAL YEAR 2016 LEVEL: \$295 MILLION

*Gun Violence Prevention (CDC)*

Gun violence is a serious public health issue, and the dearth of research on how best to prevent related morbidity and mortality makes it difficult to implement a public health approach to addressing this public health problem. The AAP supports funding to research how gun violence affects children, and believes that more research into this matter will allow for pediatricians and others who care for children to better understand how to protect children from these injuries and deaths.

FISCAL YEAR 2017 REQUEST: \$10 MILLION;  
FISCAL YEAR 2016 LEVEL: N/A

*Ryan White HIV/AIDS Program Part D (HRSA)*

Part D of the Ryan White Program provides family-centered, primary medical care to women, infants, children, and youth living with HIV/AIDS throughout the U.S. when payments for such services are unavailable from other sources. Part D improves access to primary HIV medical care through coordinated, comprehensive, culturally, and linguistically competent services. More than 90,000 women, infants, children, youth and family members access Ryan White Part D funded program services each year. In 2014, Part D provided funding to 114 community-based organizations, safety net and university hospitals and health departments in 39 States and Puerto Rico. We oppose the President's budget proposal to consolidate funds from Parts C and D of the Ryan White Program. Ryan White Part D is the lifeline for women, infants, children, and youth living with HIV/AIDS, and has proved instrumental in preventing mother-to-child transmission of HIV.

FISCAL YEAR 2017 REQUEST: \$75.08 MILLION  
(AND NO CONSOLIDATION OF PARTS C AND D);

FISCAL YEAR 2016 LEVEL: \$75.08 MILLION

On behalf of the 75 million American children and their families that we serve and treat, the Nation's pediatricians hope that Congress will respond to mounting evidence that child health has life-long impacts and prioritize children while determining fiscal year 2017 Federal spending levels. Federal support for children's health programs will yield high returns for the American economy. Investing in children is not only the right thing to do for the long-term physical, mental, and emo-

tional health of the population, but is imperative for the Nation's long-term fiscal health as well.

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, focusing 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 extraordinary dividends for years to come.

There are many ways Congress can help meet children's needs and protect their health and wellbeing. Adequate funding for children's health programs is one of them. 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 2017 and beyond. If we may be of further assistance please contact the AAP Department of Federal Affairs at [pjohnson@aap.org](mailto:pjohnson@aap.org). Thank you for your consideration.

[This statement was submitted by Benard P. Dreyer, MD, FAAP, President, American Academy of Pediatrics.]

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PREPARED STATEMENT OF THE AMERICAN ALLIANCE OF MUSEUMS

Chairman Blunt, Ranking Member Murray, and members of the Subcommittee, thank you for allowing me to submit this testimony on behalf of our members and the Nation's larger museum community. My name is Laura L. Lott and I serve as President and CEO of the American Alliance of Museums. I respectfully request that the Subcommittee make a renewed investment in museums in fiscal year 2017. I urge you to fully fund the Office of Museum Services (OMS) at the Institute of Museum and Library Services (IMLS) at its authorized level of \$38.6 million.

Before explaining this request, I want to express gratitude for the increase of roughly \$1.2 million for OMS that was enacted last year by the Subcommittee in the Consolidated Appropriations Act, Public Law 114-113. Your support for museums will help them make a bigger impact in communities nationwide. I know that the Subcommittee once again faces a very limited 302(b) allocation, and must make difficult decisions. In this context, however, I would posit that this extremely small program is a vital investment in protecting our Nation's cultural treasures, educating students and lifelong learners, and bolstering local economies around the country.

The Alliance is proud to represent the full range of our Nation's museums—including aquariums, art museums, botanic gardens, children's museums, culturally specific museums, historic sites, history museums, maritime museums, military museums, natural history museums, planetariums, presidential libraries, science and technology centers, and zoos, among others—along with the professional staff and volunteers who work for and with museums.

Museums are economic engines and job creators: We are proud to report that U.S. museums employ 400,000 people and directly contribute \$21 billion to their local economies.

This Subcommittee may be especially interested in the ways museums are providing educational programming and the results of this investment:

- Museums spend more than \$2 billion each year on education activities; the typical museum devotes three-quarters of its education budget to K-12 students, and museums receive approximately 55 million visits each year from students in school groups.
- Children who visited a museum during kindergarten had higher achievement scores in reading, mathematics and science in third grade than children who did not. This benefit is also seen in the subgroup of children who are most at risk for deficits and delays in achievement.
- According to a recent study by researchers at the University of Arkansas, students who attended a field trip to an art museum experienced an increase in critical thinking skills, historical empathy and tolerance. For students from rural or high-poverty regions, the increase was even more significant.
- Museums help teach the State and local curriculum, adapting their programs in math, science, art, literacy, language arts, history, civics and government, economics and financial literacy, geography and social studies.
- Many museums are tailoring programs to serve homeschooling families.

IMLS is the primary Federal agency that supports the museum field, and OMS awards grants in every State 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.

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. That bill (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 2016 appropriation of \$31.3 million still falls well below its recent high of \$35.2 million in fiscal year 2010.

While the funding increase proposed by the president's budget is extremely small, it reflects some priority areas in which museums could make a greater impact with more Federal investment, such as STEM education, national digital infrastructure, and early childhood-family learning. The budget also sets out key strategic focuses on training for collections care, deepening museums' role as community-centered organizations, and serving veterans and military families.

We applaud the 33 Senators who wrote to you in support of fiscal year 2017 OMS funding, including Subcommittee members Durbin, Reed, Shaheen, Schatz, and Baldwin, as well as Committee members Leahy, Feinstein, Tester, Coons, and Murphy.

Here are a few examples, just from 2015, of how IMLS Office of Museum Services funding is used:

*Early Childhood STEM Engagement and Resources—The Magic House (Saint Louis, MO)* was awarded \$150,000 to research, develop, fabricate, and assess a new early childhood STEM exhibit for children ages two through six. The 1,500-square-foot learning environment will engage children in self-directed activities that align with State educational standards for science and math. The museum will also create a new guided field trip program, a professional development workshop for educators in early childhood STEM education, and tools and resources for parents and caregivers.

*Collections Access and Coordination—Tennessee Aquarium (Chattanooga, TN)* was awarded \$112,078 to partner with Tennessee Technological University to develop the Freshwater Information Network, an interactive portal that combines museum records, recent survey data, and photo archives to provide biologists and resource managers with a platform for connecting and sharing the best scientific information on aquatic animals. This will enhance the conservation value of museum data by better connecting it to researchers, students, resource managers, conservation organizations, and others.

*Place-based Education—Port Townsend Marine Science Center (Port Townsend, WA)* was awarded \$148,346 to expand an existing initiative that integrates local resources with area schools in a place-based educational system. By orienting education around the community's maritime heritage, the Maritime Discovery Schools initiative is a comprehensive framework that increases student engagement. Through this grant, the museum will be able to bring in nationally recognized education leaders for both teacher professional development and student programs.

*Community Anchors—Baltimore Museum of Art (Baltimore, MD)* was awarded \$150,000 to create an exhibition and related programming that will use art to examine housing issues in the community. The project will include a traveling exhibit that will reach at least twenty-four neighborhoods throughout Baltimore, as well as hands-on, interactive workshops for Baltimore entities working to address homelessness, affordable housing, vacant properties, and other home-related issues. These organizations will gain knowledge, skills, and resources that enable them to integrate art-based activities into their service portfolio.

It should be noted that each time a museum grant is awarded, additional local and private funds are also leveraged. In addition to the dollar-for-dollar match required of museums, grants often spur additional giving by private foundations and individual donors. Two-thirds of Museums for America grantees report that their grant positioned the museum to receive additional private funding.

IMLS grants to museums are highly competitive and decided through a rigorous, peer-review process. Even the most ardent deficit hawks ought to view the IMLS grant-making process as a model for the Nation. Due to the large number of grant applications and the limited funds available, many highly-rated grant proposals go unfunded each year. In 2015:

—Only 39 percent of Museums for America project proposals were funded;

- Only 30 percent of National Leadership Grants for Museums project proposals were funded;
- Only 15 percent of Sparks! Ignition Grants for Museums project proposals were funded;
- Only 66 percent of Native American/Hawaiian Museum Services project proposals were funded; and
- Only 37 percent of African American History and Culture project proposals were funded.

Again, I know the subcommittee faces difficult decisions and am grateful for your previous support. If I can provide any additional information about the essential role of the museums in your community, I would be delighted to do so. Thank you once again for the opportunity to submit this testimony today.

[This statement was submitted by Laura L. Lott, President and CEO, American Alliance of Museums.]

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PREPARED STATEMENT OF THE AMERICAN ASSOCIATION FOR CANCER RESEARCH

The American Association for Cancer Research (AACR) is the world's first and largest scientific organization focused on every aspect of high-quality, innovative cancer research. The mission of the AACR and its more than 35,000 members is to prevent and cure cancer through research, education, communication, and collaboration. The AACR calls on Congress to provide at least \$34.5 billion for the National Institutes of Health (NIH) in fiscal year 2017 (a 7.7 percent increase), and to provide a \$680 million increase above fiscal year 2016 levels for the National Cancer Institute (NCI) to initiate the National Cancer "Moonshot" Initiative.

Keeping the NIH and NCI on a path of sustained, robust, and predictable funding growth is the only way we will seize the unparalleled scientific opportunities in cancer research that lie before us, and the only way we will overcome the challenges we face in conquering this complex disease.

We thank the United States Congress for its longstanding, bipartisan support for the NIH and for its commitment to funding cancer research. We especially thank Senate Appropriations Subcommittee on Labor, Health and Human Services (HHS), Education Chairman Roy Blunt and Ranking Member Patty Murray for their unwavering support for the NIH. We are grateful for the \$2 billion increase appropriated to the NIH in the fiscal year 2016 omnibus spending bill, the most significant boost in a decade for the agency. Through Congress making medical research a national priority, Federal funding for this lifesaving work has turned a corner and is once again headed in the right direction.

*A Unique Moment for Cancer: Supporting the National Cancer "Moonshot" Initiative*

We live in an extraordinary time of scientific opportunity in the field of cancer research. The AACR looks forward to continuing to work with Congress to accelerate progress against the more than 200 diseases we call cancer in the next 5 to 10 years. To that end, the AACR strongly supports the National Cancer "Moonshot" Initiative. Now is the time for a major, new initiative cancer science that both supports and builds upon the strong, basic science foundation that has been established, and translates the exciting scientific discoveries into improved therapies for cancer patients. Nowhere is this more evident than in genomics, immuno-oncology and precision medicine, an area in which cancer research has been leading the way for more than a decade. A strong commitment to the NIH and the NCI is required to move this Initiative forward, in addition to continued support for existing NIH programs such as the Precision Medicine Initiative, which has an important oncology component.

*Investments in Cancer Research are Saving and Improving Lives*

Significant progress has been made against cancer because of the decades of Federal investment in medical research and the dedicated work of researchers, physician-scientists, and patient advocates throughout the biomedical research ecosystem. Federal support has cultivated new and improved approaches to the prevention, detection, diagnosis, and treatment of cancer, and investments in basic research have enabled scientists to capitalize on the understanding of what causes and drives cancer. As is detailed in the AACR Cancer Progress Report 2015, support from the NIH and the NCI for basic, translational, and clinical research has led to decreases in the incidence of many cancers, cures for a number of these diseases, and higher quality and longer lives for many individuals whose cancers cannot yet be prevented or cured.

Consider the progress made in just the last 18 months. Cancer patients now have access to:

- 21 new anticancer therapeutics;
- 13 new uses for previously approved cancer drugs;
- 1 new use for an imaging agent;
- 1 new cancer screening test; and,
- 1 new cancer prevention vaccine.

One of the most exciting breakthroughs in the past 5 years in cancer research has been the ability to harness the power of a patient's own immune system to fight cancer, leading to the development of immunotherapies. The concept of immunotherapy as a means to target cancer cells is not new, but we now have achieved the ability to effectively translate decades of knowledge about the immune system into revolutionary advances in patient care. In 2015 alone, the FDA approved five cancer immunotherapies, including the first immunotherapies for lung cancer and for children with cancer.

Perhaps most illustrative of our progress is the fact there are now an estimated 14.5 million cancer survivors living today in the United States, and this number is expected to grow to 18 million by the year 2020. These remarkable achievements would never have been possible without a national commitment to funding cancer research, screening, and treatment programs at the NCI, NIH, and other agencies. We can continue to make significant advances, but only if we redouble our efforts to ensure the Federal resources are there to continue, and increase, the pace of progress.

In addition to improving health and saving lives, cancer research and biomedical science also serves as one of our country's primary paths to innovation, global competitiveness, and economic growth. According to United for Medical Research, NIH funding directly and indirectly supported more than 402,000 jobs in 2012 alone, and generated more than \$57.8 billion in new economic activity.

Lastly, conquering cancer is important to the American public. In a poll of eligible voters commissioned by the AACR last year, more than 80 percent of respondents recognized that progress was being made against cancer, but the progress was not happening quickly enough. The same poll showed that a majority of Americans (3 out of 4 individuals polled) support increasing Federal funding for medical research.

#### *Cancer Remains a Significant Public Health Challenge*

Even in the face of the promise and progress highlighted above, cancer remains a formidable opponent, and the 2015 AACR poll found that it remains the disease Americans fear most. An estimated 1.7 million Americans will be diagnosed with cancer this year, and 1 in every 3 women and 1 in every 2 men will likely develop cancer in their lifetimes. It is also projected that more than 595,000 people will die this year in the U.S. from cancers. There also are a number of cancers, including pancreatic, liver and lung cancers, for which the mortality rate remains extraordinarily high and 5-year survival rates are typically less than 50 percent. Further, racial and ethnic minorities, as well as low-income, rural and elderly populations, continue to suffer disproportionately in cancer incidence, prevalence, and mortality.

Because of the steady increase in cancer incidence rates, which is due in part to our aging and growing minority populations, continuing and strengthening our Nation's commitment to cancer research and biomedical science is more critical now than ever. Increasing the Federal investment in cancer research and biomedical science will play a vital role in addressing the current challenges in cancer, while at the same time curbing the overall annual costs of this devastating disease —the economic cost of which exceeded \$263 billion in 2010 and is expected to continue to rise as the number of cancer deaths increases.

#### *Progress Against Cancer Requires a Sustained Commitment to Funding*

Our Nation's ability to realize the exciting future that awaits us in cancer research depends on a continued, strong commitment by Congress to provide sustained, robust, and predictable funding increases for the NIH and the NCI. We have reached an inflection point, where discoveries are being made at an ever-accelerating pace. These discoveries are saving lives and bringing enormous hope for cancer patients, even those with advanced disease.

We must seize the opportunity to continue to invest in our Nation's medical research ecosystem by providing at least \$34.5 billion for the NIH in fiscal year 2017. We also must make, as Vice President Biden said in October 2015, an "absolute national commitment to end cancer as we know it today" by funding the National Cancer Moonshot Initiative with the requested \$680 million for the NCI.

Fulfilling these requests will ensure we can continue to transform cancer care, spur innovation and economic growth, maintain our position as the global leader in



science and medical research, and most importantly, bring hope to cancer patients and their loved ones everywhere. The AACR looks forward to working with you to ensure that researchers have the resources they need to continue to deliver hope to those who are confronting this dreaded disease.

[This statement was submitted by Margaret Foti, PhD, MD (hc), Chief Executive Officer, American Association for Cancer Research.]

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION FOR DENTAL RESEARCH AND THE FRIENDS OF NATIONAL INSTITUTE OF DENTAL AND CRANIOFACIAL RESEARCH

On behalf of the American Association for Dental Research (AADR) and the Friends of National Institute of Dental and Craniofacial Research (FNIDCR), I am pleased to submit testimony describing our fiscal year 2017 requests, which include at least \$34.5 billion for the National Institutes of Health (NIH) and \$452 million for the National Institute of Dental and Craniofacial Research (NIDCR). We are extremely grateful that last year Congress provided the most significant increases for NIH and NIDCR in over a decade.

In the fiscal year 2017 Labor, Health and Human Services and Education Appropriations bill, we strongly urge Congress to build on this momentum and continue to provide predictable and sustainable funding for NIH and NIDCR this year and beyond. Increasing funding for NIDCR by an approximate 9 percent would allow for 6 percent real growth in this Institute. This increased investment will improve the oral health of the Nation, reduce societal costs of dental care and enhance the scientific evidence base for the dental profession. Specifically, increased funding would enable NIDCR to expand its portfolio of work on immunotherapies for oral cancer; research on cleft lip and cleft palate; and address oral health disparities among the aging population.

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 make it difficult to eat, drink, swallow, smile, communicate and maintain proper nutrition. Scientists also have discovered important linkages between periodontal (gum) disease and heart disease, stroke, diabetes and pancreatic cancer.

Investments in NIDCR funded research during the past half century have led to improvements in oral health for millions of Americans through its impact on areas such as community water fluoridation; the implementation of dental sealants to reduce cavities in children; and emerging opportunities to assess the efficacy of a human papilloma virus (HPV) vaccine for oral and pharyngeal cancers.

As a result of these investments, today over 200 million Americans are benefiting from community water fluoridation. The percent of children from 1960–2000 in the U.S. without any dental decay in their permanent teeth has almost tripled from about 25 percent to 70 percent. Absent advances in oral health research in the fight against dental caries (tooth decay) and periodontal diseases there would be an additional 18.6 million Americans aged 45 or older who have lost all of their natural teeth. Perhaps most striking is that since the 1950s the total Federal investment in NIH-funded oral health research has saved the American public at least \$3 for every \$1 invested.

Despite these improvements, however, treating oral health conditions remains extremely costly—with the Nation spending \$113.5 billion on dental services in 2014. While tooth decay and gum disease are the most prevalent threats to oral health, complete tooth loss, oral cancer and craniofacial congenital anomalies, such as cleft lip and palate, impose massive health and economic burdens on Americans. Below for your reference are additional examples of the important research supported by NIDCR to address some of these topic areas:

—*Point of Care Diagnostics*: Salivary diagnostics are devices that draw and analyze saliva to test for conditions and infections such as HIV, human papillomavirus (HPV), substance abuse, caries, periodontitis and oral cancer. As a result of research supported by NIDCR over the last decade, diagnostics are also showing great promise in screening for systemic diseases such as diabetes, heart disease, lung cancer, ovarian cancer and pancreatic cancer.

—*E-Cigarettes*: According to the CDC the use of electronic cigarettes has tripled among middle and high school students in 1 year. Currently, there is no scientific evidence to support the safety of e-cigarettes, and initial studies indicate that a variety of chemicals and metal particles are produced during the vaporization of nicotine and additives by these devices. To help address this research gap and inform policymakers, NIDCR has recently provided funding to support

several new studies to determine the biological and physiological effects of e-cigarette aerosol mixtures. This research will also include the development of new tools and clinically-relevant model systems to assess their effects on oral and periodontal tissues.

- Precision Medicine*: Precision medicine is an approach for disease prevention and treatment that takes into account people’s individual variations in genes, environment and lifestyle. NIDCR supports a diverse precision medicine research portfolio related to diseases and conditions of the dental, oral and craniofacial region including research on cancer, craniofacial developmental disorders and salivary diagnostics. Further, NIDCR is a leader in conducting research within networks composed of individual and group dental practices where most personalized oral healthcare in the U.S. is provided.
- Oral Microbiome*: NIDCR funds a community resource providing comprehensive information on over 700 different microbial species present in the oral cavity. To reduce and eliminate oral health disparities, research on the oral microbiome in children will help identify those at increased risk of developing early childhood caries (tooth decay).
- Enhanced Tissue Regeneration*: NIDCR-funded scientists have developed effective techniques to reduce inflammation and enable the use of stem cells to form new bone and cartilage for oral, dental and craniofacial purposes. The isolation and enrichment of stem cells is also being explored, which would further enhance the cells’ ability to regrow bone and cartilage at the sites where it is most needed. NIDCR recently funded a tissue engineering consortium employing multidisciplinary teams to translate basic research into innovative tools and strategies to regenerate damaged and diseased tissues.
- HPV-Related Oral Cancer*: Scientists predict that oral cancer will be the most common HPV-related cancer by 2020. In fact, HPV is now causing more oral cancers than smoking. But simply identifying the presence of HPV in a mouth swab or a blood draw does not definitively indicate the presence of cancer. More research is needed to facilitate the early detection of HPV-related oral cancer, as well as enhancing prevention and treatment approaches.
- Cleft Lip and/or Cleft Palate*: Craniofacial anomalies such as cleft lip and/or cleft palate are among the most common birth defects. Both genetic and environmental factors contribute to oral clefts. Studies supported by NIDCR are providing important new leads about the role genetic factors and gene-environment interactions play in the development of these conditions.
- Evidenced-Based Practice*: NIDCR supports a National Dental Practice Based Research Network (NDPBRN) that 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 their staffs working in concert with academic scientists. The network provides practitioners with an opportunity to propose or participate in research studies that address critical issues that affect oral healthcare. These studies help to expand the profession’s evidence base and further refine the delivery of quality oral healthcare.
- Oral Health Disparities*: NIDCR supports a broad portfolio of research strategies to reduce and eliminate oral health disparities. The Institute recently funded a new consortium that will combine health promotion and disease prevention, community-based participation and multilevel interventions to take decisive action to reduce oral health disparities in vulnerable children. Some of the innovative strategies include the use of interactive parent text-messaging, social networks and financial incentives.
- Generating Smiles*: Tremendous advances in the development of new tooth-colored materials are restoring and replacing tooth structure lost to dental disease. These discoveries are providing the opportunity for millions of Americans to again smile with comfort and confidence, greatly affecting their emotional well-being, as well as their ability to chew and speak.

From a patient perspective, the research at NIDCR has impacted millions of patients with a wide range of conditions that impede quality of life, are physically debilitating, and create a major financial and social burden. Many complex systemic diseases, ranging from TMJ to autoimmune disorders, such as Behcet’s, and to ectodermal dysplasias, have a major oral component. Through research into the basic science that is clearly needed to better understand these diseases; through the discovery of biomarkers for better diagnosis and clinical care; and by the development of new and improved tools for management and treatment, NIDCR has provided hope for these patients and their families that their lives will one day be improved substantially.

An example of an area in which NIDCR is making huge gains is in the understanding of Sjögren’s syndrome, a systemic autoimmune disease that affects about

four million Americans. In addition to affecting the entire body and causing symptoms of extensive dryness, serious complications can include profound fatigue, chronic pain, major organ involvement, neuropathies and lymphomas. No therapies have been approved for the systemic complications of Sjögren's, but this is changing because NIDCR recently funded a major international registry for Sjögren's that is currently providing researchers with critical data and biospecimens that are being and will continue to be used by many researchers to expand our knowledge. The registry also is an example of how initial NIDCR funding can lead to a major ripple effect in increased research across the country, because new information increases interest in a disease, facilitates fertilization of ideas across diseases and provides a basis upon which researchers in many specialty areas can build. Clinical practice guidelines are currently being developed for many of these conditions for the first time and are pointing out the vast gaps in our knowledge about the lack of treatment for specific symptoms, which treatments are most effective, the order in which available treatments should be initiated and identifying which patients will benefit most from a specific treatment. NIDCR is leading the cause by proposing funding that would address the important questions raised and the gaps in knowledge. Only with sufficient funding can we build on the incredible advances being made in science and medicine and find answers for the problems affecting millions of desperate patients.

We recognize the fiscal realities and that the overall amount of funding for non-defense discretionary programs is essentially level with the previous year, providing little opportunity for growth. However, the Nation's investment in overall discretionary spending is still inadequate to meet the most pressing needs of our country, and we encourage Congress to work together to develop a long-term solution to our debt and deficit that does not rely on cuts to these critical non-defense discretionary spending initiatives like oral health.

Congress has been asked to provide mandatory funding to NIH to help get it through this period of austerity. It is vitally important that no matter how NIH receives additional funding, that Congress honor the long-standing tradition of allocating resources equitably across the entire biomedical research enterprise at NIH including all of the Institutes and Centers. For it is important to note that a discovery in one area of research may benefit another. Maintaining flexibility, honoring the scientific peer-review process and supporting all research is critical to our endeavor to bring much needed cures to tens of millions of Americans.

In addition to the NIH, our 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 our funding recommendations for these agencies depicted in the chart below.

Agency	Fiscal Year				
	2012	2014	2016	2017 PBR	2017 AADR
NIH .....	\$30.7b	\$29.9b	\$32.3b	\$33.1b	\$34.5b
NIDCR .....	\$410m	\$398m	\$413m	\$413m	\$452m
NIMHD .....	\$268m	\$271m	\$281m	\$281m	\$302m
AHRQ .....	\$405m	\$371m	\$334m	\$364m	\$364m
CDC, Oral Health .....	\$15m	\$16m	\$18m	\$18m	\$19m
CDC, NCHS .....	\$154m	\$155m	\$160m	\$160m	\$170m
HRSA, Title VII Oral Health .....	\$32m	\$32m	\$35.8m	\$35.8m	\$35.8m

Thank you for the opportunity to submit this testimony. We stand ready to answer any questions you may have.

[This Statement was submitted by Jack Ferracane, President, American Association for Dental Research and the Friends of National Institute of Dental and Craniofacial 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 over 780 schools of nursing that educate over 457,000 students and employ more than 18,000 faculty members. Collectively, these institutions prepare our Nation's Registered Nurses

(RNs), Advanced Practice Registered Nurses (APRNs), nurse faculty members, and nurse scientists.

AACN respectfully requests that the subcommittee invests in America's health by providing \$244 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.]), at least \$34.5 billion for the National Institutes of Health (of which, \$157 million is provided for the National Institute of Nursing Research (NINR)),\* and to provide a discretionary appropriation for the National Health Service Corps (NHSC) in fiscal year 2017. These programmatic requests will ensure that our Nation's nurses are prepared to care for the growing number of patients requiring a complex range of healthcare services.

\*The Ad Hoc Group for Medical Research, of which AACN is a member, requests at least \$34.5 billion for NIH in fiscal year 2017, and the request level of \$157 million for NINR denotes the same percentage increase for NIH applied to NINR.

#### *The Role of Nurses in our Healthcare System*

As integral members of the healthcare team, and as the largest sector of the workforce with over three million licensed providers,<sup>1</sup> nurses collaborate with other professions and disciplines to improve the quality of America's healthcare system and ensure employment of timely and effective services. Nurses serve in a multitude of settings, including hospitals, long-term care facilities, community centers, local and State health departments, schools, workplaces, and patient homes. RNs and APRNs treat and educate patients across the entire life span and ensure individuals follow through with care plans for optimal health outcomes.

It is imperative that individuals seeking to enter the nursing profession have the financial support to pursue advanced education. Federal investments are essential to ensure that a robust workforce of RNs and APRNs are available to provide the care that Americans need now and in the years to come. Moreover, the nursing pipeline will need to supply highly-educated nurses to respond to innovative, team-based delivery models that promote safe, efficient, patient-centered care.

#### *Title VIII Programs are Improving Healthcare Today and in the Future*

For over 50 years, the Nursing Workforce Development programs have helped build the supply and distribution of qualified nurses to meet our Nation's healthcare needs. The programs strengthen nursing education at all levels, from entry preparation through graduate study, and provide support to educate nurses who practice in rural and medically underserved communities. 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. Moreover, the goals of these programs align with the Institute of Medicine's report, *Future of Nursing: Leading Change, Advancing Health*, which calls for nurses to "achieve higher levels of education and training through an improved education system that promotes seamless academic progression."<sup>2</sup>

Title VIII programs address specific aspects of the nursing workforce and patient populations experiencing high need, such as primary care, diversity in the workforce, and the aging population. The demand for APRNs (which include nurse practitioners (NPs), certified registered nurse anesthetists (CRNAs), certified nurse-midwives (CNMs), and clinical nurse specialists), necessitates a greater number of nurses with advanced degrees. According to the U.S. Bureau of Labor Statistics, the projected employment of NPs, CRNAs, and CNMs is expected to grow 31 percent between 2012–2022.<sup>3</sup> APRNs are a real solution to the challenge of employing high-quality providers in primary care and underserved communities. Title VIII programs, such as the Advanced Education Nursing Traineeship (AENT) and Nurse Anesthetist Traineeship (NAT) provide nurses with exposure to populations in need of their care and offer potential future employment opportunities. In academic year 2014–2015, AENT supported 3,008 students, of which 72 percent were trained in primary care settings.<sup>4</sup> In the same academic year, NAT supported 3,229 students, of which 64 percent were trained in medically underserved areas.<sup>4</sup>

<sup>1</sup>National Council of State Boards of Nursing. (2016). Active RN Licenses: A profile of nursing licensure in the U.S. as of January 23, 2016. Retrieved from: <https://www.ncsbn.org/6161.htm>.

<sup>2</sup>Institute of Medicine. (2010). *Future of Nursing: Leading Change, Advancing Health Report Recommendations*. Retrieved from: <http://www.iom.edu/Reports/2010/The-Future-of-Nursing-Leading-Change-Advancing-Health/Recommendations.aspx>.

<sup>3</sup>U.S. Bureau of Labor Statistics. (2014). *Occupational Outlook Handbook. Nurse Anesthetists, Nurse Midwives, and Nurse Practitioners*. Retrieved from: <http://www.bls.gov/ooh/healthcare/nurse-anesthetists-nurse-midwives-and-nurse-practitioners.htm>.

<sup>4</sup>U.S. Department of Health and Human Services. (2016). *Health Resources and Services Administration fiscal year 2016 Justification of Estimates for Appropriations Committees*. Retrieved from: <http://hrsa.gov/about/budget/budgetjustification2017.pdf>.

Ensuring a diverse nursing pipeline that reflects an increasing diverse population is a national priority. The Title VIII Workforce Diversity Grants program specifically targets groups under-represented in nursing by awarding grants and contract opportunities. In academic year 2014–2015, the program supported 13,225 students and aspiring students and partnered with over 900 clinical training sites.<sup>4</sup>

According to the U.S. Census Bureau, as of July 2013, 44.7 million people (14.1 percent of the Nation’s population) are over the age of 65, and by 2060, one in four U.S. residents will be 65 years of age or older.<sup>5</sup> The IOM identified that in order to adequately meet the demands of our aging population, our healthcare system must address the severe shortage of geriatric specialists and providers with geriatric skills and the increased demand for chronic care management skills.<sup>2</sup> The Title VIII Comprehensive Geriatric Education program directly addresses those target areas identified by the IOM. In academic year 2014–2015, the program supported 22,743 nurses and health professionals who provide direct care to our Nation’s elderly patients.<sup>4</sup> In addition, these programs help prepare faculty members and provide continuing education those pursuing advanced degrees in geriatric nursing.<sup>4</sup>

AACN urges the subcommittee to preserve and support increased funding for all six of the Nursing Workforce Development programs including; Advance Education Nursing; Nursing Workforce Diversity; Nurse Education, Practice, Quality, and Retention; NURSE CORPS Loan Repayment and Scholarship Programs; Nurse Faculty Loan Program; and the Comprehensive Geriatric Education. These programs are vital investments to support the supply and distribution of qualified nurses to meet our Nation’s healthcare needs.

AACN RESPECTFULLY REQUESTS \$244 MILLION FOR THE TITLE VIII NURSING WORKFORCE DEVELOPMENT PROGRAMS IN FISCAL YEAR 2017.

*National Institute of Nursing Research: Care Across the Lifespan*

As one of the 27 Institutes and Centers at the National Institutes of Health (NIH), NINR develops knowledge to build the scientific foundation for clinical practice, prevent disease and disability, manage and eliminate symptoms caused by illness, and enhance end-of-life and palliative care.<sup>6</sup> Broadly speaking, these priorities focus on reducing disease and promoting health and wellness across the entire lifespan. Nurse scientists, often working collaboratively with other health professions, generate the evidence that serves at the foundation of the care nurses provide. For over 30 years, NINR has examined ways to improve care models to deliver safe, high-quality, and cost-effective health services to the Nation.

In addition, NINR allots a generous portion of its budget towards training new nursing scientists, thus helping to sustain the longevity and success of nursing research. According to 2015–2016 AACN data, there are 5,035 doctoral students pursuing their PhD within AACN member schools, many of whom will also serve as faculty in our Nation’s nursing schools.<sup>7</sup> NINR training opportunities, such as the National Research Service Awards, helps new nurse researchers conduct independent research and collaborate in interdisciplinary research.<sup>8</sup> These future nurse scientists will help discover new and effective care technologies and methods to improve patient wellness.

AACN RESPECTFULLY REQUESTS AT LEAST \$34.5 BILLION FOR THE NIH (AND OF THIS, \$157 MILLION FOR THE NINR) IN FISCAL YEAR 2017.

*National Health Service Corps: Supporting Providers in our Nation’s Areas of Need*

According to HRSA, as of December of 2015 there were over 61.2 million individuals living in Health Professional Shortage Areas (HPSAs).<sup>9</sup> A HPSA designation denotes an area that has a shortage of health professionals within primary, dental,

<sup>5</sup>United States Census Bureau. (2015). Older Americans Month: May 2015. Retrieved from: [http://www.census.gov/content/dam/Census/newsroom/facts-for-features/2015/cb15-ff09\\_older\\_american\\_month.pdf](http://www.census.gov/content/dam/Census/newsroom/facts-for-features/2015/cb15-ff09_older_american_month.pdf).

<sup>6</sup>National Institute of Nursing Research. (2012). FAQ. Retrieved from: <https://www.ninr.nih.gov>.

<sup>7</sup>American Association of Colleges of Nursing. (2016). 2015–2016 Enrollment and Graduations in Baccalaureate and Graduate Programs in Nursing. Washington, DC.

<sup>8</sup>National Institute of Nursing Research. (2015) Extramural Training Opportunities. Retrieved from: <https://www.ninr.nih.gov/training/trainingopportunitiesextramural#.VwveIHpl1CA>.

<sup>9</sup>U.S. Health Resources and Services Administration. (2016). Designated Health Professional Shortage Areas Statistics. Retrieved from: [https://ersrs.hrsa.gov/ReportServer?/HGDW\\_Reports/BCD\\_HPSA/BCD\\_HPSA\\_SCR50\\_Qtr\\_Smry\\_HTML&rc:Toolbar=false](https://ersrs.hrsa.gov/ReportServer?/HGDW_Reports/BCD_HPSA/BCD_HPSA_SCR50_Qtr_Smry_HTML&rc:Toolbar=false).

or mental healthcare.<sup>9</sup> The NHSC Scholarship Program and Loan Repayment Program provide financial support to graduate health professions students and providers who are committed to practicing in these health disciplines and within HPSAs. Moreover, the NHSC attracts highly-qualified APRNs to serve in our Nation's underserved communities, ensuring necessary care services reach the millions of patients currently living HPSAs. It is imperative that these programs receive an annual discretionary appropriation to ensure stability and more importantly, to ensure those necessary care services are reaching our patients in all corners of the country.

AACN RESPECTFULLY REQUESTS A DISCRETIONARY APPROPRIATION FOR THE NHSC IN FISCAL YEAR 2017.

Thank you for considering AACN's requests for fiscal year 2017. If you have any questions, or if AACN can be of assistance, please contact AACN's Senior Director of Government Affairs and Health Policy, Dr. Suzanne Miyamoto, at [Smiyamoto@aacn.nche.edu](mailto:Smiyamoto@aacn.nche.edu).

[This statement was submitted by Deborah Trautman, PhD, RN, FAAN, President and Chief Executive Officer, American Association of Colleges of Nursing.]

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 \$7.48 billion; funding for key priorities in HRSA's Title VII health professions education programs under the Public Health Service Act [\$59 million for the Primary Care Training and Enhancement (PCTE) Program; \$4 million for the Rural Physician Training Grants; \$25 million for the Centers of Excellence (COE); \$20 million for the Health Careers Opportunity Program (HCOP); \$49.1 million for the Scholarships for Disadvantaged Students (SDS) Program; \$35 million for the Geriatrics Education Centers (GECs); and \$40 million for the Area Health Education Centers (AHECs)]; \$527 million in mandatory funding for the Teaching Health Center Graduate Medical Education (THCGME) Program; funding for the National Health Service Corps (NHSC) through the annual appropriations process to create stability and sustainability for the Program; \$34.5 billion for the National Institutes of Health (NIH); and \$364 million in base discretionary funding for the Agency for Healthcare Research and Quality (AHRQ).

AACOM represents the 31 accredited colleges of osteopathic medicine in the United States. These colleges are accredited to deliver instruction at 46 teaching locations in 31 States. In the 2015–2016 academic year, these colleges are educating over 26,100 future physicians—more than 20 percent of new U.S. medical students.

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 programs are the only Federal programs designed to train primary care professionals in interdisciplinary settings to meet the needs of special and underserved populations, as well as increase minority representation in the healthcare workforce.

As the demand for health professionals increases 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 for inclusion and/or continued support for the following programs: the PCTE Program, the Rural Physician Training Grants, the COE, the HCOP, the SDS Program, the GECs, and the AHECs.

The PCTE Program provides funding to support awards to primary care professionals through grants to hospitals, medical schools, and other entities. AACOM supports a request of \$59 million to allow for a new fiscal year 2017 competitive grant cycle for the PCTE Program's physician training and development.

<sup>9</sup>U.S. Health Resources and Services Administration. (2016). Designated Health Professional Shortage Areas Statistics. Retrieved from: [https://ersrs.hrsa.gov/ReportServer?/HGDW\\_Reports/BCD\\_HPSA/BCD\\_HPSA\\_SCR50\\_Qtr\\_Smry\\_HTML&rc:Toolbar=false](https://ersrs.hrsa.gov/ReportServer?/HGDW_Reports/BCD_HPSA/BCD_HPSA_SCR50_Qtr_Smry_HTML&rc:Toolbar=false).

The Rural Physician Training Grants will help rural-focused training programs recruit and graduate students most likely to practice medicine in underserved rural communities. Health professions workforce shortages are exacerbated in rural areas, where communities struggle to attract and maintain well-trained providers. According to HRSA, approximately 65 percent of primary care health professional shortage areas are rural. AACOM supports the inclusion of \$4 million for the Rural Physician Training Grants.

The COE Program is integral to increasing the number of minority youth who pursue careers in the health professions. AACOM supports \$25 million for the COE Program.

The HCOP Program provides students from disadvantaged backgrounds with the opportunity to develop the skills needed to successfully compete, enter, and graduate from health professions schools. AACOM supports an appropriation of \$20 million for HCOP.

The SDS Program provides scholarships to health professions students from disadvantaged backgrounds with financial need, many of whom are underrepresented minorities. AACOM supports increased funding in the President's fiscal year 2017 budget of \$49.1 million for the SDS Program.

GECs are collaborative arrangements between health professions schools and healthcare facilities that provide training between health professions schools and healthcare facilities that provide the training of health professions students, faculty, and practitioners in the diagnosis, treatment, and prevention of disease, disability, and other health issues. AACOM supports \$35 million for the GECs.

The AHEC Program provides funding for interdisciplinary, community-based, primary care training programs. Through a collaboration of medical schools and academic centers, a network of community-based leaders work to improve the distribution, diversity, supply, and quality of health personnel, particularly primary care personnel in the healthcare services delivery system, specifically in rural and underserved areas. AACOM supports an appropriation of \$40 million for the AHEC Program in fiscal year 2017 and strongly opposes the elimination of this vital program in the President's fiscal year 2017 budget.

AACOM continues to strongly support the long-term sustainment 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 690 medical and dental residents and are caring for more than half a million patients in underserved rural and urban communities. This program will also provide long-term benefits. According to 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. AACOM supports the President's fiscal year 2017 budget request for the THCGME Program of \$527 million in mandatory funding through fiscal year 2018–fiscal year 2020. We will continue to work with Congress to support a sustainable and viable funding mechanism for the continuation of this successful program.

The NHSC supports physicians and other health professionals who practice in health professional shortage areas across the U.S. In fiscal year 2015, the NHSC had over 9600 primary care clinicians providing healthcare services. The NHSC projects that a field strength of more than 15,000 primary care clinicians will be in health professional shortage areas in fiscal year 2017. In addition, more than 1200 students, residents, and health providers receive scholarships or participate in the NHSC Loan Repayment Program or Student to Service Loan Repayment Program to prepare to practice. While we were pleased to see a 2-year extension of this program in the Medicare Access and CHIP Reauthorization Act of 2015 (PL: 114–10) for fiscal year 2016 and fiscal year 2017, the appropriation committees retain primary responsibility for funding the administrative functions of the NHSC and for avoiding lapses in future years. Therefore, AACOM supports the stability and sustainability of this critical program by requesting that the Subcommittee provide a discretionary appropriation for the NHSC Program.

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 supports an appropriation of \$34.5 billion for NIH in fiscal year 2017, which accounts for inflation associated with biomedical research plus 5 percent.

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 \$364 million in base discretionary funding, consistent with the President's fiscal year 2017 budget request and fiscal year 2015 levels. 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, DO, MPH, President and Chief Executive Officer, American Association of Colleges of Osteopathic Medicine.]

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF COLLEGES OF PHARMACY

The American Association of Colleges of Pharmacy (AACP) is pleased to submit this statement for the record regarding fiscal year 2017 funding. The 135 accredited pharmacy schools are engaged in a wide range of programs funded by the agencies of the Department of Health and Human Services (HHS) and the Department of Education. Recognizing the difficult task of balancing needs and expectations with fiscal responsibility, AACP respectfully requests that the following agencies and programs be funded appropriately as you undertake your deliberations:

- Health Resources and Services Administration (HRSA)—\$7.48 billion
- Title VII & VIII—\$524 million
- Agency for Healthcare Research and Quality (AHRQ)—\$364 million
- Centers for Disease Control and Prevention (CDC)—\$7.8 billion
- National Center for Health Statistics (NCHS)—\$172 million
- National Institutes of Health (NIH)—\$34.5 billion

In addition, AACP respectfully requests that the Fund for the Improvement of Post-Secondary Education (FIPSE) be funded at \$100 million and that the maximum Pell grant appropriated discretionally be maintained at \$4860.

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

*Health Resources and Services Administration (HRSA).*—AACP supports the Friends of HRSA recommendation of \$7.48 billion for HRSA in fiscal year 2017. Dr. Nathaniel Rickles from Northeastern University Bouve College of Health Sciences School of Pharmacy received \$161,769 from HRSA to research interprofessional geriatric education for team based care. Faculty at schools of pharmacy are integral to the success of many HRSA programs conducting research on rural health delivery via telemedicine. Schools of pharmacy are supported by HRSA to operate some of the 55 Poison Control Centers. AACP supports the Bureau of Health Workforce (BHW) and the National Center for Health Workforce Analysis (NCHWA). Through the Pharmacy Workforce Center, AACP joins HRSA-funded efforts to compile national health workforce statistics to better inform future health professions workforce needs in the United States. AACP supports the Health Professions and Nursing Education Coalition (HPNEC) recommendation of \$524 million for Title VII and VIII programs in fiscal year 2016. AACP member institutions are active participants in BHW programs. Schools of pharmacy participate in Title VII programs, including Geriatric Education Centers and Area Health Education Centers (AHEC). These community-based, interprofessional programs are essential for supporting innovative educational models addressing national issues at the local level through team-based, patient-centered care. They serve as valuable experiential education sites for student pharmacists and other health professions students. Pharmacy schools are eligible to participate in the Centers of Excellence program and the Scholarships for Disadvantaged Students program, to increase the number of underserved individuals attending health professions schools and increase minority health workforce representation. Colleges of pharmacy, including Xavier University of Louisiana, develop and maintain centers of excellence in diversity supported by HRSA Centers of Excellence grants.

*Agency for Healthcare Research and Quality (AHRQ).*—AACP supports the Friends of AHRQ recommendation of \$375 million in budget authority for AHRQ programs in fiscal year 2017. Pharmacy faculty are strong partners with the Agency for Healthcare Research and Quality (AHRQ). Drs. Margie E. Snyder, Karen Hudmon and Michael Murray received \$144,197 from PHS–AHRQ for optimizing medication therapy management for chronically ill Medicare Part D beneficiaries.

*Centers for Disease Control and Prevention (CDC).*—AACP supports the CDC Coalition's recommendation of \$7.8 billion for CDC core programs in fiscal year 2017 and the Friends of NCHS recommendation of \$172 million for the National Center



for Health Statistics. Information from the NCHS is essential for faculty engaged in health services research and for the professional education of the pharmacist. The educational outcomes for pharmacy graduates include those related to public health. The opportunity for pharmacists to identify potential public health threats through regular interaction with patients provides public health agencies with on-the-ground epidemiologists providing risk identification measures when patients seek medications associated with preventing and treating travel-related illnesses. Pharmacy faculty are engaged in CDC-supported research and activities including delivery of immunizations, integration of pharmacogenetics in the pharmacy curriculum, inclusion of pharmacists in emergency preparedness, and the Million Hearts campaign. Dr. Johnnye Lewis at the University of New Mexico received \$1,000,000 to study uranium exposure in the Navajo nation.

*National Institutes of Health.*—ACCP supports the Adhoc Group for Medical Research recommendation of at least \$34.5 billion for NIH funding in fiscal year 2017. Pharmacy faculty are supported in their research by nearly every institute at the NIH. The NIH-supported research at ACCP member institutions spans the full spectrum from the creation of new knowledge through the translation of that new knowledge to providers and patients. In fiscal year 2014, pharmacy faculty researchers received nearly \$343 million in grant support from the NIH. Academic pharmacy sustains a strong commitment to increasing the number of biomedical researchers. Dr. Jim Wang at the University of Illinois received \$404,011 to study protein kinase mechanisms for chronic pain in sickle cell disease.

#### U.S. DEPARTMENT OF EDUCATION

The Department of Education supports the education of healthcare professionals by assuring access to education through student financial aid programs, educational research allows faculty to determine improvements in educational approaches; and the oversight of higher education through the approval of accrediting agencies. ACCP supports the Student Aid Alliance's recommendations to maintain the discretionary contribution to the \$4860 maximum Pell grant. Admission to a pharmacy professional degree program requires at least 2 years of undergraduate preparation. Student financial assistance programs are essential to assuring student have access to undergraduate, professional and graduate degree programs. ACCP recommends a funding level of at least \$100 million for the Fund for the Improvement of Post-Secondary Education (FIPSE) as this is the only Federal program that supports the development and evaluation of higher education programs that can lead to improvements in higher education quality.

[This statement was submitted by William Lang, Senior Policy Advisor, American Association of Colleges of Pharmacy.]

#### 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 2017 appropriations for the National Institutes of Health (NIH). AAI recommends an appropriation of at least \$35 billion for NIH for fiscal year 2017 to fund new and ongoing research, stabilize and strengthen the biomedical research enterprise, and encourage the world's most talented scientists, trainees, and students to pursue biomedical research careers in the United States.

#### THE IMPORTANCE OF IMMUNOLOGY AND THE IMMUNE SYSTEM

"[I]mmunology kind of transcends it all." So said Senator Richard Shelby (R-AL), a senior member of the Senate Appropriations Committee and its subcommittee on Labor, Health and Human Services, Education, and Related Agencies, during the committee's April 2, 2014, hearing on the fiscal year 2015 budget request for NIH.<sup>1</sup> What Senator Shelby correctly noted is the extraordinary importance—and nearly unlimited potential—of the immune system. And the more we learn, the more we realize that what was true in 2014 is even more true today.

As the body's primary defense against viruses, bacteria, parasites and carcinogens, the immune system can protect its host from a wide range of infectious diseases and from many chronic illnesses, including cancer, Alzheimer's disease, and cardiovascular disease. But the immune system can underperform, leaving the body vulnerable to infections such as influenza, Zika virus, HIV/AIDS, tuberculosis, ma-

<sup>1</sup> [Http://www.appropriations.senate.gov/hearings/fy15-nih-budget-request](http://www.appropriations.senate.gov/hearings/fy15-nih-budget-request).

laria, and the common cold. It can also become overactive, attacking normal organs and tissues, and causing autoimmune diseases including allergy, asthma, inflammatory bowel disease, lupus, multiple sclerosis, rheumatoid arthritis, and type 1 diabetes. Understanding how the immune system works and how it may be harnessed to help prevent, treat, or cure disease: this is the mission of immunologists as we strive to protect people and animals from chronic and acute diseases and from natural or man-made infectious organisms (including plague, smallpox and anthrax) that could be used as bioweapons.

RECENT IMMUNOLOGICAL ADVANCES PROVIDE GREAT HOPE FOR TOMORROW

*New Potential Treatments for Hard-to-Treat Cancers*

Cancer immunotherapies mobilize an individual's immune system to destroy cancer cells without harming healthy cells. Less toxic than standard chemotherapy and radiation, immunotherapies have already been approved for some cancers, including lymphoma and melanoma. Until recently, however, immunotherapy had not shown great efficacy against some hard-to-treat cancers, like non-small cell lung cancer. The 2015 approval of Nivolumab and Pembrolizumab (anti PD-1 therapy)<sup>2</sup> was, therefore, a landmark event for the treatment of lung cancer. Because this therapy specifically blocks the PD-1/PD-L1 pathway that prevents T cells from killing tumor cells, it improves the immune system's ability to combat cancer.<sup>3</sup>

*Using the Immune System to Control HIV Infection in HIV-Positive Patients*

A recent NIH-funded study demonstrated how the immune systems of HIV-positive "elite controllers," people whose natural immunity controls HIV infection, produce antibodies that have the potential to be developed to treat others infected with HIV.<sup>4</sup> In this Phase I clinical trial, copies of the protective antibodies produced by elite controllers successfully reduced HIV viral levels when transferred to other HIV-positive patients. This method of harnessing "broadly neutralizing antibodies"<sup>5</sup> can potentially be used more widely against other viruses, protecting whole populations from dangerous infections until vaccines are available.

*Preventing and Treating Emerging Infectious Diseases*

With increased globalization and worldwide travel, emerging infectious diseases can create a serious health threat locally as well as an international public health crisis, as evidenced by the recent Ebola virus epidemic in Africa, outbreak of dengue fever in Hawaii,<sup>6</sup> and Zika virus outbreaks in Latin America, Central America, the Caribbean, and the U.S. territories.<sup>7</sup> It is essential, therefore, that NIH continually fund basic research on pathogens and the host response to pathogens, as well as potential medical interventions, in order to be able to prevent and respond to both current and future epidemics.

Because NIH has long supported such basic and clinical research, we have made progress on a vaccine against the Ebola virus,<sup>8</sup> which killed more than 11,300 people in West Africa in 2014–2015.<sup>9</sup> Last month, NIH announced that an experimental vaccine against dengue fever had protected all of its recipients, an important advance in the fight against a disease that infects 390 million people worldwide each year.<sup>10</sup> And because the dengue virus is in the same virus family as the Zika virus, scientists are applying what they have learned from dengue to their efforts to develop a vaccine for Zika,<sup>11</sup> which is linked to both microcephaly and Guillain-Barre

<sup>2</sup> <http://www.fda.gov/Drugs/InformationOnDrugs/ApprovedDrugs/ucm466576.htm>;  
<http://www.fda.gov/Drugs/InformationOnDrugs/ApprovedDrugs/ucm465650.htm>.

<sup>3</sup> Chen, L and Han, X. 2015. Anti-PD-1/PD-L1 therapy of human cancer: past, present, and future. *The Journal of Clinical Investigation* 125: 3384–3391.

<sup>4</sup> Caskey, M. et al. 2015. Viraemia suppressed in HIV-1 infected humans by broadly neutralizing antibody 3BNC117. *Nature* 522: 487.

<sup>5</sup> "In first human study, new antibody therapy shows promise in suppressing HIV Infection." *NewsWire*. <http://newswire.rockefeller.edu/2015/04/08/in-first-human-study-new-antibody-therapy-shows-promise-in-suppressing-hiv-infection/>.

<sup>6</sup> Dengue "is endemic in Puerto Rico and in many popular tourist destinations in Latin America, Southeast Asia and the Pacific islands." <http://www.cdc.gov/dengue/>.

<sup>7</sup> <http://www.cdc.gov/zika/geo/index.html>.

<sup>8</sup> <http://www.niaid.nih.gov/news/newsreleases/Archive/2003/pages/ebolahumantrial.aspx>;  
<https://www.niaid.nih.gov/news/newsreleases/2016/Pages/CROI-ZMapp.aspx>.

<sup>9</sup> <http://www.cdc.gov/vhf/ebola/outbreaks/2014-west-africa/case-counts.html>.

<sup>10</sup> <http://www.nih.gov/news-events/news-releases/experimental-dengue-vaccine-protects-all-recipients-virus-challenge-study>. The experimental vaccine was developed primarily by NIH scientists at the NIAID Laboratory of Infectious Diseases, with assistance from scientists at the FDA Center for Biologics Evaluation and Research.

<sup>11</sup> *Ibid.*

syndrome.<sup>12</sup> Zika is of increasing international concern due to a recent surge in the number of cases, particularly in Brazil, where more than 3,000 newborns have been affected thus far.<sup>13</sup>

#### NIH'S ESSENTIAL ROLE IN THE RESEARCH ENTERPRISE

As the Nation's main funding agency for biomedical and behavioral research, NIH supports the work of "more than 300,000 members of the research workforce, including 35,000 principal investigators" located at universities, medical schools, and other research institutions in all 50 States and the District of Columbia.<sup>14</sup> More than 80 percent of its budget supports the work of these "extramural" scientists through almost 50,000 grants, while about 10 percent of the budget supports roughly 6,000 "intramural" researchers and clinicians who work at NIH research and clinical facilities in Maryland, Arizona, Massachusetts, Michigan, Montana and North Carolina.<sup>15</sup>

NIH funding strengthens the economies of the communities and States where these researchers live and work; in 2014, it supported more than 400,000 jobs across the United States.<sup>16</sup>

NIH also provides irreplaceable scientific leadership to the national and international biomedical research communities. NIH personnel and policies are essential to the coordination of scientists and scientific projects from academia and government,<sup>17</sup> and to fostering important collaborations with industry, whose own advances in drug and medical device development rely heavily on NIH-funded discoveries.<sup>18</sup>

#### RECENT FUNDING BOOST EASED, BUT DID NOT ELIMINATE, EROSION OF NIH PURCHASING POWER

A \$2 billion boost in NIH funding in fiscal year 2016, generously provided by this subcommittee and the Congress, has helped restore some of the loss in NIH's purchasing power that had resulted from years of inadequate budgets eroded further by biomedical research inflation.<sup>19</sup> Although AAI is extremely grateful for this funding increase, NIH's purchasing power remains more than 19 percent below what it was in fiscal year 2003.<sup>20</sup> In addition to limiting the advancement of important re-

<sup>12</sup> <http://www.cdc.gov/zika/about/gbs-qa.html>; <http://www.cdc.gov/zika/pregnancy/question-answers.html>.

<sup>13</sup> Maron, Dina Fine. Surge in Babies Born with Small Heads. *Scientific American*. <http://www.scientificamerican.com/article/what-s-behind-brazil-s-alarmed-surge-in-babies-born-with-small-heads/>.

<sup>14</sup> <http://www.nih.gov/sites/default/files/about-nih/strategic-plan-fy2016-2020-508.pdf>; <http://www.nih.gov/about-nih/what-we-do/budget>.

<sup>15</sup> *Ibid*; [https://www.training.nih.gov/resources/intro\\_nih/other\\_locations](https://www.training.nih.gov/resources/intro_nih/other_locations).

<sup>16</sup> Ehrlich, Everett. NIH's Role in Sustaining the U.S. Economy. United for Medical Research, <http://www.unitedformedicalresearch.com/wp-content/uploads/2015/10/UMR-NIH-FY2014-Economic-Update-10.01.15.pdf>.

<sup>17</sup> AAI strongly opposes policies that limit government scientists' ability to attend privately sponsored scientific meetings and conferences and believes that "the rules have . . . 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." Written 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](http://aai.org/Public_Affairs/Docs/2014/AAI_Testimony_to_Senate_HSGAC_01142014.pdf)).

<sup>18</sup> According to Dr. Marc Tessier-Lavigne, former chief scientific officer at Genentech and current president of The Rockefeller University, "if we invest adequately in basic biomedical research, we can create the knowledge that will in turn trigger private-sector investment to develop therapies to conquer such diseases . . . . For every drug approved by the FDA at the top of the pyramid, the foundation consists of dozens of insights into diseases generated over a period of decades, largely through Federal funding of basic, knowledge-driven research." Written Testimony of Dr. Marc Tessier-Lavigne, Submitted to the House Committee on Science, Space, and Technology, Subcommittee on Research and Technology, for the Hearing Record of July 17, 2014: "Policies to Spur Innovative Medical Breakthroughs from Laboratories to Patients." <https://science.house.gov/sites/republicans.science.house.gov/files/documents/HHRG-113-SY14-WState-MTessierLavigne-20140717.pdf>.

<sup>19</sup> Federation of American Societies for Experimental Biology. U.S. Biological and Medical Research Fell for Over a Decade. [http://www.faseb.org/Portals/2/PDFs/opa/2016/Factsheet\\_Restore\\_NIH\\_Funding.pdf](http://www.faseb.org/Portals/2/PDFs/opa/2016/Factsheet_Restore_NIH_Funding.pdf).

<sup>20</sup> Federation of American Societies for Experimental Biology. NIH Research Funding Trends: fiscal year 1995–2015. <http://www.faseb.org/Science-Policy-and-Advocacy/Federal-Funding-Data/NIH-Research-Funding-Trends.aspx>

search and the potential treatments or cures that might have been discovered, these funding constraints continue to have a deleterious impact on many productive researchers: some are being forced to lay off staff or close their labs entirely, while others are moving overseas, where support for biomedical research continues to grow.<sup>21</sup> Perhaps most importantly, inadequate funding is deterring many of our most promising young people from pursuing careers in biomedical research; they witness their mentors' unrelenting and time consuming search for funding, rather than their conduct of research or teaching of the Nation's future researchers, doctors, inventors and innovators. Regular and predictable funding increases for NIH would provide the stability that science, scientists, and the scientific enterprise urgently need.

#### CONCLUSION

AAI greatly appreciates the subcommittee's strong bipartisan support for NIH and biomedical research, and for the reasons described above, recommends an appropriation of at least \$35 billion for NIH in fiscal year 2017.

[This statement was submitted by Clifford V. Harding, M.D., Ph.D., American Association of Immunologists.]

#### PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF NURSE ANESTHETISTS

##### FISCAL YEAR 2017 APPROPRIATIONS REQUEST SUMMARY

	Fiscal year 2015 enacted	Fiscal year 2016 enacted	AANA fiscal year 2017 request
HHS/HRSA/BHPr Title 8 Advanced Education Nursing, Nurse Anesthetist Education Reserve.	No report language	No report language	Report language supporting at least \$5 million for nurse anesthesia education
Total for Advanced Education Nursing, from Title 8.	\$63.581	\$64.581	\$66 million for advanced education nursing
Title 8 HRSA BHPr Nursing Education Programs	\$231.622	\$229.472	\$244

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

The AANA is the professional association for more than 49,000 CRNAs and student nurse anesthetists, representing over 90 percent of the nurse anesthetists in the United States. Today, CRNAs deliver approximately 40 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 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 study published in *Health Affairs* in 2010 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

<sup>21</sup>Moses, H., et al. 2015. The Anatomy of Medical Research: U.S. and International Comparisons. *JAMA* 313: 174–189. According to Moses et al., while U.S. funding for biomedical and health services research increased at a rate of 6 percent per year from 1994–2004, it decreased to just 0.8 percent annually from 2004–2012.

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.](http://www.gao.gov/products/GAO-07-463)) (Liao CJ, Quraishi JA, Jordan, LM. Geographical Imbalance of Anesthesia Providers and its Impact on the Uninsured and Vulnerable Populations. *Nurs Econ.* 2015; 33(5):263–270.)

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

Our profession's chief request of the Subcommittee is for \$5 million to be reserved for nurse anesthesia education and \$66 million for advanced education nursing from the HRSA Title 8 program, out of a total Title 8 budget of \$244 million. We request that the Report accompanying the fiscal year 2017 Labor-HHS-Education Appropriations bill include the following language: "Within the allocation, the Committee encourages HRSA to allocate funding of at least \$5 million 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 \$66 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, driven by an aging population requiring more care, and a growing percentage of surgical procedures requiring anesthesia being offered in outpatient settings. The supply of clinical providers has increased in recent years, stimulated by increases in the number of CRNAs trained. From 2006–2015, the annual number of nurse anesthesia educational program graduates increased from 1,900 to 2,468, according to the Council on Accreditation of Nurse Anesthesia Educational Programs (COA). The number of accredited nurse anesthesia educational programs grew from 105 to 115 during this time, and is currently 118. 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 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 Connecticut, Kentucky, Maryland, Mississippi, Missouri, New York, and Washington. 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 prac-

tice model is by far the most cost-effective, and ensures patient safety. (Hogan P et al. Cost effectiveness analysis of anesthesia providers. *Nursing Economic\$,* Vol. 28 No. 3, May–June 2010, p. 159 et seq.) Nurse anesthesia education represents a significant educational cost-benefit for competitively awarded Federal funding in support of CRNA educational programs.

[This statement was submitted by Juan Quintana, DNP, MHS, CRNA, President, American Association of Nurse Anesthetists.]

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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 2017. ACP is the largest medical specialty organization and the second-largest physician group in the United States. ACP members include 143,000 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 2017, ACP is urging funding for the following proven programs to receive appropriations from the Subcommittee:

- Health Resources Services Administration (HRSA), \$7.48 billion;
- Title VII, Section 747, Primary Care Training and Enhancement, HRSA, at no less than \$71 million;
- National Health Service Corps (NHSC), HRSA, \$380 million in total program funding, including at least \$20 million through discretionary appropriations;
- Agency for Healthcare Research and Quality (AHRQ), \$364 million.

The United States is facing a shortage of physicians in key specialties, 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), the Congressional Budget Office has estimated, as of March 2016, the demand for primary care services will increase with the addition of 38 million Americans receiving access to health insurance, including an additional 19 million under Medicaid/CHIP, by 2026. With increased demand, current projections indicate there will be a shortage of 14,900 to 35,600 primary care physicians by 2025. (IHS Inc., prepared for the Association of American Medical Colleges. 2016 Update, *The Complexities of Physician Supply and Demand: Projections from 2013 to 2025*. April 5, 2016. Accessed at: [https://www.aamc.org/download/458082/data/2016\\_complexities\\_of\\_supply\\_and\\_demand\\_projections.pdf](https://www.aamc.org/download/458082/data/2016_complexities_of_supply_and_demand_projections.pdf)). HRSA is responsible for improving access to health-care services for people who are uninsured, isolated or medically vulnerable. Without critical funding for vital workforce programs, this physician shortage will only grow worse. A strong primary care infrastructure is an essential part of any high-functioning healthcare system, with over 100 studies showing primary care is associated with better outcomes and lower costs of care ([http://www.acponline.org/advocacy/where\\_we\\_stand/policy/primary\\_shortage.pdf](http://www.acponline.org/advocacy/where_we_stand/policy/primary_shortage.pdf)). Therefore we urge the Subcommittee to provide \$7.48 billion for discretionary HRSA programs for fiscal year 2017 to improve the care of medically underserved Americans by strengthening the health workforce.

The health professions' education programs, authorized under Title VII of the Public Health Service Act and administered through (HRSA), support the training and education of 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 sixth 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 \$380 million in total program funding for the National Health Service Corps (NHSC), as requested in the President's fiscal year 2017 budget; this amount includes \$310 million in existing mandatory funds under current law, \$20 million in discretionary spending through new budget authority, and \$50 million in new mandatory funding. Since the enactment of the ACA, the NHSC has awarded over \$1.5 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 a field strength of 9,700 primary-care clinicians, NHSC members are providing culturally competent care to over 10 million patients at 16,000 NHSC-approved healthcare sites in urban, rural, and frontier areas. The increase in funds would expand NHSC field strength to over 10,150 and would serve the needs of more than 10.7 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. For fiscal year 2016, the NHSC's funding situation was particularly dire and faced a funding cliff because its mandatory funding was set to expire and was without any budget authority to at least temporarily continue operations with discretionary funding. The College was therefore pleased that the Medicare Access and CHIP Reauthorization Act, H.R. 2, continued the NHSC at its fiscal year 2015 funding level for fiscal year 2016 and fiscal year 2017 (through an extension of mandatory resources). However, with fiscal year 2017 being the last year of enacted dedicated mandatory funding, ACP believes that the Corps urgently needs discretionary funding to be able to continue its operations should it face another mandatory funding cliff.

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 \$364 million, restoring the agency to its fiscal year 2015 enacted level after a cut in fiscal year 2016. 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 marketplace more efficient by providing quality measures to health professionals, and, ultimately, help transform health and healthcare.

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 2017 appropriations process.

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#### PREPARED STATEMENT OF THE AMERICAN COLLEGE OF PREVENTIVE MEDICINE

The American College of Preventive Medicine (ACPM) urges the House Labor, Health and Human Services, Education, and Related Agencies Appropriations Subcommittee to reaffirm its support for training preventive medicine physicians by providing \$11 million in fiscal year 2017 to the Health Resources and Services Administration's (HRSA) public health and preventive medicine line-item contained within the public health workforce development program. ACPM also supports the recommendation of the Health Professions and Nursing Education Coalition of restoring HRSA's discretionary budget authority to the fiscal year 2010 level of \$7.48 billion.

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

Organizations across the spectrum have recognized the growing demand for preventive medicine professionals. The Institute of Medicine released a report in 2007 calling for an expansion of preventive medicine training programs by an “additional 400 residents per year,” and the Accreditation Council on Graduate Medical Education (ACGME) recommends increased funding for preventive medicine residency training programs. Additionally, the Association of American Medical Colleges released statements in 2011 that stressed the importance of incorporating behavioral and social sciences in medical education as well as announcing changes to the Medical College Admission Test that would test applicants on their knowledge in these areas. Such measures strongly indicate increasing recognition of the need to take a broader view of health that goes beyond just clinical care—a view that is a unique focus and strength of preventive medicine residency training.

In fact, preventive medicine is the only one of the 24 medical specialties recognized by the American Board of Medical Specialties that requires and provides training in both clinical and population-based medicine. Preventive medicine residency training programs provide a blueprint on how to train our future physician workforce; physicians trained to provide individual patient care needs as well as practice at 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 2014 Physician Specialty Data Book released by the Association of American Medical Colleges, preventive medicine had the biggest decrease (–29 percent) in the number of first-year ACGME residents and fellows between 2008 and 2013. This decrease represents a worsening trend in the number of preventive medicine residents and is not due to a lack of interest or need but is due to a lack of funding. 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 is likely to 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. At a time of unprecedented national, State, and community need for properly trained physicians in public health, disaster preparedness, prevention-oriented practices, quality improvement, and patient safety, preventive medicine training programs and their residents are in need of enhanced Federal support.

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 a small number of preventive medicine residency programs, as it represents the largest Federal funding source for these programs.

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

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



—Fourteen percent of all preventive medicine residents are under-represented minorities, the largest proportion of any medical specialty.

In addition to training under-represented minorities and generating physicians who work in medically underserved areas, preventive medicine residency programs equip our society with health professionals and public health leaders who possess the tools and skills needed in the fight against the chronic disease epidemic that is threatening the future of our Nation's health and prosperity. Correcting the root causes of this critical problem of chronic diseases will require a multidisciplinary approach that addresses issues of access to healthcare; social and environmental influences; and behavioral choices. ACPM applauds the initiation of programs such as Care Coordination Organizations 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 by providing \$11 million in fiscal year 2017 for preventive medicine residency training under the public health and preventive medicine line-item at HRSA.

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PREPARED STATEMENT OF THE AMERICAN CONGRESS OF OBSTETRICIANS AND GYNECOLOGISTS

The American Congress of Obstetricians and Gynecologists, representing more than 57,000 physicians and partners in women's health, is pleased to offer this statement to the Senate Committee on Appropriations, Subcommittee on Labor, Health and Human Services, Education, and Related Agencies. We thank Chairman Blunt, Ranking Member Murray, and the entire Subcommittee for this 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 believes that Federal research investments, including comprehensive data collection and surveillance, biomedical research, and translating research into evidence-based care for women and babies is necessary to improve maternal and infant health. We urge you to make funding of the following programs and agencies a top priority in fiscal year 2017.

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

In order to conduct robust research, it is critical to collect uniform, accurate and comprehensive data. The National Center for Health Statistics is the Nation's principal health statistics agency and collects raw vital statistics from State records like birth and death certificates. This information provides key data about both mother and baby during pregnancy, labor, and delivery. Effective data collection depends on all States having adequate resources to expand technical assistance to maximize electronic death reporting by funeral directors and physicians. In addition, States must be able to modernize their systems to keep pace with new technology. ACOG requests funding to be used to support States in upgrading antiquated systems and improving the quality and accuracy of vital statistics reporting. For fiscal year 2017, ACOG requests \$170 million for the National Center for Health Statistics.

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 Eunice Kennedy Shriver National Institute of 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.

In addition, adequate levels of research require a robust research workforce. The years of training combined with uncertainty in receiving grant funding are major disincentives for students considering a career in this field. This has resulted in a huge gap between low number of 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 \$34.5 billion for NIH and \$1.441 billion within that funding request for NICHD in fiscal year 2017.

*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 serve the essential purpose of translating research into evidence-based practice. 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 and Child Health Block Grant (HRSA):* The Maternal and 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 postpartum 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. Even so, block grant funding has been significantly diminished. Over \$90 million has been cut from the Block Grant since 2003. ACOG requests \$880 million for the Block Grant in fiscal year 2017 to maintain its current level of services.

*Title X Family Planning Program (HRSA):* Family planning and interconception care are imperative to ensuring healthy women and healthy pregnancies. The Title X Family Planning Program provides essential services to more than 4.5 million low income men and women who may not otherwise have access to these services. Title X clinics accounting for \$5.3 billion in healthcare savings in 2010 alone. For every \$1 spent on publicly funded family planning services, Medicaid and other public expenditures saved \$7.09. ACOG supports \$327 million for Title X in fiscal year 2017 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, local health departments, consumers and community stakeholders to address local issues contributing to infant mortality. Today, more than 172 local programs in over 30 States find FIMR a powerful tool to help reduce infant mortality and address issues related to preterm delivery. ACOG has partnered with the Maternal and Child Health Bureau to sponsor the National FIMR Program for over 25 years. ACOG supports \$0.5 million in fiscal year 2017 for HRSA to increase the number of Healthy Start programs that use FIMR.

*Maternal Health Initiative (HRSA):* The Maternal and 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 mor-

tality. For fiscal year 2017, ACOG requests, at a minimum, level funding for MCHB to advance this important work.

*Safe Motherhood, Maternity and Perinatal Quality 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 Quality Collaboratives that improve birth outcomes by encouraging use of evidence-based care, including reducing early elective deliveries. For instance, 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 Health estimated that reducing early elective deliveries can save from \$2.4 million to \$9 million per year. Currently, there are active Perinatal Quality Collaboratives in many States, like Maryland and Washington, that have demonstrated significant progress in reducing early elective deliveries, among other quality improvement initiatives. They do so without Federal funds, and face major financial stability challenges. Many States do not yet have collaboratives, and could benefit greatly using active, successful, and well-funded collaboratives as a model to build a collaborative tailored to unique and local needs. The PREEMIE Reauthorization Act, enacted in 2013, authorizes funding to increase the number of States receiving assistance for Perinatal Quality Collaboratives. ACOG urges you to reinstate the pre-term birth sub-line at a funding level of \$2 million, as authorized by PREEMIE, and fund the Safe Motherhood Initiative at \$46 million to implement PREEMIE and help States expand or establish Maternity and Perinatal Quality Collaboratives.

*Advancing Maternal Therapeutics at the Department of Health and Human Services (HHS)*

Each year, more than 4 million women give birth in the United States and more than 3 million breastfeed their infants. However, little is known about the effects of most drugs on the woman and her child, or the ways in which pregnancy and lactation alter the uptake, metabolism, and effect of medication. Pregnant and breastfeeding women have historically been excluded from most research trials. Although there have been substantial encouraging developments in this arena, including the recently updated drug labeling rule on pregnancy and lactation by FDA and relevant research at NIH and CDC, significant gaps remain. In order to achieve meaningful progress, HHS must ensure the coordination of all efforts being made at the agency level. As such, ACOG supports the establishment of a Federal work group to improve coordination and provide guidance on how clinical research might be done appropriately in this area.

*Quality Assessment Programs at the Agency for Healthcare Research and Quality (AHRQ)*

*Consumer Assessment of Healthcare Providers and Systems (CAHPS):* The Consumer Assessment of Healthcare Providers and Systems (CAHPS) program was established within AHRQ in 1995 to address concerns regarding the lack of available consumer health plan reviews. The information collected through the CAHPS program can be a critical element of patient decisionmaking, while also informing providers and insurers about the impact and reception of their initiatives and services. Unfortunately, the CAHPS program has not yet established a survey to collect data about maternity care. Given the frequency and complex nature of interactions that an expectant mother will have with an effective healthcare system, we support the creation of a CAHPS survey focused on maternity care. ACOG encourages the CAHPS program to direct funds towards the development of a maternity care-oriented assessment.

Again, we would like to thank the Committee for its commitment to improving women's health, and we urge you to fund the programs we have identified in fiscal year 2017.

*U.S. Government Response to Zika Virus*

In order to continue to adequately respond to and better understand the Zika virus' origins, transmission, and public health risks, particularly to pregnant women, ACOG urges Congress to fund a robust and comprehensive public health response to the rapid spread of the Zika virus.

ACOG applauds the Administration's recent steps to bolster U.S. capacity to combat Zika by previously committed Federal funds, but additional funding is desperately needed. ACOG urges Congress to prioritize emergency supplemental funding to combat Zika and replenish funds that have been transferred by the Administration. The health of women and infants is central to ACOG's mission, and we be-

lieve that these funding measures are essential to ensure execution of a comprehensive Zika response.

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PREPARED STATEMENT OF THE AMERICAN DENTAL EDUCATION ASSOCIATION

The American Dental Education Association (ADEA) represents all 66 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. ADEA submits this testimony for the record and for your consideration as you begin prioritizing fiscal year 2017 appropriation requests.

ADEA's dental schools' clinics and extramural dental school facilities provide care to more than 3 million patients annually. America's dental schools are one of the Nation's largest oral health care safety nets, providing more than \$74 million in uncompensated healthcare annually to the uninsured and under-insured.

ADEA's academic dental institutions educate and train future oral health providers and dental and craniofacial researchers. As one of the largest safety-net providers of dental care in the United States, these dental schools provide significant care to the uninsured and underserved populations. Given the fact that research has proven that there is an indivisible link between good oral health and overall health, it is imperative that adequate funding be provided to programs that facilitate access to dental care and continues cutting-edge dental and craniofacial research which seeks to reduce the burden of oral disease.

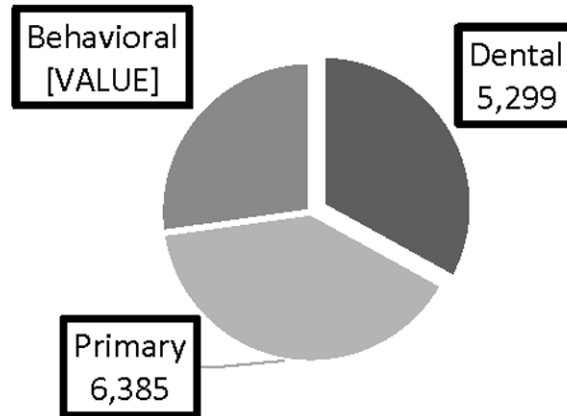
ADEA urges you to adequately fund and protect funding for Title VII of the Public Health Service Act and the National Institute of Dental and Craniofacial Research (NIDCR). Title VII, through its various grants and programs, facilitates access to dental care to millions of Americans and NIDCR fosters globally recognized cutting-edge dental and craniofacial research.

Specifically, we are requesting funding for the following: (1) Title VII of the Public Health Service Act; (2) National Institute of Dental and Craniofacial Research (NIDCR); (3) Centers for Disease Control and Prevention (CDC), Division of Oral Health; (4) Ryan White HIV/AIDS Treatment and Modernization Act, Part F: Dental Reimbursement Program (DRP) and the Community-Based Dental Partnerships Program.

As you deliberate funding for fiscal year 2017, ADEA respectfully makes the following funding requests:

I. \$35.9 million: Title VII, Section 748, Public Health Service Act

## Health Profession Shortage Areas



The dental programs in Title VII, Section 748 of the Public Health Service Act, provide critical training in general, pediatric and public health dentistry and dental hygiene. Support for these programs will help ensure an adequately prepared dental workforce. The funding supports predoctoral dental education and postdoctoral pediatric, general and public health dentistry residency training. The investment made by Title VII not only educates dentists, dental therapists and dental hygienists, but also expands access to care for underserved communities since much of the care is provided in community-based settings located in health profession shortage areas.

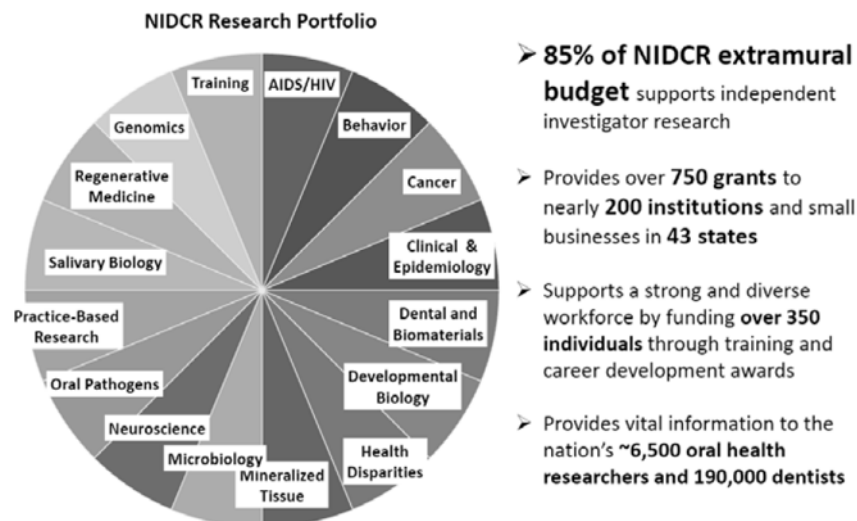
Additionally, Section 748 addresses the shortage of professors in dental schools with the dental faculty loan repayment program and faculty development courses for those who teach pediatric, general or public health dentistry and dental hygiene. There are currently more than 200 open, budgeted faculty positions in dental schools. These two programs provide schools with assistance in recruiting and retaining faculty. ADEA is increasingly concerned that with projected restrained funding, the dental research community will not be able to grow and that the pipeline of new researchers will not meet future need.

Title VII Diversity and Student Aid programs play a critical role in diversifying the health professions student body and, thereby, the healthcare workforce. For the last several years, these programs have not received adequate funding to sustain the progress necessary to meet the challenges of an increasingly diverse U.S. population.

We are pleased that the budget request this year contained funding for the Health Careers Opportunity Program (HCOP). This program provides a vital source of support for dental professionals serving underserved and disadvantaged patients by providing a pipeline for individuals from these populations. This unique workforce program encourages young people from diverse and disadvantaged backgrounds to explore careers in healthcare generally and dentistry specifically. ADEA requests that this program continue to be funded.

ADEA is most concerned that the Administration did not request any funds for the Area Health Education Centers (AHEC) program. This vital program is targeted at enhancing high quality, culturally competent care in community-based inter-professional clinical training settings. The infrastructure development grants and point of service maintenance and expansion grants ensure that patients from underserved populations receive quality care and that health professionals receive training with diverse populations. ADEA strongly encourages the Committee to continue funding the vitally important AHEC program.

II. \$452 million: National Institute of Dental and Craniofacial Research (NIDCR)



Dental research serves as the foundation of the profession of dentistry. Discoveries stemming from dental research have reduced the burden of oral diseases, led to better dental health for millions of Americans and uncovered important links between oral and systemic health. ADEA and dental school researchers are grateful for the increase NIDCR received in fiscal year 2015, however the increased funding was allocated to required NIH-wide initiatives. The requested increase will provide for a 6 percent real growth to ensure continued growth of the Precision Medicine Initiative and progress to meet the goals outlined in the 21st Century Cares Act and the Biomedical Innovation Agenda legislation currently being debated by Congress. Through NIDCR grants, dental researchers in academic dental institutions have enhanced the quality of the Nation's dental and overall health. Dental researchers are poised to make dramatic breakthroughs, such as restoring natural form and function to the mouth and face as a result of disease, accident, or injury; and diagnosing systemic disease (such as HIV and certain types of cancer) from saliva instead of blood and urine samples. These breakthroughs and countless others, which continue America's role as a global scientific leader, require adequate funding.

III. \$19 million: Centers for Disease Control and Prevention (CDC) Division of Oral Health

The CDC Division of Oral Health expands the coverage of effective prevention programs. The Division 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 dental disease affecting children and vulnerable populations. The current path of decreased funding will have a significant negative effect upon the overall health and preparedness of the Nation's States and communities.

IV. \$18 million: Ryan White HIV/AIDS Treatment and Modernization Act, Part F: Dental Reimbursement Program (DRP) and Community-Based Dental Partnerships Program

Patients with compromised immune systems are more prone to oral infections like periodontal disease and tooth decay. The Dental Reimbursement Program (DRP) is a cost-effective Federal/institutional partnership providing partial reimbursement to academic dental institutions for costs incurred in providing dental care to people living with HIV/AIDS. Simultaneously, the program provides educational and training opportunities to dental students, residents and allied dental students. However, DRP reimbursement only averages 26 percent of the dental schools' unreimbursed costs. The current reimbursement rate is unsustainable. Adequate funding of the Ryan White Part F programs will help ensure that people living with HIV/AIDS receive necessary oral healthcare.

ADEA thanks you for your consideration of these funding requests and looks forward to working with you to ensure the continuation of these critical programs to ensure the health and well-being of the Nation.

Please use ADEA as a resource on any matter pertaining to dental education and training of the dental workforce under your purview. For additional information contact: Yvonne Knight, J.D., ADEA Chief Advocacy Officer at [Knighly@adea.org](mailto:Knighly@adea.org).

PREPARED STATEMENT OF THE AMERICAN DENTAL HYGIENISTS' ASSOCIATION

INTRODUCTION

The American Dental Hygienists' Association (ADHA) appreciates this opportunity to provide testimony of fiscal year 2017 appropriations. 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. While virtually all dental disease is fully preventable, nearly 25,000,000 children eligible for dental Medicaid benefits (60 percent) did not receive any preventive dental services in fiscal year 2014.<sup>1</sup> With the Nation confronting an oral health access crisis, there is no dispute that new types of dental providers are needed; the disagreement relates to what types of new providers are needed. This underscores the need for demonstration projects under Section 340G-1 of the Public Health Service Act in order to explore what types of new providers work best in various settings. Regrettably, there is a persistent appropriations statutory provision blocking funding specifically for this grants program at the Health Resources and Services Administration (HRSA). There is simply no legal or health policy justification to perpetuate this funding block. Indeed, it is only organized dentistry that actively works to block funding for Section 340G-1. ADHA, along with State dental hygiene associations across the Nation, urges that the block on funding for Section 340G-1 be lifted, that \$2,000,000 be appropriated for Section 340G-1 and that the following report language be included in the fiscal year 2017 HHS funding bill:

Requested Report Language: "The Nation continues to confront an oral health access crisis, which will not be ameliorated without better utilization of existing dental providers and exploration of new types of licensed dental providers. The Committee urges a stakeholder meeting be convened in order to determine how best to create new entry points into the oral healthcare delivery system for rural and other underserved populations, better utilization of existing dental personnel, and exploration of new types of dental providers."

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. Even lifting the block and not funding the program would be a positive message to States. Importantly, the authorizing language requires that the grants be conducted in compliance with State law, that they must increase access to dental healthcare in rural and other underserved communities, and that the Institute of Medicine provide a qualitative and quantitative evaluation of the grants. Importantly, nothing in Section 340 G-1 would enable oral health practitioners to perform dental surgery or "irreversible procedures," unless a State specifically allowed such services. Further, because the authorizing language requires 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.

*Widespread Support for Dental Workforce Innovation*

The American Dental Association (ADA), ADHA and numerous other groups have called for new types of dental providers. Innovative oral health practitioner models were authorized in Minnesota in 2009, followed by Maine in 2014. A February 2014 Report to the Minnesota Legislature on the early impact of the new providers found that benefits include "direct cost savings, increased dental team productivity, improved patient satisfaction and lower appointment fail rates."<sup>2</sup> Several States have mid-level oral health practitioner legislation pending including Connecticut, Georgia, Hawaii, Kansas, Massachusetts, New Mexico, North Dakota, South Carolina, Texas, Vermont and Washington State. Both the W.K. Kellogg Foundation and the PEW Charitable Trust Dental Campaign are investing in State efforts to increase

<sup>1</sup> <https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Early-and-Periodic-Screening-Diagnostic-and-Treatment.html>.

<sup>2</sup> <http://www.health.state.mn.us/divs/orhpc/workforce/dt/dtlegisrpt.pdf>.

oral healthcare access by adding new types of dental providers to the dental team. Groups as disparate as Families USA, Americans for Tax Reform, and Americans for Prosperity have called for exploration of new dental providers. In a January 2015 report, Families USA called for “improving access to care through greater use of mid-level providers such as nurse practitioners and dental therapists.”<sup>3</sup> Grover Norquist, President of Americans for Tax Reform, observed in March 2015 that “It is undeniable that there is a dentist shortage”. Norquist further noted that “Innovative ideas like this [mid-level dental provider] faced intense opposition but are very similar to the fights that took place decades ago with the emergence of nurse practitioners.” Americans for Prosperity wrote in January 2015 that States should be “free to innovate” in the dental workforce to solve access issues. The National Dental Association, representing 6,000 Black dentists, released its “Position on Access to Care and Emerging Workforce Models” in July 2014, which stated that the NDA “supports the development and continuation of demonstration projects that can demonstrate the impact and effectiveness of Emerging Workforce Models [expanded function dental hygienists, expanded function dental assistants, or dental therapists] on access to care, and total health outcomes.”<sup>4</sup>

The U.S. Federal Trade Commission (FTC) supported dental workforce expansion in November 2014, 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.”<sup>5</sup> In January, 2016, the FTC noted that “By eliminating the direct supervision requirement for dental hygienists’ services delivered in expanded safety-net setting . . . H.B. 684 will likely promote greater competition in the provision of preventive dental care services, leading to increased access and more cost-effective care . . . .”<sup>6</sup> Importantly, the FTC observed that “authoritative sources have found no countervailing health or safety benefits to healthcare consumers from such [direct supervision] requirements.”<sup>7</sup>

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.”<sup>8</sup> The Department of Health and Human Services, in its Oral Health Strategic Framework, called for expanding the number of health-care settings that provide oral healthcare and urged strengthening the oral health workforce and expanding the capabilities of existing providers.<sup>9</sup>

*Dentist Shortage and Dental Hygienist Surplus Demand Better Utilization of Dental Hygienists*

In February 2015, HRSA projected that all 50 States and the District of Columbia will experience a shortage of dentists by 2025. In contrast, there will be an excess supply of dental hygienists at the national level while five States (MI, MT, ND, SD, and WV) will experience dental hygienist shortages from 21–93 FTEs.<sup>10</sup>

*Title VII Program Grants to Expand and Educate the Dental Workforce—ADHA Urges Funding at a Level of \$35.8 Million in Fiscal Year 2017*

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

<sup>3</sup> <http://familiesusa.org/press-release/2015/families-usa-proposes-health-reform-20>.

<sup>4</sup> (<http://ndaonline.org/position-on-access-to-care-and-emerging-workforce-models>).

<sup>5</sup> [https://www.ftc.gov/system/files/documents/advocacy\\_documents/ftc-staff-comment-commission-dental-accreditation-concerning-proposed-accreditation-standards-dental/141201codacomment.pdf](https://www.ftc.gov/system/files/documents/advocacy_documents/ftc-staff-comment-commission-dental-accreditation-concerning-proposed-accreditation-standards-dental/141201codacomment.pdf).

<sup>6</sup> [https://www.ftc.gov/system/files/documents/advocacy\\_documents/ftc-staff-comment-georgia-state-senator-valencia-seay-concerning-georgia-house-bill-684/160201gadentaladvocacy.pdf?utm\\_source=govdelivery](https://www.ftc.gov/system/files/documents/advocacy_documents/ftc-staff-comment-georgia-state-senator-valencia-seay-concerning-georgia-house-bill-684/160201gadentaladvocacy.pdf?utm_source=govdelivery).

<sup>7</sup> *Ibid.*

<sup>8</sup> <http://www.nga.org/files/live/sites/NGA/files/pdf/2014/1401DentalHealthCare.pdf>.

<sup>9</sup> HHS Oral Health Strategic Framework, 2014–2017, Public Health Reports, Vol. 131, March–April 2016, pp248–249. <http://www.publichealthreports.org/issueopen.cfm?articleID=3498>.

<sup>10</sup> HRSA March 2015 “National and State-Level Projections of Dentists and Dental Hygienists in the U.S., 2012–2025” <http://bhpr.hrsa.gov/healthworkforce/supplydemand/dentistry/nationalstatelevelprojectionsdentists.pdf>.



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 2017*

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 (NIDCR)—Fund at a Level of \$452 Million in Fiscal Year 2017*

NIDCR cultivates oral health research that leads to greater understanding of oral diseases and their treatments and the link between oral health and overall health. ADHA joins with others in the oral health community to support NIDCR funding at a level of \$452 million in fiscal year 2016.

CONCLUSION

ADHA is the largest national organization representing the professional interests of more than 185,000 licensed dental hygienists across the country. Thirty-nine States enable patients to directly access oral health services provided by dental hygienists in settings outside the private dental office. Seventeen State Medicaid programs (AZ, CA, CO, CT, ME, MA, MI, MN, MO, MT, NE, NM, NV, OR, RI, WA and WI) provide direct reimbursement to dental hygienists for oral health services provided to Medicaid-eligible individuals. ADHA urges the Subcommittee to lift the block on funding for Section 340G-1 of the PHSA, dental workforce demonstration grants, in its fiscal year 2017 HHS funding bill. It is time for an evidence-based decision to be made on this grant program for the underserved. 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. Without the appropriate supply, diversity and distribution of the oral health workforce, the current oral health access crisis will only be exacerbated. In closing, ADHA recommends funding at a level of \$2 million for fiscal year 2017 to support these vital dental workforce demonstration projects. ADHA also requests that report language (see page 2) be included noting that the Committee recognizes that the oral health access crisis will not be ameliorated without better utilization of existing dental providers and exploration of new types of licensed dental providers. In addition, ADHA urges that this Subcommittee convene a stakeholder meeting in order to move beyond the tired appropriations rider that blocks funding for Section 340G-1, a dental workforce demonstration program to improve access to care for vulnerable and underserved populations. Thank you for the opportunity to submit the views of the ADHA.

[This statement was submitted by Jill Rethman, RDH, BA, President, American Dental Hygienists' Association.]

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PREPARED STATEMENT OF THE AMERICAN DIABETES ASSOCIATION

For fiscal year 2017, the American Diabetes Association (Association) urges the Subcommittee to deepen its investment in research and prevention to find a cure, and improve the lives of those living with, and at risk for, diabetes. We ask the Subcommittee to provide \$2.165 billion for the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) at the National Institutes of Health (NIH), \$170.129 million for the Division of Diabetes Translation (DDT) at Centers for Disease Control and Prevention (CDC), and \$25 million for the National Diabetes Prevention Program (National DPP) at CDC.

Nearly 30 million Americans live with diabetes and 86 million Americans have prediabetes. I have been living with type 1 diabetes since was 10 years old. I remember listening as the doctor told my mom that I would never be able to have children and that diabetes would shorten my life. Thanks to the many medical discoveries and advancements at the NIH and translational research from CDC, I have

proven her wrong. I have two beautiful, healthy children and have lived 36 years with diabetes, without complications.

I also remember a more recent conversation about diabetes with my family. Two years ago, my sister was diagnosed with type 1 diabetes at age 38. As we talked that day and I helped to console her and then connect her to the healthcare she would need to live with diabetes, I couldn't help but think how much farther we need to go to ensure that no one has to receive a diagnosis of diabetes again.

As a person living with diabetes who is also an emergency department nurse and president of a charitable clinic, I see the human and economic toll diabetes extracts from my patients and their families. The lives of people living with, and at risk for, diabetes are better because of NIH research and CDC prevention activities. Progress has been great, but much more must be done to stop diabetes and the devastating complications I see every day. I am proud to share my testimony with you on behalf of my sister, my patients, and the millions of American adults and children living with diabetes or prediabetes.

The diabetes epidemic is one of our country's biggest challenges and one touching all of our lives. According to the CDC, as many as one in three adults in our country—closer to one in two among minority populations—will have diabetes in 2050 if present trends continue. The sobering cost of this horrific disease is lived everyday by those who face blindness, suffer heart attacks and strokes, struggle with kidney failure and lose limbs, along with other deadly complications. Every year, 1.7 million Americans aged 20 years or older are diagnosed with diabetes. That means every 23 seconds someone in this country is diagnosed with diabetes. Today, diabetes will cause 200 Americans to undergo an amputation, 136 to enter end-stage kidney disease treatment, and 1,795 to develop severe retinopathy that can lead to vision loss.

In addition to the horrendous physical toll, diabetes is economically devastating to our country. A 2017 report found the total annual cost of diagnosed and undiagnosed diabetes, prediabetes, and gestational diabetes in our country has skyrocketed by an astonishing 78 percent over 5 years—to \$322 billion. People with diagnosed diabetes have healthcare costs 2.3 times higher than those without diabetes. One in three Medicare dollars is spent caring for people with diabetes. Despite the escalating cost of diabetes to our Nation, the Federal investment for diabetes research and programs at the NIH and CDC has not equaled the shocking pace of the diabetes epidemic. It doesn't have to be this way. America has the power to stop the diabetes epidemic and make the final chapter a success story for the ages. The state of our Nation's diabetes epidemic justifies increased Federal funding in fiscal year 2017 for diabetes research and prevention programs.

#### BACKGROUND

Diabetes is a chronic disease impairing the body's ability to utilize food. The hormone insulin, which is made in the pancreas, is needed for the body to change food into energy. In people with diabetes, either the pancreas does not create insulin, which is type 1 diabetes, or the body does not create enough insulin and/or cells are resistant to insulin, which is type 2 diabetes. Diabetes results in too much glucose in the blood stream. Blood glucose levels that are too high or too low (as a result of medication to treat diabetes) can be life threatening in the short term. In the long term, diabetes is the leading cause of kidney failure, new cases of adult-onset blindness, and non-traumatic lower limb amputations, and a leading cause of heart disease and stroke. Additionally, up to 9.2 percent of women are affected by gestational diabetes, a form of glucose intolerance diagnosed during pregnancy placing both mother and baby at risk for complications and for type 2 diabetes. Those with prediabetes have higher than normal blood glucose levels and are at risk for type 2 diabetes, but can take action to lower that risk.

#### THE NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASES AT NIH

The American Diabetes Association requests funding for NIDDK of \$2.165 billion in fiscal year 2017 to support groundbreaking research. Research at NIDDK has led to many discoveries helping Americans prevent or better manage diabetes. For example, people with diabetes now manage their disease with a variety of insulin formulations and regimens far superior to those used in decades past, which have reduced the risk for the serious complications of diabetes: heart disease, stroke, lower extremity amputation, blindness, and kidney disease. NIDDK research has led to the availability of tools to prevent life-threatening high and low blood glucose levels such as continuous glucose monitors and insulin pumps.

Further, the transformative Diabetes Prevention Program (DPP) at NIDDK showed individuals with prediabetes can lower their risk of developing type 2 diabe-

tes by 58 percent through dietary changes and increased physical activity. Building on these results, the CDC, working with community, healthcare, and faith-based organizations, private insurers, employers, and government agencies has put this research into practice through the National Diabetes Prevention Program. The Centers for Medicare and Medicaid Services (CMS) has recognized the value of this approach to prevent type 2 diabetes and has proposed Medicare coverage of the National DPP. This would not have been possible without NIDDK's clinical trial.

Additional research is needed to build on these advancements. Diabetes researchers across the country are poised for further innovation to transform diabetes prevention and care. With fiscal year 2017 funding of \$2.165 billion, the NIDDK would be able to fund additional investigator-initiated research grants to meet critical needs in areas such as expansion of NIDDK's comparative effectiveness clinical trial testing different medications to determine the best treatments for type 2 diabetes and continued development of the artificial pancreas, a closed looped system combining continuous glucose monitoring with insulin delivery. Additionally, the NIDDK would be able to move forward with research to improve the treatment of diabetic foot ulcers to reduce amputations, understand the relationship between diabetes and neuro-cognitive conditions like dementia and Alzheimer's disease, and discover how drugs to treat diabetes may help those facing heart disease and cancer.

#### THE DIVISION OF DIABETES TRANSLATION AT CDC

The Federal Government's role in coordinating efforts to prevent diabetes and its serious complications through the Division of Diabetes Translation and its evidenced-based, outcomes-focused diabetes programs is essential. In fiscal year 2016, Congress recognized this by providing \$170.129 million for DDT, whose mission is to eliminate the preventable burden of diabetes through research, education, and by translating science into clinical practice. DDT has a proven record of success in primary prevention efforts as well as programs to help those with diabetes manage their disease and avoid complications.

We urge Congress to again provide \$170.129 million in fiscal year 2017. With these resources, the DDT will be able to continue diabetes prevention activities at the State and local levels. Funding will support these efforts through the State and Local Public Health Actions to Prevent Obesity, Diabetes, and Heart Disease grants, with a focus on improving prevention at the community and health system levels in populations with highest risk for diabetes. It will support basic and enhanced diabetes prevention efforts under the State Public Health Actions grant program for cross-cutting approaches to prevent and control diabetes, heart disease and stroke. It will also enable the DDT to expand its translational research activities to improve diabetes prevention, and continue its valuable diabetes surveillance work.

#### THE NATIONAL DIABETES PREVENTION PROGRAM AT CDC

I am alarmed 86 million Americans have prediabetes and are on the cusp of developing type 2 diabetes. Nine of ten individuals with prediabetes do not know they have it, and 15–30 percent of individuals with prediabetes develop type 2 diabetes within 5 years. Managed by the CDC, the National Diabetes Prevention Program (National DPP) is a public-private partnership of community organizations, private insurers, employers, healthcare organizations, faith-based organizations, and government agencies focused on type 2 diabetes prevention.

The National DPP grew out of a successful NIDDK clinical study showing weight loss of 5 to 7 percent of body weight, achieved by reducing calories and increasing physical activity to at least 150 minutes per week, reduced risk of developing type 2 diabetes by 58 percent in people with prediabetes and by 71 percent for those over 60 years old. Additional translational research was then done, showing the program also works in the less-costly community setting—at a cost of about \$725 per participant.

The National DPP supports a national network of local sites where trained staff provides those at high risk for diabetes with cost-effective, group-based lifestyle intervention programs. There are four key components to the National DPP. First, community-based diabetes prevention sites where those at high risk for diabetes attend the intervention program. Second, a national recognition program coordinated by CDC to establish evidence-based standards for participating intervention sites, and provide the quality monitoring to ensure success. Third, public and healthcare provider education efforts giving trustworthy information on the availability of high quality diabetes prevention programs in communities so people understand what they need to do when they are diagnosed with prediabetes. Fourth, informed referral networks so healthcare providers can refer patients with prediabetes to the local intervention sites.

Recently the Secretary of HHS announced that the CMS Office of the Actuary found that seniors participating in a National DPP program have Medicare costs that are \$2,650 less than nonparticipants over a 15 month period. Through a demonstration project administered by the YMCA, we now know that this program not only improves health, but lowers healthcare costs and will have a valuable impact on our Nation's economy. The Secretary will now take steps to implement coverage for this program as a Medicare benefit.

We urge Congress to provide \$25 million for the National DPP in fiscal year 2017 to continue its nationwide expansion. This level of funding for the National DPP will allow CDC to increase the number of sites that offer this critical program and continue to manage its recognition program to ensure sites follow the evidence-based curriculum and achieve the same high level of results.

#### CONCLUSION

We can and must change our country's story with regard to diabetes. We urge the Subcommittee's fiscal year 2017 appropriations decisions to reflect the necessity of taking action in light of the human and economic burden of this horrendous disease. The Association looks forward to working with you to stop diabetes.

[This statement was submitted by Gina Gavlak, RN, Chair, National Advocacy Committee, American Diabetes Association.]

#### PREPARED STATEMENT OF THE AMERICAN ECONOMIC ASSOCIATION

Chairman Blunt, Ranking Member Murray, and members of the Subcommittee, I am Robert Moffitt, Professor of Economics at the Johns Hopkins University and Chair of the Committee on Economic Statistics of the American Economic Association (AEA), the primary professional association of economists in the United States. On behalf of the Committee, I am pleased to provide this testimony in support of the programs of the Bureau of Labor Statistics, U.S. Department of Labor.

The AEA has about 20,000 members. As the Bureau of Labor Statistics (BLS) indicates that the Nation has 21,500 jobs for economists, it is reasonable to suggest that the AEA represents a sizable proportion of the profession.

The charter of the AEA states our organization's mission:

- The encouragement of economic research, especially the historical and statistical study of the actual conditions of industrial life.
- The issue of publications on economic subjects.
- The encouragement of perfect freedom of economic discussion. The Association as such will take no partisan attitude, nor will it commit its members to any position on practical economic questions.

Succinctly put, the AEA promotes the conduct, publication, and discussion of economic research based on historical and statistical study. In 1885, the AEA's founders sought to migrate the economics profession from the realm of philosophy to that of the social sciences. Since that time, the results of AEA members' work has guided the development of the U.S. economy to become the largest and one of the most dynamic in the world.

As the AEA charter indicates, statistics are the lifeblood of economic research. The growth and achievements of our profession would not have been possible without the sustained work over two centuries of the U.S. Congress to create, direct, and fund a robust, inventive, adaptive national statistical system.

At the core of that system is the Bureau of Labor Statistics, the Nation's oldest continuously operating principal Federal statistical agency—created by Congress 1 year before the AEA's founding. In a real sense, the BLS and the economics profession have grown up together. Each has made the work of the other possible.

Since Congress established the BLS, it has regularly expanded the agency's mandated duties.<sup>1</sup> The topics of these responsibilities are reflected in the four BLS program accounts—labor force statistics, prices and cost of living, compensation and working conditions, and productivity and technology. Congress has made clear that it has given the BLS these responsibilities in order to promote several important public policy goals:

- Effective fiscal and monetary policy
- U.S. businesses competitive in world markets
- Efficient U.S. markets for labor, goods, and services

<sup>1</sup>Congress added current BLS responsibilities to the U.S. Code in 1888, 1913, 1940, 1966, 1970, 1975, and 1998. Congress most recently re-affirmed broad BLS labor force statistics responsibilities with the passage of the Workforce Innovation and Opportunity Act of 2014.

—Research that describes and explains the current and historical dynamics of the U.S. economy

Given the breadth of these aims, it is fair to say that the health of the U.S. economy very much depends upon the value of the statistics produced by the BLS. In my view, that value historically has been extraordinarily high.

In recent years, however, the BLS has not received resources sufficient to fulfill its mandated duties. BLS appropriations peaked in fiscal year 2010 at \$611.4 million. Accounting for inflation, its fiscal year 2016 appropriation of \$609.0 million represents a decline of 8.9 percent in real terms (using BLS price data). The current BLS staffing level is 8.3 percent below that of 2010.

As a result of 6 years of significant budget shortfalls, the BLS has eliminated several data programs, reduced the reliability of a number of others, and curtailed investments in research, information technology, and staff. In fiscal year 2014, BLS ended the International Labor Comparisons and Mass Layoff Statistics programs, despite the fact that the latter is congressionally mandated. It also announced plans to stop publishing Export Price Indexes, a Principal Federal Economic Indicator, but then found temporary funding from another Federal agency. Last fall, faced with uncertain appropriations, BLS considered eliminating the Job Openings and Labor Turnover Survey, the National Longitudinal Survey, the American Time Use Survey, and Employment Projections (another congressionally mandated program).

The AEA Statistics Committee strongly believes that the continuation of insufficient BLS funding is likely to have severe consequences for the capacity of the agency to serve the Nation's economic policymakers, research economists, and market participants. Further, the Statistics Committee believes that the BLS's inability to measure trends in two important aspects of the economy—contingent work and employer-provided training—is detrimental to economic research that informs good economic and workforce policy. Therefore, the Statistics Committee strongly urges this Subcommittee to provide sufficient support for the BLS to continue its current programs and add surveys on the important two subjects just mentioned.

As the Subcommittee considers this request, I ask that it keep in mind some version of “dynamic scoring,” that is, the full fiscal and economic impacts of appropriations to the BLS. Compared to other public policy tools, statistics is remarkably inexpensive and has an extraordinarily high return on taxpayer investment.

Thank you for your consideration of the AEA Statistics Committee's request. I very much appreciate the opportunity to provide this testimony, hope the Subcommittee finds it of value, and look forward to the Subcommittee's decision with regard to the BLS.

[This statement was submitted by Professor Robert Moffitt, Chair, Committee on Economic Statistics, American Economic Association.]

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#### PREPARED STATEMENT OF THE AMERICAN EDUCATIONAL RESEARCH ASSOCIATION

Chairman Blunt, Ranking Member Murray, and Members of the Subcommittee, thank you for the opportunity to submit written testimony on behalf of the American Educational Research Association. Appreciative of these stringent times, we recommend that the Institute of Education Sciences (IES) receive \$728 million in fiscal year 2017. This recommendation is consistent with the request from the Friends of IES coalition, in which we are a leading member.

AERA is the major national scientific association of 25,000 faculty, researchers, graduate students, and other distinguished professionals dedicated to advancing knowledge about education, encouraging scholarly inquiry related to education, and promoting the use of research to improve education and serve the public good.

With the passage of the Every Student Succeeds Act (ESSA) as well as the Evidence-Based Policymaking Commission Act, we see a bipartisan commitment to evidence-based decisionmaking. In 2016, the budget for IES was just over 1 percent of the Department of Education budget, underscoring the underinvestment in research on education as compared with comparable research and development investments in other fields. As we look ahead to 2017, we anticipate that the ESSA requirements that States, districts, and schools assess the evidence when selecting interventions should if anything amplify the demand for the very work of IES.

Since IES was created in 2002, it has made dramatic contributions to the progress of education. Yet, we in the U.S. have a far way to go to provide high-quality education to all of our students. In addition to old questions that remain unanswered—such as how to best prepare teachers—we have barely begun to understand the opportunities provided by advances in technology. IES needs increased funding to continue our progress, using rigorous research to inform education policy. IES com-

prises the four national centers listed below. Each serves a critical role in improving the quality of education in the U.S.

*National Center for Education Statistics (NCES)*

Established by an Act of Congress in 1867, NCES is one of the 13 principal Federal statistical agencies in the United States. It collects, analyzes, and reports on education data and statistics on the condition of education in our country; conducts long-term longitudinal studies and surveys; and supports international assessments in accordance with the highest methodological standards and practices for data confidentiality and data security.

Federal, State, and local policy makers rely on over two dozen NCES-supported survey programs, assessments, and administrative data sets, as do schools, educators, and researchers across the country. NCES's annual report, *The Condition of Education*, provides a comprehensive statistical overview of U.S. early childhood, K–12, and postsecondary education.

NCES also provides technical assistance to public and private education agencies and to States improving their statistical systems. Grants from the Statewide Longitudinal Data Systems (SLDS) program supports States to build quality data systems that span early childhood, K–12, and postsecondary education into the labor force. In recent testimony to the House Education and the Workforce Committee, Robert Swiggum, Deputy Superintendent, Georgia Department of Education spoke of the tremendous value of the Federal SLDS grant that enabled Georgia to construct a statewide longitudinal system. In his testimony he said that the teachers access to the data has improved their teaching and has been a major factor in the dramatic increase in the State graduation rate from 59 percent in 2009 to 78 percent in 2015.

The President has requested a significant increase for this program from \$35 million in fiscal year 2016 to \$81 million in fiscal year 2017. This would enable States and districts to build on existing work and make possible a new competition in fiscal year 2017, allowing more States to leverage existing data to examine local education issues and concerns and achieve improvements in educational outcomes as have been achieved in Georgia.

NCES is home to the National Assessment of Educational Progress (NAEP), known as the “Nation’s Report Card.” NAEP is an important resource for identifying long-term trends in educational proficiency in each State and—through the Trial Urban District Assessment—in the largest school districts in the Nation.

Furthermore, NCES manages the U.S. participation in international assessments and surveys, which prominently include the Program for International Student Assessment (PISA), the Trends in International Mathematics and Science Study (TIMSS), and the Progress in International Reading Literacy Study (PIRLS). Continued adequate funding for these international assessments, enable NCES to accurately gauge U.S. performance in reading, math, and science in comparison to other countries. This information is particularly useful in a time of increasing global economic competition.

The proposed budget increase would enable NCES to adequately fund the most timely information on several high-priority education policy issues: early childhood development and education, student loan repayment and default, and the development of P–12 and postsecondary information hubs to make accessible actionable data and research.

*National Center for Education Research (NCER)*

Over the past decade, NCER-funded research has made significant advances in our understanding on a broad range of questions, from how to increase math achievement in pre-school; improve literacy skills in third grade, and reduce drop-out rates. The investments in the research are leading to measurable improvements in classrooms across the country. The Building Blocks curriculum, born out of IES and NSF funded research, has recently been adopted by Boston, New York City, and several California districts, and is showing positive effects on young children’s mathematics and literacy skills.

*National Center for Special Education Research (NCSEER)*

NCSEER supports research that investigates how to improve developmental and education outcomes for infants, toddlers, children, and youth with, or at risk of developing, disabilities. Since its creation in 2004 under the Individuals with Disabilities Education Act, NCSEER has made important contributions to research goals such as identifying effective interventions for children and youth with autism and supporting the independence of youth with disabilities post high school. Another example of an IES-funded work that is leading to tangible improvements for students is the development of the Early Literacy Skills Builder program, currently being

used in nearly 1,300 school districts, has been demonstrating improvements in reading outcomes for students with significant intellectual disabilities.

*National Center for Education Evaluation and Regional Assistance (NCEE)*

NCEE conducts evaluations of large-scale educational projects and Federal education programs and advances the use of IES knowledge by informing the public and reaching out to practitioners with a variety of dissemination strategies and technical assistance programs. The Education Resources Information Center (ERIC) is a well-used resource throughout the Department of Education. In the past year, there were more than 18 million individual sessions—more than 49,500 per day. In addition, the What Works Clearinghouse (WWC) provides valuable information on the findings and methodologies of evaluations of various education practices and policies. The most viewed practice guides include *Assisting Students Struggling with Mathematics: Response to Intervention (RtI) for Elementary and Middle Schools*; *Reducing Behavior Problems in the Elementary School Classroom*; and *Improving Reading Comprehension in Kindergarten Through 3rd Grade*—being viewed between 30,000 to 50,000 times each.

The investment in resources for IES is small in comparison to the challenging issues that our country faces with respect to quality education and learning. Only the most competitive research, capacity building programs, and data assets are supported by IES, and the yield from IES projects has been high for well more than a decade. Further, IES funding and emphases are a resource for the very concerns that drive this committee and its work. Improving the educational outcomes of our citizens would not only help to solve or prevent future labor and workforce problems but also improve the health and wellbeing of our citizens.

Thank you for the opportunity to submit written testimony in support of \$728 million for the Institute of Education Sciences in fiscal year 2017. AERA welcomes working with you and your subcommittee on strengthening investments in essential research, data, and statistics related to education and learning.

[This statement was submitted by Felice J. Levine, Ph.D., Executive Director, American Educational Research Association.]

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 nearly 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 2017 Labor-HHS 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 (PHS) Act, additional primary care programs under the Health Resources and Services Administration (HRSA), and for aging research within the National Institutes of Health (NIH)/National Institute on Aging (NIA).

We ask that the subcommittee consider the following funding levels for these programs in fiscal year 2017:

- \$45 million for the Geriatrics Workforce Enhancement Program (PHS Act Title VII, Sections 750 and 753(a) and PHS Act Title VIII, Section 865)
- \$9.7 million for additional primary care workforce programs under HRSA
- An increase of \$500 million over the fiscal year 2016 enacted level for aging research across the NIH, in addition to the funding allocated for Alzheimer's disease and related dementias

Sustained and enhanced Federal investments in these initiatives are essential to delivering high quality, better coordinated, and more cost effective care to our Nation's seniors, whose numbers are projected to increase dramatically in the coming years. According to the U.S. Census Bureau, the number of people age 65 and older will more than double between 2010 and 2050 to 88.5 million or 20 percent of the population; and those 85 and older will increase threefold to 19 million. To ensure that our Nation is prepared to meet the unique healthcare needs of this rapidly growing population, we request that Congress provide 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.

PROGRAMS TO TRAIN GERIATRICS HEALTHCARE 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 geriatrics healthcare professionals, who are trained to care for the most complex and frail in-

dividuals 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.

*Geriatrics Workforce Enhancement Program (\$45 million)*

The Geriatrics Workforce Enhancement Program (GWEP) is currently the only Federal program designed to increase the number of providers, in a variety of disciplines, with the skills and training to care for older adults.

In May 2015, HRSA announced 41 three-year grant funded programs that consolidated the Title VIII Comprehensive Geriatric Education Program and the Title VII Geriatric Academic Career Award, Geriatric Education Centers, and Geriatric Training for Physicians, Dentists and Behavioral and Mental Health Providers programs.

This consolidation—a change made by HRSA in December 2014—provides greater flexibility to grant awardees by allowing applicants to develop programs that are responsive to the specific interprofessional geriatrics and training needs of their communities. While the AGS is encouraged by elements of this new approach, we are concerned that there is no longer a sufficient focus on the training and education of health professionals who wish to pursue academic careers in geriatrics or gerontology. The Geriatric Academic Career Award (GACA) program is the only Federal program that is intended to increase the number of faculty with geriatrics expertise in a variety of disciplines. In the past, the number of GACA awardees has ranged from 52 to 88 in a given grant cycle; in the most recent round of GWEP grants, it appears that only a small number of the grantees will be dedicating resources to train faculty in geriatrics and gerontology.

At a time when our Nation is facing a severe shortage of both geriatrics healthcare providers and academics with the expertise to train these providers, the AGS believes the number of educational and training opportunities in geriatrics and gerontology should be expanded, not reduced.

To address this issue, we request additional funding for the Title VII and Title VIII geriatrics professions programs for fiscal year 2017:

—Geriatrics Workforce Enhancement Program (\$45 million)

GWEP seeks to improve high-quality, interprofessional geriatric education and training to the health professions workforce, including geriatrics specialists, as well as increase geriatrics competencies of primary care providers and other health professionals to improve care in medically underserved areas. It supports the development of a healthcare workforce that improves health outcomes for older adults by integrating geriatrics with primary care, maximizing patient and family engagement and transforming the healthcare system. We ask the subcommittee to provide a fiscal year 2017 appropriation of \$45 million for the Geriatrics Workforce Enhancement Program. With more resources available, we also ask for a renewed emphasis to address the severe shortfall of faculty with expertise in geriatrics and gerontology.

*Additional Workforce Programs under the Health Resources and Services Administration (\$9.7 million)*

—National Health Care Workforce Commission (\$3 million)

The National Health Care Workforce Commission was established in the Affordable Care Act to identify barriers to healthcare workforce development and to formulate a national strategy to address the shortage; however, Congress has not provided funding for the Commission to be convened. The AGS believes that the Commission's work—including research on topics such as workforce priorities and goals; current and projected workforce supply; and needs and assessments of current education and training activities—is an important first-step in the effort to bolster the healthcare workforce in order to meet the needs of the burgeoning number of older Americans. We request \$3 million for the Commission so that it can accomplish its essential mission.

—Geriatric Career Incentive Awards Program (\$3.3 million)

Congress authorized this program under the Affordable Care Act to provide financial support to foster greater interest among a variety of health professionals entering the field of geriatrics, long-term care, and chronic care management. Our funding request includes \$3.3 million for this program.

—Training Opportunities for Direct Care Workers (\$3.4 million)

Under the Affordable Care Act, Congress approved a program that will offer advanced training opportunities for direct-care workers. The AGS believes this program should be funded to improve training and enhance the recruitment and



retention of direct care workers, particularly those in long-term care settings. As our population ages, these workers are an integral part of efforts to ensure that older adults have access to high-quality care. We are requesting \$3.4 million for this program.

RESEARCH FUNDING INITIATIVES

*National Institutes of Health (additional \$500 million over fiscal year 2016)*

The institutes that make up the NIH and specifically the NIA lead the national 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—the AGS urges a minimum increase of \$500 million over the enacted fiscal year 2016 level in the fiscal year 2017 budget for biomedical, behavioral, and social sciences aging research efforts across the NIH. The AGS also supports an additional \$400 million for NIH-funded Alzheimer’s disease and related dementias research over the enacted fiscal year 2016 level.

The Federal Government spends a significant and increasing amount of funds on healthcare costs associated with age-related diseases. By 2050, for example, the number of people age 65 and older with Alzheimer’s disease and related dementias is estimated to reach 13.8 million—nearly triple the number in 2016—and is projected to cost more than \$1 trillion. Further, chronic diseases related to aging, such as diabetes, heart disease, and cancer continue to afflict 80 percent of people age 65 and older and account for more than 75 percent of Medicare and other Federal health expenditures. Continued and increased Federal investments in scientific research will ensure that the NIH and NIA have the resources to conduct groundbreaking research related to the aging process, foster the development of research and clinical scientists in aging, provide research resources, and communicate information about aging and advances in research on aging.

Strong support such as yours will help ensure that every older American is able to receive high-quality care.

Thank you for your consideration.

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PREPARED STATEMENT OF THE AMERICAN HEART ASSOCIATION

On behalf of our 30 million volunteers and supporters, the American Heart Association commends Congress for providing a major fiscal year 2016 boost for the National Institutes of Health and for the Centers for Disease Control and Prevention’s heart disease and stroke programs, and for placing an enhanced focus on disease burden. The association strongly believes that fact-based disease burden measures should be a guide when Congress and policymakers allocate research and prevention funding and set program priorities for NIH and CDC for fiscal year 2017.

Measuring how much actual harm and suffering a specific disease exacts upon our society—through numbers of deaths, disability and associated medical costs—is an invaluable tool in making better informed funding decisions. By aligning resources to these analytics, we can have the greatest impact in improving the health and well-being of tens of millions of Americans while reducing healthcare costs.

Sadly, cardiovascular disease (CVD), including heart disease and stroke, rank at the top of the disease burden list. Today, nearly 86 million U.S. adults suffer from some form of CVD and it is projected that by the year 2030, nearly 44 percent of U.S. adults will live with CVD at a cost over \$1 trillion annually. For example, stroke deaths have fallen, but there has been little stroke risk reduction. So, more people are living with permanent cognitive or physical disability post stroke.

Yet inexplicably, research and prevention remain disproportionately underfunded when compared to the crushing burden CVD inflicts upon our Nation’s physical and economic health—one that we all shoulder. Despite a whopping \$30-to-\$1 return on investment, NIH funds a meager 4 percent of its budget on heart research, a mere 1 percent on stroke research, and a scant 2 percent on other CVD research. This glaring disparity must be addressed—and addressed soon—beginning with the fiscal year 2017 appropriations process.

AHA and its millions of volunteers want to work with Congress to protect, preserve, and restore funding for NIH-funded research. We want to build healthier lives free of cardiovascular diseases and stroke. Leveraging disease burden measures is crucial to achieving that goal

## FUNDING RECOMMENDATIONS: INVESTING IN THE HEALTH OF OUR NATION

Despite the very real threat CVD poses to our Nation's health and economy, research that could ultimately develop a cure goes unfunded. Inadequate and unreliable funding are two of the most intractable problems we face. However, the American Heart Association's funding recommendations are both fiscally responsible and reflect the burden CVD imposes.

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

Robust NIH-funded research helps prevent and cure disease, transforms patient care, inspires economic growth, advances innovation, and maintains U.S. leadership in pharmaceuticals and biotechnology. NIH is the world's leader of basic research—the foundation for all medical advances—and an essential Federal Government function the private sector cannot replace. But, our Nation's competitive edge in research has been eroded in recent years by scarce resources.

In addition to improving health, NIH produces a solid return on investment. In 2014, NIH supported more than 400,000 U.S. jobs and over \$58 billion in economic activity. Every \$1 in NIH funding created \$2 in economic activity in 2007. Yet, due to inadequate resources since 2003, NIH has lost more than 19 percent of its purchasing power. Ironically, this decline has occurred at a time of unprecedented scientific opportunity as other countries, like China, wisely increased investment in science—some by double digits. These cuts have disheartened early U.S. career scientists who may decide against pursuing careers in research unless Congress acts.

*American Heart Association Advocates.*—We urge Congress to appropriate \$34.5 billion for NIH to continue to restore its purchasing power and advance cardiovascular disease research.

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

NIH research plays a vital role in cutting CVD death rates. Today, scientists are closer to discoveries that could result in revolutionary treatments and even cures. In addition to saving lives, NIH studies can produce substantial cost savings. For example, investments in the NIH Women's Health Initiative postmenopausal estrogen plus progesterin trial generated an economic return of \$140 for every \$1 invested and led to 76,000 fewer cases of cardiovascular disease. The first NIH tPA drug trial led to a 10-year net \$6.47 billion cut in stroke care costs.

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

Much of the decline in CVD death rates is a result of NHLBI research. However, current funding is not commensurate with CVD disease burden, nor does it allow us to capitalize on investments that have led to major advances. For example, a landmark clinical trial showed setting a systolic blood pressure goal of 120 mm Hg in adults over age 50 cut cardiovascular events (heart attack, heart failure, and stroke) by 25 percent and reduced the risk of death by 27 percent, compared to the standard treatment target of 140 mm Hg.

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

Stroke continues to place an immense burden on our society and economy. An estimated 795,000 Americans will suffer a stroke this year, and nearly 129,000 will die. Many of the 7 million survivors face grave physical, mental, and emotional distress. In addition, stroke costs an estimated \$33 billion in medical expenses and lost productivity each year and a study projects that direct costs of stroke will triple between 2012 and 2030.

NINDS funding must be substantially increased if we are to exploit advances in stroke research, including studies showing that a specific molecule plays a key role in brain repair after stroke. More stroke funding could also boost the NIH Stroke Clinical Trials Network, including early stroke recovery; hasten translation of pre-clinical animal models into clinical studies; prevent vascular cognitive damage; expedite comparative effectiveness research trials; develop imaging biomarkers; refine clot-busting treatments; achieve robust brain protection; and promote the use of neural interface devices. Additional resources are needed to support the BRAIN Initiative.

*American Heart Association Advocates.*—We recommend that NHLBI be funded at \$3.4 billion and NINDS at \$1.8 billion.

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

Prevention is the best way to protect against the ravages of CVD. Yet, proven efforts are not fully executed due to insufficient resources. In addition to funding re-

search and evaluation and developing a surveillance system, the Division for Heart Disease and Stroke Prevention directs Sodium Reduction in Communities and the Paul Coverdell National Acute Stroke programs. DHDSP and the CMS coordinate the Million Hearts™ initiative to prevent 1 million heart attacks and strokes by 2017. DHDSP also runs WISEWOMAN, serving uninsured and under-insured, low-income women ages 40 to 64 through preventive health services, referrals to local healthcare, and tailored lifestyle plans to foster lasting behavioral change.

*American Heart Association Advocates.*—We join the CDC Coalition in asking for \$7.8 billion for the agency. AHA requests \$160.037 million for the DHDSP to intensify work on the State Public Health Actions and on the State and Local Public Health Actions To Prevent Obesity, Diabetes, and Heart Disease, and Stroke; and \$37 million for WISEWOMAN for expansion to additional and currently-funded States. We ask for \$5 million for Million Hearts™ to support enhanced ways to implement ABCS: aspirin when appropriate, blood pressure control, cholesterol management, and smoking cessation; and activities to increase the use of cardiac rehabilitation. Although cardiac rehabilitation can reduce cardiovascular deaths by nearly 30 percent, and re-hospitalizations by more than 30 percent, less than 20 percent of eligible patients participate.

#### CONCLUSION

Cardiovascular disease, including heart disease and stroke, inflicts the highest disease burden on Americans. Our budgetary recommendations for NIH and CDC will save lives and reduce healthcare costs. We respectfully ask Congress to enact our recommendations that are a wise investment for the long-term health and economic well-being of our Nation.

[This statement was submitted by Mark Creager, M.D., President, American Heart Association.]

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#### PREPARED STATEMENT OF THE AMERICAN INDIAN HIGHER EDUCATION CONSORTIUM

This statement includes the fiscal year 2017 requests of the Nation's Tribal Colleges and Universities (TCUs). The following is a summary of our requests including Department, program, and amount requested:

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##### *Department of Education*

###### Office of Postsecondary Education

- HEA Title III–A, Sec. 316: \$60,000,000 (discretionary and mandatory)
- Perkins Career and Technical Education Programs (Sec. 117): \$10,000,000
- Office of Career, Technical, and Adult Education
- American Indian Adult and Basic Education: \$8,000,000, from existing funds

##### *Department of Health And Human Services*

- Administration for Children and Families/Office of Head Start: \$8,000,000, from existing funds
  - Substance Abuse and Mental Health Services Administration (SAMHSA): \$10,000,000
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#### U.S. DEPARTMENT OF EDUCATION

##### *I. Higher Education Act Programs*

- Strengthening Developing Institutions, Title III–A Sec. 316.*—TCUs urge the Subcommittee to restore the discretionary and mandatory funding for HEA Title III–A, Sec. 316 to \$60,000,000 in fiscal year 2017. Titles III and V of the Higher Education Act support institutions that enroll large proportions of financially disadvantaged students. The TCUs, which are truly developing institutions, are funded under Title III–A Sec. 316 and provide quality higher education opportunities to some of the most rural, impoverished, and historically underserved people in the country. In fact, more than 50 percent of our students are first generation. Average family income is \$15,260; local unemployment rates often exceed 50 percent. The goal of HEA-Titles III/V programs is “to improve the academic quality, institutional management and fiscal stability of eligible institutions . . . 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 American Indian students and their communities, to ef-

fectively prepare them to succeed in a globally competitive workforce. Yet, in fiscal year 2011 this program was cut by over 11 percent and received subsequent cuts, including sequestration, until last year. Despite a small increase in fiscal year 2016, TCUs still have not recovered from the earlier cuts to this vitally important program. In fiscal year 2016, the TCU section (Sec.316) was the only Title III/V program that emerged from Conference with a funding level BELOW the level passed by either the House or Senate in their respective appropriations bills.

—*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 were created out of a recognition that college access is not enough to ensure advancement and that multiple factors work to prevent successful completion by many low-income and first-generation students and students with disabilities. In addition to providing the maximum Pell Grant award level, it is critical that Congress sustain and increase support for TRIO programs so that low-income and minority students have the support they need to access and complete postsecondary education programs.

—*Pell Grants*.—The importance of Pell Grants to TCU students cannot be overstated. Eighty-five 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. At TCUs, 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 postsecondary education, an essential step toward becoming active, productive members of the workforce.

## II. Carl D. Perkins Career and Technical Education Programs

—*Tribally Controlled Postsecondary Career and Technical Institutions*.—AIHEC requests \$10,000,000 to fund grants under Sec. 117 of the Perkins Act. 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, which are providing vitally needed workforce development and job creation education and training programs to American Indians and Alaska Natives (AI/ANs) from tribes and communities with some of the highest unemployment rates in the Nation. Jayvion Chee of Rabbitbrush, NM is an example of a young Native student benefiting from this modest program. In March, Jayvion was named as Navajo Technical University's (NTU) Student of the Year. Jayvion spent much of last year working on a geographic information technology (GIT) degree project that assessed the potential impacts on water resources posed by hydraulic fracturing in San Juan County, NM. Jayvion used his education in NTU's Associate of Applied Science-GIT degree program to map current natural gas fracking wells to better understand the potential risks associated with the fracking process. Through his research, he found that 87 documented wells within the San Juan region could possibly lead to adverse impacts on local communities—including the land of which his grandfather resides. He has now presented the results of his research at national STEM and education conferences around the country.

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

## III. Adult Education and Family Literacy Act—Adult Education, Basic Grants to States

—*American Indian Adult and Basic Education*.—AIHEC requests the Subcommittee to direct that \$8,000,000 of the approximately \$582,000,000 appropriated for Adult Education & Literacy State Formula Grants be made available to make competitive awards to TCUs to help meet the growing demand for adult basic education and GED training services in tribal communities. This program, which Congress stopped funding in the mid-1990s, was designed to support much-needed adult basic education (ABE) and GED training for AI/ANs through federally recognized Indian Tribes and TCUs. (A specific Tribal/TCU set-aside within any Federal-to-State block grant program is necessary, because States generally do not provide funding to Indian tribes or TCUs for programs on Federal trust land, even when there is no comparable Federal program for tribes.) In the absence of dedicated funding for American Indians and a severe

constraint on—and in many cases, a complete lack of—funding allocated from State programs to TCUs, our colleges must find a way, often using already insufficient institutional operating funds, to provide ABE and GED classes for AI/ANs that the present K–12 Indian education system has failed. TCUs, like most community colleges, are open door institutions. More than 71 percent of all TCU students need developmental education in at least one subject (math, science, or reading/composition) before beginning college-level coursework and 15 percent of all first-time entering TCU students must first prepare for and pass a high school equivalency test, yet little or no funding is available for these critical programs. Challenges have intensified since the GED test was revamped in January 2014. The new computer-based and more rigorous test has posed difficulties for many TCUs to implement (with little or no funding for staff professional development or technical assistance) and much more difficult for American Indians to pass. One TCU, Oglala Lakota College, reports that prior to the new GED test, an average of 29 students successfully passed the GED test each year and enrolled in the college. Often, these students became some of the OLC's most successful graduates. However, since the new GED was implemented, only seven students passed in 2014 and two in 2015. OLC and all of the TCUs are in critical need of adequate and stable funding to provide rural AI/ANs the preparation and testing they need to move from victims of generational poverty and unemployment to productive and tax-paying members of the U.S. workforce.

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES PROGRAMS

*I. Administration for Children and Families—Office of Head Start*

—*Tribal Colleges and Universities Head Start Partnership Program.*—AIHEC requests that \$8 million of the \$9.6 billion proposed for making payments under the Head Start Act be designated for the TCU-Head Start Partnership program, as reauthorized in PL 110–134, so that TCUs can provide high-quality, culturally appropriate training for teachers and workers in Indian Head Start programs. With the reauthorization of the Head Start program in the mid-1990s, Congress mandated that by 2013, 50 percent of Head Start teachers nationwide must have at least a baccalaureate degree in Early Childhood Education and all teacher assistants must have a child development associate credential or be enrolled in an associate's degree program. Today, 73 percent of Head Start teachers nationwide hold the required bachelor's degree; but only 39 percent of Head Start teachers in Indian Country (Region 11) meet the requirement, and only 38 percent of workers met the associate-level requirements. This disparity in preparation and teaching demands our attention: AI/AN children deserve—and desperately need—qualified teachers. TCUs are ideal catalysts for filling this inexcusable gap. From 2000 to 2007, the U.S. Department of Health and Human Services provided modest funding for the TCU-Head Start Program, which helped TCUs build capacity in early childhood education by providing scholarships and stipends for Indian Head Start teachers and teacher's aides to enroll in TCU early childhood programs. Before the program ended in 2007 (ironically, the same year that Congress specifically authorized the program in the Head Start Act), TCUs had trained more than 400 Head Start workers and teachers, many of whom have since left for higher paying jobs in elementary schools. Today, Tribal Colleges such as Salish Kootenai College in Pablo, Montana are providing culturally based early childhood education free of charge to local Head Start workers. With restoration of this modestly funded program, similar programs could be available to the teachers and aides throughout Indian Country.

*II. Substance Abuse and Mental Health Services Administration (SAMHSA)*

—*New TCU Opioid/Substance Abuse Research and Prevention Program.*—AIHEC requests that as part of the ongoing national opioid/prescription drug initiative, \$10 million be appropriated to establish a Tribal Colleges and Universities Substance Abuse/Behavioral Health Research and Prevention Initiative within SAMHSA to strategically identify and address the drug abuse and behavioral health issues impacting Native youth. The most at-risk population in the United States is American Indian and Alaska Native college-aged youth (ages 15–24). Suicide of friends, classmates, and relatives; alcohol and substance abuse; domestic violence and abuse; bullying and extreme poverty are all too common to Tribal College students. In fact, a seminal behavior health survey

of TCU students,<sup>1</sup> revealed that 50.4 percent of TCU students surveyed reported being physically intimidated, assaulted, or bullied/excessively teased by a peer. Twenty-four percent—one-quarter—reported having used opioids, compared to less than 9 percent of mainstream college students (in a 2013 national survey, which is the only comparable data available). Of the TCU students who had used opioids, 25 percent reported feeling signs of addiction, and nearly 34 percent had taken opioids without a prescription in the last 3 months. AIHEC and partnering entities are on the leading edge nationally in collecting data of this type due in large part to modest grants from the under-funded “Native American Research Centers on Health” program operated by the National Institutes of Health and the Indian Health Service (and in need of increased funding). Data of this type has never been collected nationally among college students, but the TCUs know that we must get a handle on this problem before it spirals out of control. Without serious, sustained, and community-based intervention, it will rapidly spiral out of control. Already, the death rates among American Indians from heroin overdose has increased 236 percent between 2010 and 2014. The Centers for Disease Control and Prevention (CDC) reported that in 2014, American Indians were dying at double or triple the rates of African-Americans and Latinos from opioid, including heroin, addiction.

“Administrators at Fort Peck Community College estimate that our decreasing enrollment of degree seeking students is attributed to the increasing number of community members who are addicted to meth, heroin and prescription drugs,” stated Fort Peck Community College (Poplar, MT) president, Haven Gourneau. “[N]o one wants to be an addict, and if asked every addict would willingly take a ‘magic’ pill that would cure them if they could. With that said, we know there is no ‘magic’ pill and so we will continue to see a decline in our community socially and economically unless we can beat addictions that are sucking the life out of our communities.”

As engaged, place-based institutions, Tribal Colleges are committed to addressing the many challenges facing our communities, including the growing opioid epidemic. TCUs are leading the way through student-based participatory research to identify the specific needs of tribal communities (youth and students), so that community-relevant solutions can be identified and culturally adapted, tested, and then shared with others. SAMHSA, which has modest tribal drug abuse prevention programs and an ongoing effort with Historically Black Colleges and Universities, seems an appropriate agency to administer a TCU Behavioral Health Research and Prevention Initiative to assist TCUs, working with local communities and researchers, in taking strategic steps to identify the behavioral health challenges, develop or adapt innovative and community-practiced intervention strategies, forge relationships with local and regional non-profit providers, and create and test models that can be replicated and adapted at other TCUs and tribal communities. This targeted approach will help ensure that tribal youth have the same chance as others to become healthy, productive adults who will greatly benefit their local communities and the Nation as a whole.

We respectfully request that the Members of the Subcommittee recognize the significant contribution of the Tribal Colleges and Universities to our students, their communities, and the Nation as a whole by continuing and expanding the Federal investment our institutions and careful consideration our fiscal year 2017 appropriations needs and requests.

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#### PREPARED STATEMENT OF THE AMERICAN LIBRARY ASSOCIATION

The American Library Association (ALA) is the oldest and largest library association in the world, with more than 58,000 members in academic, public, school, government, and special libraries. Our mission is to provide leadership for the development, promotion and improvement of library and information services and the profession of librarianship in order to enhance learning and ensure access to information for all. On behalf of ALA, I want to thank the Labor, Health and Human Services, Education, and Related Agencies Subcommittee for the opportunity to provide comments in support of two important, long-standing, cost-effective and highly successful programs that assist and empower students, families, businesses, veterans, families with differently-abled members, and many others.

<sup>1</sup>TCU-CCC Baseline Survey Conducted in 22 TCUs Nationally between March 2015 and Feb 2016. Preliminary Data. This research is supported by grants from the NIAAA, 1R01AA022068 and the NIMHD, 5P60-MD006909 through the National Institutes of Health.

Specifically, we urge the Subcommittee to include in its appropriations bill \$186.6 million for the Library Services and Technology Act (LSTA) under the Institute of Museum and Library Services (IMLS) and \$27 million for the Innovative Approaches to Literacy (IAL) program under the Department of Education (DOE). Both LSTA and IAL are authorized by Congress. Below are just a few examples, among hundreds, of the profound, day-to-day impact that Congress' modest but essential investment LSTA produces for Americans everywhere every day:

- One of the most fundamental roles of the public library is to help young children become future readers. To aid in this effort, the Missouri State Library leveraged its LSTA grant to embark on a statewide initiative called Racing to Read. The Racing to Read program, developed by the Springfield-Greene Public Library in Springfield features fun activities that help children get ready to learn to read by focusing on five basic skills: telling stories, talking and reading, singing and rhyming, playing with letters, and loving books. These activities are easily incorporated into a library's preschool story times, and are shared with parents and caregivers for use at home, at day care centers and with partner agencies.
- When returning soldiers in Modesto, CA, needed help readjusting to [re-entering] the civilian world, the Stanislaus Public Library was able to step in and provide the transitional assistance they needed. The library used its LSTA grant to create a program educating veterans about the array of services and benefits available to them and their families. The library also has assisted vets with their online education and employment needs. The Stanislaus Public Library is one of 38 California public libraries offering a Veterans Resource Center, all of them made possible in part by LSTA funding.
- New businesses in Kings Mountain, NC struggled to survive yet were closing at a high rate. Local businesses in this rural community needed resources to more effectively compete. The Mauney Memorial Library used its LSTA grant to create the Downtown Kings Mountain Small Business Success Project, hiring a business librarian all of whose time was dedicated to assisting local businesses in development of a successful 21st century market online presence. The Success Project's business librarian worked with businesses on learning to: develop business plans, manage social media, analyze marketing and other data, conduct market research, plan more effectively, and to improve safety and security audits. The librarian also helped individual businesses to develop professional caliber websites.

Without LSTA funding, these and many other specialized programs targeted to the needs of their communities across the country likely will be entirely eliminated, not merely scaled back. In most instances, LSTA funding (and its required but smaller State match) allows libraries to create new programs for their patrons, like those described above. Without LSTA underwriting, however, tight State and local budgets mean that libraries simply will not have the resources to institute and keep these programs, which are so valuable to so many Americans.

The beneficiaries of the many services that libraries offer are by no means limited, however, to the targeted participants in special programs like the ones just described, Mr. Chairman. Rather, America's nearly 17,000 public libraries serve an astonishing 4 million people daily in communities of every size and in every corner of the country. In addition to the kinds of veterans outreach and business-building assistance described above, libraries routinely also offer Americans from every walk of life ready and free access to all types of information, career and workforce skills training, digital and print literacy instruction, job searching databases, resume workshops, summer reading projects, creative programming for children, best practices training for local librarians, access to teleconferencing facilities, and 3D printers, and so much more. Indeed, according to an ALA report, more than 92 percent of public libraries offer services that help patrons complete job applications, create resumes, and access job databases and research. Libraries also provide resources and specialized collections for small businesses, which help them create business plans, develop new growth strategies, and research target markets.

Perhaps most critically, however, every day thousands of libraries across the country also provide no-fee public access to computers and the Internet in some of our most distressed communities, both rural and urban. For the approximately 19 million Americans who cannot afford broadband at home, or who live in rural areas where the infrastructure does not support home broadband, libraries are an indispensable access point to the Internet. According to a recent ALA report, 65 percent of all libraries nationwide are the only provider of free Internet access in their communities. In rural areas, public libraries are even more critical, with 73 percent serving as their community's only free Internet provider. Increasingly, the Internet is the only means by which an individual can research job opportunities, take their

GED, apply for a job, or submit government forms, such as tax filings or benefit claims. Many individuals could not even submit comments to this Subcommittee without access to broadband at their local library. LSTA funding often is what makes these services possible.<sup>1</sup>

The bulk of LSTA funds are distributed to each State through IMLS according to a population-based grant formula. Each State must match the Federal funds received and determines for itself how to best allocate its LSTA awards. As the examples above merely hint at, libraries have used LSTA funding myriad diverse and innovative programs that profoundly touch and better the lives of tens of millions of Americans in every State in the Nation. LSTA is truly a local decisionmaking success story.

During this time of increased and increasing demand, many libraries are under severe budget pressure. The support they receive through the LSTA, the primary source of annual funding for libraries in the Federal budget, is thus critical to meeting the needs of Americans everywhere and, in so doing, building our economy one job and one community at a time.

Accordingly, Mr. Chairman, ALA asks that you and the Committee provide \$186.6 million for LSTA in fiscal year 2017 to ensure that Americans of all ages continue to have access to the life-sustaining, -affirming and -expanding resources that their trusted local libraries provide. ALA respectfully submits, Mr. Chairman, that there can be few, if any, more democratic, cost-effective and impactful uses of Federal dollars than LSTA in the entirety of the Federal budget.

Libraries, of course, also have tremendous impact upon the Nation's children, especially our most needy, opening their eyes and minds to books and information of all kinds that help them gain and enhance literacy skills. Surveys show that many of our Nation's children living in poverty have no books at home. These children depend on their local libraries' story-time and summer reading programs to help them prepare to learn in school and to succeed.

In addition to supporting LSTA, ALA also asks that you maintain fiscal year 2016's modest, but critical, Federal investment of \$27 million in the Innovative Approaches to Literacy (IAL) program. IAL provides competitive awards to school libraries and national not-for-profit organizations (including partnerships that reach families outside of local educational agencies) to put books into the hands of children and their families in high-need communities. Providing books and childhood literacy activities to such children is crucial to their learning to read, which is crucial to their—and the Nation's—economic futures. The program also supports parental engagement in their children's reading life, and focuses on promoting student literacy from birth through high school. IAL was authorized under the Every Student Succeeds Act of 2015.

Congress first recognized the importance of this program in fiscal year 2012 when \$28.6 million was appropriated for early literacy support. In 2012, the U.S. Department of Education awarded 2-year IAL grants to 46 nonprofit organizations and school districts in 21 States and the District of Columbia. In 2014, the Department made 32 new awards to national non-profits and school libraries. As with LSTA funds, school libraries and others are doing remarkable, valuable work with IAL support, as these brief examples reveal:

—The Waukegan Community Unit School District in Illinois sought to improve literacy achievement in this lower income community with a high percentage of families where English is the second language. The school's library used an IAL grant to implement its "Ladders to Literacy" program, and innovative print and e-book based curriculum that also provided targeted literacy coaching and development for teachers. It measurably succeeded in improving participants' reading achievement.

—In the Milwaukee Public Schools, an IAL grant supported a project by its Focus on Literacy Foundation (nicknamed "FLF"). FLF sought to improve kindergarten through 4th grade literacy through innovative uses of technology, encouraging family reading-involvement opportunities, and the distribution of books to students with which they could expand their own home libraries. FLF was implemented at four low-achieving schools serving economically disadvantaged children who often had no books at home at all.

Studies show that strong literacy skills and year-round access to books is a critical first-step towards literacy and life-long learning. For American families living in

<sup>1</sup> LSTA also funds: the Native American and Native Hawaiian Library Services program to support improved access to library services for those populations; National Leadership Grants to support activities of national significance that enhance the quality of library services nationwide, and provide pilots for coordination between libraries; and the Laura Bush 21st Century Librarians program, used to help develop and promote the next generation of librarians.



poverty, access to reading materials is severely limited. These children have fewer books in their homes than their peers, which hinders their ability to prepare for school and to stay on track.

Congress has taken an important step in supporting the needs of disadvantaged students by providing IAL funding for book distribution, early literacy services, and effective school library programs. We urge the Subcommittee and full Committee to continue this important work by maintaining a \$27 million investment in IAL in the fiscal year 2017 Labor, Health and Human Services, Education, and Related Agencies bill.

ALA urges and appreciates the Subcommittee's continued strong support of LSTA and IAL, Mr. Chairman. Thank you for your commitment to sustaining and strengthening our communities and our Nation by sustaining and strengthening America's libraries.

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#### PREPARED STATEMENT OF THE AMERICAN LUNG ASSOCIATION

The American Lung Association was founded in 1904 to fight tuberculosis and is one of the oldest voluntary health organization in the United States. Since the beginning, the organization has been on the front lines advocating for laws that protect the air we breathe and our lungs. Accordingly, the Lung Association is the leading organization working to save lives by improving lung health and preventing lung disease through education, advocacy and research. As the result of funding from this Committee, public health and research programs will help to work to prevent lung disease, improve health and, by extension save lives of millions of Americans.

#### IMPROVING PUBLIC HEALTH AND MAINTAINING OUR INVESTMENT IN MEDICAL RESEARCH

The American Lung Association strongly supports an increase in funding to \$34.5 billion for the National Institute of Health (NIH). We need sustained and robust investments for NIH so that the promise of biomedical research can be achieved. While our focus is on lung disease research, we support robust, sustained and predictable investments in research funding across the entire NIH with particular emphasis on the National Cancer Institute, the National Heart, Lung and Blood Institute, the National Institute of Allergy and Infectious Diseases, the National Institute of Environmental Health Sciences, the National Institute of Nursing Research, the National Institute on Minority Health & Health Disparities, the National Institute on Drug Abuse and the Fogarty International Center.

#### LUNG DISEASE

Lung disease is the third highest killer in America. It takes the lives of almost 419,000 Americans each year, and is responsible for one in every six deaths. It has been estimated that more than 33 million Americans suffer from a chronic lung disease and lung disease costs the economy \$129 billion each year.

#### THE PREVENTION AND PUBLIC HEALTH FUND

The Lung Association strongly supports the Prevention and Public Health Fund that was established in the Affordable Care Act. We ask the Committee to oppose any attempts to divert or use the Fund for any purposes other than what it was originally intended. The Prevention Fund provides funding to the Centers for Disease Control and Prevention (CDC) and its critical public health initiatives, such as the necessary community programs that provide resources for those who want to quit smoking, support groups for lung cancer patients, and classes that educate people on ways to avoid asthma attacks. The Prevention Fund also supports CDC's media campaign "Tips from Former Smokers."

#### LUNG CANCER

Lung cancer is the number one cancer killer of both women and men. It is estimated that 224,390 new cases of lung cancer will be diagnosed in 2016, and over 156,000 Americans will die from the disease—85,710 in men and 70,542 in women. Survival rates for lung cancer tend to be lower than those of leading cancers, due to the lack of early detection and diagnosis. African Americans are more likely to die from lung cancer than persons of any other racial group.

Personalized and targeted therapies hold tremendous potential in the fight against lung cancer. As the result of previous investments in biomedical research, in 2015, the Food and Drug Administration approved seven new medications for patients with metastatic lung cancer. The American Lung Association thanks the

Committee for its 5 percent increase in funding for NIH, including funds for the President's Precision Medicine Initiative with its ALCHEMIST and Lung-MAP trials that target lung cancer. We ask the Committee to continue to build on this momentum by increasing funding for the National Institutes of Health to \$34.5 billion in fiscal year 2017.

#### TOBACCO USE

The use of tobacco is the number one preventable cause of death in the United States. It kills approximately half a million people every year. 40 million American adults smoke and 4.7 million children use tobacco products. Annual healthcare and lost productivity costs total \$332 billion in the U.S. each year. Each day, over 2,500 kids under 18 years of age try their first cigarette and close to 600 kids become new, regular daily smokers.

The CDC Office on Smoking and Health (OSH) must continue to receive robust funding to help combat the tobacco-caused diseases that are burdening the Nation. Public health interventions have been scientifically proven to reduce tobacco use, the leading cause of preventable death in the United States. The American Lung Association urges that \$220 million be appropriated to OSH for fiscal year 2017.

The American Lung Association respectfully requests the Committee's support for the Office of Smoking and Health and the "Tips from Former Smokers" Campaign. Over the past 5 years, hundreds of thousands of Americans have successfully quit smoking because of "Tips" and millions more have made quit attempts. The "Tips" campaign has been an incredible return on investment that continues to generate positive outcomes. An accepted threshold for cost-effective public health interventions is approximately \$50,000. The 2012 Tips campaign spent \$480 per smoker who quit and \$393 per year of life saved.

#### ASTHMA

Twenty-four million Americans have asthma, including 6.3 million children. It is highly prevalent and a costly disease. The Nation is making progress to combat against asthma but this advancement can only continue with sustained investment. Asthma prevalence rates are over 45 percent higher among African Americans than whites. Asthma costs our healthcare system over \$50.1 billion annually and indirect costs from lost productivity add another \$5.9 billion, for a total of \$56 billion dollars annually.

The American Lung Association thanks the Committee for its increase in fiscal year 2016 and asks to appropriate \$30.596 million to the CDC's National Asthma Control Program (NACP) in fiscal year 2017. The NACP tracks asthma prevalence, promotes asthma control and prevention and builds capacity in State programs. This program has been highly effective: the rate of asthma has increased, yet asthma mortality and morbidity rates have decreased. Currently, only 23 States receive funding—leaving a nationwide public health void that can lead to unnecessary asthma-related attacks and healthcare costs. Increased funding could help develop asthma programs in the remaining 27 States and the District of Columbia.

Additionally, we recognize the importance of a robust and sustained increases for the National Heart, Lung and Blood Institute and National Institute of Allergy and Infectious Diseases. With increased support, both agencies will be able to continue their investments in asthma research in pursuit of treatments and cures.

#### CHRONIC OBSTRUCTIVE PULMONARY DISEASE

COPD (Chronic Obstructive Pulmonary Disease) is the third leading cause of death in the U.S. More than 24 million U.S. adults had evidence of impaired lung function, indicating an under diagnosis of COPD. In 2013, 145,575 people in the U.S. died of COPD, representing one COPD death every 4 minutes. The American Lung Association also asks the Committee to continue its support of the National Heart, Lung and Blood Institute working with the CDC and other appropriate agencies to act on its national action plan to address COPD, which should include public awareness and surveillance activities. The American Lung Association requests sustained and robust funding for the National Heart, Lung and Blood Institute.

#### PNEUMONIA AND INFLUENZA

In 2013, there were a combined 56,979 deaths due to pneumonia and influenza combined. While other infectious diseases may receive much more public attention, a moderate flu epidemic could result in hundreds of thousands of deaths in the U.S. To prepare for a potential pandemic, the American Lung Association supports funding the Federal CDC Influenza efforts of at least \$187.558 million.

## TUBERCULOSIS

TB (Tuberculosis), an airborne infectious disease, is now the leading global infectious killer, ahead of HIV/AIDS, causing 1.5 million deaths annually. In the U.S., every State reports cases of TB annually, with California, Texas, Hawaii and Alaska having the highest burdens. TB outbreaks continue to occur across the country in schools, workplaces and prisons.

Drug resistant TB poses a particular challenge to 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 per case and can be over \$1 million for treatment of extensively drug resistant (XDR) TB, which can outstrip State and local public health department budgets. The U.S. had 17 cases of extensively XDR- TB between 2008 and 2015.

Funding for CDC's national TB program has been cut back to the fiscal year 2005 level. We are deeply concerned that this funding level is eroding State TB programs and leaving communities vulnerable to TB, including drug resistant TB. We request that Congress increase funding for tuberculosis programs at CDC to \$243 million for fiscal year 2017.

## IMPACT OF CLIMATE CHANGE ON LUNG HEALTH

CDC's Climate and Health Program is the only HHS program devoted to identifying the risks and develop effective responses to the health impacts of climate change, including worsening air pollution; diseases that emerge in new areas; stronger and longer heat waves; more frequent and severe droughts, and provides guidance to States in adaptation. Pilot projects in 16 States and two city health departments use CDC's Building Resilience Against Climate Effects (BRACE) framework to develop and implement health adaptation plans and address gaps in critical public health functions and services. As climate-related challenges intensify, CDC must have increased resources to support States and cities in meeting the challenge. The Lung Association supports \$10 million for the Center for Disease Control and Prevention's Climate and Health Program.

## CONCLUSION

Lung disease remains a growing problem in the United States and is leading the Nation as the third highest killer. There has been advancements in technology and medications, however, progress against lung disease has been overshadowed by developments against other major causes of death in the U.S. Significant strides must be taken to combat the lung disease. The level of support this committee approves for lung disease programs should be reflective of the urgency and magnitude that lung disease has had on Americans.

The American Lung Association respectfully requests that the Committee supports funding requests and strongly encourages you to oppose all policy riders on appropriations bills. The Lung Association is appreciative of your support and we thank you for your consideration of our recommendations.

[This statement was submitted by Harold Wimmer, National President and CEO, American Lung Association.]

## PREPARED STATEMENT OF THE AMERICAN MOSQUITO CONTROL ASSOCIATION

Chairman Blunt, Ranking Member Murray, and members of the Subcommittee, thank you for your continued leadership and support for mosquito control.

The American Mosquito Control Association (AMCA) appreciates this opportunity to submit our views regarding the fiscal year 2017 Labor, Health and Human Services, and Education, and Related Agencies appropriations bill, and respectfully requests this statement be made part of the official hearing record. AMCA is a non-profit organization of 1600 members dedicated to enhancing health and quality of life through the suppression of mosquitoes and other vectors of public health importance.

With the emergence and spread of the Zika virus in the western hemisphere on the heels of diseases such as dengue, West Nile and chikungunya, it would appear prudent to increase a sustainable nationwide capacity for the surveillance and control of their mosquito vectors. In the absence of vaccines for these diseases, vector control remains the first line of defense. To increase that defense, we ask for your consideration and favorable support for the following appropriations recommendations:

Increase the Centers for Disease Control (CDC)—Division of Vector-Borne Diseases (DVBD) annual budget for arbovirus work from its current level of about \$26.8 million/year to at least \$50 million/year. Of this overall sum, it would be beneficial to ensure that substantial sums are dedicated to on-the-ground activities. AMCA suggests the Committee provide direction in the following manner:

- \$13.75 million for State, county or municipal public health agencies or labs to help support arbovirus testing and reporting.
- \$13.75 million for State, county, district or municipal mosquito control programs to help support mosquito control-related work on the frontlines.
- \$22.5 million (or 45 percent of the total) will be kept by the CDC/DVBD to help support myriad arbovirus-related programs and activities at the Federal level.

The Epidemiology and Laboratory Capacity (ELC) grant program provides local health jurisdictions with personnel, equipment and resources to detect and respond to mosquito transmitted diseases, but the program in its current state is insufficient to prevent the spread of the Zika virus.

Funding for the Mosquito Abatement for Safety and Health Act (MASH) of at least \$100,000,000:

- The Mosquito Abatement for Safety and Health (MASH) Act was designed to support local government mosquito control activities and was originally passed during the first West Nile Virus outbreak. This bill authorized Federal funds for local governments to protect our communities from mosquitoes and other disease vectors. Local program funds were to be matched by Federal funding by a ratio of at least 1 to 3 and additional funding was to be for each State to monitor the local program funding. But by the time the MASH Act was signed into law no funds were ever appropriated. Today we face another imminent outbreak of a disease for which mosquito control is the only viable solution. Fortunately, Congress has the means readily at hand to help prevent or minimize the risk, if it chooses to devote dollars to the existing authority.

Funding for data collection efforts to support the vector control toolbox: At least \$27,000,000:

- At least \$12,000,000 to bolster the Food Quality Protection Act of 1996 (FQPA) that helps retain registrations of existing public health pesticides facing increasingly stringent data collection requirements to prove safety to humans and the environment.
- At least \$15,000,000 to support the development and registration of new vector control tools effective against *Aedes aegypti* and *Aedes albopictus*.

In 1996 Congress unanimously approved FQPA (PL 104–170) to modernize the regulation of pesticides and expand data requirements to demonstrate their safety to people and the environment. A key element was authorization to use Federal funds when the cost of new data for public health pesticides—those for mosquitoes and similar disease vectors—was more than their producers could afford, putting registration at risk. Unfortunately, these essential funds have never been appropriated.

Given the Federal commitment to ensuring the health of Americans, we believe these small preventative investments are vastly preferable to the enormous healthcare costs required after large mosquito-borne disease outbreaks. Establishing sustainable training research and suppression programs for vector-borne disease surveillance and control will ensure a robust capacity to mitigate the impacts of not only the current Zika threat but also dangerous exotic viruses yet to reach our shores.

AMCA thanks you in advance for considering these critical proposals and we urge their inclusion in the pending appropriations process. We sincerely appreciate the opportunity to share our views on these important public health matters.

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PREPARED STATEMENT OF THE AMERICAN NATIONAL RED CROSS

Chairman Roy Blunt, Ranking Member Patty Murray, and Members of the Subcommittee, the American Red Cross and the United Nations Foundation appreciate the opportunity to submit testimony in support of measles control activities of the U.S. Centers for Disease Control and Prevention (CDC). The American Red Cross and the United Nations Foundation recognize the leadership that Congress has shown in funding CDC for these essential activities. For fiscal year 2017, we request that this subcommittee support CDC's global measles control activities at \$50 million.

In 2001, CDC—along with the American Red Cross, the United Nations Foundation, the World Health Organization (WHO), and UNICEF—founded the Measles Initiative, a partnership committed to reducing measles deaths globally. In 2012, the Initiative expanded to include rubella control and adopted a new name, the Measles & Rubella Initiative. In 2013, all WHO regions established measles elimination goals by 2020. The Measles & Rubella Initiative is committed to reaching these goals by providing technical and financial support to governments and communities worldwide.

The Measles & Rubella Initiative has achieved impressive results by supporting the vaccination of more than 2 billion children since 2001. In part due to the Measles & Rubella Initiative, global measles mortality dropped 79 percent, from an estimated 548,000 deaths in 2000 to 114,900 in 2014 (the latest year for which data is available). During this same period, measles deaths in Africa fell by 88 percent. However, about 315 children still die from measles each day from a virus that can be countered with a safe, effective and inexpensive vaccine. Measles is among the most contagious diseases ever known, and a top killer of children in low-income countries where children have little or no access to medical treatment and are often malnourished. Measles spreads much more easily than the flu or the Ebola virus. In fact, one person infected with measles can infect up to 18 others if s/he has not been vaccinated. In addition, each year more than 100,000 children are born with congenital rubella syndrome (CRS). CRS can cause severe birth defects, including blindness, deafness, heart defects and mental retardation. CRS treatment is very costly to treat, yet very inexpensive to prevent.

Working closely with host governments, the Measles & Rubella Initiative has been the main international supporter of mass measles immunization campaigns since 2001. The Initiative mobilized more than \$1.3 billion and provided technical support in more than 88 developing countries on vaccination campaigns, surveillance and improving routine immunization services. From 2000 to 2014, an estimated 17.1 million measles deaths were averted as a result of these accelerated measles control activities, making measles mortality reduction one of the most cost-effective public health interventions.

The majority of measles vaccination campaigns have been able to reach more than 90 percent of their target populations. Countries recognize the opportunity that measles vaccination campaigns provide in accessing mothers and young children, and “integrating” the campaigns with other life-saving health interventions has become the norm. In addition to measles vaccine, other health interventions are often distributed during campaigns including vitamin A which is crucial for preventing blindness in under nourished children, de-worming medicine to reduce malnutrition, and screening for malnutrition. Doses of oral polio vaccines are also frequently distributed during measles campaigns in polio endemic and high-risk countries. The delivery of polio vaccines in conjunction with measles vaccines in these campaigns strengthens the reach of elimination and eradication efforts of these diseases. The delivery of multiple child health interventions during a single campaign is far less expensive than delivering the interventions separately, and this strategy increases the potential positive impact on children’s health from a single campaign.

The extraordinary reduction in global measles deaths greatly contributed to reducing under-five child mortality. However, large outbreaks in several African, European and Asian countries from 2011 to 2014 compromised 2015 measles elimination goals of 90 percent national coverage rates and 95 percent reduction in mortality, resulting in a plateau in progress towards measles elimination due in large part to decreased funding support from donors and host governments. These outbreaks highlight the fragility of the last decade of progress. If mass immunization campaigns are not continued with robust funding and support, measles deaths will rapidly increase.

In addition to the lifesaving benefits of measles vaccines, immunization makes sound economic sense. A recent study by Johns Hopkins University revealed the economic benefits of increased investment in global vaccination programs. The study compared the costs for vaccinating against 10 disease antigens in 94 low- and middle-income countries during the period 2011–2020 versus the costs for estimated treatments of unimmunized individuals during the same period. Their findings show that—across the board—prevention of diseases results in an average return on investment, with \$58 saved in future costs for every \$1 spent.

To achieve 2020 elimination goals and avoid a resurgence of measles, the following actions are required:

- Sustaining the gains in reduced measles deaths, especially in Africa, by strengthening immunization programs to ensure that more than 90 percent of infants are vaccinated against measles through routine health services as well as conducting timely, high quality mass immunization campaigns. Routine im-

munization is the foundation to achieving and sustaining high levels of immunity to measles in the community.

- Accelerating the introduction of a second dose of measles containing vaccine into the routine immunization program of eligible countries with support from Gavi, the Vaccine Alliance.
- Fully implementing activities, both campaigns and strengthening routine measles vaccination coverage, in Democratic Republic of Congo, Ethiopia, India, Indonesia, Nigeria, and Pakistan which together account for the majority of measles cases and 65 percent of measles deaths.
- Securing sufficient funding for measles and rubella-control activities both globally and nationally. This year the Measles & Rubella Initiative faces a funding shortfall of an estimated U.S. \$73 million. Implementation of timely measles campaigns is increasingly dependent upon countries funding these activities locally. The decrease in donor funds available at a global level to support measles elimination activities makes increased political commitment and country ownership of the activities critical for achieving and sustaining the goal of reducing measles mortality by 95 percent.

If these challenges are not addressed, the remarkable gains made since 2000 will be lost and a major resurgence in measles deaths will occur.

By controlling measles and rubella cases in other countries, U.S. adults and children are also being protected from the diseases. Measles can cause severe complications such as pneumonia, encephalitis, and even death. A resurgence of measles occurred in the United States between 1989 and 1991, with more than 55,000 cases reported. This resurgence was particularly severe, accounting for more than 11,000 hospitalizations and 123 deaths.

Measles is one of the most contagious diseases known to humans and, due to our highly interconnected world, measles can be spread globally including to countries that have already eliminated the disease. The threat of importation of measles was one of the reasons that the Global Health Security Agenda has selected measles as an important indicator. The occurrence of measles cases in a country is a reliable indication that a country's routine immunization system is not vaccinating all children. Additionally, the ability of a country to rapidly detect and respond to measles cases is a marker of the quality of a routine immunization system to identify and respond to disease outbreaks more generally.

In the United States, measles control measures have been strengthened, and endemic transmission of measles cases have been eliminated since 2000 and rubella in 2002. However, importations of measles cases into this country continue to occur each year. Since 2000, the annual number of people reported to have measles ranged from a low of 37 in 2004 to a high of 667 people across 27 States in 2014; the greatest number of cases reported in the U.S. since measles was declared eliminated in 2000. Additionally, on July 2, 2015, Washington State Department of Health confirmed a measles-related death. The human and financial impact of measles cases, deaths, and outbreaks are substantial, both in terms of the costs to public health departments to conduct contact tracing and in terms of productivity losses among people with measles and parents of sick children. Studies show that a single case of measles in the United States can cost between \$100,000 and \$200,000 in government expenditures to control.

#### THE ROLE OF CDC IN GLOBAL MEASLES MORTALITY REDUCTION

Since fiscal year 2001 and until 2015, Congress has provided funding for the purchase of measles vaccine for use in large-scale measles vaccination campaigns in more than 88 countries in Africa and Asia, and for the provision of technical support to Ministries of Health. Specifically, this technical support includes:

- Planning, monitoring, and evaluating large-scale measles vaccination campaigns;
- Conducting epidemiological investigations and laboratory surveillance of measles outbreaks; and
- Conducting operations research to guide cost-effective and high quality measles control programs.

In addition, CDC epidemiologists and public health specialists have worked closely with WHO, UNICEF, the United Nations Foundation, and the American Red Cross to strengthen measles control programs at global and regional levels, and will continue to work with these and other partners in implementing and strengthening rubella control programs. While it is not possible to precisely quantify the impact of CDC's financial and technical support to the Measles & Rubella Initiative, there is no doubt that CDC's support—made possible by the funding appropriated by Con-

gress—was essential in helping achieve the sharp reduction in measles deaths in just 13 years.

The American Red Cross and the United Nations Foundation would like to acknowledge the leadership and work provided by CDC and recognize that CDC brings much more to the table than just financial resources. The Measles & Rubella Initiative is fortunate to have a partner that provides critical personnel and technical support for vaccination campaigns and in response to disease outbreaks. CDC personnel have routinely demonstrated their ability to work well with other organizations and provide solutions to complex problems that help critical work get done faster and more efficiently.

In fiscal year 2015, Congress appropriated \$49.8 million to fund CDC global measles control activities, and \$50 million in fiscal year 2016 for such activities. In fiscal year 2017, the American Red Cross and the United Nations Foundation request sustained funding at the level approved by this committee last year for CDC's measles and rubella control activities to protect the investment of the last decade, prevent measles cases and deaths in the United States. We hope this committee will also look at how we can address the shortfall in funding within the Measles and Rubella Initiative in future years.

Your commitment has brought us unprecedented victories in reducing measles mortality around the world. In addition, your continued support for this initiative helps prevent children from suffering from this preventable disease both abroad and in the United States.

Thank you for the opportunity to submit testimony.

[This statement was submitted by Harold Brooks, Senior Vice President of International Operations, American National Red Cross, and Kathy Calvin, President, United Nations Foundation.]

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#### 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). The \$2 billion funding boost you provided in fiscal year 2016 provided a much needed restoration of resources at a critical time, but great challenges are still before us. In order to continue meeting those challenges, the APS urges you to make every effort to provide the NIH with at least \$35 billion in fiscal year 2017.

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. Moreover, the Federal Government is the primary funding source for discovery research through competitive grants awarded by the NIH. The private sector may develop new treatments, but it 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 because other nations have been increasing their investments in research and development while the United States investment has been stagnant.

Federal research dollars also have a significant impact at the local level: Approximately 84 percent of the NIH budget is awarded throughout the country to some 35,000 researchers. They in turn use these grant funds to pay research and administrative staff, purchase supplies and equipment, and cover other costs associated with their research.

The \$2 billion increase provided for fiscal year 2016 was an important first step toward correcting the effects of sequestration and several years of declining budgets at the NIH. To set the agency on a more sustainable path forward, we urge you to provide predictable annual budget increases that will allow the scientific enterprise to keep up with the rate of inflation and move in new directions.

The fiscal year 2017 budget request for the NIH highlights important initiatives for the agency, including the National Cancer Moonshot, the Precision Medicine Initiative and the Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative. These initiatives will focus resources on critical areas of scientific opportunity that are ripe for innovation, but it is important to bear in mind that these projects are only possible because of decades of basic research. NIH must continue to invest in creative investigator-initiated research to advance our knowledge and create future opportunities for innovation.

Over the past several decades, NIH has used a merit-based peer review system to identify and fund the best research proposals. As a result, Americans can expect to live longer and healthier lives. However, significant challenges still loom for our Nation: Researchers are already working to understand emerging diseases such as

the Zika virus; learning how it spreads, what effects it has on people who become infected, and what sort of threat it poses in the United States. An aging population will continue to strain an already stressed system of healthcare in the U.S. As the baby boom generation continues to age, we can expect to see increases in diseases that affect an aging population including diabetes, heart disease, and cancer. Developing better ways to detect and treat these diseases will reduce disease burden and ultimately help manage the strain that will be placed on the American healthcare system. To continue to be able to address these and other challenges, the NIH needs additional resources.

This year the NIH issued the agency's first ever NIH-wide Strategic Plan.<sup>1</sup> This document lays out NIH's plans to address the needs of the Nation while maximizing scientific opportunity and supporting the biomedical research enterprise. Implementing the plan will require predictable, sustainable funding increases over the next several years. The APS joins the Federation of American Societies for Experimental Biology (FASEB) in urging that NIH be provided with no less than \$35 billion in fiscal year 2017.

The American Physiological Society 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.

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

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#### 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 over 123,000 researchers, educators, clinicians, consultants and students. Many programs in the Labor-HHS-Education bill impact science, education, and the populations served by clinical psychologists.

#### DEPARTMENT OF HEALTH AND HUMAN SERVICES

*National Institutes of Health (NIH).*—APA thanks this subcommittee for its leadership in securing \$32.1 billion for NIH in the fiscal year 2016 omnibus spending bill. As a member of the Ad Hoc Group for Medical Research, APA requests \$34.5 billion for NIH in fiscal year 2017. If this Nation is to continue to accelerate the development of life-changing cures, pioneering treatments, and innovative prevention strategies, it is essential to sustain predictable increases in the NIH budget. Psychological scientists are supported by research grants or training programs in almost all of NIH's 27 institutes and centers. Behavioral research is critical to NIH's mission: the Institute of Medicine recently reaffirmed that over 50 percent of premature mortality in the U.S. is due to behaviors such as smoking, sedentary lifestyle, and alcohol and other drug consumption. Two areas of great scientific opportunity at NIH are research on Alzheimer's disease and related dementias, and health disparities research at the National Institute of Minority Health and Health Disparities.

*Centers for Disease Control and Prevention (CDC).*—As a member of the CDC Coalition, APA supports an appropriation of at least \$7.8 billion for core programs in fiscal year 2017. APA strongly supports the President's request for increased funding for the National Injury Prevention and Control Center, including \$25 million for the National Violent Death Reporting System to allow for its expansion to all 50 States and DC, \$20 million for core injury prevention programs, and \$10 million for research into the causes and prevention of gun violence. As a member of the Friends of the National Center for Health Statistics, APA recommends \$170 in budget authority for the agency. APA also supports the Administration's \$30 million mandatory funding request for implementation and evaluation of comprehensive suicide prevention programs.

*Agency for Healthcare Research and Quality (AHRQ).*—APA requests that the Subcommittee support \$364 million in budget authority—consistent with the president's discretionary funding request and fiscal year 2015 level. AHRQ plays a critical role in the research continuum—helping patients get the most from new discoveries in basic and clinical research by improving healthcare delivery. For example,

<sup>1</sup> <http://www.nih.gov/sites/default/files/about-nih/strategic-plan-fy2016-2020-508.pdf>.



with the burgeoning opioid epidemic AHRQ research will help optimize delivery of behavioral and pharmacotherapies for the treatment of this devastating substance use disorder. In a variety of healthcare settings, AHRQ funded research is reducing medical errors and the incidence of Hospital Acquired Infections.

*Health Resources and Services Administration (HRSA).*—APA recommends that a portion of funding for the Maternal and Child Health Bureau be used to raise awareness of the availability of depression screening to pregnant women. APA encourages the subcommittee to fund the Melanie Blocker Stokes Act and to support incorporation of depression screening into the Title V programs administered by HRSA. We also encourage the Subcommittee to urge the Secretary to prioritize the issue of PPD by raising awareness, expanding research, and establishing grants to operate and coordinate cost-effective services to afflicted women and their families.

APA strongly supports funding of \$327 million for the Title X Family Planning program. Title X is the sole source of Federal funding for family planning for underserved populations, and provides vital access to birth control, cancer screenings, and testing for sexually transmitted infections for those who would otherwise not have access to these services.

APA recommends continued investments in the mental and behavioral health workforce, including \$12 million for the interprofessional Graduate Psychology Education Program to increase the number of health service psychologists (including doctoral-level clinical, counseling and school psychologists) trained to provide integrated services to high-need underserved populations in rural and urban 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. APA encourages HRSA to invest in geropsychology training programs to serve the aging population and to help integrate health service psychology trainees at federally Qualified Health Centers.

APA supports the transfer of the Behavioral Health Workforce Education and Training Program to HRSA and the broadened target populations of people to be served. In light of the new competition that will be held in 2017, APA requests that eligible entities for this program include accredited programs that train Master's level social workers, psychologists, counselors, marriage and family therapists, doctoral psychology students and interns, as well as behavioral health paraprofessionals. APA is concerned about the uneven distribution of funds among specialties resulting from the initial grant competition in 2014 and therefore encourages HRSA to ensure that funding is distributed relatively equally among the participating health professions and to consider strategies such as issuing separate funding opportunity announcements for each participating health profession.

#### SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION

APA strongly supports the President's fiscal year 2017 budget proposal that supports increased initiatives to address prescription and opioid abuse. APA encourages Congress to adopt the President's fiscal year 2017 request for a \$500 million mental health initiative. This investment would increase access to early intervention programs for serious mental illness, expand the Community Behavioral Health Clinic demonstration, and provide substantial funding for suicide prevention in collaboration with the CDC. APA recommends funding the National Child Traumatic Stress Network (NCTSN) at the President's requested level of \$46.9 million. We urge increased funding of the Minority Fellowship Program to reach a level of \$20 million by 2020. While ethnic minorities represent 30 percent of the U.S. 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 ethnic minorities. APA urges the continued support of the Minority AIDS Initiative funding which enhances and expands effective, culturally-competent HIV/AIDS-related behavioral services in minority communities.

APA strongly supports the 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 by increasing access to prevention, education, and outreach services to reduce suicide risk in States, tribes, and institutions of higher education. First authorized in 2004, the Garrett Lee Smith Memorial Act has supported 370 youth suicide prevention grants in 50 States, 48 Tribes or Tribal organizations, and 175 institutions of higher education.

## ADMINISTRATION ON CHILDREN AND FAMILIES

We urge support for the existing funding level of \$1.7 billion for the Social Services Block Grant for fiscal year 2017.

## ADMINISTRATION FOR COMMUNITY LIVING ADMINISTRATION ON AGING

We urge support of an additional \$5 million authorized under the Elder Justice Act for the Long-Term Care Ombudsman Program, which was previously requested by the President. We urge support for \$197 million in funding for programs that support the vital role of family caregivers in providing care for older adults.

## DEPARTMENT OF EDUCATION

*Institute of Education Sciences (IES).*—As a member of the Friends of IES, APA requests \$728 million for the Institute of Education Sciences which supports programs to evaluate the effects of Federal and local education policies, gather and analyze data on student outcomes, develop and promote evidence-based practices for schools and teachers, and advance rigorous education research. APA also supports increasing funding for the National Center for Special Education Research (NCSER) which did not see an increase in fiscal year 2016. NCSER's research informs evidence-based interventions to support the development and academic success of children with disabilities, which includes strategies for improving early childhood special education; advancing reading, writing, and language development; educating students with autism spectrum disorders; and helping students transition to post-secondary education and careers.

We support the proposed funding level for IDEA and urge you to maintain this amount without negatively impacting funding for other education programs. IDEA is the major—but not sole—vehicle for providing education to students with disabilities. In fact, students with disabilities are general education students first, with nearly two-thirds of students with disabilities spending at least 80 percent of their time in a general education setting.

APA encourages the subcommittee to make a significant investment in the newly reauthorized Student Support and Academic Enrichment Grants program (SSAEG), found in Title IV, Part A of the bipartisan Every Student Succeeds Act (ESSA). This program is a consolidation of over 20 Federal programs that is intended to be more widely accessible to more students. It will now support: safe and healthy students activities, such as providing mental health services to students; increasing student access to STEM, computer science and accelerated learning courses, physical education, art, music, foreign languages and college and career counseling; funds for an effective school library program; and providing students with access to technology and digital materials and educators with technology professional development opportunities. Authorized at \$1.65 billion, this formula grant program to States and LEAs, if appropriately funded, will make a significant difference in the academic achievements of all students.

APA supports increased funding for the Graduate Assistance in Areas of National Need (GAANN) program. GAANN supports fellowships to institutions of higher education for outstanding students with financial need pursuing degrees in areas of national need, including psychology. Supporting our Nation's graduate students is an investment worth making. APA urges the Committee not to shortchange this population of students and to support programs that make graduate study more affordable and accessible to students with financial need. Investments in graduate study are part of an effective strategy of ensuring our Nation's future economic competitiveness as well as ensuring we have a highly trained workforce to meet the healthcare needs of the Nation's population.

## INDIAN HEALTH SERVICE

APA supports increased funding for the American Indians Into Psychology Program (In Psych). The In Psych program addresses the need for culturally competent psychologists in the American Indian community to help address extremely high rates of suicide and substance use. We ask that the program be funded at \$1.5 million up from \$715,078 as it has not kept up with the need. Thank you again for the opportunity to submit this testimony for the record.

## PREPARED STATEMENT OF THE AMERICAN PUBLIC HEALTH ASSOCIATION

APHA 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 2017.

CENTERS FOR DISEASE CONTROL AND PREVENTION

We believe Congress should support CDC as an agency and urge a funding level of \$7.8 billion in fiscal year 2017. We are disappointed President Obama's budget request would cut CDC's program level by \$194 million below fiscal year 2016. We acknowledge that the president's budget provides increased funding for important programs and initiatives such as combating antibiotic resistance, preventing prescription drug overdose and research into the causes and prevention of gun violence. In addition, we are pleased his budget would fully allocate the Prevention and Public Health Fund for public health activities. Unfortunately, the president's budget cuts or eliminates other important programs including the REACH program, the Preventive Health and Health Services Block Grant, cancer prevention and control, immunizations and environmental health tracking and we urge you to maintain the funding for these important programs.

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 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. Given the challenges of terrorism and disaster preparedness we urge you to provide adequate funding for the Public Health Emergency Preparedness grants.

CDC serves as the command center for the Nation's public health defense system against emerging and reemerging infectious diseases. From aiding in the surveillance, detection and prevention of the Zika virus to playing a lead role in the control of Ebola in West Africa and detecting and responding to cases in the U.S., to monitoring and investigating last year's multi-State measles outbreak to pandemic flu preparedness, CDC is the Nation's—and the world'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. States, communities and the international community rely on CDC for accurate information and direction in a crisis or outbreak.

Programs under the National Center for Chronic Disease Prevention and Health Promotion address heart disease, stroke, cancer, diabetes and arthritis that are the leading causes of death and disability in the U.S. These diseases, many of which are preventable, are also among the most costly to our health system. The center provides funding for State programs to prevent disease, conduct surveillance to collect data on disease prevalence, monitor intervention efforts and translate scientific findings into public health practice in our communities.

The National Center for Environmental Health protects public health by helping to control asthma, protect from threats associated with natural disasters and climate change, reduce, monitor and track exposure to lead and other hazards and ensure access to safe and clean water. We urge you to support the president's request for the Climate and Health and Safe Water programs, increase funding for Childhood Lead Poisoning Prevention, Environmental Health Laboratory and Asthma programs, restore proposed cuts to the National Environmental and Public Health Tracking Network and restore funding for the Built Environment and Health program which was eliminated in 2016.

Prescription drug overdose is an ongoing public health problem in the U.S. killing more than 145,000 over the past decade. We urge you to support the president's request for increased funding to prevent and reduce prescription drug and heroin overdose deaths.

The development of antimicrobial resistance is occurring at an alarming rate and far outpacing the struggling research and development of new antibiotics. We urge you to support the president's request for the CDC Antibiotic Resistance Initiative that will expand fiscal year 2016 healthcare-associated infections and AR prevention efforts from 25 States to up to 50 States, six large cities and Puerto Rico.

We strongly support the president's request to provide \$10 million in unrestricted funding to CDC to conduct research into the causes and prevention of gun violence.

## HEALTH RESOURCES AND SERVICES ADMINISTRATION

HRSA (Health Resources and Services Administration) operates programs in every State and U.S. territory and has a strong history in improving the health of Americans through the delivery of quality health services and supporting a well-prepared workforce, serving people who are medically underserved or face barriers to needed care. While Congress has restored a portion of HRSA's discretionary budget authority over the past 3 years, funding for HRSA remains far too low—at 18 percent under the fiscal year 2010 level—significantly limiting the agency's ability to meaningfully respond to growing or emerging health demands such as the Zika virus and the opioid epidemic, while still addressing persistent health needs. The Nation faces a shortage of health professionals, and a growing and aging population which will demand more healthcare. HRSA grantees are well positioned to address these issues, but additional funding is required to effectively do so.

HRSA has contributed to the decrease in infant mortality rate, a widely used indicator of the Nation's health, which is now at a historic low of 5.8 deaths per 1,000 live births. People receiving care through the Ryan White HIV/AIDS Program achieve significantly higher viral suppression in comparison to the national average, which is central to preventing new HIV infections. The Title X Family Planning Program has helped prevent over 941,000 unintended pregnancies in 2014 and 1,176 cases of sexually transmitted disease-related infertility.

A strong investment from Congress is needed to build on these health improvements and pave the way for new achievements by supporting critical HRSA programs, including:

- Primary Care programs support more than 9,000 health center sites in every State and U.S. territory, improving access to care for more than 22.9 million patients in geographically isolated and economically distressed communities. Close to half of these health centers serve rural populations. Health centers deliver comprehensive, cost-effective care and have demonstrated their ability to reduce the use of costlier providers of care.
- Health Workforce supports the education, training, scholarship and loan repayment of a broad range of health professionals. These are the only Federal programs focused on filling the gaps in the supply of health professionals, and improving the distribution and diversity of the workforce. The programs are responsive to the changing delivery systems, models of care and healthcare needs, and encourage collaboration between disciplines to provide effective and efficient coordinated care.
- Maternal and Child Health including 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 34.3 million children, including children with special healthcare needs such as autism and developmental disabilities.
- HIV/AIDS programs provide assistance to States and communities most severely affected by HIV/AIDS. The programs deliver comprehensive care, prescription drug assistance and support services for 512,000 people living with HIV/AIDS, nearly 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 more than 4.1 million low-income women, men and adolescents. This program promotes healthy families and helps improve maternal and child health outcomes and reduce unintended pregnancies, infertility and related morbidity.
- Rural Health improves access to care for 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. Cuts to 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 interven-

tions that are effective and available for everyone so that we can meet the mounting health challenges facing our Nation.

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

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PREPARED STATEMENT OF THE AMERICAN SOCIETY FOR MICROBIOLOGY

The American Society for Microbiology (ASM) asks that Congress give special consideration and high priority to increasing the fiscal year 2017 budget for the Centers for Disease Control and Prevention (CDC), the Nation's leading health protection agency. The CDC's responsibilities, particularly in the area of infectious diseases, continue to expand annually because of globalization and biosecurity issues, including antimicrobial resistance and the Ebola and Zika virus outbreaks. The fiscal year 2017 CDC overall program level request of \$7.013 billion is \$164 million below the fiscal year 2016 level, due to changes in block grant funding. Within the CDC budget request, the ASM strongly supports the targeted increases for the following programs related to infectious diseases: combating antibiotic resistant bacteria (+\$40 million), Vaccines for Children Program (+\$225.9M), global health (+\$10 million), polio eradication (+\$5 million), quarantine activities like expanded refugee vaccination and electronic health records (+\$15 million), viral hepatitis (+\$5 million), new grants to increase use of HIV pre-exposure prophylaxis among high burden communities (+\$20 million), additional resources to upgrade CDC's Select Agent Program (+\$5.4M) and greater support for continued enhancement of CDC lab safety and quality (+\$5 million). The ASM urges Congress to approve these proposed program increases in the fiscal year 2017 budget for CDC.

The ASM would like to highlight programs that require additional resources and show CDC's enormous contributions to science and public health, both in the United States and worldwide.

CDC PROGRAMS DEFEND AGAINST INFECTIOUS DISEASES

Many of CDC's programs and initiatives are related to infectious diseases, including offensives against the Zika virus, the Ebola virus, field and laboratory investigations of foodborne outbreaks and drug resistant infections. The following statistics from CDC's surveillance networks and the World Health Organization (WHO) reveal the enormity of CDC's protective tasks and point to the importance of adequate funding for CDC programs:

- Respiratory infectious diseases are the leading cause of pediatric hospitalizations and outpatient visits in the United States.
- More than 1.2 million Americans live with HIV infection, an estimated 13 percent unaware of their status; about 50,000 are newly infected each year. Lifetime costs to treat HIV infection currently exceed \$400,000 per person.
- U.S. cases of sexually transmitted diseases keep increasing, despite highly effective prevention measures available. CDC estimates that nearly 20 million new STDs occur every year, costing nearly \$16 billion in healthcare.
- Drug resistant pathogens are thought responsible for an estimated 2 million U.S. illnesses and about 23,000 deaths annually. More than 400,000 Americans acquire antibiotic-resistant Salmonella or Campylobacter bacteria each year.
- During 2000–2014, about 43 million lives were saved by the global campaign to diagnose and treat tuberculosis, yet the infectious disease persists as a leading cause of death worldwide. The pathogen infected about 1 million children in 2014, causing 140,000 deaths.
- One in six Americans becomes sick from contaminated foods or beverages, year after year. CDC officials point out that reducing foodborne illness by just 10 percent would prevent five million illnesses annually.
- Nearly half of the world's population, about 3.2 billion, is at risk of mosquito transmitted malaria. Between 2000 and 2015, health agency collaborations that included CDC reduced the annual rate of new cases and mortality by 37 percent and 60 percent respectively.
- Last year, 15.8 million people living with HIV infection were receiving antiretroviral therapy, a global effort with strong assistance from CDC and other U.S. agencies. WHO estimates suggest today there are >40 million HIV positive people worldwide.
- Foodborne illnesses caused by Salmonella bacteria alone account for \$365 million in direct U.S. medical costs annually.
- An estimated >50 percent of antibiotics prescribed for upper respiratory infections in outpatient settings are unnecessary.

- One in 25 hospitalized patients develops healthcare-associated infections.
- Of the \$2.5 trillion spent on healthcare each year in the United States, preventable conditions, which include infectious diseases, account for 75 percent of costs.

The CDC Office of Infectious Diseases focuses on protecting against infectious disease, overseeing the National Center for Emerging and Zoonotic Infectious Diseases (NCEZID), the National Center for HIV/AIDS, Viral Hepatitis, STD and TB Prevention (NCHHSTP) and the National Center for Immunization and Respiratory Diseases (NCIRD). Other CDC centers and offices also address infectious diseases, such as the Center for Global Health and the Center for Surveillance, Epidemiology and Laboratory Services (CSELS). Each of these must have the resources to readily access the latest computing, communication and laboratory technologies needed for optimal responses to microbial threats. The fiscal year 2017 budget must provide adequate resources to fully realize these new capabilities through additional equipment and highly specialized personnel like bioinformaticians. For example, CDC must develop cutting-edge capabilities and collaborative partnerships as sampling techniques evolve, such as receiving and processing whole genome sequences of suspected pathogens from clinical and public health laboratories across the country.

The CDC's 2014–2015 Ebola effort included activation of the CDC Emergency Operations Center (EOC), definitive lab testing of patient specimens, travel warnings for the affected region, a CDC laboratory established in Sierra Leone, multiple CDC outbreak teams deployed, expanded Ebola testing at U.S. labs and airports, CDC facilitated health worker safety courses and improved hospital readiness in Africa and the United States, public education campaigns and strategic partnerships initiated with health agencies and governments.

Similar CDC activities are focused today against the Zika virus, just the latest examples of CDC's unique skillset to counter emerging and vector borne threats. It has confirmed cases in this country and other nations, issued travel advisories, already shipped 62,000 Zika diagnostic tests for pregnant women to U.S. health departments, accelerated surveillance data analyses and released guidelines for prevention. CDC researchers are working to confirm suspected neurotropic links between Zika infection and medical conditions like microcephaly and Guillain-Barré syndrome. Others are developing more accurate, faster diagnostic tests.

In response to the explosive spread of Zika in South America, the highest Level 1 activation of the Emergency Operations Center follows similar designations for the recent Ebola epidemic, the 2009 H1N1 influenza pandemic, and post-Hurricane Katrina. The EOC currently is coordinating more than 300 CDC staff at the agency's laboratories and in affected nations, in collaboration with local, national and international response partners.

#### CDC LEADERSHIP PREVENTS ILLNESS, SAVES HEALTH CARE COSTS

CDC programs, laboratories and staff provide leadership in sectors of public health and national security. The Federal Select Agent Program, both at CDC and the Department of Agriculture, oversees the use and transfer of biological select agents and toxins that might pose a risk. The agency's Vaccines for Children program, annual influenza response planning and immunization campaigns are guiding the Nation toward better health. There have been dramatic declines in vaccine preventable diseases, both in the United States and abroad. A goal now within reach is eradication of polio; CDC is leading the U.S. contribution to the global immunization program. Such efforts not only safeguard individuals but also demonstrably reduce health costs.

CDC laboratories can definitively identify suspected pathogenic agents, the contaminated products causing disease outbreaks and disease clusters in populations like hospitalized patients or consumers of certain foods. Detective work by CDC staff has repeatedly exposed causes and effects: Last year, microbe-contaminated cucumbers, restaurant chain meals, and packaged salad greens were among dozens of culprits identified. Other investigations involved a dengue fever outbreak in Hawaii, increased Legionnaires' disease in Michigan and a report concluding that nearly half a million Americans were infected with *Clostridium difficile*.

CDC's science based disease prevention prompts new agency guidance documents distributed to healthcare workers, industry, public health agencies or others. CDC prevention guidelines, along with CDC testing and surveillance, have helped reduce incidences of hospital acquired infections, foodborne illnesses and vaccine preventable diseases. The agency anticipates that similar recommendations for drug resistant pathogens will likewise reduce case numbers. In 2015, for example, CDC released its interim protocol for healthcare facilities that responded to carbapenem resistant Enterobacteriaceae transmission via duodenoscopes.

## CDC PARTNERSHIPS BUILD PUBLIC HEALTH CAPACITY

CDC contributes to national health initiatives and congressional mandates like the Food Safety Modernization Act (FSMA). A notable example is the National Action Plan for Combating Antibiotic Resistance Bacteria (CARB). Among its many CARB activities, CDC joined with the Food and Drug Administration last year to launch a precedent setting Antimicrobial Resistance Isolate Bank, providing its partners with specimens for R&D of new diagnostic tests and antimicrobial drugs. CDC also utilizes a network of regional labs able to characterize emerging resistance and identify outbreaks. One near term goal is greatly increased drug susceptibility testing for high priority pathogens. Another is expanding local capability to detect and prevent these infections in all 50 States, six large U.S. cities and Puerto Rico. CDC has set a national goal of 100 percent of all U.S. hospitals having antibiotic stewardship programs by 2020.

At both State and Federal levels, CDC education efforts routinely include laboratory and field training that help prepare the Nation's next generation of disease detectives.

CDC partnerships are important to building stronger public health infrastructures in the United States and in other nations. The agency provides its partners with testing and surveillance, onsite field teams, portable labs, medical supplies like vaccines and diagnostics and direct financial assistance. Last August, it announced awards of nearly \$110 million to help States under the Epidemiology and Laboratory Capacity for Infectious Diseases Cooperative Agreement. In July, it distributed \$216 million to community based organizations to improve HIV prevention.

By effectively using its own capabilities and collaborating with others, CDC has a long tradition of effectively improving our quality of life. The ASM encourages Congress to provide CDC with the resources needed to respond aggressively against any risk, whether familiar or unexpected.

## PREPARED STATEMENT OF THE AMERICAN SOCIETY FOR MICROBIOLOGY

The American Society for Microbiology (ASM) urges Congress to continue its bipartisan support for biomedical research as it considers the fiscal year 2017 budget for the National Institutes of Health (NIH). We appreciate the \$2 billion increase for NIH that Congress approved for fiscal year 2016. This increased investment will help improve public health, will lead to progress in scientific discovery and will help sustain U.S. leadership in biomedical research. We believe it is critical that sustained increases continue for the NIH budget and, therefore, join with the Ad Hoc Group for Medical Research in recommending that Congress appropriate at least \$34.5 billion for the NIH in the fiscal year 2017 appropriations bill for the Department of Health and Human Services. This proposed level of funding would provide 5 percent real growth for NIH as a further step to ensuring that biomedical research fulfills its promise to discover new cures, treatments and preventions for infectious and chronic diseases that continue to result in human tragedy. ASM is firmly convinced that a steady, predictable, growth of the biomedical research budget is the correct funding strategy to maximize the benefits from research investments, and to optimize the workforce pipeline. The recommended increase would enable NIH to take advantage of exciting scientific opportunities to make medical advances as well as contribute to substantial economic and societal returns on investments in innovative research.

The ASM would like to highlight some important areas of biomedical research to illustrate the importance of increased funding for the NIH.

## NIH DISCOVERIES FIGHT INFECTIOUS DISEASES AND ADVANCE BIOMEDICAL DISCOVERY

Infectious diseases remain among the leading causes of mortality and morbidity in the United States and worldwide. No single approach or product alone can successfully stop infectious disease, but NIH funded research enlarges our arsenals against menacing pathogens. The National Institute of Allergy and Infectious Diseases (NIAID) maintains a wide spectrum research portfolio on numerous infectious diseases and their prevention, diagnosis and treatment. The National Institute of General Medical Sciences (NIGMS) contributes insights into basic pathogen biology and more, as well as new products and technologies directly applicable to microbiology, immunology, and healthcare. Other NIH institutes also conduct studies in these areas important to the Nation's health.

The intensifying mobilization against the Zika virus is just the latest example of NIH potential to find R&D solutions that target specific threats and boost inter-agency public health initiatives. Previous examples include innovative NIH re-

sponses to Ebola, HIV/AIDS, and influenza. The recent Administration request for emergency supplemental funding to prepare for and respond to the Zika outbreak underscores the challenges ahead for biomedical research. At present, there are no vaccines, no rapid diagnostics and no cures for Zika infection. Much of the responsibility for identifying candidate Zika related products will rest on both NIAID's own intramural scientists and the many more supported by NIAID extramural grants to scientists working in universities and the private sector. Any successful multiagency fight against Zika virus and public policies must be grounded in solid scientific information about the pathogen, its transmission, and how it causes disease (pathogenesis) in infected humans.

When NIH unveiled its fiscal year 2016–2020 Strategic Plan recently, the agency rightly argued that it is positioned to capitalize on today's promising biomedical trends and discoveries. The NIH plan cited 21st century R&D opportunities like mobile health technologies and wearable biosensors, interdisciplinary initiatives like precision medicine and microbiome research, cutting edge structural biology for drug discovery, bioinformatics and massive datasets, and pharmacogenomics to optimize therapeutics.

NIAID HIV/AIDS focused programs have generated life extending drugs, improved diagnostics, and candidate vaccines, the rewards of sustained R&D strategies and long term funding. Not only have HIV treatments transformed life expectancies, but many study results have added to our general scientific knowledge. In 2015, NIAID funded researchers reported evidence supporting early antiretroviral therapy in all those infected with HIV, tested a potential HIV infection preventing drug in an animal model that utilized gene therapy and conducted encouraging studies using or eliciting neutralizing antibodies against HIV. In the decades since HIV/AIDS was first identified, NIH has compiled the world's leading HIV/AIDS research portfolio with remarkable success, but continuing its efforts is essential. There are an estimated 40,000 Americans still infected each year and more than one million living with the infection.

In its 5 year strategic plan, NIH outlines ambitious expectations that include reaching clinical trials with an influenza vaccine that induces host immunity against multiple viral strains. A universal flu vaccine is one of the "golden rings" sought by biomedical researchers. Influenza costs the U.S. economy an estimated \$87.1 billion annually in medical costs, loss of lives and lost productivity. Other hoped for clinical trials would evaluate NIH vaccines for respiratory syncytial virus, a leading cause of childhood pneumonia.

Stakeholders in U.S. and global public health have voiced rising concern in recent years over the shrinking industry pipeline of upcoming novel products against infectious diseases, particularly worrisome in the face of expanding drug resistance among pathogens. NIAID funded research is central in the national effort to accelerate R&D for new antimicrobial drugs and vaccines. In 2015, scientists with NIH funding reported various advances in vaccines that would target drug resistant tuberculosis, West Nile virus, Middle East Respiratory Syndrome (MERS), Epstein-Barr virus, influenza, malaria and Ebola. Others reported a clinical study of antibiotic treatment for skin infections of methicillin resistant *Staphylococcus aureus* (MRSA). NIGMS supported investigators described antibiotic effects on gut microbiomes and host susceptibility to *Clostridium difficile* infection, use of high throughput screening to identify candidate tuberculosis drugs and intracellular mechanisms employed by pathogens to resist antimicrobial compounds.

Advances in microbiology and immunology also come from other NIH institutes and programs. Much of the National Cancer Institute's research focuses on the body's immune systems. The National Institute of Child Health and Human Development devotes much of its portfolio to infectious diseases like malaria and HIV infection in children and pregnant women. The National Eye Institute's experimental immunology research investigates the pathogenesis of inflammatory eye diseases, while the National Institute of Dental and Craniofacial Research includes biofilms, microbial genomics, and microbial virulence among its research areas. At the National Institute of Neurological Disorders and Stroke, scientists study microbial pathogens like those causing shingles, meningitis, and encephalitis.

#### NIH EXPERTISE SUPPORTS U.S. R&D ENTERPRISE, NATIONAL HEALTH INITIATIVES

Over 80 percent of NIH's annual budget underwrites extramural research in all 50 States and the District of Columbia. Distributed through more than 57,000 research and training grants, NIH funding directly supports more than 400,000 jobs in the Nation's biomedical R&D enterprise. It also underwrites the training of current and future scientists and other technical workforces. NIH funding in fiscal year 2017 will further boost research at U.S. universities and other institutions by ena-



bling access to breakthrough research tools like high throughput screening of candidate drug compounds and the CRISPR gene editing technique. Agency funding also indirectly benefits millions of Americans employed in industries that have utilized NIH discoveries, such as biotechnology, pharmaceuticals and suppliers of R&D technologies for research purposes.

The ASM is disappointed that the proposed fiscal year 2017 budget signals a near record low in the success rate for new and competing research grants (estimated 17.5 percent of reviewed grants would receive funding). NIH remains the world's largest source of biomedical funding, but this failure to fully encourage innovation within newly proposed research seems shortsighted. NIH provides the majority of Federal support for all university R&D, an additional indication of its importance. Arguments for increasing research funding can point to the estimated U.S. healthcare expenditures (>\$2.5 trillion/year) or the slowing growth in U.S. biomedical R&D spending in relation to other key nations, as well as our declining global biomedical market share.

NIH institutes and centers routinely find innovative ways to fulfill the agency's mission, to discover basic knowledge about living systems and apply that knowledge to enhance human health. As a result, NIH funded expertise provides unique contributions to national and global public health initiatives. Examples are the National Action Plan for Combating Antibiotic Resistant Bacteria announced last March and the national call to action from the White House's Fast Track Action Committee on Mapping the Microbiome released in November, and most recently the National Action Plan for Multidrug Resistant TB. They stress interdisciplinary approaches and partnerships among institutions with relevant capabilities, both traditional strengths of NIH programs.

The ASM urges Congress to steadily, predictably and consistently increase the NIH budget to ensure adequate funding for research and training programs allowing appropriate planning and optimization of resources. We appreciate the opportunity to submit a statement in support of biomedical research funding and stand ready to assist Congress during the budget process.

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PREPARED STATEMENT OF THE AMERICAN SOCIETY FOR NUTRITION

Dear Chairman Blunt and Ranking Member Murray: Thank you for the opportunity to provide testimony regarding fiscal year 2017 appropriations. The American Society for Nutrition (ASN) respectfully requests \$35 billion dollars for the National Institutes of Health (NIH) and \$170 million dollars for the Centers for Disease Control and Prevention/National Center for Health Statistics (CDC/NCHS) in fiscal year 2017. 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

The NIH (National Institutes of Health) 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 8 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 \$35 billion dollars would help to restore the funding that was lost to sequestration and support additional competing research project grants. ASN recommends \$35 billion dollars for NIH in fiscal year 2017, an additional \$3 billion up from the President's budget request to enable NIH to fund more R01 grants while still providing much needed increases to other parts of the portfolio. 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

The National Center for Health Statistics (NCHS), housed within the Centers for Disease Control and Prevention (CDC), is the Nation's principal health statistics agency. ASN recommends a fiscal year 2017 funding level of \$170 million dollars for NCHS, \$10 million more than in fiscal year 2016 and the President's budget request, to help ensure uninterrupted collection of vital health and nutrition statistics, and help cover the costs needed for technology and information security maintenance and upgrades that are necessary to replace aging survey infrastructure.

The NCHS provides critical data on all aspects of our healthcare 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 a fiscal year 2017 funding level of \$170 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 2017 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.

Sincerely,

[This statement was submitted by Patrick J. Stover, Ph.D., President, American Society for Nutrition.]

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 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 (FY) 2017 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. Much 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.

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.

*Future Promise*

The era of precision medicine has arrived. The field of hematology has experienced a recent surge in progress thanks to novel technologies, mechanistic insights, and cutting-edge therapeutic strategies that have driven significant and meaningful advances in the quality of care. Insights into new genetic and biologic markers can be used to understand what causes a disease, the risk factors that predispose to disease, and how patients will respond to a particular treatment. These foundational insights are reframing modern research with the continued goal of improving outcomes and discovering cures for the most challenging hematologic diseases.

Translating these new discoveries and technologies into personalized patient care offers the possibility of better survival, less toxicity, disease prevention, improved quality of life, and lower health-care costs. Yet today, a number of specific and critically important research questions must be answered to gain the insights that will launch the field into the next generation of care for hematologic conditions. A wide variety of blood-related diseases—from malignancies such as lymphoma and leukemia, to non-malignant diseases including hemoglobinopathies such as sickle cell disease and thalassemia—continue to be associated with significant morbidity and mortality and demand attention to reduce their burden and improve the quality of care worldwide.

## FISCAL YEAR 2017 REQUESTS

*NIH Funding*

ASH thanks Congress for the robust bipartisan support that resulted in the welcome and much needed funding increase for the NIH that Congress provided in the fiscal year 2016 Consolidated Appropriations Act. ASH supports the Ad Hoc Group for Medical Research recommendation that NIH receive at least \$34.5 billion in fiscal year 2017 as the next step toward a multi-year increase in our nation's investment in medical research. If the nation is to continue to accelerate the development of life-changing cures, pioneering treatments, and innovative prevention strategies, it is essential to sustain predictable increases in the NIH budget. 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. This requested \$2.4 billion increase represents 5 percent real growth above the projected rate of biomedical inflation, and will help ensure that NIH-funded research can continue to improve our nation's health and enhance our competitiveness in today's global information and innovation-based economy.

Additionally, the Society strongly supports the Administration's proposed Moonshot Initiative, which seeks to accelerate progress across all cancers by supporting research in cancer prevention and vaccine development, early detection, immunotherapy and combination therapy, genomic analysis, data sharing, and pediatric cancer.

*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 over \$4 million in the Consolidated Appropriations Act of 2014. ASH respectfully requests that the Committee restore funding for the Division of Blood Disorders, by including increased funding to the public health approach to blood disorders account to enable CDC to meet growing needs for programs to address sickle cell disease and deep vein thrombosis/pulmonary embolism (DVT/PE). This funding will allow CDC to improve health outcomes and limit complications to those who are risk or currently have bleeding and clotting disorders, by promoting a comprehensive care model; identifying and evaluating effective prevention strategies; and increasing public and healthcare provider awareness.

*Additional Activities*

In fiscal year 2017, ASH also urges the Subcommittee to recognize the following activities impacting hematology:

—Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities

—Report Language:

*Sickle Cell Disease.*—The Committee believes more can be done to educate patients and medical providers about sickle cell disease (SCD) and sickle cell trait (SCT). It is especially important that individuals know their sickle cell status, the potential for medical complications, and the implications when making reproductive choices and that providers be informed of the current recommendations (best practices) for providing medical care to individuals with SCD/SCT. The Committee asks that the Center's Blood Disorders Division provide a plan on how to carry out a public health awareness and education campaign to meet these goals.

—Background:

Sickle cell disease is the most common inherited red blood cell disorder in the United States, affecting approximately 100,000 Americans (mostly but not exclusively of African ancestry). SCD causes the production of abnormal hemoglobin, which can get stuck and block blood flow, causing pain and infections. Complications of sickle cell anemia include stroke, acute chest syndrome, organ damage, other disabilities, and in some cases premature death. Most SCD patients can expect to live into adulthood, but the cost of care and the burden of pain, end-organ injury, and premature death remain high.

—Centers for Medicare and Medicaid Services, Program Management

—Report Language:

*Sickle Cell Disease.*—The Committee encourages CMS working through the Center for Medicare and Medicaid Innovation to explore with the interested provider and patient organizations, the development of model programs to provide integrated comprehensive care for adults with sickle cell disease (SCD). With an estimated 50 percent of the SCD population served under Medicaid and another 25 percent on Medicare, CMS has every incentive to assure that individuals with SCD are able to access specialized high quality services. Consideration should be given to funding of care coordinators/case managers for this population with incentives to reduce hospital admissions/readmissions and emergency department visits.

## —Background:

Sickle cell disease is the most common inherited red blood cell disorder in the United States, affecting approximately 100,000 Americans (mostly but not exclusively of African ancestry). SCD causes the production of abnormal hemoglobin, which can get stuck and block blood flow, causing pain and infections. Complications of sickle cell anemia include stroke, acute chest syndrome, organ damage, other disabilities, and in some cases premature death. According to the Agency for Healthcare Research and Quality (AHRQ) Healthcare Cost and Utilization Project—2012, Sickle cell disease was the 5th most common discharge diagnosis for hospital “super users” for Medicaid patients under 64 and patients with SCD are high utilizers of emergency room services. Most SCD patients can expect to live into adulthood, but the cost of care and the burden of pain, end-organ injury, and premature death remain high.

Thank you again for the opportunity to submit testimony. Please contact Tracy Roades, ASH Legislative Advocacy Manager, at [troades@hematology.org](mailto:troades@hematology.org), if you have any questions or need further information concerning hematology research or ASH’s fiscal year 2017 requests.

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PREPARED STATEMENT OF THE AMERICAN SOCIETY OF NEPHROLOGY

On behalf of the more than 20 million children, adolescents, and adults living with kidney diseases in the United States, the American Society of Nephrology requests \$2.165 billion for the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) at the National Institutes of Health (NIH) for fiscal year 2017. The society also requests an additional \$150 million per year over 10 years for NIDDK-funded kidney research above the current funding level. These are crucial and necessary investments for preventing illness and maintaining fiscal responsibility. Investing in research to slow the progression of kidney diseases and improve therapies for patients would yield significant savings to Medicare in the long run.

Once kidney disease progresses to end-stage renal disease (ESRD), patients need either costly dialysis treatments or a kidney transplant. Because there are not enough kidney donations for every patient who needs one, most of the 662,000 Americans with ESRD are on dialysis at an annual cost of \$85,000 per patient. In 1972, Congress made a commitment to provide Medicare coverage for every American with ESRD so all Americans who needed dialysis would have access to it.

Consequently, ESRD is the only health condition Medicare automatically provides coverage for regardless of age and income. At an annual cost of \$35 billion—more than NIH’s entire budget of \$32 billion—the Medicare ESRD Program represents 7 percent of Medicare’s budget even though ESRD patients represent less than 1 percent of the Medicare population. Despite the burden of kidney disease, NIH investments in kidney research are less than 1 percent of total Medicare costs for patients with kidney diseases (approximately \$591 million vs. \$98.9 billion in 2013).

The vast majority of Federal research leading to advances in the care and treatment of Americans with kidney diseases is funded by NIDDK, and there have been several major breakthroughs in the past several years thanks to NIDDK-funded research.

For example, geneticists focused on the kidney have made advances in understanding the biological processes leading to the development of some common kidney diseases. In addition, scientists have announced a method for growing new kidneys in a laboratory, as well as a rapid method for screening new prescription medications using kidney cells that would spare the expense and time of conducting human clinical trials. NIDDK-funded research also led to the development of bioengineered kidneys that are currently undergoing clinical testing.

Change is on the way because of advances made through NIDDK-funded kidney research. Additional, sustained funding is needed to accelerate these and other novel therapies that could improve the care of patients with kidney diseases and result in significant savings to Medicare. 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.

The American Society of Nephrology urges Congress to uphold its longstanding legacy of bipartisan support for biomedical research. Should you have any questions or wish to discuss NIDDK kidney research in more detail, please contact Grant Olan, Senior Policy and Government Affairs Associate of the American Society of Nephrology, at [golan@asn-online.org](mailto:golan@asn-online.org).

## ABOUT AMERICAN SOCIETY OF NEPHROLOGY

The American Society of Nephrology is a 501(c)(3) non-profit, tax-exempt organization that leads the fight against kidney disease by educating the society's nearly 16,000 nephrologists, scientists, and other healthcare professionals, advancing research and innovation, communicating new knowledge, and advocating for the highest quality care for patients. For more information, visit [www.asn-online.org](http://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 are a critical component of economic growth and job creation in our Nation. ASPB supports the maximum fiscal year 2017 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 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, 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 and support more funding opportunities similar to the "Genomes to Natural Products" which will hopefully pave the way for new plant-related medicinal research.

#### 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 direct 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](http://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 \$)

National Institutes of Health .....	34,500
National Heart, Lung & Blood Institute .....	3,400
National Institute of Allergy & Infectious Disease .....	4,715
National Institute of Environmental Health Sciences .....	732.2
Fogarty International Center .....	70.7
National Institute of Nursing Research .....	152
Centers for Disease Control and Prevention .....	7,800
National Institute for Occupational Safety & Health .....	339.1
Asthma Programs .....	30.5
Div. of Tuberculosis Elimination .....	243
Office on Smoking and Health .....	220
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

Respiratory diseases are 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, influenza, sleep disordered breathing, pediatric lung disorders, tuberculosis, 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 sequestration, annual funding cuts and a lack of inflationary adjustments over the past decade have eroded the NIH research budget. NIH's spending power in inflation-adjusted dollars has declined by over 20 percent since 2003. The number of grants supported by the NIH is now at the lowest level since 2001. The ATS is very concerned that due to reductions in Federal research funding, there is a lack of opportunities for young investigators who represent the future of scientific innovation. We ask the subcommittee to provide at least \$34.5 billion in funding for the NIH in fiscal year 2017.

Despite the fact that lung disease is the third leading cause of death in the U.S., lung disease research is underfunded. The COPD death rate has doubled within the last 30 years and is still increasing, while the rates for the other top causes of death (heart disease, cancer and stroke) have decreased by over 50 percent. In fiscal year 2014, lung disease, critical illness and sleep research represented 27.3 percent of the National Heart Lung and Blood Institute's (NHLBI) budget. Despite the growing lung disease burden, 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 2017.

#### ANTIBIOTIC RESISTANCE

According to the Centers for Disease Control and Prevention's (CDC) 2013 report, Antibiotic Resistance Threats in the United States, as many as 23,000 deaths occur in the U.S. annually due to antibiotic resistant bacterial and fungal pathogens including drug resistant pneumonia and sepsis infections. The rise of antibiotic resistance demonstrates the need to increase efforts through the CDC, NIH and other Federal agencies to monitor and prevent antibiotic resistance and develop rapid new diagnostics and treatments. This includes the following recommendations for CDC programs:

- \$200 million for the Antibiotic Resistance Solutions Initiative
- \$21 million for the National Healthcare Safety Network (NHSN)
- \$30 million for the Advanced Molecular Detection (AMD) Initiative

To address antibiotic resistance research needs, we urge the committee to provide \$4,715 million for the National Institutes of Allergy and Infectious Disease (NIAID) to spur research into rapid new diagnostics, new treatments and other activities and \$512 million for the Biomedical Advanced Research and Development Authority (BARDA) to support antimicrobial research and development.

#### COPD

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 dis-



ease 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 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

Tobacco use 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 top priority. Tobacco cessation and prevention activities are among the most effective and cost-effective investments in disease prevention. The CDC's Office on Smoking and Health (OSH) is the lead Federal program for tobacco prevention and control and created the "Tips from Former Smokers" Campaign, which has prompted hundreds of thousands of smokers to call 1-800-QUIT-NOW or visit [smokefree.gov](http://smokefree.gov) for assistance in quitting—with even more smokers making quit attempts on their own or with the assistance of their physicians. 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 \$220 million for the Office of Smoking and Health in fiscal year 2017.

#### ASTHMA

Asthma is a significant public health problem in the United States. Approximately 25 million Americans currently have asthma. In 2013, 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 2017 that funding for CDC's National Asthma Control Program be maintained at a funding level of at least \$30.596 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 2017 to support activities related to sleep and sleep disorders at the CDC, including surveillance activities and public educational activities. The ATS also recommends an increase in funding for research on sleep disorders at the Nation Center for Sleep Disordered Research (NCSDR) at the NHLBI.

#### TUBERCULOSIS

Tuberculosis (TB) is the leading global infectious disease killer, ahead of HIV/AIDS, claiming 1.5 million lives each year. In the U.S., every State reports cases of TB annually and in 2015, the CDC reported the first national increase in TB cases in over 20 years. Drug resistant tuberculosis was identified as a serious public health threat to the U.S. in the CDC's 2013 report on antimicrobial resistance. Drug-resistant TB strains poses a particular challenge to domestic TB control due to the high costs of treatment, intensive healthcare resources and burden on patients. Treatment costs for multidrug-resistant (MDR) TB, which is up to 2 years in length, range from \$100,000 to \$300,000. The continued global pandemic of this airborne infectious disease and spread of drug resistant TB demand that the U.S. strengthen our investment in global and domestic TB control and research to develop new TB diagnostic, treatment and prevention tools.

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 2017 for CDC's Division of TB Elimination, as authorized under the CTEA, and urges the NIH to expand efforts to develop new tools to address TB. Additionally, in recognition of the unique public health threat posed by drug resistant TB, we urge BARDA to support research and development into new drug resistant TB diagnostic, treatment and prevention tools.

#### 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 2010, 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. For instance, 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 and NICHD to sustain and expand 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 funded and encouraged 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 \$70.7 million for FIC in fiscal year 2017, 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 2017, the ATS urges the subcommittee to provide at least \$339.1 million in funding for the National Institute for Occupational Safety and Health (NIOSH). NIOSH, within the Centers for Disease Control and Prevention (CDC), is the primary Federal agency responsible for conducting research and making recommendations for the prevention of work-related illness and injury.

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

[This statement was submitted by Atul Malhotra, MD, President, American Thoracic Society.]

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#### PREPARED STATEMENT OF THE ARTHRITIS FOUNDATION

On behalf of the more than 50 million adults and 300,000 children living with doctor-diagnosed arthritis in the U.S., the Arthritis Foundation thanks Chairman Blunt and Ranking Member Murray for the opportunity to provide written testimony to the Appropriation Subcommittee on Labor, Health and Human Services (HHS), and Education and Related Agencies for fiscal year 2017. We respectfully request \$16 million for the Centers for Disease Control and Prevention (CDC) Arthritis Program and sufficient funding for the National Institutes of Health (NIH) for fiscal year 2017.

Arthritis affects 1 in 5 Americans and is the leading cause of disability in the U.S., according to CDC. It limits the daily activities of nearly 23 million Americans and causes work limitations for 40 percent of the people with the disease. This translates to \$156 billion a year in direct and indirect costs from two forms of arthritis alone—osteoarthritis (OA) and rheumatoid arthritis (RA). There is no cure

for arthritis, and for some forms of arthritis like OA, there is no effective pharmaceutical treatment. Research is critical to build towards a cure, to develop better treatments with fewer severe side effects, and to identify biomarkers and therapies for types of arthritis for which none exist. A strong investment in public health research and programs is essential to making breakthroughs in treatments finding a cure for arthritis, and for delivering those breakthroughs to the people who suffer from this debilitating disease.

#### CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC) ARTHRITIS PROGRAM

The CDC Arthritis Program is the only Federal program dedicated solely to arthritis. It provides grants to 12 States to support public health programs, provide education services, perform public health research, and support data collection. Its goal is to connect all Americans with arthritis to resources to help them manage their disease. Evidence-based programs like Enhance Fitness help keep older adults active, and have shown a 35 percent improvement in physical function, resulting in fewer hospitalizations and lower health costs compared to non-participants. Further, 1 in 3 veterans has doctor-diagnosed arthritis, and these evidence-based exercise programs are recommended by the CDC to help our veterans reduce the impact of arthritis on their lives.

Missouri is one of the 12 CDC-funded States, and with this Federal support, the State Arthritis and Osteoporosis Program and its partners have been able to develop and disseminate specific marketing material for arthritis programs, offer more programs in more communities and in more sites, involve more agencies and partners, and involve more referrals from doctor's offices. The impact to-date is a 50 percent increase in the number of self-management programs offered across the State in 2 years, a doubling of the offering of the Walk with Ease program, and an increase of 18 active partners in the Health Delivery System partnership.

Not only does the Arthritis Program provide resources to people with arthritis, it also supports data collection on the prevalence and severity of arthritis. Because of this support, we know that 1 in 5 Americans has doctor-diagnosed arthritis, including 27 percent of people in Oklahoma and 24 percent of people in Connecticut, and 415,000 of those people in Oklahoma and 267,000 of those people in Connecticut are limited by their arthritis. Without the Arthritis Program, the robust level of data collection we have now would not exist. As you know, this data is critical for determining where to direct public health programs and how to set research priorities. For example, because of the data on the high number of people with arthritis who also have at least one other chronic disease like heart disease (24 percent) or diabetes (16 percent), we know that research on co-morbidities and coordinated chronic disease programs are important to reducing the overall impact of chronic disease on people with arthritis.

Given the high prevalence and severity of this disease, the Arthritis Program is woefully under-funded compared to the investment in other chronic diseases. Funding for the program was cut by 25 percent in fiscal year 2015, bringing the fiscal year 2015 total down from \$13 million to \$9.5 million. As a result, program staff had to cut program activities between 10–50 percent, with some eliminations, and were unable to make new investments in arthritis programs. While \$1.5 million was restored in fiscal year 2016, the Arthritis Program is still not operating at its full funding level of \$13 million, and combined with previous flat funding, has lost millions of dollars in purchasing power over the last 6 fiscal years.

In 2013 for the first time, data showed that arthritis affects at least 20 percent of the population in every State. All 50 States need funding from the Arthritis Program. While this is a long-term goal, a critical first step is to increase funding in fiscal year 2017 by \$5 million so it can continue its current level of operations in the 12 States it supports and begin to expand into additional States. With this increase, the Arthritis Program could operate in an additional 2 States, support more national grants and increase its investment in public health research. Therefore, we urge you to fund the CDC Arthritis Program at \$16 million in fiscal year 2017.

#### NATIONAL INSTITUTES OF HEALTH (NIH)

As previously stated, there is no cure for arthritis, and for some forms of the disease, no effective pharmaceutical treatments. Even for auto-immune forms of the disease like RA, biologic medications—which have revolutionized treatment by halting the progress of disease in many patients—have severe side effects. There is also no “gold standard” diagnostic for many forms of arthritis like RA and juvenile arthritis, and therefore it can take a long time to diagnose these diseases. It is not uncommon for children to go months without an official diagnosis, which can delay the start of critical treatment. Research is the key to identifying better diagnostics

and better treatments, so that people have access to treatments early in their disease, ensuring a higher quality of life and better health outcomes.

The National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) is one of the primary NIH Institutes that supports arthritis research. There are a number of initiatives supported by NIAMS to better understand arthritis. The Osteoarthritis Initiative is a public-private, multi-center, longitudinal study of knee OA that was launched in 2002 with the goal of identifying biomarkers for OA as potential surrogate endpoints for onset and progression. The recently launched Accelerating Medicines Partnership is a public-private partnership that includes RA/lupus as one of three disease topics with the goal of accelerating drug development.

Research currently supported by NIAMS is addressing major questions necessary to unlocking the unknowns of arthritis, such as: how gene-environment interactions can help determine the relationship between RA and environmental and genetic factors that trigger onset; which biological pathways are affected in people with RA and how drug development can target those pathways to expand the pool of drugs available to people with RA; and how existing successful anti-rheumatic drugs may be used for other arthritis-related diseases.

Most recently, researchers have found the gene that confirms the existence of psoriatic arthritis. This is a breakthrough that has the potential to lead to targeted therapies for psoriatic arthritis, and even treatments that can prevent its onset. These research breakthroughs can have an enormous impact on the quality of life for people with arthritis, in addition to generating a strong return on investment in reduced healthcare costs and better quality of life for patients.

Future research efforts can explore how changes to DNA regions can lead to disease, with the goal of uncovering additional targeted treatments. A strong overall NIH funding level is critical to maintaining the investment in research on arthritis in all its forms. Therefore, we urge you to provide sufficient funding for NIH in fiscal year 2017 to keep pace with the growing research needs in the arthritis community.

We thank the subcommittee for its commitment to public health. As you write the fiscal year 2017 Labor-HHS-Education appropriations bill, we urge you to fund the CDC Arthritis Program at \$16 million and provide sufficient funds to the NIH in order to continue the investment in improving the lives of people with arthritis. Please contact Sandie Preiss, the Arthritis Foundation National VP of Advocacy and Access at spreiss@arthritis.org or the Arthritis Foundation Senior Director of Advocacy and Access Anna Hyde at ahyde@arthritis.org with any questions.

[This statement was submitted by Sandie Preiss, National Vice President of Advocacy and Access.]

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PREPARED STATEMENT OF THE ASSOCIATION FOR CAREER AND TECHNICAL EDUCATION

Chairman Blunt, Ranking Member Murray and members of the subcommittee, on behalf of the Association for Career and Technical Education (ACTE), the Nation's largest not-for-profit association committed to the advancement of education that prepares youth and adults for successful careers, I would like to urge you to help support career and technical education (CTE) through a strong Federal investment in the Carl D. Perkins Career and Technical Education Act (Perkins) for fiscal year 2017. To ensure that students are equipped with the academic, technical and employability skills they need for success in the jobs that are available today, and the careers of tomorrow, I respectfully request that the subcommittee increase the Perkins Basic State Grant program (Title I), administered by U.S. Department of Education, Office of Career, Technical, and Adult Education, to \$1.3 billion in the fiscal year 2017 Labor, Health and Human Services, and Education appropriations bill.

Perkins is the principal source of dedicated Federal funding for CTE programs in secondary and postsecondary institutions across the country. This Federal investment is crucial to ensuring that students are prepared for careers in expanding fields like engineering, information technology, advanced manufacturing and healthcare. 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 working adults.

Despite the importance of Perkins funding in advancing high-quality CTE programs for more than 11 million students nationwide, congressional appropriations have not kept pace with the growing need. Funding for the Perkins Basic State Grant program is still \$5.4 million below its pre-sequestration level. From fiscal year 2007 through fiscal year 2016, total Perkins grant funding to States declined

by 13 percent—nearly \$170 million less in funding to support CTE, and an even greater loss if you take into account the effects of inflation.

The erosion of Perkins funds comes at a time when CTE programs are experiencing new attention and growth. States are using Perkins funding to strengthen student performance results in areas such as attainment of academic and technical skills, and transitioning to further education or employment. In the most recent data available, the average high school graduation rate for students concentrating in CTE programs is 93 percent. Students involved in CTE programs are engaged in their education, perform well academically, gain critical employability skills and earn industry-recognized credentials. Perkins provides a strong return on our Federal investment by fostering an educated and highly skilled workforce that delivers direct benefits to American employers, and further strengthens the economy through productivity and innovation.

The Obama administration's fiscal year 2017 budget request includes an increase of \$75 million for the proposed American Technical Training Fund, which would provide competitive grants to support the development job training programs in high-demand fields. The additional request of a \$2 million increase for CTE National Programs would provide technical assistance and evaluation support for projects under the American Technical Training Fund proposal. While these resources would help meet the needs of a few programs, the administration's budget, once again, fails to provide any additional funding for the formula Perkins Basic State Grant program. It is the position of ACTE that limited resources for education and job training are better directed to proven, formula-driven programs that serve students in communities across the country, and we remain committed to expanding equitable access to high-quality CTE.

Increasing the Perkins Basic State Grant to \$1.3 billion, a 15 percent increase over the current level, would restore funding for States to the fiscal year 2007 level and could support an additional 1.7 million students by expanding access to CTE programs of study that create a seamless educational pathway by strengthening the integration of academics and CTE content in the classroom, providing career guidance and academic counseling services, ensuring that CTE classrooms have the latest technology and equipment, and providing professional development and technical assistance for CTE educators. Thank you for your continued leadership and for your thoughtful consideration of our request. We look forward to working in a bipartisan fashion with the subcommittee throughout the fiscal year 2017 appropriations process.

[This statement was submitted by Stephen DeWitt, Deputy Executive Director.]

PREPARED STATEMENT OF THE ASSOCIATION FOR RESEARCH IN VISION AND  
OPHTHALMOLOGY

EXECUTIVE SUMMARY

ARVO requests fiscal year 2017 appropriated National Institutes of Health (NIH) and the National Eye Institute (NEI) funding of at least \$34.5 billion and \$770 million, respectively, a 7.5 percent increase reflecting 5 percent real growth above projected 2.5 percent biomedical inflation.

—ARVO thanks Congress for its bipartisan action in fiscal year 2016 to increase NIH funding by \$2 billion over fiscal year 2015, which is the largest actual dollar and percent increase since fiscal year 2003.

—We request a second year of budget increases to rebuild NIH's discretionary funding base—especially as it has lost 22 percent of purchasing power since fiscal year 2003, in terms of constant dollars—and to create a trend of predictable and sustained funding.

—ARVO also thanks Congress for the \$31 million National Eye Institute (NEI) increase over fiscal year 2015, especially since it reflects the first time in 4 years that NEI's operating budget exceeds that of the pre-sequester fiscal year 2012 level, albeit by a modest 0.8 percent. Further increases this year will continue to rebuild NEI's discretionary funding base—especially as it has lost 25 percent of purchasing power since fiscal year 2003, in terms of constant dollars—and go far to ensure predictable and sustained funding.

ARVO shares the concerns expressed by bipartisan Leaders and Members of the Appropriations Committee and the LHHs Appropriations Subcommittee regarding the President's proposal to replace \$1 billion of the NIH discretionary base funding with mandatory funding. ARVO is especially concerned that the President proposes to not only flat-fund most of the Institutes and Centers (I/Cs), but achieve this through the use of mandatory funding. In the case of the NEI, its discretionary base

would be reduced to \$687 million, with the difference reflecting mandatory funding that would raise it to the flat-funded level of \$708 million.

ARVO looks forward to working with the appropriators to secure an increase of 5 percent real growth above inflation in fiscal year 2017 NIH and NEI funding as the next step in ensuring the security and momentum of the Nation's biomedical research enterprise. We also stand ready to work with the authorizers on potential mechanisms to provide short-term "surge" funding to take advantage of the exceptional scientific opportunities now available to address current and emerging health challenges.

NEI'S BUDGET IS NOT KEEPING PACE AS THE BURDEN OF EYE DISEASE AND VISION  
IMPAIRMENT GROWS

NEI's fiscal year 2016 enacted funding of \$715.9 million—reduced to a \$708 million operating budget due to pass-throughs—reflects the first time in four fiscal years that NEI's operating budget exceeds that of the pre-sequester fiscal year 2012 funding level of \$702 million. In the 4 years it has taken the NEI budget to grow a modest 0.8 percent, it has experienced the compounded loss of purchasing power due to biomedical inflation rates ranging from 2 to 2.5 percent. During that time-frame, NEI's operating budget was also reduced as a result of a transfer back to the NIH Office of AIDS Research (OAR) for funding of the successfully completed NEI-sponsored Studies of the Ocular Complications of AIDS (SOCA). Although OAR's funding to NEI was not committed indefinitely, its return to NIH Central in the amounts of \$5.6 million (fiscal year 2013), \$6.9 million (fiscal year 2014), and \$7.4 million (fiscal year 2015) had essentially cut NEI's budget further, resulting in a new baseline upon which future funding increases were calculated.

In June 2014, Prevent Blindness (PB) released a report entitled "The Future of Vision: Forecasting the Prevalence and Costs of Vision Problems," which it commissioned from the University of Chicago's National Opinion Research Center (NORC). This report estimates the current annual cost (inclusive of direct and indirect costs) of vision disorders at \$145 billion, an increase of \$6 billion from the \$139 billion estimate in PB's 2013 study entitled "Cost of Vision Problems: The Economic Burden of Vision Loss and Eye Disorders in the United States," which also concluded that direct medical costs associated with vision disorders are the fifth highest—only less than heart disease, cancers, emotional disorders, and pulmonary conditions. PB's 2014 study projects that the total annual cost of vision disorders, which includes government, insurance, and patient costs, will grow to \$373.2 billion in 2050 when expressed in 2014 dollars—which is \$717 billion when adjusted for inflation. Of the \$373.2 billion estimated 2050 costs, \$154 billion or 41 percent will be borne by the Federal Government as the Baby-Boom generation ages into the Medicare program.

Current NEI funding of \$708 million is still less than 0.5 percent of the \$145 billion annual cost of vision disorders. The U.S. is spending only \$2.20 per-person, per-year for vision research at the NEI, while the 2013 PB report estimates that the cost of treating low vision and blindness is at least \$6,690 per-person, per-year.

The very health of the vision research community is also at stake. The convergence of past factors which have reduced NEI funding has affected both young and seasoned investigators and threatened the continuity of research and the retention of trained staff, while making institutions more reliant on private bridge and philanthropic funding. Tahreem Mir, MD, a postdoctoral research at Wilmer Eye Institute, summed up the situation facing young investigators:

"I have witnessed several of my colleagues, all brilliant scientists, struggle to fund their research. Many spend more time writing grants than conducting actual science."

\$770 MILLION FISCAL YEAR 2017 FUNDING ENABLES NEI TO PURSUE ITS AUDACIOUS GOAL  
OF RESTORING VISION

Among NEI's most exciting pursuits is the "Audacious Goals Initiative (AGI)," which aims to restore vision within the next decade through regeneration of the retina by replacing cells that have been damaged by disease and injury and restoring their visual connections to the brain. The AGI builds upon discoveries from past investment in biomedical research, such as gene sequencing, gene therapy, and stem cell therapies, and combines these with new discoveries—such as imaging technologies that enable researchers to non-invasively view in real-time biological processes occurring in the retina at a cellular level—to develop new therapies for degenerative retinal disorders.

NEI has awarded the first set of grants associated with novel imaging technologies to help clinicians observe the function of individual neurons in human pa-

tients and follow them over time as they test new therapies. It is proceeding with a second round of awards associated with identifying new factors that control regeneration and comparing the regenerative process among model organisms, rodents, and non-human primates.

As NEI Director Paul Sieving, M.D., Ph.D. noted in his February 2013 comments at the first AGI meeting:

“Success would transform life for millions of people with eye and vision diseases. It would have major implications for medicine of the future, for vision diseases, and even beyond this, for neurological diseases.”

These are ambitious goals that require sustained and predictable funding increases. 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.

#### AMERICANS FEAR VISION LOSS, WHICH IS A GROWING PUBLIC HEALTH PROBLEM

The 2012 study entitled “Vision Problems in the United States,” released by Prevent Blindness and funded in part by the NEI reported that, of the nearly 143 million Americans age 40-plus (per the 2010 U.S. Census), 4 million were blind or had significant vision impairment and 37 million had an age-related eye disease, such as AMD, glaucoma, diabetic retinopathy, or cataracts. An additional 48 million Americans have a refractive error. This prevalence of vision impairment and eye disease will only grow, driven by:

- The aging of the population—the “Silver Tsunami” of the 78 million baby boomers who will turn age 65 this decade and experience increased risk for eye disease.
- The disproportionate risk/incidence of eye disease in Hispanic and African American communities, which increasingly account for a larger share of the U.S. population.
- Vision loss as a co-morbid condition of chronic disease, such as diabetes, which is at epidemic levels due to the increased incidence of obesity.

In September 2014, the Alliance for Eye and Vision Research (AEVR) released results of a new poll entitled “The Public’s Attitudes about the Health and Economic Impact of Vision Loss and Eye Disease.” It was commissioned by Research!America and conducted by Zogby Analytics with a grant from Research to Prevent Blindness (RPB), a private vision funding foundation which conducted the first-ever poll of the public’s attitudes about vision loss in 1965. The 2014 poll—the most rigorous conducted to-date of attitudes about vision and vision loss among ethnic and racial groups including non-Hispanic Whites, African Americans, Hispanics, and Asian Americans—found that:

- A significant number of Americans across all racial lines rate losing their eyesight as having the greatest impact on their daily life, affecting independence, productivity, and quality of life.
- African Americans, when asked what disease or ailment is the worst that could happen, ranked blindness first, followed by HIV/AIDS. Hispanics and Asians ranked cancer first and blindness second, while non-Hispanic Whites ranked Alzheimer’s disease first, followed by blindness.
- America’s minority populations are united in the view that not only is eye and vision research very important and needs to be a national priority, but many feel that the current annual Federal funding is not enough and should be increased.

In summary, ARVO requests fiscal year 2017 NIH funding of at least \$34.5 billion and NEI funding of \$770 million—the latter to better understand the scientific bases upon which to save sight and restore vision.

#### ABOUT ARVO

ARVO is a community of 12,000 vision researchers from 80 countries; we are the largest, most respected vision research organization in the world. Our aim to advance research worldwide into understanding the visual system and into preventing, treating and curing its disorders.

## PREPARED STATEMENT OF THE ASSOCIATION OF AMERICAN CANCER INSTITUTES

The Association of American Cancer Institutes (AACI), representing 95 premier academic and free-standing cancer centers, appreciates the opportunity to submit this statement for consideration by the subcommittee. Barbara Duffy Stewart, Executive Director of AACI submits this request for the Department of Health and Human Services budget for the National Institutes of Health (NIH) in the amount of at least \$34.5 billion for fiscal year 2017. In light of President Obama and Vice President Biden's National Cancer Moonshot initiative, we request that funding for the National Cancer Institute (NCI) be prioritized and that NCI receive at least \$5.9 billion, in order to begin the initiative.

AACI appreciated Congress' fiscal year 2016 bipartisan spending bill, which provided the NIH with the largest boost in annual appropriations since fiscal year 2003. AACI cancer centers believe the partnership between the Federal Government and academic cancer centers is cooperative, and cancer centers continue to make strides in biomedical research thanks to the support of the Federal Government. Without such support, research projects with the potential to discover breakthrough therapies would not be possible.

## THE PRESIDENT'S FISCAL YEAR 2017 BUDGET BLUEPRINT

The President's fiscal year 2017 budget request for the NIH is \$33.136 billion, \$825 million above the enacted fiscal year 2016 level. This includes \$5.893 billion for the NCI. In his budget blueprint, the President outlined the National Cancer Moonshot initiative, which includes an investment of \$680 million, as well as \$100 million for the Precision Medicine Initiative.

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 accelerated if researchers could count on an appropriate and predictable investment in Federal cancer funding.

While the President's proposed budget would allow for 36,440 competing Research Project Grants (RPG's) in 2017, an increase from the 35,840 RPG's in 2016, academic cancer centers nationwide continue to grapple with budget constraints and the issue of investigator retention. Uncertainty surrounding RPG's and cancer center resources often drives promising scientists to explore opportunities abroad or outside of the biomedical research community. 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. It is imperative that we enable America's scientists to master their craft.

Therefore, AACI requests that Congress surpass the President's budget request and provide the NIH with at least \$34.5 billion for fiscal year 2017. AACI is encouraged by the National Cancer Moonshot initiative and requests that the NCI receive at least \$5.9 billion in fiscal year 2017.

## NATIONAL CANCER MOONSHOT INITIATIVE

AACI cancer centers are invigorated by the National Cancer Moonshot initiative and their potential to contribute to the elimination of cancer. A goal of the "moonshot" initiative is collaboration among academic institutions and revolutionizing the sharing of medical and research data. AACI cancer centers are a primary source for the generation, collection and use of molecular, clinical and outcomes data. Steady, predictable funding for the NIH and NCI is vital as cancer centers work to share data and improve information systems and communication across the cancer continuum.

The "moonshot" initiative also aims to accomplish a decade's worth of advances in 5 years, making new therapies available to patients, while also improving our ability to prevent and detect cancer at an early stage. Prevention and early detection are highly important to AACI cancer centers, as they offer patients the latest advances in cancer prevention, detection, diagnosis, and treatment.

AACI member centers value the renewed investment in biomedical research supported by the NIH and the NCI, but robust funding for these important agencies will be necessary in order to accept the call for a "moonshot" and accelerate scientific progress. Peaks and valleys in the NIH and NCI budget merely slow ad-



vances in biomedical research and also undermine cancer centers' ability to: conduct and support multidisciplinary cancer research; train cancer physicians and scientists; provide state-of-the-art care; and, disseminate information about cancer detection, diagnosis, treatment, prevention, control, palliative care, and survivorship across our communities.

With excitement mounting about the scientific opportunities ahead and our potential to leverage the resulting advances to benefit cancer patients nationwide, it is imperative that Congress fully fund the agencies responsible for advancing cancer research. The broad portfolio of science supported by the NIH and NCI is essential for improving our basic understanding of cancer and has contributed to the health and well-being of Americans.

#### CANCER: THEN AND NOW

Progress in cancer research has reached unprecedented levels since the enactment of the National Cancer Act in 1971, yet cancer remains one of the leading causes of death and disability in the United States. This year, nearly 1.7 million Americans will receive a cancer diagnosis and more than 595,000 Americans will lose their lives to cancer.<sup>1</sup> As the population ages, cancer incidence is expected to grow significantly, reaching 2.3 million diagnoses per year by 2030.<sup>2</sup>

Despite these alarming statistics, progress continues to be made in cancer research, discovery, and the delivery of care. The 5-year survival rate for all types of cancer was greater than 65 percent in 2011, improving between 1981 and 2011, and more than 14.5 million cancer survivors were living in the U.S. in 2015.<sup>3</sup> The improvement in survival reflects the advances being made by diagnosing cancers at an earlier stage and providing better treatments to cancer patients.

The Agency for Healthcare Research and Quality estimates that the direct medical costs (total of all healthcare expenditures) for cancer in the U.S. were \$74.8 billion in 2013.<sup>4</sup> Even as the cost of cancer continues to rise, investment in cancer research could one day significantly reduce or even eliminate the health and economic burden that cancer imposes on all Americans. Ensuring stable, predictable funds are provided to the NIH and NCI will aid our Nation's cancer center researchers in discoveries which ultimately improve cancer treatment outcomes.

#### CONCLUSION

Our country has contributed to a steady decrease in the mortality rate for cancer, but America can do better. Now is the time for Congress to invest in biomedical research in general and cancer research in particular. AACI joins our colleagues in the biomedical research community in recommending that the subcommittee recognize the NIH as a critical national priority by providing at least \$34.5 billion in funding in the fiscal year 2017 Labor-HHS-Education appropriations bill. Additionally, we ask that the subcommittee funds the NCI with at least \$5.9 billion in funding for fiscal year 2017.

A robust Federal investment in our Nation's NCI-designated cancer centers and emerging academic cancer centers will allow the cancer community to heed the call for a "moonshot to cure cancer." This is an important moment in our Nation's history and we ask the subcommittee to invest in academic cancer centers as they work to accomplish the goal to end cancer for the good of our country.

[This statement was submitted by Barbara Duffy Stewart, Executive Director, Association of American Cancer Institutes.]

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#### PREPARED STATEMENT OF THE ASSOCIATION OF AMERICAN MEDICAL COLLEGES

The Association of American Medical Colleges is a not-for-profit association dedicated to transforming healthcare through innovative medical education, cutting-edge patient care, and groundbreaking medical research. Its members comprise all 145 accredited U.S. and 17 accredited Canadian medical schools; nearly 400 major teaching hospitals and health systems, including 51 Department of Veterans Affairs medical centers; and more than 80 academic societies. Through these institutions

<sup>1</sup>American Cancer Society. Facts and Figures, 2016. <http://www.cancer.org/acs/groups/content/@research/documents/document/acspc-047079.pdf>.

<sup>2</sup>Smith BD, Smith GL, Hurria A, Hortobagyi GN, Buchholz TA. Future of cancer incidence in the United States: burdens upon an aging, changing nation. *J Clin Oncol*. 2009 Jun 10;27(17):2758-65.

<sup>3</sup>American Cancer Society. Facts and Figures.

<sup>4</sup>American Cancer Society. Facts and Figures.

and organizations, the AAMC serves the leaders of America's medical schools and teaching hospitals and their 148,000 faculty members, 83,000 medical students, and 115,000 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 \$34.5 billion for the National Institutes of Health (NIH); \$364 million in budget authority for the Agency for Healthcare Research and Quality (AHRQ); \$524 million for the Title VII health professions and Title VIII nursing workforce development programs at the Health Resources and Services Administration (HRSA)'s Bureau of Health Workforce; and continued support for student aid through the Department of Education and HRSA's National Health Service Corps. The AAMC appreciates the subcommittee's longstanding, bipartisan efforts to strengthen these programs.

*National Institutes of Health.*—Congress's long-standing bipartisan support for medical research through the NIH has created a scientific enterprise that is the envy of the world and has contributed greatly to improving the health and well-being of all Americans. The foundation of scientific knowledge built through NIH-funded research drives medical innovation that improves health through new and better diagnostics, improved prevention strategies, and more effective treatments.

Nearly 84 percent of the NIH's budget is competitively awarded through almost 50,000 research and training grants to more than 300,000 researchers at over 2,500 universities and research institutions located 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.

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 translate this knowledge into the next generation of diagnostics, therapeutics, and other clinical innovations. This partnership not only lays the foundation for improved health and quality of life, but also strengthens the Nation's long-term economy.

The AAMC thanks Congress for the bipartisan support that resulted in the inclusion of \$32.1 billion in the fiscal year 2016 omnibus spending bill for medical research conducted and supported by the NIH.

If this Nation is to continue to meet current and emerging health challenges, improve our Nation's health, sustain our leadership in medical research, and remain competitive, it is essential to sustain predictable increases in the NIH budget.

The AAMC supports the Ad Hoc Group for Medical Research recommendation that Congress appropriates at least \$34.5 billion through the Labor-HHS-Education spending bill for fiscal year 2017. This \$2.4 billion increase represents 5 percent real growth above the projected rate of biomedical inflation, and will help ensure that NIH-funded research can continue to improve our Nation's health and enhance our competitiveness in today's global information and innovation-based economy.

The AAMC continues to be concerned about the long-lasting impact of the decline in the NIH budget on the next generation of scientists, who see training funds threatened and the possibility of sustaining a career in research diminished. The continued success of the biomedical research enterprise relies heavily on the imagination and dedication of a diverse and talented scientific workforce. Of particular concern is the challenge of maintaining a cadre of clinician-scientists to facilitate translation of basic research to human medicine. NIH supports many innovative training programs and funding mechanisms that foster scientific creativity and exploration.

Additional funding is needed if we are to strengthen our Nation's research capacity, ensure a biomedical research workforce that reflects the racial and gender diversity of our citizenry, and inspire a passion for science in current and future generations of researchers.

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 \$364 million in budget authority for the agency in fiscal year 2017.

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 workforce development 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, 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).

In addition to promoting educational innovations and preparing the workforce for changing delivery systems, the programs also support faculty development, curriculum development, and continuing education opportunities. These are all important components to ensure faculty and providers are equipped to meet the Nation's changing needs and train the next generation of health professionals.

The AAMC joins the Health Professions and Nursing Education Coalition (HPNEC) in recommending \$524 million for these important workforce programs in fiscal year 2017. This funding level is necessary to ensure continuation of all existing Title VII and Title VIII programs while also supporting promising initiatives such as the Pediatric Subspecialty Loan Repayment program, the Clinical Training in Interprofessional Practice program, the Rural Physician Training Grants, and other efforts to bolster the workforce. Additionally, because HRSA has been administering the Behavioral Health Workforce Education and Training (BHWET) Program, we also support the President's fiscal year 2017 budget proposal of shifting funds previously appropriated to the Substance Abuse and Mental Health Services Administration to HRSA.

The AAMC objects to the administration's proposal to eliminate the Title VII Area Health Education Centers (AHEC) program, which, in academic year 2014–2015 alone, trained health professions students in over 11,000 sites across the country, including community-based and ambulatory care settings and CHCs. We appreciate the administration's proposal to enhance the focus on academic support and pre-professional engagement for students from disadvantaged backgrounds through supporting the Health Careers Opportunity Program (HCOP). Research shows that HCOP has helped students from disadvantaged backgrounds throughout the educational pipeline achieve higher grade point averages and matriculate into health professions programs. Continued support for these and the full spectrum of Title VII programs is essential to prepare our next generation of medical professionals to adapt to the changing healthcare needs of the Nation's aging and increasingly diverse population.

In addition to funding for Title VII and Title VIII, HRSA's Bureau of Health Workforce 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 spe-

cialty care workforce for our Nation's children. We strongly support full funding for the Children's Hospitals Graduate Medical Education program at \$300 million in fiscal year 2017.

*Student Aid and the National Health Service Corps (NHSC).*—The AAMC urges the subcommittee 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 \$183,000, and typical repayment can range from \$329,000 to \$480,000.

Along with more than 50 stakeholder organizations, the AAMC urges the subcommittee to provide a discretionary appropriation for the National Health Service Corps (NHSC) in fiscal year 2017. As the Nation faces multiple health professional shortages, sustained investments in workforce programs are necessary to help care for our Nation's most vulnerable populations.

Recognizing that mandatory funding may be provided through other mechanisms, the appropriations committees retain primary responsibility for funding the administrative functions of the NHSC and for avoiding budgetary lapses in future years. We look forward to working with Congress to help ensure a long-term investment in the NHSC without sacrificing other Federal health professions training support.

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 2017 spending bill.

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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 \$2 billion increase in the final fiscal year 2016 omnibus appropriations bill was a much needed increase for NIH. This increase is essential to addressing current and emerging health challenges and building a healthier nation. However, this increase did not make up for funds cut by sequestration in fiscal year 2013 nor did it restore the purchasing power NIH has lost over the past decade. In fact, despite budget increases in each of the past two fiscal years, the NIH budget remains lower than it was in fiscal year 2012 in actual dollars, and since 2003, NIH funding has declined by 22 percent after adjusting for biomedical inflation.

While the President's fiscal year 2017 budget request for NIH would provide a much needed next step by increasing NIH funding above biomedical inflation, AIRI believes that the ongoing and emerging health challenges confronting the United States and the world, and the unparalleled scientific opportunities to address these burdens demand a funding level of at least \$34.5 billion in fiscal year 2017. 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 invaluable scientific opportunities, discourage young scientists, threaten medical progress and continued improvements in our Nation's health, and jeopardize our economic future.

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 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 26 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. However, one of the most destructive and long-lasting impacts of the decline in the NIH budget is on the next generation of scientists, who see training funds slashed and the possibility of sustaining a career in research diminished. The continued success of the biomedical research enterprise relies heavily on the imagination and dedication of a diverse and talented scientific workforce.

In addition, strong support for NIH is critical to the Nation’s competitiveness. This 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 the 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.

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.

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 at least \$34.5 billion for NIH in the fiscal year 2017 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.

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PREPARED STATEMENT OF THE ASSOCIATION OF MATERNAL & CHILD HEALTH PROGRAMS

Chairman Blunt, Ranking Member Murray and distinguished subcommittee members—I am grateful for this opportunity to submit written testimony on behalf of the Association of Maternal & Child Health Programs (AMCHP), our members, and the millions of women, children and families that are served by the Title V Maternal and Child Health (MCH) Services Block Grant. I am asking the subcommittee to support an increase of \$12 million in funding for the Title V MCH Services Block Grant for a total of \$650 million in fiscal year 2017.

At this time, two of the most critical emerging public health issues facing the United States today—the Zika virus and the opioid use epidemic—have explicit consequences for maternal and child health. The Title V program stands ready to play an important role in our Nation's response by employing evidence-based services and strategies that further the program's statutory purpose to improve the health of all mothers and children.

As you may know, the Title V MCH Block Grant already works to (1) ensure access to quality maternal and child health services, (2) reduce infant mortality and preventable diseases and conditions, and (3) provide and promote family centered, community-based, coordinated care for children with special healthcare needs and facilitate the development of community-based systems of services for such children and their families.

Thank you for recognizing the value provided by the MCH Block Grant and providing small increases in funding over the past few years. I know you and your colleagues understand that the current level of funding does not allow us to address all the health needs of our Nation's women, children, fathers and families. We are proud of the recent progress in lowering our Nation's infant mortality rate, reducing teen pregnancy and decreasing the incidence of childhood injury. However, despite recent strides, close to 24,000 babies tragically die each year. Many others are born too soon and cost our society upwards of \$26 billion per year. Gaps in both private and public insurance create barriers for families needing services. Many pregnant women still smoke. The obesity epidemic continues to plague our country and the list goes on and on. In the face of these challenges, public health programs have already borne more than their fair share of deficit reduction with years of cuts and a budget cap that could cut funding even further.

We strongly urge you to reward programs that work and are showing results by providing a \$12 million increase in funding for the Federal investment in the Title V MCH Services Block Grant. States and jurisdictions use the Title V MCH Block Grant formula funds to design and implement a wide range of maternal and child health programs that respond to locally defined needs. For example, the "Every Week Counts" initiative in Oklahoma, funded in part by Title V, demonstrated a 96 percent decrease in early elective deliveries between 2011–2014. In Mississippi, the Title V program is a partner in the Healthy Teens for a Better Mississippi initiative, which recently reported a 15 percent decrease in the State teen birth rate between 2012–2015.

One of the primary focus areas for State Title V programs is supporting systems of services for children and youth with special healthcare needs (CYSHCN). These systems serve a diverse group of children ranging from children with chronic conditions such as asthma or diabetes, to children with autism, to those with more medically complex health issues such as spina bifida or other congenital disorders and

include children with behavioral or emotional conditions. Overall, CYSHCN are defined as children birth to age 21 who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and require health and related services of a type or amount beyond that required by children generally. In a recent national survey, children with a chronic condition represented approximately 15 percent of the entire child population in the United States.

Care coordination is an essential component of delivering services to children and youth with special healthcare needs. State Title V programs improve care coordination by working collaboratively with parents, providers and payers. In Colorado, the Title V CYSHCN program spearheaded an effort to streamline coordination of care by working to reduce duplication of services and unnecessary costs in collaboration with Medicaid and other programs that serve these children.

Another key component of the Title V MCH Block Grant is the Special Projects of Regional and National Significance (SPRANS). SPRANS funding complements and helps ensure the success of State Title V, Medicaid and the Children's Health Insurance Program (CHIP) by driving innovation, training young professionals and building capacity to create integrated systems of care for mothers and children. Examples of innovative projects funded through SPRANS include guidelines for child health supervision from infancy through adolescence (i.e. Bright Futures); nutrition care during pregnancy and lactation; recommended standards for prenatal care; successful strategies for the prevention of childhood injuries; and health safety standards for out of home child care facilities.

SPRANS grants are awarded to training programs at universities across the country including University of Alabama at Birmingham, University of Illinois, University of Oklahoma, University of Tennessee, University of Washington, Tulane University, Medical University of South Carolina and Johns Hopkins University. These institutions utilize SPRANS funding to prepare the next generation of maternal and child health leaders who will go on to serve in communities throughout the United States.

One of the most exciting developments with the Title V MCH Block Grant is a transformation that is happening right now under the leadership of Dr. Michael Lu, Associate Administrator of the Health Resources and Services Administration Maternal and Child Health Bureau. This transformation is focused on three main goals—to reduce burden, maintain flexibility and improve accountability. At its center is an effort to improve our performance measurement framework with a sharpened focus on national outcome measures, national performance measures and evidence-based strategy measures.

This transformation ensures that investments made by the programs support evidence-based or informed strategies. Title V focuses on accountability and delivering results, and we are confident this transformation will build and strengthen that important focus so you can be assured that we are getting the best value for the taxpayer dollar while making real and measurable differences in the lives of our mothers and children. For more information on this effort, my staff will be happy to help arrange for further briefing and information on what this means for your State.

In our view, one of the biggest under-celebrated success stories of recent times are the contributions this subcommittee makes in funding programs such as the Title V MCH Services Block Grant that contribute to substantial progress in reducing infant mortality.

Ensuring that babies are born in optimal health is all the more important considering the recent scientific advances in our understanding about how a baby's early years are critical to building a strong foundation for the rest of their life course. That is the good news—but there also are a few caveats and contradictions. First, there are persistent and unacceptable disparities among racial and ethnic groups that have existed since the data collection began. The black and Native American infant mortality rates are twice the rates of whites, and in some communities it is even three times higher.

The second caveat is that the political will to accelerate progress and eliminate disparities is inconsistent. Perhaps the biggest contradiction is that the United States spends more money on maternity care than any other nation on earth, yet still lags behind 26 other industrialized nations on the key outcome of infant mortality.

Part of the problem is that too often we spend more on high tech treatments—think elective C-sections and neonatal intensive care units—than on basic prevention programs to address risk factors that can lead to poor birth outcomes. For example, we know that breastfeeding, family planning, immunization, smoking cessation and safe sleep are effective in reducing infant mortality. However, funding levels for these key public health programs have never matched actual need, have

slowly eroded over time, and are suffering further threats from budget caps and looming sequestration.

The Collaborative Improvement and Innovation Network (CoIIN) to Reduce Infant Mortality, funded in part by Title V SPRANS dollars, is a public-private partnership to reduce infant mortality and improve birth outcomes. Participants learn from one another and national experts, share best practices and lessons learned, and track progress toward shared benchmarks. Declines in infant mortality, non-medically indicated early term deliveries, the number of women smoking during pregnancy and preterm birth have already been observed in the 13 Southern States where the CoIIN began. These successes illustrate the return on investment in low-tech prevention efforts that can be realized through greater support for Title V.

Congress, of course, has the power of the purse, but has not consistently delivered on its obligation to annually review programmatic funding levels for public health programs and match resources to national needs. Currently funded at \$638.2 million, 1 year of spending on the Title V MCH Block Grant preventive program represents just a half day's spending on the Medicaid program, which at \$1.3 billion a day reached a total of \$475 billion in 2014. This demonstrates once again that our health system spends plenty on healthcare but invests precious little in prevention and public health efforts. In terms of total potential cost savings to our health system, far too little attention is consistently given to health economics and the measurable financial impact of public health and the prevention of disease, illness and early death.

Finally, I would like to briefly mention the work being done by State Title V programs to respond to emerging public health issues such as Zika and the opioid use epidemic, both of which have direct implications for maternal and child health. You may be interested to know that Title V is already stepping in to conduct outreach and surveillance on Zika. In Puerto Rico, for example, the Title V Children with Special Health Care Needs program is providing clinical training and outreach to pediatric providers to ensure they are familiar with CDC guidelines and are able to evaluate infants with possible congenital Zika virus infection in accordance with those guidelines. Regarding opioid use, many State Title V programs are particularly involved with efforts to address neonatal abstinence syndrome (NAS). In Kentucky, the Title V agency has invested significant time working with other public health agencies to identify best practices for treatment options for women with substance use disorders, especially during pregnancy.

Unfortunately, both of these issues represent major threats to the health and wellbeing of our Nation's women, children and their families. Therefore, I also urge the Appropriations Subcommittee to act quickly on emergency supplemental funding packages in order to meet the full demands required to tackle both Zika and the opioid use epidemic.

Thank you again for your support in recent years to increase funding for the Title V MCH Block Grant. We hope to continue to build on recent successes and that you can support the \$12 million increase in funding for the Federal investment in the cost effective and accountable Title V MCH Block Grant.

*About AMCHP:* The Association of Maternal & Child Health Programs is a national resource, partner and advocate for State public health leaders and others working to improve the health of women, children, youth and families, including those with special healthcare needs.

[This statement was submitted by Lori Tremmel Freeman, Chief Executive Officer, Association of Maternal & Child Health Programs.]

## PREPARED STATEMENT OF THE ASSOCIATION OF SCIENCE-TECHNOLOGY CENTERS

### INTRODUCTION

Chairman Blunt, Ranking Member Murray, and members of the subcommittee, thank you for the opportunity to submit written testimony for the record. My name is Anthony (Bud) Rock, and I serve as the President and Chief Executive Officer of the Association of Science-Technology Centers (ASTC). My testimony today addresses the importance of science, technology, engineering, mathematics (STEM), and health education, and will focus specifically on the fiscal year 2017 budgets for offerings at three Federal agencies over which your subcommittee has jurisdiction, including: (1) the 21st Century Community Learning Centers (21st CCLC) program at the Department of Education (ED), which would receive \$1 billion under the President's fiscal year 2017 request; the Office of Museum Services (OMS) at the Institute of Museum and Library Services (IMLS), which would receive \$31.6 million under the President's fiscal year 2017 request; and the Science Education Part-



nership Award (SEPA) program at the National Institutes of Health (NIH), which would receive \$18.5 million under the President's fiscal year 2017 request.

#### OUR REQUEST

On behalf of ASTC and the nearly 400 science centers and museums we represent here in the United States, I urge the subcommittee to continue its strong support for critical STEM and health education programs within ED, IMLS, and NIH as the Labor, Health and Human Services, Education, and Related Agencies appropriations bill for fiscal year 2017 moves forward. Specifically, I ask you to:

- Provide \$1.3 billion for the 21st CCLC program (fiscal year 2017 request is \$1 billion) at ED;
- Provide \$38.6 million for the OMS at IMLS (fiscal year 2017 request is \$31.6 million);
- Provide \$20 million for the SEPA program at NIH (fiscal year 2017 request is \$18.5 million); and
- Continue to thoroughly examine any proposals that would seek to consolidate, reorganize, or eliminate Federal STEM, health, and environmental education programs in an effort to ensure that stakeholder input has been sought and that proven, successful programs are maintained.

Before providing more detail about ASTC and the science center and museum field, I want to first offer a brief snapshot of these Federal programs and why they are so vital to communities across the country.

#### DEPARTMENT OF EDUCATION

For years, the 21st Century Community Learning Centers program has supported the creation of community learning centers that provide academic enrichment opportunities during non-school hours for children—particularly those students who attend high-poverty and low-performing schools. The 21st CCLC program helps students meet State and local student standards in core academic subjects, such as reading and math; offers students a broad array of enrichment activities that can complement their regular academic programs; and offers literacy and other educational services to the families of participating children. ASTC members across the country have utilized 21st CCLC funding to partner with local school districts in an effort to highlight STEM in afterschool.

The President's fiscal year 2017 budget request for the Department of Education includes \$1 billion for the 21st Century Community Learning Centers program—\$167 million less than the amount available for fiscal year 2016. I encourage the subcommittee to continue to support the program by providing \$1.3 billion for fiscal year 2017.

#### INSTITUTE OF MUSEUM AND LIBRARY SERVICES

IMLS is driven by its mission to inspire libraries and museums to advance innovation, lifelong learning, and cultural and civic engagement by providing leadership through research, policy development, and grant making. The agency's Office of Museum Services offers and administers competitive grant programs that undergo a rigorous peer review process in an effort to identify well-designed projects. Just last fall, IMLS announced new grants for 217 museum projects through the Museums for America and National Leadership Grants for Museums programs. Recipients included Exploration Place (Wichita, Kansas), which will use the funding to create a new 400-square-foot aquifer exhibit and ten on-site and outreach STEM educational programs that will incorporate Next Generation Science Standards and 21st Century Skills to elevate the level of water awareness and encourage individual conservation, community policy discussion, creative problem solving, and technological intervention; the Discovery Center at Murfree Spring (Murfreesboro, Tennessee), which will use the funding to expand its STEAM Bus program's outreach visits to two underserved, rural elementary schools and deliver hands-on, discovery-based science lessons to grades 3–5 to address the need for substantive, informal science education in rural elementary schools and to encourage lifelong learning of STEM subjects while supporting Tennessee State curriculum standards; the Oregon Museum of Science and Industry (Portland, Oregon), which will use the funding to help to develop, design, and fabricate two new innovative exhibits in the museum's MOVE thematic area, which will be transformed into a maker-inspired space and present visitors with large-scale design challenges around how things move; and the Madison Children's Museum (Madison, Wisconsin), which will use the funding to model a creative approach to behavioral change encouraging increased physical activity by redesigning stairwells in its historic building and by producing related pro-

gramming to counteract decreased activity and a rise in obesity among Wisconsin children.

The President's fiscal year 2017 budget request includes \$31.6 million for the Office of Museum Services at the Institute of Museum and Library Services. ASTC asks the subcommittee to provide \$38.6 million—the congressionally authorized level of funding—for OMS programs for fiscal year 2017.

#### NATIONAL INSTITUTES OF HEALTH

According to NIH, the goal of the Science Education Partnership Award program is to invest in educational activities that assist in workforce development to meet the Nation's biomedical, behavioral and clinical research needs. By supporting partnerships between researchers and teachers, schools, and institutions like science centers and museums, the SEPA program provides opportunities for students from underserved communities to consider careers in research, provides teachers with professional development in science- and health-related content and teaching skills, and improves community health literacy through exhibits and programming at science centers and museums.

To highlight one recent example from the last round of SEPA grants, the John A. Burns School of Medicine at the University of Hawaii at Manoa received an award to support the Hawaii Science Career Inspiration (HiSCI) program, the goal of which is "to enhance science education resources and training available to teachers and students in disadvantaged communities of Hawaii in order to ensure a maximally large and diverse workforce to meet the Nation's biomedical, behavioral and clinical research needs." The program will provide a number of benefits to teachers, including professional development in molecular biology techniques, the opportunity to attend focus group meetings, and the chance to apply for classroom resources. K–12 students who are interested in health careers will benefit from offerings like a Teen Health Camp, interactions with expert speakers, and mentoring by medical students.

The President's fiscal year 2017 budget request includes \$18.5 million—the same amount available for fiscal year 2016—for SEPA. Given the program's impact and importance, I ask the subcommittee to continue its strong support by providing \$20 million for SEPA for fiscal year 2017.

#### STEM EDUCATION CONSOLIDATION AND REORGANIZATION

With regard to the Federal STEM education consolidation plan first released by the administration for fiscal year 2014 and amended in each of the last three budget requests, I recognize the importance of creating efficiencies within the Federal Government whenever possible. Nevertheless, I continue to have serious concerns about a proposal that would eliminate effective programs that support informal STEM, health, and environmental learning. Integral Federal investments, including the SEPA program itself, have been slated for termination in previous fiscal years. While SEPA now enjoys the support of the administration, programs at the National Aeronautics and Space Administration and the National Oceanic and Atmospheric Administration were not as fortunate and are, once again, on the chopping block. I sincerely appreciate the subcommittee's thoughtful consideration of the harmful effect of the proposed terminations, and ask you to remain steadfast in your support of these programs.

#### ABOUT ASTC AND SCIENCE CENTERS

The Association of Science-Technology Centers is a global organization providing collective voice, professional support, and programming opportunities for science centers, museums, and related institutions, whose innovative approaches to science learning inspire people of all ages about the wonders and the meaning of science in their lives. Science centers are sites for informal learning, and are places to discover, explore, and test ideas about science, technology, engineering, mathematics, health, and the environment. They feature interactive exhibits, hands-on science experiences for children, professional development opportunities for teachers, and educational programs for adults. In science centers, visitors become adventurous explorers who together discover answers to the myriad questions of how the world works—and why. As members of this subcommittee know, it is imperative that we spark an interest in STEM fields at an early age—a key role for community-based science centers and museums, who often undertake this effort with the aforementioned support from ED, IMLS, and NIH, in addition to other Federal agencies.

ASTC works with science centers and museums to address critical societal issues, locally and globally, where understanding of and engagement with science are essential. As liaisons between the science community and the public, science centers

are ideally positioned to heighten awareness of critical issues like agriculture, energy, the environment, infectious diseases, and space; increase understanding of—and exposure to—important and exciting new technologies; and promote meaningful exchange and debate between scientists and local communities. ASTC now counts 651 members, including 486 operating or developing science centers and museums in 42 countries. Collectively, our institutions garner 100 million visits worldwide each year. Here in the United States alone, your constituents pass through science center doors 69 million times to participate in intriguing educational science activities and explorations of scientific phenomena.

Our centers reach a wide audience, a significant portion of which are school groups. Here in the U.S., 94 percent of our members offer school field trips, and we estimate that more than 13 million children attend science centers and museums as part of those groups each year. Field trips, however, are truly just the beginning of what science centers and museums contribute to our country's educational infrastructure, as: 92 percent offer classes and demonstrations; 90 percent offer school outreach programs; 76 percent offer workshops or institutes for teachers; 74 percent offer programs for home-schoolers; 67 percent offer programs that target adult audiences; 65 percent offer curriculum materials; 50 percent offer after-school programs; 34 percent offer youth employment programs; and 22 percent offer citizen science projects.

#### CONCLUSION

With this in mind, and while I am fully aware of the significant budget challenges that face this subcommittee, Congress, and the Nation, I hope you will continue to recognize the important educational offerings science centers and museums make available to students, families, and teachers, along with the essential Federal support they receive from ED, IMLS, and NIH.

Again, I respectfully request that you provide \$1.3 billion for the 21st Century Community Learning Centers program at the Department of Education; \$38.6 million for the Office of Museum Services at the Institute of Museum and Library Services, and \$20 million for the Science Education Partnership Awards program at the National Institutes of Health. In addition, please continue to closely examine any proposals that would seek to consolidate, reorganize, or eliminate Federal STEM, health, and environmental education programs in an effort to ensure that stakeholder input has been sought and that proven, successful programs are maintained.

Thank you once again for your strong support for America's science centers and museums—and for the opportunity to present these views. My staff and I would be happy to respond to any questions or provide additional information as needed by the subcommittee.

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#### 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 10 Agricultural Centers for Disease and Injury Research, Education, and Prevention (Agricultural Centers) funded by the National Institute for Occupational Safety and Health (NIOSH), we respectfully request that the fiscal year 2017 Labor, Health and Human Services appropriations bill include no less than \$339.121 million for NIOSH, including \$28.5 million for the Education and Research Centers and \$25 million for the Agriculture, Forestry and Fishing (AFF) Program from which the Agricultural Centers receive their funding.

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 day more than 8,000 workers are seriously injured on the job, 12 die from an injury suffered at work, and 145 die from work-related diseases. This huge health burden costs industry and citizens an estimated \$4.8 billion per week. This is an especially tragic situation because work-related fatalities, injuries and illnesses most often affect the most productive individuals in our society and are preventable with effective, professionally directed, health and safety programs.

In addition to its extensive research mission, NIOSH is the Federal agency responsible for supporting education and training to prevent work-related injuries and illnesses in the United States. The most significant NIOSH education program aims to provide training to current health professionals while educating the next generation of professionals in university settings. These Education and Research Centers

(ERCs) are regional and national 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 Federal 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 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 employers, healthcare professionals, and workers on issues related to occupational health and safety.

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, work related injury and fatality rates increase as workers get older, with rates for workers 65 years and older nearly three times greater than younger workers. For example, between 2002 and 2022, the number of workers 55 years and older will increase over 100 percent to over 41 million (BLS 2016). 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. Newly emerging risks, such as Ebola and other infectious disease outbreaks, require swift responses to the need for worker protection.

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.

In response to risks posed by potential Ebola exposure, ERCs have delivered educational programs and provided expertise in developing protocols and policies to prevent worker exposure. In one case, a single webinar developed for this purpose reached more than 320 company, academic, and government organizations. Additionally, NIOSH is the Federal agency that is charged with certifying and approving the respirators that are required to protect U.S. workers.

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.

NIOSH also focuses research and outreach efforts on the Nation's most dangerous workplaces. People who work in agriculture, forestry and fishing experience occupational fatality rates that are 6 times to more than 32 times higher than the average for American workers. The Agricultural 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 Agricultural Centers 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 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, immi-

grants, part-time, contract and/or seasonal labor. Many of these agricultural workers are excluded from labor protections, including OSHA oversight, on the vast majority of American farms.

The AFF sector averages 540 fatalities per year resulting in the highest fatality rate 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 the most dangerous farms—those 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 in order to learn about the 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. Similar programs are now offered to prevent serious injuries due to entanglement in other farm machinery.
- Working in partnership with producers and farm owners, the Agricultural Centers have teamed to develop evidence-based solutions for reducing exposure to pesticides and other farm chemicals among farmers, farm workers and their children.
- Commercial Fishing has an annual fatality rate nearly 60 times higher than the rate for all U.S. workers. Research has shown that knowledge of maritime navigation rules and emergency preparedness means survival. An Agricultural Center 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 NIOSH Agricultural 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.
- New tools and work processes developed by Agricultural Center researchers have been introduced and widely adopted by agricultural producers because they reduce musculoskeletal injury and pain and at the same time improve productivity.
- The logging industry has a fatality rate more than 25 times higher than that of all U.S. workers. NIOSH Agricultural Centers, including those in the Southeast and the Northwest, have ongoing studies and outreach efforts 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 wellbeing of others in our communities.

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#### PREPARED STATEMENT OF THE ASSOCIATION OF ZOOS AND AQUARIUMS

Thank you Chairman Blunt and Ranking Member Murray for allowing me to submit testimony on behalf of the Nation's 216 AZA-accredited zoos and aquariums. Specifically, I want to express my support for the inclusion of \$38.6 million for the Institute of Museum and Library Services' (IMLS) Office of Museum Services in the fiscal year 2017 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 183 million visitors, collectively generate more than

\$17 billion in annual economic activity, and support more than 166,000 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.

As valued members of local communities, AZA-accredited 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.

Unfortunately, current funding has allowed IMLS to fund only a small fraction of all highly-rated grant applications. Meanwhile, zoo and aquarium attendance has increased and the educational services zoos and aquariums provide to schools and communities are in greater demand than ever, as is the need for greater funding to develop these programs. AZA-accredited 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 2017 Labor, Health and Human Services, Education, and Related Agencies appropriations bill.

Thank you for your consideration of our comments.

[This statement was submitted by Kristin L. Vehrs, Executive Director, Association of Zoos and Aquariums.]

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#### PREPARED STATEMENT OF THE BRAIN INJURY ASSOCIATION OF AMERICA

Chairman Blunt and Ranking Member Murray, thank you for the opportunity to submit this written testimony with regard to the fiscal year 2017 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. Currently, more than 5 million Americans live with a TBI-related disability.

Increasing numbers of servicemembers 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.

*Administration for Community Living.*—The TBI Act authorizes the Administration for Community Living (ACL) in the Department of Health and Human Services (HHS) to award grants to (1) States, American Indian Consortia and territories to improve access to service delivery and to (2) State Protection and Advocacy (P&A) Systems to expand advocacy services to include individuals with traumatic brain injury. For the past 17 years the 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, the number of State grant awards was reduced to 15, later adding three more States, in order to increase each monetary award from \$118,000 to \$250,000. This means that many States that had participated in the program in past years have now been forced to close down their operations, leaving many unable to access brain injury care.

Increased funding of the program will provide resources necessary to sustain the grants for the 20 States currently receiving funding and to ensure funding for additional States. Steady increases 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. This year we ask for an additional \$1,000,000 to allow for the funding of four more State programs, bringing the total State grant allocation to just over \$7,000,000.

Similarly, the 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. We request \$5,000,000 be allocated to the TBI P&A program to allow them to serve more individuals in each State.

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. An increased appropriation in this area would ensure that each P&A can move towards providing a significant PATBI program with appropriate staff time and expertise.

*CDC—National Injury Center.*—\$10 million (+ \$5 million) for the Centers for Disease Control and Prevention TBI Registries and Surveillance, Brain Injury Acute Care Guidelines, Prevention and National Public Education/Awareness.

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 2014 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.

In 2013, the National Academies of Sciences, Engineering, and Medicine (formerly known as the Institute of Medicine, or the IOM) issued a report calling on the CDC to establish a surveillance system that would capture a rich set of data on sports- and recreation-related concussions among 5–21 year olds that otherwise would not be available. To meet this goal, we request an increase of \$5 million in the CDC budget to establish and oversee a national surveillance system to accurately determine the incidence of concussions, particularly among the most vulnerable of Americans—our children and youth. In the President's fiscal year 2017 budget, a \$5 million increase was included for the Centers for Disease Control and Prevention (CDC) Injury Prevention and Control Center to develop sports concussion surveillance to accurately determine the incidence of sports related concussions among youth ages 5–21.

*NIDILRR TBI Model Systems of Care.*—Funding for the TBI Model Systems in the Administration on Community Living 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 increase funding in fiscal year 2017 for NIDILRR's TBI Model Systems of Care program, in order to add one new Collaborative Research Project. In addition, given the national importance of this research program, the TBI Model Systems of Care should receive "line-item" status within the broader NIDILRR budget. Specifically, the Congressional Brain Injury Task Force requests increased funding by \$13 million over the next 6 years to support the TBI Model Systems program:

- Increase funding for the National Data and Statistical Center by \$100,000 annually to allow all participants to be followed; when re-competed, increase from \$625,000 to \$1 million annually;
- Increase funding for centers by \$150,000 annually from the current average of \$437,500;
- Increase the number of competitively funded centers from 16 to 18; and
- Increase the number of multicenter TBI Model Systems Collaborative Research projects from one to five, each with an annual budget of \$1.5 million (current funding is \$600,000 each).

We ask that you consider favorably these requests for the Administration for Community Living, the CDC, and the NIDILRR's 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.

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#### PREPARED STATEMENT OF THE CAMPAIGN FOR TOBACCO-FREE KIDS

I am Matthew Myers, President of the Campaign for Tobacco-Free Kids. I am submitting this written testimony for the record in support of funding for the Office on Smoking and Health (OSH) at the Centers for Disease Control and Prevention (CDC). We urge the subcommittee to include at least \$210 million for CDC's OSH in the Labor-HHS-Ed appropriations bill for fiscal year 2017.

Tobacco use remains the leading cause of preventable disease and death in the United States. More than 480,000 Americans die from tobacco use each year, and 16 million Americans are currently living with a tobacco-caused disease.<sup>1</sup> Tobacco use is responsible for 32 percent of heart disease deaths, 30 percent of all cancer deaths, 87 percent of lung cancer deaths, and 61 percent of all pulmonary disease deaths.<sup>2</sup> Smoking shortens the life of a smoker by more than a decade and increases the risk of early death much more than other risk factors.<sup>3</sup>

Tobacco use almost always begins during adolescence. Ninety percent of adult smokers begin as teenagers, or earlier.<sup>4</sup> As youth become adults, they typically continue to use tobacco because they have become addicted to nicotine. Given the addictiveness of nicotine, smoking is not simply a matter of choice. Most adult smokers want to quit (nearly 70 percent) and wish they never started (about 90 percent).<sup>5</sup> But overcoming an addiction to nicotine is difficult, and tobacco users often must make multiple quit attempts before they succeed.

Fortunately, we know how to reduce tobacco use. Smoking rates have been cut by more than half since the first Surgeon General's report on the harms from smoking in 1964.<sup>6</sup> According to recent surveys, the smoking rate among adults declined nearly 20 percent from 2005 to 2014, and the smoking rate among 12th graders declined nearly 70 percent between 1997 and 2015.<sup>7</sup> This progress has been driven by the implementation of policies and programs that have proven to be highly effective in preventing youth from starting to use tobacco products and helping adult tobacco users to quit.

These successful efforts to reduce tobacco use have generated enormous gains for public health. People are living longer, healthier lives. Over the past 50 years, tobacco control measures have prevented about eight million people from dying pre-

<sup>1</sup>U.S. Department of Health and Human Services (HHS), *The Health Consequences of Smoking—50 Years of Progress: A Report of the Surgeon General*, 2014, <http://www.surgeongeneral.gov/library/reports/50-years-ofprogress/>.

<sup>2</sup>HHS, *The Health Consequences of Smoking—50 Years of Progress: A Report of the Surgeon General*, 2014.

<sup>3</sup>HHS, *The Health Consequences of Smoking—50 Years of Progress: A Report of the Surgeon General*, 2014.

<sup>4</sup>Substance Abuse and Mental Health Services Administration (SAMHSA), Calculated based on data in 2013 *National Survey on Drug Use and Health*.

<sup>5</sup>HHS, *The Health Consequences of Smoking—50 Years of Progress: A Report of the Surgeon General*, 2014; and Fong, G., et al., "The Near-Universal Experience of Regret Among Smokers in Four Countries: Findings from the International Tobacco Control Policy Evaluation Survey," *Nicotine & Tobacco Research*, Vol. 6, Supplement 3, December 2004.

<sup>6</sup>HHS, *The Health Consequences of Smoking—50 Years of Progress: A Report of the Surgeon General*, 2014.

<sup>7</sup>Ahmed, J., et al., "Current Cigarette Smoking Among Adults—United States, 2005–2014," *Morbidity and Mortality Weekly Report*, November 13, 2015: 64(44) [http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6444a2.htm?s\\_cid=mm6444a2\\_w](http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6444a2.htm?s_cid=mm6444a2_w); and Monitoring the Future, University of Michigan, December 2015.



maturely.<sup>8</sup> About 30 percent of the gain in life expectancy between 1964 and 2012 is due to efforts to reduce tobacco use, an especially remarkable achievement when one considers the enormous medical innovations that occurred during this time.<sup>9</sup>

The CDC's Office on Smoking and Health plays a critical role in continuing our Nation's successful efforts to reduce the toll that tobacco takes on our health. OSH translates science into best practices for reducing tobacco use, provides funding and technical support to implement them, and monitors progress in reducing tobacco use rates.

Since 2012, OSH has funded a national media campaign, Tips from Former Smokers (Tips), to encourage smokers to quit. It features real people discussing the harsh reality of living with a disease caused by smoking, and it has proven to be highly successful and cost-effective. A recent evaluation found that over a 9-week period in 2014 the Tips media campaign motivated 1.8 million smokers to make a quit attempt and helped 104,000 people to quit.<sup>10</sup> CDC estimates that over the past 3 years this media campaign has motivated about 5 million smokers to make a quit attempt, helped 300,000 smokers to quit for good, and saved at least 50,000 people from premature death.<sup>11</sup> It cost just \$393 for each year of life saved, which is considered a "best buy" in public health.<sup>12</sup>

CDC also provides funding to States for quitlines, which provide telephone-based counseling services to help tobacco users to quit and, in some States, provide tobacco cessation medications. Smokers who use quitlines are at least two to three times more likely to succeed than those who try to quit on their own.<sup>13</sup>

In addition, CDC provides grants to all 50 States and the territories to help establish and maintain tobacco prevention and cessation programs at the State and local level. Comprehensive State tobacco programs like the ones CDC helps to maintain have been found to be cost effective. A study of Washington State's tobacco prevention and cessation program found that for every dollar spent by the State on tobacco prevention, the State saved more than \$5 in reduced hospitalization costs.<sup>14</sup>

CDC also conducts important surveillance and other research on tobacco use and its impact on health. For example, the National Youth Tobacco Survey, which CDC conducts with FDA, found that e-cigarette use among youth tripled between 2013 and 2014.<sup>15</sup>

Last year, the House Labor-HHS-Ed appropriations bill for fiscal year 2016 would have reduced funding for OSH by 50 percent, from \$216.5 million to \$105.5 million. This substantial reduction would have undermined CDC's efforts to prevent youth from starting to use tobacco and to help adults to quit. Programs we know are working would have been curtailed and possibly eliminated. CDC would have had to end its successful and cost-effective media campaign. It would also likely have had to reduce funding for State quitlines and State and local tobacco prevention and cessation programs.

We were pleased that the Senate Labor-HHS-Ed appropriations bill for fiscal year 2016 would have provided level funding for OSH and were relieved that the Consolidated Appropriations Act for fiscal year 2016 included a much smaller cut than what the House had proposed.

<sup>8</sup>Holford, T., et al., "Tobacco Control and the Reduction in Smoking-Related Premature Deaths in the United States, 1964–2012," *Journal of the American Medical Association*, January 8, 2014: 311(2).

<sup>9</sup>Holford, T., et al, *JAMA*, January 8, 2014: 311(2).

<sup>10</sup>Neff, L., et al, "Evaluation of the National Tips From Former Smokers Campaign: the 2014 Longitudinal Cohort," *Prev Chronic Dis* 2016; 13: 150556.

<sup>11</sup>Centers for Disease Control and Prevention (CDC), Fiscal Year 2017 Justification of Estimates for Appropriations Committees <http://www.cdc.gov/budget/documents/fy2017/fy-2017-cdc-congressional-justification.pdf>.

<sup>12</sup>Xu, Xin, et al., "Cost-Effectiveness Analysis of the First federally Funded Antismoking Campaign," *American Journal of Preventive Medicine*, 2014.

<sup>13</sup>Fiore, MC, et al., *Treating Tobacco Use and Dependence: 2008 Update—Clinical Practice Guideline*, U.S. Public Health Service, May 2008, [http://www.surgeongeneral.gov/tobacco/treating\\_tobacco\\_use08.pdf](http://www.surgeongeneral.gov/tobacco/treating_tobacco_use08.pdf).

<sup>14</sup>Dilley, Julia A., et al., "Program, Policy and Price Interventions for Tobacco Control: Quantifying the Return on Investment of a State Tobacco Control Program," *American Journal of Public Health*, Published online ahead of print December 15, 2011. See also, Washington State Department of Health, Tobacco Prevention and Control Program, Progress Report, March 2011, <http://www.doh.wa.gov/tobacco/program/reports/2011ProgReport.pdf>. Washington State Department of Health, Tobacco Prevention and Control Program, News Release, "Thousands of lives saved due to tobacco prevention and control program," November 17, 2010, [http://www.doh.wa.gov/Publicat/2010\\_news/10-183.htm](http://www.doh.wa.gov/Publicat/2010_news/10-183.htm).

<sup>15</sup>U.S. Centers for Disease Control and Prevention (CDC), "Tobacco Use Among Middle and High School Students—United States, 2011–2014," *Morbidity and Mortality Weekly Report (MMWR)* 64(14):381–385, April 2015, [http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6414a3.htm?s\\_cid=mm6414a3\\_e](http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6414a3.htm?s_cid=mm6414a3_e).

We urge the subcommittee to provide at least \$210 million for OSH for fiscal year 2017, which is the funding level enacted for fiscal year 2016. Without continued attention and resources, we risk undermining the progress that has been made in reducing the disease and death caused by tobacco use. We risk more cancers, heart disease, respiratory disease, and other tobacco-caused diseases and more people dying years earlier than if they did not smoke. Without urgent action, 5.6 million children alive today will die prematurely from a smoking-related disease.<sup>16</sup>

The Federal Government cannot afford to take a hands-off approach to tobacco use. Tobacco use not only harms the health of tobacco users but also burdens families, the healthcare system, and government budgets. It is responsible for approximately \$170 billion in healthcare costs each year. Nearly 60 percent of these healthcare costs are paid by government programs such as Medicare and Medicaid.<sup>17</sup>

At a time when Congress is working on a bipartisan basis to facilitate the development of new cures and treatments for devastating diseases, the subcommittee should, at a minimum, maintain existing funding for programs that have proven effective at preventing cancers, heart disease, chronic obstructive pulmonary disease (COPD) and other diseases caused by tobacco. At a time of concern about high healthcare costs, the subcommittee should, at a minimum, maintain existing investments to address risk factors like tobacco use that, if left unaddressed, will lead to higher medical costs for treating preventable diseases in the future.

We appreciate the opportunity to share our views on the importance of OSH's work and the need to maintain, at a minimum, its current funding level.

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PREPARED STATEMENT OF DONNA CARMICAL

Thank you for the opportunity to submit testimony regarding the National Institute of Health (NIH) 2017 budget request. My name is Donna Carmical, I am the grandmother of a child who died from pediatric cancer. We lived in blissful ignorance about childhood cancer before Declan was diagnosed. We assumed, like most Americans, that our country was doing everything imaginable to ensure that children would have the most advanced cures and treatments possible. We were wrong, horribly wrong. The National Institute of Health (NIH) is unfairly discriminating against children—the children who have battled cancer, who are battling cancer as well as the children yet to be diagnosed—and doing children a grave injustice. NIH has called childhood cancer “rare” not really a problem and said they could do more if Congress provided more funding. Childhood cancer research is not a priority for NIH.

Despite the fact that Senate report language has urged NIH to increase funding for childhood cancer research in a variety of statements over the past decade, NIH has barely acknowledged this problem. It is hard to understand their rationale. Some compelling facts:

- Childhood cancer is the #1 disease related killer of kids in the U.S., killing thousands of children each and every year.
- The incidence of childhood cancer has been increasing steadily over the past decades. Today 1 in 285 children will be diagnosed with cancer before they reach the age of 20.
- 20 percent of children diagnosed are terminal on diagnosis.
- 60 percent of children diagnosed suffer life altering impacts of treatments, largely due to the lack of pediatric protocols, treatments are often a guess game of experiments and use of downsized adult protocols.
- 95 percent of the survivors of childhood cancer will suffer serious health impacts before they reach the age of 45.
- Adult cancers and childhood cancers are different, while childhood cancer research often benefits adults with cancer the opposite is less common.

Childhood cancer is not one disease, there are 16 major types of cancer and over 100 subtypes. Many of these childhood cancers, like DIPG, AT/RT, receive little to no funding for research. The National Cancer Institute indicates that survival rates for a few childhood cancers like acute lymphoblastic leukemia (ALL) have improved dramatically over the past decades, ironically this is due to the investment in research. NIH makes little mention of statistics regarding the deadly childhood cancers where there has been little to no research for decades.

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<sup>16</sup>HHS, *The Health Consequences of Smoking—50 Years of Progress: A Report of the Surgeon General*, 2014.

<sup>17</sup>Xu, X et al., “Annual Healthcare Spending Attributable to Cigarette Smoking: An Update,” *American Journal of Preventive Medicine*, 2014.

There are many urgent reasons to invest in childhood cancer research yet NIH persists in ignoring this issue at great peril to our children and their children. At last year's Senate hearing, I listened to Dr. Fauci state that NIH spends more than \$3 billion a year trying to cure AIDS. As one Senator said, if you take your medicine, AIDS is not killing anyone in this country. Dr. Fauci stated that \$6 billion a year would be saved by curing AIDS. Thousands of children are dying each year as a result of childhood cancer, and tens of thousands of survivors are irreparably harmed largely because we have done so little to develop pediatric cancer treatments and protocols. A cost analysis about the realities of childhood cancer should be done by NIH. Considering that 16,000 children under the age of 19 are diagnosed each year, one could speculate that curing childhood cancer could save more than \$8 billion a year.

The average age of a child diagnosed with cancer is 8 years old, the long term costs of 380 thousand survivors who have been treated with less than the best treatments has a long term cost to society that hasn't been calculated. If survivors pass the 5 year survival rate—they are statistically considered cured; yet, many children suffer long term impacts, secondary cancers, heart problems, infertility, learning disabilities, stunted growth, hearing problems and more. The increase in survivors, burden of disease, growing number of survivors, as well as number of deaths each year are a great cost to society. An investment in childhood cancer research could deliver big results—pediatric protocols that might result in cures, less invasive treatments, reduction in life altering impacts, etc.

Congress required the Government Accounting Office to review how NIH sets priorities and review the strategic planning process a few years ago, GAO Report 14-246. The Senate required NIH to submit an overarching strategic plan by December 2015. The manner in which NIH sets priorities, how they make decisions that will result in the best outcomes for the American people is difficult to understand and like their budget process less than transparent. The strategic planning process requires that NIH consult internally and externally, that they consult with Congress, stakeholders and the public. Despite stakeholder requests to be part of the strategic planning effort, there was no real outreach to make this happen. The Strategic Plan recently completed does not really comport with the intent of the legislation. The NIH Strategic Plan does not give the public a sense of its 4 year long range strategic goals, short range agency priorities and in fact mostly expands the mission statement. There is no real sense in terms of what kind of results and outcomes the public should expect in terms of a \$120 billion investment. However, NIH strategic plan objectives could all benefit by significant investment in childhood cancer research (advance opportunities in biomedical research, foster innovation by setting NIH priorities, enhance scientific stewardship, excel as a Federal science agency by managing for results).

NIH has a less than transparent budget process, the RCDC indicates that approximately \$6 billion is dedicated to research in the following areas: AIDS, Drug Abuse, Obesity, Tobacco and Alcoholism (recognizing that it is difficult to understand the RCDC portfolio as there is lots of double counting). As a taxpayer and investor in the NIH portfolio the childhood cancer community would like to see NIH re-prioritize their research and find significant investment in childhood cancer research as well as a childhood cancer research line item in their budget. This means investment in research, not more studies but research grants that will result in real research towards finding less invasive treatments for kids and specific childhood cancer drugs, treatments and cures. This is not a matter of more money for NIH, it's a matter of priorities and childhood cancer research should be a national priority. Our kids deserve no less. We need specific childhood cancer research, not more studies and administrative costs.

As reported by *The Atlantic* in a January 2013 article, "there is not enough funding for childhood cancer, specifically. The National Cancer Institute, a Government organization, provides funding for researchers, but only 10 percent of them can move forward with their findings due to budget cuts. Most of the financial support researchers receive is from philanthropists. In the meantime, research that could benefit children on an individual level stays in the lab, and doctors prescribe the same regimens that can be successful, but can also hurt the patient in several ways. Researchers say they are working hard to discover new theories and treatments, but they feel they are being held back." The article goes on to quote, Dr. William Carroll, researcher and director of the cancer institute at New York University saying, "Ninety-six percent of grants (sic childhood cancer) don't get funded . . . There's no doubt there's less funding available, and it's driving people out of the field."

Ironically many pediatric cancer organizations raising funds for childhood cancer research have started by families who have lost a child to pediatric cancer. These families are trying to fund research because their eyes have been opened to

the lack of childhood cancer research funding, they have seen their children suffer and die and they want to create awareness and change this picture for kids. Families desperately want other kids to have cures denied to their own children. The thing is that all the money we can raise by shaving heads, selling lemonade, golf tournaments, car washes, races, bake sales—all of this will not make a dent in this problem. Even the largest organizations that are raising tens of millions of dollars means that cures for children are probably 100 years into the future. Our children need significant Federal investment in childhood cancer research now. Childhood cancer research needs a huge investment, an investment of billions—the kind of investment we have made in AIDS research, EBOLA, etc, the kind of research that will ensure results.

Dr. Collins says we should envision the first AIDS free generation since the virus emerged more than 30 years ago. This success would not have been possible without the substantial investment of dollars in AIDS research, an investment of tens of billions of taxpayer dollars over the last two decades. NIH is seeking a cure, a vaccine and that is great but only around 20 percent of that \$3 billion annually is being used to develop a cure for AIDS. It is time to re-prioritize those programs and as required by law determine where dollars will achieve the most in terms of results and “manage for results” as stated in the NIH strategic plan.

Congress has urged NIH to deal with the issue, the Children’s Health Act (CHA) of 2000 required NIH to study risk factors for childhood cancer and improve outcomes for children with cancer; it required NIH to conduct and support research directly related to disease in children; to insure investment in tomorrow’s pediatric research. It’s hard to understand how these requirements have been carried out—where are the results of this requirement. The National Children’s Study was passed in 2002, Congress appropriated over \$1 billion to this debacle with little to show for these funds, where is the accountability. It is also mind-boggling that this 15 year journey to put together a cohort of 1000,000 children failed at great cost to the taxpayer and it appears not even the remnants of this study will factor into the newly funded Precision Medicine Initiative. As taxpayers and investors in the country’s largest research organization, the public deserves accountability, transparency and answers in how NIH sets priorities and why childhood cancer research is continually ignored in the funding process. It seems the statistical answer is that annually 1.6 million adults are diagnosed with cancer and only around 16,000 children; but, numbers can be used to tell the story you want. If you consider that 77 percent of those 1.6 million adults are over the age of 55, grandparents like me, most of us would tell you that we think childhood cancer research should be a priority in funding decisions! Our grandchildren deserve the best that we can give them, not what’s left over.

What we learned during Declan’s battle has left us forever changed. What we saw and learned during those many months in the hospital is life altering. What we see every single day, what these brave kids, these babies endure—you have to see the horror to understand where the childhood cancer community is coming from. Watching our kids being treated with experimental protocols—knowing there are no cures that the poison, cut and burn techniques are used because this is all our medical community has—it is wrong. The medical community trying to save our kids deserves better treatment options and drugs that will only come through research.

I’m nobody special, just a mother and grandmother. I understand that I don’t know much compared to the wonderful scientists at NIH. I understand that the budget process is hard work for the committees, and resources are limited. But my experience over the past 5 years compels me to fight for kids. I can’t do anything to change what happened to our sweet Declan, but I believe research will result in more funding for those deadly childhood cancers. Much like the prognosis has changed for AIDS over the past decades, I believe research could provide pediatric treatments and protocols that will offer cures to children like Declan in the future. We can’t keep condemning these kids to death year after year and do nothing because of money.

I hope you will investigate and legislate more about the childhood cancer issue. Making childhood cancer research a priority in the Federal budget process would be a tremendous legacy for Congress and has great potential to give children the cures and hope they deserve. Thank you.

#### THE ASKS FOR NIH BUDGET

1. *Transparency*—meet the requirement of GPRA by providing a strategic plan, annual plan, annual performance report on performance.gov. Eliminate double counting in the RCDC information.

2. *Burden of Disease Study*—require NIH to contract out a burden of disease study that considers all aspects of childhood cancer costs to society, annually and over time.
3. *Childhood Cancer Research*—legislate an appropriation floor for funding that should go directly into childhood cancer research grants in keeping with the Children’s Health Act of 2000.
4. Line Item—Require that NIH develop a funding line item for childhood cancer research. This creates transparency and accountability in the budget process.

PREPARED STATEMENT OF THE CENTERS FOR DISEASE CONTROL AND PREVENTION  
COALITION

The CDC Coalition is a nonpartisan coalition of more than 140 organizations committed to strengthening our Nation’s prevention programs. We represent millions of public health workers, clinicians, researchers, educators and citizens served by CDC programs.

We believe Congress should support CDC as an agency, not just its individual programs and urge a funding level of \$7.8 billion for CDC’s programs in fiscal year 2017. We are disappointed President Obama’s budget request would cut CDC’s program level by \$194 million below fiscal year 2016. We acknowledge that the President’s budget provides increased funding for several important programs and initiatives such as combating antibiotic resistance and preventing prescription drug overdose. We are also pleased that the President’s budget would fully allocate the Prevention and Public Health Fund for public health activities. Unfortunately, the President’s budget cuts or completely eliminates other important programs including the REACH program, the Preventive Health and Health Services Block Grant, cancer prevention and control, immunizations and environmental health tracking and we urge you to restore the funding.

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 the Nation’s public health defense system against emerging and reemerging infectious diseases. From aiding in the surveillance, detection and prevention of the Zika virus to playing a lead role in the control of Ebola in West Africa and detecting and responding to cases in the U.S., to monitoring and investigating last year’s multi-state measles outbreak to pandemic flu preparedness, CDC is the Nation’s—and the world’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 infectious disease, laboratory and emergency preparedness and response activities.

Heart disease is the Nation’s No. 1 cause of death. In 2014, over 614,000 people in the U.S. died from heart disease, accounting for nearly 23 percent of all U.S. deaths. More males than females died of heart disease in 2014, while more females than males died of stroke that year. Stroke is the fifth leading cause of death and is a leading cause of disability. In 2014, nearly 133,000 people died of stroke, accounting for about one of every 20 deaths. CDC’s Heart Disease and Stroke Prevention Program, WISEWOMAN, and Million Hearts 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 595,690 deaths from cancer are expected in 2016. In 2013 the direct medical costs of cancer were \$74.8 billion. The 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.

Cigarette smoking causes more than 480,000 deaths each year. CDC’s Office of Smoking and Health funds important programs and education campaigns such as the Tips From Former Smokers campaign that help to prevent tobacco addiction and

provide resources to encourage smokers to quit. We must continue to support these vital programs to reduce the enormous health and economic costs of tobacco use in the United States.

Of the 29.1 million Americans who have diabetes, more than 8 million cases are undiagnosed. Each year, about 1.4 million people are newly diagnosed with diabetes. Diabetes is the leading cause of kidney failure, nontraumatic lower-limb amputations, and new cases of blindness among adults in the United States. The total direct and indirect costs associated with diabetes were \$245 billion in 2012. We urge you to provide adequate resources for the Division of Diabetes Translation which 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 53 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 and we urge you to support adequate funding for the program.

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 1.2 million Americans are living with HIV with 12.8 percent 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.

Sexually transmitted diseases continue to be a significant public health problem in the U.S. Nearly 20 million new infections occur each year. CDC estimates that STDs, including HIV, cost the U.S. healthcare system almost \$16 billion annually.

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 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, more than \$10 is saved in direct and indirect costs. Over the past 20 years, CDC estimates childhood immunizations have prevented 732,000 deaths and 322 million illnesses. We urge you to restore the President's proposed cuts to the Section 317 Immunization program.

Injuries are the leading causes of death for people ages 1–44. Unintentional and violence-related injuries, such as older adult falls, prescription drug overdose, child maltreatment and sexual violence, account for approximately 27 million emergency department visits each year. In 2013, injury and violence cost the U.S. approximately \$671 billion in direct and indirect medical costs. The National Center for Injury Prevention and Control must be adequately funded to prevent injuries and minimize their consequences.

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 it is estimated that up to 57 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 and must be adequately funded.

The National Center for Environmental Health works to protect public health by helping to control asthma, protect from threats associated with natural disasters and climate change, reduce, monitor and track exposure to lead and other hazards and ensure access to safe and clean water. We urge you to support the President's

request for the Climate and Health and Safe Water programs, increase funding for the Childhood Lead Poisoning Prevention, Environmental Health Laboratory and Asthma programs, restore proposed cuts to the National Environmental and Public Health Tracking Network and restore funding for the Built Environment and Health program which was eliminated in 2016.

In order to meet the many ongoing public health challenges outlined above, we urge you to support our fiscal year 2017 request of \$7.8 billion for CDC's programs.

[This statement was submitted by Donald Hoppert, Director of Government Relations, American Public Health Association.]

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PREPARED STATEMENT OF CENTERS FOR INDEPENDENT LIVING

I am writing to support the National Council on Independent Living's request for Congress to reaffirm your commitment to the more than 57 million Americans disabilities by increasing funding in the HHS appropriations for Centers for Independent Living (CILs). I am asking that you increase funding by \$200 million, for a total of \$301 million for the Independent Living line item in fiscal year 2017.

CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. Each of the 365 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services, which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012–2014, CILs provided the core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals. During this same period, prior to transition being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community.

Transition services were added as a fifth core service with the 2014 reauthorization of the Rehabilitation Act within the Workforce Innovation and Opportunity Act. Transition services include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

Every day, CILs are fighting to ensure that people with disabilities gain and maintain control over our own lives. We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions from 2012–2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and States. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services.

In 2016, the Independent Living Program is receiving \$2.5 million less in funding than it was in 2010. It is simply not possible to meet the increasing demand for services and effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to

increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony.

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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 2017 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 (\$236.899 million) and its programs, including: Healthy Homes and Lead Poisoning Prevention Program (\$35 million); National Asthma Control Program (\$30.596 million); and the National Environmental Public Health Tracking Program (\$50 million)
- National Institute of Environmental Health Sciences (NIEHS) (\$717.7 million), to continue support of efforts and research focused on children's health
- Pediatric Environmental Health Specialty Units (PEHSUs) (\$2 million)

The 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 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.<sup>1</sup> Additionally, protecting our children—those born as well as those yet to be born—from environmental hazards is 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. American competitiveness depends on having healthy, educated children who grow up to be healthy productive adults. We strongly urge the subcommittee to support and expand children's environmental health programs.

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 2017.

NATIONAL CENTER FOR ENVIRONMENTAL HEALTH

The National Center for Environmental Health (NCEH) is particularly important in protecting the environmental health of young children. This is especially evident as seen by the recent crisis in Flint, Michigan, where the critical role that core environmental health services must play in protecting our families and communities is front and center. 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. We urge the subcommittee to provide \$236.899 million to NCEH to support these critical programs.

HEALTHY HOMES AND LEAD POISONING PREVENTION PROGRAM

Support critically underfunded childhood lead poisoning prevention activities by funding the CDC Healthy Homes and Lead Poisoning Prevention Program at \$35 million. This funding level will provide grants in all 50 States for surveillance to determine the extent of childhood lead poisoning, as well as educate the public and healthcare providers about lead poisoning, and ensure that lead-exposed children received needed medical and environmental follow-up services. There is no safe level of lead exposure and lead damage can be permanent and irreversible leading to a myriad of academic and behavioral problems in school, failure to graduate and a

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



host of other health impairments later in life. Today over 500,000 children are exposed to unacceptably high levels of lead.

#### NATIONAL ASTHMA CONTROL PROGRAM

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 subcommittee to fund this vital program at \$30.596 million in fiscal year 2017.

#### NATIONAL ENVIRONMENTAL PUBLIC HEALTH TRACKING PROGRAM

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. Today's pediatric health challenges are chronic conditions such as obesity, asthma, learning disabilities, and autism; and for all of these health challenges, environment plays a role in cause, prevention, or mitigation. Recent NIEHS funded studies have shown that exposure to traffic-related air pollution (nitrogen dioxide, PM<sub>2.5</sub>, and PM<sub>10</sub>) during pregnancy and the first year of life is associated with the development of autism. Additional research on likely biological pathways is needed to determine whether these associations are causal. CEHN recommends that \$732.3 million be provided for NIEHS' fiscal year 2017 budget.

#### PEDIATRIC ENVIRONMENTAL HEALTH SPECIALTY UNITS

Pediatric Environmental Health Specialty Units (PEHSUs) form a valuable resource network for parents and clinicians around the Nation and 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, and 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 2017.

Again, thank you for the opportunity to submit this testimony.

[This statement was submitted by Nsedu Obot Witherspoon, M.P.H., Executive Director, Children's Environmental Health Network.]

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#### PREPARED STATEMENT OF THE CHILDREN'S HOSPITALS GRADUATE MEDICAL EDUCATION PROGRAM

The Children's Hospitals Graduate Medical Education (CHGME) program is administered by the Bureau of Health Workforce in the Health Resources and Services Administration at the Department of Health and Human Services. The statement testimony focuses on the purpose of CHGME and its benefit to all children. The testimony includes a request for the subcommittee to appropriate \$300 million for CHGME in fiscal year 2017.

The Children's Hospital Association advances child health through innovation in the quality, cost and delivery of care. Representing more than 220 institutions, the Association is the voice of children's hospitals nationally. As organizations dedicated to protecting and advancing the health of America's children, we thank the sub-

committee for its longstanding bipartisan support of the Children’s Hospital Graduate Medical Education program (CHGME).

A robust pediatric workforce is essential to ensuring that no child lacks access to high quality medical care. The CHGME program supports this goal by providing funding for the training of pediatric providers at independent children’s teaching hospitals, much as Medicare supports training in teaching hospitals that serve primarily adults. 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.

For fiscal year 2016, Congress provided \$295 million for CHGME, the program’s first funding increase since fiscal year 2010. Children’s hospitals are extremely grateful to the subcommittee for this strong commitment to the health of America’s children. For fiscal year 2017, the Children’s Hospitals Association urges the subcommittee to continue to advance children’s health and fund CHGME at its authorized level of \$300 million.

Congress created CHGME in 1999 with bipartisan support because it recognized that the absence of dedicated GME funding for freestanding children’s teaching hospitals created gaps in the training of pediatric providers, which potentially threatened access to care for children. Since then, the CHGME program has had a tremendous impact. Although the 58 hospitals that currently receive CHGME funding comprise only 1 percent of all hospitals, they train approximately half (49 percent) of all pediatric residents—more than 6,000 annually—including 45 percent of all general pediatricians and 51 percent of all pediatric specialists.

CHGME has enabled children’s hospitals to increase their overall training by more than 45 percent since the program began in 1999. In addition, the CHGME program has accounted for more than 74 percent of the growth in the number of new pediatric subspecialists being trained nationwide. Bipartisan legislation reauthorizing CHGME through fiscal year 2018 was enacted in 2014, demonstrating the high level of ongoing support among lawmakers for the program.

However, while much has been achieved in strengthening the pediatric workforce, much remains to be done. Since 2000, the national population of children has grown 3 percent, increasing from 72.3 million to 74.2 million today. At the same time, the healthcare needs of the pediatric population are increasing. The number of children with complex medical conditions is growing at a faster rate than the overall child population, requiring an increased number of specialty care providers.<sup>1</sup>

Unfortunately, funding to train the doctors to serve these children has not kept pace. While children under 18 currently comprise about 23 percent of the U.S. population, only 9 percent of all Federal support for graduate medical education is targeted toward training pediatric providers (combining CHGME and Medicare funding for pediatric residents).<sup>2</sup>

Our Nation’s commitment to children’s healthcare still lags behind our investment in adults with respect to workforce training. Freestanding children’s hospitals, which, as noted, train approximately half of all pediatricians and pediatric specialists, receive almost no Federal GME support through Medicare. Furthermore, analysis commissioned by the Children’s Hospital Association shows that at current funding levels, the average CHGME payment per full-time equivalent (FTE) resident represents only 45 percent of what Medicare GME provides to support training in adult teaching hospitals.

Strengthening funding for CHGME will help children and their families, including those with rare and complex conditions. Nationwide, serious pediatric workforce shortages persist, most acutely among pediatric subspecialties. The most recent survey data available from children’s hospitals shows the following wait times for scheduling appointments due to shortages:

- Developmental pediatrics—Average wait time of 13 weeks
- Endocrinology—Average wait time of 10 weeks
- Neurology—Average wait time of nine weeks
- Pulmonology—Average wait time of eight weeks
- Gastroenterology—Average wait time of five weeks

Localized shortages of pediatric primary care also continue, particularly in certain rural areas.

<sup>1</sup>2014 report, “Summary of Available Evidence and Methodology for Determining Potential Medicaid Savings from Improving Care Coordination for Medically Complex Children”, prepared for Children’s Hospital Association by Dobson DaVanzo & Associates, p. vi.

<sup>2</sup>Sources: U.S. Census Bureau; 2014 report, “Comparative Analysis of GME Funding for Children’s Hospitals and General Acute Care Teaching Hospitals”, prepared for Children’s Hospitals Association by Dobson DaVanzo & Associates.

CHGME has allowed children's hospitals to develop training programs in highly specialized disciplines that target the unique needs of children, including, for example, pediatric surgical oncology, radiation oncology, pediatric pathology and bone marrow transplantation. Only a small number of institutions provide training in some of these areas.<sup>3</sup> Strong ongoing support is vital to maintain and expand programs focused on these subspecialties, and reductions in funding slow the ability to train providers in areas of need. During a period of reduced CHGME funding earlier in this decade, some hospitals reported that their resident FTE levels, which had been increasing in response to demand, leveled off and declined.

Even with CHGME, children's hospitals incur significant additional costs to subsidize their teaching mission, costs that can be as high as \$40 million annually above what they receive from CHGME. These additional costs are particularly difficult to bear given that children's hospitals are typically large Medicaid providers, with more than 50 percent of the average number of days of care covered by Medicaid. Medicaid reimbursement levels in many States remain well below those of private insurance and other government programs, creating another significant fiscal challenge for children's hospitals, particularly as State Medicaid programs have been scaled back significantly in recent years. Without CHGME, hospitals would be at risk of having to cut back training experiences and patient care services impacting children's access to care and the future pediatric workforce.

Furthermore, there are currently no adequate substitutes for CHGME to support training at freestanding children's hospitals. Other potential sources of support, such as Medicaid GME—which has been significantly reduced or eliminated in many States—or competitive grant funding, are not available to many children's hospitals and cannot support training on the scale necessary to meet current and future workforce needs.

The White House's fiscal year 2017 budget proposes converting CHGME to a mandatory funding program, funded at a level of \$295 million annually. Children's hospitals applaud the White House for recognizing the need to provide steady, predictable funding for pediatric training. We also are pleased that the President has supported a funding level consistent with that provided by Congress in fiscal year 2016. Children's hospitals look forward to working with Congress on long-term steps to strengthen CHGME. However, in the present term, we believe that it is vital that Congress continue its history of strong bipartisan support of the program through the annual appropriations process.

The CHGME program is critical to protecting gains in pediatric health and ensuring access to care for children nationwide. 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 the time to take a step forward in pediatric medicine and ensure our children have access to the healthcare services they need.

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. We respectfully request that the subcommittee continue its history of bipartisan support for children's health and fund CHGME at its authorized funding level of \$300 million in the fiscal year 2017 Labor-HHS appropriations bill.

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, Kansas.

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PREPARED STATEMENT OF THE COALITION FOR CLINICAL AND TRANSLATIONAL  
SCIENCE

Chairman Blunt, Ranking Member Murray, and distinguished members of the subcommittee, thank you for your time and your consideration of the priorities of

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<sup>3</sup>Children's Hospital Association fact sheet, "Percentage of Pediatric Specialists Trained at CHGME Hospitals", 2012.

the clinical and translational research community as you work to craft the fiscal year 2017 L–HHS appropriations bill. The community would like to thank you for your past support of the full spectrum of medical research, including the \$2.1 billion funding increase for NIH in fiscal year 2016. Our fiscal year 2017 recommendations include:

- CCTS joins the broader medical research and public health community in asking Congress to provide NIH with \$34.5 billion, an increase of \$2.4 billion over fiscal year 2016, with proportional increases for various Institutes and Centers.
- Please provide the National Center for Advancing Translational Sciences (NCATS) with \$736.6 million in fiscal year 2017 (a proportional 7.47 percent increase).
- Please continue to support and provide meaningful funding increases for the Clinical and Translational Science Awards (CTSA) program at NCATS and oppose the diversion of designated CTSA funds by NCATS to non-CTSA activities at CTSA institutions.
- Please continue to support and provide meaningful funding increases for the Institutional Development Awards (IDeA) program at the National Institute for General Medical Sciences and the Research Centers in Minority Institutions (RCMI) program at the National Institute on Minority Health and Health Disparities.
- CCTS joins the broader medical research community in asking Congress to restore funding for the Agency for Healthcare Research and Quality (AHRQ) to the fiscal year 2015 level of \$363.7 million (an increase of \$29.7 million).
- Please continue to support research training and career development activities at AHRQ, specifically established “K” and “T” award mechanisms.

#### ABOUT THE COALITION FOR CLINICAL AND TRANSLATIONAL SCIENCE

CCTS is the unified voice of the clinical and translational science research community. CCTS is a nationwide, grassroots network of dedicated individuals who work together to educate Congress and the administration about the value and importance of Federal clinical and translational research and research training and career development activities. The Coalition includes the Nation’s leading health research institutions. 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 13 member institutions, CRF has grown to 60 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.

#### 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 \$34.5 billion in fiscal year 2017 so ongoing research projects can be adequately supported and new research activities can be initiated.

#### THE FULL SPECTRUM OF MEDICAL RESEARCH

##### *Clinical and Translational Science Awards (CTSAs)*

Thank you for providing CTSA's with \$500 million in fiscal year 2016. We hope you will provide a proportional increase of nearly 7 percent for CTSAs in fiscal year 2017. Further, we hope funds appropriated by Congress for CTSAs continue to be used by NCATS for infrastructure and core long-term activities at CTSA sites.

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 a handful of centers in 2006, the CTSA program has expanded to 62 of the leading 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.

Recently, based on a recommendation by your subcommittee, 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:

- Strengthen NCATS leadership of the CTSA program;
- Reconfigure and streamline the CTSA Consortium;
- Build on the strengths of individual CTSAs across the spectrum of clinical and translational research;
- Formalize and standardize evaluation processes for individual CTSAs and the CTSA Program;
- Advance innovation in education and training programs;
- Ensure community engagement in all phases of research; and
- 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 continue to be implemented quickly. Another emerging opportunity is to promote collaboration between CTSAs and all NIH Institutes and Centers. 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.

##### *Institutional Development Awards Program (IDeA)*

Thank you for providing the IDeA program with a meaningful funding increase in fiscal year 2016. We hope you will continue to invest in this important program for fiscal year 2017.

The IDeA program broadens the geographic distribution of NIH funding for biomedical research. The program fosters health-related research and enhances the competitiveness of investigators at institutions located in States in which the aggregate success rate for applications to NIH has historically been low. The program

also serves unique populations—such as rural and medically underserved communities—in these States. The IDEa program increases the competitiveness of investigators by supporting faculty development and research infrastructure enhancement at institutions in 23 States and Puerto Rico. Through Centers of Biomedical Research Excellence and IDEa Networks for Biomedical Research Excellence, the IDEa program builds important infrastructure and works to advance the field of clinical and translational research.

RESEARCH CENTERS IN MINORITY INSTITUTIONS (RCMI)

Thank you for providing over \$2 million in new funding for RCMI in fiscal year 2016. Please provide another important funding increase for this emerging program in fiscal year 2017.

RCMI develops and strengthens the research infrastructure of minority institutions by expanding human and physical resources for conducting basic, clinical, and translational research. It provides grants to institutions that award doctoral degrees in the health professions or health-related sciences and have a significant enrollment of students from racial and ethnic minority groups that are underrepresented in biomedical sciences. The RCMI program serves the dual purpose of bringing more racial and ethnic minority scientists into mainstream research and promoting minority health research because many of the investigators at RCMI institutions study diseases that disproportionately affect minority populations.

PREPARED STATEMENT OF THE COALITION OF NORTHEASTERN GOVERNORS

The Coalition of Northeastern Governors (CONEG) is pleased to share with the Subcommittee on Labor, HHS, Education, and Related Agencies this testimony for the hearing record regarding fiscal year 2017 appropriations for the Low Income Home Energy Assistance Program (LIHEAP). The Governors recognize the challenging fiscal decisions facing Congress this year, and deeply appreciate the subcommittee's long-standing support for this vital program. They also recognize the struggles that millions of the Nation's low-income households face to safely heat and cool their homes. Therefore, they urge the subcommittee to provide no less than \$4.7 billion in regular LIHEAP block grant funding in fiscal year 2017. They also urge the subcommittee to provide these funds in a manner consistent with the LIHEAP statutory objective of assisting those households with the highest energy burden; and to ensure that the full appropriated funds are released to the States in a timely manner.

LIHEAP provides a vital lifeline to the most vulnerable households—the elderly, disabled and families with children under the age of 5. Moreover, approximately 20 percent of LIHEAP households have at least one member who served this country in the military. Many of these LIHEAP-eligible households live on fixed, very modest incomes: approximately \$24,000 annually for a two-person household and \$36,450 for four persons. Even though the average cost of heating a home (for all fuel types) slightly decreased in the past year from \$880 to a projected \$779 for the just-ended heating season, many LIHEAP households across the country still struggle to pay their heating bills.

Households in the Northeast face some of the Nation's highest home heating bills due to the extended winter heating season and heating fuel prices that typically exceed national averages regardless of the fuel used. Approximately 30 percent of households in the northeast States rely upon delivered fuels, such as home heating oil or propane. For these delivered-fuel households, the average cost for heating their home—\$1,282 for home heating oil; \$1,368 for propane—is much higher than the national average cost to heat a home. Low-income households that are dependent on delivered fuels face additional challenges in managing their home-heating costs. Compared to homes heating with natural gas or electricity, these delivered-fuel households 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. LIHEAP funds are particularly critical for these households, as the typical LIHEAP benefit covers, on average, one-third of the total home heating bill for the season. If LIHEAP funds are not available to these households, the fuel delivery truck simply does not come.

Reducing home energy costs also presents unique challenges to northeast States. The region has some of the country's oldest homes, many of which have structural issues that make them ineligible for weatherization assistance. Low-income families are more likely to rent than to own a home and therefore have less ability or incentive to make significant energy efficiency upgrades. In addition, the cost of switching

to less expensive heating fuels is often prohibitive and is simply not possible in rural and metropolitan areas not served by natural gas infrastructure.

State LIHEAP programs continue to develop innovative ways to stretch scarce LIHEAP dollars while providing a meaningful benefit to those households with the greatest need. States have negotiated with fuel vendors to receive discounts on delivered fuels and have worked with utilities to develop payment plans to reduce the possibility of service shut-offs once the moratoria end. Even with these cost-efficient changes, in recent years 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. They urge you to fund the core block grant program at the level of no less than \$4.7 billion in fiscal year 2017, and to provide the funds in a manner that is consistent with the LIHEAP statutory objective of addressing those households with the highest energy burden while also ensuring that the full appropriated funds are released to the States in a timely manner.

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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 research funded by 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 of scholars 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.

Recognizing that so many health research issues are inter-related, we request that the subcommittee provide at least \$34.5 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 year 2017 Labor, Health and Human Services, Education and Related Agencies appropriations bill. We also respectfully request the inclusion of the following NIDA specific report language.

*Opioid Misuse and Addiction.* The Committee is concerned about the escalating epidemic of prescription opioid and heroin use, addiction and overdose in the U.S. Nearly 130 people die each day in this country from opioid overdose, making it one of the most common causes of death for adolescents and young adults. The Committee appreciates the important role that research can and should play in the various Federal initiatives aimed at this crisis. The Committee urges NIDA to (1) continue funding research on medications to alleviate pain, including the development of those 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 opioid analgesics to heroin abuse and addiction within affected populations.

*Adolescent Brain Development.* The Committee recognizes and supports the Adolescent Brain and Cognitive Development (ABCD) Study. We know that the brain continues to develop into the mid-twenties. However, we do not yet know enough about the dramatic brain development that takes place during adolescence and how the various experiences children are exposed to during this time (e.g., sports injuries, lack of sleep, marijuana or other substance use) interact with each other and a child's biology to affect brain development and, ultimately, social, behavioral, health and other outcomes. As part of the Collaborative Research on Addiction (CRAN), a trans-NIH consortium involving NIDA, NIAAA, and NCI, and in partnership with NICHD, NINDS, NIMH, NIMHD, and OBSSR, the ABCD study intends to address this knowledge gap. As the largest ever longitudinal brain-imaging study of youth, the ABCD study will follow approximately 10,000 U.S. children from ages 9-10 into early adulthood, who will provide behavioral, neuroimaging, genetic, and other health data throughout development. The ABCD study will yield critical insights into the foundational aspects of adolescence that shape life trajectories. The committee also recommends and recognizes that the cost of this comprehensive study should not inhibit investigator initiated studies or any potential special appropriation for its ongoing support.

*Marijuana Research.* The Committee is concerned that marijuana public policies in the States (medical marijuana, recreational use, etc.) are being changed without the benefit of scientific research to help guide those decisions. The Committee is also concerned that restrictions associated with Schedule 1 of the Controlled Substance Act effectively limit the amount or type of research that can be conducted on mari-

juana or its component chemicals. NIDA is encouraged to continue supporting a full range of research on the effects of marijuana and its components, including policy research focused on policy change and implementation across the country. The Committee also directs NIDA to provide a short report on the barriers to research that result from the classification of marijuana as a Schedule 1 substance.

*Raising Awareness and Engaging the Medical Community in Drug Abuse and Addiction Prevention and Treatment.* Education is a critical component of any effort to curb drug use and addiction, and it must target every segment of society, including healthcare providers (doctors, nurses, dentists, and pharmacists), patients, and families. Through its NIDAMeD initiative, NIDA is advancing addiction awareness, prevention, and treatment in primary care practices through seven Centers of Excellence for Physician Information. Intended to serve as national models, these centers target physicians-in-training, including medical students and resident physicians in primary care specialties (e.g., internal medicine, family practice, and pediatrics). NIDA also developed, in partnership with the Office of National Drug Control Policy, two online continuing medical education courses on safe prescribing for pain and managing patients who abuse prescription opioids. These courses were viewed by over 200,000 individuals and completed for credit by over 100,000 clinicians combined. The Committee continues to be pleased with NIDAMed, and 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.

*Medications Development.* The Committee recognizes that new technologies are required for the development of next-generation pharmaceuticals. 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 research is the development of safe and effective vaccines or antibodies that target specific addictive drugs, like nicotine, cocaine, and heroin, or drug combinations. The Committee is encouraged 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 ultimately prevent addiction.

*Drug Treatment in Justice System Settings.* The Committee understands that providing evidence-based treatment for substance use disorders offers the best alternative for interrupting the drug use/criminal justice cycle for offenders with drug problems. Untreated substance using offenders are more likely to relapse into drug use and criminal behavior, jeopardizing public health and safety and taxing criminal justice system resources. Treatment has consistently been shown to reduce the costs associated with lost productivity, crime, and incarceration caused by drug use. This reality represents a significant opportunity to intervene with a high-risk population. In 2013 NIDA launched the Juvenile Justice Translational Research on Interventions for Adolescents in the Legal System (JJ-TRIALS) program to identify and test strategies for improving the delivery of evidence-based substance abuse and HIV prevention and treatment services for justice-involved youth. The JJ-TRIALS initiative will provide insight into the process by which juvenile justice and other service settings can successfully adopt and adapt existing evidence-based programs and strategies to improve treatment for at-risk youth. The Committee supports this important work and asks for a progress report in the next appropriations cycle.

*Electronic Cigarettes.* The Committee understands that electronic cigarettes (e-cigarettes) are increasingly popular among adolescents. Lack of regulation, easy availability, and a wide array of cartridge flavors may make them particularly appealing to this age group. In addition to the unknown health effects, early evidence suggests that e-cigarette use may serve as an introductory product for youth who then go on to use other tobacco products, including conventional cigarettes, which are known to cause disease and lead to premature death. Early evidence also reveals that these devices are widely used as tools for smoking derivatives of marijuana (hash oil, “shatter,” etc.) The Committee requests that NIDA fund research on the use and consequences of these devices.

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 emphasize the fact that drug addiction is 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 lethality due to heroin and synthetic fentanyl, as well as the continued abuse of prescription opioids and the recent increase in availability of designer drugs 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 2017 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.

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PREPARED STATEMENT OF THE COLUMBIA UNIVERSITY

On behalf of my colleagues at Columbia University, I would like to thank this subcommittee and the rest of your congressional colleagues for the long standing support this subcommittee has provided to this Nation’s biomedical research enterprise. Your support of the National Institutes of Health (NIH) and other research agencies is vital to the long term health of this Nation.

I am very pleased to submit this testimony which recommends funding the NIH in fiscal year 2017 at a level of \$34.5 billion. The fiscal year 2017 appropriation for NIH must build on and expand the agency’s capacity to fund research in order to improve quality of life, address the rising costs of caring for our aging population, and reduce illness and disability.

The National Institutes of Health (NIH) is the largest source of funding for biomedical research in the world. More than 83 percent of NIH funds are distributed through competitive grants to over 300,000 scientists employed at universities, medical schools, and other research institutions in all 50 States and nearly every congressional district. To date, 145 Nobel Laureates were funded by NIH over the course of their careers, including the 2014 winner of the Nobel Prize in Chemistry. My own research has been supported almost entirely by NIH grants over a period of nearly 40 years. NIH has produced an outstanding legacy of discoveries that have improved health, saved lives, and generated new knowledge. Many of these advances arose from scientists investigating questions designed to explain fundamental molecular, cellular, and biological mechanisms. Research supported by NIH has also expanded our understanding of the molecular roots of various cancers and led to important insights into how microbial communities affect a range of chronic diseases including obesity and diabetes. In addition, research supported by NIH led to the development of innovative technologies and created entirely new global industries that are a critical component of our Nation’s economic growth. Investment in biomedical research funded by NIH has supported discoveries that lowered death

and disability from polio, heart disease, and cancer, prolonging life and reducing suffering. New scientific breakthroughs have given us the opportunity to dramatically accelerate desperately needed progress on therapies for thousands of diseases and conditions.

One example of the importance of NIH funding is the developing Precision Medicine Initiative which is aimed at tailoring medical care to the individual patient. The Precision Medicine Initiative will pioneer a new model of patient-powered research that promises to accelerate biomedical discoveries and provide clinicians with new tools, knowledge, and therapies to select which treatments will work best for which patients.

Most medical treatments have been designed for the “average patient.” As such treatments can be very successful for some patients but not for others. This is changing with the emergence of precision medicine that takes into account individual differences in people’s genes, environments, and lifestyles. Precision medicine gives clinicians tools to better understand the complex mechanisms underlying a patient’s health, disease, or condition, and to better predict which treatments will be most effective.

Advances in precision medicine have already led to powerful new discoveries and several new treatments that are tailored to specific characteristics of individuals, such as a person’s genetic makeup, or the genetic profile of an individual’s tumor. This is leading to a transformation in the way we can treat diseases such as cancer. Patients with breast, lung, and colorectal cancers, as well as melanomas and leukemias, for instance, routinely undergo molecular testing as part of patient care, enabling physicians to select treatments that improve chances of survival and reduce exposure to adverse effects.

Translating initial successes to a larger scale will require a coordinated and sustained national effort. Through collaborative public and private efforts, the Precision Medicine Initiative (PMI) will leverage advances in genomics, emerging methods for managing and analyzing large data sets while protecting privacy, and health information technology to accelerate biomedical discoveries. The Initiative will also engage a million or more Americans to volunteer to contribute their health data to improve health outcomes, fuel the development of new treatments, and catalyze a new era of data-based and more precise medical treatment.

A key feature of the PMI is to build a large research cohort that will provide the platform for expanding our knowledge of precision medicine approaches and that will benefit the Nation for many years to come. In March 2015, NIH Director, Dr. Francis Collins formed the PMI Working Group of the Advisory Committee to the NIH Director to develop a plan for creating and managing such a research cohort. In September 2015, this working group released its report which identified a number of high value scientific opportunities including:

- Development of quantitative estimates of risk for a range of diseases by integrating environmental exposures, genetic factors, and gene-environment interactions;
- Identification of determinants of individual variation in efficacy and safety of commonly used therapeutics;
- Discovery of biomarkers that identify people with increased or decreased risk of developing common diseases;
- Use of mobile health technologies to correlate activity, physiologic measures and environmental exposures with health outcomes; determination of the health impact of heterozygous loss of function mutations;
- Development new disease classifications and relationships;
- Empowerment of participants with data and information to improve their own health; and
- Creation of a platform to enable trials of targeted therapy.

#### PRECISION MEDICINE AT COLUMBIA UNIVERSITY

Precision medicine in practice and research at Columbia University is realized via collaborations across all of our academic centers, ranging from law, business, ethics and engineering to the basic sciences, converging on clinical practice. Our diverse scientific expertise readily contributes to enhancing precision medicine: genomics, proteomics, bioinformatics, systems biology, data and computational science, as well as core science, engineering, and other disciplines. The results should improve patient outcomes, reduce adverse treatment effects, and yield greater patient satisfaction.

In particular, Columbia University Medical Center’s (CUMC’s) efforts play a vital role in Columbia University’s institution-wide priority to realize the potential of precision medicine. Through the efforts of the Precision Medicine Task Force, the Uni-

versity's internal expertise is coordinated and growing. The synergies of CUMC specialists' biomedical expertise with that of other University faculty and leaders will define the medical, legal, policy, and economic implications anticipated from the applications of precision medicine.

Many of the more than 40 state-of-the-art shared research facilities within CUMC participate in precision medicine initiatives. Already our discoveries are making a difference. For example, using genomic analysis, scientists sequence the DNA of individual tumors to find FDA-approved drugs likely to target crucial areas of each tumor's genetics. In addition, scientists developed a way to recreate an individual's immune system in a mouse, an unprecedented tool for customized analysis of autoimmune diseases such as type 1 diabetes. The tool also may be useful to analyze a patient's response to existing treatments or to develop new therapies.

Among CUMC's plans for precision medicine is a comprehensive biological repository that will store and allow analysis of 100,000 patient specimens to enable translational researchers to develop new therapies that, in turn, will transform the way clinicians diagnose and treat patients. Along with our clinical partner, the New York-Presbyterian Hospital, we are founding members of the New York Genome Center, which has brought together all of the New York academic, medical, and industry leaders in a consortium dedicated to translating genomic research into clinical solutions for treating disease.

#### CONCLUDING THOUGHTS

The rising costs of drug development and healthcare in the U.S. suggest that a new model of clinical care is needed that will rely on robust and innovative health research. Drug discovery has slowed, and only a small fraction of proposed medications is successfully translated into approved and prescribed therapeutics. Clinical trials of new therapeutics may often be underpowered due to unrecognized heterogeneity in disease pathogenesis among enrolled patients such that drugs that are highly beneficial for a definable subset are rejected because the majority of patients in the trial fail to respond. The discovery of genetic factors underlying disease can be used to identify drug targets as well as to selectively give those drugs to patients that are most likely to have the greatest efficacy with the least adverse effects. Understanding the genetics of disease and biomarkers will allow us to rationally select patient groups that are most likely to respond to particular agents, not only improving "numbers" (e.g., lower cholesterol) but also improving health outcomes (e.g., reduced heart attacks) and quality of life.

To be successful, it would be ideal and cost effective to study a single, very large cohort that would provide sufficient power to study ostensibly all relatively common diseases within a single cohort. The barriers to such a study have been the relatively high cost of ascertaining cohort members, collecting comprehensive clinical and experimental data, and following participants over time. Over the last decade, however, a number of technological advances have converged to dramatically reduce the barriers to the assembly, evaluation, and analysis of cohorts of one million or more people—including information technology improvements related to data storage and computation; vast improvements in DNA sequencing; and the emergence of electronic health records.

Given these rapid and ongoing transformations in medicine, technology, and society, the time is right for the U.S. to undertake an ambitious expanded research agenda focused on development and implementation of precision medicine to improve the health of the Nation.

We urge the subcommittee to provide the NIH with an appropriation totaling \$34.5 billion to enable the NIH and its partners in the biomedical research enterprise to develop better, more targeted, more effective, and more efficient healthcare for society.

Thank you for the opportunity to provide this information to the subcommittee.

[This statement was submitted by Dr. Tom Maniatis, Director, Columbia Precision Medicine Initiative.]

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#### PREPARED STATEMENT OF COMMUNITY SERVINGS

We are pleased to submit this testimony to the members of this subcommittee on the urgency of continuing to support the Ryan White Program through the Appropriations process and increasing funding for the domestic HIV/AIDS portfolio in fiscal year 2017. This support and funding will be decisive for achieving the goals of the National HIV/AIDS Strategy (NHAS) 2020, the AIDS Free Generation and halting the devastating effects of the HIV Treatment Cascade.

Community Servings is part of a nationwide coalition, the Food is Medicine Coalition, of over 80 food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PWH) and other chronic illnesses. In our service area, we provide half a million medically tailored, home delivered meals annually. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

*Why Food and Nutrition Services (FNS) Matter for PWH*

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PWH at any stage of their illness. For those who are most mobile, there are congregate meals, walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective core medical service in the Ryan White Program. These services play a critical role in ensuring that PWH enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

*FNS as a Care Completion Service Unique to Ryan White*

Social and economic interventions, most often in the form of care completion service like food and nutrition services, are fundamental to making healthcare work for PWH. Support services for PWH are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PWH are poised to remain connected to care and treatment.

*Access to FNS and the Triple Aim*

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PWH.

*Better Health Outcomes*

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines.<sup>1</sup> Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections<sup>2</sup> and the resulting decreases in their healthcare costs. Compare these outcomes to PWH who are food insecure, who have:

<sup>1</sup>Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at [https://www.health.ny.gov/diseases/aids/ending\\_the\\_epidemic/docs/key\\_resources/housing\\_and\\_supportive\\_services/chain\\_factsheet3.pdf](https://www.health.ny.gov/diseases/aids/ending_the_epidemic/docs/key_resources/housing_and_supportive_services/chain_factsheet3.pdf).

<sup>2</sup>Academy of Nutrition and Dietetics (formerly American Dietetic Association). HIV/AIDS Nutrition Evidence Analysis Project at [http://www.adaevidencelibrary.com/conclusion.cfm?conclusion\\_statement\\_id=250707](http://www.adaevidencelibrary.com/conclusion.cfm?conclusion_statement_id=250707) Accessed 29 July 2012.

- Lower CD4 counts & lower likelihoods of having undetectable viral loads<sup>3</sup>
- More ER visits<sup>4</sup> & increased morbidity and mortality<sup>5</sup>
- More missed primary care appointments & reduced use of antiretroviral therapy.<sup>6</sup>

#### *Lower Healthcare Costs*

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PWH. A recent study comparing participants in a medically-tailored FNS program vs. a control group within a local managed care organization found that average monthly healthcare costs for PWH fell 80 percent in first 3 months after receiving FNS.<sup>7</sup> If hospitalized, nourished clients' costs were 30 percent lower, their hospital length of stay was cut by 37 percent and they were 20 percent more likely to be able to be discharged to their homes rather than a more expensive institution.<sup>8</sup> Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

#### *Improved Patient Satisfaction*

Studies show nutrition counseling improves quality of life.<sup>9</sup> Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

#### *FNS and the National HIV/AIDS Strategy (NHAS)*

Access to FNS for PWH is fundamental to fulfilling the goals of the NHAS.

- NHAS Goal: Reducing new HIV infections:* PWH who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96 percent of the time,<sup>10</sup> thus, FNS is key to prevention.<sup>11</sup>
- NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV:* PWH who receive effective FNS are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines.<sup>12</sup>
- NHAS Goal: Reducing HIV-related disparities and health inequities:* By providing FNS to PWH who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities.<sup>13</sup>
- NHAS Goal: Achieving a more coordinated national response to the HIV epidemic:* There remains a tremendous variation by State in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White HIV Program all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including Ryan White and the ACA.

<sup>3</sup>Aidaia A., Yomogida M., and the HIV Food & Nutrition Study Team (2011); Singe AW, Weiser SD McCoy, SI. Does Food Insecurity Undermine Adherence to Antiretroviral Therapy? A Systematic Review. *AIDS Behav* (2015) 19:1510–1526.

<sup>4</sup>Ibid.

<sup>5</sup>Anema A, Chan K, Yip B, Weiser S, Montaner JSG, Hogg RS. Impact of food insecurity on survival among HIV-positive injection drug users receiving antiretroviral therapy in a Canadian cohort. 141st APHA Annual Meeting, Nov. 2–6, 2013. Boston, MA. Abstract #: 290277.

<sup>6</sup>Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).

<sup>7</sup>Gurvey J, Rand K, Daugherty S, Dinger C, Schmeling J, Laverty N. Examining Health Care Costs Among MANNA Clients and a Comparison Group. *J Prim Care Community Health*. (2013) 4:311–317.

<sup>8</sup>Ibid.

<sup>9</sup>Rabeneck L, Palmer A, Knowles JB, Seidehamel RJ, Harris CL, Merkel KL, Risser JMH, Akrabawi SS. A randomized controlled trial evaluating nutrition counseling with or without oral supplementation in malnourished HIV-infected patients. *J Am Diet Assoc*. (1998) 98: 434–438; Schwenk A, Steuck H, Kremer G. Oral supplements as adjunctive treatment to nutritional counseling in malnourished HIV-infected patients: randomized controlled trial. *Clinical Nutrition* (1999) 18(6): 371–374.

<sup>10</sup>M. S. Cohen et al., Prevention of HIV-1 Infection with Early Antiretroviral Therapy. *N. Engl. J. Med.*(2011) 365, 493–505 . HPTN 052.

<sup>11</sup>Palar K, Laraia B, Tsai A, Weiser SD Food insecurity is associated with sexually transmitted infections and HIV serostatus among low income adults in the National Health and Nutrition Examination Survey (NHANES) (1999–2010). Presented at the American Public Health Association 141st Annual Meeting, Boston, MA, November 5, 2013.

<sup>12</sup>Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014.

<sup>13</sup>Available at Weiser SD, Frongillo EA, Ragland K, Hogg RS, Riley ED, Bangsberg DR. Food insecurity is associated with incomplete HIV RNA suppression among homeless and marginally housed HIV-infected individuals in San Francisco. *J Gen Intern Med*. (2009) 24(1):14–20.

*Conclusion*

We are deeply aware of the difficult decisions that face the members of the Subcommittee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PWH live healthy and productive lives, produces better overall health outcomes and reduces healthcare costs.

Along with our colleagues, we appreciate the opportunity to offer this testimony regarding the fiscal year 2017 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you.

[This statement was submitted by David B. Waters, CEO, Community Servings.]

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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 2017 appropriations of the agencies under the subcommittee's jurisdiction. COSSA recommends that the National Institutes of Health (NIH) receive at least \$34.6 billion in fiscal year 2017 and urges the subcommittee to appropriate \$7.8 billion for the Centers for Disease Control and Prevention (CDC), \$170 million for the National Center for Health Statistics (NCHS), \$364 million for the Agency for Healthcare Research and Quality (AHRQ), \$728 million for the Institute of Education Sciences (IES), and \$78.7 million for the Department of Education's International Education and Foreign Language programs.

COSSA serves as a united voice for a broad, diverse network of organizations, institutions, communities, and stakeholders who care about a successful and vibrant social science research enterprise. It represents the collective interests of all fields of social and behavioral science research, including but not limited to sociology, anthropology, political science, psychology, economics, statistics, language and linguistics, population studies, law, communications, educational research, criminology and criminal justice research, geography, history, and child development. It is appreciative of the Subcommittee's and the Congress' continued support of NIH, CDC, NCHS, AHRQ, IES, and Title VI and Fulbright-Hays programs. Strong, sustained funding for these agencies is essential to our national priorities of better health and economic revitalization.

*NIH (at least \$34.6 billion), U.S. Department of Health and Human Services*

Since 2003, NIH funding has declined by 23 percent after adjusting for biomedical inflation, despite recent budget increases provided by the Congress the past two fiscal years. The agency's budget remains lower than it was in fiscal year 2012 in actual dollars. COSSA appreciates the subcommittee's leadership and its long-standing bipartisan support of NIH, as demonstrated by the \$2 billion increase provided in the fiscal year 2016 omnibus spending bill. There are, however, ongoing and emerging health challenges confronting the United States and the world. To that end, COSSA believes that to address these challenges the NIH requires a funding level of at least \$34.6 billion in fiscal year 2017, representing 5 percent real growth above the projected rate of biomedical inflation.

As this subcommittee 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." COSSA, however, remains extremely concerned about continued criticism of the NIH's funding decisions and the accompanying mischaracterization of NIH-supported research. The ongoing targeting of specific grants produces a chilling effect across the scientific community.

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 cru-

cial 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.

The fundamental understanding of how disease works, including the impact of social environment on 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. Congress' continued support of the BRAIN (Brain Research through Advancing Innovative Neurotechnologies) initiative is an important first step to begin to address these challenges.

Thanks to 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.

COSSA continues to applaud the administration's Precision Medicine Initiative (PMI) and the NIH's involvement of its Office of Behavioral and Social Sciences Research (OBSSR) in the planning phase of this million-person cohort, including its commitment to including behavioral, physiological, and environmental measures. To this end, recent advances in mobile and wireless sensor technologies, also known as mHealth, to assess these behavioral, physiological, and environmental parameters are an integral aspect of this initiative. This technology has great potential to transform medical research. OBSSR has led the NIH's efforts in using, understanding, and training scientists in the use of mHealth which allows for more rapid and accurate assessment in modifying behavior, biological states, and contextual variables. Its support of the NIH mHealth Training Institutes is designed to break down to scientific silos by bringing together scientists from diverse fields to enhance the quality of mHealth research.

*CDC (\$7.8 billion) and NCHS (\$170 million), U.S. Department of Health and Human Services*

COSSA urges the subcommittee to appropriate \$7.8 billion for the Centers for Disease Control and Prevention (CDC), including \$170 million for the CDC's National Center for Health Statistics. As the country's leading health protection and surveillance agency, the CDC works with State, local, and international partners to keep Americans safe and healthy. CDC relies on insights from the social and behavioral sciences to "explore the effects of behavioral, social, and cultural factors on public health problems" and to rigorously evaluate public health interventions, policies, and programs.<sup>1</sup>

Scientists from 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, and in identifying and understanding health disparities. The social and behavioral sciences also 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.

COSSA requests \$170 million in budget authority for the National Center for Health Statistics (NCHS), the Nation's principal health statistics agency. 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.

<sup>1</sup>Deborah Holtzman, M. Neumann, E. Sumartojo, and A. Lansky, "Behavioral and Social Sciences and Public Health at CDC," *Morbidity and Mortality Weekly Report*, December 22, 2006, <http://www.cdc.gov/mmwr/preview/mmwrhtml/su5502a6.htm>.

The requested increase for NCHS' budget would be used to support NCHS's major data collection systems—the National Vital Statistics System, the National Health Interview Survey, the National Health and Nutrition Examination Survey, and the National Health Care Surveys. The increase would also allow NCHS to continue its expansion of electronic death reporting, which improves the availability and specificity of data on deaths of public health importance, such as from prescription drug overdoses.

*AHRQ (\$364 million), U.S. Department of Health and Human Services*

COSSA urges the subcommittee to appropriate \$364 million for the Agency for Healthcare Research and Quality (AHRQ). AHRQ funds research on improving the quality, safety, efficiency, and effectiveness of America's healthcare system. It is the only agency in the Federal Government with the expertise and explicit mission to fund research on improving healthcare at the provider level (i.e., in hospitals, medical practices, nursing homes, and other medical facilities). Its work complements—not duplicates—research supported by other HHS agencies.

AHRQ-funded research provides us with the evidence and tools we need to tackle some of the healthcare system's greatest challenges. For example, AHRQ-funded research:

- Has been instrumental in reducing healthcare-associated infections (HAIs) by 17 percent in 5 years, translating to 87,000 lives and nearly \$20 billion in healthcare costs saved.
- Improves care for people suffering from multiple chronic conditions, a group that accounts for two-thirds of U.S. healthcare spending.
- Helps doctors make better decisions and improve patients' health by taking advantage of electronic health records and other IT advances.

AHRQ reports and data give us vital information about the state of the U.S. healthcare system and identify areas we can improve. The congressionally-mandated National Healthcare Quality & Disparities Report is the only comprehensive source of information on healthcare quality and healthcare disparities among racial and ethnic minorities, women, children, and low-income populations. AHRQ's Medical Expenditure Panel Survey (MEPS) collects data on how Americans use and pay for medical care, providing vital information on the impact of healthcare on the U.S. economy.

COSSA urges the subcommittee to ensure robust support for AHRQ's critical health services research.

*IES (\$728 million), U.S. Department of Education*

The Institute of Education Sciences is the research arm of the Department of Education. COSSA recommends a funding level of \$728 million for IES, which would restore funding for the Regional Educational Laboratories and the National Center for Special Education Research to the fiscal year 2010 funding level. As this subcommittee knows, IES supports research and produces statistics and data to improve our understanding of education at many levels—early childhood, elementary and secondary education, and higher education. Research examining special education, rural education, teacher effectiveness, education technology, student achievement, reading and math interventions, and many other areas is also supported by IES.

More important, IES-supported research has substantially improved the quality of education research, led to the development of early interventions for improving child outcomes, generated and validated assessment measures for use with children, and led to the establishment of the "What Works Clearinghouse" for education research (highlighting interventions that work and identifying those that do not). There is an increasing demand for evidence-based practices in education. Adequate funding for IES would support studies that not only increase knowledge of the factors that influence teaching and learning, but also apply those findings to improve educational outcomes. Further, adequate funding will allow IES to continue to support this important research, data collection and statistical analysis, and dissemination. The COSSA-recommended funding level will also allow IES to build upon existing findings and to conduct much-needed new research.

*International Education and Foreign Language Programs (\$78.7 million), U.S. Department of Education*

The Department of Education's International Education and Foreign Language programs play a significant role in developing a steady supply of graduates with deep expertise and high quality research on foreign languages and cultures, international markets, world regions, and global issues. COSSA urges a total appropriation of \$78.7 million (\$70.15 million for Title VI and \$8.56 million for Fulbright-Hays) for these programs. This sum represents a modest increase in funding, which



would broaden opportunities for students in international and foreign language studies. It would also allow for the strengthening of the U.S.' human resource capabilities on strategic areas of the world that impact our national security and global economic competitiveness.

Thank you for the opportunity to present this testimony on behalf of the social and behavioral science research community. Please do not hesitate to contact me should you require additional information.

*Governing Associations*

American Anthropological Association	Association of American Law Schools
American Association for Public Opinion Research	Law And Society Association
American Economic Association	Linguistic Society of America
American Educational Research Association	Midwest Political Science Association
American Political Science Association	National Communication Association
American Psychological Association	Population Association of America
American Society of Criminology	Society for Personality and Social Psychology
American Sociological Association	Society for Research in Child Development
American Statistical Association	

[This statement was submitted by Angela L. Sharpe, MG, Deputy Director, Consortium of Social Science Associations.]

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PREPARED STATEMENT OF THE CORPORATION FOR NATIONAL AND COMMUNITY SERVICE

Dear Chairman Blunt and Ranking Member Murray: We write to respectfully urge your support for the Corporation for National and Community Service (CNCS) in fiscal year 2017 Appropriations and for an increased funding level for CNCS to \$1.47 billion which includes \$720.1 million for AmeriCorps State and National; \$35 million for the NCCC; \$142.1 million for VISTA; \$444.3 million for the National Service Trust (Education Awards); and \$24.6 million for State Commissions. Thank you for the opportunity to provide written testimony for the record. We also greatly appreciate your efforts in the fiscal year 2016 Omnibus to ensure AmeriCorps received additional funding. While there are many critical priorities under your jurisdiction, we know programs like CNCS' AmeriCorps meet some of the most vital public needs in communities around the country, leverage significant additional private funding and resources, and save the government money in the long run. A recent study put the return on investment in AmeriCorps at 4:1.

The Corps Network (TCN) represents the Nation's 130+ Service and Conservation Corps (Corps) as they harness the power of youth and veterans to tackle some of America's greatest challenges and transform their own lives. Corps are comprehensive youth development service programs that work in all states and the District of Columbia and enroll around 24,000 youth each year. Corps follow a model of adult mentors (Crewleaders) guiding crews of youth (Corpsmembers, ages 16–25 and veterans up to 35) which perform community and conservation service projects in urban areas or on public lands. Tied to those projects, Corpsmembers receive educational, workforce development, and supportive services. Corps enroll diverse Corpsmembers, and prioritize providing opportunity for disconnected youth to have opportunities to serve in AmeriCorps. Over 60 percent of Corpsmembers were below the poverty line, unemployed, not in school and had no High School Diploma/GED, or were formerly incarcerated or court-involved.

As a result of CNCS' AmeriCorps State and National, AmeriCorps VISTA, and AmeriCorps NCCC, Corps are able to leverage additional match funds to accomplish a wealth of conservation, infrastructure improvement, and human service projects identified as critical by local communities and partners. Recently, 45 AmeriCorps members with Washington Conservation Corps were deployed in response to flooding in Grays Harbour County, WA and conducted damage assessments, debris removal, and volunteer support. Another instance of severe weather in Van, Texas led to the engagement of nine AmeriCorps members from American Youth Works Texas Conservation Corps in the set up and management of a volunteer reception center that saw more than 1,000 volunteers. Corps also work on other infrastructure projects like transportation and water infrastructure and specifically engage veterans in Conservation and Fire Corps and Native Americans through conservation and restoration projects on Tribal land like in Acoma Pueblo and the Navajo Nation. Many Corps improve and preserve our public lands and national parks while others

provide energy conservation services, including weatherization and alternative energy installation. Corps also restore natural habitats and create urban parks and gardens.

In particular, The Corps Network urges your support for the Summer Opportunity Youth Initiative. According to CNCS' budget justification, "The request includes an Opportunity Youth initiative that would enable up to 8,000 disconnected youth to serve as AmeriCorps members during the summer, giving them a chance to help their communities while exploring potential career paths, developing skills, and earning an education award they can use for college. CNCS is interested in expanding funding for summer service programs that expand opportunity for youth." There is a significant need to reengage disconnected youth, and help them get on a path to furthering their education and into the workforce.

The Corps Network is presently operating a full-time Opportunity Youth Service Initiative with support from CNCS to enroll thousands of out of school and out of work youth in national service environmental stewardship initiatives at Corps around the country. While serving, they gain career skills, hands on work experience, and advance their education. They also earn AmeriCorps education awards that help encourage them to enroll in postsecondary education/training. As of 2015, there are approximately 5.8 million young Americans who meet the definition of Opportunity Youth. These young men and women represent a social and economic opportunity: many of them are eager to further their education, gain work experience and help their communities, but need meaningful ways to do so. Not investing in these young people, and those that might be at-risk of fully disconnecting at 14 or 15, means greater cost to taxpayers and society in the hundreds of thousands of dollars later on as they remain disconnected.

CNCS has worked for many years in communities around the country and with non-profit organizations like ours to address the most pressing social challenges with significant buy-in from local public and private entities. We are pleased to be able to participate in new partnerships that CNCS has established through the President's National Service Task Force and urge your support for encouraging more of such partnerships. For example, The Corps Network has been able to enroll court-involved youth in AmeriCorps and partner them with mentors while helping them be seen as an asset to their community, not a liability. Additionally, we've worked with CNCS and the U.S. Department of Agriculture to enroll AmeriCorps members in a 21st Century Conservation Service Corps to accomplish important work on public lands and help address the millions of dollars in backlogged maintenance and meet wildfire suppression and fighting needs.

As you can see, CNCS supports many important initiatives that engage a diverse population of youth serving in Corps including veterans, Native Americans and individuals with disabilities. With increasing strains on public support systems, it is more important than ever to support this type of community-needs-based service to fill-in the gaps of need. There is also significant demand for these positions, with all of our Corps being oversubscribed and CNCS reporting in 2011, 582,000 AmeriCorps applications were received with only 82,000 slots available. Through your support, we can provide more service opportunities for our youth to reengage in education, work, and their communities and get on a productive path for the United States' continued growth and prosperity.

Thank you for the opportunity to provide written testimony for the record. We again respectfully urge your support for CNCS and for increased funding of \$1.47 billion for the Corporation for National and Community Service in fiscal year 2017. Thank you for your time and consideration of this testimony.

Sincerely,

[This statement was submitted by Mary Ellen Sprenkel, President & CEO, Corporation for National and Community Service.]

PREPARED STATEMENT OF THE COUNCIL OF ACADEMIC FAMILY MEDICINE

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 CAFM collectively includes family medicine medical school and residency faculty, community preceptors, residency program directors, medical school department chairs, research scientists, and others involved in family medicine education. We urge the subcommittee to appropriate at least \$59 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 subcommittee fund the Agency for Healthcare Research and Quality (AHRQ) at no less than \$364 million in base discretionary funding to support research vital to primary care.

More than 44,000 primary care physicians will be needed by 2035, and current primary care production rates will be unable to meet the demand, noted the authors of a recent article in *Annals of Family Medicine* (Pettersen, et al Mar/Apr 2015) The programs we support in our testimony will help build upon our Nation's workforce and health infrastructure. They improve primary care services that will produce better health outcomes and help reduce the ever rising costs of healthcare. In this difficult fiscal climate, we hope the subcommittee will recognize that the production of a robust primary care workforce is a necessary investment that 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 and timely workforce needs. The most recent authorization directs HRSA to prioritize training in the new competencies that provide care in the patient-centered medical home model. It also calls for the development of infrastructure within primary care departments, as well as innovations in team management of chronic disease, integrated models of care, and health transitions.

As experimentation with new or different models of care continues, departments of family medicine and family medicine residency programs will rely further on Title VII, Section 747, grants to help develop curricula and research training methods for transforming practice delivery. Passage of the Medicare Access and Chip Reauthorization Act (MACRA), which changes Medicare payment methodologies to incentivize alternatives to traditional fee for service, increases the need for adequate Section 747 funding. Some areas in need of support for future training include: training in clinical environments that are transforming to include integrated care with other health professionals (e.g. behavioral health, care coordination, nursing, oral health); development and implementation of curricula to give trainees the skills necessary to build and work in interprofessional teams that include diverse professions; and development and implementation of curricula to develop leaders and teachers in practice transformation.

The Advisory Committee on Training in Primary Care Medicine and Dentistry December 2014 report states that “[r]esources currently available through Title VII, Part C, sections 747 and 748 have decreased significantly over the past 10 years, and are currently inadequate to support the [needed] system changes.”<sup>1</sup> In order to address some of these challenges, the Advisory Committee recommends that Congress increase funding levels for training under the primary care training health professions program, both in fiscal year 2017 and for the next 5 years. The current funding of \$38.9 million does not allow for the pent up demand caused by reduced and stagnant funding levels. Only 35 schools or institutions were able to obtain grant funding in the fiscal year 2015 cycle; we expect approximately another 37 awards to be made in fiscal year 2016, and no new awards in fiscal year 2017 without additional appropriations. Family medicine alone has over 100 departments in medical schools and over 450 residencies.

A recent study in the *Annals of Family Medicine* (Phillips and Turner, March/April 2012) stated that “Meeting this increased demand [for primary care physician production] requires a major investment in primary care training.” The study continues, “Expansion of Title VII, Section 747 with the goal of improving access to primary care would be an important part of a needed, broader effort to counter the decline of primary care. Failure to launch such a national primary care workforce revitalization program will put the health and economic viability of our Nation at risk.”

Primary care health professions training grants under Title VII is vital to the continued development of an updated workforce designed to care for the most vulnerable populations. We urge your continued support for this program and an increase in funding to \$59 million in fiscal year 2017 to allow for a robust competitive funding cycle. The following information contains real world examples of Title VII at work in several of your districts.

**KANSAS:** The University of Kansas in Wichita used primary care training grant funding to improve research and scholarly activities in residency programs and to

<sup>1</sup> <http://www.hrsa.gov/advisorycommittees/bhpradvisory/actpcmd/Reports/eleventhreport.pdf>.

improve Patient Centered Medical Home (PCMH) training through curriculum changes and junior faculty mentoring. The faculty development grant greatly improved scholarly production, research and teaching and faculty retention.

*ALABAMA:* The University of South Alabama used primary care training funding to lead in curricular innovation being the first to incorporate multimedia education, standardized patients, and point of care evidence-based teaching and patient-based evaluation of medical students. This resulted in a new primary care patient curriculum for first and second year medical students.

*RHODE ISLAND:* Brown University has used primary care training funds to transform medical student education and the PCMH, including new curricula and rotations, as well as the facilitation work to transform 10 family medicine teaching practices and to run three national “think tanks” to discuss practical and theoretical issues related to models for practice transformation.

*ARKANSAS:* University of Arkansas Medical School (UAMS) in Little Rock used a five year grant to increase their medical student family medicine match by 67 percent over 3 years. The Federal increase relied heavily on the Arkansas growth. Grant strategies included program development, increasing program visibility, and support for interested students.

#### AGENCY FOR HEALTH CARE RESEARCH AND QUALITY (AHRQ)

We are grateful that Congress included budget authority for AHRQ in the fiscal year 16 omnibus funding bill. This strengthens the viability of an agency that supports primary care research around the country. The majority of research funding in the United States supports research of one specific disease, organ system, cellular, or chemical process—not for primary care despite 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 caring for patients, better organizing 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 such research and to help disseminate it nationwide.

There are six areas that AHRQ highlights 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. Primary care research needs more adequately trained researchers and AHRQ deliberately promotes this training. Below are some examples of successful AHRQ work that supports primary care practice and patient safety:

*OKLAHOMA:* The University of Oklahoma, College of Medicine, in Oklahoma City, created the Oklahoma Primary Healthcare Improvement Center to serve as a resource to the emerging Oklahoma Primary Healthcare Extensions System. Part of the Evidence Now Initiative, this grant will support the dissemination of patient-centered outcomes research findings into practices, support 300 primary care practices in risk management around smoking cessation, blood pressure control, statins, and low-dose aspirin, and evaluate the intervention’s impact on practice performance. Similar to Oklahoma, as part of the nationwide AHRQ Evidence Now initiative, grants fund six other collaboratives in 11 additional States; they are all led by primary care (general internal medicine or family medicine) and are all working to help small to medium primary care practices do a better job of reducing cardiovascular risk in their patients. These other collaboratives, include: Northwest (led by Group Health, Seattle)—involving practices in Washington, Idaho, and Oregon; Southwest (led by U Colorado DFM)—involving Colorado and New Mexico; Midwest (led by Northwestern)—involving Wisconsin, Illinois, and Indiana; North Carolina (led by UNC); Virginia, (led by VCU) and New York (led by NYU).

*MISSOURI:* AHRQ funding has allowed the University of Missouri to build infrastructure for patient-centered outcomes research in three arenas. The first study evaluated the advantages and disadvantages of endovascular vs. open surgery for legs with inadequate blood flow. The second project focuses on improved discharge plans from skilled nursing facilities through improved primary care connections. Missouri partnered with the AAFP to create a national research network to improve chronic pain for the third project.

*NEW MEXICO:* The University of New Mexico School of Medicine has used AHRQ funding to create and evaluate an innovative model for disseminating evidence-based information to rural primary care providers. A Health Extension Regional Officer conducted individual academic detailing visits with providers to reinforce evidence-based information on the management of chronic non-cancer pain in con-

tinuing professional development workshops. This detailing identified and adapted information for the longitudinal learning needs of the rural providers.

*OREGON:* Through AHRQ funding at the Oregon Health & Science University, the Rural Practice-based Research Network is helping lead Healthy Hearts Northwest by recruiting 100 primary care practices to develop team-based quality improvement infrastructure improvements in small to medium-size practices. The Evidence Now Initiative will attempt to reach 130 practices, operating as health extension agents in frontier communities.

AHRQ's funds research into multiple chronic conditions—a hallmark of primary care practice. Additionally, funding will be used for data collection to identify how healthcare teams are organized and if care and outcomes look different in team based practices, compared to traditional practices.

Highlighting the success of AHRQ's patient safety initiatives, a 2014<sup>2</sup> report showed hospital care to be much safer in 2013 compared to 2010. The report noted a decline of 17 percent in hospital-acquired conditions, in harm to 1.3 million individuals, as well as 50,000 lives saved, and \$12 billion savings in health spending during that period. Research related to the most common acute, chronic, and comorbid conditions treated by primary care clinicians is lacking. AHRQ supports this research that is essential to create a robust primary care system for our Nation. 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. Sufficient funding for AHRQ can help researchers address these problems. We recommend the subcommittee fund AHRQ at a base, discretionary level of at least \$364 million for fiscal year 2017.

[This statement was submitted by Todd Shaffer, MD, MBA, 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. CSWE is a nonprofit national association representing more than 2,500 individual members and more than 750 baccalaureate and master's programs of professional social work education. I will focus my testimony on the importance of fostering a skilled, sustainable, and diverse social work workforce to meet the health-care needs of the Nation through professional education, training, and financial support programs for social workers at the Department of Health and Human Services (HHS) and the Department of Education (ED). CSWE requests:

Agency	Account	Program	Funding requested
HHS	HRSA	Title VII Health Professions Programs	\$280 million
HHS	HRSA	Title VII Mental and Behavioral Health Education and Training Program	\$1 million for the Leadership in Public Health Social Work Education (LPHSWE) Program
HHS	HRSA	HRSA Behavioral Health Workforce Education and Training Grant Program	\$56 million
HHS	SAMHSA	Minority Fellowship Program	\$11.7 million including at least \$6.4 million for MFP core activities
ED	N/A	Pell Grant	\$5,935 for the maximum Pell Grant
ED	N/A	GAANN	\$31 million
ED	N/A	Loan Repayment Programs	Support without a cap on forgiveness
HHS	NIH	Overall Funding for National Institutes of Health	\$34.5 billion

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

<sup>2</sup>Publication # 15-0011-EF.

than the average for all occupations through 2022.<sup>1</sup> While CSWE understands the difficult funding decisions facing Congress, it is my hope that the Committee will prioritize funding for health professions training in fiscal year 2017 to help ensure that the Nation continues to foster a sustainable, skilled, and culturally competent workforce that will be able to accommodate the increasing demand for social work services and meet the unique health-care needs of diverse communities.

#### HEALTH RESOURCES AND SERVICES ADMINISTRATION

##### TITLE VII AND TITLE VIII HEALTH PROFESSIONS PROGRAMS

CSWE urges the Committee to provide \$280 million in fiscal year 2017 for the health professions education programs authorized under Titles VII of the Public Health Service Act and administered through the Health Resources and Services Administration (HRSA). HRSA's Title VII health professions programs represent Federal programs designed to train health-care providers in an interdisciplinary way to meet the health-care needs of all Americans, including the underserved and those with special needs, and expand minority representation in the health-care workforce. The Title VII programs, for which social workers and social work students are eligible, provide loans, loan guarantees, and scholarships to students, as well as grants to institutions of higher education and non-profit organizations to help build and maintain a robust health-care workforce.

CSWE urges the Committee to provide \$1 million for the Leadership in Public Health Social Work Education (LPHSWE). This funding supports the next generation for public health and social workers and ensures critical leadership, resources, and training.<sup>2</sup>

#### HEALTH RESOURCES AND SERVICES ADMINISTRATION

##### BEHAVIORAL HEALTH WORKFORCE EDUCATION AND TRAINING PROGRAM

CSWE urges the Committee to provide \$56 million for the Behavioral Health Workforce Education and Training (BHWET) Program at HRSA. Previously, this program was a partnership between HRSA and the Substance Abuse and Mental Health Services Administration (SAMHSA); however, the President's budget request would move this funding to HRSA to administer the program. The BHWET program has provided critical support to increase the number of behavioral health professionals. This program builds on HRSA's mental and behavioral health training efforts by providing important grant funding for mental health and substance abuse workforce serving children, adolescents, and transitional-age youth at risk for developing, or who have developed, a recognized behavioral health disorder.<sup>3</sup> This program is significant to CSWE and social work. In 2015, for the first year of this program, social work programs were awarded about \$19,087,780 and we estimate about 4,196 students will be served through this program. This makes important progress in meeting the workforce needs for mental and behavioral health providers.

The President's fiscal year 2017 budget request would continue to support this program by providing \$56 million. This funding is an increase of \$6 million above the fiscal year 2016 enacted level and would expand behavioral health workforce activities and award additional grants. CSWE urges the Committee to support \$56 million for the BHWET Grant Program. CSWE also encourages the Committee to include language specifying that accredited master's-level schools and programs of social work must be CSWE accredited to receive funding. Similar criteria has been placed on mental and behavioral health grants at HRSA.

#### SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION

##### MINORITY FELLOWSHIP PROGRAM

CSWE urges the Committee to appropriate the highest level possible for the Minority Fellowship Program (MFP) in fiscal year 2017. 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

<sup>1</sup>U.S. Bureau of Labor Statistics. 2012. Occupational Outlook Handbook: Social Workers, <http://data.bls.gov/cgi-bin/print.pl/oco/ocos060.htm>. Retrieved March 21, 2014.

<sup>2</sup>HRSA Congressional Budget Justification for fiscal year 2017 <http://www.hrsa.gov/about/budget/budgetjustification2017.pdf>. Retrieved February 26, 2016.

<sup>3</sup>[http://www.integration.samhsa.gov/integrated-care-models/safety\\_net\\_providers](http://www.integration.samhsa.gov/integrated-care-models/safety_net_providers).

fields.<sup>4</sup> 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.

In addition, CSWE also administers funds for the Minority Fellowship Program-Youth (MFP-Y). The purpose of the program is to reduce health disparities and improve behavioral health-care outcomes for racially and ethnically diverse populations by increasing the number of culturally competent master's-level behavioral health professionals serving children, adolescents, and populations in transition to adulthood (aged 16-25).

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 struggles to keep pace with the demands facing these health professions. Severe shortages of mental health professionals often arise in underserved areas due to the difficulty of recruitment and retention in the public sector. Nowhere are these shortages more prevalent than within Tribal communities, where mental illness and substance use go largely untreated and incidences of suicide continue to increase. Studies have shown that ethnic minority mental health professionals practice in underserved areas at a higher rate than non-minorities. Also, a direct positive relationship exists between the numbers of ethnic minority mental health professionals and the utilization of needed services by ethnic minorities.<sup>5</sup> The President's fiscal year 2017 budget request includes \$11,669,000 to support six MFPs, two MFP-Y, two MFP-AC grants, and three technical assistance and evaluation support contracts. CSWE urges the Committee to support this request, including at least \$6.4 million for MFP core activities, the same as the fiscal year 2016 enacted level.

#### DEPARTMENT OF EDUCATION: STUDENT AID PROGRAMS

CSWE supports full funding to bring the maximum individual Pell Grant to \$5,935 in fiscal year 2017. Pell Grants are one of the most important programs in increasing access and improving affordability to ensure that all students, regardless of their economic circumstances, can access 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 like Pell Grants, many low-income individuals would not be able to access higher education, and in turn, would not acquire the 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 include social work in the GAANN program in future years. Inclusion of social work would enhance graduate education opportunities in social work, which is critically needed to foster a sustainable health professions workforce. CSWE urges the Subcommittee to provide the fiscal year 2012 pre-sequester funding level of \$31 million for the GAANN Program and include social work as an area of national need.

CSWE supports efforts at ED to help students with high debt loads serve in low paying positions. The income-driven repayment programs and the Public Service Loan Forgiveness program, in particular, provide financial stability and support to

<sup>4</sup> 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/>.

<sup>5</sup> U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services. (2001). *Mental Health: Culture, Race, and Ethnicity—A Supplement to Mental Health: A Report of the Surgeon General*. Retrieved from <http://www.surgeongeneral.gov/library/mentalhealth/cre/sma-01-3613.pdf>.

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 loan forgiveness.

NATIONAL INSTITUTES OF HEALTH: SUPPORT FOR RESEARCH

CSWE supports the community's recommendation for at least \$34.5 billion for the National Institutes of Health (NIH) in fiscal year 2017 and advocates for continued investments in biomedical and health-related research that incorporates the social and behavioral science research necessary to better understand, and appropriately address, the needs of high-risk populations including children, racial and ethnic minority populations, and geriatric populations.

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.]

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PREPARED STATEMENT OF THE CROHN'S AND COLITIS FOUNDATION OF AMERICA  
SUMMARY OF FISCAL YEAR 2017 RECOMMENDATIONS

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- \$34.5 Billion for the National Institutes of Health (NIH). Increased funding for the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK).
  - Continued Focus on Digestive Disease Research and Education at NIH, and Support for the Inflammatory Bowel Disease (IBD) Portfolio.
  - \$1,000,000 for the Centers for Disease Control and Prevention's (CDC) IBD Epidemiology Activities.
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Chairman Blunt and distinguished members of the Subcommittee, thank you for your time and your consideration of the priorities on behalf of the Crohn's and Colitis Foundation of America (CCFA). 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.

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).

NATIONAL INSTITUTES OF HEALTH

For NIH, CCFA recommends:

- \$34.5 billion for NIH
- \$2.165 billion for the National Institute of Diabetes and Digestive and Kidney Disease (NIDDK)

We at 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, CCFA would like to highlight the research being accomplished by NIDDK which warrants the increase for NIH.

In recent years researchers have made significant progress in the fight against IBD. The CCFA encourages the subcommittee to continue its support of IBD research at NIDDK and NIAID at a level commensurate with the overall increase for each institute. CCFA commends NIH for continuing to support cross-cutting research at multiple institutes and centers through the Human Microbiome Project supported through the Common Fund. Specifically, CCFA is excited about the NIH-



funded research being done characterizing the gut microbial ecosystem for diagnosis and therapy in IBD. CCFA applauds NIDDK for its strong commitment to IBD research through the Inflammatory Bowel Disease Genetics Research Consortium which has contributed to furthering our understanding of how these diseases operate on a molecular and biological level. The Committee urges NIDDK to continue efforts to identify the etiology of the disease in order to inform the development of cures for inflammatory bowel disease.

CENTERS FOR DISEASE CONTROL AND PREVENTION

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, CCFA, and CDC, has piloted the Ocean State Crohn's and Colitis Registry (OSCAR), which includes both pediatric and adult patients. Since 2008, 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 an NIH research award.

—Since 2006, CDC epidemiologists have been working in conjunction with CCFA and a large health maintenance organization to better understand the natural history of IBD as well as factors that predict the course of disease.

CCFA commends CDC for implementing a robust IBD epidemiology study and communicating study results with the public. In this regard, recent research has shown a shifting paradigm in the populations that IBD affects. IBD is historically prevalent in Jews of European descent (Ashkenazi Jews), however, minority populations in the United States are increasingly affected. One study of IBD patients in California looked at interracial variations in disease characteristics. It included Caucasian, African American, Hispanic, and Asian subjects. Asians were diagnosed with IBD at older ages than Caucasians and African Americans, and Hispanics were diagnosed at older ages than Caucasians. Incidence also seemed to rise over the course of a period of time. Nationwide epidemiologic data (such as incidence and prevalence) about minority populations with IBD is very limited and as the incidence of IBD rises in minority populations, investment in this area becomes increasingly important.

CCFA supports the continued exploration of the disease burden of IBD, and communication of these findings to patients and providers in an effort to improve current interventions and inform best public health practices in managing IBD.

CCFA encourages CDC to continue to support a nationwide IBD surveillance and epidemiological program at \$1 million in fiscal year 2017 to expand current efforts to identify the incidence and prevalence of IBD, specifically in minority populations.

Conclusion

CCFA understands the challenging budgetary constraints 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 NIH. On behalf of our patients, we appreciate your consideration of our views. We look forward to working with you and your staff.

[This statement was submitted by Laura Wingate, Vice President, Patient and Professional Services.]

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PREPARED STATEMENT OF CURE ALZHEIMER'S FUND

Chairman Blunt, Ranking Member Murray, and members of the Senate Labor, Health & Human Services, Education, and Related Agencies Appropriations Subcommittee, I am Tim Armour, President and CEO of Cure Alzheimer's Fund. I appreciate the opportunity to thank Congress for the additional funding for Alzheimer's disease research through NIH, and to submit this written testimony to re-

quest at least an additional \$400 million in fiscal year 2017 for Alzheimer's disease research at the National Institutes of Health (NIH).

Cure Alzheimer's Fund is a national nonprofit, based in Massachusetts that funds research throughout the United States and internationally, starting with the genetic aspects of Alzheimer's disease. It is the belief of Cure Alzheimer's Fund that we will not be able to cure the disease if we do not know what causes the disease.

Cure Alzheimer's Fund has a venture philanthropy model which invests in proven talent and empowers them to succeed; invests in ideas early for the biggest possible impact; evaluates potential projects rigorously, but funds them quickly; takes smart risks for the biggest rewards; and has a focused strategy, but is nimble to react to, and take advantage of, new developments. Cure Alzheimer's Fund takes no intellectual property interest in the research it supports.

Since its founding in 2004, Cure Alzheimer's Fund has invested almost \$40 million in Alzheimer's research. Often, this investment has been in projects that are considered too risky or early for NIH investment. But because Cure Alzheimer's Fund has provided the vital initial philanthropic investment, researchers are able to prove their concept and compile the necessary data to secure NIH investment.

The \$40 million invested by Cure Alzheimer's Fund has led to more than \$45 million in NIH grants for a total of more than \$85 million invested in Alzheimer's disease research as a result of Cure Alzheimer's Fund's willingness to fund basic research.

The research supported by these investments have led to more than 160 published papers which have been cited more than 10,000 times. This demonstrates the value of "priming the pump" for research and investment in early stage and basic research.

Cure Alzheimer's Fund has assembled a Research Consortium of the leading Alzheimer's researchers. These researchers say that Alzheimer's research is budget, not science, constrained. We are entering a very exciting stage of Alzheimer's disease research with a very real possibility of meeting the National Plan's goal of preventing and effectively treating Alzheimer's disease by 2025.

Recent advancements funded by Cure Alzheimer's Fund include research on the effect of gamma secretase modulators, how beta amyloid is an anti-microbial and part of the body's immune system, moving from gene discovery to therapy development, and the Alzheimer's in a Dish project which will dramatically speed the screening of therapeutic interventions.

These advancements were funded initially by Cure Alzheimer's Fund and then were supported by NIH and others once the proof of concept was established. They are concrete examples of the importance of public-private partnerships and the role each will play in finally curing Alzheimer's disease.

Cure Alzheimer's Fund has worked closely with other advocacy organizations and with Congressional members and staff to showcase the need for additional resources for Alzheimer's disease research. Cure Alzheimer's Fund is very thankful and appreciative of the efforts of this Subcommittee in providing more funding for Alzheimer's disease research at NIH. Cure Alzheimer's Fund realizes how difficult this can be during these times of continuing budget constraints, so it truly appreciates these ongoing efforts by the Subcommittee members and staff, as well as the full Committee members and staff.

For the first time in history, NIH is approaching nearly \$1 billion in funding for Alzheimer's disease research funding. This is a more than doubling from where the funding was just a few years ago.

As outstanding as this increase has been, the non-Federal members of the Advisory Council established by the National Plan passed by Congress has called for \$2 billion a year in Alzheimer's disease research funding being necessary to meet the 2025 goal of the National Plan.

An additional \$400 million for Alzheimer's disease research at NIH would be another step in the right direction in meeting the \$2 billion investment level called for by the research community. And it would be an important step toward ensuring that promising research funded by organizations like Cure Alzheimer's Fund will have the necessary resources available for it to continue on the discovery continuum without interruption.

Cure Alzheimer's Fund see itself as a partner in this process. It realizes that both government and private organizations have an important role in reaching the day when we can say we have cured Alzheimer's disease. We must all worked together to reach this goal.

Because of this, Cure Alzheimer's Fund fully endorsed the House Report Language last year calling on NIH and private organizations to develop a system to generate investment in meritorious but unfunded grants at NIH. Cure Alzheimer's

s Fund, along with other organizations, has been working with NIH on this, and the hope is to have a system in place shortly to spur greater research investment.

This system would allow private organizations to identify worthy research proposals that match their own organizational focus and expertise. It would help get early investment into promising research and would generate more understanding of Alzheimer's disease and targets for intervention. It could be a model for public-private partnerships in other diseases.

But for the partnership to work effectively, there needs to be sufficient public investment in Alzheimer's disease research. An at least additional \$400 million for Alzheimer's disease research at NIH would support even more new discoveries that can be fully vetted and developed.

As we all know, we are paying for Alzheimer's disease already. Alzheimer's disease is the only Top Ten Mortality condition that has its mortality rates increasing. It is the only condition without a therapeutic intervention. It is the only condition that will bankrupt the Centers for Medicare & Medicaid Services. It has to be stopped.

Cure Alzheimer's Fund knows that as it is asking Congress for additional funding, it must also increase its commitment. In 2015, Cure Alzheimer's Fund more than doubled its yearly commitment to research funding to more than \$10 million. The goal for 2016 is to have an additional increase of approximately 25 percent to \$12.5 million.

Cure Alzheimer's Fund sees the advancements being made in Alzheimer's disease research and the opportunities these advancements are creating. As I stated earlier, we are entering a very exciting and productive time for Alzheimer's disease research. Cure Alzheimer's Fund has worked closely with the Subcommittee in the past and looks forward to working with it in the future as we continue toward our shared goal of curing Alzheimer's disease.

The Subcommittee has shown its commitment to this issue, and at times when allocating additional funding has not been easy. But know that this increased funding has produced much progress in combatting Alzheimer's disease. As this progress is being made, I hope that it can continue with increased research funding.

Thank you for the opportunity to submit this written testimony and to respectfully request at least an additional \$400 million in fiscal year 2017 for Alzheimer's disease research at NIH. Cure Alzheimer's Fund looks forward to working with you as the appropriations process continues and to being a resource to the Subcommittee on Alzheimer's disease research issues.

Respectfully,

[This statement was submitted by Timothy Armour, President and CEO, Cure Alzheimer's Fund.]

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#### 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 2017. The Foundation requests funding levels of at least \$34.5 billion for the National Institutes of Health (NIH) for the coming year. We encourage special consideration and support for 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) as well as the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), the National Institute of General Medical Sciences (NIGMS), and the National Heart, Lung, and Blood Institute (NHLBI), all of which play a vital role in CF research.

We also recommend that the Committee provide robust resources to the Health Resources and Services Administration (HRSA) and the Centers for Disease Control and Prevention (CDC), particularly their work to support nationwide newborn screening programs. Further, we urge the Committee to provide ample funding for the Center for Medicare and Medicaid Innovation (CMMI) to allow this agency the resources to update and streamline payment systems as well as the provision of robust resources for the Agency for Healthcare Research and Quality (AHRQ) and the Patient-Centered Outcomes Research Institute (PCORI).

#### CONSISTENT, ROBUST FUNDING FOR NIH IS CRITICAL FOR AMERICAN RESEARCH

The National Institutes of Health is a showcase for American ingenuity and a shining example of our country's generational legacy. NIH effectively uses appro-

appropriated funds to promote basic research and encourage collaboration across academic and commercial sectors to develop the building blocks of drug development. Basic research is a vital prerequisite for the discovery of new treatments and cures, and consistent, robust funding for NIH is crucial to support efforts that are developing novel therapies for serious and life threatening diseases.

The NIH received a \$2 billion budget increase in fiscal year 2016, and it is critical that this momentum continue in this year's appropriations process. Researchers need consistent, reliable funding to run successful laboratories and plan long-term projects. Further, this one-time increase has not overcome the devastating and lasting effects of many years of sequestration and stagnant funding on American research labs both at the NIH and in collaborative programs across the country. Funding success rates for all investigators remain below sustainable levels, and promising young investigators struggle to obtain sufficient funding to remain in the field. The result has been a marked erosion of the U.S. biomedical infrastructure.

Cuts to funding at the NIH have been detrimental to those seeking support for cystic fibrosis research. Large Center Core Grants, awarded by the NIDDK, support shared resources and facilities for use by multiple investigators and provide much needed funding for clinical and basic cystic fibrosis research centers. The funding increase in fiscal year 2016 has provided much needed financial relief for these programs, but if this momentum does not continue, large centers may be at risk of losing research programs and infrastructure. This is both detrimental to the individual centers and causes immense interruption and uncertainty in CF research overall.

Additionally, work performed at the NIH has had large benefits for the U.S. economy. The agency supports more than 400,000 jobs across the country, and a report by Families USA estimates every \$1 of NIH funding generates more than double that in local economic growth. Increased investment in this agency can provide even greater economic payoff and support for the scientific progress that makes the United States the worldwide leader in biomedical research.

#### RESEARCH AT NIH SUPPORTS ADVANCES IN CF THERAPEUTICS

As the Committee considers its funding priorities for the coming fiscal year, we urge consideration of the critical role that NIH plays in the development of treatments for cystic fibrosis and other rare diseases. NIH-funded advances in fundamental cellular and molecular processes, such as the mapping of the human genome, and the development of high throughput screening were essential for the creation of two therapies that have been approved to treat the underlying cause of CF in more than 50 percent of those with the disease. These breakthrough drugs, Kalydeco and Orkambi, developed by Vertex Pharmaceuticals with significant support from the CF Foundation, relied heavily on discoveries funded by the NIH.

More exciting advancements are in the pipeline, and the Foundation is supporting 45 studies in 2016, including examination of several new genetically targeted therapies. Robust NIH funding is critical to maintain innovation in basic research and ensure a full pipeline of efficacious and affordable therapies for those with CF.

In particular, we urge the committee to support funding for behavioral research, especially with regard to treatment adherence in chronic conditions like CF. Cystic fibrosis is a progressive condition with complex treatment regimens that often require several hours per day. Adherence research can help those with CF optimize the efficacy of available treatments.

#### NIH COLLABORATION PROMOTES COST-EFFICIENT RESEARCH

Research supported by the NIH takes place at thousands of institutions across the country, and support of funding for the agency is a vital and effective way to foster collaboration among public and private stakeholders and allows for an efficient, well-funded research process. The CF Foundation collaborates with the NIH to fund and organize a number of research initiatives. For example, the OPTIMIZE study, which receives joint funding from the NIH and the CF Foundation, has brought together hospital systems in nearly 30 States to compare efficacy of antibiotic treatments for lung infections in those with cystic fibrosis. The CF Foundation urges the committee to allow expansion of cost-effective and efficient collaboration nationwide by providing funding for the NIH to continue growing its efforts.

NIH and the CF Foundation also jointly fund a research program at the University of Iowa to study the effects of CF in a pig model. The program is yielding fundamental new insights to help advance developments in the search for a cure. The University of Alabama has also developed a CF rat model using joint funding from NIH and the Foundation to examine methods for studying basic mechanisms and treatment of the disease.

We also urge the Committee to support collaboration through the expansion of research networks, such as NIH's Childhood Liver Disease Research Network (ChiLDRen) consortium at the NIDDK. This collaboration helps researchers discover treatments not only for CF liver disease but for other diseases that affect thousands of children each year.

The CF Foundation also urges the Committee to support and facilitate collaborative efforts by the FDA and NIH, such as the Regulatory Science Initiative and programs that allow for the placement of employees who will be engaged part-time at FDA and part-time at the NIH. The Foundation additionally encourages the creation of collaborative workshops with the NIH and FDA to promote pediatric drug development and novel methodologies to streamline the research and development process.

#### SUPPORTING THE NEXT GENERATION OF RESEARCHERS

We strongly urge the Committee to provide robust resources for the NIH to support the next generation of researchers. Recruiting and retaining a strong scientific workforce, especially in the area of pediatric specialties is critical in the fight to find a cure for CF and countless other diseases for which there are not adequate treatment options. Challenges in this area include recruiting new researchers to the CF field, ensuring funding for promising work, and retaining talented researchers who are committed to research careers. Again, this will simply not happen without sustained support and infrastructure that is supported by the NIH

#### THE PRECISION MEDICINE INITIATIVE

There are more than 1800 mutations within the CF gene that are linked to the underlying cause of CF, and with the advent of precision medicine, therapies like Kalydeco™ and Orkambi™ are being customized to treat a patient's genetic makeup. We urge the Committee to support the President's Precision Medicine Initiative by providing robust funding to the NIH to spearhead the development of new therapies that target the genetic cause of serious diseases. The CF Foundation urges the NIH to adopt precision medicine as a focus in an array of applicable areas, but this powerful initiative can only be possible through Federal funding and resources.

#### PRIORITIZING A CENTRALIZED INSTITUTIONAL REVIEW BOARD

Trials evaluating CF therapies are multi-site studies that can be slowed by repetitive review of local institutional review boards (IRBs). We commend the National Institutes of Health (NIH) for publishing and seeking comment on a policy that is intended to produce efficiencies in the clinical trials process while still protecting research participants by centralizing and simplifying the rigorous clinical trial review process. The CF Foundation sees the NIH as the logical choice to lead the centralization of institutional review boards and requests that the Committee take special consideration of the funds needed to implement this valuable initiative. At a time when research resources are restrained, efforts to reduce redundancy and improve efficiency in research are of the utmost importance.

#### ADVANCING TRANSLATIONAL SCIENCE AT THE NIH

The Foundation requests robust funding for NIH's National Center for Advancing Translational Sciences (NCATS), which catalyzes innovation by improving the diagnostics and therapeutics development process and removing obstacles to translating basic scientific research into treatments. Research in dissemination and implementation science that focuses on integrating scientific findings and effective clinical practice into real-world service settings is crucial to providing the best possible care to those with CF and other conditions.

The specific programs housed in NCATS are integral to this mission, including the Clinical and Translational Science Awards (CTSA), the Cures Acceleration Network (CAN), and the Therapeutics for Rare and Neglected Diseases (TRND) program. Such initiatives transform the way in which clinical and translational research is conducted and funded. NIH Director Dr. Francis Collins has cited the CF Foundation's Therapeutics Development Network (TDN) as a model for TRND's innovative therapeutics development model.

#### CLINICAL TRIAL DATA SHARING

The CF Foundation is enthusiastic about the potential for clinical trial, clinical care, claims, and other healthcare-related data to be used to advance drug discovery and development. The Foundation has been a pioneer in the advancement and utilization of a robust data repository through the CF Patient Registry, and our Thera-

peutics Development Network (TDN) has successfully encouraged clinical partners to share data. We ask that Congress support efforts by the NIH to explore strategies and guidelines for clinical trial data sharing. As drug development research advances, data sharing is vital to the acceleration of new discovery.

#### SUPPORTING GREATER ACCESS TO QUALITY HEALTH CARE

The CF Care Center Network is a model of quality, coordinated care that can be used as an example by policymakers and the rare disease community. We urge the Committee to allow greater access to this specialized care network by providing adequate resources and support for the Center for Medicare and Medicaid Innovation (CMMI) and their work to promote affordable access to specialized care. We also encourage funding for programs and agencies that promote research in healthcare quality and systems as well as clinical effectiveness and patient reported outcomes, including the Agency for Healthcare Research and Quality (AHRQ) and Patient-Centered Outcomes Research Institute (PCORI).

#### NATIONWIDE NEWBORN SCREENING PROGRAMS

Newborn screening is critically important to the CF community because it allows for the early detection and treatment of symptoms as well as early use of CF modulator therapies, which can significantly reduce cumulative damage caused by the disease. The Foundation urges the Committee to provide ample funding for HRSA, which evaluates the effectiveness of newborn screening and follow-up programs and provides grants for programs to support other critical aspects of newborn screening. We also encourage the Committee to provide adequate funding to the CDC, which is responsible for strengthening and enhancing laboratory quality assurance programs; enabling public health laboratories to develop and refine screening tests; conducting pilot studies; implementing new methods to improve detection of treatable disorders; and enhancing newborn disorder detection through the Innovative Molecular Quality Program.

#### CONCLUSION

Cystic fibrosis is a rare genetic disease that causes the body to produce thick mucus that clogs the lungs and other bodily systems, resulting in life-threatening infections, diabetes, malnutrition, and other medical complications. This is a time of great hope and optimism for the CF community and those with other rare diseases as more research is being conducted to effectively treat these life threatening conditions. We urge you to provide at least \$34.5 billion for the National Institutes of Health as well as robust funding for other relevant agencies to support and expand work already being done in biomedical programs and translational science and encourage cost-efficient collaboration of varied experts and stakeholders.

We stand ready to work with the Committee and Congressional leaders on the challenges ahead. Thank you for your consideration.

[This statement was submitted by Preston W. Campbell, III, M.D., President and CEO, Cystic Fibrosis Foundation.]

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#### PREPARED STATEMENT OF DEFEATMALNUTRITION.TODAY

Chairman Blunt, Ranking Member Murray: I thank you for the opportunity to offer testimony in support of the Department of Health and Human Services' proposed increase of \$13.8 million for Older Americans Act Title III(C) senior nutrition programs within the Administration for Community Living. This testimony is on behalf of DefeatMalnutrition.Today, a coalition of 36 community, healthy aging, nutrition, advocacy, healthcare professional, faith-based, and private sector stakeholders and organizations who share the goals of achieving the recognition of malnutrition as a key indicator and vital sign of adult health and working to achieve a greater focus on malnutrition screening and intervention through regulatory and/or legislative change across the Nation's healthcare system.

Older Americans Act congregate and home-delivered meals programs are provided in every State and congressional district in this Nation. Approximately 2.4 million seniors in 2014 received these services.

In fiscal year 2016, Older Americans Act Title III(C) programs received appropriations in the amount of \$835 million. Though we are thankful that this represents an increase from fiscal year 2015, unfortunately, this does not keep pace with the rising cost of food, inflation, and the growing numbers of older adults. In fact, the number of older adults receiving meals is shrinking even as the need grows.

The additional \$13.8 million in funding for congregate and home-delivered meals will help to counteract inflation and provide more than 1.3 million additional meals. This does not keep up with the growing demand for services, but it would at least prevent further reductions in services.

Studies have found that 50 percent of all persons age 85 and over need help with instrumental activities of daily living, including obtaining and preparing food. Older Americans Act nutrition programs address these concerns. These meal recipients are thus able to remain independent in their homes and communities and are not forced into hospitals or nursing homes due to an inability to maintain a proper diet.

Investing in these programs is cost-effective because many common chronic conditions such as hypertension, heart disease, diabetes, and osteoporosis can be effectively prevented and treated with proper nutrition. The Academy of Nutrition and Dietetics estimates that 87 percent of older adults have or are at risk of hypertension, high cholesterol, diabetes, or some combination of all of these. These seniors need healthy, nutritious meals that may be medically tailored for various conditions, access to lifestyle programs, and nutrition education and counseling to avoid serious medical care.

Older adults who are not receiving proper meals can also become malnourished and undernourished. This makes it harder for them to recover from surgery and disease, makes it more difficult for their wounds to heal, increases their risk for infections and falls, and decreases their strength that they need to take care of themselves. Malnourished older adults are more likely to have poor health outcomes and to be readmitted to the hospital—their health costs can be 300 percent greater than those who are not malnourished on entry to the healthcare system.

Keeping older adults well-nourished is essential to keeping them in the community—and studies have consistently found that the highest rates of malnutrition in older adults are found in those who live in care settings as opposed to community-based settings. A Kaiser study found 38 percent prevalence of malnutrition among older adults in their communities, as compared to 91 percent in rehabilitation facilities, 86 percent in hospitals, and 67 percent among those in nursing homes. While direct cause and effect has not entirely been established, it also seems that older adults in the community who are well-nourished are less likely to need to move to these care settings in the first place. We would also note that there is a great need here for tools for providers and practitioners to support the discovery and reduction of senior malnutrition, whether older adults are in care settings or not—38 percent is still an extremely high number of malnourished community-dwelling older adults, considering that fewer than 5 percent of older adults live in nursing homes.

Access to Older Americans Act meals is essential to keeping these older adults out of costly nursing facilities and hospitals. On average, a senior can be fed for a year for about \$1,300. (And, on average, only 37 percent of this funding comes from the Federal Government; the rest of the funding for Older Americans Act meals comes from local, State and private sources, making this nutrition program a true public-private partnership.) The cost of feeding a senior for a year is approximately the same as the cost of one day's stay in a hospital or less than the cost of 10 days in a nursing home. The cost savings to Medicare and Medicaid that this creates cannot be over-emphasized. One study estimates that for every dollar invested in the Older Americans Act nutrition programs, Medicaid saves \$50.

Further, these services are designed to target those in the "greatest social and economic need," according to the Older Americans Act. According to ACL's studies, approximately two-thirds of home-delivered meal recipients have annual incomes of \$20,000 or less. Sixty-two percent of these recipients report that these meals represent at least half their food intake each day. And yet, the Government Accountability Office found that only about 9 percent of low-income older adults are even receiving meal services. For a small investment, more at-risk older adults could receive nutritious meals.

For over 40 years, the Older Americans Act nutrition programs have been serving older adults who are frail, isolated, and in great need of assistance. With more than 10,000 seniors turning 65 every day, now is the time to provide an even greater investment in these proven and cost-effective programs.

Thank you for your past and future support.

[This statement was submitted by Robert Blancato, National Coordinator, DefeatMalnutrition.Today.]

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PREPARED STATEMENT OF THE DISABILITY RESOURCE CENTER

I respectfully submit this written testimony to request that you increase funding in the HHS budget for Centers for Independent Living (CIL) by \$200 million, for

a total of \$301 million for the Independent Living line item in fiscal year 2017. This is an important opportunity for Congress to reaffirm its commitment to the more than 57 million Americans with disabilities.

The disAbility Resource Center (dRC) is one of 17 CILs in Virginia, providing services to over 2,000 people each year in the Fredericksburg Region. These services assist people in maintaining independence, contributing to the community, and avoiding costly and restrictive institution. CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. Our organizations are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities.

Each of the 365 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services, which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012–2014, CILs provided the core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals. During this same period, prior to transition being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community.

Transition services were added recently as a fifth core service with the passage of the Workforce Innovation and Opportunity Act and reauthorization of the Rehabilitation Act within WIOA. Transition services include transitioning individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, helping individuals with significant disabilities at risk of entering institutions to remain in the community, and assisting youth with significant disabilities transition to adult life. This core service is vital to achieving full participation for people with disabilities.

Now that transition services have been added, the need for funding is more critical than ever.

Every day, CILs are fighting to ensure that people with disabilities gain and maintain control over their own lives. We know that this cannot occur when people reside in institutional settings. While opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm, we know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions across the country from 2012–2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and States. Community-based services enable people with disabilities to become less reliant on long-term government supports and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

The dRC, like many other CILs, maximizes every dollar and accomplishes its broad ranging mission with relatively little funding. CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In 2016, the Independent Living Program is receiving nearly \$2.5 million less in funding than it was in 2010. It is simply not possible to meet the demand for services and to effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

CILs play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money.

Please increase funding for Independent Living.

Thank you for the opportunity to provide this written testimony.

[This statement was submitted by Debra Fults, Executive Director, disAbility Resource Center.]



## PREPARED STATEMENT OF THE DYSTONIA MEDICAL RESEARCH FOUNDATION

## SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2017

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- Provide \$34.5 billion for the National Institutes of Health (NIH) and proportional increases across its Institutes and Centers
  - Continue to support natural history studies on dystonia, like 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), the National Eye Institute (NEI), and NCATS
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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)

The DAN urges the subcommittee to continue its support for natural history studies on dystonia that will advance the pace of clinical and translational research to find better treatments and a cure. In addition, Congress should support NINDS, NCATS, NIDCD, and NEI in conducting and expanding critical research on dystonia.

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. Studies like the Coalition remain a priority for the community and Congress should continue to support these initiatives.

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.

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.

In summary, the DAN recommends the following for fiscal year 2017:

- Provide \$34.5 billion for NIH and a proportional increase for its Institutes and Centers
- Support natural history studies on dystonia like the Dystonia Coalition, part of the Rare Diseases Clinical Research Network coordinated by ORDR within NCATS
- Expand the dystonia research portfolio at NIH through NINDS, NIDCD, NEI, and NCATS

#### AWARENESS & EDUCATION

The Dystonia Medical Research Foundation (DMRF) provides a number of resources to help patients and families become informed about the disorder and treatment options. The DMRF offers newsletters, brochures, and fact sheets on dystonia subtypes and dystonia-related topic. These publications are available in print and online. The DMRF offers a comprehensive website and is available to the community by phone, email, and social media for inquiries. Educational patient meetings featuring movement disorder specialists and other experts are scheduled in communities across the country; online educational webinars on treatment and research topics are also provided.

The DMRF works year round to promote greater public awareness of dystonia. Dystonia Moves Me is the DMRF's awareness campaign that takes place each September during Dystonia Awareness Month. Individuals who have been impacted by dystonia use their experiences to educate others in their local communities and via social media.

#### *Personal Story*

Pamela Sloate—New York, New York

Pamela Sloate can barely remember life before dystonia. Her symptoms began over 40 years ago when she was just 8 years old. She recalls the bizarre feeling of not being able to physically keep her right arm on the table as she wrote. Then her left leg began to move unpredictably. Her involuntary movements spread to her left arm and right leg. She felt like a marionette on strings; an unseen puppeteer commanded control of her body, limbs, and speech.

To this day, dystonia is Pamela's constant unwelcome sidekick, inserting chaos into nearly every move she makes. She explains: "Imagine you're trying to . . . [walk] across a room. You lift your leg to begin that first step when a mischievous troll screws up your balance by pulling your foot inward, causing you to land on the side of your foot and desperately search for stability. Simultaneously, some imp twists your knee while your hip dips and swings in a motion that would swirl a hula-hoop."

Walking her dog down the block requires focusing every ounce of her energy on each laborious step. Crowds of people rush past as she precariously carries her folded walker down three flights of stairs to the subway. It is a challenge to stay still for a routine MRI. Despite access to leading movement disorder clinicians, her cocktail of oral medications requires constant fine-tuning in search of a balance between reducing the dystonia symptoms while avoiding intolerable side-effects that limit her functioning even further.

As a self-admitted perfectionist and born go-getter, Pamela has fought the limitations imposed by dystonia every step of the way. She rejects the suggestion that she is "disabled" in the conventional sense. Pamela graduated Brown University and earned a law degree from New York University School of Law. She has held positions with Bozell Worldwide and BEN Marketing Group, free-lanced as a marketing consultant, and worked as an attorney.

Well into her 20s, Pamela often felt isolated and alone. Until that time she had never met another person with dystonia. The Internet allowed her to connect with others in the dystonia community from around the world, and she eventually started a widely recognized blog, *Chronicles Of A Dystonia Muse*. She is a multi-tasking dystonia advocate, engaging in legislative advocacy, leading a dystonia support group, fundraising to support medical research, and promoting dystonia awareness.

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 EASTER SEALS, INC.

Easter Seals respectfully asks that you add four key Federal programs to your fiscal year Labor-HHS-Education appropriations Member submission form to help homeless veteran and older adult find jobs in their communities and to ensure that children with disabilities can access the early intervention and educational supports they require to grow and develop.

Easter Seals is a national nonprofit that break down barriers for Americans through individualized, evidence-based services from one of our 74 statewide and local affiliates. We urge you to prioritize funding, at no less than the President's fiscal year 2017 budget recommendations, for the Homeless Veterans' Reintegration Program (\$50,000,000), Early Intervention Grants for Infants and Families (\$503,556,000), Community Service Employment for Older Americans (\$434,371,000), and Preschool Grants for Children with Disabilities (\$403,238,000).

## HOMELESS VETERANS' REINTEGRATION PROGRAM

*Easter Seals Request: \$50,000,000*

The Homeless Veterans' Reintegration Program (HVRP) provides job training, counseling, and placement services to help homeless veterans reintegrate into society and the labor force. With the dramatic decrease in veterans' homelessness since 2010, HVRP employment services are needed now more than ever to ensure those veterans who were formerly homeless secure employment to help them maintain their housing. Recognizing the growing demand for services among homeless and at-risk veterans, Congress has authorized HVRP funding at \$50 million annually. The President's fiscal year 2017 budget request would, for the first-time, meet this authorized level and allow community providers to serve an additional 5,000 veterans.

Submission Form Information:

Program:	Homeless Veterans' Reintegration Program
Federal Department or Agency:	U.S. Department of Labor
Account:	Veterans Employment & Training
FY 2017 LHHS Request:	\$434,371,000
FY 2017 President's Budget:	\$434,371,000
FY 2016 Enacted:	\$434,371,000
FY 2015 Enacted:	\$434,371,000
FY 2014: Enacted:	\$434,371,000

## EARLY INTERVENTION GRANTS FOR INFANTS AND FAMILIES

*Easter Seals Fiscal Year 2017 Request: \$503,556,000*

The Early Intervention Grants for Infants and Families program (also known as Part C of the Individuals with Disabilities Education Act) provides formula grants to all 50 States to implement statewide systems of coordinated, comprehensive, multidisciplinary, interagency programs and make early intervention services available to children with disabilities, aged birth through 2. The increased prevalence of childhood disability and stagnant funding levels has meant fewer children benefit from the early intervention services and supports they need to meet key developmental milestones. The President's recommended increase will help to demonstrate innovative strategies to meet the needs of at-risk infants and toddlers and increase the State grant size.

Submission Form Information:

Program:	Early Intervention Grants for Infants and Families
Federal Department or Agency:	U.S. Department of Education
Account:	Special Education
FY 2017 LHHS Request:	\$503,556,000
FY 2017 President's Budget:	\$503,556,000
FY 2016 Enacted:	\$458,556,000
FY 2015 Enacted:	\$438,556,000
FY 2014: Enacted:	\$438,498,000

## COMMUNITY SERVICE EMPLOYMENT FOR OLDER AMERICANS

*Easter Seals Fiscal Year 2017 Request: \$442,263,738*

The Community Service Employment for Older Americans program (also known as the Senior Community Service Employment Program or SCSEP) assists unemployed, low-income older adults in developing new work skills and experience through paid, work-based training in their communities. SCSEP-funded services are available in nearly all 3,000 U.S. counties and territories. In addition to helping thousands of older Americans find jobs, the program strengthens communities through the training contributions participants make to local nonprofit and public facilities, such as libraries, schools and senior centers. Easter Seals was disappointed that the President's request failed to account for the increased operating costs (nearly \$8 million) due to increases in State minimum wages. Easter Seals requests no less than the President's fiscal year 2017 budget request for SCSEP.

Submission Form Information:

Program:	Community Service Employment for Older Americans
Federal Department or Agency:	U.S. Department of Labor
Account:	Employment & Training Administration
FY 2017 LHHS Request:	\$434,371,000
FY 2017 President's Budget:	\$434,371,000
FY 2016 Enacted:	\$434,371,000
FY 2015 Enacted:	\$434,371,000
FY 2014: Enacted:	\$434,371,000

## PRESCHOOL GRANTS FOR CHILDREN WITH DISABILITIES

*Easter Seals Fiscal Year 2017 Request: \$403,238,000*

Preschool Grants for Children with Disabilities (Part B of the Individuals with Disabilities Education Act) supports the educational needs of children between the ages of 3 and 5 years who have disabilities and also require special education services. Through IDEA, Congress guaranteed the right of these children to free, appropriate, public education and set a goal of providing \$1500 to States for each eligible child. Past funding levels have fallen well short of this per pupil goal. The President proposes to build upon the investments made last year by Congress by recommending \$46 more per child, for an average of \$535 per child. Easter Seals support no less than the President's fiscal year 2017 proposal to ensure the only Federal program dedicated to preschool-aged children with disabilities has resources to meet its statutory obligations in providing these children with the critical academic and behavior supports.

Submission Form Information:

Program:	Preschool Grants for Children with Disabilities
Federal Department or Agency:	U.S. Department of Education
Account:	Special Education
FY 2017 LHHS Request:	\$403,238,000
FY 2017 President's Budget:	\$403,238,000
FY 2016 Enacted:	\$368,238,000
FY 2015 Enacted:	\$353,238,000
FY 2014: Enacted:	\$353,238,000

Thank you in advance for your consideration of Easter Seals' Labor-HHS-Education funding priorities for fiscal year 2017. Please let us know if you have any questions or need any additional information in support of your submission forms. Thank you.

## PREPARED STATEMENT OF THE ELDER JUSTICE COALITION

Chairman Blunt, Ranking Member Murray: On behalf of the bipartisan Elder Justice Coalition and its 3,000 members, we thank you for the opportunity to offer testimony in support of \$25 million in funding for the Elder Justice Act within the Department of Health and Human Services' Administration for Community Living, as well as for maintaining funding for the Social Services Block Grant.

Our topic must always be a bipartisan issue: preventing elder abuse, neglect and exploitation. We ask this subcommittee to provide this funding in a bipartisan fashion as part of the solution to the national disgrace of elder abuse.

According to the Department of Justice, there are more than six million victims of elder abuse per year; roughly one of every 10 persons over 60 will end up a victim of elder abuse. However, a New York State study found for every elder abuse case known to agencies, 24 were unreported. Victims of elder financial abuse lose at least \$2.9 billion per year, which can include entire life savings. A 2015 study published by True Link Financial found that the problem of financial exploitation may be as great as \$36 billion per year. One-half of those with dementia will fall victim to elder abuse, neglect and/or exploitation. In short, the situation is dire.

The Elder Justice Act, passed in 2010, would address these problems. The Act, if funded, would strengthen the State Long-Term Care Ombudsman Program. It would provide for the development of forensic centers to study the problem of abuse and how we can better detect abuse and potential abusers. It would also enhance and train long-term care staffing in facilities.

Funding for the Elder Justice Act has not been provided to fulfill the provisions of the Act. We are very grateful for the funding from the Appropriations Committee last year for the Act in the amount of \$8 million, but the Act needs more of an investment in order to fulfill its potential. This is why we support funding for the Act at last year's proposed \$25 million level.

Data collection is essential to understanding and preventing elder abuse. Other forms of crime, such as child abuse, have standardized national databases—the National Child Abuse and Neglect Data System (NCANDS) database has been in existence since 1998. This allows States to more easily discover trends and researchers to learn about perpetrators and victims. A lack of data has also hurt the elder justice community's efforts to call awareness to the problem of elder abuse and to compete effectively for resources in an era where data often drives dollars. Continuing the work started in fiscal year 2013 with the continued funding of a National Adult Maltreatment Reporting System (NAMRS), a national Adult Protective Services (APS) data collection system, is vital for consistency in the field.

The Coalition also supports the evaluation and analysis of APS programs using an evidence-based approach and best practices. To be effective, APS programs must have consistency and high quality nationally. Elder abuse happens in all States and congressional districts, and in some cases, elder abuse happens across county and State lines. Thus, having uniform best practices is key to ensuring that victims receive uniform services.

Research in the elder abuse field, like data collection, is desperately needed. Money has never been specifically appropriated for research; the limited resources that the field has go straight into assisting victims. However, victims can be more appropriately—and cost-effectively—assisted if they are identified early via effective screening. A great deal of trauma can be prevented with effective screening. Thus, research into how to screen accurately is exceedingly important.

This increased investment of \$25 million would mean that current Federal and State resources could be used more effectively while also responding to elder abuse systematically. For these reasons, as well as the potential of lowering rates of future victimization, the investment would provide a solid return on investment.

This is an investment because, according to the National Center on Elder Abuse, the direct medical costs associated with elder abuse now exceed \$5 billion annually. Since these victims are older adults, Medicare and Medicaid bear the bulk of these costs. Other Federal programs may end up paying for elder abuse victims, including income support programs, because financial abuse victims who were once self-supporting may lose everything in one scam. We can begin to save money for the Federal Government if we make this relatively small investment today.

We also support maintaining, if not increasing, the amount of money available for Social Services Block Grant programs, which in addition to providing APS funding, also provides important funding for supportive services available to elder abuse victims. APS is primarily funded through optional State distributions from their Social Services Block Grant allotment; only 37 States provide any additional Federal funding for their Federal APS programs.

Since the Elder Justice Act has many more important provisions that are not funded in this proposal, please view this \$25 million as a floor to build on, and not a ceiling. We look forward to working with you to ensure that this elder justice appropriation provides our Nation with the best possible return on investment and outcomes.

Thank you for your past and future support.

[This statement was submitted by Robert Blancato, National Coordinator, Elder Justice Coalition.]

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PREPARED STATEMENT OF THE ELDERCARE WORKFORCE ALLIANCE

Chairman Blunt, Ranking Member Murray, and members of the subcommittee: We are writing on behalf of the Eldercare Workforce Alliance (EWA), which is comprised of 31 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 2017, the Alliance<sup>1</sup> 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 boomer 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 \$470 billion in 2013, an increase from an estimated \$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 geriatrics programs and Administration for Community Living (ACL) programs that support family caregivers, and the research efforts of the National Institute on Aging (NIA) 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.

Specifically, we recommend the following levels:

- \$45 million for Title VII Geriatrics Workforce Enhancement Program;
- \$197 million for Family Caregiver Support Programs;
- \$1.7 billion for National Institute on Aging; and
- \$9.7 million for additional workforce programs.

EWA specifically requests the following levels of funding:

*Title VII Geriatrics Workforce Enhancement Program*:<sup>2</sup> Appropriations Request: \$45 Million

The Geriatrics Workforce Enhancement Program (GWEP) seeks to improve high quality, inter-professional geriatric education and training to the health professions workforce, including geriatric specialists, as well as increase geriatrics competencies of primary care providers and other health professionals to improve care for this often underserved population. It supports the development of a healthcare workforce that improves health outcomes for older adults by integrating geriatrics with primary care, maximizing patient and family engagement, and transforming the healthcare system.

GWEP is the only Federal program that increases the number of faculty with geriatrics expertise in a variety of disciplines who provide training in clinical geriatrics, including the training of interdisciplinary teams of health professionals.

In fiscal year 2015, the Title VII geriatrics programs provided continuing education on Alzheimer's disease and related dementias, among other topics, to more

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<sup>1</sup>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.

<sup>2</sup>In December 2014, HRSA combined the existing Title VIII Comprehensive Geriatric Education Program and the Title VII Geriatric Academic Career Award, Geriatric Education Centers, and Geriatric Training for Physicians, Dentists and Behavioral and Mental Health Providers programs into the Geriatrics Workforce Enhancement Program. The fiscal year 2016 Omnibus also consolidated these programs, citing HRSA's combined competition for the program.

than 150,000 providers. Additionally, in academic year 2014–2015 alone, Title VII supported 54 fellows in medicine, geriatrics, dentistry, and psychiatry who cared for older adults. Overall, in the 2014–2015 academic year, these geriatrics and gerontology programs provided training to more than 200,000 individuals.

In May 2015, HRSA announced 41 three-year grant funded programs. For fiscal year 2017, we request increased funding for this program to close current geographic and demographic gaps in geriatric workforce training.

*Administration for Community Living Family Caregiver Support:* Appropriations Request: \$197 million

These programs support caregivers, elders, and people with disabilities by providing critical respite care and other support services for family caregivers, training and recruitment of care workers and volunteers, information and outreach, counseling, and other supplemental services.

—*Family Caregiver Support Services:* EWA requests \$158.5 million. This program provides a range of support services to approximately 700,000 family and informal caregivers annually in States, including counseling, respite care, training, and assistance with locating services that assist family and informal caregivers in caring for their loved ones.

—*Native American Caregiver Support:* EWA requests \$8 million. This program provides a range of services to Native American caregivers, including information and outreach, access assistance, individual counseling, support groups and training, respite care and other supplemental services.

—*Alzheimer’s Disease Support Services:* EWA requests \$10.5 million. One critical focus of this program is to support the family caregivers who provide countless hours of unpaid care, thereby enabling their family members with dementia to continue living in the community. It funds evidence-based interventions and expands the dementia-capable home and community-based services.

—*Lifespan Respite Care:* EWA requests \$5 million. This program funds grants to improve access to respite care for family caregivers of children or adults with special needs.

—*Family Support Initiative:* EWA requests \$15 million. The new initiative will encourage use of community assets and opportunities to help families reduce stress, improve emotional well-being, develop support skills and knowledge, and plan for the future. Special attention will be given to efforts that assist families with balancing workforce participation and caregiving responsibilities, and those facing the dual demands of caring for older parents while raising children and/or supporting a family member with disabilities.

*National Institute on Aging:* Appropriations Request: \$1.7 billion

The National Institute on Aging, one of the 27 Institutes and Centers of the National Institute of Health, leads a broad scientific effort to understand the aging process in order to promote the health and well-being of older adults. Funding will aid in researching training initiatives for the workforce that cares for older adults and research on physician-family communications during end-of-life and critical care.

*Additional Workforce Programs:* Appropriations Request: \$9.7 million

—*National Health Care Workforce Commission:* EWA requests \$3 million. The National Health Care Workforce Commission, established by the ACA, plays a central role in formulating a national strategy for bolstering the healthcare workforce in order to meet the needs of the burgeoning numbers of older Americans. On behalf of the members of the Eldercare Workforce Alliance, thank you for your past support for geriatric workforce programs.

—*Geriatric Career Incentive Awards Program:* EWA requests \$3.3 million. Congress authorized this new program through the ACA. Assuming it is extended, these funds foster greater interest among a variety of health professionals in entering the field of geriatrics, long-term care, and chronic care management.

—*Training Opportunities for Direct Care Workers:* EWA requests \$3.4 million. In the ACA, Congress approved a program administered by HHS that will offer advanced training opportunities for direct care workers. While this vital training program was left out of President Obama’s budget, EWA believes Congress must extend and fund it to create new employment opportunities by offering new skills through training.

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, Alliance Co-Convener, 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 2017, ENA respectfully requests \$28 million for Trauma and Emergency Care Programs (HHS; ASPR), \$244 million for Nursing Workforce Development programs (HHS; HRSA), \$20.213 million for the Emergency Medical Services for Children program (HHS; HRSA), \$22.846 million to fund poison control centers (HHS; HRSA) and \$157 million for the National Institute of Nursing Research (HHS; NIH).

#### 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. Further, 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 2017 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.

A 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. In addition, demand for nurses will grow because of the increased emphasis on preventative care and the growing number of Americans with health insurance. A 2014 projection from the U.S. Bureau of Labor Statistics' *2014 Occupational Outlook Handbook* anticipates that the number of practicing RNs will grow 26 percent by 2020 and the employment of Advanced Practice Registered Nurses will grow even more rapidly.

At the same time, 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 a 2013–2014 survey by the American Association of Colleges of Nursing, 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 com-



munities. 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 65,000 nurses and nursing students were trained and educated last year with the help of Title VIII nursing workforce development programs.

Therefore, ENA respectfully requests \$244 million in fiscal year 2017 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 \$20.213 million in fiscal year 2017 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 55 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 \$22.846 million in fiscal year 2017 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 \$157 million in fiscal year 2017 for the NINR.

## PREPARED STATEMENT OF THE ENDOCRINE SOCIETY

The Endocrine Society thanks the subcommittee for the opportunity to submit the following testimony regarding fiscal year 2017 Federal appropriations for biomedical research.

The Endocrine Society is the world's largest and most active professional organization of endocrinologists representing more than 18,000 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 basic and clinical scientists who receive Federal support from the NIH to fund endocrine-related research focusing on, among other challenges, diabetes, cancer, fertility, aging, obesity and bone disease. Our membership also includes clinicians who depend on new scientific advances to better treat and cure their patients' diseases.

## 100 YEARS OF ENDOCRINE RESEARCH: AN INVESTMENT IN THE NATION'S HEALTH

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. Their research has led to new medical treatments, saved innumerable lives, reduced human suffering, and launched entire new industries.

Endocrine scientists are a vital component of our Nation's biomedical research enterprise and integral to the healthcare infrastructure in the United States. Endocrine Society members study how hormones contribute to the overall function of the body, and how the glands and organs of the endocrine system work together to keep us healthy. Consequently, endocrinologists have a unique approach to and understanding of how the various systems of the human body communicate and interact to maintain health. The areas governed by the endocrine system are broad and essential to overall wellbeing; endocrine functions include reproduction, the body's response to stress and injury, sexual development, energy balance and metabolism, bone and muscle strength, and others. Endocrinologists study glands such as the adrenal glands, pancreas, thyroid, and specific sections of the brain, such as the hypothalamus, that control these glands. Endocrinologists also study interrelated systems, for example how hormones produced by fat can influence the development of bone disease.

This year, the Endocrine Society is celebrating its centennial anniversary. The past 100 years have seen hundreds of millions of people helped by the lifesaving treatments and quality care developed through research on hormones funded by the Federal Government. Some examples include:

- Endocrine scientists discovered and figured out how the hormone insulin works, resulting in treatments for diabetes.
- Endocrine scientists identified and characterized the effects of hormones such as aldosterone on the heart, leading to new treatments for heart failure.<sup>1</sup>
- Endocrine scientists discovered that hormones produced by the thyroid gland are necessary for normal cognitive and physical development. Subsequent isolation and characterization of thyroid hormones lead to the development of new, better, and safer therapies for patients with thyroid disorders.<sup>2</sup>
- Endocrine scientists have used animal models for obesity to better understand the neuroendocrine basis of obesity, discovering new hormones that regulate energy balance and hunger, such as leptin.<sup>3</sup>
- Endocrine scientists improved our understanding of hormone-responsive cancers, such as estrogen-sensitive breast cancer. This knowledge has improved our treatment of certain cancers; tamoxifen, for example, has been used for over 30 years to treat hormone-receptor positive breast cancer by selectively blocking estrogen receptors.<sup>4</sup>

<sup>1</sup>Richard J. Auchus "Classics in Cardiovascular Endocrinology: Aldosterone Action Beyond Electrolytes" *Endocrinology*, February 2016, 157(2):429–431.

<sup>2</sup>Anthony N. Hollenberg "The Endocrine Society Centennial: The Thyroid Leads the Way" *Endocrinology*, January 2016, 157(1):1–3.

<sup>3</sup>Manuel Tena-Sempere "The Endocrine Society Centennial: Genes and Hormones in Obesity . . . or How Obesity Met Endocrinology" *Endocrinology*, March 2016, 157(3):979–982.

<sup>4</sup> <http://www.cancer.gov/types/breast/breast-hormone-therapy-fact-sheet#q6> Accessed April 11, 2016.

## THE FUTURE OF ENDOCRINE RESEARCH

More research progress is within reach and could lead to exciting new treatments for serious diseases, for example:

- For patients with diabetes, new treatments could use stem cells derived from skin cells to replace pancreatic cells lost during the progression of the disease; more research has begun to enable the creation of a bionic pancreas that automatically responds to a patient's needs throughout the day.
- New classes of drugs could be developed to combat the obesity epidemic.<sup>5</sup>
- Combination approaches that combine chemotherapy with hormonal therapy could improve the treatment of metastatic prostate cancer.<sup>6</sup>
- Hormonal therapies could help women with primary ovarian insufficiency restore their bone density to normal levels.<sup>7</sup>

As we enter a new era of precision medicine, endocrine scientists are also learning how genetic and biologic markers can be used to understand what causes a disease, the risk factors that predispose to disease, and how patients will respond to a particular treatment. Translating these new discoveries and technologies into personalized patient care offers the possibility of more effective treatments, less toxicity, increased disease prevention, improved quality of life, and lower healthcare costs. Several endocrine-specific conditions are on the cusp of a breakthrough in diagnostic testing. The ability to test for specific genetic mutations that cause the syndrome of resistance to thyroid hormone can dramatically alter potential treatment options. Additionally, rare adrenal tumors called pheochromocytomas and paragangliomas are notoriously challenging to diagnose. Genetic tests can reduce delays in diagnosis, help determine whether a tumor is likely to be malignant, and provide doctors with critical data to help monitor family members who might also carry a problematic mutation.<sup>8</sup>

## FLAT FUNDING THREATENS SCIENTIFIC MOMENTUM

The Endocrine Society was encouraged by the \$2 billion increase for NIH in the fiscal year 2016 Omnibus Appropriations bill. This increase was desperately needed to allow the NIH to keep pace with inflation. However, the biomedical research community requires steady, sustainable increases in funding to ensure that the promise of scientific discovery can efficiently be translated into new cures. NIH grant success rates are predicted to remain at historically low averages, meaning that highly skilled scientists will continue to spend more time writing highly meritorious grants that will not be funded. Young scientists will also continue to be driven out of biomedical research careers due to the lack of funding.

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 gifted scientists pursue other careers or leave the United States to develop important research breakthroughs and therapies elsewhere. In 2013, the number of NIH-supported scientists declined significantly, with nearly 1,000 NIH scientists dropping out of the workforce.<sup>9</sup> 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.<sup>10</sup>

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.”<sup>11</sup> 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

<sup>5</sup> Ken K. Y. Ho “Endocrinology: the next 60 years” *Journal of Endocrinology* (2006) 190, 3–6.

<sup>6</sup> Harrison Wein “Combination Therapy for Metastatic Prostate Cancer” *NIH Research Matters* August 24, 2015. <http://www.nih.gov/news-events/nih-research-matters/combination-therapy-metastatic-prostate-cancer> Accessed April 6, 2015.

<sup>7</sup> <http://www.nih.gov/news-events/news-releases/hormone-treatment-restores-bone-density-young-women-menopause-condition> Accessed April 6, 2015.

<sup>8</sup> Eric Seaborg, “Family History.” *Endocrine News*, Feb. 2015. 15–17.

<sup>9</sup> 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.

<sup>10</sup> Everett Ehrlich “Engine Stalled: Sequestration’s Impact on NIH and the Biomedical Research Enterprise.” *United for Medical Research*. (2012).

<sup>11</sup> Teresa K. Woodruff “Budget Woes and Research.” *The New York Times*. September 10, 2013.

therapeutic treatments for Parkinson's disease, and evaluate the effect of metal contaminants on reproductive health, among many others, are delayed or terminated.<sup>12</sup>

FISCAL YEAR 2017 NIH FUNDING REQUEST

The Endocrine Society recommends that the Subcommittee provide at least \$35 billion in funding for NIH in the fiscal year 2017 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.

It is critical that we continue to invest in biomedical research to improve the Nation's future financial situation. Rising healthcare costs threaten to consume an increasing percentage of the United States' GDP and also the individual budgets of workers and businesses.<sup>13</sup> The cost of diabetes, in particular, represents a staggering \$245 billion in 2012 alone.<sup>14</sup>

We live during an age of tremendous scientific opportunity that can only be realized through Federal funding of biomedical research. Researchers are just 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. We fully understand that the Appropriations Committee faces challenging decisions in fiscal year 2017; however, we assert that additional cuts to the NIH and other non-defense discretionary programs is not the way to solve the budgetary issues facing the United States.

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 levels would threaten the Nation's scientific enterprise. 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 in the world. The Endocrine Society therefore asks that the NIH receive at least \$35 billion in fiscal year 2017.

[This statement was submitted by Henry Kronenberg, MD, President, Endocrine Society.]

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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 arthropod-borne disease research at the U.S. Department of Health and Human Services (HHS). ESA requests a robust fiscal year 2017 appropriation for the National Institutes of Health (NIH), including funding equal to fiscal year 2016 enacted levels for arthropod-borne disease research at the National Institute of Allergy and Infectious Diseases (NIAID). The Society also supports the President's 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.

Cutting-edge research in the biological sciences, including the field of entomology, is essential for addressing societal needs related to environmental and human health. Many species of insects and their arachnid relatives (including ticks and mites) serve as vectors of a diversity of infectious diseases that threaten the health and well-being of people across the globe, including populations in every State and territory of the United States and U.S. military personnel serving abroad. Vector-borne diseases can be particularly challenging to control; effective vaccines are not available for many of these diseases, and controlling the vectors is complicated by their mobility and their propensity for developing pesticide resistance. The risk of emerging infectious diseases grows as global travel increases in speed and frequency and as environmental conditions conducive to vector population growth continue to

<sup>12</sup> 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/](http://www.unitedformedicalresearch.com/advocacy_reports/sequestration-profiles/) Accessed March 20, 2014.

<sup>13</sup> Dan Mangan "Job health insurance costs rising faster than wages." CNBC. 9 Dec. 2014. <http://www.cnbc.com/id/102249938#>. Accessed March 19, 2015.

<sup>14</sup> <http://www.diabetes.org/advocacy/news-events/cost-of-diabetes.html> Accessed March 19, 2015.

expand globally. The exponential rise of the Zika virus in the Americas is an example of the astonishing rapidity with which an insect-borne disease can become pandemic. Entomological research aimed at elucidating the relationships between arthropod vectors and the diseases they transmit—including, in the case of mosquitoes, dengue, Zika virus, and chikungunya, and, in the case of ticks, Lyme disease, human anaplasmosis and ehrlichiosis—is essential for reliable monitoring and prediction of outbreaks, effective prevention of disease transmission, and rapid diagnosis and treatment of diseases. The magnitude of the challenges presented by vector-borne diseases cannot be overstated; mosquitoes alone are considered responsible for the deaths of more people than all other animal species together (including humans). Given the enormous impact of arthropod vectors on 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 support of research on basic human and pathogen biology and by development of prevention and treatment strategies. More than 80 percent of NIH funding is 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 study examining the mechanism by which DEET, a widely used synthetic mosquito repellent discovered more than 60 years ago, is perceived by the southern house mosquito, a vector of St. Louis encephalitis and West Nile virus. DEET was shown to bind to and activate a specific odorant receptor on the antennae of female mosquitoes; moreover, inactivating the gene that codes for the receptor protein dramatically reduced the repellency of DEET. These investigators also showed that methyl jasmonate, a plant-derived mosquito repellent, activates the same receptor, opening up the possibility that this specific odorant receptor may be a useful target for developing new, safe and affordable repellents.<sup>1</sup> Another example of infectious disease research supported by NIAID is an ongoing study aimed at understanding the molecular mechanisms underlying the feeding behavior of the black-legged tick and the lone star tick; these two species are principal vectors for multiple human tick-borne diseases in the United States, including Lyme disease. These ticks, which must feed for several days, remain attached to their hosts by producing an adhesive secretion known as tick cement. In this study, investigators are working to identify the proteins in tick cement that are injected first into the feeding site, before transmission of disease-causing pathogens, including the Lyme disease agent. Identifying these proteins and disabling them can provide an entirely new strategy for disrupting the transmission cycle of Lyme disease and other tick-borne human illnesses.<sup>2</sup> To ensure funding for future groundbreaking projects of great utility for public health, ESA supports increased funding for NIAID and encourages the committee to support vector-borne disease research at NIH. In particular, ESA supports funding equal to the fiscal year 2016 enacted level of \$1.375 billion for Biodefense and Emerging Infectious Diseases.

CDC, serving as the Nation's leading health protection agency, conducts science and provides health information to prevent and respond to infectious diseases and other global health threats, irrespective of whether they arise naturally or via acts of bioterrorism. Within the core infectious diseases budget of CDC, the Division of Vector-Borne Diseases (DVBD) aims to protect the 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 mosquito-borne diseases and the TickNET system for tick-borne diseases. ArboNET is a nationwide network managed by CDC and State health departments that monitors West Nile virus, Zika virus and other arthropod-borne diseases through a variety of activities, including the collection and testing of mosquitoes. TickNET is a partnership between State and local health departments and the CDC's Division of Vector-Borne Diseases and Division of Parasitic Diseases that tracks tick-borne diseases such as Lyme disease and funds applied research aimed at prevention and pathogen discovery. As well, a component of CDC's global health budget supports activities on malaria and other parasitic diseases,

<sup>1</sup>Xu, P et al. 2014. Mosquito odorant receptor for DEET and methyl jasmonate. *Proc. Natl. Acad. Sci. USA* 111: 16593–16597 (NIAID NIH Award R01AI095514).

<sup>2</sup>Mulenga, A. 2016. *Ixodes scapularis* and *Amblyomma americanum* tick cement proteome. (NIAID NIH Award 1R21AI119873–01A1).

which include maintaining a global reference insectary that houses colonies of mosquitoes from around the world to be used by the agency for studies on malaria transmission.

Specifically, within the President's fiscal year 2017 budget request for CDC, there was a proposed increase of \$34.6 million for Core Infectious Diseases over the fiscal year 2016 enacted level, which includes the vector-borne diseases program. The CDC fiscal year 2017 budget justification also highlights the Zika virus, along with several other vector-borne diseases, including dengue, chikungunya, West Nile virus, and Lyme disease, as program priorities. ESA applauds the identification of vector-borne diseases as a fiscal year 2017 priority for CDC and encourages the inclusion of entomological sciences in future research addressing these diseases. Given that the contributions of the CDC are vital for the health security of the Nation, ESA requests that the subcommittee provide the President's requested increased support for CDC programs addressing vector-borne diseases.

ESA, headquartered in Annapolis, Maryland, is the largest organization in the world serving the professional and scientific needs of entomologists and individuals in related disciplines. Founded in 1889, ESA has nearly 7,000 members affiliated with educational institutions, health agencies, private industry, and government. Members are researchers, teachers, extension service personnel, administrators, marketing representatives, research technicians, consultants, students, pest management professionals, and hobbyists.

Thank you for the opportunity to offer the Entomological Society of America's support for HHS research programs. For more information about the Entomological Society of America, please see <http://www.entsoc.org/>.

[This statement was submitted by May Berenbaum, Ph.D., President, Entomological Society of America.]

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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 \$35 billion in fiscal year 2017 for the National Institutes of Health (NIH) within the Department of Health and Human Services.

FASEB, a federation of 30 scientific societies, represents 125,000 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.

The National Institutes of Health (NIH) is the largest source of funding for biomedical research in the world. Approximately 84 percent of NIH funds are distributed through more than 60,000 research and training grants to over 300,000 scientists employed at universities, medical schools, and other research institutions in all 50 States and nearly every congressional district. To date, 148 Nobel Laureates were funded by NIH over the course of their careers, including the 2015 winners of the Nobel Prizes in Chemistry and Economics.

NIH has produced an outstanding legacy of discoveries that have improved health, saved lives, generated new knowledge and trained generations of scientists. Investment in biomedical research funded by NIH has supported discoveries that reduced deaths from cancer and rates of disability due to stroke, heart disease, Hepatitis B, and osteoporotic fractures, prolonging life and reducing suffering. Many of these advances arose from scientists investigating questions designed to explain fundamental molecular, cellular, and biological mechanisms in non-human and even non-mammalian study systems. Research supported by NIH has expanded our understanding of the molecular roots of various cancers and led to important insights into how microbial communities affect a range of chronic diseases including diabetes. Investigators funded by NIH have also made critical advances in genomics and proteomics, leading to the discovery of more than a thousand risk factors for various diseases. In addition, entirely new global industries and innovative technologies have been created, stimulating our Nation's economic growth.

New scientific breakthroughs such as advanced cellular imaging are being used to view the inner workings of living tissues in greater detail and with more accuracy. Basic research supported by NIH also fuels advances in our understanding of infectious diseases, improving the lives of millions of people worldwide.

NIH-funded research is continuing to produce the insights that are needed for tomorrow's improvements in health and clinical care. Recent discoveries include:

—*Vaccines: Weapons in the Fight Against Disease:* Vaccines are powerful weapons in the fight against disease. They have averted more than 100 million cases of disease in the United States and continue to prevent 2.5 million deaths globally

every year. Using advances in immunology and molecular genetics, scientists continue to develop new kinds of vaccines that hold promise for better efficacy by eliciting immune responses similar to those that occur naturally upon entry of an intruding microbe. For example, researchers at the National Institute of Allergy and Infectious Diseases have co-developed a vaccine aimed at preventing the devastating disease, Ebola. This vaccine was shown to be safe and induced an immune response in human trials, and has moved on for further testing in West African populations affected by this disease.<sup>1</sup>

- The Microbiome: Our Personal Ecosystem*: For more than 300 years, scientists have observed, identified, and implicated individual microorganisms in specific diseases. More recently, with a convergence of scientific disciplines, an explosion in technical capabilities, and revolutionary new ways of thinking, scientists are exploring the organisms with which we share our bodies. Understanding of the microorganisms that live in and on us—our microbiome—will provide insights into how they can influence human health and disease. NIH-funded researchers at the Washington University in St. Louis recently discovered that babies can be populated with their mother’s microbes in utero in contrast to the commonly held belief that the newborns’ microbiomes were not established until after birth. This finding can help scientists further understand how a mother’s microbial status can impact the long-term health of the child.<sup>2</sup>
- Organs-on-a-Chip: Tools for Drug Discovery and Study of Disease*: This emerging technology of organs-on-a-chip allows scientists to watch the cascade of events that takes place in organs in response to drugs or during disease. These 3-D biochips contain living human cells from an organ or tissue that can mimic the mechanical motion of internal organs and structures. The artery-on-a-chip developed by NIH-funded researchers at the University of California Davis provides an unprecedented view of how atherosclerosis develops in coronary arteries and how activation of white blood cells related to inflammation influences the risk of heart problems. This improved understanding could lead to novel anti-inflammation therapies and, eventually, to new tools to predict, monitor, and treat atherosclerosis.<sup>3</sup>
- Nanoparticles: A Targeted Approach to Medicine*: Nanomedicine is beginning to change the way scientists and physicians diagnose and treat disease. Unlike conventional therapies, these tiny particles—1,000 times smaller than the diameter of a human hair—can seek out diseased tissue and access hard to reach places in the body. NIH-funded researchers at Clemson University designed nanoparticles that can identify sites of vascular injury in an animal model of cardiovascular disease. Specialized imaging showed that the nanoparticles only adhere to damaged blood vessels, while avoiding healthy tissue. In the future, researchers hope to modify these nanoparticles to deliver drugs to the sites of vascular injury and repair the damaged tissue.<sup>4</sup>
- Precision Medicine: Fine-Tuning Disease Diagnosis and Treatment*: Precision medicine is a medical paradigm offering customizable medicine based on one’s genes that can be used to prevent, diagnose, and treat disease. Innovations in precision medicine come from technological advances that make it both feasible and affordable to decipher a person’s complete genetic make-up. This new genetic landscape is already causing a paradigm shift in how cancer is diagnosed and treated, with molecular diagnosis adding to or replacing traditional pathological diagnosis based on microscopic features of tumors. For example, a group of scientists working with NIH’s Cancer Genome Atlas analyzed the DNA profiles of over 300 malignant melanoma cancer tissues, the results of which unveiled a set of 13 genetic mutations that can drive the cancer’s growth and will enable physicians to treat each patient with drugs targeted to the specific mutation.<sup>5</sup>

<sup>1</sup> <http://www.faseb.org/Portals/2/PDFs/opa/2015/10.23.15%20FASEB-BreakthroughsInBioscience-Vaccines%20-WEB.pdf>.

<sup>2</sup> <http://www.faseb.org/Portals/2/PDFs/opa/2015/Breakthroughs%20In%20Bioscience%20Human%20Microbiome.pdf>.

<sup>3</sup> <http://www.faseb.org/Portals/2/PDFs/opa/2015/FASEB-HorizonsInBioscience-OrgansOnAChip-Web.pdf>.

<sup>4</sup> <http://www.faseb.org/Portals/2/PDFs/opa/2015/nanoparticles%20horizons%20article.pdf>.

<sup>5</sup> <http://www.faseb.org/Portals/2/PDFs/opa/2014/Individualized%20Medicine%20Breakthroughs.pdf>.

SUSTAINED FUNDING IS CRITICAL TO CONTINUE PROGRESS AND TAKE ADVANTAGE OF  
NEW SCIENTIFIC OPPORTUNITIES

NIH needs sustained increases in funding to continue the research that paves the way to new therapies and to respond to urgent public health needs as they arise. We can now address new questions about biology and behavior that were previously thought to be unanswerable. New scientific breakthroughs such as advanced cellular imaging to view the inner workings of living tissues in greater detail and with more accuracy will be possible. Increasing collaborations between researchers from different fields of science are facilitating ideas for better strategies to prevent, diagnose, and treat a variety of diseases. As the fiscal year 2016–2020 NIH-wide strategic plan notes, “a strengthened and sustained commitment to NIH-supported research is critical because delays in scientific progress can have a dire impact on the health of individuals and the communities in which they live, as well as our Nation’s overall public health and wellbeing”.<sup>6</sup>

The fiscal year 2017 appropriation for NIH must build on and expand the agency’s capacity to fund research in order to improve quality of life, address the rising costs of caring for our aging population, and reduce illness and disability. In July 2015, the House of Representatives recognized the challenges facing the biomedical research enterprise and passed the 21st Century Cures Act (H.R. 6). The bipartisan bill, which was supported by more than 300 members of Congress, recommended that NIH receive an additional \$3.0 billion per year in discretionary and mandatory funding in fiscal year 2016–2018. Related legislation is currently being developed in the U.S Senate.

Congress took a much-needed first step towards fulfilling the goals of the 21st Century Cures Act by providing a \$2 billion dollar increase for NIH in fiscal year 2016. We encourage Congress to continue the funding trajectory envisioned in this legislation as there are excellent proposals for outstanding research that are unable to be funded with current budget levels. When the American Recovery and Reinvestment Act enabled NIH institutes to support additional R01 grants, analyses demonstrated that these added grants were as productive on a per-dollar basis as those that were funded with the regular appropriation.<sup>7</sup> An increase of \$3.0 billion for fiscal year 2017 levels would enable NIH to fund more R01 grants while still providing much needed increases to other parts of the portfolio. If the percentage of the new funding used for R01 grants is the same as in prior years, NIH could fund more than 2,200 additional R01 grants. This would bring the total number of R01 grants back to the level supported in fiscal year 2003 (7,400), the highest in the agency’s recent history.

Sustained increases in funding are necessary for the NIH to continue to train and support the next generation of researchers. For example, increased funding can also be used to raise the stipends for postdocs and other trainees as recommended by FASEB.<sup>8</sup> Additional funding can be used to supplement research and training grants by 5 percent as a first step toward a multi-year commitment to reaching the target salary recommendations from the National Academy of Sciences,<sup>9</sup> the National Postdoctoral Association,<sup>10</sup> and FASEB.<sup>11</sup>

To continue to grow the Nation’s capacity for biomedical research, and as a first installment of a multi-year program of sustainable increases, FASEB recommends at least \$35.0 billion for NIH in fiscal year 2017.

FASEB MEMBERS

The American Physiological Society

American Society for Biochemistry and  
Molecular Biology

<sup>6</sup>NIH-Wide Strategic Plan, fiscal years 2016–2020: *Turning Discovery Into Health*. <http://www.nih.gov/sites/default/files/about-nih/strategic-plan-fy2016-2020-508.pdf>.

<sup>7</sup>Narasimhan S. Danthi, Colin O. Wu, Donna M. DiMichele, W. Keith Hoots, and Michael S. Lauer, “Citation Impact of NHLBI R01 Grants Funded Through the American Recovery and Reinvestment Act as Compared to R01 Grants Funded Through the Standard Payline,” *Circulation Research*, 2015; 116:784–788.

<sup>8</sup>Federation of American Societies for Experimental Biology, *Sustaining Discovery*, Bethesda, MD: FASEB.

<sup>9</sup>National Academies of Science. (2014). *The Postdoctoral Experience Revisited*. Washington, D.C.: The National Academies Press.

<sup>10</sup>National Postdoctoral Association website [https://c.ymcdn.com/sites/npamembers.site-ym.com/resource/resmgr/Docs/NPA\\_Overtime\\_Response\\_-\\_08.2.pdf](https://c.ymcdn.com/sites/npamembers.site-ym.com/resource/resmgr/Docs/NPA_Overtime_Response_-_08.2.pdf).

<sup>11</sup>In 2011, FASEB recommended a stipend level of \$45,000 with subsequent cost of living increases.



American Society for Pharmacology and Experimental Therapeutics	The Endocrine Society
American Society for Investigative Pathology	The American Society of Human Genetics
American Society for Nutrition	International Society for Computational Biology
The American Association of Immunologists	American College of Sports Medicine
American Association of Anatomists	Biomedical Engineering Society
The Protein Society	Genetics Society of America
Society for Developmental Biology	American Federation for Medical Research
American Peptide Society	The Histochemical Society
Association of Biomolecular Resource Facilities	Society for Pediatric Research
The American Society for Bone and Mineral Research	Society for Glycobiology
American Society for Clinical Investigation	Association for Molecular Pathology
Society for the Study of Reproduction	Society for Redox Biology and Medicine
The Teratology Society	Society for Experimental Biology and Medicine
	American Aging Association
	U.S. Human Proteome Organization

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PREPARED STATEMENT OF FIRST FOCUS

Thank you for the opportunity to submit a statement for the record on the fiscal year 2017 Labor, Health and Human Services and Education Appropriations bill. On behalf of First Focus, I respectfully request you fund the following critical programs that greatly benefit children and families accordingly:

*U.S. Department of Health and Human Services*

- The Runaway and Homeless Youth Act (RHYA) programs, \$165,000,000;
- Child Care and Development Block Grant (CCDBG), \$3,961,000,000;
- Head Start and Early Head Start, \$9,602,095,000;
- Childhood Lead Poisoning Prevention Program, \$35,000,000; and
- Healthy Homes Program, \$35,000,000

*U.S. Department of Education*

- McKinney-Vento Education for Homeless Children and Youth (EHCY) program, \$85,000,000

INVESTING IN KIDS

First Focus is a bipartisan children's advocacy organization dedicated to making children and families the priority in Federal policy and budget decisions. Our organization is committed to ensuring that all of our Nation's children have equal opportunity to reach their full potential.

There are more than 200 distinct child and family programs and the Appropriations Subcommittee on Labor, Health & Human Services and Education has jurisdiction over many. Every year for the last 10 years, First Focus has published an annual Children's Budget book that offers a detailed analysis and guide to Federal spending levels and priorities on children and families.

Last year's Children's Budget 2015 showed that the share of Federal spending dedicated to children fell to just 7.89 percent, down from its highest level of 8.5 percent in 2010. Consequently, the Federal share of discretionary spending dedicated to children has dropped by 7.2 percent over the last 5 years.

On an inflation-adjusted basis, Federal discretionary spending on children has dropped by 11.6 percent between 2010 and 2015. Discretionary funding dedicated to children's health, education, child welfare, training, safety, and nutrition have all decreased, even without adjusting for inflation.

We ask that you reverse this trend and increase funding for these critical programs under your subcommittee's jurisdiction that benefit children.

*The Runaway and Homeless Youth Act Programs*

Agency: U.S. Department of Health and Human Services  
 FY 2017 Request: \$165,000,000

National estimates have found that 1.3 to 1.7 million youth experience one night of homelessness a year with 550,000 youth being homeless for a week or longer. As

a result of these significant numbers, we request \$165 million for the Runaway and Homeless Youth Act programs.

The funding would help prevent trafficking, identify survivors, and provide services to runaway, homeless and disconnected youth. Previous funding has laid the foundation for a national system of services for our most vulnerable young people who are at risk of becoming or have already been victims of exploitation and trafficking, abuse, familial rejection, unsafe communities, and poverty.

*Child Care and Development Block Grant*

Agency: U.S. Department of Health and Human Services  
FY 2017 Request: \$3,961,000,000

There is great promise in the reforms included in the bipartisan reauthorization of CCDBG. Unfortunately, there is still insufficient funding to implement these reforms, which are designed to achieve the important goals of ensuring the health and safety of child care, improve quality of care, and make it easier for families to obtain and retain child care assistance. Without a significant increase in CCDBG funding, States may be forced to cut the number of children receiving child care assistance or reduce payment rates for already low-paid child care providers. We request \$3.961 billion for the Child Care and Development Block Grant to make high-quality child care more available and affordable for the families who need it most.

*Head Start and Early Head Start*

Agency: U.S. Department of Health and Human Services  
FY 2017 Request: \$9,602,095,000

Head Start and Early Head Start play an important role in providing vulnerable children under age five with the comprehensive care and education that they need to prepare for school. At the current funding level, Head Start can serve only slightly over two out of five eligible preschoolers. Early Head Start serves just 4 percent of eligible infants and toddlers. Proposals for more Head Start programs to provide full-school-day, full-school-year services would help to ensure that our lowest-income children receive a strong early learning experience. We request \$9,602,095,000 for Head Start and Early Head Start to improve the outcomes of our earliest learners and future generations.

*Childhood Lead Poisoning Prevention Program*

Agency: U.S. Department of Health and Human Services  
FY 2017 Request: \$35,000,000

Current lead poisoning surveillance is limited to 29 States and the District of Columbia due to severe funding cuts. National lead poisoning surveillance would enable communities to identify lead poisoning outbreaks to prevent catastrophes such as that of Flint, Michigan.

The Centers for Disease Control and Prevention is the only agency that houses the information regarding where and when children are poisoned, maintaining it through a surveillance system that monitors blood test results for 4 million children each year. The U.S. Department of Housing and Urban Development (HUD), as well as State and local health and housing agencies, rely on this surveillance system to target funds and enforcement to the highest-risk areas. The recent funding cuts have geographically restricted the surveillance effort and hurt local health departments in their prevention and case management efforts. We request \$35 million for the Childhood Lead Poisoning Prevention program.

*Healthy Homes Program*

Agency: U.S. Department of Health and Human Services  
FY 2017 Request: \$35,000,000

The Healthy Homes Program helps children and families avoid the effects multiple childhood diseases and injuries in the home. This initiative takes a comprehensive approach to these activities by focusing on housing-related hazards in a coordinated effort, rather than addressing a single hazard at a time.

Through robust grants, enforcement efforts, research, and outreach, the Healthy Homes program has been instrumental in achieving a 70 percent reduction in childhood lead poisoning cases since the early 1990s. In addition to saving lives and improving the health of children, this program has saved the Nation billions of dollars

by increasing productivity, decreasing medical and special education costs, and potentially reducing criminal activity. In order to continue this progress, we request \$35 million for the Healthy Homes program.

*McKinney-Vento Education for Homeless Children and Youth Program*

Agency: U.S. Department of Education  
 FY 2017 Request: \$85,000,000

Public schools identified a record 1,301,239 homeless children and youth in 2013–2014. This is a 7 percent increase from the previous year, and a 100 percent increase since 2006–2007. With this rise in homeless children and youth, we request \$85 million to implement the McKinney-Vento Act’s Education for Homeless Children and Youth program. This amount was authorized in the recently enacted Every Student Succeeds Act which is an increase of \$10 million.

This funding would provide services to and identify homeless children and youth, who are at high risk of human trafficking. The EHCY program is effective in mitigating the devastating effects of child and youth homelessness. With the support of EHCY program grants, local education agencies have provided identification, enrollment and transportation assistance, as well as academic support and referrals for basic services. The EHCY program has given homeless children and youth the extra support they need to enroll and succeed in school.

[This statement was submitted by Bruce Lesley, President, First Focus.]

PREPARED STATEMENT OF FOOD & FRIENDS

We are pleased to submit this testimony to the Members of this Subcommittee on the urgency of continuing to support the Ryan White Program through the Appropriations process and increasing funding for the domestic HIV/AIDS portfolio in fiscal year 2017. This support and funding will be decisive for achieving the goals of the National HIV/AIDS Strategy (NHAS) 2020, the AIDS Free Generation and halting the devastating effects of the HIV Treatment Cascade.

Food & Friends is part of a nationwide coalition, the Food is Medicine Coalition, of over 80 food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PWH) and other chronic illnesses. In our service area, we provide over 1 million medically tailored, home delivered meals annually. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

*Why Food and Nutrition Services (FNS) Matter for PWH*

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient’s overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PWH at any stage of their illness. For those who are most mobile, there are congregate meals, walk-in food pantries and voucher programs. For those whose disease has progressed, home delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective core medical service in the Ryan White Program.

These services play a critical role in ensuring that PWTI enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

*FNS as a Care Completion Service Unique to Ryan White*

Social and economic interventions, most often in the form of care completion services like food and nutrition services, are fundamental to making healthcare work for PWH. Support services for PWH are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PWH are poised to remain connected to care and treatment.

*Access to FNS and the Triple Aim*

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PWH.

*Better Health Outcomes*

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines.<sup>1</sup> Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections<sup>2</sup> and the resulting decreases in their healthcare costs. Compare these outcomes to PWH who are food insecure, who have:

- Lower CD4 counts & lower likelihoods of having undetectable viral loads<sup>3</sup>
- More ER visits<sup>4</sup> & increased morbidity and mortality<sup>5</sup>
- More missed primary care appointments & reduced use of antiretroviral therapy<sup>6</sup>

*Lower Healthcare Costs*

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PWH. A recent study comparing participants in a medically-tailored FNS program vs. a control group within a local managed care organization found that average monthly healthcare costs for PWH fell 80 percent in first 3 months after receiving FNS.<sup>7</sup> If hospitalized, nourished clients' costs were 30 percent lower, their hospital length of stay was cut by 37 percent and they were 20 percent more likely to be able to be discharged to their homes rather than a more expensive institution.<sup>8</sup> Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

*Improved Patient Satisfaction*

Studies show nutrition counseling improves quality of life.<sup>9</sup> Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

<sup>1</sup>Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at [https://www.health.ny.gov/diseases/aids/ending\\_the\\_epidemic/docs/key\\_resources/housing\\_and\\_supportive\\_services/chain\\_factsheet3.pdf](https://www.health.ny.gov/diseases/aids/ending_the_epidemic/docs/key_resources/housing_and_supportive_services/chain_factsheet3.pdf).

<sup>2</sup>Academy of Nutrition and Dietetics (formerly American Dietetic Association). HIV/AIDS Nutrition Evidence Analysis Project at [http://www.adaevidencelibrary.com/conclusion.cfm?conclusion\\_statement\\_id=250707](http://www.adaevidencelibrary.com/conclusion.cfm?conclusion_statement_id=250707) Accessed 29 July 2012.

<sup>3</sup>Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011); Singe A W, Weiser SO, McCoy, SI. Does Food Insecurity Undermine Adherence to Antiretroviral Therapy? A Systematic Review. *AIDS Behav* (2015) 19:1510–1526.

<sup>4</sup>Ibid.

<sup>5</sup>Anema A, Chan K, Yip B, Weiser S, Montaner JSG, Hogg RS. Impact of food insecurity on survival among HIV-positive injection drug users receiving antiretroviral therapy in a Canadian cohort. 141 st APHA Annual Meeting, Nov. 2–6, 2013. Boston, MA. Abstract #: 290277.

<sup>6</sup>Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).

<sup>7</sup>Gurvey J, Rand K, Daugherty S, Dinger C, Schmeling J, Laverty N. Examining Health Care Costs Among MANNA Clients and a Comparison Group. *J Prim Care Community Health*. (2013) 4:311–317.

<sup>8</sup>Ibid.

<sup>9</sup>Rabeneck L, Palmer A, Knowles JB, Seidehamel RJ, Harris CL, Merkel KL, Risser JMH, Akrabawi SS. A randomized controlled trial evaluating nutrition counseling with or without oral supplementation in malnourished HIV-infected patients. *JAm Diet Assoc*. (1998) 98: 434–438; Schwenk A, Steuck H, Kremer G. Oral supplements as adjunctive treatment to nutritional counseling in malnourished HTV-infected patients: randomized controlled trial. *Clinical Nutrition* (1999) 18(6): 371–374.

*FNS and the National HIV/AIDS Strategy (NHAS)*

Access to FNS for PWH is fundamental to fulfilling the goals of the NHAS.

- NHAS Goal: Reducing new HIV infections: PWH who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96 percent of the time,<sup>10</sup> thus, FNS is key to prevention.<sup>11</sup>
- NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV: PWH who receive effective FNS are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines.<sup>12</sup>
- NHAS Goal: Reducing HIV-related disparities and health inequities: By providing FNS to PWH who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities.<sup>13</sup>
- NHAS Goal: Achieving a more coordinated national response to the HIV epidemic: There remains a tremendous variation by State in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White HIV Program all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including Ryan White and the ACA.

*Conclusion*

We are deeply aware of the difficult decisions that face the members of the Subcommittee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PWH live healthy and productive lives, produces better overall health outcomes and reduces healthcare costs.

Along with our colleagues, we appreciate the opportunity to offer this testimony regarding the fiscal year 2017 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you.

[This statement was submitted by Craig Shniderman, Executive Director, Food & Friends.]

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PREPARED STATEMENT OF THE FOOD BANK OF CONTRA COSTA AND SOLANO

We are pleased to submit this testimony to the Members of this Subcommittee on the urgency of continuing to support the Ryan White Program through the Appropriations process and increasing funding for the domestic HIV/AIDS portfolio in fiscal year 2017. This support and funding will be decisive for achieving the goals of the National HIV/AIDS Strategy (NHAS) 2020, the AIDS Free Generation and halting the devastating effects of the HIV Treatment Cascade.

The Food Bank of Contra Costa and Solano is part of a nationwide coalition, the Food is Medicine Coalition, of over 80 food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PWH) and other chronic illnesses. Through the Food Bank of Contra Costa's Extra Helpings program, we provide 30 pounds of nutritious food at no cost to over one hundred people living with HIV. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS

<sup>10</sup>M.S. Cohen et al., Prevention of HIV-1 Infection with Early Antiretroviral Therapy. *N. Engl. J. Med.*(2011) 365, 493–505 . IPTN 052.

<sup>11</sup>Palar K, Laraia B, Tsai A, Weiser SO Food insecurity is associated with sexually transmitted infections and HIV serostatus among low income adults in the National Health and Nutrition Examination Survey (NHANES) (1999–2010). Presented at the American Public Health Association I 41st Annual Meeting, Boston, MA, November 5, 2013.

<sup>12</sup>Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014.

<sup>13</sup>Available at Weiser SD, Frongillo EA, Ragland K, I Jogg RS, Riley ED, Bangsberg DR. Food insecurity is associated with incomplete HIV RNA suppression among homeless and marginally housed HIV-infected individuals in San Francisco. *J Gen Intern Med.* (2009) 24(1):14–20.

and to expanding access to this indispensable intervention for people living with other severe illnesses.

*Why Food and Nutrition Services (FNS) Matter for PWH*

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PWH at any stage of their illness. For those who are most mobile, there are congregate meals, walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective core medical service in the Ryan White Program. These services play a critical role in ensuring that PWH enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

*FNS as a Care Completion Service Unique to Ryan White*

Social and economic interventions, most often in the form of care completion service like food and nutrition services, are fundamental to making healthcare work for PWH. Support services for PWH are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PWH are poised to remain connected to care and treatment.

*Access to FNS and the Triple Aim*

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PWH.

*Better Health Outcomes*

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines.<sup>1</sup> Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections<sup>2</sup> and the resulting decreases in their healthcare costs. Compare these outcomes to PWH who are food insecure, who have:

—Lower CD4 counts & lower likelihoods of having undetectable viral loads<sup>3</sup>

<sup>1</sup>Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at [https://www.health.ny.gov/diseases/aids/ending\\_the\\_epidemic/docs/key\\_resources/housing\\_and\\_supportive\\_services/chain\\_factsheet3.pdf](https://www.health.ny.gov/diseases/aids/ending_the_epidemic/docs/key_resources/housing_and_supportive_services/chain_factsheet3.pdf).

<sup>2</sup>Academy of Nutrition and Dietetics (formerly American Dietetic Association). HIV/AIDS Nutrition Evidence Analysis Project at [http://www.adaevidencelibrary.com/conclusion.cfm?conclusion\\_statement\\_id=250707](http://www.adaevidencelibrary.com/conclusion.cfm?conclusion_statement_id=250707) Accessed 29 July 2012.

<sup>3</sup>Aidala A, Yomogida M., and the HIV Food & Nutrition Study Team (2011); Singe AW, Weiser SD McCoy, SI. Does Food Insecurity Undermine Adherence to Antiretroviral Therapy? A Systematic Review. *AIDS Behav* (2015) 19:1510–1526.

- More ER visits<sup>4</sup> & increased morbidity and mortality<sup>5</sup>
- More missed primary care appointments & reduced use of antiretroviral therapy.<sup>6</sup>

#### *Lower Healthcare Costs*

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PWH. A recent study comparing participants in a medically-tailored FNS program vs. a control group within a local managed care organization found that average monthly healthcare costs for PWH fell 80 percent in first 3 months after receiving FNS.<sup>7</sup> If hospitalized, nourished clients' costs were 30 percent lower, their hospital length of stay was cut by 37 percent and they were 20 percent more likely to be able to be discharged to their homes rather than a more expensive institution.<sup>8</sup> Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

#### *Improved Patient Satisfaction*

Studies show nutrition counseling improves quality of life.<sup>9</sup> Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

#### *FNS and the National HIV/AIDS Strategy (NHAS)*

Access to FNS for PWH is fundamental to fulfilling the goals of the NHAS.

- NHAS Goal: Reducing new HIV infections: PWH who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96 percent of the time,<sup>10</sup> thus, FNS is key to prevention.<sup>11</sup>
- NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV: PWH who receive effective FNS are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines.<sup>12</sup>
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- NHAS Goal: Achieving a more coordinated national response to the HIV epidemic: There remains a tremendous variation by State in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White HIV Program all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including Ryan White and the ACA.

#### *Conclusion*

We are deeply aware of the difficult decisions that face the members of the Subcommittee in the current fiscal environment. Yet, research shows that investment

<sup>4</sup> Ibid.

<sup>5</sup> Anema A, Chan K, Yip B, Weiser S, Montaner JSG, Hogg RS. Impact of food insecurity on survival among HIV-positive injection drug users receiving antiretroviral therapy in a Canadian cohort. 141st APHA Annual Meeting, Nov. 2–6, 2013. Boston, MA. Abstract #: 290277.

<sup>6</sup> Aidala A, Yomogida M., and the HIV Food & Nutrition Study Team (2011).

<sup>7</sup> Gurvey J, Rand K, Daugherty S, Dinger C, Schmeling J, Laverty N. Examining Health Care Costs Among MANNA Clients and a Comparison Group. *J Prim Care Community Health.* (2013) 4:311–317.

<sup>8</sup> Ibid.

<sup>9</sup> Rabeneck L, Palmer A, Knowles JB, Seidehamel RJ, Harris CL, Merkel KL, Risser JMH, Akrabawi SS. A randomized controlled trial evaluating nutrition counseling with or without oral supplementation in malnourished HIV-infected patients. *J Am Diet Assoc.* (1998) 98: 434–438; Schwenk A, Steuck H, Kremer G. Oral supplements as adjunctive treatment to nutritional counseling in malnourished HIV-infected patients: randomized controlled trial. *Clinical Nutrition* (1999) 18(6): 371–374.

<sup>10</sup> M. S. Cohen et al., Prevention of HIV-1 Infection with Early Antiretroviral Therapy. *N. Engl. J. Med.* (2011) 365, 493–505. HPTN 052.

<sup>11</sup> Palar K, Laraia B, Tsai A, Weiser SD Food insecurity is associated with sexually transmitted infections and HIV serostatus among low income adults in the National Health and Nutrition Examination Survey (NHANES) (1999–2010). Presented at the American Public Health Association 141st Annual Meeting, Boston, MA, November 5, 2013.

<sup>12</sup> Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014.

<sup>13</sup> Available at Weiser SD, Frongillo EA, Ragland K, Hogg RS, Riley ED, Bangsberg DR. Food insecurity is associated with incomplete HIV RNA suppression among homeless and marginally housed HIV-infected individuals in San Francisco. *J Gen Intern Med.* (2009) 24(1):14–20.

in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PWH live healthy and productive lives, produces better overall health outcomes and reduces healthcare costs.

Along with our colleagues, we appreciate the opportunity to offer this testimony regarding the fiscal year 2017 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you.

[This statement was submitted by Carly Finkle, Advocacy Manager, Food Bank of Contra Costa and Solano.]

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PREPARED STATEMENT OF THE FOUNDATION FOR INDIVIDUAL RIGHTS IN EDUCATION

Dear Chairman Cochran, Vice-Chairwoman Mikulski, Chairman Blunt, and Ranking Member Murray: The Foundation for Individual Rights in Education (FIRE; [thefire.org](http://thefire.org)) is a nonpartisan, nonprofit organization dedicated to defending student and faculty rights on America's college and university campuses. These rights include freedom of speech, freedom of assembly, legal equality, due process, religious liberty, and sanctity of conscience—the essential qualities of individual liberty and dignity. We write to express our opposition to requests for increasing the funding of the Department of Education's Office for Civil Rights (OCR) in the upcoming appropriations legislation.

As you are aware, on March 17, 2016, 22 Senators sent a joint letter urging the Subcommittee on Labor, Health and Human Services, and Education to increase OCR's funding from \$102 million to \$137.7 million for fiscal year 2017. If this request were to be approved, it would amount to an increase of nearly 30 percent over the agency's funding for the current fiscal year.

While FIRE supports OCR's goal of effectively addressing sexual assault and sexual harassment on college campuses, we have serious concerns about the manner in which the agency is pursuing that mission. In pursuit of this objective, OCR has unlawfully ordered institutions of higher education to reduce the due process protections afforded to individuals accused of sexual misconduct and has redefined sexual harassment to include speech protected by the First Amendment under precedent from the Supreme Court of the United States. Until OCR stops infringing on the First Amendment and rolling back due process protections, the agency should not receive budget increases.

It should be self-evident that institutions adjudicating guilt or innocence in sexual assault cases must do so in a fair and impartial manner reasonably calculated to reach the truth. Indeed, in the April 4, 2011, "Dear Colleague" letter issued by OCR, the agency acknowledged that "a school's investigation and hearing processes cannot be equitable unless they are impartial."<sup>1</sup>

Disappointingly, however, OCR's own rhetoric and actions have been decidedly one-sided, almost exclusively emphasizing the rights of the complainant while paying little to no attention to the rights of the accused. For example, OCR has mandated that institutions of higher education utilize our judiciary's lowest burden of proof, the "preponderance of the evidence" standard, despite the absence of any of the fundamental procedural safeguards found in civil courts of law. Without basic procedural protections, campus tribunals are making life-altering findings using a low evidentiary threshold that amounts to little more than a hunch that one side is right. This mandate is not just unfair to the accused—it reduces the accuracy and reliability of the findings and compromises the integrity of the system as a whole.

Gary Pavela, editor of the Association of Student Conduct Administration's Law and Policy Report and former president of the International Center for Academic Integrity, recently told Inside Higher Ed that "[c]olleges and universities are escalating and criminalizing the prosecution of sexual misconduct cases, while eliminating basic due process for the accused."<sup>2</sup> He continued:

<sup>1</sup> U.S. Dep't of Educ., Office for Civil Rights, Dear Colleague Letter: Sexual Violence (Apr. 4, 2011), <http://www2.ed.gov/about/offices/list/ocr/letters/colleague-201104.html>.

<sup>2</sup> Jake New, Out of Balance, Inside Higher Ed (Apr. 14, 2016), <https://www.insidehighered.com/news/2016/04/14/several-students-win-recent-lawsuits-against-colleges-punished-them-sexual-assault>.



Title IX does not require this approach and courts are unlikely to allow it. Silence on procedural fairness, however, sends the subliminal message that due process is an impediment to more “convictions.” We’re seeing the fruits of OCR’s due process silence now. University sexual misconduct policies are losing legitimacy in the eyes of the courts. That’s a disaster for Title IX enforcement. And OCR shares ample responsibility for it.

The merits of the preponderance of the evidence standard aside, there is little doubt that OCR’s insistence that institutions of higher education use any particular standard exceeds the agency’s authority. The Dear Colleague letter was not subjected to the notice-and-comment process required under the Administrative Procedure Act before an agency like OCR can impose new substantive rules.<sup>3</sup> Despite repeated sworn testimony to congressional committees from top officials at the Department of Education insisting that the terms of the Dear Colleague letter are not binding on institutions of higher education,<sup>4</sup> OCR continues to demand conformance with those terms when negotiating agreements with institutions of higher education.<sup>5</sup>

The agreement OCR and the Department of Justice entered into with the University of Montana on May 9, 2013, is a particularly galling example of OCR’s willingness to exceed its authority. In the findings letter accompanying that agreement, OCR rejected the university’s sexual harassment policy, stating that “sexual harassment should be more broadly defined as ‘any unwelcome conduct of a sexual nature,’” including “verbal conduct”—that is, speech. The letter, which proclaimed itself a “blueprint” for schools across the Nation to follow, then explicitly stated that allegedly harassing expression need not even be offensive to an “objectively reasonable person of the same gender in the same situation.” If the listener takes offense to sex-related speech for any reason, no matter how irrationally or unreasonably, the speaker may be punished. To comply with this “blueprint,” institutions nationwide are adopting unconstitutionally broad speech codes.<sup>6</sup>

OCR’s overreach is so blatant that it has drawn criticism from Senators Lamar Alexander<sup>7</sup> and James Lankford,<sup>8</sup> the American Association of University Professors,<sup>9</sup> Feminists for Free Expression,<sup>10</sup> the National Coalition Against Censorship,<sup>11</sup> former American Civil Liberties Union president and New York Law School professor Nadine Strossen,<sup>12</sup> columnist George Will,<sup>13</sup> and University of California Sys-

<sup>3</sup> 5 U.S.C. § 553.

<sup>4</sup> Help Committee GOP, Alexander Questions Dept. of Ed. Witness at HSGAC Hearing on Regulatory Guidance, YouTube (Sept. 23, 2015), <https://www.youtube.com/watch?v=dliXuv-Oirw>; Joe Cohn, Second Department of Education Official in Eight Days Tells Congress Guidance Is Not Binding, Found. for Individual Rights In Educ.: The Torch (Oct. 2, 2015), <https://www.thefire.org/second-department-of-education-official-in-eight-days-tells-congress-guidance-is-not-binding>.

<sup>5</sup> See, e.g., U.S. Dep’t of Educ., Office for Civil Rights, OCR Review No. 11–11–6001, UVA Letter of Finding (Sept. 21, 2015), <http://www2.ed.gov/documents/press-releases/university-virginia-letter.pdf>; U.S. Dep’t of Educ., Office for Civil Rights, OCR Review No. 15–11–2098 and 15–14–2113, MSU Letter of Finding (Sept. 1, 2015), <http://www2.ed.gov/documents/press-releases/michigan-state-letter.pdf>; U.S. Dep’t of Justice, Civil Rights Division, and U.S. Dep’t of Educ., Office for Civil Rights, DOJ No. DJ 169–44–9, OCR No. 10126001, UM Letter of Finding (May 9, 2013), <https://www.justice.gov/sites/default/files/opa/legacy/2013/05/09/um-ltr-findings.pdf>.

<sup>6</sup> Found. for Individual Rights In Educ., Spotlight on Speech Codes 2016: The State of Free Speech on Our Nation’s Campuses, available at <https://www.thefire.org/spotlight-on-speech-codes-2016>.

<sup>7</sup> Susan Kruth, Senators Ask Key Questions at Hearing on Campus Sexual Assault, Found. for Individual Rights In Educ.: The Torch (June 30, 2014), <https://www.thefire.org/senators-ask-key-questions-at-hearing-on-campus-sexual-assault>.

<sup>8</sup> Letter from Senator James Lankford to Acting Secretary John B. King, Jr., U.S. Department of Education (Jan. 7, 2016), available at <https://www.thefire.org/sen-james-lankford-letter-to-the-education-department>.

<sup>9</sup> The History, Uses, and Abuses of Title IX, Am. Ass’n of Univ. Professors (Mar. 24, 2016), <http://www.aaup.org/file/TitleIX-Report.pdf>.

<sup>10</sup> Dept. of Education Challenged by FIRE, Coalition about Silence on Threats to Student Rights, Found. for Individual Rights In Educ.: The Torch (May 7, 2012), <https://www.thefire.org/dept-of-education-challenged-by-fire-coalition-about-silence-on-threats-to-student-rights> (listing Feminists for Free Expression as a member of the coalition challenging the Department of Education).

<sup>11</sup> *Id.*

<sup>12</sup> Alex Morey, Strossen Praises FIRE at Harvard Free Press Lecture, Criticizes OCR for Chilling Speech, Found. for Individual Rights In Educ.: The Torch (Oct. 21, 2015), <https://www.thefire.org/strossen-praises-fire-at-harvard-free-press-lecture-criticizes-ocr-for-chilling-speech>.

<sup>13</sup> George F. Will, The legislative and judicial branches strike back against Obama’s overreach, Wash. Post (Feb. 19, 2016), <https://www.washingtonpost.com/opinions/the-legislative-and-judi>

tem president and former secretary of the Department of Homeland Security Janet Napolitano.<sup>14</sup> Napolitano's observations are particularly noteworthy:

Unfortunately, OCR neglected to provide notice or an opportunity for comment in advance of issuing either the Dear Colleague Letter or the April 2014 Questions and Answers guidance regarding Title IX and sexual violence, even though both documents clearly imposed new mandates on schools. Campuses facing these new mandates had no opportunity to provide feedback for the Department of Education's consideration prior to the issuance of the guidance documents and were left with significant uncertainty and confusion about how to appropriately comply after they were implemented.<sup>15</sup>

FIRE is eager to work with Congress and OCR to effectively address campus sexual assault and sexual harassment. But until Congress holds OCR accountable for its unlawful abuse of power and its blatant disregard for campus civil liberties, the agency will continue to both exceed its authority and take an inappropriately one-sided approach to addressing these issues.

We hope that Congress requires OCR to abide by the rule of law before it rewards the agency with a budget increase.

Thank you for your consideration of our testimony. We would be pleased to discuss our concerns with you further. I may be reached via email (joe@thefire.org) at your convenience.

Respectfully,

[This statement was submitted by Joseph Cohn, Legislative and Policy Director, Foundation for Individual Rights in Education.]

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PREPARED STATEMENT OF THE FRIENDS OF THE HEALTH RESOURCES AND SERVICES  
ADMINISTRATION

Friends of HRSA is a nonpartisan coalition of 170 national organizations representing millions of public health and healthcare professionals, academicians and consumers invested in the Health Resources and Services Administration's mission to improve health and achieve health equity. For fiscal year 2017, we recommend restoring HRSA's discretionary budget authority to the fiscal year 2010 level of \$7.48 billion. HRSA is the primary Federal agency responsible for improving health, and does so through access to quality health services, a skilled workforce and innovative programs. Over the past 3 years, HRSA's discretionary budget authority has slowly been restored, but still remains nearly 18 percent below the fiscal year 2010 level—far too low to fully address the Nation's current health needs. Restoring funding to HRSA will allow the agency to more effectively fill preventive and primary care gaps.

Our Nation's ability to deliver health services that meet the pressing health challenges of the 21st century is essential for a healthy and thriving population. To meet our Nation's persistent and changing health needs, and to keep pace with our growing, aging and diversifying population, and evolving healthcare system, we must make deliberate investments in robust systems of care and a high-performing workforce ready to respond to the current demands and able to take on unexpected health needs as they arise. The agency is continuously exploring and supporting efforts that drive quality care, better leverage existing investments and achieve improved health outcomes at a lower cost. HRSA's programs have been successful in improving the health of people at highest risk for poor health outcomes.

HRSA operates programs in every State and U.S. territory. The agency is a national leader in improving the health of Americans by addressing the supply, distribution and diversity of health professionals and supporting training in contemporary practices, and providing quality health services. HRSA programs work in coordination with each other to maximize resources and leverage efficiencies. For example, Area Health Education Centers, a health professions training program, was originally authorized at the same time as the National Health Service Corps to create a complete mechanism to provide primary care providers for health centers and other direct providers of healthcare services for underserved areas and populations. AHECs serve as an integral part of the mechanism that recruits providers into pri-

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cial-branches-strike-back-against-obamas-overreach/2016/02/19/15f403b8-d672-11e5-be55-2cc3c1e4b76b\_story.html.

<sup>14</sup> Janet Napolitano, "Only Yes Means Yes": An Essay on University Policies Regarding Sexual Violence and Sexual Assault, 33 Yale L. & Pub. Pol'y 387 (2015), available at [http://ylpr.yale.edu/sites/default/files/YLPR/33.2\\_policy\\_essay\\_-\\_napolitano\\_final.pdf](http://ylpr.yale.edu/sites/default/files/YLPR/33.2_policy_essay_-_napolitano_final.pdf).

<sup>15</sup> Id. at 394-95.

mary health careers, diversifies the workforce and develops a passion for service to the underserved in these future providers.

HRSA's programs also work synergistically across the Federal Government to enhance health outcomes. Through maternal and child health programs, HRSA has contributed to the decrease in infant mortality rate, a widely used indicator of the Nation's health. While HRSA has contributed to driving down the national rate, which is now at a historic low of 5.8 deaths per 1,000 live births, it would not have been possible without the effort of other Federal public health programs, including those that address perinatal care, cessation programs for tobacco and other substances, healthy eating and physical activity programs, among other efforts.

HRSA grantees also have the potential to play an active role in addressing emerging health challenges. For example, HRSA's programs are well positioned to provide outreach, education, prevention, screening and treatment services for populations at risk for or infected with the Zika virus and are already doing so in Puerto Rico and affected territories. However, as we approach warmer months and the opportunity to encounter mosquitos that can spread the Zika virus increases, additional funding will be required to increase capacity in health centers, support additional National Health Service Corps providers to deliver the care needed and expand maternal and child health services. Strong, sustained funding would allow HRSA to build a consistent approach to quickly and effectively respond to emerging and unanticipated future needs, while continuing to address persistent health challenges.

Our recommendation is based on the need to continue improving the health of Americans and to provide HRSA with the resources needed to pave the way for new achievement by supporting critical HRSA programs, including:

- Primary care programs support more than 9,000 health center sites in every State and territory, improving access to preventive and primary care for more than 22.9 million patients in geographic areas with few healthcare providers. Health centers coordinate a full spectrum of health services including medical, dental, behavioral and social services. Close to half of all health centers serve rural populations. For 50 years, health centers have delivered comprehensive, cost-effective care for people who otherwise may not have obtained care and have demonstrated their ability to reduce the use of costlier providers of care.
- Health workforce programs support the education, training, scholarship and loan repayment 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 that health professionals are well-equipped to care for the Nation's changing needs and demographics.
- Maternal and child health programs, including the Title V Maternal and Child Health Block Grant, Leadership Education in Neurodevelopmental and Related Disabilities, 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 34.3 million 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 coordinated long-term follow-up is available for babies with a positive screen, and also help improve early identification and coordination of care for children with autism and other developmental disabilities.
- 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 to 512,000 people living with HIV/AIDS, which accounts for nearly 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. People receiving care through the Ryan White HIV/AIDS Program achieve significantly higher viral suppression compared to the national average, and viral suppression is central to preventing new HIV infections.
- Family planning Title X services ensure access to a broad range of reproductive, sexual and related preventive health services for more than 4.1 million low-income women, men and adolescents. 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. In 2014, Title X family planning helped prevent over 941,000 unintended pregnancies and an estimated 1,176 cases of sexually transmitted disease-related infertility.

- Rural health programs improve access to care for people living in rural areas. The Office of Rural Health Policy serves as the Nation’s primary advisor on rural policy issues, conducts and oversees research on rural health issues and administers grants to support healthcare delivery in rural communities. Rural health 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. In addition to improving the health of rural residents, an analysis completed in 2013 showed that for every dollar HRSA invested, about \$1.63 in additional revenue was generated in the community—the cumulative impact added up to \$19.4 million in new local economic activity over a 3-year project period of an original investment of \$11.9 million.
- 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 over 50 years. Poison control centers contribute to significantly decreasing a patient’s length of stay in a hospital and save the Federal Government \$662.8 billion each year in medical costs and lost productivity.

We urge you to consider HRSA’s central role in strengthening the Nation’s health and advise you to adopt our fiscal year 2017 request of \$7.48 billion for HRSA’s discretionary budget authority. Thank you for the opportunity to submit our recommendation to the subcommittee.

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PREPARED STATEMENT OF THE FRIENDS OF THE NATIONAL INSTITUTE OF DIABETES  
AND DIGESTIVE AND KIDNEY DISEASES

For the fiscal year 2017 funding cycle, the Friends of NIDDK encourages the Subcommittee to increase funding for research programs and activities at the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) that focus on preventing acute and chronic disease and other illnesses in adults as well as youth, and reducing health disparities. In particular, the Friends of NIDDK request a funding level of \$2.165 billion in fiscal year 2017 for the Institute. This funding level is an increase of approximately 10 percent over the fiscal year 2016 omnibus bill. Given the large burden that acute and chronic diseases place on the U.S. healthcare system, economy, and quality of life years, the Friends of NIDDK believe that increased support for efforts in fiscal year 2017 to will reduce this burden is warranted.

The Friends of NIDDK is a coalition of professional societies and patient advocacy groups with a vested interest in promoting and sustaining the vital research activities of the NIDDK. The Friends of NIDDK was established in 2013 with the vision of uniting organizations to speak with one voice about the important research being conducted by the Institute and to ensure that the investment in the NIDDK is deepened in future years. The Friends of NIDDK engage Members of Congress and other stakeholders on the prolific scientific advances made through the Institute’s ongoing research and the critical importance of increased Federal funding for future scientific initiatives. In just the short time since its inception, nearly 50 national and local organizations have joined the Friends of NIDDK to rally their support of the Institute’s activities.

ABOUT NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASES

NIDDK is the fifth largest institute at the National Institutes of Health and coordinates research on many of the most serious diseases affecting public health. The mission of NIDDK is to “conduct and support medical research and research training and to disseminate science-based information on diabetes and other endocrine and metabolic diseases; digestive diseases, nutritional disorders, and obesity; and kidney, urologic, and hematologic diseases, to improve people’s health and quality of life.”

The NIDDK supports a wide range of medical research through grants to universities and other medical research institutions across the country, and supports scientists who conduct basic, translational, and clinical research across a broad spec-

trum of research topics and serious chronic diseases and conditions. In addition, the NIDDK supports research training for students and scientists at various stages of their careers and a range of education and outreach programs, including the National Diabetes Education Program, the National Kidney Disease Education Program and the Weight-control Information Network, to bring science-based information to patients and their families, healthcare professionals, and the public.

#### UNITED STATES DISEASE BURDEN

The diseases that are included within the NIDDK research portfolio are some of the most common, yet costly, diseases impacting Americans and demand increased research funding in fiscal year 2017. Chronic diseases are the Nation's leading causes of morbidity and mortality and account for 75 cents of every dollar spent on healthcare in the U.S. For example, nearly 30 million Americans have diabetes and 86 million have prediabetes. Diagnosed and undiagnosed diabetes, prediabetes and gestational diabetes cost the Nation \$322 billion a year, an increase of 48 percent in just 5 years. About 26 million American adults have chronic kidney disease (CKD) and millions of others are at increased risk, although NIH investments in kidney research are less than 1 percent of Medicare costs for kidney care. It is estimated that 1.4 million Americans suffer from Crohn's disease and ulcerative colitis with approximately 30,000 new cases diagnosed each year, costing more than \$2.2 billion in direct and indirect costs annually in the United States. Urologic diseases affect people of all ages, result in significant healthcare expenditures, and may lead to substantial disability and impaired quality of life. Patients with cystic fibrosis, an inherited disease that primarily affects the lungs and digestive system, continue to face much lower life expectancy compared to healthy adults, despite dramatic advances in treatment. These diseases represent only a portion of the NIDDK research portfolio, but nonetheless underscore the need for continued investment.

#### NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASES SUCCESSES

The researchers at NIDDK are collaborating and using innovative technologies to discover cross-cutting solutions that will ultimately reduce healthcare costs and improve quality of life for millions of Americans. NIDDK releases an annual report to illustrate the Institute's scientific advances, and incorporates personal stories of individuals that participate in NIDDK-sponsored clinical research. Funding of \$2.165 billion in fiscal year 2017 would allow NIDDK to move forward on the following recent innovations outlined in the report:

- A proposed human kidney biopsy project that would incorporate the systematic collection, storage, and preservation of kidney tissue-combined with advances in genetics and precision medicine-in order to lead to new research discoveries, treatments, and cures for kidney disease patients.
- Findings that indicate cells or exosomes that are shed by the primary tumor in the bloodstream can potentially be used as biomarkers when screening for Pancreatic Disease.
- New research has found a link between gut sensory cells and nerves. This connection shows that the gut is able to directly communicate about ingested nutrients to the nervous system.
- Advancing progress toward the development of an artificial pancreas for people with Type 1 diabetes by using smartphone technology.
- Research areas for treatment of liver disease including experimental cell based approaches for liver cell regeneration.

Thank you for this opportunity to present our views to the Subcommittee. We urge your fiscal year 2017 appropriations decisions reflect the need to address the broad spectrum of diseases in the Institute's portfolio. We look forward to working with you to prevent chronic illness, improve the quality of lives, and save billions of dollars in healthcare spending through an increased investment in the NIDDK. Should you have any questions or require additional resources regarding NIDDK activities, please contact the Friends of NIDDK's Washington representative, Jim Twaddell, at [Jim.Twaddell@dbr.com](mailto:Jim.Twaddell@dbr.com).

[This statement was submitted by Jim Twaddell, Staff Consultant, Friends of National Institute of Diabetes and Digestive and Kidney Diseases.]

#### PREPARED STATEMENT OF THE FRIENDS OF THE NATIONAL INSTITUTE ON AGING

Chairman Blunt, Ranking Member Murray, and members of the Committee, this testimony is being submitted on behalf of the Friends of the National Institute on Aging (FoNIA), [www.friendsofnia.org](http://www.friendsofnia.org), a coalition of more than 50 academic, patient-

centered and non-profit organizations that supports the research and training missions of the National Institute on Aging (NIA) by promoting and advocating for the NIA and its initiatives as public policies in health and research take shape. We appreciate the opportunity to provide testimony in support of the NIA and to comment on the need for sustained, long-term growth in aging research funding. Considering the resources the Federal government spends on healthcare costs associated with age-related diseases, we feel it makes sound economic sense to increase Federal resources for aging research. Specifically, given the unique challenges created by an aging population and the range of promising scientific opportunities in the field of aging research, the FoNIA recommends an additional \$500 million in the fiscal year 2017 National Institutes of Health (NIH) budget to support biomedical, behavioral and social sciences aging research efforts at the NIH. We believe that this funding is the minimum essential to sustain research needed to make progress in attacking the chronic diseases that are driving significant increases in our national healthcare costs. In addition, given the exceptional challenges presented by Alzheimer's Disease and Related Disorders (ADRD), FoNIA endorses a minimum increase of an additional \$400 million for ADRD research across NIH in fiscal year 2017 to ensure that overall NIH research progress continues.

NIA's mission is urgent. The number of Americans aged 65 and older is growing at an unprecedented rate. By 2030, there will be 72 million Americans in this age group; more than double the number from 2000. The number of "oldest old"—people age 85 or older—is expected to more than triple between 2010 and 2050. Age is a primary risk factor for many disabling diseases and conditions—most notably, Alzheimer's disease (AD). The NIA is the primary Federal agency responsible for AD research. We know that over 5 million Americans aged 65 years and older may have AD with a predicted increase to 13.8 million by 2050. NIA's comprehensive AD research program spans the spectrum of discovery, from basic neuroscience through translational research and clinical application. The National Alzheimer's Plan, 2012 and 2015 Research Summits, and allocation of additional funds over the past several years have accelerated momentum in this field. Recommendations from the Research Summits have been incorporated into new Funding Opportunity Announcements (FOAs) that cover virtually every aspect of AD research including health disparities, caregiving, epidemiology, diagnosis and prediction, molecular and cellular mechanisms, brain aging and clinical trials.

Efforts in AD research have been bolstered by the advent of new technologies to generate and analyze enormous data sets. These new technologies have been particularly effective in identifying risk and protective genes for AD. Researchers can now access genome sequence data from the Alzheimer's Disease Sequencing Project (ADSP), a collaboration between the NIA and the National Human Genome Research Institute to facilitate identification of risk and protective genes. The opening of a new data sharing and analysis resource developed under AMP (Accelerating Medicines Partnership), the AMP-AD Knowledge Portal, and the release of the first wave of data will enable large and complex biomedical datasets to be shared and analyzed. Researchers believe this approach will ultimately lead to selecting novel disease targets.

Because aging is the single biggest risk factor for the development of many chronic diseases, a better understanding of the basic biology of aging may open up new avenues for prevention and cures. Therefore investing in research on the basic biology of aging is a major priority for NIA. The establishment of the trans-NIH GeroScience Interest Group (GSIG) to facilitate discovery on the common risks and mechanisms behind age-related diseases and conditions has invigorated the field of basic geroscience. Recommendations from the 2013 GSIG Summit entitled "Advances in Geroscience: Impact on Healthspan and Chronic Disease" continue to energize researchers in this field.

Understanding that up to half of premature deaths in the United States are due to behavioral and social factors, NIA is committed to supporting basic behavioral and social research in aging. The NIA-supported Health and Retirement Study remains the world's premier multidisciplinary source of data on the health and well-being of older Americans, linking objective and subjective measures of health with information about retirement, economic status, family structure, personality, as well as health behaviors and service utilization. Funds from the American Recovery and Reinvestment Act facilitated expansion of the study, including genotyping DNA samples from participants. In fiscal year 2016, research will be ongoing to take advantage of the newly available genetic data to advance understanding of how genetic, behavioral and psychosocial factors affect health and well-being. NIA remains an active participant in the trans-NIH Science of Behavior Change initiative and the Basic Behavioral and Social Science Opportunity Network.

Personalized medicine is closer than ever to being realized for many aging-related diseases and conditions. One example involves AD—approaches to systems biology identifying complex genetic and molecular networks, such as AMP, will enable identification of molecular signatures and networks underlying the various disease processes that lead to symptoms associated with AD. NIA is also partnering with the Patient-Centered Outcomes Research Institute (PCORI) to test an individually-tailored injurious falls prevention strategy that includes a “fall care manager” in community healthcare systems. Falls are a key cause of disability in older people. Multiple chronic health conditions are common among older adults and another NIA initiative supports research to identify behavioral interventions, targeted at older adults with multiple chronic conditions, with high potential impact on health outcomes.

NIA also supports several innovative programs dedicated to training the next generation of aging researchers. These include the Paul Beeson Career Development Awards in Aging Research for outstanding clinician-scientists and the Butler-Williams Scholars Program, a “boot camp” for emerging investigators in aging research to prepare them to compete successfully for grant funding.

Despite the recent infusion of money targeted at ADRD research, which we greatly appreciate, NIA’s current budget does not reflect the tremendous responsibility it has to meet the health research needs of a growing U.S. aging population. According to National Health Expenditure Data, in 2010 out of each healthcare dollar spent, 34 cents was spent on adults age 65 and older. Yet only 3.6 cents out of every dollar appropriated to NIH in 2010 went to support the work of NIA (NIH Almanac). With a continuation of support for ADRD research and an infusion of much needed support for all other aging research in fiscal year 2017, NIA can expand promising, recent research activities, such as:

- Implement new prevention and treatment clinical trials, research training initiatives, care interventions, and genetic research studies developed to meet the goals of the National Plan to Address Alzheimer’s disease;
- bolster trans-NIH initiatives developed by the NIH GeroScience Interest Group to understand basic cellular and molecular underpinnings of aging as a principal risk factor for chronic disease and to explore common mechanisms governing relationships between aging and chronic disease;
- understand the impact of economic concerns on older adults by examining work and retirement behavior, health and functional ability, and policies that influence individual well-being; and
- support personalized medicine initiatives that will better target treatments and interventions to individuals who will most benefit from them.

NIA is poised to accelerate the scientific discoveries that we as a Nation are counting on. With millions of Americans facing the loss of their functional abilities, their independence and their lives to chronic diseases of aging, there is a pressing need for robust and sustained investment in the work of the NIA. In every community in America, healthcare providers depend upon NIA-funded discoveries to help their patients and caregivers lead healthier and more independent lives. In these same communities, parents are hoping NIA-funded discoveries will ensure that their children have a brighter future, free from the diseases and conditions of aging that plague our Nation today. We do not yet have the knowledge needed to predict, preempt and prevent the broad spectrum of diseases and conditions associated with aging. We do not yet have sufficient knowledge about disease processes to fully understand how best to prevent, diagnose and treat diseases and conditions of aging, nor do we have the knowledge needed about the complex relationships among biology, genetics, and behavioral and social factors related to aging. Bold, visionary and sustainable investments in the NIA will make it possible to achieve substantial and measurable gains in these areas sooner rather than later, and perhaps too late.

We recognize the tremendous fiscal challenges facing our Nation and that there are many worthy, pressing priorities to support. However, we believe a commitment to the Nation’s aging population by making bold, wise investments in programs will benefit them and future generations. Investing in NIA is one of the smartest investments Congress can make.

[This statement was submitted by Kathryn Jedrziewski, PhD, Chair, Friends of the National Institute on Aging and Deputy Director, University of Pennsylvania Institute on Aging.]

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).

Recognizing that so many health research issues are inter-related, we request that the subcommittee provide at least \$34.5 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 2017 Labor, Health and Human Services, Education and Related Agencies Appropriations bill. We also respectfully request the inclusion of the following NIDA specific report language.

*Opioid Misuse and Addiction.*—The Committee is concerned about the escalating epidemic of prescription opioid and heroin use, addiction and overdose in the U.S. Nearly 130 people die each day in this country from opioid overdose, making it one of the most common causes of death for adolescents and young adults. The Committee appreciates the important role that research can and should play in the various Federal initiatives aimed at this crisis. The Committee urges NIDA to 1) continue funding research on medications to alleviate pain, including the development of those 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 opioid analgesics to heroin abuse and addiction within affected populations.

*Adolescent Brain Development.*—The Committee recognizes and supports the Adolescent Brain and Cognitive Development (ABCD) Study. We know that the brain continues to develop into the mid-twenties. However, we do not yet know enough about the dramatic brain development that takes place during adolescence and how the various experiences children are exposed to during this time (e.g., sports injuries, lack of sleep, marijuana or other substance use) interact with each other and a child's biology to affect brain development and, ultimately, social, behavioral, health and other outcomes. As part of the Collaborative Research on Addiction (CRAN), a trans-NIH consortium involving NIDA, NIAAA, and NCI, and in partnership with NICHD, NINDS, NIMH, NIMHD, and OBSSR, the ABCD study intends to address this knowledge gap. As the largest ever longitudinal brain-imaging study of youth, the ABCD study will follow approximately 10,000 U.S. children from ages 9–10 into early adulthood, who will provide behavioral, neuroimaging, genetic, and other health data throughout development. The ABCD study will yield critical insights into the foundational aspects of adolescence that shape life trajectories. The committee also recommends and recognizes that the cost of this comprehensive study should not inhibit investigator initiated studies or any potential special appropriation for its ongoing support.

*Marijuana Research.*—The Committee is concerned that marijuana public policies in the States (medical marijuana, recreational use, etc.) are being changed without the benefit of scientific research to help guide those decisions. The Committee is also concerned that restrictions associated with Schedule 1 of the Controlled Substance Act effectively limit the amount or type of research that can be conducted on marijuana or its component chemicals. NIDA is encouraged to continue supporting a full range of research on the effects of marijuana and its components, including policy research focused on policy change and implementation across the country. The Committee also directs NIDA to provide a short report on the barriers to research that result from the classification of marijuana as a Schedule 1 substance.

*Raising Awareness and Engaging the Medical Community in Drug Abuse and Addiction Prevention and Treatment.*—Education is a critical component of any effort to curb drug use and addiction, and it must target every segment of society, including healthcare providers (doctors, nurses, dentists, and pharmacists), patients, and families. Through its NIDAMeD initiative, NIDA is advancing addiction awareness, prevention, and treatment in primary care practices through seven Centers of Excellence for Physician Information. Intended to serve as national models, these centers target physicians-in-training, including medical students and resident physicians in primary care specialties (e.g., internal medicine, family practice, and pediatrics). NIDA also developed, in partnership with the Office of National Drug Control Policy, two online continuing medical education courses on safe prescribing for pain and managing patients who abuse prescription opioids. These courses were viewed by over 200,000 individuals and completed for credit by over 100,000 clinicians com-



bined. The Committee continues to be pleased with NIDAMed, and 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.

*Medications Development.*—The Committee recognizes that new technologies are required for the development of next-generation pharmaceuticals. 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 research is the development of safe and effective vaccines or antibodies that target specific addictive drugs, like nicotine, cocaine, and heroin, or drug combinations. The Committee is encouraged 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 ultimately prevent addiction.

*Drug Treatment in Justice System Settings.*—The Committee understands that providing evidence-based treatment for substance use disorders offers the best alternative for interrupting the drug use/criminal justice cycle for offenders with drug problems. Untreated substance using offenders are more likely to relapse into drug use and criminal behavior, jeopardizing public health and safety and taxing criminal justice system resources. Treatment has consistently been shown to reduce the costs associated with lost productivity, crime, and incarceration caused by drug use. This reality represents a significant opportunity to intervene with a high-risk population. In 2013 NIDA launched the Juvenile Justice Translational Research on Interventions for Adolescents in the Legal System (JJ-TRIALS) program to identify and test strategies for improving the delivery of evidence-based substance abuse and HIV prevention and treatment services for justice-involved youth. The JJ-TRIALS initiative will provide insight into the process by which juvenile justice and other service settings can successfully adopt and adapt existing evidence-based programs and strategies to improve treatment for at-risk youth. The Committee supports this important work and asks for a progress report in the next appropriations cycle.

*Electronic Cigarettes.*—The Committee understands that electronic cigarettes (e-cigarettes) are increasingly popular among adolescents. Lack of regulation, easy availability, and a wide array of cartridge flavors may make them particularly appealing to this age group. In addition to the unknown health effects, early evidence suggests that e-cigarette use may serve as an introductory product for youth who then go on to use other tobacco products, including conventional cigarettes, which are known to cause disease and lead to premature death. Early evidence also reveals that these devices are widely used as tools for smoking derivatives of marijuana (hash oil, “shatter,” etc.) The Committee requests that NIDA fund research on the use and consequences of these devices.

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 emphasize the fact that drug addiction is 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 lethality due to heroin and synthetic fentanyl, as well as the continued abuse of prescription opioids and the recent increase in availability of designer drugs 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 2017 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.

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PREPARED STATEMENT OF THE FSH SOCIETY ON FACIOSCAPULOHUMERAL MUSCULAR DYSTROPHY

*Agency:* National Institutes of Health (NIH).

*Account:* The NIH; National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), National Institute of Neurological Disorders and Stroke (NINDS), Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), National Human Genome Research Institute (NHGRI) and other institutes.

*Fiscal Year 2017 Report Language:* The Committee strongly encourages the NIH to accelerate research efforts and significantly increase projects and funding on facioscapulohumeral muscular dystrophy (FSHD). The Committee hopes and recognizes that scientific opportunities and recent epigenetic breakthroughs in FSHD will help NIH access therapies for this and many other grave diseases such as cancer.

Honorable Chairman Blunt, Ranking Member Murray, and distinguished members of the subcommittee, thank you for the opportunity to submit this testimony. It is an honor to have the opportunity to present the fiscal year 2017 request for NIH funding for research on facioscapulohumeral muscular dystrophy (FSHD) and update you on scientific opportunities. We thank this subcommittee for making research funding a national priority and for its strong investment in the NIH with the \$2 billion funding increase in the fiscal year 2016 Omnibus Appropriation bill.

*About FSHD, about our disease, my disease.* FSHD, a heritable disease, is among the most common forms of muscular dystrophy with a prevalence of 1:8,000,<sup>1</sup> affecting approximately 870,000 children and adults of both sexes worldwide. It can affect multiple generations and entire families. FSHD is characterized by the progressive loss of muscle strength. Muscle weakness typically starts at the face, shoulder girdle and upper arms, often progressing to the legs, torso and other muscles. The symptoms can develop at any age. The progression of FSHD is highly variable. FSHD has a high burden of disease and can cause significant disability and, in severely affected individuals, premature death, mainly through respiratory failure. Around 20 percent of affected individuals use a wheelchair or scooter. Besides muscle weakness, FSHD can also have the following manifestations: high-frequency sensorineural hearing loss, respiratory insufficiency, abnormalities of blood vessels in the back of the eye, and non-symptomatic cardiac arrhythmias.

The National Institutes of Health (NIH) is the principal worldwide source of funding of research on FSHD currently at the \$8.398 million level fiscal year 2015 actual (and \$12.616 million fiscal year 2016 current), a fraction of the \$77 million fiscal year 2015 actual it spent on all of the muscular dystrophies. For two decades, this subcommittee has supported the incremental growth in funding for FSHD research. I am pleased to report that this investment has produced remarkable results and remarkable advances in scientific understanding of human diseases.

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<sup>1</sup>Deenen JC, et al, Population-based incidence and prevalence of FSHD. *Neurology*. 2014 Sep 16;83(12):1056–9. Epub 2014 Aug 13.

*A partnership of Congress, NIH, patients and scientists has made truly outstanding progress in identifying areas in need of funding and in communicating these objectives to the public.* Congress is responsible for this success by its sustaining support of the overall NIH budget, and specifically through the enactment of the Muscular Dystrophy Community Assistance, Research and Education Amendments of 2001 (MD-CARE Act, Public Law 107-84). Several days ago, NIH leadership and staff that oversees muscular dystrophy published an editorial in *Muscle & Nerve* describing the work of the truly collaborative Muscular Dystrophy Coordinating Committee (MDCC), mandated by the MD CARE Act, which publicizes the 2015 NIH Action Plan for the Muscular Dystrophies as the roadmap for all funding, patient, family, and research communities.<sup>2</sup> The 81 objectives of the Action Plan, released in November, are organized within 6 sections: mechanism, screening, treatments, trial readiness, access to care, infrastructure including workforce. I have been very involved in creating the MD CARE Act, remain of service to the MDCC, and helped draft, write and edit the first and revised Action Plans. NIH leadership, program and grant review staff have our highest respect and I echo Stephen I. Katz, M.D., Ph.D., chair of the MDCC, director of the NIAMS at the NIH when he says we can all use this plan “to guide research, collaborations and strategies to extend and improve the quality of life of people suffering from these disorders.” 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. We hope 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 and achieves more efficiency out of a non-growing research budget.

*As tiny as it is, the FSH Society continues to deliver huge results in improving our understanding of FSHD*—and in turn helping scientists be more competitive at NIH with respect to the grant application and review process. As the Nation’s most expert and largest FSHD research funding non-profit, the FSH Society’s mission is to conduct research, increase awareness, understanding and education on FSHD. While we remain ever curious about how FSHD works, our goal is to improve health, reduce disability and illness and lengthen life for those living with FSHD. As of April 13, 2016, the FSH Society has provided approximately \$6.97 million, since the inception of its research fellowships and grants program, in seed funds and grants to pioneering FSHD research areas and education worldwide and created an international collaborative network of patients and researchers. Recent advances in understanding the molecular genetics and cellular biology of FSHD have led to the identification of potential therapeutic targets. Impressive scientific progress was again achieved in 2015 in the basic molecular and clinical understanding of the disease largely due to cumulative Society funding of research. In 2015, the Society issued twelve new grants and fellowships, continued funding five ongoing grants, and issued three travel grants to facilitate travel for professionals working on FSHD. The Society also works with various research institutions doing clinical research on FSHD to help facilitate patient travel for evaluation and tissue and blood donation by covering patient travel and lodging expenses. Dollar for dollar the Society is one of the best investments one can make in FSHD research funding outside of NIH funding and we have been effective and successful stewards of the resources we have been given by our donors to provide individuals, data and new hypotheses of extraordinary quality that the NIH can fund research on FSHD.

*Quantum leaps in our understanding of FSHD.* The past year and one-half has brought forth exceptional if not remarkable contributions made by a very small but extremely dedicated tribe of researchers funded by the Society, NIH and other non-profits.

—On September 25, 2014, researchers from United States, France, Spain, Netherlands and United Kingdom narrow the focus mechanistically opening the possibility of all types of FSHD having an epigenetic basis.<sup>3</sup>

—On March 29, 2015, different researchers involved with the NIH Senator Paul A. Wellstone Cooperative Research Center using its large collection of different FSHD patient samples and different techniques arrive at the same answer that

<sup>2</sup>Rieff HI, Katz SI et al. The Muscular Dystrophy Coordinating Committee Action Plan for the Muscular Dystrophies. *Muscle Nerve*. 2016 Mar 21. [Epub ahead of print].

<sup>3</sup>Lemmers RJ, et al. Inter-individual differences in CpG methylation at D4Z4 correlate with clinical variability in FSHD1 and FSHD2. *Hum Mol Genet*. 2015 Feb 1;24(3):659–69. Epub 2014 Sep 25.

there is an underlying principle of epigenetics defining asymptomatic or non-manifesting and playing a role in disease severity.<sup>4</sup>

—On September 1, 2015, researchers from Fred Hutchinson Cancer Research Center, Seattle, Rochester, New York and the Netherlands funded by a NIH P01 program project describe the role of siRNA-directed AGO/DICER-dependent epigenetic repression (silencing the DUX4 retrogene with the D4Z4 region) showing a pathway to therapeutically target FSHD.<sup>5</sup>

—On November 3, 2015, researchers at the University of Massachusetts Medical School (UMMS) successfully used a derivation of the CRISPR-based gene-editing method known as dCas9 to target and silence the DNA sequence implicated in FSHD. For the very first time a CRISPR-based system was been used to ameliorate pathogenic gene expression in FSHD successfully in primary human muscle cells.<sup>6</sup>

—On March 6, 2016 researchers at the University of Minnesota define an important function of the C-terminal domain of DUX4, namely to recruit the acetyltransferases p300 and CBP, which modify chromatin in the vicinity of DUX4 binding.<sup>7</sup>

Many of these findings have their origins in seed funding from the FSH Society to researchers who have then used preliminary data to secure funding from the NIH. We are thrilled that our grantees and colleagues have data and publications that prove that the FSHD-causing DUX4-fl and cascading events can be turned off. Also in this last year in clinical and preclinical research multiple groundbreaking papers have emerged in whole body MRI, xenograph and transgenic/Cre-lox mouse models, improved diagnostic testing, biomarkers and clinical aspects of FSHD and the very first evidenced based guideline were written, compiled and distributed by the Centers for Disease Control, American Academy of Neurology and FSH Society.<sup>3,8,9,10,11</sup> Despite this, the FSHD research and clinical enterprise is still starved for Federal funding from NIH!

*We must keep moving forward.* In October 2015 the FSH Society held its annual FSHD International Research Consortium meeting in Boston, Massachusetts. The meeting was funded in part by the NIH NICHD University of Massachusetts Medical School Wellstone center for FSHD. Over 100 researchers from around the world gathered to present latest data and discuss research strategies. Areas defined by the FSHD clinical and research community as priority areas are as follows:

TABLE 1.

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*Genetics and epigenetics*

- Priority 1: Continued identification of the parameters that determine disease severity and progression, including identification of additional modifier and disease loci.
- Priority 2: Improved diagnostic tests and tests to better predict onset and severity.

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<sup>4</sup>Jones, TI, et al. Individual epigenetic status of the pathogenic D4Z4 macrosatellite correlates with disease in facioscapulohumeral muscular dystrophy. *Clinical Epigenetics* 2015, 72–6, 29 March 2015.

<sup>5</sup>Lim JW, et al. DICER/AGO-dependent epigenetic silencing of D4Z4 repeats enhanced by exogenous siRNA suggests mechanisms and therapies for FSHD. *Hum Mol Genet.* 2015 Sep 1;24(17):4817–28.

<sup>6</sup>Himeda CL, Jones, et al. CRISPR/dCas9-mediated Transcriptional Inhibition Ameliorates the Epigenetic Dysregulation at D4Z4 and Represses DUX4-fl in FSH Muscular Dystrophy. *Mol Ther.* 2016 Mar;24(3):527–35. epub 2015 Nov 3.

<sup>7</sup>Choi SH, et al. DUX4 recruits p300/CBP through its C-terminus and induces global H3K27 acetylation changes. *Nucleic Acids Res.* 2016 6 Mar [Epub ahead of print].

<sup>8</sup>Tawil R, et al. Evidence-based guideline summary: Evaluation, diagnosis, and management of FSHD: Report of the Guideline Development, Dissemination, and Implementation Subcommittee of the American Academy of Neurology and the Practice Issues Review Panel of the American Association of Neuromuscular & Electrodiagnostic Medicine. *Neurology.* 2015 Jul 28;85(4):357–64.

<sup>9</sup>Leung DG, et al. Whole-body magnetic resonance imaging evaluation of facioscapulohumeral muscular dystrophy. *Muscle Nerve.* 2015 Oct;52(4):512–20. Epub 2015 Mar 31.

<sup>10</sup>Sakellariou P, Bloch R, et al. Neuromuscular electrical stimulation promotes development in mice of mature human muscle from immortalized human myoblasts. *Skelet Muscle.* 2016 Feb 27;6:4. eCollection 2015.

<sup>11</sup>Calandra P, et al. Allele-specific DNA hypomethylation characterises FSHD1 and FSHD2. *J Med Genet.* 2016 Feb 1. pii: jmedgenet-2015–103436. [Epub ahead of print].

*Mechanisms and targets*

- Priority 3: Determine the major mechanism(s) of muscle damage caused by DUX4 expression. DUX4 in muscle activates a diverse panel of pathways and mechanisms, which individually, or combined lead to muscle pathology.
- Priority 4: Determine the relationship between DUX4 expression and disease onset and progression.
- Priority 5: Determine how the expression of DUX4 in one muscle cell nucleus results in the spread of the pathology throughout the muscle.

*Models*

- Priority 6: Continued development and validation of pre-clinical models to test specific pre-clinical goals.

*Clinical and therapeutic studies*

- Priority 7: Validation of subjective and objective measurements of disease onset and progression. Quality of life, muscle function measurements and other physical biomarkers, molecular biomarkers, and imaging biomarkers all show tremendous promise. Individual and cooperative studies to identify, validate, and determine the best standard measurements are critical for trial preparedness in FSHD.

The detailed priorities stated for 2016, at the October 5–6, 2015, FSH Society FSHD IRC meetings can be found at: <http://www.fshsociety.org/international-research-consortium/>. We need to be prepared for this new era in the science of FSHD. Many leading experts are now turning to work on FSHD 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 with epigenetic origin.

*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 in 2001, research funding at NIH for muscular dystrophy has increased 4-fold (from \$21 million). While FSHD research funding has increased 16-fold fiscal year 2015 (from \$0.5M) during this period, the level of funding is still too underpowered for FSHD given the remarkable discoveries in the past 6 years.

FSHD RESEARCH DOLLARS & FSHD AS A PERCENTAGE OF TOTAL NIH MUSCULAR DYSTROPHY FUNDING

[Dollars in millions]

Fiscal Year	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016e	2017e
All MD (\$ millions) .....	\$39.5	\$39.9	\$47.2	\$56	\$83	\$86	\$75	\$75	\$76	\$78	\$77	\$80	\$80
FSHD (\$ millions) .....	\$2.0	\$1.7	\$3	\$3	\$5	\$6	\$6	\$5	\$5	\$7	\$8	\$9	\$9
FSHD (% total MD) .....	5%	4%	5%	5%	6%	7%	8%	7%	7%	9%	10%	11%	11%

Sources: NIH/OD Budget Office & NIH OCPL & NIH RePORT RCDC (e = estimate).

Despite the great success of the past 6 years in the science of FSHD brought about by Congress, NIH, non-profit funding agencies, patients, families and researchers we are gravely concerned that FSHD research is too under-represented in the NIH portfolio. Though in our story DUX4 is inappropriately expressed in the context of muscle only and is harmful in FSHD; there now are several papers in the last month showing DUX4 at work in other diseases and conditions—in the out layer of skin it is harmful to keratinocytes in another context of gene fusions it causes cells to divide uncontrollably and cause cancer (B cell acute lymphoblastic leukemia).<sup>12,13</sup> The extraordinary depth and impact of discovery should soon allow a flood of new talent and higher quality and complete proposals to help NIH redress the imbalance of funding in the FSH muscular dystrophy portfolio by fostering opportunities for multidisciplinary research on FSHD commensurate with its prevalence and disease burden. We are concerned, very concerned that economy of scale

<sup>12</sup>Gannon OM, et al. DUX4 Is Derepressed in Late-Differentiating Keratinocytes in Conjunction with Loss of H3K9me3 Epigenetic Repression. *J Invest Dermatol.* 2016 Feb 9. pii: S0022-202X(16)00464-4. [Epub ahead of print].

<sup>13</sup>Yasuda T, et al. Recurrent DUX4 fusions in B cell acute lymphoblastic leukemia of adolescents and young adults. *Nat Genet.* 2016 Mar 28. doi: 10.1038/ng.3535. [Epub ahead of print].

is so different in particular for FSHD within the muscular dystrophy funding group. There are no quotas on peer-reviewed research above pay line at the NIH and given now that all the requisites are in place—funding for FSHD should increase rapidly at this time.

There are 32 active projects NIH-wide totaling \$12.616 million as of April 14, 2016 versus 26 on March 12, 2015 (source: NIH Research Portfolio Online Reporting Tools (RePORT) <http://report.nih.gov> keyword 'FSHD or facioscapulohumeral or DUX4') the 32 projects cover 2 F32, 1 K22, 1 K23, 1 R03, 4 R21, 15 R01, 1 P01, and 2 U54 grants. It was back in 2010, that the NIH Director Dr. Francis Collins said "If we were thinking of a collection of the genome's greatest hits, this [FSHD] would go on the list."<sup>14</sup> In the last year alone, incredible opportunities for public, private and non-profit entities engaged in FSHD research and clinical research have emerged. Oddly these discoveries clearly belonging to the leading edge of human genetics and our understanding the epigenome and treating epigenetic diseases are sitting somewhat idle. NIH needs to maximize research funding by capitalizing on the low hanging fruit that FSHD presents as a gateway to treating human epigenetic disease.

*We request for fiscal year 2017, a doubling of the NIH FSHD research portfolio to at least \$24 million.* 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. , and NIH has conveyed to researchers that it has a revised plan and an interest in funding research in FSHD and muscular dystrophy. Mr. Chairman, thank you for this opportunity to testify before your subcommittee.

[This statement was submitted by Daniel Paul Perez, President & CEO, FSH Society on Facioscapulohumeral Muscular Dystrophy.]

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#### PREPARED STATEMENT OF THE GBS/CIDP FOUNDATION INTERNATIONAL

Chairman Blunt 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), variants and related conditions as you work to craft the fiscal year 2017 L-HHS Appropriations Bill.

#### ABOUT GBS, CIDP, VARIANTS AND RELATED CONDITIONS

##### *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), and 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.

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<sup>14</sup>Kolata, G., Reanimated 'Junk' DNA Is Found to Cause Disease. New York Times, Science. Published online: August 19, 2010 <http://www.nytimes.com/2010/08/20/science/20gene.html>.

*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.

## JIM'S STORY

I had GBS in 1973. This is important because the subject matter, IVIG treatments, were not available in 1973 and I believe that because it was not available, my experience with GBS was many times worse than it needed to be. I was totally paralyzed and only my head was able to move side to side. When the disease hit me, I was a college student in St. John's University in NYC in my fourth year and a newlywed of 3 months and I was also working 30 hours a week as a night manager in a busy Tire and Auto repair business. My wife and I were just beginning our lives together when GBS struck us down like a lightning bolt. My wife was also working full time and now the care of her totally paralyzed husband was in the hands of a 19 year woman who was asked to do things and make decisions that no 19 year old woman should have to make. I never finished college due to the amount of medical bills the accumulated and this affected my working life for decades. Keeping in mind the year, 1973, ICU care was very different then it is now. She was only allowed to visit me in the ICU for five minutes every hour. The rest of the time, she spent in a tiny waiting room with other ICU patient's families. She was at the hospital before work, at lunchtime and in the evening totaling about forty minutes a day. Imagine the stress on this young lady. I spent five weeks in the ICU, totally paralyzed with a tracheotomy and with no movement and no ability to communicate in anyway at all. Any need that I had had to be guessed by the four person nursing staff who also had a dozen other very ill patients who were in the open room that held all of these patients. Nights were a nightmare. They were long mostly because I was not sleeping well, day or night. Minutes seemed like hours, and hours seemed like weeks. I was aware all of the time and it was like I was in a glass shell, unable to get out. The hospital staff tried, but no one could understand what it was like to be in that bed. One memorable evening, the tube that was connected to the MA-1 ventilator popped out of my neck and I was not getting any oxygen. Nobody saw that the bellows of the ventilator had dropped down. Someone had to see the situation or I was in big trouble. I had passed out from lack of air. Someone finally saw that it was not breathing for me. The "crash cart" finally got to me and I began to get some air. People started yelling "why

didn't the alarm sound" There was an alarm that sounds if the machine failed for any reason. Two D cells powered the alarm and they were dead. Two D cells almost did me in.

I firmly believe that if IVIG was available for me in 1973, I would have never been so paralyzed and in need of a ventilator. My life was in the hands of a hospital staff and machinery and humans who make mistakes. Time and time again, IVIG has arrested the progress of GBS patients and prevented a patient from needing a vent and putting their life in danger. GBS in and of itself generally does not cause a patient to die, it is poor care or a late diagnosis or preexisting conditions. IVIG is a lifesaver and huge factor in reducing the level of paralysis and the amount of time that a patient is in hospital and rehab. I wish that IVIG was available when I had GBS. Its availability would have a huge difference in my case.

#### 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, variants 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.

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#### PREPARED STATEMENT OF THE GENETICS SOCIETY OF AMERICA

Thank you for the opportunity for the Genetics Society of America (GSA) to provide our perspective on the fiscal year 2017 appropriations for the National Institutes of Health (NIH). GSA recommends a minimum of \$35 billion for NIH to continue its mission to further biomedical research.

GSA is a professional scientific society with more than 5,500 members from all 50 States working to deepen our understanding of the living world by advancing the field of genetics, from the molecular to the population level. Members of our community rely on support from the NIH to answer underlying biological questions that are the foundation for biomedical innovation. Whether termed foundational, fundamental, or basic research, these studies are critical to expanding our knowledge of the biological world around us. Indeed, the NIH recognized the importance of fundamental research in its agency-wide strategic plan<sup>1</sup> and in a recent letter from Director Francis Collins and other NIH leaders published in *Science* magazine.<sup>2</sup> Funding NIH at a minimum of \$35 billion for fiscal year 2017 will allow the agency to increase its support for the fundamental research necessary to further biomedical breakthroughs.

Many of our members utilize model organisms in their research, which allow for extensive experimentation without the ethical implications of human subject research. Traditionally, the term "model organism" included systems such as fruit

<sup>1</sup>NIH-wide Strategic Plan <http://www.nih.gov/sites/default/files/about-nih/strategic-plan-fy2016-2020-508.pdf>.

<sup>2</sup><http://science.sciencemag.org/content/351/6280/1405.1.full>.



flies, roundworms, mice, yeast, and bacteria; but it now encompasses a growing collection of other systems including plants, zebrafish, frogs, and more—with new ones being developed regularly to study biological phenomena and disease States. Indeed, advances in technology have enhanced scientists' ability to use a diverse array of biological systems to advance understanding of the mechanisms of life.

Fundamental research supported by the NIH has led to ground-breaking discoveries in our field and beyond. For example, research into the mechanisms of bacterial immunity funded by NIH led to the development of CRISPR/Cas9, the breakthrough technology which has accelerated the potential for gene editing.<sup>1</sup> As a result, researchers now have an unprecedented ability to study biological processes at the molecular level in a growing array of experimental systems, and a new universe for biotechnological applications is now open for exploration. In another example, ongoing studies in the genetics of mosquitoes are currently informing public health discussions around containing and ameliorating the threat of the Zika virus in U.S. The scientific evidence from these fundamental research projects created a body of evidence upon which officials can build more targeted studies to determine whether genetically engineered mosquitoes will impede the spread of the Zika virus.<sup>3</sup>

Because humans share much of their basic biology with all living systems, we believe that robust and expanded support for model organisms—from invertebrates and plants to microbes and mammals—is an essential part of this pursuit of foundational knowledge. One of the most effective ways to advance progress in biomedical research is to understand the fundamental biology of model systems. Time and time again, model organisms have led the way in advancing biological understanding to enable cures and treatments for human disease. Green fluorescent protein (GFP), a Nobel Prize-winning tool that allows scientists to observe biological processes in living animals that were once invisible to researchers was developed in worms. Model organisms are now routinely engineered to express GFP to study the activity of specific genes to understand cancer and other diseases.<sup>1</sup> Similarly, the 2009 Nobel Prize for the discovery of the enzyme telomerase—which is critically important in cellular aging and integral to cancer cell proliferation—was first identified in the unicellular ciliate organism and yeast. Furthermore, several Nobel Prizes have been awarded for work in fruit flies, including for fundamental discoveries of the mechanisms of inheritance and embryonic development.

Sustainable funding for the National Institutes of Health is critical to ensure that these types of investigator-initiated projects, which have implications for society at large, continue to be supported. An increase of \$3.0 billion for fiscal year 2017 would enable NIH to fund more fundamental research projects while still providing increases to other critical portions of the agency's portfolio. If the percentage of the new funding used for R01 grants is the same as in prior years, NIH could fund more than 2,200 additional R01 grants—any number of which could yield the next biomedical breakthrough.

A significant fraction of the GSA membership are trainees—undergraduates, graduate students and postdoctoral scholars—who are concerned about the future of research funding and its implications for their careers. NIH has renewed its commitment to recruit and retain these early career scientists in order to cultivate an outstanding biomedical research workforce.<sup>1</sup> The requested funding increase would ensure that undergraduate and graduate students and postdoctoral scholars advance to research careers, making strides in science and technology that will allow the U.S. to remain a world leader in STEM advances.

Finally, we wish to emphasize the importance of sustainable support for research infrastructure. Biological databases, stock centers, and other shared research resources are essential for maintaining consistency across different research laboratories and are vital to scientists nationwide. For example, genomic databases speed innovation by providing accelerated access to well-curated data that can be used to validate new techniques. They also serve as searchable data repositories that allow scientists to connect their research findings and identify collaborators rapidly. Further, research databases function as a central place for data sharing, improving research transparency, and positively impacting research reproducibility. We believe that sustained public support for these community resources is essential and allows them to operate on an open access model, thus assuring that all researchers have the tools they need for discovery.

We appreciate the opportunity to provide input into your deliberations about NIH appropriations. We are happy to provide any additional information about the impact of NIH funding on our community and the advancement of genetics research. Please contact GSA's Executive Director, Adam P. Fagen, PhD (AFagen@genetics-

<sup>3</sup> <http://www.nytimes.com/2016/03/12/business/test-of-zika-fighting-genetically-altered-mosquitoes-gets-tentative-fda-approval.html>.

gsa.org) or GSA's Policy and Communications Manager, Chloe N. Poston, PhD (CPoston@genetics-gsa.org) with any questions.

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PREPARED STATEMENT OF THE GLOBAL HEALTH TECHNOLOGIES COALITION

Chairman Blunt, Ranking Member Murray, and members of the Committee, thank you for the opportunity to provide testimony on the fiscal year 2017 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. I am submitting this testimony on behalf of the Global Health Technologies Coalition (GHTC), a group of more than 25 nonprofit organizations working together to advance U.S. policies that can accelerate the development of new global health innovations—including new vaccines, drugs, diagnostics, microbicides, multipurpose prevention technologies, and other tools—to combat global health diseases and conditions.

GHTC members strongly believe that in order to meet the world's most pressing global health needs, it is critical to invest in research today so that the most effective health solutions are available now and in the future. Sustainable investment in research and development (R&D) for a broad range of neglected diseases and health conditions is critical to tackling both endemic and emerging global health challenges that impact people around the world and at home in the United States. This need is particularly acute now, as the world is facing an increasing Zika epidemic and is still recovering from the 2014 Ebola outbreak—two diseases about which we knew little, and have no approved tools to diagnose, prevent, or treat.

My testimony reflects the needs expressed by our member organizations, which work with a wide variety of partners to develop new and more effective lifesaving 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:

- Sustaining and supporting U.S. investment in global health research and product development and fully funding the NIH at a level of at least U.S.\$34.5 billion, and providing robust funding for the CDC, with \$457 million for the CDC Center for Global Health, and \$629.49 million for the CDC National Center for Emerging Zoonotic and Infectious Diseases (NCEZID).
- Urging leaders at the NIH, CDC, the Food and Drug Administration, and other entities within the U.S. Department of Health and Human Services, like the Office of Global Affairs, the Biomedical Advanced Research and Development Authority, and the National Center for Advancing Translational Science (NCATS), 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.

CRITICAL NEED FOR NEW GLOBAL HEALTH TOOLS

While we have made tremendous gains in global health over the past 15 years, millions of people around the world are still threatened by HIV/AIDS, tuberculosis (TB), malaria, and other neglected diseases and health conditions. In 2014, TB killed 1.5 million people, surpassing deaths from HIV/AIDS. Sub-Saharan Africa saw 1.4 million new HIV infections. Half the global population remains at risk for malaria and drug-resistant strains are growing. Maternal mortality is 14 times greater in under-resourced regions than developed countries. One out of every 12 children in sub-Saharan Africa dies before the age of five, often from vaccine-preventable and other communicable diseases. These figures highlight the tremendous global health challenges that still remain and the need for sustained investment in global health research to deliver new tools to combat endemic and emerging threats.

New tools and technologies are critical, both to address unmet global health needs and address challenges of drug resistance; outdated and toxic treatments; and difficulty administering current health technologies in poor, remote, and unstable settings. As seen with recent outbreaks of Ebola and Zika, we simply do not have the tools needed to prevent, diagnose, and treat many neglected diseases. While it is important to work to increase access to proven, existing drugs, vaccines, diagnostics, and other health tools, it is just as critical to invest in the development of next generation tools to fight existing and emerging disease threats. Particularly in our era of globalization where diseases know no borders, investments today in global health innovations for existing global health threats and new and emerging infections will mean millions of future lives saved—at home and around the world.

## RESEARCH AND U.S. GLOBAL HEALTH EFFORTS

The United States is at the forefront of innovation in global health, with the NIH and CDC leading much of our global health research.

*NIH*

The groundbreaking science conducted at the NIH has helped make the United States a global leader in medical research. Not only does NIH research lead to novel medical technologies for American patients, but it also fuels important discoveries and innovative applications of tools that help address both longstanding and emerging global health challenges.

Within the NIH, the National Institute of Allergy and Infectious Diseases, the Office of AIDS Research, the Fogarty International Center, and NCATS all play critical roles in developing new health technologies that save lives around the world and at home in the United States. Recent activities have led to the development of new tools to combat neglected diseases, including vaccines for dengue fever and trachoma; new drugs to treat malaria and TB; and multiple projects to develop diagnostics, vaccines, and treatments for Ebola, including the development of ZMapp and the development and testing of Ebola vaccine candidates. NIH Director Dr. Francis Collins, recognizes the critical role the agency plays in global health R&D, and has named global health as one of the agency's top five priorities.

For this important work to continue, the NIH needs adequate funding. We recognize and are grateful for Congress' work to bolster funding for the critical programs supported by NIH. However, Dr. Collins recently noted that the Bureau of Economic Analysis has calculated that due to rising costs of biomedical research expenses, the NIH has had a 23 percent drop in purchasing power since 2003. To deliver on the remarkable progress being made across the institutes, it is vital that we renew our commitment to health research and maintain steady support for the NIH.

It is also important to stress the critical role that NCATS plays in translating basic research for neglected diseases into urgently needed tools and technologies. R&D conducted at NCATS has contributed to the development of early stage compounds to treat diseases including Chagas disease, schistosomiasis, giardia, and HIV/AIDS. We remain concerned that NCATS is the only NIH center limited by statute from supporting clinical trials beyond phase IIA. There is little risk of NCATS duplicating the global health activities of private industry, as this sector does not typically target neglected diseases due to limited commercial markets. We hope you will work to remove this statutory barrier and extend NCATS' ability to conduct trials through stage III—the final pre-market stage where safety and efficacy of a treatment are tested in large groups of individuals.

*CDC*

The CDC also makes significant contributions to global health research. The CDC's ability to respond to disease outbreaks, such as the current Zika outbreak and 2014 Ebola Virus Disease epidemic in West Africa, is essential to protecting the health of citizens both at home and abroad. The work of its scientists has led to major advancements against devastating diseases, including the eradication of smallpox and early identification of HIV/AIDS.

Within the CDC, the Center for Global Health and NCEZID are critical to global health R&D and global health security efforts. Important work at NCEZID includes innovative technologies to provide a rapid diagnostic test for the Ebola virus; a new vaccine to improve rabies control; a new and more accurate diagnostic test for dengue virus; and coordination of the National Strategy for Combating Antibiotic Resistant Bacteria, focused on preventing, detecting, and controlling outbreaks of antibiotic resistant pathogens, such as drug-resistant tuberculosis. Programs at CDC's Center for Global Health—including the Global HIV/AIDS, Global Immunization, Parasitic Diseases and Malaria, Global Disease Detection and Emergency Response, and Global Public Health Capacity Development programs—have also yielded tremendous results in the development of new vaccines, drugs, microbicides, and other tools to combat HIV/AIDS, TB, malaria, and lesser known diseases like leishmaniasis, dengue fever, and schistosomiasis.

In addition, the CDC works to implement the Global Health Security Agenda—a whole-of-government initiative that works to build capacity in 30 low- and middle-income countries to detect global health risks rapidly. We urge your support for this initiative alongside the vital work already ongoing at the Center for Global Health and NCEZID.

## INNOVATION AS A SMART ECONOMIC CHOICE

Global health R&D brings lifesaving tools to those who need them most. However, the benefits of investing in these research efforts 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 of every U.S. dollar invested in global health R&D goes directly to U.S.-based researchers. As just one example of the many States positively impacted by global health R&D, the global health industry in Washington State includes 168 global health organizations, 54 percent of whom work on global health technology and devices. This industry directly accounts for \$5.8 billion in output and provided 12,620 direct global health jobs in the State. In addition, investments in global health R&D today can help save significant money in the future. New therapies to treat drug-resistant TB, for example, have the potential to reduce the price of TB treatment by 90 percent and cut health system costs significantly.

Smart investments in medical research in the past have yielded lifesaving breakthroughs for global health diseases, as well as important advances in diseases endemic to the United States. We must continue to build on those investments, and turn discoveries into new vaccines, drugs, tests, and other tools. Now more than ever, Congress must make smart budget decisions. Global health research that improves the lives of people around the world—while at the same time supporting U.S. interests, creating jobs, and spurring economic growth at home—is a win-win. 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 Erin Will Morton, Coalition Director, Global Health Technologies Coalition.]

## PREPARED STATEMENT OF GOD'S LOVE WE DELIVER

We are pleased to submit this testimony to the Members of this Subcommittee on the urgency of continuing to support the Ryan White Program through the Appropriations process and increasing funding for the domestic HIV/AIDS portfolio in fiscal year 2017. This support and funding will be decisive for achieving the goals of the National HIV/AIDS Strategy (NHAS) 2020, the AIDS Free Generation and halting the devastating effects of the HIV Treatment Cascade.

God's Love We Deliver is part of a nationwide coalition, the Food is Medicine Coalition, of food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PWH) and other chronic illnesses. In our service area, we provide 1.5 million medically tailored, home delivered meals annually. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

*Why Food and Nutrition Services (FNS) Matter for PWH*

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PWH at any stage of their illness. For those who are most mobile, there are congregate meals, walk-in food pantries and voucher programs. For those whose disease has

progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective core medical service in the Ryan White Program. These services play a critical role in ensuring that PWH enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

*FNS as a Care Completion Service Unique to Ryan White*

Social and economic interventions, most often in the form of care completion services like food and nutrition services, are fundamental to making healthcare work for PWH. Support services for PWH are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PWH are poised to remain connected to care and treatment.

*Access to FNS and the Triple Aim*

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PWH.

*Better Health Outcomes*

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines.<sup>1</sup> Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections<sup>2</sup> and the resulting decreases in their healthcare costs. Compare these outcomes to PWH who are food insecure, who have:

- Lower CD4 counts & lower likelihoods of having undetectable viral loads<sup>3</sup>
- More ER visits<sup>4</sup> & increased morbidity and mortality<sup>5</sup>
- More missed primary care appointments & reduced use of antiretroviral therapy.<sup>6</sup>

*Lower Healthcare Costs*

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PWH. A recent study comparing participants in a medically-tailored FNS program vs. a control group within a local managed care organization found that average monthly healthcare costs for PWH fell 80 percent in first 3 months after receiving FNS.<sup>7</sup> If hospitalized, nourished clients' costs were 30 percent lower, their hospital length of stay was cut by 37 percent and they were 20 percent more likely to be able to be discharged to their homes rather than a more expensive institution.<sup>8</sup> Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

<sup>1</sup>Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at [https://www.health.ny.gov/diseases/aids/ending\\_the\\_epidemic/docs/key\\_resources/housing\\_and\\_supportive\\_services/chain\\_factsheet3.pdf](https://www.health.ny.gov/diseases/aids/ending_the_epidemic/docs/key_resources/housing_and_supportive_services/chain_factsheet3.pdf).

<sup>2</sup>Academy of Nutrition and Dietetics (formerly American Dietetic Association). HIV/AIDS Nutrition Evidence Analysis Project at [http://www.adaevidencelibrary.com/conclusion.cfm?conclusion\\_statement\\_id=250707](http://www.adaevidencelibrary.com/conclusion.cfm?conclusion_statement_id=250707) Accessed 29 July 2012.

<sup>3</sup>Aidala A, Yomogida M., and the HIV Food & Nutrition Study Team (2011); Singe AW, Weiser SD McCoy, SI. Does Food Insecurity Undermine Adherence to Antiretroviral Therapy? A Systematic Review. *AIDS Behav* (2015) 19:1510–1526.

<sup>4</sup>Ibid.

<sup>5</sup>Anema A, Chan K, Yip B, Weiser S, Montaner JSG, Hogg RS. Impact of food insecurity on survival among HIV-positive injection drug users receiving antiretroviral therapy in a Canadian cohort. 141st APHA Annual Meeting, Nov. 2–6, 2013. Boston, MA. Abstract #: 290277.

<sup>6</sup>Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).

<sup>7</sup>Gurvey J, Rand K, Daugherty S, Dinger C, Schmeling J, Laverty N. Examining Health Care Costs Among MANNA Clients and a Comparison Group. *J Prim Care Community Health*. (2013) 4:311–317.

<sup>8</sup>Ibid.

*Improved Patient Satisfaction*

Studies show nutrition counseling improves quality of life.<sup>9</sup> Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

*FNS and the National HIV/AIDS Strategy (NHAS)*

Access to FNS for PWH is fundamental to fulfilling the goals of the NHAS.

—NHAS Goal: Reducing new HIV infections: PWH who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96 percent of the time,<sup>10</sup> thus, FNS is key to prevention.<sup>11</sup>

—NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV: PWH who receive effective FNS are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines.<sup>12</sup>

—NHAS Goal: Reducing HIV-related disparities and health inequities: By providing FNS to PWH who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities.<sup>13</sup>

—NHAS Goal: Achieving a more coordinated national response to the HIV epidemic: There remains a tremendous variation by State in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White HIV Program all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including Ryan White and the ACA.

*Conclusion*

We are deeply aware of the difficult decisions that face the members of the Subcommittee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PWH live healthy and productive lives, produces better overall health outcomes and reduces healthcare costs.

Along with our colleagues, we appreciate the opportunity to offer this testimony regarding the fiscal year 2017 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you.

[This statement was submitted by Karen Pearl, President & CEO, God's Love We Deliver.]

## PREPARED STATEMENT OF THE HARLEM UNITED

We are pleased to submit this testimony to the Members of this Subcommittee on the urgency of continuing to support the Ryan White Program through the Appropriations process and increasing funding for the domestic HIV/AIDS portfolio in fiscal year 2017. This support and funding will be decisive for achieving the goals

<sup>9</sup>Rabeneck L, Palmer A, Knowles JB, Seidehamel RJ, Harris CL, Merkel KL, Risser JMH, Akrabawi SS. A randomized controlled trial evaluating nutrition counseling with or without oral supplementation in malnourished HIV-infected patients. *J Am Diet Assoc.* (1998) 98: 434–438; Schwenk A, Steuck H, Kremer G. Oral supplements as adjunctive treatment to nutritional counseling in malnourished HIV-infected patients: randomized controlled trial. *Clinical Nutrition* (1999) 18(6): 371–374.

<sup>10</sup>M. S. Cohen et al., Prevention of HIV-1 Infection with Early Antiretroviral Therapy. *N. Engl. J. Med.*(2011) 365, 493–505 . HPTN 052.

<sup>11</sup>Palar K, Lاراia B, Tsai A, Weiser SD Food insecurity is associated with sexually transmitted infections and HIV serostatus among low income adults in the National Health and Nutrition Examination Survey (NHANES) (1999–2010). Presented at the American Public Health Association 141st Annual Meeting, Boston, MA, November 5, 2013.

<sup>12</sup>Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014.

<sup>13</sup>Available at Weiser SD, Frongillo EA, Ragland K, Hogg RS, Riley ED, Bangsberg DR. Food insecurity is associated with incomplete HIV RNA suppression among homeless and marginally housed HIV-infected individuals in San Francisco. *J Gen Intern Med.* (2009) 24(1):14–20.

of the National HIV/AIDS Strategy (NHAS) 2020, the AIDS Free Generation and halting the devastating effects of the HIV Treatment Cascade.

Harlem United is part of the nationwide Food is Medicine Coalition of over 80 food and nutrition services providers, affiliates, and their supporters providing food and nutrition services to people living with HIV/AIDS (PLWHA) and other chronic illnesses. In Harlem and the South Bronx in New York City, we provide nearly 12,000 medically tailored, hot and nutritious meals to over 270 unique clients per year.

As part of the Food is Medicine Coalition, Harlem United is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

#### *Why Food and Nutrition Services (FNS) Matter for PLWHA*

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. For example, proper nutrition is needed to increase absorption of medication, reduce side effects, and to maintain healthy body weight.

Research has also identified HIV as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Additionally, several HIV medications can cause nausea and vomiting, and some can also affect lab results that test lipids and kidney and liver function. These compounding health effects reinforce the important role a nutrient-rich diet plays in patients' overall care plans.

In addition, providing FNS at Harlem United facilitates connection to and engagement with the primary medical and dental care, housing, substance use treatment, and other services we provide, especially among vulnerable populations. In fact, over 50 percent of our FNS clients are actively engaged in other programs and services provided by Harlem United.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and FNS. MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions. MNT also involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit.

The range of FNS provided through the Ryan White program complements the needs of PLWHA at any stage of their illness. For those who are most mobile, there are congregate meals, such as what we provide to clients at our two Adult Day Health Care (ADHC) programs, as well as walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective, core medical service in the Ryan White Program. These services play a critical role in ensuring that PLWHA enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

#### *FNS as a Care Completion Service Unique to Ryan White*

Social and economic interventions, most often in the form of care completion service like FNS, are fundamental to making healthcare work for PLWHA. Support services for this population are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act (ACA). As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PLWHA remain connected to care and treatment.

#### *Access to FNS and the Triple Aim*

Access to FNS is increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PLWHA.

##### *Better Health Outcomes*

When clients receive effective FNS and become food secure, they are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays, and are more likely to take their medica-

tions.<sup>1</sup> Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections and the resulting decreases in their healthcare costs.<sup>2</sup> Compare these outcomes to PLWHA who are food insecure, who have:

- Lower CD4 counts & lower likelihoods of having undetectable viral loads<sup>3</sup>
- More ER visits<sup>4</sup> & increased morbidity and mortality<sup>5</sup>
- More missed primary care appointments & reduced use of antiretroviral therapy<sup>6</sup>

#### *Lower Healthcare Costs*

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PLWHA. A recent study comparing participants in a medically-tailored FNS program to a control group within a local managed care organization found that average monthly healthcare costs for PLWHA fell 80 percent in the first 3 months after receiving FNS.<sup>7</sup> If hospitalized, nourished clients' costs were 30 percent lower, their hospital length of stay was cut by 37 percent, and they were 20 percent more likely to be able to be discharged to their homes rather than a more expensive institution.<sup>8</sup> Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

#### *Improved Patient Satisfaction*

Studies show nutrition counseling improves quality of life.<sup>9</sup> Members overwhelmingly report that our services help them live more independently, eat more nutritiously, and manage their medical treatment more effectively.

#### *FNS and the National HIV/AIDS Strategy (NHAS)*

Access to FNS for PLWHA is fundamental to fulfilling the goals of the NHAS.

- Reducing new HIV infections: PLWHA who are food insecure are statistically significantly less likely to have undetectable viral loads. Undetectable viral loads prevent transmission 96 percent of the time,<sup>10</sup> thus FNS is key to prevention.<sup>11</sup>
- Increasing access to care and improving health outcomes for people living with HIV: PLWHA who receive effective FNS are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays, and are more likely to take their medications.<sup>12</sup>

<sup>1</sup>Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at [https://www.health.ny.gov/diseases/aids/ending\\_the\\_epidemic/docs/key\\_resources/housing\\_and\\_supportive\\_services/chain\\_factsheet3.pdf](https://www.health.ny.gov/diseases/aids/ending_the_epidemic/docs/key_resources/housing_and_supportive_services/chain_factsheet3.pdf).

<sup>2</sup>Academy of Nutrition and Dietetics (formerly American Dietetic Association). HIV/AIDS Nutrition Evidence Analysis Project at [http://www.adaevidencelibrary.com/conclusion.cfm?conclusion\\_statement\\_id=250707](http://www.adaevidencelibrary.com/conclusion.cfm?conclusion_statement_id=250707) Accessed 29 July 2012.

<sup>3</sup>Aidala A, Yomogida M., and the HIV Food & Nutrition Study Team (2011); Singe AW, Weiser SD McCoy, SI. Does Food Insecurity Undermine Adherence to Antiretroviral Therapy? A Systematic Review. *AIDS Behav* (2015) 19:1510–1526.

<sup>4</sup>Ibid.

<sup>5</sup>Anema A, Chan K, Yip B, Weiser S, Montaner JSG, Hogg RS. Impact of food insecurity on survival among HIV-positive injection drug users receiving antiretroviral therapy in a Canadian cohort. 141st APHA Annual Meeting, Nov. 2–6, 2013. Boston, MA. Abstract #: 290277.

<sup>6</sup>Aidala A, Yomogida M., and the HIV Food & Nutrition Study Team (2011).

<sup>7</sup>Gurvey J, Rand K, Daugherty S, Dinger C, Schmeling J, Laverty N. Examining Health Care Costs Among MANNNA Clients and a Comparison Group. *J Prim Care Community Health*. (2013) 4:311–317.

<sup>8</sup>Ibid.

<sup>9</sup>Rabeneck L, Palmer A, Knowles JB, Seidehamel RJ, Harris CL, Merkel KL, Risser JMH, Akrabawi SS. A randomized controlled trial evaluating nutrition counseling with or without oral supplementation in malnourished HIV-infected patients. *J Am Diet Assoc*. (1998) 98: 434–438; Schwenk A, Steuck H, Kremer G. Oral supplements as adjunctive treatment to nutritional counseling in malnourished HIV-infected patients: randomized controlled trial. *Clinical Nutrition* (1999) 18(6): 371–374.

<sup>10</sup>M. S. Cohen et al., Prevention of HIV-1 Infection with Early Antiretroviral Therapy. *N. Engl. J. Med.*(2011) 365, 493–505 . HPTN 052.

<sup>11</sup>Palar K, Laraia B, Tsai A, Weiser SD Food insecurity is associated with sexually transmitted infections and HIV serostatus among low income adults in the National Health and Nutrition Examination Survey (NHANES) (1999–2010). Presented at the American Public Health Association 141st Annual Meeting, Boston, MA, November 5, 2013.

<sup>12</sup>Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014.



- Reducing HIV-related disparities and health inequities: By providing FNS to PLWHA who are in need largely because of poverty, we improve health outcomes and reduce health disparities.<sup>13</sup>
- Achieving a more coordinated national response to the HIV epidemic: There remains a tremendous variation by State in coverage of FNS, both inside and outside of Ryan White, making support for Ryan White HIV Programs all the more needed. Ultimately, if we are going to achieve a more coordinated, national response to the HIV epidemic, as well as our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including Ryan White and the ACA.

#### *Conclusion*

We are deeply aware of the difficult decisions that face the members of the Committee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, is vital to lowering the number of new infections in the domestic HIV epidemic, and to ultimately reducing healthcare costs and preserving healthcare resources for the future.

A client's diet has life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PWH live healthy and productive lives, produces better overall health outcomes, and reduces healthcare costs. Along with our Food is Medicine Coalition colleagues, we appreciate the opportunity to offer this testimony regarding the fiscal year 2017 Appropriations process.

Thank you.

[This statement was submitted by Jacquelyn Kilmer, Esq., CEO, Harlem United.]

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#### PREPARED STATEMENT OF THE HARM REDUCTION COALITION

The Harm Reduction Coalition appreciates the opportunity to submit this testimony to the Senate Appropriations Subcommittee on Labor, Health and Human Services, and Education, regarding opportunities to address the prescription opioid and heroin overdose epidemic. Harm Reduction Coalition recommends prioritizing funding needs under SAMHSA, HRSA and CDC towards three key strategies which address overdose risk and mortality: medication-assisted treatment, overdose education and naloxone distribution, and syringe exchange programs.

Opioid overdose fatality is the leading cause of accidental death in the United States and has been declared an epidemic by the Centers for Disease Control and Prevention (CDC). According to CDC data, overdose deaths involving opioids—including prescription painkillers and heroin—claimed 28,647 lives in 2014. This figure represents a 14 percent increase in age-adjusted overdose death rates since 2013. Increased mortality was driven by a dramatic rise in heroin overdose deaths, with heroin overdose death rates more than tripling since 2010, accompanied by a surge in deaths involving illicit fentanyl, a synthetic opioid increasingly combined with—or even sold as—heroin. These high rates of overdose will persist as long as the two most proven tools to prevent overdose deaths—medication-assisted treatment for opioid use disorders, and the overdose reversal drug naloxone—remain starkly underutilized and difficult to access.

#### MEDICATION-ASSISTED TREATMENT

Medication-assisted treatment (involving methadone, buprenorphine, or Vivitrol, accompanied by counseling and support) is the most effective means of facilitating recovery from opioid use disorders, and use of medication improves retention in treatment. Moreover, evidence shows that use of medication-assisted treatment reduces overdose by 50 percent compared to treatment without medication. However, the majority of people with opioid use disorders do not have access to medication-assisted treatment: 90 percent of U.S. counties do not have a methadone clinic, and only 32,000 doctors are waived to prescribe buprenorphine, leaving 43 percent of U.S. counties without prescriber capacity.

<sup>13</sup> Available at Weiser SD, Frongillo EA, Ragland K, Hogg RS, Riley ED, Bangsberg DR. Food insecurity is associated with incomplete HIV RNA suppression among homeless and marginally housed HIV-infected individuals in San Francisco. *J Gen Intern Med.* (2009) 24(1):14–20.

## OVERDOSE EDUCATION AND NALOXONE DISTRIBUTION

Overdose prevention education and training programs that distribute the FDA-approved, opioid rescue medication naloxone have been proven to significantly reduce mortality. When administered in a timely fashion, naloxone can reverse an opioid overdose; however, tragically it is not yet neither utilized broadly nor widely available in many parts of the country. In response to the opioid overdose epidemic, over 40 States and numerous communities and have taken action to make naloxone available within their jurisdictions. CDC recently reported that 150,000 community members have been trained on overdose prevention and provided with naloxone over the last 20 years, and of those over 26,000 successful overdose reversals have been reported by laypersons.<sup>1</sup> However resources to support overdose education and naloxone distribution are still scarce. If naloxone was more accessible and overdose education and awareness efforts were expanded, countless lives could be saved.

Harm Reduction Coalition believes that meaningful access to naloxone requires a four-pronged strategy to achieve a measurable impact on opioid overdose mortality:

1. Support for community-based overdose education and naloxone distribution (OEND) programs and initiatives training and equipping laypersons (family, friends, and people at risk of overdose) with naloxone
2. Promoting and incentivizing healthcare providers to prescribe naloxone to at-risk patients and their caregivers
3. Advancing innovative models for pharmacy access to naloxone through models including standing orders and collaborative practice agreements
4. Ensuring that first responders, including law enforcement officers, are trained and equipped with naloxone

No single strategy will have a sufficiently broad population-level impact on opioid overdose mortality. However, the strongest available evidence suggests that direct support for increasing access to medication-assisted treatment and for community-based OEND programs must be a cornerstone of scale-up and expansion efforts.

## SYRINGE EXCHANGE PROGRAMS

Syringe exchange programs operate on the frontlines of the opioid and heroin crisis, and pioneered the use of naloxone outside of medical settings. Syringe exchange programs are effective outreach and engagement strategies that provide early intervention to people who inject drugs, linking them to healthcare and drug treatment. In recent years, new syringe exchange programs have emerged in several communities hard hit by the opioid and heroin epidemic, including in Indiana, Kentucky, Ohio, and West Virginia. These and other communities are grappling with the health and social consequences of increased injection drug use, including rising hepatitis C and hepatitis B infections and an HIV outbreak in Indiana.

Syringe exchange programs operate on the frontlines of community-based efforts to reach and assist people at risk of opioid overdose. These programs are highly effective in engaging and supporting people who use drugs and their communities on overdose education and naloxone distribution, and work to link people struggling with substance use disorders to effective treatment programs, including medication-assisted treatment. In fiscal year 2016, Congress modified provisions to allow more flexibility in use of Federal funding to support syringe exchange programs in communities experiencing or at risk of an increase in hepatitis C cases or an HIV outbreak. Congress maintained a restriction prohibiting use of Federal funds for the purchase of syringes, but allowed for Federal funding to support counseling, education, outreach and other services. Harm Reduction Coalition advocated for and supports the revised Federal funding policy.

HHS recently released implementation guidance on use of Federal funds to support aspects of syringe exchange programs allowable under the provisions of the fiscal year 2016 Omnibus, and operating in accordance with State and local law. Harm Reduction Coalition's work with these new and emerging syringe exchange programs in high-need areas has convinced us that Congress should appropriate funding in fiscal year 2017 to ensure that these programs have resources to prevent disease transmission, provide overdose education and naloxone distribution, and connect people who use drugs to treatment and healthcare.

<sup>1</sup>Wheeler E, Davidson PJ, Jones TS, Irwin KS. Community-based opioid overdose prevention programs providing naloxone—United States, 2010. *Morb Mortal Wkly Rep.* 2012; 61(6):101–105.

## RECOMMENDATIONS FOR FISCAL YEAR 2017

Harm Reduction Coalition recommends that the Subcommittee consider the following investments:

*Substance Abuse and Mental Health Services Administration (SAMHSA)*

Grants to Prevent Prescription Drug/Opioid Overdose Related Deaths (Center for Substance Abuse Prevention, Programs of Regional and National Significance). Harm Reduction Coalition proposes an increase of \$8 million over fiscal year 2016 levels to provide support to additional States for this critical overdose prevention program.

Fiscal Year		Harm Reduction Coalition request
2016 Enacted	2017 President's request	
\$12,000,000	\$12,000,000	\$20,000,000 (+\$8 million)

*Health Resources and Services Administration (HRSA)*

Rural Opioid Overdose Reversal Grant Program (ROOR—Office of Rural Health Policy). These funds would support rural communities in addressing opioid misuse and overdose through education and prevention, training of healthcare professionals, emergency transport, treatment referrals and care coordination, and naloxone purchase.

Fiscal Year		Harm Reduction Coalition request
2016 Enacted	2017 President's request	
N/A	\$10,000,000	\$10,000,000

*Centers for Disease Control and Prevention (CDC)*

Grants to Support Syringe Exchange Programs (Division of Viral Hepatitis). Harm Reduction Coalition proposes additional funding on top of any increases to core Division of Viral Hepatitis for targeted support to syringe exchange programs.

Proposed language:

Grants may be awarded to State, local and Tribal governments and community-based organizations to support syringe exchange programs. Funds may be used to carry out programs, including through providing outreach, counseling, health education, case management, syringe disposal, and other program components in accordance with allowable use of funds. Funds may also be used to provide technical assistance, including training and capacity-building, to assist the development and implementation of syringe exchange programs. At least 15 percent of grants shall be made to syringe exchange programs that have been in operation for less than 3 years.

Fiscal Year		Harm Reduction Coalition request
2016 Enacted	2017 President's request	
N/A	N/A	\$15,000,000

Harm Reduction Coalition supports the following Administration requests addressing medication-assisted treatment under SAMHSA:

—\$50.1 million (+\$25.1 million over fiscal year 2016) for *Medication-Assisted Treatment for Prescription Drug and Opioid Addiction* (MAT PDOA—Center for Substance Abuse Treatment, Programs of Regional and National Significance)

—\$10 million for *Buprenorphine-Prescribing Authority Demonstration* (Center for Substance Abuse Treatment, Programs of Regional and National Significance)

In addition, Harm Reduction Coalition strongly supports the Administration's request for \$1 billion over fiscal year 2017 and fiscal year 2018 to expand access to treatment for opioid use disorders. This represents a critical investment in treatment capacity at a pivotal moment in the opioid epidemic. While the Administration requested these monies as mandatory funding, Harm Reduction Coalition does not have a position on whether these funds should be discretionary or mandatory. However, we agree with the Administration that a substantive and targeted investment is critical at this juncture, and endorse the proposed approach to allocate the bulk

of these funds through new State Targeted Response Cooperative Agreements, with the remaining dollars supporting workforce development and cohort monitoring and evaluation of medication-assisted treatment expansion and outcomes.

We thank you again for your consideration of our testimony and for the subcommittee's previous support for these priorities in fiscal year 2016. Please do not hesitate to contact us if you have any questions.

[This statement was submitted by Daniel Raymond, Policy Director, Harm Reduction Coalition.]

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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 \$524 million in fiscal year 2017 for the health professions education and training programs authorized under Titles VII and VIII of the Public Health Service Act and administered through the Health Resources and Services Administration (HRSA). Additionally, because HRSA has been administering the Behavioral Health Workforce Education and Training (BHWET) Program, we also support the President's fiscal year 2017 budget proposal of shifting funds previously appropriated to the Substance Abuse and Mental Health Services Administration to 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 professionals, 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.

HPNEC recognizes the Subcommittee faces difficult decisions in a constrained budget environment; therefore, we are grateful the Subcommittee recognized that these programs are a high priority and continued its commitment to programs supporting healthcare workforce development in the fiscal year 2016 omnibus spending package. The Nation faces a shortage of health professionals, which will be exacerbated by increasing demand for healthcare services. 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. According to HRSA, approximately 20 percent of Americans live in rural or urban areas designated as health professional shortage areas (HPSA). The primary care medical and oral health training grants are also used to develop curricula and test training methods to transform healthcare practice and delivery, including innovations in the primary care team's management of chronic disease, patient-centered models of care, and transitioning across healthcare settings. 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 final fiscal year 2016 omnibus spending package combined the Title VIII Comprehensive Geriatric Education program, which establishes traineeships for individuals who are preparing for advanced education in geriatric nursing, with the Title VII geriatrics programs, including the Geriatrics Education Centers programs, which support interprofessional geriatrics education and training for geriatrics specialists and non-specialists, Geriatric Training for Physicians, Dentists, and Behavioral/Mental Health Professionals programs, which increase the supply of geriatrics faculty and re-train faculty in geriatrics, and the Geriatric Academic Career Awards (GACA) program, which promote the development of academic clinician educators who provide clinical training in geriatrics. Individually, these programs 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. The newly combined program—the Geriatrics Workforce Enhancement program (GWEP)—seeks to improve integration of geriatrics with primary care across health settings and disciplines. However, due to the nature of the program consolidation, it is not yet clear if or how all of the previous activities will be supported in the new program. Specifically, we are concerned that the GACAs may not continue to play their important role in the new GWEP structure. 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 minority 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 nurses and 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 supports nurses and nursing students as well as numerous academic nursing institutions and healthcare facilities. At the same time, the need for high-quality nursing services is expected to grow, particularly in rural and underserved areas. The Advanced Nursing Education program awards grants to train a variety of nurses with advanced education, including clinical nurse specialists, nurse practitioners, certified nurse-midwives, certified registered nurse anesthetists, public health nurses, nurse educators, and nurse administrators. Nursing Workforce Diversity grants help to recruit and retain students from minority and disadvantaged backgrounds to the nursing profession through scholarships, stipends, and other retention activities. Graduate nursing students are provided reimbursement for tuition and program costs through the Advanced Education Nursing Traineeships and Nurse Anesthetist Traineeships. The Nurse Education, Practice, Quality, and Retention program helps 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 critical shortage facility. The Comprehensive Geriatric Education grants support the education of registered nurses and 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 supports graduate students pursuing the opportunity to become nursing faculty members through loan repayment in exchange for service as nursing 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 \$524 million for the Title VII and VIII programs in fiscal year 2017, and providing BHWET funding directly to HRSA. We look forward to working with the Subcommittee to prioritize the health professions programs in fiscal year 2017 and into the future.

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PREPARED STATEMENT OF HELEN KELLER INTERNATIONAL

Mr. Chairman, thank you for this opportunity to provide testimony to the Subcommittee on behalf of Helen Keller International's ChildSight® program. My name is Kathy Spahn, and I serve as the President and Chief Executive Officer of Helen Keller International (HKI). I am requesting that this Subcommittee recommend in its fiscal year 2017 Appropriations report that the Department of Education provide funding for programs that identify and provide prescription eyeglasses to children from low income families whose educational performance and future vocational success may be hindered because of poor vision.

It is HKI's hope that with the continued support of the Department of Education and private donors we can deliver free vision screenings and eyeglasses to thousands of economically disadvantaged children who have extremely limited access to immediate and affordable vision care.

CHILDSIGHT®

Established in 1994, ChildSight® tackles the common problem of refractive error among children and adolescent students in underserved communities in the United States. More commonly known as nearsightedness, farsightedness, and astigmatism, refractive error affects one in four children and adolescents nationwide.

The mission of ChildSight® is to improve the vision and academic potential of economically disadvantaged children. Research has established a clear link between vision and learning. Most learning platforms—books, computer screens, blackboards and classroom presentations—require clear vision in order for a child to interact, assimilate information and respond. Yet in thousands of classrooms, millions of children are unable to make the most of their education simply because they cannot see well. This is especially tragic since most cases of poor vision are due to refractive error and are easily corrected.

If not detected and treated promptly, refractive error and other eye conditions can lead to long term visual deficiencies and developmental problems. Students must have clear, healthy eyesight in order to fully focus on schoolwork and classroom lessons or the opportunity to gain a valuable education is severely diminished. Adults whose visual impairment denied them the chance to gain core academic skills are at a disadvantage in seeking employment and achieving economic independence.

In most cases, the solution is simple: the provision of correctly prescribed eyeglasses. ChildSight® helps students directly by going into the schools to conduct vision screenings, identifying children with refractive error and providing prescription eyeglasses to address this need, all free of charge. In so doing, ChildSight® “brings education into focus™” for children who would otherwise be left with untreated vision problems—and lost opportunities.

Millions of students do not get the care they need due to limited access to vision screening and the prohibitive cost of a pair of prescription eyeglasses. ChildSight® targets these communities and serves at-risk children by providing free on-site screening, free eyeglasses and follow-up care so that students can focus in the classroom in order to achieve their potential for future academic and vocational success.

ChildSight® is distinguished by its high clinical standards and its efforts to educate children and their families about the importance of corrected vision and the availability of related healthcare resources in their community. ChildSight® provides direct access to vision screening and refraction by a licensed optometrist who prescribes the necessary lenses for each child.

ChildSight® goes one step further. Students identified with potentially severe eye conditions beyond basic refractive error are referred to our partnering ophthalmologists for a full eye exam and follow-up treatment as needed. This final step ensures that children who need further assessment and care will be able to receive it.

ChildSight® also addresses the needs of out of school youth. Services are offered to runaway and homeless youth, in partnership with organizations like Covenant House and the Ali Forney Center in New York, and for high school dropouts seeking to pass the General Educational Development (GED) test. By addressing the eye care needs of vulnerable youth, ChildSight® helps to reintegrate these young people into the educational system and enables them to seek and maintain employment.

## POSITIVE RESULTS

Since its inception, ChildSight® has screened over 1.7 million children and delivered over 243,000 pairs of free eyeglasses to children in need, with support from this Subcommittee, the Department of Education and private donations. We have seen the positive results of the ChildSight® program.

Teachers we have surveyed throughout the country report that a majority of students who had their vision corrected with ChildSight® eyeglasses exhibited significant improvement in the completion of schoolwork and homework; increased class participation and a reduction in disruptive behavior; and improvement in grades, self-confidence and self-perception as reported by the teachers.

## PUBLIC/PRIVATE UNDERTAKING

ChildSight® is truly a public/private endeavor. The program's success is due in large part to the dedication and commitment of our partner physicians, educators, community activists and business people in each of our local sites. With their support and the contributions of foundations and corporations, we continue to seek the institutionalization and long term sustainability of our programs. Government funding is also crucial to achieving long term sustainability and expanding access. For example, a recent grant from the City of New York has supported the integration of ChildSight® eye health services into a package of social and health services offered at designated Community School locations in the Bronx.

The endorsement and support of the Department of Education have played an integral role in our ability to leverage committed support from the private sector. ChildSight® has received significant long term funding from foundations including The Community Foundation for Greater New Haven, Lavelle Fund for the Blind, Mt. Sinai Health Care Foundation, The New York Community Trust, Children's Aid Society, The Rose Hills Foundation, Victoria Foundation, The Healthcare Foundation of New Jersey, and Reader's Digest Partners for Sight Foundation.

Local healthcare professionals, such as optometrists, pediatric ophthalmologists and opticians, at our program sites are members of the ChildSight® team who help us meet the vision care needs of the students we serve. ChildSight® contracts with ophthalmic clinics and optical shops selected according to their strong professional credentials. The services of these community professionals are either donated or provided at a reduced, reasonable rates.

## CONCLUSION

ChildSight® provides an invaluable—and often life changing—service to local youth in a pragmatic and cost-effective manner. Of particular concern is the need to reach at-risk children and provide them free screening, free eyeglasses and free follow-up care.

I ask this Subcommittee to recommend in its fiscal year 2017 Committee report that the United States Department of Education support programs that provide vision care for children from economically disadvantaged families. These Department of Education funds will support ongoing programs and will provide vision screening and prescription eyeglasses for such children.

Corrective treatment eye treatment is needed to overcome the economic, social and transportation barriers that prevent many children from economically disadvantaged families from obtaining the vision care they need. Students with corrected vision can focus in the classroom in order to achieve their potential for academic and vocational success.

As our founding board member Helen Keller said: We are never really happy until we try to brighten the lives of others.

[This statement was submitted by Kathy Spahn, President and Chief Executive Officer, Helen Keller International.]

## PREPARED STATEMENT OF THE HEPATITIS APPROPRIATIONS PARTNERSHIP

The Hepatitis Appropriations Partnership (HAP) is a national coalition based in Washington, DC. The coalition includes community-based organizations, public health and provider associations, national hepatitis and HIV organizations, and diagnostic, pharmaceutical and biotechnology companies. HAP works with policy makers and public health officials to increase Federal support for hepatitis prevention, testing, education, research and treatment. On behalf of HAP, we urge your support for increased funding for Federal hepatitis programs in the fiscal year 2017 Labor-



Health-Education Appropriations bill, and thank you for your consideration of the following critical funding needs for hepatitis programs in fiscal year 2017:

Agency	Program	HAP Funding Request
Centers for Disease Control and Prevention	Division of Viral Hepatitis	\$62.8 million

According to the Centers for Disease Control and Prevention (CDC), hepatitis mortality rates have increased substantially in the United States over the past decade. In fact, for nearly 10 years, deaths from HCV have surpassed deaths from HIV and the CDC now reports that deaths associated with HCV now surpass deaths associated with all 59 other notifiable infectious diseases combined. Addressing HIV co-infection rates, as high as 25 percent for HCV and 10 percent for HBV, remains a significant challenge. Until more is done to address hepatitis it will remain the leading non-AIDS cause of death in people living with HIV. Further, HBV and HCV are the leading causes of liver cancer—one of the most lethal, expensive, and fastest growing cancers in America. As CDC's 2016 Annual Report to the Nation on the Status of Cancer show, while overall incidences of, and deaths from, cancer have declined, liver cancer is an exception. Both cases of and deaths from liver cancer are on the rise. While HBV and HCV are completely preventable and treatable, as many as 5.3 million people in the U.S. live with HBV and/or HCV and 50–65 percent of them remain undiagnosed, leaving them vulnerable for progression to liver disease, cancer, and ultimately death. However, as indicated in the April 2016 report from the National Academies of the Sciences, *Eliminating the Public Health Problem of Hepatitis B and C in the United States*, elimination of hepatitis in the United States is feasible, but only if we dedicate the necessary resources and address the underlying barriers.

Although most people living with HCV, who also have the greatest risk for HCV-related morbidity and mortality, are baby boomers—those born between 1945 through 1965—hepatitis transmission among young people has skyrocketed in recent years. Just last year, in Scott County, Indiana, an outbreak of nearly 185 cases of HIV, of which more than 90 percent were already infected with HCV, demonstrated the danger of a public health infrastructure lacking in the basic resources necessary to stop the spread of completely preventable infections. Between 2010 and 2013 there was a significant increase in new HBV and HCV infections, with HCV rising by 150 percent. States like Indiana, Kentucky, West Virginia, Washington and 25 others have reported increases in HCV, while at least Kentucky, Tennessee and West Virginia have seen increases in HBV. Increases in both HBV and HCV in those areas are tied to increases in injection drug use.

In addition to the above concerns, mother-to-child transmission of hepatitis remains a challenge, again despite the availability of prevention tools. Although hepatitis B vaccination coverage among newborns has increased, it remains below the Healthy People 2020 goals. Approximately 24,000 infants are born to mothers living with HBV, resulting in as many as 1000 perinatal transmissions per year. Additionally, the ongoing HCV epidemic among young people who inject drugs has led to increases, in some areas, of mother-to-child transmission of HCV. Elimination of mother-to-child transmission is possible, with increased vaccination for HBV and early detection and treatment of new hepatitis infections.

Even with these challenges, the availability of effective new curative treatments for HCV, and an effective vaccine and good treatments to control HBV, brings the elimination of HCV and HBV in the United States within our reach, setting the stage for an enormous new public health victory. But not without increased investments in comprehensive, national hepatitis prevention, screening, linkage to care, education and surveillance programs. The CDC's 2010 professional judgment (PJ) budget provided the need estimate of \$170.3 million annually from fiscal year 2014–fiscal year 2017 to comprehensively address HBV and HCV. HAP's request of \$62.8 million recognizes the current budgetary limitations while also balancing the very urgent need to accomplish the goals of the Action Plan for the Prevention, Care, & Treatment of Viral Hepatitis (Viral Hepatitis Action Plan), to implement the United States Preventive Services Task Force (USPSTF) HBV and HCV screening recommendations, and to ultimately end the epidemics. HAP recommends that these funds be used on the following priority areas, allocated in proportion to HBV and HCV burden, using available epidemiological data.

#### *Screening and Linkage to Care*

The Viral Hepatitis Action Plan established a goal of increasing the proportion of persons who are aware of their hepatitis infection to 66 percent for both HBV and HCV. Full implementation of the CDC and USPSTF recommendations for HBV and

HCV testing and linkage to care by State Medicaid programs, Medicare, and private health systems and providers are necessary to accomplish these goals. As studies have shown, identifying and treating a person living with hepatitis early, before the disease progresses, as opposed to at later stages both averts advanced liver disease and is cost effective: treating a person living with HCV before there is liver scarring gains, or saves, more than \$187,000 per person per year. Increased resources would enable DVH to:

- Work to advance testing in private clinical settings, public health settings, and other settings to increase the number of persons diagnosed with HBV and HCV infection and linked to lifesaving care earlier in their infection
- Explore opportunities for utilizing electronic health records to monitor implementation of CDC/USPSTF recommendations

#### *Surveillance*

As testing and linkage to care activities increase and improve, strengthening local and State capacity to execute hepatitis monitoring and surveillance activities takes on an even greater importance. The CDC currently funds only 5 State health departments and 2 local health departments to conduct minimal surveillance in their jurisdictions. CDC also provides funds to State and local health departments, the cornerstone implementers of national public health policies, to coordinate prevention and surveillance efforts via the Viral Hepatitis Prevention Coordinator Program (VHPC). The VHPC program is the only national program dedicated to the prevention and control of the hepatitis epidemics. This program provides funding to support a coordinator position in each jurisdiction, though not enough for a full time position, and leaves little to no money for the provision of public health services, such as surveillance, public education and access to prevention services like testing and hepatitis A and B vaccinations, which must be cobbled together from other sources year-to-year. Hepatitis disproportionately impacts several communities, particularly people who inject drugs (PWID)—as demonstrated by the Indiana outbreak, men who have sex with men, persons living with HIV, African immigrants and African Americans, Asian immigrants and Asian Americans, Pacific Islanders, Latinos, tribal communities, veterans, and residents of rural and remote areas with limited access to medical treatment or culturally and linguistically-appropriate services. Surveillance is needed in order to adequately address the epidemics in these populations. Increasing funding would allow DVH to:

- Establish a regional health training and technical assistance center to support detection and investigations of new HBV and HCV cases, including mother to child HCV transmission; promote implementation of prevention practices among State/local health departments, substance use disorder treatment programs, correctional organizations, and nongovernmental organizations
- Support the development model projects for the elimination of HCV transmission and related mortality throughout an indicated area
- Increase the number of funded sites to increase surveillance in those jurisdictions hardest hit by the hepatitis epidemics.

#### *Addressing the Emerging Hepatitis C Epidemic Among Young Persons at Risk*

HCV prevalence among PWIDs is as high as 70 percent, and between 20–30 percent of people who inject drugs acquires HCV each year. This trend is largely due to the prescription opiate epidemic and the transition many young people have made from using opiate pills to injecting heroin. This increase, and the ongoing outbreaks in several States, makes the need to enhance and expand these prevention efforts all the more urgent and underscore the need to prioritize immediate support in the field, strengthening health department and community responses that target youth and young adults, specifically persons who injection drugs, persons under 30 years old, and persons living in rural areas. Increased funding would enable DVH to:

- Investigate networks of transmission in order to improve implementation and evaluation of prevention services
- Promote HBV vaccinations, and HBV and HCV screening in settings that reach and provide services for populations at highest risk for transmission
- In addition to HBV and HCV testing, DVH would assure implementation of prevention services to stop HBV and HCV transmission, including counseling, locally supported syringe services programs, treatment for substance use disorders, and linkage to care treatment for people living with HBV and HCV

#### *Elimination of Mother-to-Child Transmission of Hepatitis B*

Due in part to the success of the Perinatal Hepatitis B Coordinator program at CDC's National Center for Immunization and Respiratory Diseases (NCIRD), great strides have been made to reduce HBV among newborns and youth. However, be-

tween 800 to 1000 perinatal HBV transmissions still occur each year in the U.S. With increased resources, DVH would:

- Monitor and improve implementation of vaccination of all infants within three days of birth through continued collaborations with birthing hospitals
- Continue to work with State epidemiologists to implement revised State and local reporting criteria for pregnant women and their newborns living with HCV
- Consider routine testing HCV testing for women of child bearing age to identify young women living with HCV who would benefit from treatment, and to provide preventive services to their newborns

As the National Academies of the Sciences and the World Health Organization has recognized, prevention and elimination of hepatitis is a feasible goal and should be a public health priority. It is certainly possible in the United States. We have the tools to accomplish this goal and we hope the fiscal year 2017 Labor HHS bill will reflect this priority through the allocation of significant resources to rein in the current epidemics and begin to identify those who are already living with HBV and HCV.

As you contemplate the fiscal year 2017 Labor, Health and Human Services, Education and Related Agencies appropriations bill, we ask that you consider these critical funding needs. We thank the Chairman, Ranking Member and members of the Subcommittee, for their thoughtful consideration of our recommendations. Our response to the viral hepatitis epidemics in the United States defines us as a society, as public health agencies, and as individuals living in this country. There is no time to waste in our Nation's fight against these epidemics.

[This statement was submitted by Mariah Johnson, Coordinator, Hepatitis Appropriations Partnership.]

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#### PREPARED STATEMENT OF THE HEPATITIS B FOUNDATION

The Hepatitis B Foundation appreciates the opportunity to submit testimony to the U.S. Senate Appropriations Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies (LHHS) regarding the fiscal year 2017 Appropriations bill. The Hepatitis B Foundation is the Nation's leading 501(c)(3) nonprofit organization dedicated to finding a cure for hepatitis B and improving the lives of those affected worldwide through research, education and patient advocacy. To further expand its reach and impact, the HBF established and co-chairs 'Hep B United,' a national coalition of 30 community-based multi-sectoral coalitions and national organizations with a reach to more than 4 million high-risk individuals—working across 14 States and 24 cities to address and eliminate hepatitis B in the United States. We are concerned funding to combat chronic viral hepatitis in the United States continues to be severely inadequate, and does not come close to reflecting the burden of disease, with as many as 5.7 million people living with chronic hepatitis B and C, and highly alarming rates of new infections. We therefore urge the Subcommittee to address the issue across several agencies and programs within its jurisdiction in order to help meet the goal of developing new and better treatments, to find a cure, and to reduce the incidence and transmission of the hepatitis B virus. Specifically, we urge the subcommittee to increase appropriations as follows:

- Health Resources and Services Administration Bureau of Primary Health Care: + \$3 million. This funding is necessary to demonstrate, test, and validate the most effective protocols to eliminate the perinatal transmission of hepatitis B.
- Centers for Disease Control and Prevention: +\$28.8 million. This will permit a more comprehensive response to control the spread of acute and chronic hepatitis B infection through increased surveillance, testing, education, and linkage to care and treatment.
- National Institutes of Health: + \$2.4 billion in total including +\$49 million for hepatitis B research. This will permit a doubling of NIH research funding focused on finding a cure for hepatitis B in a trans-Institute initiative guided by a professional judgement budget. NIH funding for hepatitis B has actually decreased by almost 16 percent since fiscal year 2011. These additional resources will put us on a path to find a cure. The Hepatitis B Foundation joins with the Ad Hoc Group for Biomedical Research and requests at least \$34.5 billion for the NIH in fiscal year 2017.

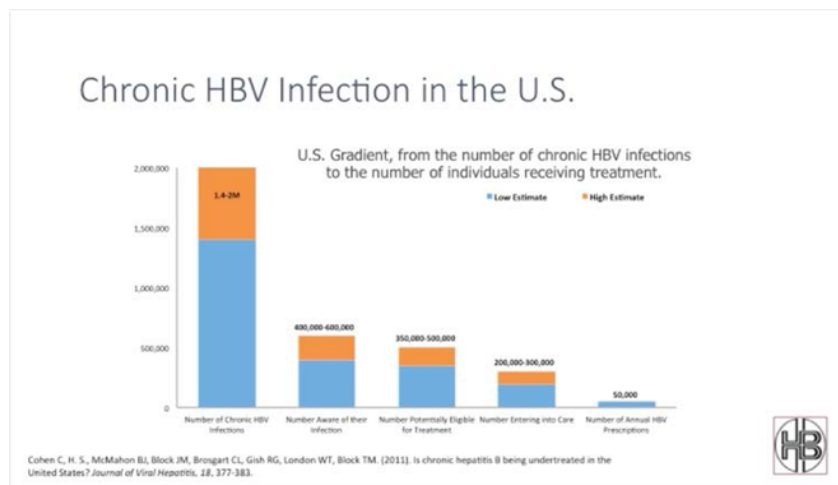
#### *Scope of the Epidemics*

In the United States, CDC estimates that as many as 5.7 million people are living with chronic hepatitis B virus (HBV) and hepatitis B C virus (HCV) infection, and

at least half of persons living with HBV or HCV do not know they are infected.<sup>1</sup> However, these are likely conservative prevalence estimates as state surveillance systems are inconsistent and underfunded. HBV and HCV are silent infections, often asymptomatic, and without early diagnosis or intervention, can lead to serious liver diseases and liver cancer. There is a safe and highly effective vaccine and treatments to prevent and control HBV, and revolutionary curative treatments for HCV. Strategies to increase testing, vaccination, treatment and linkages to care, can dramatically reduce disease and premature deaths due to chronic viral hepatitis.

#### *Hepatitis B and Liver Cancer*

In the U.S., it is estimated that over 2 million Americans are living with chronic HBV infection, but only 25 percent are aware of their infection and less than 10% of infected individuals are able to access care and receive treatment.<sup>2</sup> Chronic HBV infection disparately impacts and represents serious public health inequities for racial and ethnic communities in the U.S. For example, Asian Americans and Pacific Islanders make up 5 percent of the total U.S. population, yet account for more than 50 percent of Americans living with chronic HBV.<sup>3</sup> Additionally, a CDC assessment found significant increases in acute HBV infections in the Appalachian region (Kentucky, Tennessee, and West Virginia) among non-Hispanic whites, persons aged 30–39 years, and injection drug users. This represents an increased incidence of 114 percent in acute HBV infections during 2009–2013 in these States.<sup>4</sup>



Left untreated, 1 in 4 of those with chronic HBV infection will die prematurely from liver failure and/or liver cancer. The CDC 2016 Annual Report to the Nation on the Status of Cancer found that unlike other cancers, liver cancer incidence and death rates are rising. In the U.S., liver cancer is the second deadliest cancer with a 5-year survival rate of only 10 percent.<sup>5</sup> This underscores the urgent need for hepatitis B screening to identify new and chronic infections, and furthermore, with the HBV vaccine (the first “anti-cancer” vaccine, according to the FDA) that has been available for over 20 years, preventing hepatitis B infections can prevent primary liver cancer. According to the CDC, hepatitis B vaccination coverage is low among adults; the 2013 National Health Interview Survey data indicated that coverage with at least 3 doses of HBV vaccine was 32.6 percent for adults aged 19–49 years, the group at highest risk for new infections.<sup>6</sup>

<sup>1</sup> <http://www.cdc.gov/hepatitis/abc/index.htm>.

<sup>2</sup> Cohen C, H. S., McMahon BJ, Block JM, Brosgart CL, Gish RG, London WT, Block TM. (2011). Is chronic hepatitis B being undertreated in the United States? *Journal of Viral Hepatitis*, 18, 377–383.

<sup>3</sup> <http://www.cdc.gov/knownhepatitisb>.

<sup>4</sup> [http://www.cdc.gov/mmwr/volumes/65/wr/mm6503a2.htm?s\\_cid=mm6503a2\\_\\_e](http://www.cdc.gov/mmwr/volumes/65/wr/mm6503a2.htm?s_cid=mm6503a2__e).

<sup>5</sup> [http://www.cdc.gov/cancer/dpcp/research/articles/arn\\_7512.htm](http://www.cdc.gov/cancer/dpcp/research/articles/arn_7512.htm).

<sup>6</sup> <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6404a6.htm>.

### *Elimination of Perinatal Hepatitis B Transmission*

The transmission of HBV from mother to child, or perinatal transmission, during birth is the most common route of transmission worldwide. Despite prevention efforts, approximately 800 to 1,000 babies are born each year in the U.S. and develop a chronic HBV infection.<sup>7</sup> Without intervention, babies exposed to the hepatitis B virus during delivery have a 90 percent risk of developing a chronic infection, and 25 percent of infants chronically infected will die prematurely from HBV-related complications. Effective post-exposure prophylaxis comprised of the HBV vaccine and HBV immune globulin, can prevent mother-to-child transmission with a success rate of more than 95 percent.<sup>8</sup>

The Hepatitis B Foundation believes that the elimination of perinatal HBV transmission is within reach if resources are dedicated to strengthening surveillance and referral systems and enhancing prevention efforts. We are pleased that after 4 years of urgings from the Committee, the Bureau of Primary Health Care has finally agreed to look an evaluation of intervention strategies to eliminate the perinatal transmission of hepatitis B in HRSA funded healthcare settings. However, a full evaluation of intervention strategies will require the training of healthcare professionals, followed by service delivery, data collection, and evaluation and we urge that the Bureau's funding plans accommodate these components and this necessary sequence of activities in order to accommodate a full evaluation of the recommended intervention strategies.

### *Strengthening Surveillance and State/Local Capacity*

A strong national surveillance system is critical towards understanding the true burden of disease, monitoring trends, outbreaks, and tracking progress in public health interventions. The current state of surveillance, especially to track chronic HBV infections, is sorely lacking and masks the true state of the epidemic in the U.S. Currently, the CDC funds merely five States and two large cities to conduct enhanced chronic viral hepatitis surveillance. CDC also provides a small amount of funding to State and local health departments through the Viral Hepatitis Prevention Coordinator Program (VHPC).<sup>9</sup> The VHPC program, which funds a prevention coordinator position, is the only dedicated effort at a State and local level to coordinate viral hepatitis prevention activities. This position is severely underfunded and rarely enough to address HBV or HCV full time. Both are inadequate efforts and resources to address these large-scale epidemics and alarming new infections. In order to effectively combat chronic viral hepatitis in the U.S., we must increase State, local, and territorial capacity to address these epidemics and strengthen coordination, including surveillance systems, across the country.

### *Research for a Cure*

We depend upon the NIH to fund research that will lead to new and more effective interventions to treat people with HBV and liver cancer. The Hepatitis B Foundation joins with the Ad Hoc Group for Biomedical Research and requests at least \$34.5 billion for the NIH in fiscal year 2017. We thank the Committee for their continued investment in the NIH, and specifically for the robust \$32.1 billion of funding in fiscal year 2016. Sustaining predictable increases for NIH is essential for development of life changing cures, pioneering treatments, and innovative prevention strategies.

Additional funding could make transformational advances in research leading to curative treatments for HBV. In view of the fact that an estimated 2.2 million Americans are chronically infected with HBV, and on average more than 10 people die each day from the disease, it is incredibly disappointing that funding for HBV research at NIH has declined by almost 16 percent since fiscal year 2011. And yet, despite this decline in investment, there is the greatest momentum for discovery. For the first time it is now possible to study the entire hepatitis B virus life cycle and therefore identify targeted vulnerabilities that can be exploited to cure this deadly disease. In order to take advantage of this new scientific opportunity, funding for HBV research should be doubled with the goal of discovering more effective treatments and finding a complete cure. In addition, the Hepatitis B Foundation requests a stronger focus on liver cancer at the National Cancer Institute and urges the funding of a series of Specialized Programs of Research Excellence (SPORes) focused on liver cancer. While SPORes currently exist for every other major cancer, none currently exist that are focused on liver cancer.

<sup>7</sup> [https://blog.aids.gov/wp-content/uploads/Perinatal\\_HBV\\_Report\\_FINAL\\_12-21-15-508.pdf](https://blog.aids.gov/wp-content/uploads/Perinatal_HBV_Report_FINAL_12-21-15-508.pdf).

<sup>8</sup> *Ibid.*

<sup>9</sup> <http://www.cdc.gov/hepatitis/partners/vhpc.htm>.

*Summary*

We are at a critical point in public health research and understanding to eliminate chronic HBV in the U.S. and reduce incidence and deaths from liver cancer. We strongly urge the Subcommittee to take this opportunity and increase the appropriation for HRSA's Bureau of Primary Health Care (+\$3 million); the CDC Division of Viral Hepatitis (+\$28.8 million); and for NIH (+\$2.4 billion including +\$49 million for hepatitis B research). We thank Chairman Blunt, Ranking Member Murray, and members of the Subcommittee for their thoughtful consideration of our request.

[This statement was submitted Kate Moraras, Senior Program Director, Hepatitis B Foundation.]

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PREPARED STATEMENT OF HERITAGE HEALTH & HOUSING

We are pleased to submit this testimony to the Members of this Subcommittee on the urgency of continuing to support the Ryan White Program through the Appropriations process and increasing funding for the domestic HIV/AIDS portfolio in fiscal year 2017. This support and funding will be decisive for achieving the goals of the National HIV/AIDS Strategy (NHAS) 2020, the AIDS Free Generation and halting the devastating effects of the HIV Treatment Cascade.

Heritage Health & Housing is part of a nationwide coalition, the Food is Medicine Coalition, of over 80 food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PWH) and other chronic illnesses. In our service area, we provide 20,000 congregate meals and 12,000 home delivered annually. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

*Why Food and Nutrition Services (FNS) Matter for PWH*

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PWH at any stage of their illness. For those who are most mobile, there are congregate meals, walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective core medical service in the Ryan White Program. These services play a critical role in ensuring that PWH enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

*FNS as a Care Completion Service Unique to Ryan White*

Social and economic interventions, most often in the form of care completion service like food and nutrition services, are fundamental to making healthcare work for PWH. Support services for PWH are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk

of HIV. When needs are met, and life's emergencies are held at bay, PWH are poised to remain connected to care and treatment.

*Access to FNS and the Triple Aim*

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PWH.

*Better Health Outcomes*

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines.<sup>1</sup> Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections<sup>2</sup> and the resulting decreases in their healthcare costs. Compare these outcomes to PWH who are food insecure, who have:

- Lower CD4 counts & lower likelihoods of having undetectable viral loads<sup>3</sup>
- More ER visits<sup>4</sup> & increased morbidity and mortality<sup>5</sup>
- More missed primary care appointments & reduced use of antiretroviral therapy.<sup>6</sup>

*Lower Healthcare Costs*

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PWH. A recent study comparing participants in a medically-tailored FNS program vs. a control group within a local managed care organization found that average monthly healthcare costs for PWH fell 80 percent in first 3 months after receiving FNS.<sup>7</sup> If hospitalized, nourished clients' costs were 30 percent lower, their hospital length of stay was cut by 37 percent and they were 20 percent more likely to be able to be discharged to their homes rather than a more expensive institution.<sup>8</sup> Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

*Improved Patient Satisfaction*

Studies show nutrition counseling improves quality of life.<sup>9</sup> Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

*FNS and the National HIV/AIDS Strategy (NHAS)*

Access to FNS for PWH is fundamental to fulfilling the goals of the NHAS.

- NHAS Goal: Reducing new HIV infections: PWH who are food insecure are less likely to have undetectable viral loads in a statistically significant way.

<sup>1</sup>Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at [https://www.health.ny.gov/diseases/aids/ending\\_the\\_epidemic/docs/key\\_resources/housing\\_and\\_supportive\\_services/chain\\_factsheet3.pdf](https://www.health.ny.gov/diseases/aids/ending_the_epidemic/docs/key_resources/housing_and_supportive_services/chain_factsheet3.pdf).

<sup>2</sup>Academy of Nutrition and Dietetics (formerly American Dietetic Association). HIV/AIDS Nutrition Evidence Analysis Project at [http://www.adaevidencelibrary.com/conclusion.cfm?conclusion\\_statement\\_id=250707](http://www.adaevidencelibrary.com/conclusion.cfm?conclusion_statement_id=250707) Accessed 29 July 2012.

<sup>3</sup>Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011); Singe AW, Weiser SD McCoy, SI. Does Food Insecurity Undermine Adherence to Antiretroviral Therapy? A Systematic Review. *AIDS Behav* (2015) 19:1510–1526.

<sup>4</sup>Ibid.

<sup>5</sup>Anema A, Chan K, Yip B, Weiser S, Montaner JSG, Hogg RS. Impact of food insecurity on survival among HIV-positive injection drug users receiving antiretroviral therapy in a Canadian cohort. 141st APHA Annual Meeting, Nov. 2–6, 2013. Boston, MA. Abstract #: 290277.

<sup>6</sup>Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).

<sup>7</sup>Gurvey J, Rand K, Daugherty S, Dinger C, Schmelting J, Laverty N. Examining Health Care Costs Among MANNA Clients and a Comparison Group. *J Prim Care Community Health*. (2013) 4:311–317.

<sup>8</sup>Ibid.

<sup>9</sup>Rabeneck L, Palmer A, Knowles JB, Seidehamel RJ, Harris CL, Merkel KL, Risser JMH, Akrabawi SS. A randomized controlled trial evaluating nutrition counseling with or without oral supplementation in malnourished HIV-infected patients. *J Am Diet Assoc*. (1998) 98: 434–438; Schwenk A, Steuck H, Kremer G. Oral supplements as adjunctive treatment to nutritional counseling in malnourished HIV-infected patients: randomized controlled trial. *Clinical Nutrition* (1999) 18(6): 371–374.

Undetectable viral loads prevent transmission 96 percent of the time,<sup>10</sup> thus, FNS is key to prevention.<sup>11</sup>

- NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV: PWH who receive effective FNS are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines.<sup>12</sup>
- NHAS Goal: Reducing HIV-related disparities and health inequities: By providing FNS to PWH who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities.<sup>13</sup>
- NHAS Goal: Achieving a more coordinated national response to the HIV epidemic: There remains a tremendous variation by State in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White HIV Program all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including Ryan White and the ACA.

### Conclusion

We are deeply aware of the difficult decisions that face the members of the Subcommittee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PWH live healthy and productive lives, produces better overall health outcomes and reduces healthcare costs.

Along with our colleagues, we appreciate the opportunity to offer this testimony regarding the fiscal year 2017 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you.

[This statement was submitted by Sonia Grant, Program Director, Food and Nutrition Services Program, Heritage Health and Housing.]

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### 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 frontlines 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. As you work on the fiscal year 2017 appropriations process, we urge you to invest in the medical research supported by the National Institutes of Health (NIH), sustain robust funding for the Ryan White Program at the Health Resources and Services and Administration (HRSA) and support adequate funding for 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.<sup>1</sup> Treatment not only saves the lives of individuals with HIV but directly benefits public health by reducing HIV transmission risk

<sup>10</sup>M. S. Cohen et al., Prevention of HIV-1 Infection with Early Antiretroviral Therapy. *N. Engl. J. Med.* (2011) 365, 493–505 . HPTN 052.

<sup>11</sup>Palar K, Lاراia B, Tsai A, Weiser SD Food insecurity is associated with sexually transmitted infections and HIV serostatus among low income adults in the National Health and Nutrition Examination Survey (NHANES) (1999–2010). Presented at the American Public Health Association 141st Annual Meeting, Boston, MA, November 5, 2013.

<sup>12</sup>Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014.

<sup>13</sup>Available at Weiser SD, Frongillo EA, Ragland K, Hogg RS, Riley ED, Bangsberg DR. Food insecurity is associated with incomplete HIV RNA suppression among homeless and marginally housed HIV-infected individuals in San Francisco. *J Gen Intern Med.* (2009) 24(1):14–20.

<sup>1</sup>Kitahata, Gange, Abraham, et al. Effect of early versus deferred antiretroviral therapy for HIV on survival. *New Engl J Med* 2009;360:1815-26.



to near zero.<sup>2</sup> However, despite our remarkable progress in HIV prevention, diagnosis and treatment, the HIV/AIDS epidemic is far from over. HIV/AIDS continues to pose a serious disease burden and public health threat in the United States with more than 1.2 million people living with HIV infection. Almost 1 in 8 (12.8 percent) individuals living with HIV are not aware of their HIV infection and there are an estimated 50,000 new infections occurring annually in the U.S. 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.<sup>3</sup> Globally, there are more than 35.3 million people living with HIV, the great majority of them in Sub-Saharan Africa.

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.

*NIH—Office of AIDS Research (OAR)*

HIVMA strongly supports an overall fiscal year 2017 budget request level of at least \$34.5 billion for the NIH, and urges that at least \$3.45 billion be allocated to the NIH Office of AIDS Research. This level of funding is vital to sustain the pace of research that will improve the health and quality of life for millions of people in the U.S. and in the developing world. Flat funding of HIV/AIDS research since fiscal year 2015 threatens to slow progress toward a vaccine and a cure, erode our capacity to sustain our Nation's historic worldwide leadership in HIV/AIDS research and innovation, and discourage the next generation of scientists from entering the field.

Our past investment in HIV/AIDS research paid off in dramatic 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. Sustained investments in NIH funding are also essential to train the next generation of scientists and prepare them to make tomorrow's HIV discoveries.

The NIH-Wide Strategic Plan<sup>4</sup> identifies criteria for setting the NIH's research priorities, including consideration of the value of permanently eradicating a disease—noting that biomedical research stands at another such pivotal moment today: the very real possibility of entirely eliminating HIV/AIDS. The plan also notes that such an investment makes good economic sense: every new case of HIV diagnosed in the United States translates into a lifetime cost of approximately \$350,000 for treatment with antiretroviral drugs. Getting to zero new cases of HIV/AIDS would save our Nation an estimated \$17.5 billion annually.<sup>5</sup> Congress should ensure our Nation does not delay vital HIV/AIDS research progress.

*HRSA—HIV/AIDS Bureau (HAB)*

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 and keeps patients engaged and working, it is essential to maintain overall funding levels 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. The Ryan White Program annually serves more than half a million individuals living with HIV in the U.S., providing the care and treatment that allows them to live close to a normal lifespan. HIVMA urges an allocation of \$225.1 million, or a \$20 million increase, for Ryan White Part C programs in fiscal year 2017. Part C-funded HIV medical clinics currently struggle to meet the demand of increasing patient caseloads. The expert, 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. Patients with HIV who receive Ryan White services are more likely to

<sup>2</sup> 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/NEJMoa1105243>.

<sup>3</sup> CDC Fact Sheet, February, 2014, accessed online at: <http://www.cdc.gov/hiv/risk/raciaethnic/aa/facts/index.html>.

<sup>4</sup> NIH-Wide Strategic Plan, fiscal years 2016–2020: Turning Discovery Into Health, (December, 2015).

<sup>5</sup> *Ibid*, p. 32.

be prescribed HIV treatment and to be virally suppressed.<sup>6</sup> We also know that 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.<sup>7</sup>

While the Affordable Care Act (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, especially in the South, necessitate an essential and ongoing role for the Ryan White Program to avoid life-threatening and costly disruptions in care.

HIVMA does not support the proposal to consolidate Ryan White Part D funding into Part C. Ryan White Part C and D programs both provide comprehensive, effective care and treatment for women, infants, children and youth living with HIV/AIDS. Part D programs have cultivated special expertise for engaging and retaining women, including pregnant women, HIV-exposed infants, and young people in care. The programs provide services tailored to women and young people and in some communities, Part D-funded programs are the main providers of HIV care and treatment.

Additionally, we support the President's request to increase by \$9 million the Special Projects of National Significance in order to increase hepatitis C virus (HCV) testing, and care and treatment for people living with HIV who are co-infected with HCV.

*CDC—National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP)*

HIVMA appreciates the much needed increase of \$5 million proposed in the President's fiscal year 2017 budget for the CDC's NCHHSTP, to be directed to viral hepatitis—however, an increase on the order of \$30 million would more adequately meet the urgent need to ramp up the national response to the burgeoning viral hepatitis epidemic which has been fueled by injection drug use in the wake of the opioid and heroin addiction crisis. We also support sustained funding for HIV and STD prevention and surveillance, plus the Division of Adolescent School Health (DASH). We are also especially concerned about flat funding of CDC's global HIV programs, and request an increase of at least \$3.3 million for a total of \$132 million, which includes resources for the agency's essential role in implementing PEPFAR programs in developing nations.

*Policy Riders—Continue Progress on Federal Funding for Syringe Exchange Programs*

HIVMA applauds the subcommittee's work in advancing report language that allows for the judicious use of Federal funding for syringe exchange programs (SEPs) as an important prevention and public health intervention. We support the continuation of this policy. SEPs are associated with decreases in HIV and viral hepatitis incidence, and provide an important point of healthcare access, including initiation of HIV and viral hepatitis education, counseling and testing, linkage to care, and entry into substance use treatment. SEPs also benefit community safety by reducing the number of improperly disposed syringes as well as reducing needle stick injuries to law enforcement officers and other first responders.

*Conclusion*

We are at serious risk of losing ground against the HIV pandemic if we fail to prioritize HIV public health, treatment and research programs. HIV remains the leading infectious killer worldwide, and we must fully leverage and invest in HIV prevention, care and treatment and research to save the lives of millions who are infected or at risk of infection here in the U.S. and around the globe, and ultimately to end the HIV/AIDS epidemic.

<sup>6</sup>Bradley, H., et al. Ryan White HIV/AIDS Program Assistance and HIV Treatment Outcomes in the United States. CROI 2015. Abstract: 1064. Accessed online at: <http://www.croiconference.org/sessions/ryan-white-hiv-aids-program-assistance-and-hiv-treatment-outcomes-united-states>.

<sup>7</sup>Based on data from Gilman BH, Green, JC. Understanding the variation in costs among HIV primary care providers. *AIDS Care*.2008;20:1050—6.

PREPARED STATEMENT OF THE HUMANE SOCIETY OF THE UNITED STATES AND  
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 House Labor, Health and Human Services, Education and Related Agencies Appropriations Subcommittee in fiscal year 2017.

RETIREMENT OF FEDERALLY-OWNED CHIMPANZEES  
BY THE NATIONAL INSTITUTES OF HEALTH

The HSUS and HSLF would like to thank the committee for all their hard work to ensure that the National Institutes of Health (NIH) retires government-owned chimpanzees from laboratories to sanctuary. Since their announcement in June of 2013, when the NIH laid out their plans to retire all but 50 government-owned chimpanzees to sanctuary, the agency has decided to retire all chimpanzees—including the group of 50 reserve chimpanzees. There are currently approximately 300 chimpanzees cared for by the government who need to be moved from laboratories to the National Chimpanzee Sanctuary.

Chimpanzees should be moved as quickly as possible to sanctuary, since it is in their best interest for their welfare as well as good for taxpayers. At Chimp Haven, the National Chimpanzee Sanctuary, chimpanzees are the sole focus of the facility and its staff. There, chimpanzees receive the very best care possible, including access to expansive outdoor habitats, large social groups and regular and varying enrichment. Accredited sanctuaries provide the highest welfare standards for chimps at a lower cost to taxpayers than housing chimpanzees in barren labs. It is estimated that transferring the government-owned chimpanzees who are slated for retirement from the laboratories where they are currently housed to the national sanctuary would save taxpayer dollars for care and maintenance costs. For these reasons, it is imperative that the NIH move the remaining government-owned chimpanzees to sanctuary as soon as possible.

To facilitate this transfer, the National Chimpanzee Sanctuary will need to expand, which will be a significant expense for the sanctuary. There is no doubt that relief of this financial strain would expedite the faster movement of the chimpanzees to sanctuary.

We respectfully request that the Subcommittee continue to work with the NIH to ensure the remainder of the government-owned chimpanzees housed in laboratories are sent to sanctuary in a timely manner.

THE NATIONAL CENTER FOR ADVANCING TRANSLATIONAL SCIENCES

The National Center for Advancing Translational Sciences (NCATS) is one of 27 Institutes and Centers (ICs) at the NIH. Established to transform and accelerate the translational research process, NCATS is all about getting more treatments to more patients more quickly. The Center complements other NIH ICs, the private sector and the nonprofit community; rather than concentrating on specific diseases, NCATS focuses on what is common among them. The Congress awarded \$53,000,000 over the president's budget for fiscal year 2016.

*Translation* is the process of turning observations in the laboratory, clinic and community into interventions that improve the health of individuals and the public—from diagnostics and therapeutics to medical procedures and behavioral changes.

*Translational science* is the field of investigation focused on understanding the scientific and operational principles underlying each step of the translational process.

*Bridging the Gap*

Several thousand genetic diseases affect humans, of which only about 500 have any treatment. A novel drug, device or other intervention can take about 14 years and cost \$2 billion or more to develop, and about 95 percent never make it past clinical trials. Even when a new drug or other intervention is developed and shown to be effective in clinical trials, many years may pass before all patients who could benefit from it are identified and treated.

Here are some areas the animal protection community and industry have supported:

—*Tissue Chip for Drug Screening (Tissue Chip) Initiative.*—This partnership with the Defense Advanced Research Projects Agency and the Food and Drug Administration (FDA) is designed to develop 3-D human tissue chips that model the structure and function of human organs, such as the lung, liver and heart, and

then combine these chips into an integrated system that can mimic complex functions of the human body.

—*Toxicology in the 21st Century (Tox21) Initiative.*—Tox21 is a collaborative effort among NIH—including NCATS and the National Toxicology Program at the National Institute of Environmental Health Sciences—the Environmental Protection Agency and the FDA. Through Tox21, researchers are testing 10,000 drugs and environmental chemicals for their potential to affect molecules and cells in ways that can cause health problems. The compounds undergo testing in NCATS’ high-speed robotic screening system.

We respectfully request the Subcommittee request an update from NCATS on the plans for translational work to ultimately eliminate the use of animals in chemical testing and drug development.

We appreciate the opportunity to share our views for the Labor, Health and Human Services, Education and Related Agencies Appropriations Act for fiscal year 2017.

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PREPARED STATEMENT OF THE INFECTIOUS DISEASES SOCIETY OF AMERICA

On behalf of the Infectious Diseases Society of America (IDSA), I offer testimony in support of the U.S. Department of Health and Human Services (HHS) agencies and programs that contribute to the prevention, detection and treatment of infectious diseases (ID). IDSA represents more than 10,000 physicians and scientists dedicated to promoting health through excellence in ID research, education, prevention, and patient care. IDSA urges the Subcommittee to provide necessary fiscal year 2017 funding for public health and biomedical research activities that ultimately save lives, contain healthcare costs and promote economic growth. More specifically, IDSA encourages the Subcommittee to provide \$7.8 billion for the Centers for Disease Control and Prevention (CDC) and \$34.5 billion for the National Institutes of Health (NIH). IDSA also asks that the Subcommittee act swiftly to provide the \$1.9 billion requested by the administration to prevent and respond to the Zika virus.

Our community of infectious diseases professionals is particularly concerned by the growing public health crisis of antimicrobial resistance (AR). We witness firsthand the impact that AR has on individuals. As a result, we have aggressively advocated for the creation and implementation of a comprehensive Federal response. IDSA applauds Congress, and in particular the many champions on this Subcommittee, for appropriating approximately \$380 million in new funding during the fiscal year 2016 cycle to begin implementation of the National Action Plan for Combating Antibiotic-Resistant Bacteria (Action Plan). The Action Plan details and coordinates prevention, surveillance, antibiotic stewardship, as well as research and development (R&D) activities across Federal agencies—as recommended by the President’s Council of Advisors on Science and Technology (PCAST) in their September 2014 Report to the President on Combating Antibiotic Resistance.

We know that the Federal response to antimicrobial resistance must be sustained in order to stem the tide that already results in over two million infections and 23,000 deaths each year. In March 2016, the Presidential Advisory Council on Combating Antibiotic-Resistant Bacteria (PACCARB) released a draft of its Initial Assessments of the National Action Plan for Combating Antibiotic-Resistant Bacteria. The report states that “Combating AMR [antimicrobial resistance] requires an adequate resource base to slow down, control, and hopefully reverse the problem. Simply stated, the USG [U.S. Government] must commit sufficient resources to solving the problem with funding continued over a long period of time.” The president’s budget for fiscal year 2017 requests the resources necessary to continue implementation of the Action Plan. IDSA urges the Subcommittee to provide the funding increase requested for the CDC Antibiotic Resistance Solutions Initiative. We ask that the final fiscal year 2017 Labor-HHS-Education Appropriations bill also support the Action Plan activities carried out by the NIH, Biomedical Advanced Research and Development Authority (BARDA) and the Agency for Healthcare Research and Quality (AHRQ).

The Zika virus is another serious public health threat that is of considerable interest to our members. We are witnessing the first widespread transmission of the Zika virus in the Americas. While the mosquito-borne virus generally causes mild illness or no symptoms, it has been linked to birth defects in infants born to mothers who were infected during pregnancy. The Federal Government now has a window of opportunity to help contain the Zika virus in Zika-endemic countries, as well as to enhance State/local prevention and response efforts, increase epidemiology and surveillance capacity, and support R&D for vaccines, diagnostics and therapeutics.

We ask that Congress immediately fund the president's request to combat the Zika virus. As a temporary measure, the Obama administration recently repurposed \$600 million to address the Zika Virus. However, these funds will need to be replaced and are insufficient to provide the necessary response.

CENTERS FOR DISEASE CONTROL AND PREVENTION

*National Center for Emerging and Zoonotic Infectious Diseases (NCEZID)*

The NCEZID leads CDC efforts to address antibiotic resistance as well as helps confront emerging public health threats such as the Zika virus.

We ask that NCEZID be provided the \$629.5 million requested by the Obama administration, including \$200 million for continuation of the Antibiotic Resistance Solutions Initiative, which was initiated with fiscal year 2016 support from this Subcommittee. The requested fiscal year 2017 funding would allow CDC to expand fiscal year 2016 Healthcare-Associated Infections (HAI)/AR prevention efforts from 25 States to up to 50 States, six large cities, and Puerto Rico. CDC plans to award the majority of the fiscal year 2017 increased AR funding to States. The CDC projects that over 5 years the initiative will lead to a 60 percent decline in health-care associated carbapenem-resistant Enterobacteriaceae (CRE), 50 percent reduction in *Clostridium difficile*, 50 percent decline in bloodstream methicillin-resistant *Staphylococcus aureus* (MRSA), 35 percent decline in health-care associated multidrug-resistant *Pseudomonas* spp., and 25 percent reduction in multidrug-resistant *Salmonella* infections, eclipsing the costs of the program.

IDSA also supports the proposed budget of \$21 million for the National Healthcare Safety Network (NHSN) to increase the number of participating healthcare facilities from 19,000 to as many as 20,000 by the end of fiscal year 2017, as well as to increase the number of sites reporting antibiotic use data from 130 in 30 States to 750 in all 50 States. Information provided to the NHSN is critical for evaluating the success of interventions designed to reduce inappropriate antibiotic use and limit the development of resistance.

IDSA recommends that at least \$30 million be allocated for the Advanced Molecular Detection (AMD) initiative in fiscal year 2017. This funding will allow CDC to more rapidly determine where emerging diseases come from, whether microbes are resistant to antibiotics, and how microbes are moving through a population. During the 2014/2015 Ebola outbreak, AMD methods were utilized to determine whether the virus was changing as it spread through different populations, which facilitated appropriate responses.

*Global Health Security*

IDSA supports CDC continued efforts to implement the Global Health Security Agenda, which would accelerate the efforts of the U.S. and partner nations to prevent, detect and slow the spread of infectious diseases across borders. We ask that you provide the Global Health Security initiative with at least the funding requested in the fiscal year 2017 PBR.

CDC plays a central role in responding to new outbreaks such as of Ebola virus disease in 2014/2015 and Zika virus infections in 2015/2016. The spread of Zika virus through South America, Central America, the Caribbean and now into the U.S. is the latest example of the fact that infectious diseases respect no national borders and that CDC must be appropriately funded to maintain readiness to be ahead of new crises. The requested funding will build response and prevention in the U.S. and territories as well as international surveillance and public health capacity. The request expands the Field Epidemiology Training Program, laboratory testing, healthcare provider training, and surveillance and control in countries at highest risk. The requested resources will also accelerate R&D of medical countermeasures, including vaccines and diagnostics, which will be a necessary to combat the Zika virus.

IDSA also urges the Subcommittee to include \$132 million for the CDC Global AIDS Program, which plays a unique role in building sustainability by funding physicians, epidemiologists, and public health advisors in countries hit hardest by the AIDS epidemic.

*National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP)*

Despite a misperception as a disease of the past, tuberculosis now causes more deaths than any other single infectious disease agent, with 9.6 million new illnesses and 1.5 million deaths in 2014. Approximately 480,000 of those cases were caused by multidrug-resistant (MDR) tuberculosis, including 9.7 percent that were extensively drug-resistant (XDR). In December, 2015, the Obama administration released the National Action Plan to Combat Multi-Drug Resistant (MDR) Tuberculosis, a

comprehensive plan to address drug-resistant TB in the U.S. and abroad and accelerate MDR-TB R&D. In order to fund the plan and put the U.S. back on the path towards TB elimination, IDSA recommends a budget of \$243 million in fiscal year 2017 for the CDC Division of Tuberculosis Elimination.

IDSA recommends an increase of \$30 million for NCHHSTP to enhance the response to the viral hepatitis epidemic that has been fueled by injection drug use associated with opioid addiction. Sustained funding of \$157.3 million is also necessary for HIV and STD prevention and surveillance activities.

*National Center for Immunization and Respiratory Diseases*

Immunizations are among the most cost-effective clinical preventive services. However, national adult immunization rates remain low for most routinely recommended vaccines. Each year in the U.S., tens of thousands of adults die from illnesses that are preventable through vaccination. Additionally, vaccine-preventable diseases and related complications result in billions of dollars annually in direct and indirect healthcare costs. IDSA asks that the CDC Immunization Grant Program (Section 317) be funded at least at the fiscal year 2016 level of \$611 million.

IDSA recommends that the Subcommittee provide at least the \$188 million proposed in the PBR for CDC efforts to control influenza. CDC plays a critical role in seasonal and pandemic influenza preparedness and response, including conducting surveillance activities that inform response efforts and providing public communications regarding influenza prevention and treatment.

NATIONAL INSTITUTES OF HEALTH

*National Institute of Allergy and Infectious Diseases (NIAID)*

Within NIH, NIAID should be funded at least at \$4.716 billion as requested in the fiscal year 2017 PBR. Further, we believe that NIAID should be provided an increase that is proportionate to any increase provided to the NIH as a whole. The NIAID plays a leading role in research for new rapid ID diagnostics, vaccines and therapeutics. The January 2015 IDSA report, *Better Tests, Better Care: The Promise of Next Generation Diagnostics* explains that advances in biomedical research over the last few decades have created the potential for increasingly simple, fast and reliable diagnostic tests for infectious diseases. By allowing physicians to quickly distinguish between bacterial and viral infections, better diagnostics can lead to faster and more appropriate treatments for patients, help preserve the utility of our existing drugs, and aid in identifying individuals to participate in clinical trials. Last year, NIAID awarded more than \$11 million in first-year funding for research to develop diagnostics to rapidly detect antibiotic-resistant bacteria. NIAID also recently announced awards of approximately \$5 million for non-traditional alternatives to antibiotics. These efforts as well as research on new antimicrobials and vaccines are set to ramp up with the \$100 million increase made last year. We ask that the Subcommittee continue this work in fiscal year 2017.

The Antibacterial Resistance Leadership Group (ARLG), led by researchers at Duke University and the University of California San Francisco, is an example of extramural research to address AR made possible by NIAID. The ARLG manages a clinical research agenda to increase knowledge of antibacterial resistance. The ARLG has supported early clinical research on new antibacterials as well as on diagnostics that rapidly identify resistant bacteria. Continued operation of the ARLG depends on support from the NIAID.

*Office of AIDS Research*

Federal investments in HIV/AIDS research have led to much longer lives for those living in countries where treatment is available. Continued investment in HIV/AIDS research through NIH is critically important. We urge the Subcommittee to provide at least \$3.45 billion for the Office of AIDS Research (OAR). The level-funding of HIV/AIDS research since 2015 threatens work towards a vaccine as well as discourages individuals from entering the field.

ASSISTANT SECRETARY FOR PREPAREDNESS AND RESPONSE

*Biomedical Advanced Research and Development Authority*

BARDA is a critical initiator of public-private collaborations for antibiotic, diagnostic and vaccine R&D. PCAST has identified BARDA as best positioned to elicit private investments necessary to address antibiotic resistance. IDSA recommends that the Subcommittee provide \$607 million for BARDA in fiscal year 2017. Such funding is necessary to allow BARDA to pursue additional work on antibiotic development while maintaining its strong focus on other medical countermeasures to address biothreats.

We also request that in any final version of fiscal year 2017 appropriations language, you strongly urge BARDA to include TB in their new and emerging infectious disease efforts and invest in the development of new TB diagnostics, drugs and vaccines as part of the CARB initiative and the Emerging Infectious Diseases program at BARDA.

CENTER FOR MEDICARE AND MEDICAID SERVICES

Despite the significant and vital contributions ID physicians make to patient care, research and public health, their work continues to be undervalued. Over 90 percent of the care provided by ID physicians is considered evaluation and management (E&M). Current E&M codes fail to reflect the increasing complexity of E&M work. ID physicians often care for patients with chronic illnesses, including HIV, hepatitis C, and recurrent infections. Such care involves preventing complications and exploring complicated diagnostic and therapeutic pathways. ID physicians also conduct significant post-visit work, such as care coordination, patient counseling and other necessary follow up.

New research is needed to better identify and quantify the inputs that accurately capture the elements of complex medical decisionmaking. Such studies should take into account the evolving healthcare delivery models with growing reliance on team-based care, and should consider patient risk-adjustment as a component to determining complexity. Research activities should include the direct involvement of physicians who primarily provide cognitive care. We urge the Subcommittee to include report language in the fiscal year 2017 funding bill asking that “CMS undertake research necessary to develop new E&M codes and accompanying documentation requirements that more precisely describe the cognitive work in these physician-patient encounters, and that the results of such research be made publicly available no later than 2 years after the passage of this Act.”

AGENCY FOR HEALTHCARE RESEARCH AND QUALITY

IDSAs supports the \$12 million requested in the president’s budget for fiscal year 2017 for research to develop methods and approaches for combating antibiotic resistance and conducting antibiotic stewardship in multiple healthcare settings, with a focus on long-term and ambulatory care settings.

Once again, thank you for the opportunity to submit this statement on behalf of the Nation’s ID physicians and scientists. We rely on strong Federal partnerships to keep Americans healthy and urge you to support these efforts. Please forward any questions to Jonathan Nurse at [jnurse@idsociety.org](mailto:jnurse@idsociety.org).

PREPARED STATEMENT OF THE INSTITUTE OF MAKERS OF EXPLOSIVES

INTEREST OF THE INSTITUTE OF MAKERS OF EXPLOSIVES

The Institute of Makers of Explosives (IME) was founded in 1913 to provide accurate information and comprehensive recommendations concerning the safety and security of the commercial explosives industry. Our mission is to promote safety, and the protection of users, the public and environment, and to encourage the adoption of uniform rules and regulations in the manufacture, transportation, storage, handling, use and disposal of explosive materials used in blasting and other essential operations.

IME represents the U.S. manufacturers and distributors of commercial explosive materials and oxidizers as well as other companies that provide related services. Millions of metric tons of high explosives, blasting agents, and oxidizers are consumed annually in the U.S. Of this, IME member companies produce over 98 percent of the high explosives and a great majority of the blasting agents and oxidizers. These products are used in every State and are distributed worldwide.

IME also publishes industry best practice standards in its Safety Library Publications (SLPs). These standards have been incorporated in Federal and State regulations and are used internationally. In addition, IME publishes a number of guidance documents on various subjects, such as our Safety and Security Guidelines for Ammonium Nitrate<sup>1</sup> and has produced several DVDs, including a DVD and Leader’s Guide for first responders detailing the proper response to transportation incidents

<sup>1</sup>Safety and Security Guidelines for Ammonium Nitrate; IME, International Association of Fire Chiefs (IAFC), International Association of Explosive Engineers (ISEE), and the National Stone, Sand & Gravel Association (NSSGA), (2013).

involving explosive materials.<sup>2</sup> The SLPs are regularly reviewed and updated by the Institute and represent the most current, reliable and expert recommendations on explosives management available to the industry.

In addition, IME has developed a comprehensive quantitative risk assessment (QRA) software program, IMESA<sup>2</sup>FR. The program is a windows-based computer model for assessing the risk from a variety of commercial explosives activities as an alternative to determining safe setback distances based on decades old quantity-distance tables. IMESA<sup>2</sup>FR is a state-of-the-art, tool that, will prove invaluable to the commercial explosives industry in our continuing mission to ensure the health, safety and security of present and future generations of explosive managers, the public and the environment.

#### COMMENTS

The following comments reflect our commitment to worker and public safety.

#### *Occupational Safety & Health Administration (OSHA)*

IME would like to express our thanks to the Committee for including in the fiscal year 2016 conference report the following language:

“The Committee understands that, as a result of Executive Order 13650, Improving Chemical Safety and Security, OSHA is considering options to ensure the safety of ammonium nitrate handling and storage. The Committee also understands that there is no record thus far of an accidental detonation of ammonium nitrate in a situation where a storage facility has been compliant with OSHA’s existing regulations at 29 CFR 1910.109(i). The existing regulations are based on standards of the National Fire Protection Association. Before any new regulations are proposed for the storage of solid ammonium nitrate, the Secretary shall submit a report to the Committees on Appropriations of the House Representatives and the Senate; the Senate Health, Education, Labor and Pensions Committee; and the House Committee on Education and the Workforce that identifies any provisions of OSHA’s current 29 CFR 1910.109(i) regulations under consideration for update and that evaluates the costs and benefits of such changes.”

We regret to inform you that despite this clear direction, OSHA has determined to include the option of regulating AN within the scope of its recently proposed rule-making, “Process Safety Management and Prevention of Major Chemical Accidents (RIN: 1218-AC83).” Consequently, we urge the Subcommittee to retain this language in the committee report for the fiscal year 2017 Labor, Health and Human Services, and Education appropriations bill.

This language was necessitated by section 6(c) of Executive Order 13650, which among other things, instructed OSHA to determine if Process Safety Management (PSM) can and should be expanded to cover AN. IME supports the continued reliance on the § 1910.109(i) standard, and updating this standard to match current industry best practices. The updates include; (1) a prohibition on the use of wooden storage bins, (2) an instruction that fires involving AN should not be fought (our recommendation against fighting AN fires is aimed at offsite first responders, not to trained, in-house fire brigades that respond to emergencies in accordance with facility emergency action plans), and (3) a requirement that facilities prepare written emergency response plans and share these plans with the local emergency responder community. These recommendations are included in the previously mentioned IME Safety & Security Guidelines for Ammonium Nitrate (2013), and are largely consistent with the 2016 National Fire Protection Association (NFPA) 400 standard.

Current § 1910.109(i) rules have proven very effective. Since the standard was promulgated in 1971, there has not been an accidental detonation of AN at any facility compliant with this regulation. A 45-year record of safety is, in our opinion, a good reason to strengthen the regulations, rather than impose the PSM standard on the industry.

Not only do the current regulations work, applying PSM in our opinion, is inappropriate and is not likely to increase safety in proportion with greatly increased compliance efforts that would be required. The PSM program was developed to prevent the release of highly dangerous chemicals like those released in the catastrophic accident in Bhopal, India, and AN is simply not a highly dangerous chemical. The “technical” grade of AN used in the explosives industry has the same chemical composition as the “fertilizer” grade of AN used in the agricultural sector,

<sup>2</sup> Responding to Highway Incidents Involving Commercial Explosives, IME and Department of Transportation (2013).



only the density of the prill is different. AN, in either form, is not a volatile or self-reactive chemical requiring constant diligence in its handling. Rather, it is a stable, relatively benign substance when it is managed properly—and proper management of AN is simple, well understood, and easily accomplished. AN does not pose a threat of an accidental release of energy or fumes unless subjected to substantial and sustained heat (e.g., fire), contamination, or shock from high impact projectiles.

Considering that most IME members are small businesses, as defined by the Small Business Administration, the workload requirements associated with a PSM standard would fall hard on the industry. The PSM standard requires employers to complete 14 hazard assessment actions related to chemical processes, and completing these steps would likely require hiring additional employees or contractors. IME expects that these process hazard analyses (“PHAs”) will conclude that compliance with the current standard at 29 C.F.R. 1910.109(i) will be sufficient to ensure that AN is safely stored and managed. Just to be clear, AN is also subject to a number of other ATF, EPA, DHS, and DOT safety and security regulations. Updating the current regulations will provide clear and actionable steps that can be taken to ensure safety of workers and the public, without the substantial and reoccurring financial burden that compliance with PSM would require.

#### *Mine Safety & Health Administration*

The fiscal year 2017 budget request for MSHA contains two initiatives that we support.

##### *Safety Alliances*

IME is in advanced stages of discussion to formally enter into a voluntary alliance with MSHA to promote safety across the commercial explosives sector. MSHA’s Alliance Program enables organizations, like IME, that are committed to mine safety and health to collaborate with MSHA to prevent injuries and illnesses in the workplace. Through the program, MSHA and its allies work together to reach out to, educate, and lead the Nation’s mine operators and miners in improving and advancing mine safety and health. Alliances are formed by MSHA senior headquarters staff after initial discussions with an organization interested in collaborating with MSHA. While the safety statistics classified under Explosives and Breaking Agents by MSHA are exemplary, IME believes that safety should never take a rest. We look forward to reaching an agreement to work with MSHA to promote safety across the entire commercial explosives industry.

##### *Rules to Live By*

IME recognizes that advancement in technology allows our membership to access training resources on their own schedule and across multiple platforms. In 2015, IME rolled out a new website that will adjust to the users’ device allowing IME members and non-members to access our safety materials wherever and whenever they choose and on the device of their choice. For this reason, we applaud MSHA for innovative initiatives like “Rules to Live By” where the agency is using multiple platforms to promote safety. By putting knowledge and best practices literally at users’ fingertips, both IME and MSHA can add a level of safety by directly empowering employees with the knowledge and understanding they need to stay safe. We are hopeful that the Committee will support MSHA’s continuing efforts to increase workers’ knowledge base of safety through this initiative in fiscal year 2017.

Thank you for your attention to these requests.

[This statement was submitted by John Boling, Director of Government Affairs, Institute of Makers of Explosives.]

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#### PREPARED STATEMENT OF THE INTERSTITIAL CYSTITIS ASSOCIATION

##### SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2017

- 
- Provide \$1 million for the IC Education and Awareness Program and the IC Epidemiology Study at the Centers for Disease Control and Prevention (CDC)
  - Provide \$7.8 billion for CDC
  - Provide \$34.5 billion for the National Institutes of Health (NIH) and Proportional Increases Across all Institutes and Centers
  - Support NIH Research on IC, Including the Multidisciplinary Approach to the Study of Chronic Pelvic Pain (MAPP) Research Network
-

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 improving 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 is 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.

As prescription drug abuse and issues of opioid addiction present challenges for many areas of the country, Congress and Federal agencies are working to craft policies to address emerging problems. When Congress faces a crisis there is a tendency to create blunt and broad solutions as opposed to nuanced and thoughtful solutions. To date, the focus of the government has been on reducing and limiting access to pain medication.

The Food and Drug Administration, CDC, and other Federal agencies have all released guidance or requested community feedback on standards and guidelines for pain management therapies. A comprehensive National Pain Management Strategy was also released in late March.

We need to raise awareness on Capitol Hill that many Americans rely on unobstructed access to pain medications to manage chronic pain. Further, we need to combat perceptions and prejudices that lead to stigma and make it harder for physicians to prescribe needed medications or manage chronic pain with treatment plans. Basically, as new standards are set the chronic pain community should not be painted with the same broad brush and new policies should accommodate patients impacted by chronic pain while also addressing societal issues.

#### IC PUBLIC AWARENESS AND EDUCATION THROUGH CDC

*ICA recommends a specific appropriation of \$1 million in fiscal year 2017 for the CDC IC Program. This will allow CDC to fund the Education and Awareness Program, per ongoing congressional intent, as well as the IC Epidemiology Study.*

In December 2014, CDC switched the focus of the IC program from education and awareness to an epidemiology study. The IC community is concerned that eliminating education and awareness activities is detrimental to patients and their families. The CDC IC Education and Awareness Program is the only Federal program dedicated 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. ICA urges Congress to provide funding for IC education and awareness in fiscal year 2017.

The IC Education and Awareness 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 provided 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.

#### IC RESEARCH THROUGH THE NATIONAL INSTITUTES OF HEALTH

*ICA recommends a funding level of \$34.5 billion for NIH in fiscal year 2017. ICA also recommends continued support for IC research including the MAPP Study administered by NIDDK.*

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, including epidemiology. The MAPP Study has expanded in its second phase to include cross-cutting researchers and researchers are currently identifying different phenotypes of the disease. Phenotype information will 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 Integrative Health (NCCIH). Additionally, the NIH investigator-initiated research portfolio continues to be an important mechanism for IC researchers to create new avenues for interdisciplinary research.

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.]

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#### PREPARED STATEMENT OF THE LEADERS ENGAGED ON ALZHEIMER'S DISEASE

Dear Chairmen Cochran and Blunt and Ranking Members Mikulski and Murray: We thank Congress for recognizing and responding decisively in fiscal year 2016 to the challenges of Alzheimer's disease and related dementias (including vascular, Lewy body and frontotemporal dementia). We applaud your determination to seize the enormous opportunities for America if we invest in the science, care and support required to overcome these challenges and for recognizing the consequences if we fail to act. Doing so is a national priority, an economic and budgetary necessity, a health and moral imperative.

We urge that you build upon recent developments and include the resources necessary to support dementia and aging research within the fiscal year 2017 budget. Specifically, we urge you to move with all alacrity to commit at least 1 percent of the cost of treating persons living with dementia to research supported by the National Institutes of Health (NIH) and to move us substantially closer to this goal in fiscal year 2017. Today, this amount would be approximately \$2 billion, the minimum annual amount of public research funding leading dementia researchers have recommended must be committed to maximize the likelihood of achieving the Nation's goal of preventing and effectively treating dementia by 2025.

As you assemble the fiscal year 2017 Labor, Health and Human Services, Education and Related Agencies Appropriations Act, we urge that you include:

—A minimum increase of \$400 million in Alzheimer's disease and related dementias research at the NIH over the fiscal year 2016 enacted level. Such an increase would result in an NIH-wide dementia research budget of about \$1.336

billion in fiscal year 2017. If similar commitments are made over the following 2 years, we will meet and exceed the \$2 billion target by fiscal year 2019.

- A minimum increase of \$500 million over the fiscal year 2016 enacted level for aging research across the NIH, in addition to the funding for dementia. This increase will ensure that the NIH and NIA have the resources they need, not only to address dementia, but also the many other age-related chronic diseases.
- A minimum increase of \$25 million in the budgets for dementia care and services programs over the fiscal year 2016 enacted levels at the Administration for Community Living, Health Resources and Services Administration, the Centers for Disease Control and Prevention, and the Department of Justice.

There are few more compelling or complex issues to confront our aging society than dementia, now and over the coming decades. These conditions impose enormous costs to our Nation's health and prosperity, costs that are skyrocketing.<sup>1</sup> Due to NIA's Health and Retirement Study (HRS), we now know that the healthcare costs of caring for people with dementia in the United States are comparable to, if not greater than, those for heart disease and cancer.<sup>2</sup> A recent analysis of HRS data revealed that, in the last 5 years of life, total healthcare spending for people with dementia was more than a quarter-million dollars per person, some 57 percent greater than costs associated with death from other diseases, including cancer and heart disease.<sup>3</sup> Today, more than five million Americans<sup>4</sup> have dementia at an annual cost to our economy exceeding \$200 billion.<sup>5</sup> Alzheimer's disease contributes to the deaths of approximately 500,000 Americans each year, making it the third leading cause of death in the United States.<sup>6</sup> If the current trajectory persists, at least 13 million Americans will have dementia in 2050 and total costs of care are projected to exceed (inflation adjusted 2014 dollars) \$1 trillion annually.<sup>7</sup> The Federal Government, through Medicare and Medicaid payments, shoulders an estimated 70 percent of all such direct care costs.

The choice before our Nation is not whether to pay for dementia—we are paying dearly. The question is whether we will emulate the investment strategies that have led to remarkable progress in fighting other leading causes of death such as cancer, HIV/AIDS and heart disease and achieve similar breakthroughs, or spend trillions to care for tens of millions of people. A modernized and more robust research portfolio can help America prevent this catastrophe and move us closer to achieving our national goal of preventing and effectively treating dementia by 2025.<sup>8</sup>

Due to leadership and direction from Congress, HHS continues to increase prioritization of Alzheimer's disease and related dementias. The publicly appointed members of the Advisory Council on Alzheimer's Research, Care, and Services have generated their most thoughtful and catalytic recommendations for the annual update to the National Plan to Address Alzheimer's Disease. There is heightened focus on improving care for people with advanced dementia.<sup>9</sup> The Food and Drug Administration is encouraging new research avenues and clarifying regulatory approval pathways. Your committee and NIH have moved mountains to create additional resources, public-private partnerships, and a culture of urgency. Across the NIH, institutes are supporting promising Alzheimer's disease and related dementias research to: understand genetic risk factors;<sup>10</sup> address health disparities among women,<sup>11</sup> African Americans,<sup>12</sup> Hispanics,<sup>13</sup> and persons with intellectual disabilities;<sup>14</sup> and pursue cutting-edge trials aimed at preventing or substantially slowing disease progression by administering treatments much earlier in the disease process.<sup>15</sup> In fiscal

<sup>1</sup> <http://www.nejm.org/doi/full/10.1056/NEJMsa1204629>.

<sup>2</sup> <http://www.nejm.org/doi/full/10.1056/NEJMsa1204629>.

<sup>3</sup> <http://annals.org/article.aspx?articleid=2466364#>.

<sup>4</sup> <http://aspe.hhs.gov/daltcp/napa/NatPlan2014.pdf>.

<sup>5</sup> <http://www.nejm.org/doi/full/10.1056/NEJMsa1204629>.

<sup>6</sup> <http://www.neurology.org/content/early/2014/03/05/WNL.0000000000000240>.

<sup>7</sup> <http://www.alz.org/trajectory>.

<sup>8</sup> <http://aspe.hhs.gov/daltcp/napa/NatPlan.pdf>.

<sup>9</sup> <http://aspe.hhs.gov/daltcp/napa/012615/Mtg15-Slides4.pdf>.

<sup>10</sup> <http://www.nia.nih.gov/alzheimers/publication/2012-2013-alzheimers-disease-progress-report/genetics-alzheimers-disease>.

<sup>11</sup> [http://www.alz.org/downloads/facts\\_figures\\_2014.pdf](http://www.alz.org/downloads/facts_figures_2014.pdf).

<sup>12</sup> [http://www.usagainstalzheimers.org/sites/default/files/USA2\\_AAN\\_CostsReport.pdf](http://www.usagainstalzheimers.org/sites/default/files/USA2_AAN_CostsReport.pdf).

<sup>13</sup> <http://www.nhcoa.org/wp-content/uploads/2013/05/NHCOA-Alzheimers-Executive-Summary.pdf> and [http://www.usagainstalzheimers.org/sites/all/themes/alzheimers\\_networks/files/LatinosAgainstAlzheimers\\_Issue\\_Brief.pdf](http://www.usagainstalzheimers.org/sites/all/themes/alzheimers_networks/files/LatinosAgainstAlzheimers_Issue_Brief.pdf).

<sup>14</sup> [http://aadmd.org/sites/default/files/NTG\\_Thinker\\_Report.pdf](http://aadmd.org/sites/default/files/NTG_Thinker_Report.pdf).

<sup>15</sup> <http://www.nia.nih.gov/alzheimers/publication/2012-2013-alzheimers-disease-progress-report/advancing-discovery-alzheimers#priorities>.

year 2017, the NIA plans to increase its research focus on dementia epidemiology, health disparities, and caregiving.<sup>16</sup>

As urgently as resources are needed to enable scientific breakthroughs, millions of Americans already living with dementia deserve equal commitments to programs to protect and enhance their quality of life. New funding is essential to sustain core Older Americans Act services and develop and disseminate evidence-based services instrumental to achieving the national plan's goals to enhance care quality, efficiency and expand supports.<sup>17</sup> These programs provide needed respite to family caregivers and training in best practices to meet the many challenges of providing care to persons with dementia. Until an effective prevention, disease-modifying treatment or cure comes to market, families rely on these programs to protect their own well-being while helping their loved ones remain independent, in the community while delaying placement in institutional settings.

Thank you for considering our views and for your commitment to overcoming Alzheimer's disease and related dementias. Please contact Ian Kremer, executive director of Leaders Engaged on Alzheimer's Disease (the LEAD Coalition),<sup>18</sup> [ikremer@leadcoalition.org](mailto:ikremer@leadcoalition.org), with questions or for additional information.

Sincerely,

Abe's Garden	Beating Alzheimer's by Embracing Science
ACT on Alzheimer's	Benjamin Rose Institute on Aging
ActivistsAgainstAlzheimer's	Biogen Idec
African American Network Against Alzheimer's	Soo Borson MD (University of Washington Schools of Medicine and Nursing*)
Ageless Alliance	James Brewer, M.D., Ph.D. (UC San Diego and Alzheimer's Disease Cooperative Study*)
AgeneBio	BrightFocus Alzheimer's Disease Research
Aging and Memory Disorder Programs, Howard University	Christopher M. Callahan, MD (Indiana University Center for Aging Research*)
Allergan	Caregiver Action Network
Alliance for Aging Research	CaringKind
Alliance for Patient Access	Center for Alzheimer Research and Treatment, Harvard Medical School
Alzheimer's & Dementia Alliance of Wisconsin	Center for BrainHealth at The University of Texas at Dallas
Alzheimer's Drug Discovery Foundation	Center for Elder Care and Advanced Illness, Altarum Institute
Alzheimer's Greater Los Angeles	Sandra Bond Chapman, PhD (Center for BrainHealth at The University of Texas at Dallas*)
Alzheimers North Carolina	ClergyAgainstAlzheimer's
Alzheimer's Orange County	Cleveland Clinic Foundation
Alzheimer's Tennessee	CorTechs Labs
AMDA—The Society for Post-Acute and Long-Term Care Medicine	Jeffrey Cummings, MD, ScD (Cleveland Clinic Lou Ruvo Center for Brain Health*)
American Academy of Neurology	Cure Alzheimer's Fund
American Association for Long Term Care Nursing	CurePSP
American Association of Nurse Assessment Coordination	Darrell K. Royal Fund for Alzheimer's Research
American Federation for Aging Research (AFAR)	Dementia Friendly America
American Geriatrics Society	
ARGENTUM Expanding Senior Living	
Association of Population Centers	
Laura D. Baker, PhD (Wake Forest School of Medicine*)	
Banner Alzheimer's Institute	
David M. Bass, PhD (Benjamin Rose Institute on Aging*)	

<sup>16</sup> <https://www.nia.nih.gov/about/budget/2016/fiscal-year-2017-budget>.

<sup>17</sup> <http://aspe.hhs.gov/daltcp/napa/NatlPlan2014.pdf>.

<sup>18</sup> <http://www.leadcoalition.org> Leaders Engaged on Alzheimer's Disease (the LEAD Coalition) is a diverse national coalition of member organizations including patient advocacy and voluntary health non-profits, philanthropies and foundations, trade and professional associations, academic research and clinical institutions, and home and residential care providers, and biotechnology and pharmaceutical companies. The LEAD Coalition works collaboratively to focus the Nation's strategic attention on Alzheimer's disease and related dementias—including vascular, Lewy body or frontotemporal dementia—and to accelerate transformational progress in detection and diagnosis, care and support, and research leading to prevention, effective treatment and eventual cure. One or more participants may have a financial interest in the subjects addressed.

Department of Neurology, Washington University School of Medicine  
 Rachelle S. Doody, MD, PhD (Baylor College of Medicine\*)  
 Gary Epstein-Lubow, MD (Alpert Medical School of Brown University\*)  
 Fujirebio  
 Sam Gandy, MD, PhD (Icahn School of Medicine at Mount Sinai\*)  
 Joseph E. Gaugler, Ph.D. (School of Nursing, Center on Aging, University of Minnesota\*)  
 General Electric Healthcare  
 Daniel R. George, Ph.D, M.Sc (Penn State College of Medicine\*)  
 Georgetown University Medical Center Memory Disorders Program  
 Gerontological Society of America  
 Laura N. Gitlin, PhD (Johns Hopkins School of Medicine\*)  
 Global Coalition on Aging  
 Lisa P. Gwyther, MSW, LCSW (Duke University Medical Center\*)  
 David Holtzman, MD (Washington University School of Medicine, Department of Neurology\*)  
 Home Instead Senior Care  
 Huffington Center on Aging  
 Indiana University Center for Aging Research  
 Janssen R&D  
 Kathy Jedrziewski, PhD (University of Pennsylvania\*)  
 Katherine S. Judge, PhD (Cleveland State University\*)  
 Keep Memory Alive  
 Diana R Kerwin, MD (Texas Alzheimer's and Memory Disorders\*)  
 Walter A. Kukull, PhD (School of Public Health, University of Washington\*)  
 LatinosAgainstAlzheimer's  
 Latino Alzheimer's and Memory Disorders Alliance  
 Lewy Body Dementia Association  
 LuMind Research Down Syndrome Foundation  
 Lundbeck  
 Mary Mittelman, DrPH (New York University Medical Center\*)  
 David G. Morgan, PhD (USF Health Byrd Alzheimer's Institute\*)  
 Mount Sinai Center for Cognitive Health  
 National Alliance for Caregiving  
 National Asian Pacific Center on Aging  
 National Association of Nutrition and Aging Services Programs  
 National Certification Council for Activity Professionals  
 National Committee to Preserve Social Security and Medicare  
 National Council for Behavioral Health  
 National Down Syndrome Society  
 National Hispanic Council On Aging (NHCOA)  
 National Task Group on Intellectual Disabilities and Dementia Practices  
 Neurotechnology Industry Organization  
 New York Academy of Sciences  
 NFL Neurological Center  
 NYU Alzheimer's Disease Center  
 NYU Langone Center on Cognitive Neurology  
 Thomas O. Obisesan, MD, MPH (Howard University Hospital\*)  
 OWL-The Voice of Women 40 + Patient Engagement Program, a subsidiary of CurePSP  
 Pat Summitt Foundation  
 Piramal Imaging S.A.  
 Planetree  
 Population Association of America  
 Prevent Alzheimer's Disease 2020  
 Eric Reiman, MD (Banner Alzheimer's Institute\*)  
 Research!America  
 ResearchersAgainstAlzheimer's  
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 Second Wind Dreams, Inc./Virtual Dementia Tour  
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 Rudolph Tanzi, PhD (Department of Neurology, MGH/Harvard Medical School\*)  
 The Association for Frontotemporal Degeneration  
 The Evangelical Lutheran Good Samaritan Society  
 The Youth Movement Against Alzheimer's  
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 R. Scott Turner, MD, PhD (Georgetown University Memory Disorders Program\*)  
 UsAgainstAlzheimer's, LEAD Coalition co-convener  
 USF Health Byrd Alzheimer's Institute  
 Volunteers of America, LEAD Coalition co-convener  
 Nancy Wilson, MA LCSW (Baylor College of Medicine\*)  
 WomenAgainstAlzheimer's

\*Affiliations of individual researchers are for identification purposes only and do not necessarily represent the endorsement of the affiliated institution.

PREPARED STATEMENT OF THE LOWER ELWHA KLALLAM TRIBE

The Lower Elwha Klallam Tribe supports the President's fiscal year 2017 budget proposal for a "Department-wide Tribal Health and Well-Being Coordinated Budget

for the Department of Health and Human Services". The Affordable Care Act mandated the integration of medical and mental health disciplines at parity and is supported by the fiscal year 2017 proposed budget. This plan would be inclusive of the Substance Abuse and Mental Health Services Administration (SAMHSA), Administration for Children and Families (ACF), Health Resources and Services Administration (HRSA), Centers for Disease Control and Prevention (CDC) and the Indian Health Service (IHS appropriations not included in this Appropriations Subcommittee).

The Lower Elwha Klallam Tribal Health Department operates a multi-disciplinary, ambulatory health department with 9 programs and 81 personnel. We provide services to Lower Elwha Klallam Tribal members, other federally recognized American Indians/Alaskan Natives and people residing in the greater Clallam County area. As a Tribally operated facility, we provide direct patient care services that include medical, dental, mental health, substance abuse, community health, prevention health, integrative services, purchased/referred care and administration. We submit the following appropriations requests:

#### SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION

##### *\$30 million—Tribal Behavioral Health Grants*

We have a critical need to address the mental health and chemical dependency epidemic in our community. The proposed funding of \$30 million, as part of the Generation Indigenous initiative, in the Mental Health (\$15 million) and Substance Abuse Prevention (\$15 million) appropriations line items is appreciated but will not have a real impact on the unmet need that increases daily in Indian Country. For the Lower Elwha youth, substance abuse and suicide prevention efforts, we find that there is no budget equity and performance measures value when Tribes have to compete with each other for critically needed funding to address the widespread status of substance abuse and mental health needs of our citizens. Tribal communities have a historical and escalating need that is uncommon to the rest of the population and requires additional resources to effectively treat the overwhelming need. The Lower Elwha Klallam Tribe continues to see the effects of heroin and opioid abuse in all ages at alarming, epidemic rates within Clallam County.

The Lower Elwha Klallam Tribe subsidizes 3rd party funds in attempts to adequately address the treatment and long term needs of our patient population with addiction and behavioral disorders. We realize the need for trauma informed, long-term, American Indian/Alaskan Native treatment facilities to assist those caught in the cycle of addictions. Instead of ignoring the rising heroine and opioid epidemic, we are in support of a budget that will allow the Tribes to facilitate culturally relevant, trauma informed treatment services to our patients so that they can continue their journey of wellness far surpassing the current 30–45 day in-patient treatment process that public insurance does not adequately authorize or reimburse.

In the United States, we do not approach the treatment of other chronic diseases like cancer in this fashion. The Tribe is requesting that the payment and reimbursement model for chemical dependency in-patient and mental health services be critically scrutinized. We urge Congress to fund the integration plan to financially support our efforts in developing a Native best practice treatment and payment system utilizing trauma informed care targeted at our families and communities. There are additional funding areas and payment models that need to be addressed and worked on for the overall health of American Indians and Alaska Native citizens residing throughout the United States.

#### ADMINISTRATION FOR CHILDREN AND FAMILIES

##### *+\$20 Million—Increasing Tribal Access to Promoting Safe and Stable Families (PSSF)*

The fiscal year 2017 budget requests a \$20 million increase in the discretionary PSSF appropriations from the fiscal year 2016 enacted level to increase the capacity of Tribes to administer child welfare services. American Indian and Alaska Native children are disproportionately represented at two times their population in State child welfare systems nationally. Among individual State foster care systems they are overrepresented at as much as 10 times their population rate. This proposal aims to address this disproportionality by investing in Tribal child welfare systems and, in turn, providing culturally appropriate services to Tribal families.

Many Tribes lack infrastructure and stable funding. The Fostering Connections to Success and Increasing Adoptions Act of 2008 allowed Tribes to directly administer Title IV–E programs, but many Tribes need to build their child welfare programs before they are able to consider developing a program meeting the requirements of Title IV–E. With this increase, total funding reserved for formula grants

for Tribes would be \$31 million, including \$22 million discretionary and \$9 million mandatory. Also, the fiscal year 2017 budget includes a proposal to improve access to PSSF funding for Tribal grantees by eliminating the current statutory threshold of \$10,000 to receive a grant. It will be replaced with a minimum grant award of \$10,000 for all Tribes with approved plans, combined with a hold harmless provision that guarantees that currently funded Tribes receive not less than their current award, so as not to unintentionally undermine the capacity of currently funded grantees. This proposal allows access to critically important funding for preventive services for all Tribes that wish to participate in the program and assures greater stability and predictability in funding year-to-year.

+ \$2.75 Million—*Tribal Court Improvement—Tribal Court Improvement Grants Assist Tribal Courts to:*

- Conduct assessments of how Tribal courts handle child welfare proceedings
  - Make improvements to court processes to provide for the safety, permanency, and well-being of children as set forth in the Adoption and Safe Families Act (ASFA) and increase and improve engagement of the entire family in court processes relating to child welfare, family preservation, family reunification, and adoption
  - Ensure children’s safety, permanency, and well-being needs are met in a timely and complete manner (through better collection and analysis of data)
  - Provide training for judges, attorneys, and legal personnel in child welfare cases
- This increase will allow ACF to fund a total of 25 Tribal court improvement grants. The expansion of the Tribal Court Improvement Program would continue to strengthen the Tribal court’s capacity to exercise jurisdiction in Indian Child Welfare Act cases and to adjudicate child welfare cases in Tribal court.

#### CLOSING

There are additional funding areas and payment models that need to be addressed and worked on for the overall health of American Indians and Alaska Native citizens residing throughout the United States. The support of the Congress and the Administration with these efforts is greatly appreciated.

[This statement was submitted by Hon. Frances G. Charles, Chairwoman, Lower Elwha Klallam Tribe.]

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#### PREPARED STATEMENT OF MAMA’S KITCHEN

We are pleased to submit this testimony to the Members of this Subcommittee on the urgency of continuing to support the Ryan White Program through the Appropriations process and increasing funding for the domestic HIV/AIDS portfolio in fiscal year 2017. This support and funding will be decisive for achieving the goals of the National HIV/AIDS Strategy (NHAS) 2020, the AIDS Free Generation and halting the devastating effects of the HIV Treatment Cascade.

Mama’s Kitchen is part of a nationwide coalition, the Food is Medicine Coalition, of over 80 food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PWH) and other chronic illnesses. In our service area, we provide 450,000 medically tailored, home delivered meals annually. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

#### *Why Food and Nutrition Services (FNS) Matter for PWH*

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient’s overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS).



MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PWH at any stage of their illness. For those who are most mobile, there are congregate meals, walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective core medical service in the Ryan White Program. These services play a critical role in ensuring that PWH enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

#### *FNS as a Care Completion Service Unique to Ryan White*

Social and economic interventions, most often in the form of care completion service like food and nutrition services, are fundamental to making healthcare work for PWH. Support services for PWH are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PWH are poised to remain connected to care and treatment.

#### *Access to FNS and the Triple Aim*

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PWH.

#### *Better Health Outcomes*

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines.<sup>1</sup> Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections<sup>2</sup> and the resulting decreases in their healthcare costs. Compare these outcomes to PWH who are food insecure, who have:

- Lower CD4 counts & lower likelihoods of having undetectable viral loads<sup>3</sup>
- More ER visits<sup>4</sup> & increased morbidity and mortality<sup>5</sup>
- More missed primary care appointments & reduced use of antiretroviral therapy.<sup>6</sup>

#### *Lower Healthcare Costs*

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PWH. A recent study comparing participants in a medically-tailored FNS program vs. a control group within a local managed care organization found that average monthly healthcare costs for PWH fell 80 percent in first 3 months after receiving FNS.<sup>7</sup> If hospitalized, nourished clients' costs were 30 percent lower, their hospital length of stay was cut by 37 percent and they were 20 percent more likely to be able to be discharged to their homes rather than a more expensive institution.<sup>8</sup>

<sup>1</sup> Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at [https://www.health.ny.gov/diseases/aids/ending\\_the\\_epidemic/docs/key\\_resources/housing\\_and\\_supportive\\_services/chain\\_factsheet3.pdf](https://www.health.ny.gov/diseases/aids/ending_the_epidemic/docs/key_resources/housing_and_supportive_services/chain_factsheet3.pdf).

<sup>2</sup> Academy of Nutrition and Dietetics (formerly American Dietetic Association). HIV/AIDS Nutrition Evidence Analysis Project at [http://www.adaevidencelibrary.com/conclusion.cfm?conclusion\\_statement\\_id=250707](http://www.adaevidencelibrary.com/conclusion.cfm?conclusion_statement_id=250707) Accessed 29 July 2012.

<sup>3</sup> Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011); Singe AW, Weiser SD McCoy, SI. Does Food Insecurity Undermine Adherence to Antiretroviral Therapy? A Systematic Review. *AIDS Behav* (2015) 19:1510–1526.

<sup>4</sup> *Ibid.*

<sup>5</sup> Anema A, Chan K, Yip B, Weiser S, Montaner JSG, Hogg RS. Impact of food insecurity on survival among HIV-positive injection drug users receiving antiretroviral therapy in a Canadian cohort. 141st APHA Annual Meeting, Nov. 2–6, 2013. Boston, MA. Abstract #: 290277.

<sup>6</sup> Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).

<sup>7</sup> Gurvey J, Rand K, Daugherty S, Dinger C, Schmeling J, Laverty N. Examining Health Care Costs Among MANNA Clients and a Comparison Group. *J Prim Care Community Health*. (2013) 4:311–317.

<sup>8</sup> *Ibid.*

Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

#### *Improved Patient Satisfaction*

Studies show nutrition counseling improves quality of life.<sup>9</sup> Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

#### *FNS and the National HIV/AIDS Strategy (NHAS)*

Access to FNS for PWH is fundamental to fulfilling the goals of the NHAS.

- NHAS Goal: Reducing new HIV infections: PWH who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96 percent of the time,<sup>10</sup> thus, FNS is key to prevention.<sup>11</sup>
- NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV: PWH who receive effective FNS are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines.<sup>12</sup>
- NHAS Goal: Reducing HIV-related disparities and health inequities: By providing FNS to PWH who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities.<sup>13</sup>
- NI-IAS Goal: Achieving a more coordinated national response to the HIV epidemic: There remains a tremendous variation by State in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White HIV Program all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including Ryan White and the ACA.

#### *Conclusion*

We are deeply aware of the difficult decisions that face the members of the Subcommittee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PWH live healthy and productive lives, produces better overall health outcomes and reduces healthcare costs.

Along with our colleagues, we appreciate the opportunity to offer this testimony regarding the fiscal year 2017 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you.

[This statement was submitted by Alberto Cortés, Executive Director, Mama's Kitchen.]

<sup>9</sup>Rabeneck L, Palmer A, Knowles JB, Seidehamel RJ, Harris CL, Merkel KL, Risser JMH, Akrabawi SS. A randomized controlled trial evaluating nutrition counseling with or without oral supplementation in malnourished HIV-infected patients. *J Am Diet Assoc.* (1998) 98: 434–438; Schwenk A, Steuck H, Kremer G. Oral supplements as adjunctive treatment to nutritional counseling in malnourished HIV-infected patients: randomized controlled trial. *Clinical Nutrition* (1999) 18(6): 371–374.

<sup>10</sup>M. S. Cohen et al., Prevention of HIV-1 Infection with Early Antiretroviral Therapy. *N. Engl. J. Med.* (2011) 365, 493–505. HPTN 052.

<sup>11</sup>Palar K, Laraia B, Tsai A, Weiser SD Food insecurity is associated with sexually transmitted infections and HIV serostatus among low income adults in the National Health and Nutrition Examination Survey (NHANES) (1999–2010). Presented at the American Public Health Association 141st Annual Meeting, Boston, MA, November 5, 2013.

<sup>12</sup>Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014.

<sup>13</sup>Available at Weiser SD, Frongillo EA, Ragland K, Hogg RS, Riley ED, Bangsberg DR. Food insecurity is associated with incomplete HIV RNA suppression among homeless and marginally housed HIV-infected individuals in San Francisco. *J Gen Intern Med.* (2009) 24(1):14–20.

## PREPARED STATEMENT OF MANNA

We are pleased to submit this testimony to the Members of this Subcommittee on the urgency of continuing to support the Ryan White Program through the Appropriations process and increasing funding for the domestic HIV/AIDS portfolio in fiscal year 2017. This support and funding will be decisive for achieving the goals of the National HIV/AIDS Strategy (NHAS) 2020, the AIDS Free Generation and halting the devastating effects of the HIV Treatment Cascade.

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<sup>2</sup>Academy of Nutrition and Dietetics (formerly American Dietetic Association). HIV/AIDS Nutrition Evidence Analysis Project at [http://www.adaevidencelibrary.com/conclusion.cfm?conclusion\\_statement\\_id=250707](http://www.adaevidencelibrary.com/conclusion.cfm?conclusion_statement_id=250707) Accessed 29 July 2012.

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<sup>10</sup>M. S. Cohen et al., Prevention of HIV-1 Infection with Early Antiretroviral Therapy. *N. Engl. J. Med.*(2011) 365, 493–505 . HPTN 052.

<sup>11</sup>Palar K, Laraia B, Tsai A, Weiser SD Food insecurity is associated with sexually transmitted infections and HIV serostatus among low income adults in the National Health and Nutrition Examination Survey (NHANES) (1999–2010). Presented at the American Public Health Association 141st Annual Meeting, Boston, MA, November 5, 2013.

<sup>12</sup>Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014.

- NHAS Goal: Reducing HIV-related disparities and health inequities: By providing FNS to PWH who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities.<sup>13</sup>
- NHAS Goal: Achieving a more coordinated national response to the HIV epidemic: There remains a tremendous variation by State in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White HIV Program all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including Ryan White and the ACA.

*Conclusion*

We are deeply aware of the difficult decisions that face the members of the Subcommittee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PWH live healthy and productive lives, produces better overall health outcomes and reduces healthcare costs.

Along with our colleagues, we appreciate the opportunity to offer this testimony regarding the fiscal year 2017 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you.

[This statement was submitted by Sue Daugherty, RD, LDN, Chief Executive Officer, Metropolitan Area Neighborhood Nutrition Alliance.]

PREPARED STATEMENT OF THE MARCH OF DIMES  
 MARCH OF DIMES: FISCAL YEAR 2017 FEDERAL FUNDING PRIORITIES  
 (Dollars in thousands)

Program	Fiscal year 2017 request
National Institutes of Health (total) .....	34,500,000
National Institute of Child Health and Development .....	1,441,000
National Human Genome Research Institute .....	558,000
National Institute on Minority Health and Disparities .....	302,000
National Institute of Environmental Health Sciences .....	732,200
National Children's Study Alternative .....	165,000
Centers for Disease Control and Prevention (total) .....	7,800,000
National Center for Birth Defects and Developmental Disabilities .....	143,068
Birth Defects Research and Surveillance .....	20,045
Folic Acid Campaign .....	3,323
Section 317 Immunization Program .....	650,000
Polio Eradication .....	174,000
Safe Motherhood Initiative .....	46,000
Preterm Birth .....	2,000
National Center for Health Statistics .....	170,000
Health Resources and Services Administration (total) .....	7,480,000
Title V Maternal and Child Health Block Grant .....	650,000
SPRANS- Infant Mortality and Preterm Birth .....	3,000
Heritable Disorders .....	18,000
Universal Newborn Hearing .....	18,660
Healthy Start .....	103,500

<sup>13</sup> Available at Weiser SD, Frongillo EA, Ragland K, Hogg RS, Riley ED, Bangsberg DR. Food insecurity is associated with incomplete HIV RNA suppression among homeless and marginally housed HIV-infected individuals in San Francisco. *J Gen Intern Med.* (2009) 24(1):14–20.

## MARCH OF DIMES: FISCAL YEAR 2017 FEDERAL FUNDING PRIORITIES—Continued

(Dollars in thousands)

Program	Fiscal year 2017 request
Children's Hospitals Graduate Medical Education .....	300,000
Agency for Healthcare Research and Quality (total) .....	364,000

## ABOUT THE MARCH OF DIMES

The March of Dimes, a unique collaboration of scientists, clinicians, parents, members of the business community, and other volunteers representing every State, the District of Columbia and Puerto Rico, appreciates this opportunity to submit testimony for the record on fiscal year 2017 appropriations for the Department of Health and Human Services (HHS). For over 75 years, the March of Dimes has promoted maternal and child health through activities such as funding research and field trials for the eradication of polio, promoting newborn screening, and educating medical professionals and the public about best practices for healthy pregnancy. Today, the March of Dimes works to improve the health of women, infants and children by preventing birth defects, premature birth, and infant mortality through research, community services, education, and advocacy. The March of Dimes recommends the following funding levels for programs and initiatives that are essential investments in maternal and child health.

## ZIKA VIRUS

Our Nation faces an unprecedented challenge in the form of a mosquito-borne virus that causes devastating birth defects. It is imperative that Congress provide resources immediately to address the full span of activities necessary to track, treat, and ultimately prevent Zika infections. This includes a wide range of activities throughout HHS agencies, including vaccine research at the National Institutes of Health (NIH), vector control, diagnostic testing, public education, and birth defects surveillance at the Centers for Disease Control and Prevention (CDC), and much more. Only a robust, multi-faceted response will prevent the virus from gaining a foothold in the United States. The March of Dimes calls upon the Committee to do everything in its power to protect pregnant women and their infants from this deadly virus.

*Eunice Kennedy Shriver National Institute of Child Health and Human Development*

The March of Dimes recommends at least \$34.5 billion for NIH and \$1.441 billion for the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) in fiscal year 2017. This funding will allow NICHD to sustain vital research on preterm birth and related issues through extramural grants, Maternal-Fetal Medicine Units, the Neonatal Research Network and the intramural research program. This funding would also allow 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 how to treat or prevent them. NIH's work in transdisciplinary research is complemented by the March of Dimes commitment to invest \$75 million over 10 years in transdisciplinary research to unravel the causes of preterm birth.

*Title V Maternal and Child Health Block Grant Program*

The March of Dimes recommends funding the Title V Maternal and Child Health Block Grant Program at \$650 million. More than half of pregnant women and more than a third of infants and children benefit from maternal and child health block grant programs.

The March of Dimes also recommends Congress specify that \$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 the Collaborative Improvement & Inno-

vation Network (CoIN) to Reduce Infant Mortality, which assists States focusing on a range of interventions proven to reduce preterm birth and improve maternal and child health.

#### *Safe Motherhood Initiative*

Preterm birth is a serious health problem that costs the United States more than \$26 billion annually. Alarming, one in 10 infants in the United States is born preterm. Prematurity is the leading cause of neonatal mortality and the second leading cause of infant mortality.

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 mission of the Safe Motherhood Initiative at the Centers for Disease Control and Prevention’s (CDC) National Center for Chronic Disease Prevention and Health Promotion is to promote optimal reproductive and infant health. The March of Dimes recommends funding of \$46 million for the Safe Motherhood program and strongly urges maintenance of the preterm birth sub-line at \$2 million, as reauthorized in the PREEMIE Reauthorization Act, to retain and buttress current preterm birth research within the CDC.

#### *National Center on Birth Defects and Developmental Disabilities*

According to the CDC, an estimated 120,000 infants in the United States are born with major structural birth defects each year. While birth defects are a leading cause of infant mortality, the causes of more than 70 percent of birth defects remain 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.

The National Center on Birth Defects and Developmental Disabilities (NCBDDD) is the lead Federal agency tasked with supporting vital surveillance, research, and prevention activities aimed at birth defects and developmental disabilities. Given the center’s expertise, NCBDDD staff are playing a vital role in the international and domestic response to the Zika virus. Currently, about 12 percent of the NCBDDD’s staff are deployed to the CDC’s Emergency Operations Center, while many other staff are providing technical assistance while maintaining ongoing NCBDDD activities.

For fiscal year 2017, the March of Dimes recommends funding of \$143.068 million for the NCBDDD. We also request at least \$20.045 million to support birth defects research and surveillance, and \$3.323 million to support folic acid education.

Birth defects research and surveillance activities have been severely curtailed due to funding cuts, slowing the pace of research identifying the causes of birth defects, and decreasing the ability to track birth defects. Specifically, budgetary constraints have led to the elimination of two Centers for Birth Defects Research and Prevention. Expertise from the previously funded Centers in Texas and Utah (including knowledge regarding 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 2016, with a 40 percent (800,000) reduction in the number of live births monitored by States. This reduction in surveillance, study, and scope will mean fewer treatments, fewer reductions in birth defects, and ultimately higher healthcare costs for families and the government. These cuts also have major implications for our Nation’s ability to track birth defects caused by the Zika virus. We urge Congress in the strongest terms to bolster funding for NCBDDD, and particularly for birth defects surveillance.

#### *Immunization Programs*

The March of Dimes is also committed to ensuring that mothers and children are protected from vaccine-preventable diseases, and strongly urges the committee to reject proposed cuts to the Section 317 Immunization program included in the President’s fiscal year 2017 budget. The March of Dimes recommends funding of \$650 million for the Section 317 Immunization program and \$174 million for the continuing effort to eradicate polio worldwide.

#### *Newborn Screening*

Newborn 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 funding of \$18 million for the Health Resources and Services Administration’s heritable disorders program, which plays a critical

role in assisting States in the adoption of additional screenings, educating providers and consumers, 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 (ACHDNC), which provides recommendations to the HHS Secretary for conditions to be included in the Recommended Uniform Screening Panel (RUSP). This year, the ACHDNC added two new conditions to the RUSP, bring the total number of recommended screens to 34. Additional funding for the heritable disorders program is crucial to ensure States have adequate funds and technical assistance to implement screening tests for these new additions to the RUSP.

#### CONCLUSION

March of Dimes volunteers and staff representing every State, the District of Columbia and Puerto Rico look forward to working with appropriators and all of Congress to secure the resources needed to improve the health of the Nation's mothers, infants and children.

#### PREPARED STATEMENT OF THE MARFAN FOUNDATION

##### THE FOUNDATION'S FISCAL YEAR 2017 L-HHS APPROPRIATIONS RECOMMENDATIONS

—\$7.8 billion in program level funding for the Centers for Disease Control and Prevention (CDC), which includes budget authority, the Prevention and Public Health Fund, Public Health and Social Services Emergency Fund, and PHS Evaluation transfers.

—A proportional fiscal year 2017 funding increase for CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD).

—At least \$34.5 billion in program level funding for the National Institutes of Health (NIH).

—Proportional funding increases for NIH's National Heart, Lung, and Blood Institute (NHLBI); National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS); National Eye Institute (NEI); and National Center for Advancing Translational Sciences (NCATS).

Chairman Blunt 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 2017 L-HHS Appropriations Bill.

##### ABOUT MARFAN SYNDROME AND HERITABLE CONNECTIVE TISSUE DISORDERS

###### *Marfan Syndrome*

Marfan syndrome is a genetic disorder that affects the body's connective tissue. Connective tissue holds all the body's cells, organs and tissue together. It also plays an important role in helping the body grow and develop properly.

##### THE PATIENT PERSPECTIVE

*Krystal Kamire*—My journey with Marfan syndrome has been a long and complicated one. I was first tested when I was 19. At that time, the tests were inconclusive. I have some of the features of Marfan syndrome, such as pectus carinatum (pigeon chest), and was very tall and thin, but my measurements were borderline. I had no known family history, and I hadn't developed any serious heart problems. They told me this is not uncommon because I was still young and many people don't begin to have problems until they are older. The doctors couldn't confirm that I had Marfan syndrome, but they also couldn't confirm that I didn't have it. So here I was in limbo, and limbo was where I stayed for a long time.

It's not easy to tell a doctor that you might have Marfan syndrome and have them take you seriously. Honestly, they probably didn't know much more about the condition than I did. Because I wasn't having any luck with doctors, I did the only other thing I could think of: I googled it. That's how I found The Marfan Foundation's website. I signed up to request more information and within a week I had a packet in the mail. But then the most surprising thing happened. I received a phone call from a woman with a local chapter of The Marfan Foundation who reached out to me to help. It might not seem like much, a simple phone call, but it was one of the most influential things to happen to me. I wasn't alone. It is profound to have that realization. I signed up to become a member that very day.

About a year later, I received an email about a meeting in Seattle to form a NW Washington group. That meeting changed my life. I was able to look around the



room and see other people with this condition and, once again, saw that I wasn't alone. I met Dr. Byers, my geneticist, that day. There also was a wonderful woman from the Foundation who told me about the Annual Family Conference. She said that they had a medical clinic that allowed you to see the best Marfan specialists in the country for free. I knew then that if I wanted a definite answer, I wouldn't find any better way to get it.

I can honestly say that, if I hadn't received a scholarship to attend the conference, at 33 years old, I still might not have a diagnosis today. Much more important than that, at the conference I found a community. I met so many people who were like me and, for once, I wasn't the tallest person in the room. And I wasn't the only person who had a pigeon chest. I wasn't the only woman scared to have children. I wasn't the only person there to find answers. I wasn't alone. That, more than anything, is the biggest gift that that this organization has given to me. From now on, I'm not alone. When you spend your whole life trying to pretend that everything is okay because no one will understand, to meet so many people who know exactly what you are going through is life-changing. I found a family within The Marfan Foundation. I know that I can reach out to them at any time and someone will reach back out to me. Just like that first phone call that surprised me so much. I could not begin to express my gratitude to The Marfan Foundation. I only hope that, through this amazing organization, I am able to help someone the way that they have helped me.

#### 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 include CDC's Million Hearts Campaign and NCBDDD's newborn screening activities.

Additionally, we support the establishment of a new sports screening program to fund awareness in high schools around the country and prevent Marfan syndrome-related thoracic aortic aneurysm and dissection, which claims the lives of young athletes across the country each year. A contemporary example of this need is Isaiah Austin, who was diagnosed with Marfan syndrome just five days before he was supposed to take part in the NBA Draft. Had it not been for the intense testing each potential draftee undergoes as part of the process, Isaiah may never have been diagnosed. His story might have ended by him collapsing on national television or years before while he was playing basketball in college. He is a prime example that more needs to be done. Meaningful funding increases will allow CDC to establish this new activity.

#### 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.

#### *National Heart Lung and Blood Institute (NHLBI)*

First and foremost, the Foundation applauds NHLBI for the completion of the first clinical trial for Marfan syndrome and for its 10 year support of the GenTAC (Genetically Triggered Thoracic Aortic Aneurysms and Cardiovascular Conditions) registry. To date, the registry has produced numerous publications with data derived from over 3750 subjects. The research derived from this registry covers a wide scope of issues, including surgery, gene discovery, drug therapies outcomes and imaging needs of the community.

*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.

*National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)*

The Marfan Foundation is proud of its longstanding partnership with NIAMS. Dr. Steven Katz has been a strong proponent of basic research on Marfan syndrome during his tenure as NIAMS director. The Foundation would like to thank the Institute for its 10 years of invaluable support for the program project entitled "Consortium for Translational Research in Marfan Syndrome" which has enhanced our understanding of the disorder and increased the ability to stop the disease progression using a drug-based therapy. The discoveries of fibrillin-1, TGF-beta, and their role in muscle regeneration and connective tissue function were made possible in part through collaboration with NIAMS. NIAMS continues to support critically important research in connective tissue disorders. Unpublished results show dramatic breakthroughs in the underlying mechanisms brought about by a mutation in the fibrillin-1 gene putting Marfan women at extremely high risk during pregnancy. These studies have enabled scientists to identify four medications that can protect against pregnancy-associated aortic tear or rupture in mouse models and these therapies are now being studied for their use in all people with Marfan syndrome. Similarly, scientists have uncovered the potential importance of the interaction between the TGF- $\beta$  binding complexes and fibrillin-1 microfibrils in the control of detrimental TGF- $\beta$  signaling involved in aneurysm pathogenesis. Blocking activation of these complexes might represent a potentially novel and specific therapeutic approach to preventing aortic disease. These types of studies indicate the high potential for research to derive novel treatment strategies for Marfan syndrome, and that these insights will prove relevant to other presentations of aortic aneurysm.

In addition to research in Marfan syndrome, we look to NIAMS to help support research in other related connective tissue disorders such as Loeys-Dietz Syndrome, Ehlers Danlos, Shprintzen Goldberg, and Beals syndrome. A mouse model for Loeys-Dietz Syndrome has been established using a mutation in the TGF- $\beta$  type 2 receptor associated with severe Loeys-Dietz syndrome in humans. The skeletal phenotype observed in the Loeys-Dietz mouse closely resembles the principal structural features of bone in humans with Loeys-Dietz syndrome and establishes this mouse as a valid *in vivo* model for further investigation of TGF- $\beta$  receptor signaling in bone. We look to NIAMS to specifically support further bone and skeletal research for this group of related disorders. As always, we hope that NIAMS continues to support as basic, translational and clinical research in the pathogenesis of Marfan and related phenotypes which can lead to novel therapies for these disorders.

[This statement was submitted by Michael Weamer, President and CEO, The Marfan Foundation.]

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 PREPARED STATEMENT OF THE MEADVOCACY.ORG

Dear Ladies and Gentlemen of the Committee: MEadvocacy.org (1) is a project of the non-profit organization May12.org and is asking Health and Human Services to fund \$250 million for research into the disease myalgic encephalomyelitis (ME).

There is an urgent need for a systemic overhaul at the Department of Health and Human Services (HHS), including the National Institutes of Health (NIH) and the Centers for Disease Control (CDC), in regard to its funding and handling of this disease.

ME is a chronic, disabling, neuroimmune disease that affects an estimated one million American men, women and children in the U.S. Yet, the past three decades, since the Lake Tahoe outbreak where the disease was redefined, there have been few biomedical scientific advances and no FDA approved treatments for this heavily burdened disease. This is due to the fact HHS, NIH and CDC have had an institutional bias leading to marginalization, neglect, underfunding and mistreatment of this patient community.

Advances in the science of the disease have been repeatedly squashed by the gross lack of funding by NIH for the disease. In addition, misinformation and badly outdated information published by the CDC, along with the lack of education about the disease in medical schools, has caused a dearth of palliative care for patients nation-

wide. Most importantly, after 30 years, we still are not any closer to finding an FDA approved treatment or cure to help the estimated 17 million ME patients worldwide.

MEadvocacy.org is a non-profit grassroots movement of advocates and patients who are rising up and saying it is time for a change. We are lawyers, laborers, teachers, students, fathers, mothers, and children. Our productive lives have been cut short by this disease and we currently have no hope of treatment or cure. We have had enough and are saying, "No More!"

#### *ME Incidence and Prevalence*

ME, also known in the U.S. as chronic fatigue syndrome (CFS) and myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), sickens an estimated 1 million people in the U.S. and 17 million worldwide. A majority of patients are disabled, unable to work, attend school or participate in activities of daily life. A quarter, an estimated 250,000 people, are so severely affected as to render them bedbound, unable to care for themselves.

#### *ME History, Criteria and Name*

ME has a long history, appearing worldwide in epidemic and endemic forms. A 1955 outbreak in London resulted in what Dr. A. Melvin Ramsay (2) described it as an infectious neuromuscular illness and formally used the term "myalgic encephalomyelitis." Disregarding this, the CDC broadly redefined the disease and renamed it the marginalizing name chronic fatigue syndrome (CFS) in response to 1985 cluster outbreaks of the disease in Incline Village, Nevada and Lyndonville, New York. This redefinition resulted in three decades of confused research findings rather than answers to the cause and treatment of this disease. In addition, the unignified name and poor criteria causes stigmatization and marginalization of patients.

#### *Disease Burden and Funding*

Some ME patients have died prematurely from complications of ME. Others have died at their own hands due to the severity and length of their suffering without proper palliative care, as well as dismissal and stigmatization by the medical community. If we do not act on behalf of these severely affected patients, we are complicit in their suffering and untimely deaths. The patients will no longer carry this burden quietly and we are looking at Congress to require HHS to properly fulfill their duty to ME sufferers.

In 2009, Dr. Nancy Klimas, the director of AIDS research at the Miami Veterans Affairs Medical Center stated: "My H.I.V patients for the most part are hale and hearty thanks to three decades of intense and excellent research and billions of dollars invested. Many of my CFS patients, on the other hand, are terribly ill and unable to work or participate in the care of their families. I split my clinical time between the two illnesses, and I can tell you if I had to choose between the two illnesses, (in 2009) I would rather have HIV." (3)

In the intervening 7 years, nothing has changed. It is very clear that real change at HHS regarding this disease will not come about naturally. We have come to you, the subcommittee for Labor, Health and Human Services, Education, and Related Agencies, for help in addressing this dire need for oversight and investigation.

It is estimated that the burden to the economy for ME is between \$17 to \$24 billion, yet NIH funding for research has stagnated at a mere \$5 to \$6 million a year, less than funding for hay fever. HHS has placed funding for ME at the rock bottom of their funding budget list (4). The yearly allocation for ME/CFS is a fraction of what other similarly burdened diseases receive. Dr. Francis Collins, the director of NIH, has promised increased help, but the proposed funding for ME/CFS is only \$7 million.

HHS/NIH funding data for 2015 for several diseases: HIV/AIDS \$3 billion; M.S. \$94 million; Parkinson's \$146 million; Alzheimer's \$589 million; ME/CFS \$6 million.

The great divide between NIH funding for ME and other diseases cannot be explained away. Simply advising and recommending that NIH increase funding for ME, has not worked. The Secretaries of Health and Human Services have not responded to most of the nearly 100 recommendations made by the Chronic Fatigue Syndrome Advisory Committee (CFSAC) (5) during the past 10 years. It ignored specific requests by CFSAC, medical experts, patient advocates, patients and their families to adopt ME expert authored, well defined criteria for the disease and calls for RFAs and increases in NIH funding.

HHS did not heed the call by President Obama as a result of a call out at a town-hall meeting by the wife of a patient. It has not listened to the many recommendations by this Appropriations Committee over the past 20 years. In order to fund ME on par with MS, a similarly serious disease, ME would need \$250 million a year to bring them on par with other similarly burdened diseases yet, gets a mere \$6

million. This is just on a premise of equality, not equity. If evaluated based on equity, a disease with no FDA approved treatment and an abysmal quality of life (lower than AIDS and MS), it should be getting much more funding to bring it up to par. To be equitable ME should be funded at greater than \$3 billion.

We need a different approach and a complete overhaul at all agency levels. We need an investigation by Congress into the mishandling and neglect of ME by HHS, NIH and CDC and active, ongoing Congressional oversight until HHS' negative institutional bias is rectified. We are therefore coming to you for help in this matter.

The following are the recommendations and goals that we at MEadvocacy.org feel the Appropriations Committee needs to require that HHS meet, in order to bring myalgic encephalomyelitis back on par with other similarly burdened diseases:

- Fund biomedical research for ME commensurate with its severity and burden to patients and the economy. We are asking for specific funding in the amount of \$250 million, the amount we believe is needed to bring ME on par with other similarly burdened diseases. HHS should clearly allocate funds to study patients from past ME cluster outbreaks as well as the study of the epidemiology of patients with severe ME. The additional funding needed for ME might be accomplished by means of a sliding scale of allocation from other diseases related to immune, cognitive and nervous system dysfunctions.
- Heed the ME stakeholders' request to adopt the diagnostic and research criteria authored by those experienced in the disease, namely the 2003 Canadian Consensus Criteria (CCC) (6), which has been adopted by the International Association of Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (IACFS/ME) (7). In a letter to the Secretary of HHS, 50 experts (8) in the disease declared their consensus agreement to adopt the CCC. This was endorsed by a letter signed by 171 advocates (9) as well as a petition (10) signed by over 6,000 patients. The 2011 revision known as the International Consensus Criteria (ICC) (11) would be an alternatively acceptable criteria for adoption.
- Retain the historical name for this disease, myalgic encephalomyelitis, which has been coded since 1969 by the World Health Organization under neurological disease with the code G93.3 and is similarly coded in the 2015 U.S. ICD Codes as U.S. ICD-10-CM.

Additionally, we request that the Appropriation Committee recommends HHS:

- Ensure that NIH completes their 2015 promise of placing ME into the National Institute of Neurological Disorders and Stroke (NINDS), which also manages similar neuroimmune diseases such as MS, fibromyalgia, and Lyme Disease. The Office of Research on Women's Health, where ME is currently housed, is entirely inappropriate for a disease which also strikes men and children.
- Provide opportunities for dissemination of information through the development of a curriculum for all U.S. based medical schools, as well as physician continuing education, about ME as defined solely by disease experts, in order to provide the tools needed for physicians and other medical professionals to appropriately recognize and treat this disease. Currently, this would mean using either the 2003 Canadian Consensus Criteria or the 2011 International Consensus Criteria, not the overly broad criteria developed by the non-expert IOM panel which the CDC is defiantly implementing in their educational materials. In addition, the CCC (6) or ICC Primer (11) should be widely distributed and made available to clinicians, particularly primary care physicians, nationwide in order to facilitate the best care for their ME patients.
- Partner openly and transparently with stakeholders within 1 year to establish a comprehensive, aggressive and fully funded cross agency strategy and implementation plan, with well defined objectives and milestones, and to develop a plan to monitor progress and provide for Congressional oversight.

"We've documented, as have others, that the level of functional impairment in people who suffer from CFS is comparable to multiple sclerosis, AIDS, end stage renal failure, chronic obstructive pulmonary disease. The disability is equivalent to that of some well known, very severe medical conditions."

—Dr. William Reeves, former CDC Chief of Viral Diseases Branch (2006 CDC Press Conference)

*Links:*

- (1)—[Http://www.meadvocacy.org](http://www.meadvocacy.org).
- (2)—[Http://www.name-us.org/DefintionsPages/DefRamsay.htm](http://www.name-us.org/DefintionsPages/DefRamsay.htm).
- (3)—[Http://consults.blogs.nytimes.com/2009/10/15](http://consults.blogs.nytimes.com/2009/10/15).
- (4)—[Https://report.nih.gov/categorical\\_spending.aspx](https://report.nih.gov/categorical_spending.aspx).
- (5)—[Http://www.hhs.gov/advcomfcs/recommendations/index.html#](http://www.hhs.gov/advcomfcs/recommendations/index.html#).
- (6)—[Http://www.name-us.org/DefintionsPages/DefinitionsArticles/ConsensusDocument%20Overview.pdf](http://www.name-us.org/DefintionsPages/DefinitionsArticles/ConsensusDocument%20Overview.pdf).

- (7)—[Http://www.iacfsme.org](http://www.iacfsme.org).  
 (8)—[Https://dl.dropboxusercontent.com/u/89158245/Case%20Definition%20Letter%20Sept%2023%202013.pdf](https://dl.dropboxusercontent.com/u/89158245/Case%20Definition%20Letter%20Sept%2023%202013.pdf).  
 (9)—[Https://thoughtsaboutme.files.wordpress.com/2013/10/sebelius\\_letter\\_advocates2.pdf](https://thoughtsaboutme.files.wordpress.com/2013/10/sebelius_letter_advocates2.pdf).  
 (10)—[Https://secure.avaaz.org/en/petition/Stop\\_the\\_HHSIOM\\_contract\\_and\\_accept\\_the\\_CCC\\_definition\\_of\\_ME/?pv=4](https://secure.avaaz.org/en/petition/Stop_the_HHSIOM_contract_and_accept_the_CCC_definition_of_ME/?pv=4).  
 (11)—[Http://www.name-us.org/DefintionsPages/DefinitionsArticles/2012\\_ICC%20primer.pdf](http://www.name-us.org/DefintionsPages/DefinitionsArticles/2012_ICC%20primer.pdf).

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PREPARED STATEMENT OF MEALS ON WHEELS AMERICA

Chairman Blunt and Ranking Member Murray: Thank you for the opportunity to present testimony to your Subcommittee concerning fiscal year 2017 appropriations for Older Americans Act (OAA) Nutrition Programs administered by the Administration for Community Living (ACL)/Administration on Aging (AoA) within the U.S. Department of Health and Human Services. We are sincerely grateful for your ongoing support for these proven and effective programs, including the more than \$20 million increase provided in H.R. 2029, the Consolidated Appropriations Act of 2015. We urge you to continue to build on the bipartisan, bicameral support that exists for these vital programs and adopt the funding levels included in the President's fiscal year 2017 Budget Request to Congress. For the three OAA Nutrition Programs authorized under Title III of the Act, that request is as follows:

- Congregate Nutrition Services (Title III, C-1)—\$454 million
- Home-Delivered Nutrition Services (Title III, C-2)—\$234 million
- Nutrition Services Incentive Program (Title III, NSIP)—\$160 million

At this critical juncture in our Nation's history, when both the need and demand are already substantial and will continue to climb exponentially, we ask that you to give this request your utmost consideration due to the significant social and economic benefits that OAA Nutrition Programs offer. These programs represent one of the best examples of a successful public-private partnership, leveraging about \$3 for every \$1 appropriated through the OAA, as well as an army of two million volunteers to support their operations and reach more seniors in need. The nutritious meals, friendly visits, and safety and wellness checks these programs deliver each day are providing an efficient and vital support service for our most vulnerable seniors, our families, our communities and taxpayers as a whole. OAA Nutrition Programs (both congregate and home-delivered) enable seniors to live more nourished and independent lives longer in their own homes—where they want to be—reducing unnecessary visits to the emergency room, admissions and readmissions to hospitals and premature institutionalization. Not only are they providing more than just a meal to those who are fortunate enough to receive their services, but these programs are also an essential part of the solution to our Nation's fiscal and demographic challenges.

SERVING THE MOST VULNERABLE

For more than 50 years in communities large and small, urban and rural, OAA Nutrition Programs have been effectively serving seniors in the greatest economic and social need. What started as a demonstration project has grown into a highly effective community-based, nationwide network of more than 5,000 local programs. The Federal dollars authorized under Title III of the Act provide a pivotal foundation on which to leverage additional State, local and private resources to serve more seniors in need—those who are frail, isolated, and at significant risk of hunger and losing their ability to live in their home.

Data from ACL's State Program Reports and National Survey of OAA Participants demonstrates that the seniors receiving meals at home and in congregate settings, such as senior centers, need these services to remain healthier and independent. They are primarily women, age 75 or older, who live alone. Additionally, they have multiple chronic conditions, take six or more medications daily, are functionally impaired, and the single meal provided through the OAA Nutrition Program represents half or more of their total daily food intake. Significant numbers of seniors are impoverished, live in rural areas, and belong to a minority group. In short, the individuals served through the OAA nutrition network are high risk and potentially high cost to Medicare and Medicaid.

Furthermore, findings from a ground-breaking 2015 study entitled *More Than a Meal*, conducted by Meals on Wheels America in conjunction with Brown University and AARP Foundation, found that those receiving and/or requesting Meals on

Wheels services are significantly more vulnerable compared to a nationally representative sample of comparably aged Americans. Specifically, seniors on Meals on Wheels waiting lists were significantly more likely to:

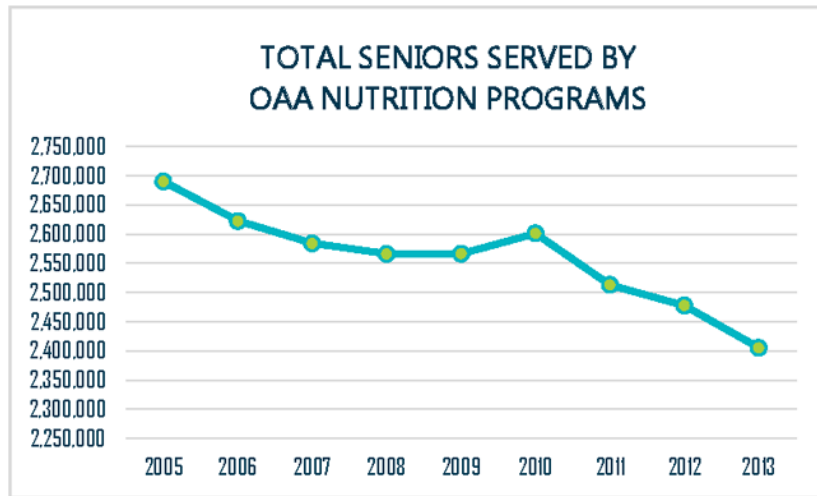
- Report poorer self-rated health (71 percent vs. 26 percent)
- Screen positive for depression (28 percent vs. 14 percent) and anxiety (31 percent vs. 16 percent)
- Report recent falls (27 percent vs. 10 percent) and fear of falling that limited their ability to stay active (79 percent vs 42 percent)

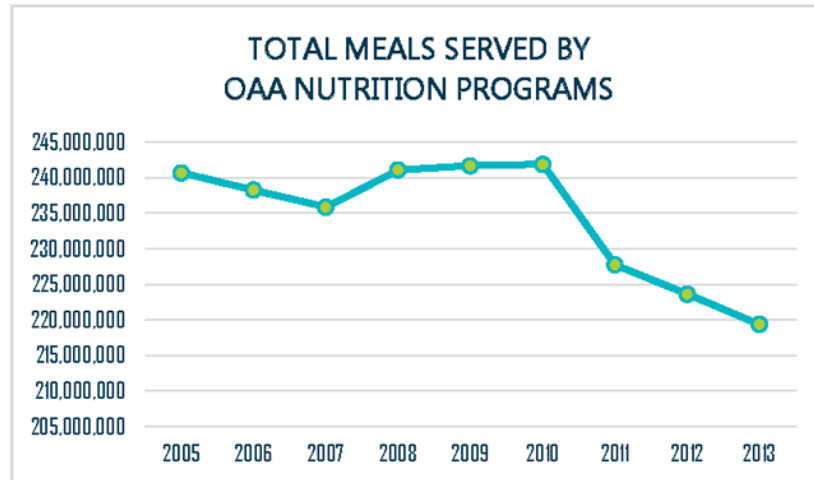
DEFINING THE MAGNITUDE OF THE PROBLEM

Regardless of what statistic you see, it is undeniable that the problem of senior hunger is grave, growing and expensive. Today, 9.6 million seniors—or one in six—may not know from where their next meal will come. Since the start of the recession in 2007 to 2013, the number of seniors age 60 or older experiencing “very low food security”—or “hunger” as expressed by the National Commission on Hunger—has increased by 63 percent. In 2013, the last year for which we have data from ACL, funding provided through the OAA supported the provision of meals to fewer than 2.5 million seniors nationwide. Tragically, the gaps continue to widen between the number of seniors struggling with hunger and those receiving nutritious meals through the OAA. Funding for the OAA has simply not kept pace with inflation or need.

In fact, a Government Accountability Office report released last summer found that about 83 percent of food insecure seniors and 83 percent of physically impaired seniors did not receive meals [through the OAA], but likely needed them. Currently, the OAA network overall is serving 21 million fewer meals annually to seniors in need than we were in 2005 due to declining Federal and State grants, stagnant private funding, and rising food and, transportation and other operational costs. At a minimum, we must stave off this continuous decline not only for the health of our seniors, but for the health of our Nation at large. The graphs on the following page illustrate this troubling trend.

[The graphics follows:]





Source: Older Americans Act (OAA) Title III Programs data derived from the AGing Integrated Database (AGID) system, the AGID State Profiles. Full reports available at: [www.agidnes.acl.gov](http://www.agidnes.acl.gov)

#### PRESENTING THE ECONOMIC CASE

We all know that without proper nutrition, one's health deteriorates and inevitably fails. It is extremely costly not only in personal terms for the individuals who struggle, but also for taxpayers in terms of increased healthcare costs. For seniors, even a slight reduction in nutritional intake can exacerbate existing health conditions, accelerate physical impairment, impede recovery from illness, injury or surgery, and increase the risk of chronic disease(s). The good news is that the infrastructure already exists to meet the escalating nutritional needs of seniors, if adequately funded. Evidence continues to build that proves that bolstering funding for OAA Nutrition Programs will substantially reduce healthcare costs—both in the short- and long-term. On average, a program can deliver Meals on Wheels to a senior for an entire year for about the same cost as just one day in the hospital or ten days in a nursing home—costs that are often incurred by Medicare and Medicaid and for which taxpayers foot the bill.

The aforementioned More Than a Meal study found that those who received daily home-delivered meals (the traditional Meals on Wheels model of a daily, in-home-delivered meal, friendly visit and safety check), experienced the greatest improvements in health and quality of life. Specifically, between baseline and follow-up, seniors receiving daily home-delivered meals were more likely to exhibit:

- Improvement in mental health (i.e., levels of anxiety)
- Improvement in self-rated health
- Reductions in the rate of falls and the fear of falling
- Improvement in feelings of isolation and loneliness
- Decreases in worry about being able to remain in home

Further, in addition to being a preventative measure for ER visits and hospital admissions, investing in home-delivered meals is also a proven way to reduce hospital readmissions and post-discharge costs. For example, Meals on Wheels America worked with a national insurer over a 5 year span, covering more than 135,000 Medicare Advantage seniors post-discharge across 36 States. While this intervention involved just a one-time delivery of ten frozen meals and follow-up phone calls, it produced significant results including average overall healthcare savings of 31 percent per member per month (PMPM) for the first month following discharge and referral opportunities for about 30 percent of recipients for ongoing meal and other needed community services. Subsequent engagements have shown that daily meal delivery over a longer period of time (30 days—6 months or more) produced even more favorable health outcomes and longer term cost savings when compared to national readmission rates. In addition, across six pilots funded by Meals on Wheels

America in CA, KS, NC, OH, ME and TX, the average reduction in 30 day readmission rates ranged from 6–7 percent as compared to national readmission rates of 15–33 percent over the same period.

#### SCALING THE SOLUTION

It is clear that those who are in need of home-delivered meal services represent our Nation's most frail and vulnerable senior population. This is a group with significant health and social support needs. The More Than a Meal study reinforces the wealth of past research, indicating that home-delivered meals improve the health and well-being of older adults, particularly for those who receive daily home-delivered meals and live alone. By decreasing feelings of isolation and loneliness and reducing the rate of falls, the research suggests that the traditional Meals on Wheels service delivery model has the greatest potential to decrease healthcare costs. When reviewing the reduction in falls alone, which adjusted for inflation equaled \$34 billion in direct medical costs in 2013, further investments in OAA Nutrition Programs are an untapped solution and have the potential to produce billions of dollars in savings to the Mandatory side of the budget.

We certainly understand the difficult decisions you and your colleagues are tasked with in Fiscal year 2017 and beyond. However, the evidence proves that these programs are not only saving lives and taxpayer dollars every day, but they are effectively reaching our Nation's most at-risk seniors and have the capacity to serve significantly more, if properly resourced. As such, we hope that you recognize the need to invest further in Discretionary programs, like OAA Nutrition Programs, as they help prevent and mitigate the effects of chronic diseases, improve quality of life, expedite recovery after an illness, injury, surgery or treatment, and reduce unnecessary Medicare and Medicaid expenses both today and in the future.

As your Subcommittee crafts and considers the fiscal year 2017 Labor-HHS-Education Appropriations Bill, we ask that you provide the funding levels included in the President's fiscal year 2017 Budget Request to Congress 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 eliminate waiting lists altogether and to increase the number of nutritious meals we can serve to seniors today. By doing so, you will be investing in a stronger fiscal path for our country by reducing future healthcare costs. Given the magnitude of the senior hunger problem, the time to act is now.

Thank you for your leadership and continued support through the appropriations process, as well as your efforts to ensure passage of S. 192, the Older Americans Act Reauthorization Act of 2016. We hope our testimony has been instructive and are pleased to offer our assistance and expertise at any time throughout this process.

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#### PREPARED STATEMENT OF THE MEDICAL LIBRARY ASSOCIATION AND ASSOCIATION OF ACADEMIC HEALTH SCIENCES LIBRARIES

##### SUMMARY OF FISCAL YEAR 2017 RECOMMENDATIONS

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- Continue the commitment to the National Library of Medicine (NLM) by supporting the President's budget proposal which requests \$395,110,000.
  - Continue to support the medical library community's role in NLM's outreach, telemedicine, disaster preparedness, health information technology initiatives, and healthcare reform implementation.
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#### INTRODUCTION

The Medical Library Association (MLA) and Association of Academic Health Sciences Libraries (AAHSL) thank the Subcommittee for the opportunity to submit testimony supporting fiscal year 2017 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. As health sciences librarians who use NLM's programs and services every day, we can attest that these resources literally save lives making NLM an investment in good health.



*NLM Leverages NIH Investments in Biomedical Research*

In today's challenging budget environment, we recognize the difficult decisions Congress faces as it works to improve our Nation's fiscal stability. We thank the Subcommittee for its long-standing commitment to strengthening NLM's budget. 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. NLM's budget 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 2017 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 expansion of 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 50 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, Genetics Home Reference (GHR), 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. More than 2.2 million users accessed consumer-level information about genetics from GHR which contains 2,649 summaries of genetic conditions, genes, gene families, and chromosomes. PubMed, with more than 25 million references to the biomedical literature, is the world's most heavily used source of bibliographic information. Approximately 806,000 new citations were added in fiscal year 2016, and the database provided high quality medical information to more than 2 million users each day. PubMed Central is NLM's digital archive which provides public access to the full-text versions of more than 3.6 million biomedical journal articles, including those produced by NIH-funded researchers. On a typical weekday more than one million users download more than 2 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 6,400 members in communities nationwide, the NN/LM educates medical librarians, health professionals and the general public about NLM's services and trains them in the most effective use of these services. Beginning with the 2016–

2021 funding cycle, the NN/LM includes Coordinating Offices that will independently support Network activities by providing technical expertise, planning, and coordination, and serve as the Network's central point of contact to reduce redundancy of effort throughout the Network.

The NN/LM serves the public by promoting 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 3 million visitors daily. NLM has continued to make enhancements to MedlinePlus, with selected materials now available in forty other languages. New versions of MedlinePlus and MedlinePlus en español have been released and have been optimized for easier use on mobile phones and tablets. 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 Subcommittee to support NLM's role in this crucial area which ensures continuous access to health information and use of libraries and librarians when disasters occur. NLM has created a comprehensive Web page to gather resources on emerging health issues arising from the Zika Virus. Many medical libraries include links to it on their Web sites. This is another example of the fine work that NLM does on behalf of the public.

In 2015, NLM and the Health and Human Services Office of the Assistant Secretary for Preparedness and Response released a new version of the Radiation Emergency Medical Management (REMM) website which gives healthcare personnel key information about the diagnosis and treatment of radiation injuries and access to interactive clinical tools and data. The site provides just-in-time, evidence-based, usable information with sufficient background and context to make complex issues understandable to health providers without formal training or expertise in radiation medicine.

#### *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 and link to relevant patient education materials.

#### *Dissemination of Clinical Trial Information*

ClinicalTrials.gov, the world's largest clinical trials registry, was expanded in fiscal year 2016, and now includes more than 212,000 registered studies and summary results for more than 21,000 trials, including many not available elsewhere. As health sciences librarians who fulfill requests for information from clinicians, scientists, and patients, we applaud the NIH and NLM for their efforts to expand and clarify the regulations for clinical trials registration and results submission, and for work to apply the ClinicalTrials.gov requirements to all NIH clinical trials. These efforts will enhance the transparency of clinical trial results, and provide patients with more information to make necessary healthcare decisions, including critical information about the safety of products and treatment options. Clinicians will have access to results information about efficacy, adverse effects, and safety; and biomedical researchers will have information on research design, safety, and scientific results that can inform future protocols and discoveries. We also support timely, easily understood, and accurate reporting of all clinical trials, especially those supported by Federal funding, regardless of agency and phase of the clinical trial, and information about studies that have been terminated due to adverse events, difficulties in research design making accrual difficult, or simply feasibility problems. Ultimately, expanding the requirements will create an incredible and vastly important database of clinical data and knowledge for clinicians, scientists, and patients who need access to cutting-edge information.

In addition to these efforts, NLM recently launched MedPix®, a free online medical image database of 53,000 indexed and curated images, from over 13,000 patients. As a public education service, NLM and MedPix provide the storage space, indexing, and Web server hosting. Individuals as well as institutions may participate with no additional software required other than an Internet browser. The primary target audience includes physicians and nurses, allied health professionals, medical students, nursing students and others, and will include a continuing medical education module in the near future.

#### *Improving Public Access to Funded Research Results*

Last year, the Department of Health and Human Services (DHHS) announced its plans and common policy approach to expanding public access to the results of scientific research funded by HHS agencies. Its operating divisions (Agency for Healthcare Research and Quality, Centers for Disease Control, Food and Drug Administration, and NIH) as well as the Assistant Secretary for Preparedness and Response will utilize NLM's PubMed Central as the common repository for its peer-reviewed publications and PubMed, a repository of citations, for the sharing of metadata. NLM's experience in developing these systems and related tools and engaging the health sciences library community in outreach will be essential to effective implementation of HSS-wide policies and improving compliance.

Thank you again for the opportunity to present our views. As health sciences librarians who use NLM's products and services, and as intermediaries who serve the information needs of researchers, clinicians, and the public, we value and rely upon the high quality resources, services, and leadership that NLM provides in support of our Nation's health professionals, educators, researchers, and the public. As the needs of these audiences continue to evolve, we are confident that NLM's vision and understanding of the role of information, data, and technology will continue to fuel the development of just-in-time resources and tools that will keep our Nation's health, biomedical, and scientific professionals at the forefront of healthcare, discovery, and innovation.

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 2017 and the years beyond to support the Library's mission and growing responsibilities.

#### *Organizational Bios*

The Medical Library Association (MLA) is a nonprofit, educational organization with 3,500 health sciences information professional members worldwide. Founded in 1898, MLA provides lifelong educational opportunities, supports a knowledgebase of health information research, and works with a global network of partners to promote the importance of quality information for improved health to the 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 vi-

sionary executive leadership and expertise in health information, scholarly communication, and knowledge management.

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PREPARED STATEMENT OF MID-OHIO BOARD FOR AN INDEPENDENT LIVING ENVIRONMENT

I am writing to support the National Council on Independent Living's request for Congress to reaffirm your commitment to the more than 57 million Americans disabilities by increasing funding in the HHS appropriations for Centers for Independent Living (CILs). I am asking that you increase funding by \$200 million, for a total of \$301 million for the Independent Living line item in fiscal year 2017.

The Mid-Ohio Board for an Independent Living Environment (MOBILE) is cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. MOBILE like other CILs across America are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. As a CIL, MOBILE is a federally funded center providing five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services, which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012–2014, CILs provided the core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals. During this same period, prior to transition being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community.

Transition services were added as a fifth core service with the 2014 reauthorization of the Rehabilitation Act within the Workforce Innovation and Opportunity Act. Transition services include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

Every day, MOBILE and the national network of CILs fight to ensure that people with disabilities gain and maintain control over our own lives. We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions from 2012–2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and States. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In 2016, the Independent Living Program is receiving \$2.5 million less in funding than it was in 2010. It is simply not possible to meet the increasing demand for services and effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony.

[This statement was submitted by John T. Coats, II, Executive Director, Mid-Ohio Board for an Independent Living Environment.]

## PREPARED STATEMENT OF THE NATIONAL ALLIANCE FOR EYE AND VISION RESEARCH

## EXECUTIVE SUMMARY

NAEVR thanks Congress for its bipartisan action in fiscal year 2016 to increase NIH funding by \$2 billion over fiscal year 2015, which is the largest actual dollar and percent increase since fiscal year 2003. To continue to rebuild NIH's discretionary funding base—especially as it has lost 22 percent of purchasing power since fiscal year 2003, in terms of constant dollars—and to ensure predictable and sustained funding, NAEVR requests fiscal year 2017 appropriated NIH funding of at least \$34.5 billion, a 7.5 percent increase reflecting 5 percent real growth above projected 2.5 percent biomedical inflation.

NAEVR also thanks Congress for the \$31 million National Eye Institute (NEI) increase over fiscal year 2015, especially since it reflects the first time in 4 years that NEI's operating budget exceeds that of the pre-sequester fiscal year 2012 level, albeit by a modest 0.8 percent. To continue to rebuild NEI's discretionary funding base—especially as it has lost 25 percent of purchasing power since fiscal year 2003, in terms of constant dollars—and to ensure predictable and sustained funding, NAEVR requests fiscal year 2017 appropriated NEI funding of \$770 million, also a 7.5 percent increase.

NAEVR shares the concerns expressed by bipartisan Leaders and Members of the Appropriations Committee and the LHHS Appropriations Subcommittee regarding the President's proposal to replace \$1 billion of the NIH discretionary base funding with mandatory funding. NAEVR is especially concerned that the President proposes to not only flat-fund most of the Institutes and Centers (I/Cs), but achieve this through the use of mandatory funding. In the case of the NEI, its discretionary base would be reduced to \$687 million, with the difference reflecting mandatory funding that would raise it to the flat-funded level of \$708 million.

NAEVR looks forward to working with the appropriators to secure an increase of 5 percent real growth above inflation in fiscal year 2017 NIH and NEI funding as the next step in ensuring the security and momentum of the Nation's biomedical research enterprise. We also stand ready to work with the authorizers on potential mechanisms to provide short-term "surge" funding to take advantage of the exceptional scientific opportunities now available to address current and emerging health challenges.

NEI'S BUDGET IS NOT KEEPING PACE AS THE BURDEN OF EYE DISEASE AND VISION  
IMPAIRMENT GROWS

NEI's fiscal year 2016 enacted funding of \$715.9 million—reduced to a \$708 million operating budget due to pass-throughs—reflects the first time in four fiscal years that NEI's operating budget exceeds that of the pre-sequester fiscal year 2012 funding level of \$702 million. In the 4 years it has taken the NEI budget to grow a modest 0.8 percent, it has experienced the compounded loss of purchasing power due to biomedical inflation rates ranging from 2 to 2.5 percent. During that time-frame, NEI's operating budget was also reduced as a result of a transfer back to the NIH Office of AIDS Research (OAR) for funding of the successfully completed NEI-sponsored Studies of the Ocular Complications of AIDS (SOCA). Although OAR's funding to NEI was not committed indefinitely, its return to NIH Central in the amounts of \$5.6 million (fiscal year 2013), \$6.9 million (fiscal year 2014), and \$7.4 million (fiscal year 2015) had essentially cut NEI's budget further, resulting in a new baseline upon which future funding increases were calculated.

In June 2014, Prevent Blindness (PB) released a report entitled *The Future of Vision: Forecasting the Prevalence and Costs of Vision Problems*, which it commissioned from the University of Chicago's National Opinion Research Center (NORC). This report estimates the current annual cost (inclusive of direct and indirect costs) of vision disorders at \$145 billion, an increase of \$6 billion from the \$139 billion estimate in PB's 2013 study entitled *Cost of Vision Problems: The Economic Burden of Vision Loss and Eye Disorders in the United States*, which also concluded that direct medical costs associated with vision disorders are the fifth highest—only less than heart disease, cancers, emotional disorders, and pulmonary conditions. PB's 2014 study projects that the total annual cost of vision disorders, which includes government, insurance, and patient costs, will grow to \$373.2 billion in 2050 when expressed in 2014 dollars—which is \$717 billion when adjusted for inflation. Of the \$373.2 billion estimated 2050 costs, \$154 billion or 41 percent will be borne by the Federal Government as the Baby-Boom generation ages into the Medicare program.

Current NEI funding of \$708 million is still less than 0.5 percent of the \$145 billion annual cost of vision disorders. The U.S. is spending only \$2.20 per-person, per-

year for vision research at the NEI, while the 2013 PB report estimates that the cost of treating low vision and blindness is at least \$6,690 per-person, per-year.

The very health of the vision research community is also at stake. The convergence of past factors which have reduced NEI funding has affected both young and seasoned investigators and threatened the continuity of research and the retention of trained staff, while making institutions more reliant on private bridge and philanthropic funding.

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 2017 LHHs spending bill, Congress can act upon its past resolutions regarding vision and ensure that NEI is funded at \$770 million to meet these challenges.

\$770 MILLION FISCAL YEAR 2017 FUNDING ENABLES NEI TO PURSUE ITS AUDACIOUS GOAL OF RESTORING VISION

Despite past funding challenges, NEI has demonstrated leadership in identifying more than 500 genes associated with common and rare eye diseases. Its International Age-related Macular Degeneration (AMD) Genomics Consortium and its Glaucoma Human Genetics Collaboration Heritable Overall Operational Database (NEIGHBORHOOD) Consortium have each announced identification of additional gene variants associated with these leading causes of vision loss. Understanding the genetic bases of these eye diseases enables researchers and clinicians to identify those at risk and to potentially develop personalized treatment approaches, which is an NIH-wide initiative.

Among NEI’s most exciting pursuits is the Audacious Goals Initiative (AGI), which aims to restore vision within the next decade through regeneration of the retina by replacing cells that have been damaged by disease and injury and restoring their visual connections to the brain. The AGI builds upon discoveries from past investment in biomedical research, such as gene sequencing, gene therapy, and stem cell therapies, and combines these with new discoveries—such as imaging technologies that enable researchers to non-invasively view in real-time biological processes occurring in the retina at a cellular level—to develop new therapies for degenerative retinal disorders.

NEI has awarded the first set of grants associated with novel imaging technologies to help clinicians observe the function of individual neurons in human patients and follow them over time as they test new therapies. It is proceeding with a second round of awards associated with identifying new factors that control regeneration and comparing the regenerative process among model organisms, rodents, and non-human primates.

As NEI Director Paul Sieving, M.D., Ph.D. noted in his February 2013 comments at the first AGI meeting:

“Success would transform life for millions of people with eye and vision diseases. It would have major implications for medicine of the future, for vision diseases, and even beyond this, for neurological diseases.”

These are ambitious goals that require sustained and predictable funding increases. 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.

AMERICANS FEAR VISION LOSS, WHICH IS A GROWING PUBLIC HEALTH PROBLEM

The 2012 study entitled *Vision Problems in the United States*, released by Prevent Blindness and funded in part by the NEI reported that, of the nearly 143 million Americans age 40-plus (per the 2010 U.S. Census), 4 million were blind or had significant vision impairment and 37 million had an age-related eye disease, such as AMD, glaucoma, diabetic retinopathy, or cataracts. An additional 48 million Americans have a refractive error. This prevalence of vision impairment and eye disease will only grow, driven by:

—The aging of the population—the “Silver Tsunami” of the 78 million baby boomers who will turn age 65 this decade and experience increased risk for eye disease.

—The disproportionate risk/incidence of eye disease in Hispanic and African American communities, which increasingly account for a larger share of the U.S. population.

—Vision loss as a co-morbid condition of chronic disease, such as diabetes, which is at epidemic levels due to the increased incidence of obesity.

In September 2014, the Alliance for Eye and Vision Research (AEVR) released results of a new poll entitled The Public’s Attitudes about the Health and Economic Impact of Vision Loss and Eye Disease. It was commissioned by Research!America and conducted by Zogby Analytics with a grant from Research to Prevent Blindness (RPB), a private vision funding foundation which conducted the first-ever poll of the public’s attitudes about vision loss in 1965. The 2014 poll—the most rigorous conducted to-date of attitudes about vision and vision loss among ethnic and racial groups including non-Hispanic Whites, African Americans, Hispanics, and Asian Americans—found that:

—a significant number of Americans across all racial lines rate losing their eyesight as having the greatest impact on their daily life, affecting independence, productivity, and quality of life.

—African Americans, when asked what disease or ailment is the worst that could happen, ranked blindness first, followed by HIV/AIDS. Hispanics and Asians ranked cancer first and blindness second, while non-Hispanic Whites ranked Alzheimer’s disease first, followed by blindness.

—America’s minority populations are united in the view that not only is eye and vision research very important and needs to be a national priority, but many feel that the current annual Federal funding is not enough and should be increased.

In summary, NAEVR requests fiscal year 2017 NIH funding of at least \$34.5 billion and NEI funding of \$770 million—the latter to better understand the scientific bases upon which to save sight and restore vision.

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.eyeresearch.org](http://www.eyeresearch.org).

[This statement was submitted by James Jorkasky, Executive Director, National Alliance for Eye and Vision Research.]

PREPARED STATEMENT OF THE NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS

The National Alliance of State & Territorial AIDS Directors (NASTAD) represents the Nation’s chief State health agency staff who have programmatic responsibility for administering HIV and hepatitis healthcare, prevention, education, and supportive service programs funded by State and Federal Governments. On behalf of NASTAD, we urge your support for increased funding for Federal HIV and hepatitis programs in the fiscal year 2017 Labor-Health-Education Appropriations bill, and thank you for your consideration of the following critical funding needs for HIV and hepatitis programs in fiscal year 2017:

Agency	Program	NASTAD Funding Request (\$ millions)
Health Resources and Services Administration .....	Ryan White Part B Base .....	437
Health Resources and Services Administration .....	Ryan White Part B ADAP .....	943.3
Centers for Disease Control and Prevention .....	Division of HIV Prevention .....	822.6
Centers for Disease Control and Prevention .....	Division of Viral Hepatitis .....	62.8

For the first time, we can visualize the end of the HIV and hepatitis epidemics. In order to achieve the goals of the National HIV/AIDS Strategy: Updated to 2020 and the Viral Hepatitis Action Plan, funding must be robust for prevention and care programs. Domestic prevention efforts must match the commitment to the care and treatment of people living with HIV (PLWH). To be successful, we must expand traditional efforts and scale-up proven new biomedical prevention modalities such as treatment as prevention, while reimaging how the compendium of effective prevention tools can work in tandem to curb incidence in the U.S. We must also prioritize funding and efforts to the populations disproportionately impacted by HIV in the

U.S.—especially men who have sex with men (MSM) of color. Among the services necessary to improve health outcomes are the needs for linkage to and retention in care, and access to medications that suppress viral load, which make HIV more difficult to transmit—ultimately leading to fewer new infections. The Centers for Disease Control and Prevention’s (CDC) prevention programs and the Ryan White Program are crucial to preventing new infections and improving health outcomes.

Even with the continued implementation of the Affordable Care Act (ACA), public health remains a critical in meeting the needs of the hardest to reach, most vulnerable populations (e.g., MSM, youth, persons who inject drugs) from actively identifying and locating persons at risk, to ensuring linkage to and retention in medical care in a manner that is responsive to the needs of PLWH and/or hepatitis. While the ACA provides opportunities to increase access for many PLWH and/or hepatitis to the care and prevention services needed to help end these twin epidemics, access to insurance alone does not replace the key role of State public health programs to monitor diseases within their borders.

#### HIV/AIDS CARE AND TREATMENT PROGRAMS

The Health Resources and Services Administration (HRSA) administers the \$2.3 billion Ryan White Program that provides health and support services to more than 500,000 PLWH. NASTAD requests a minimum increase of \$65.3 million in fiscal year 2017 for State Ryan White Part B grants, including an increase of \$22.3 million for Part B and \$43 million for AIDS Drug Assistance Programs (ADAPs). The Ryan White Part B Program funds State health departments to provide care, treatment, and support services for low-income uninsured and underinsured individuals living with HIV. With these funds States and territories provide access to HIV clinicians, life-saving and life-extending therapies, and a full range of vital coverage completion services to ensure adherence to complex treatment regimens. The State ADAPs provide medications to low-income PLWH who have limited or no coverage from private insurance, Medicare, and/or Medicaid. Health departments are creating new infrastructure and leveraging existing systems to ensure continuous, high quality care for PLWH. The Ryan White Program continues to serve PLWH in order to ensure that clients do not experience gaps in coverage or access to treatment.

#### HIV/AIDS PREVENTION AND SURVEILLANCE PROGRAMS

NASTAD requests an increase of \$67 million in fiscal year 2017 for CDC’s Division of HIV Prevention (DHAP). The flagship HIV prevention program, HIV Prevention by Health Departments, funds State and local health departments to provide the foundation for HIV prevention and control nationwide. Health departments are the cornerstone implementers of Federal public health policy and are essential to lowering HIV infections. HIV prevention activities and services are targeted to communities where HIV is most heavily concentrated, particularly among racial and ethnic minorities and gay men/MSM of all races and ethnicities.

The number of new HIV infections must decrease in order to see meaningful improvements in individual and community level health outcomes, particularly among disproportionately impacted populations. Of the 1.2 million PLWH, currently, 14 percent are unaware of their infection therefore unable to access adequate care. Furthermore, it is increasingly clear that early detection, linkage to and retention in care, and adherence to treatment will suppress individual and community viral loads and reduce the incidence of HIV. Addressing interventions along the HIV care continuum is our newest and most effective tool to reduce HIV infections; however, health departments need additional support to successfully implement these strategies.

Pre-exposure prophylaxis (PrEP) is a prevention method where a HIV-negative individual takes a daily pill to prevent the acquisition of HIV. Currently, there is limited categorical funding within public health programs to pay for the medication and costs associated with assessment and care engagement of PrEP clients. Often, these patients are among populations being disproportionately impacted by HIV. For these reasons, there needs to be appropriate funding streams for expanding PrEP implementation in public health settings and to provide technical assistance to health departments. NASTAD supports the demonstration project proposed in the President’s Budget that would allow health departments to purchase PrEP and provide other supportive services.

Robust surveillance systems are essential for high-impact prevention, including using surveillance data for program planning and response, strategically directing resources to populations and geographic areas, and linking and retaining individuals in care. Additional resources will allow improvements in core surveillance and expand surveillance for HIV incidence, behavioral risk, and receipt of point of care



information. This will, in turn, contribute to improved testing and linkage to care, retention and re-engagement in care, and reducing risk behaviors.

NASTAD requests that the Committee continue to allow States and localities the discretion to use Federal funds to support cost-effective and scientifically proven, syringe services programs (SSPs). Overwhelming scientific evidence has shown SSPs and access to sterile syringes are an evidenced-based and cost-effective means of lowering HIV and hepatitis infection rates, reducing use of illegal drugs, and helping connect people to HIV and hepatitis medical treatment, including substance abuse treatment.

#### VIRAL HEPATITIS PREVENTION PROGRAMS

NASTAD requests an increase of \$23.8 million in fiscal year 2017 for the CDC's Division of Viral Hepatitis (DVH). This increase will better enable State and local health departments to provide the basic, core public health services to combat hepatitis, increase surveillance, testing and education efforts nationwide and effectively implement the recommendations set by the IOM's Hepatitis and Liver Cancer: A National Strategy for Prevention and Control of Hepatitis B and C, the Action Plan for Viral Hepatitis, and the CDC and United States Preventive Services Task Force viral hepatitis testing recommendations for populations with risk factors, including baby boomers. NASTAD requests that CDC dedicate at least \$14.5 million for the viral hepatitis prevention coordinators (VHPC) program to support and expand programs in all existing jurisdictions. The IOM report and the Viral Hepatitis Action Plan, set prevention goals, established program priorities and assigned responsibilities for actions to HHS operating divisions, including CDC. In turn, CDC has provided funds to State and local health departments to coordinate prevention and surveillance efforts via the VHPC.

For over a decade, the VHPC program has been and remains the only national program dedicated to the prevention and control of the hepatitis epidemics. The CDC has estimated that up to 5.3 million people are living with hepatitis B (HBV) and/or hepatitis C (HCV) in the U.S. and as much as 75 percent are not aware of their infection. Additionally, recent alarming epidemiologic reports indicate a rise in HCV infection among young people throughout the country. Some jurisdictions have noted that the number of people ages 15 to 29 being diagnosed with HCV infection now exceeds the number of people diagnosed in all other age groups combined—a trend that is following the prescription drug overdose epidemic and increasing use of heroin in rural and suburban areas. NASTAD encourages the committee to prioritize disproportionately impacted populations and increase funding for primary prevention efforts.

As you contemplate the fiscal year 2017 Labor-Health-Education Appropriations bill, we ask that you consider all of these critical funding needs. We thank the Chairman, Ranking Member, and members of the Subcommittee, for their thoughtful consideration of our recommendations. Our response to the HIV and hepatitis epidemics in the U.S. defines us as a society, as public health agencies, and as individuals living in this country. There is no time to waste in our Nation's continued fight against these epidemics.

[This statement was submitted by Murray Penner, Executive Director, National Alliance of State and Territorial AIDS Directors.]

#### PREPARED STATEMENT OF THE NATIONAL ALLIANCE ON MENTAL ILLNESS

Chairman Blunt and members of the Subcommittee, I am Mary Giliberti, Chief Executive Officer of NAMI (the National Alliance on Mental Illness). I am pleased, today, to offer NAMI's views on the Subcommittee's upcoming fiscal year 2017 bill. NAMI is the Nation's largest grassroots advocacy organization dedicated to building better lives for the millions of Americans affected by mental illness.

Through NAMI State Organizations and over 900 NAMI Affiliates across the country, we raise awareness and provide support, education and advocacy on behalf of people living with mental health conditions and their families.

An estimated 1 in 5 people live with a mental health condition in the United States which means more than 43 million Americans are affected. Almost 10 million of those live with a serious mental illness, such as schizophrenia, bipolar disorder, and major depression. People with mental health conditions are our neighbors, our families and ourselves. They work in all sectors of the U.S. economy, from the boardroom to the factory floor, from academia to art.

But, without investment in research and appropriate services and supports, the social and economic costs associated with mental health conditions are tremendous.

Over 42,000 American lives are lost each year to suicide, more than 21/2 times the number of lives lost to homicide. Suicide is the 2nd leading cause of death for Americans age 15–24 and the 10th leading cause of death for adults.

Mental illness is the 3rd most costly medical condition in terms of overall healthcare expenditures, behind only heart conditions and traumatic injury. The direct and indirect financial costs associated with mental illness in the U.S. has been estimated to be well over \$300 billion annually.

Investing in mental health research and services and supports can make these startling statistics a thing of the past and improve the lives of millions of Americans who live with mental health conditions and their families. NAMI views these investments as the highest priority for our Nation and this Subcommittee.

#### *National Institute of Mental Health (NIMH) Research Funding*

As a member of the Ad Hoc Group for Medical Research Funding, NAMI supports an overall allocation of no less than \$34.5 billion for the National Institutes of Health (NIH). This \$2.4 billion increase represents 5 percent real growth above the projected rate of biomedical inflation and will help ensure that NIH-funded research can continue to improve our Nation's health and enhance our competitiveness in today's global information and innovation-based economy. As you know, the President is requesting flat funding for the National Institute for Mental Health (NIMH) for fiscal year 2017 at \$1.519 billion. This is extremely disappointing, although the President is requesting an additional \$45 million for the BRAIN Initiative. NAMI is extremely grateful for the strong bipartisan support for NIMH that resulted in the \$85 million increase for fiscal year 2016. It is critical that this momentum continues in fiscal year 2017.

#### *Supporting the NIMH Strategic Plan*

NAMI supports the current 5-year NIMH Strategic Plan and its four overarching goals:

- Leveraging progress in genomics, imaging, and cognitive science to define the biology of complex behaviors,
- Building on the concept of mental disorders as neurodevelopmental disorders to chart trajectories and determine optimal times for interventions,
- Using discoveries to focus on new treatments (and eventually cures) based on precision medicine and moving trials into community settings, and
- Increasing the public health impact of NIMH research through improved services that improve access and quality of care.

#### *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 identify quickly 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 with 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 illnesses 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 in seeking care—up to 2 years in some cases. Such delays result in periods of increased risk for adverse outcomes, including suicides, incarceration, homelessness and in a small number of cases, violence.

NIMH-funded research has focused on the prodrome, the high-risk period preceding the onset of the first psychotic episode of schizophrenia. Through the North American Prodrome Longitudinal Study (NAPLS) and other studies focused on early prediction and prevention of psychosis, NIMH has launched the 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. Through continued development, 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 (CMHS)*

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 of 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 such as assertive community treatment (ACT), 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 \$50 million increase for the MHBG that this Subcommittee enacted for fiscal year 2016, boosting funding to \$532.57 million.

NAMI strongly supports the doubling of the 5 percent set aside in the in the MHBG to 10 percent 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 approach, combining evidence-based services into an effective, coordinated package. CSC emphasizes shared decision-making—which NAMI strongly supports—with the recipient of services taking an active role in determining treatment preferences and recovery goals.

In 2014, CMHS issued guidance to the States specifying that funding as part of this 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 10 percent set aside for FEP in fiscal year 2017 and beyond. It is critically important for Congress to continue supporting the replication of evidence-based FEP programs in all 50 States. In addition to the MHBG set-aside, NAMI also supports the President's request for a new \$115 million State formula grant program for evidence-based early intervention in serious mental illness.

NAMI also recommends the following priorities for CMHS for fiscal year 2017:

- Continuation of the Children's Mental Health program at \$117 million,
- Suicide prevention programs under the Garrett Lee Smith Memorial Act at \$41.6 million,

—\$15 million in funding for States and localities as part of the Assisted Outpatient Treatment (AOT) pilot program as authorized by Congress in Section 224 of Public Law 113–93). NAMI is grateful for the initial allocation of funding made available by the Subcommittee for the AOT pilot for fiscal year 2016. NAMI supports efforts develop a variety of approaches to engaging people with serious mental illness in treatment, including voluntary approaches for engaging people before they reach the point of requiring court-based interventions.

*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 illnesses and substance use disorders are screened and treated at 126 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 reject the President’s proposal to cut this program by \$23.8 million in fiscal year 2017 and fund the PBHCI at \$50 million.

*Addressing the Needs of Homeless Individuals Living with Serious Mental Illness*

NAMI recommends allocating \$100 million for services in permanent supportive housing at CMHS. Years of reliable data and research demonstrate that the most successful intervention to solve chronic homelessness is linking housing to appropriate support services. Current SAMHSA investments in homeless programs are highly effective and cost-efficient. However, funding for SAMHSA homeless programs has remained flat for the past 4 years, often making it difficult for communities to increase the number of homeless households they are serving with the service dollars. As communities are investing additional housing resources into serving high-need homeless populations, Congress should increase investments in services to help those populations address their long-term health related issues.

For the Projects for Assistance in Transition from Homelessness (PATH) program, NAMI recommends \$75 million for fiscal year 2017. PATH provides funding for essential outreach to homeless people with serious mental illness and helps them navigate both the homeless and mainstream services systems to get the services they need. PATH-supported programs served over 185,000 people through outreach in fiscal year 2014. Of these, 28 percent were unsheltered at the time they started receiving PATH services. 64 percent needed mental health services and 52 percent had co-occurring substance use disorders. NAMI also recommends an allocation of \$10 million from PATH to a demonstration program to create permanent statewide coordination capacity for the SSI/SSDI Outreach, Access and Recovery (SOAR) program. Finally, NAMI urges an allocation of \$100 million, the fully authorized level, for services for people experiencing homelessness within the Programs of Regional and National Significance (PRNS) accounts of both SAMHSA’s Center for Mental Health Services and Center for Substance Abuse Treatment.

CONCLUSION

Chairman Blunt, thank you for the opportunity to share NAMI’s views on the Labor-HHS-Education Subcommittee’s fiscal year 2017 bill. NAMI’s members across the country thank you for your leadership on these important national priorities.

[This statement was submitted by Mary Giliberti, Chief Executive Officer, National Alliance on Mental Illness.]

PREPARED STATEMENT OF THE NATIONAL ALLIANCE TO END SEXUAL VIOLENCE

Thank you for the opportunity to present outside written testimony to the U.S. House of Representatives, Committee on Appropriations’ Labor, Health and Human Services, Education, and Related Agencies Subcommittee. I am Monika Johnson Hostler, President of the Board of Directors 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 2017 Department of Health and Human Services Federal funding to support comprehensive rape prevention and education and direct services for victims of sexual violence. Specifically, NAESV is urging Congress to provide \$50 million, including at least \$5.6 million in additional program dollars to meet the local demand for prevention and education and the implementation of evidence-based strategies through the Rape Prevention & Education program (RPE) in the Centers for Disease Control

and Prevention's (CDC) National Center for Injury Prevention and Control, Intentional Injury Prevention 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 victim services and prevention, in CDC's State, Tribal, Local and Territorial Support program 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 2015 Rape Crisis Center Survey, distributed by NAESV, demonstrated that almost half of rape crisis centers had to decrease the number of public awareness or prevention services due to insufficient funding while over 1/3 of rape crisis centers could not provide counseling services within 1 month of a request. High profile cases of sexual assault on campuses, our military bases, military academies, and by celebrities and professional athletes have resulted in unprecedented media attention. This has also resulted in a tremendous increase in sexual assault survivors seeking assistance from local rape crisis centers, as well as an increase in educators and community organizations requesting prevention and training services. The media attention certainly points to the need for comprehensive community responses to sexual violence like those funded through the CDC Rape Prevention and Education program and the Preventive Health and Health Services Block Grant. As you begin the fiscal year 2017 appropriations process, please fund these programs so critically important to the prevention and response to sexual assault.

*Rape Prevention and Education (RPE)*

The National Alliance to End Sexual Violence urges Congress to appropriate \$50 million, including at least \$5.6 million in additional program dollars to meet the demand for prevention and education and the implementation of evidence-based strategies. Funding for RPE through the CDC Injury Center's budget for Intentional Injury Prevention strengthens sexual violence prevention efforts at the State and local levels. The RPE program 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 brings 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 and the focus on campuses have increased the demand for prevention and education in middle and high schools, as well as the community, beyond the current capacity of State sexual assault coalitions and local rape crisis centers. Program funding must be increased in this unprecedented time of opportunity. With fiscal year 2013 funding, the program reached over 2 million students, answered 340,000 hotline calls, and trained nearly 160,000 professionals about sexual abuse.

*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. We support the CDC's proposed budget request for evaluation funds, but not at the expense of program funding. We do not want program funds diverted from the communities at a time when demand and opportunity for prevention and education, as well as services, is increasing at such a rapid rate. Increased program funding is required to avoid critical shortfalls at a time of increased awareness and opportunity for prevention and education.

In fiscal year 2016, CDC plans to fund a maximum of five academic or research institutions to evaluate prevention strategies that are being used in communities to address immediate and divergent needs in the field, but have limited research evidence to show effectiveness in reducing rates of sexual violence. In order to build RPE program evaluation capacity at the State health department level, CDC will fund state-wide evaluations to better assess how RPE prevention efforts are impacting health outcomes, sexual violence risk and protective factors, and rates of sexual violence. Efforts will be made to improve data collection and performance measures.

Additional research will be done to build evaluation capacity of RPE grantees and identify community developed prevention strategies ready for rigorous evaluation. Within the past year, CDC decided to make “state level evaluation” mandatory despite many States starting local, regional or targeted evaluation efforts. It was the CDC’s stated perspective that this would be “less labor intensive.” However, this strategy forced everyone down one path, without a recognition of the work and progress that was currently underway in many States, nor of each State’s individual goals, projects or bandwidth to accomplish the work. Strong partnerships between evaluators and community-based sexual assault programs and State sexual assault coalitions engaged in prevention are essential for success.

In fiscal year 2015, CDC funded two awards to evaluate strategies that engage boys/men for their impact on rates of sexual violence perpetration. An additional two research grants were awarded to focus on rigorously evaluating primary prevention strategies for dating and sexual violence among youth. One grant focuses on bystander prevention while the second grant examines a program which trains athletic coaches to modify gender norms that contribute to dating and sexual violence and to promote bystander intervention skills. Research results and recommendations are pending.

*Preventive Health & Health Services Block Grant (PHHSBG)*

We are very grateful for the fiscal year 2015 and fiscal year 2016 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 and CDC moved its administration from Chronic Disease to State, Tribal, Local and Territorial Support. Congress provided a rape set-aside provision which guarantees at least \$7 million for rape services and prevention. Please retain the block grant funding that supports local rape crisis centers providing services, statewide training and technical assistance to increase capacity to assist rape victims and prevent future victimization. Maximum funding is requested.

We must have the resources to meet the education and prevention needs in the community. Victims deserve support, our young people deserve to grow up safely, and research tells us that appropriate and early intervention and prevention can mitigate the costs and consequences of sexual violence and prevent that violence from occurring in the first place. The best way to prevent victimization is to prevent first time perpetration. The best way to convict a rapist is to support and advocate for the victim, obtain evidence and provide assistance and training to law enforcement. At this time of increased media attention, increased demand for services, increased demand for education in the schools and among community organizations, now is the best time for the implementation of community based prevention strategies.

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 2017 Appropriations bill. If we can provide further information, please contact me at [monika@nccasa.org](mailto:monika@nccasa.org) and [www.endsexualviolence.org](http://www.endsexualviolence.org), or Terri Poore, NAESV Public Policy Director, at [terri@endsexualviolence.org](mailto:terri@endsexualviolence.org). National Alliance to End Sexual Violence, 1129 20th Street, NW, Suite 801, Washington, DC 20036.

[This statement was submitted by Monika Johnson Hostler, President, Board of Directors, National Alliance to End Sexual Violence.]

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PREPARED STATEMENT OF THE NATIONAL ALOPECIA AREATA FOUNDATION  
THE ASSOCIATIONS’S FISCAL YEAR 2017 L-HHS APPROPRIATIONS RECOMMENDATIONS

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- \$7.8 billion in program level funding for the Centers for Disease Control and Prevention (CDC), which includes budget authority, the Prevention and Public Health Fund, Public Health and Social Services Emergency Fund, and PHS Evaluation transfers.
  - A proportional fiscal year 2017 funding increase for CDC’s National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP).
  - At least \$34.5 billion in program level funding for the National Institutes of Health (NIH).

—Proportional funding increases for National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) and the National Center for Advancing Translational Science (NCATS).

Chairman Blunt 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 2017 L-HHS Appropriations Bill.

#### ABOUT ALOPECIA AREATA

Alopecia areata is a prevalent autoimmune skin disease resulting in the loss of hair on the scalp and elsewhere on the body. It usually starts with one or more small, round, smooth patches on the scalp and can progress to total scalp hair loss (alopecia totalis) or complete body hair loss (alopecia universalis).

Alopecia areata affects approximately 2.1 percent of the population, including more than 6.5 million people in the United States alone. The disease disproportionately strikes children and onset often occurs at an early age. This common skin disease is highly unpredictable and cyclical. Hair can grow back in or fall out again at any time, and the disease course is different for each person. In recent years, scientific advancements have been made, but there remains no cure or indicated treatment options.

The true impact of alopecia areata is more easily understood anecdotally than empirically. Affected individuals often experience significant psychological and social challenges in addition to the biological impact of the disease. Depression, anxiety, and suicidal ideation are health issues that can accompany alopecia areata. The knowledge that medical interventions are extremely limited and of minor effectiveness in this area further exacerbates the emotional stresses patients typically experience.

#### ABOUT THE FOUNDATION

NAAF, headquartered in San Rafael, California, supports research to find a cure or acceptable treatment for alopecia areata, supports those with the disease, and educates the public about alopecia areata. NAAF is governed by a volunteer Board of Directors and a prestigious Scientific Advisory Council. Founded in 1981, NAAF is widely regarded as the largest, most influential, and most representative foundation associated with alopecia areata. NAAF is connected to patients through local support groups and also holds an important, well-attended annual conference that reaches many children and families.

Recently, NAAF initiated the Alopecia Areata Treatment Development Program (TDP) dedicated to advancing research and identifying innovative treatment options. TDP builds on advances in immunological and genetic research and is making use of the Alopecia Areata Clinical Trials Registry which was established in 2000 with funding support from the National Institute of Arthritis and Musculoskeletal and Skin Diseases; NAAF took over responsibility financial and administrative responsibility for the Registry in 2012 and continues to add patients to it. NAAF is engaging scientists in active review of both basic and applied science in a variety of ways, including the November 2012 Alopecia Areata Research Summit featuring presentations from the Food and Drug Administration (FDA) and NIAMS.

#### THE PATIENT PERSPECTIVE

*Vashti Wood—Reston, VA.*—Alopecia areata is an autoimmune skin disease that impacts millions of Americans, including children. There are currently no FDA-approved therapies indicated to treat alopecia areata and options for affected individuals are extremely limited.

My daughter Sophia, now 9 has, alopecia universalis. She was 1st diagnosed at 5. The 1st time only 40–50 percent fell out and then grew back and for almost 3 years she had a full head that she combed admirably many times a day and was a bit obsessed with it for her age but I could understand since she had experienced the loss. About a year ago, I noticed a bald spot the size of a pencil eraser and within days it was the size of a softball, and within weeks every piece of her beautiful hair was gone. One of the hardest things in my life was trying to stay strong for her and not burst into tears every time I looked at her beautiful face and bald head, but I had to be because she was not. It was devastating to her and she cried and cried. A few months ago her eyebrows disappeared and then her eyelashes. She is a vibrant girl and one who had much confidence but this condition has taken that away. I fear for the challenges she has ahead of her, going into puberty and middle

school is so stressful and hard even for those that appearance is perfect, that I will do anything and everything in my power to try to find a way to get her hair back. We have put \$1,000's of dollars on credit cards this past year for hair accessories, a wig, finding herbs from Australia and having them shipped here to the U.S., holistic doctor (that insurance doesn't cover at all), and of course dermatologist to no avail unless I would like to put or inject steroids into my 9 year old. No thanks! My husband and I fight over what I am spending and doing and that breaks our daughter's heart even more, but I refuse to not keep trying. I have asked her, do you want me to keep searching, trying things or do you want me to stop? She wants me to keep on finding a way to get her hair back.

I thank you on behalf of myself and of the entire alopecia areata community for consideration of NAAF's requests.

#### 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, researchers at Columbia University Medical Center (CUMC) have identified the immune cells responsible for destroying hair follicles in people with alopecia areata and have tested an FDA-approved drug that eliminated these immune cells and restored hair growth in a small number of patients. This huge breakthrough lead to NIAMS providing a research grant to the researchers at Columbia to continue this work. In this regard, please provide NIH with meaningful funding increases to facilitate growth in the alopecia areata research portfolio.

#### 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 jurisdiction 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.

Additionally, Congresswoman Ileana Ros-Lehtinen is working with the community on introducing a bill that will allow for Medicaid to cover a significant portion of the cost of a cranial prostheses when a doctor deems it medically necessary. The disease can be incredibly debilitating not only physically and psychologically but financially as well. This bill is designed to help lessen the burden placed upon those effected by the disease. Please consider cosponsoring the bill when it is introduced.

Thank you for your time and your consideration of the community's requests.

[This statement was submitted by Dory Kranz, Chief Executive Officer, National Alopecia Areata Foundation.]

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#### PREPARED STATEMENT OF THE NATIONAL ASSOCIATION FOR GERIATRIC EDUCATION

As members of and president of the National Association for Geriatric Education (NAGE), we are pleased to submit this statement for the record recommending at least \$44.7 million in fiscal year 2017 to support geriatrics programs under the Geriatrics Workforce Enhancement Program (GWEP) administered by the Health Resources and Services Administration (HRSA). We thank you for your past support.

Last year, the Health Resources and Services Administration (HRSA) combined the geriatric education programs in Titles VII and VIII along with portions of the Alzheimer's Disease Prevention, Education, and Outreach Program to establish the Geriatrics Workforce Enhancement Program (GWEP). The GWEP is now the only Federal program designed to improve healthcare quality and safety for older adults, plus reduce associated costs of care through appropriate training of healthcare professionals, caregivers, and direct service workers. Proven results from activities under the predecessor programs include an important increase in the number of teaching faculty with geriatrics expertise in a variety of disciplines, plus thousands of healthcare providers and family caregivers better prepared to support older Americans. Therefore, NAGE requests a total of at least \$44.7 million for these programs which are critical to caring for the elderly population. They were funded at \$38.7 million in fiscal year 2016.

We recognize that the Subcommittee faces difficult decisions in a constrained budget environment, but we believe that a continued commitment to geriatric edu-



cation 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 65 years of age. There simply are not enough geriatricians, geriatric nurse practitioners and other health professionals trained in geriatrics needed to care for this rapidly increasing older population. Too often, the result is expensive walk-in care. We believe that funding for GWEP-based geriatric education supports your important work to establish a sustainable future for the Nation's healthcare and Social Security systems by ensuring that (a) healthcare specialists trained in geriatric care do not become a rare and expensive resource and (b) direct service workers and family caregivers are prepared to support a lower cost, independent lifestyle for community residing elders.

Under the new structure of GWEP, forty newly funded education centers continue much of the work conducted by Geriatric Education Centers (GEC), Comprehensive Geriatric Education Programs (CGEP), Geriatric Academic Career Awards (GACA), and Geriatric Training for Physicians, Dentists and Behavioral and Mental Health Providers (GTPD) awards. A primary purpose of these GWEP centers is to continue training healthcare professions faculty, students, and field practitioners in inter-professional diagnosis, management and prevention of disease, disability, and other chronic health problems of older adults.

Although baseline data for the new program will be set to fiscal year 2015, it will not be reported until the fiscal year 2018 budget. However, HRSA's fiscal year 2016 Justification of Estimates for Appropriations Committees notes that for the 2014–2015 reporting year, these programs accomplished an extraordinary amount of work:

- GEC programs provided over 2,800 unique continuing education courses to over 150,900 faculty members and practicing providers, exceeding the program's performance goals again. GEC grantees offered training at primary care settings and/or in medically underserved communities, and many of the courses focused on Alzheimer's disease treatment and education.
- Grantees also provided more than 39,100 clinical training experiences for healthcare professions students at more than 1,770 healthcare delivery sites, with 32 percent located in medically-underserved communities.
- GEC grantees supported the training of faculty in geriatrics with more than 2,900 structured faculty development programs with more than 13,200 faculty members receiving training in geriatric-related topics.

New GWEP awardees received expanded authorization to provide to family caregivers and direct service workers instruction on prominent issues in the care of older adults, such as Alzheimer's disease and other dementias, palliative care, self-care, chronic disease self-management, falls, and maintaining independence, among others.

Geriatric education programs have improved the supply, distribution, diversity, capabilities, and quality of healthcare professionals who care for our Nation's growing older adult population, including the underserved and minorities. 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 and those who have benefitted in Missouri and North Carolina and from our colleagues around the country, thank you for this opportunity to share our request for support for these important programs. We ask that you thoughtfully consider our request for funding in fiscal year 2017.

NAGE is a non-profit membership organization representing Geriatrics Workforce Enhancement Programs, Geriatric Education Centers, and other programs that provide education and training to health professionals in the areas of geriatrics and gerontology.

[This statement was submitted by John E. Morley, MB, BCh, Saint Louis, University School of Medicine, Dammert Professor of Gerontology, Chair, Division of Geriatric Medicine & Department of Endocrinology; Marla Berg-Weger, Ph.D., LCSW, Executive Director, Saint Louis University Gateway Geriatric Education Center, Professor, Saint Louis University School of Social Work; Jan Busby-Whitehead, MD, Mary and Thomas Hudson Distinguished Professor of Medicine, Chief, Division of Geriatric Medicine, Department of Medicine, Director, Center for Aging and Health, University of North Carolina School of Medicine.]

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF CLINICAL NURSE  
SPECIALISTS

The National Association of Clinical Nurse Specialists (NACNS) is the voice of more than 72,000 clinical nurse specialists (CNSs). CNSs are licensed advanced practice registered nurses (APRN) who have graduate preparation (master's or doctorate) in nursing as a clinical nurse specialist. They have unique and advanced level competencies that meet the increased needs of improving quality and reducing costs in today's healthcare system. CNSs provide direct patient care, including assessment, diagnosis, and management of patient healthcare issues. They are leaders of change in health organizations, developers of scientific evidence-based programs to prevent avoidable complications, and coaches of those with chronic diseases to prevent hospital readmissions. CNSs are facilitators of multidisciplinary teams in acute and chronic care facilities to improve the quality and safety of care, including preventing hospital acquired infections, reducing length of stays, and preventing hospital readmissions.

The NACNS urges the subcommittee to fund the Title VIII Nursing Workforce Development Programs at \$244 million in fiscal year 2017.

According to the Bureau of Labor Statistics (BLS), the registered nurse (RN) workforce will grow 16 percent from 2014 to 2024, outpacing the 7 percent average for most other occupations. BLS also projects that this growth will result in 439,300 job openings, representing one of the largest numeric increases for all occupations.

In addition, employment of APRNs is projected to grow 31 percent from 2014 to 2024, much faster than the average for all occupations. Growth will occur because of an increase in the demand for healthcare services. Several factors will contribute to this demand, including a large number of newly insured patients resulting from healthcare legislation, an increased emphasis on preventive care, and the large, aging baby-boom population.

BLS notes that the healthcare sector is a critically important industrial complex for the Nation. It is key to economic recovery with the number of jobs climbing steadily. Healthcare jobs are up nationwide, and BLS projects health-care occupations and industries to have the fastest employment growth and which will add the most jobs between 2014 and 2024. Over three 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 4.331 million active, licensed RNs in the United States in January 2016.

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. NACNS 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 today. 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 more than 15-year nurse and nurse faculty shortage felt throughout the U.S. health system.

NACNS believes 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, advanced practice registered nurses, and qualified nurse educators are addressed. Your support will help ensure that future nurses exist 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 the Nation today, it will be difficult to avoid the adverse effects on the health of our Nation from the inability of our under resourced nursing education programs to produce sufficient numbers of high quality RNs and APRNs.

In closing, NACNS urges the subcommittee to maintain the Title VIII Nursing Workforce Development Programs by funding them at a level of \$244 million in fiscal year 2017.

## PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF COMMUNITY HEALTH CENTERS

## INTRODUCTION

Chairman Cochran, Ranking Member Murray, and Members of the Subcommittee: on behalf of our Nation's community health centers, we wish to thank you for the opportunity to submit testimony for the record as you consider the fiscal year 2017 Labor-Health and Human Services-Education and Related Agencies Appropriations bill.

## HEALTH CENTERS-GENERAL BACKGROUND

For over 50 years, health centers have been operating as community-owned, non-profit entities providing primary medical, dental, and behavioral healthcare as well as pharmacy and a variety of enabling and support services to patients and communities in need. In 2014, over 1,300 health center organizations served more than 9,000 urban and rural communities nationwide, serving as the "healthcare home" for more than 24 million patients, including nearly 7 million children and nearly 300,000 veterans. Health centers operate in all 50 States, the District of Columbia, all U.S. Territories, and nearly every Congressional district.

By statute and mission, health centers are located in medically underserved areas (or serve medically underserved populations) and are governed by patient-majority boards 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, regardless of ability to pay or insurance status, and offer services on a sliding fee scale. Health centers' unique model of care has resulted in savings to the entire health system of approximately \$24 billion annually. Health center care reduces preventable hospitalizations and emergency department (ED) use, as well as the need for more expensive specialty care. The services provided at health centers save \$1,263 per patient per year when compared to expenditures for non-health center patients.

In addition to reducing costs, health centers also serve as small businesses and economic drivers in their communities. Health centers employ over 175,000 individuals and generate an estimated \$26.5 billion in needed economic activity for communities that need it the most.

## FISCAL YEAR 2016 FUNDING BACKGROUND

We want to thank the members of this Subcommittee for their strong support of health centers within the Consolidated and Further Continuing Appropriations Act of 2016 to ensure health center funding continues to reach communities in need. In fiscal year 2016, the Health Centers program received a total of \$5.1 billion in total Federal funding. This includes \$1.49 billion in discretionary funding provided by the Subcommittee and \$3.6 billion in mandatory funding for health centers through the continuation of Community Health Center Fund in H.R. 2, the Medicare Access and CHIP Reauthorization Act of 2015 (MACRA).

## FISCAL YEAR 2017 FUNDING REQUEST

Thanks to investments by Congress and with support from this Subcommittee, health centers have doubled the number of patients served since 2000 and expanded to new communities. Since 2005, health centers have gone from serving one in five Americans living in poverty to one in four, and today serve a higher proportion of the uninsured than at any time in the last 10 years. In addition to serving more people and communities, health centers are offering an increasingly comprehensive range of services on-site—81 percent now offer mental health and/or substance abuse treatment, 77 percent offer oral health, and 40 percent offer pharmacy. However, continued investment is needed to make each health center a truly integrated "one-stop shop" for patient care.

Therefore, health centers are respectfully requesting Congress and this Subcommittee ensure funding for the Health Centers Program remains whole and does not suffer any funding reductions in fiscal year 2017, within either the discretionary or mandatory funding streams. This includes rejecting proposals to shift funds to mandatory spending with a corresponding reduction in discretionary funding below fiscal year 2016 levels. Continued funding for the Health Centers Program at the fiscal year 2016 program level of \$5.1 billion is consistent with the levels outlined on an overwhelmingly bipartisan basis in MACRA and will preserve the high quality cost-effective primary care offered today at health centers across the country.

We also have support from a record number of Members of Congress for continued health center funding. In March, 62 Senators signed a letter led by Sens. Roger Wicker (R-MS) and Debbie Stabenow (D-MI) to this Subcommittee as part of the annual appropriations process. The letter highlighted the important role of health centers in providing primary care and their proven track record of success in fostering innovation and cost savings within the healthcare system. A copy of the letter can be viewed here: <http://www.nachc.com/client/FY17%20Final%20SIGNED%20CHC%20letter.pdf>.

#### LEVERAGING INVESTMENTS IN ACCESS WITH A ROBUST CLINICAL WORKFORCE

As the health center model has grown and evolved to meet the increasingly complex needs for care in underserved communities, combating workforce shortages has been a constant battle for health centers. Though the ranks of health center clinical care staff have nearly doubled since 2000, workforce shortages are limiting the ability of individual health centers to serve as many patients as they could if fully staffed. A recent report issued by NACHC focusing on clinical workforce needs, entitled *Staffing the Safety Net: Building the Primary Care Workforce at America's Health Centers*, found that virtually all health centers are experiencing at least one clinical vacancy and that 70 percent of health centers say they currently have at least one vacancy for a family physician. The crucial finding related to how much further health centers collectively could leverage Federal investments: according to their own projections, if fully staffed, health centers could serve an additional two million patients.

Addressing the workforce needs of health centers is a major factor in providing high quality care to all patients. Health centers work synergistically with the National Health Service Corps (NHSC) to address staffing needs, but are also working to “grow our own” workforce through residency training programs at health centers including through Teaching Health Centers and Nurse Practitioner Residency Training Programs. However, while roughly half of all National Health Service Corps clinicians serve in health centers, many health centers still cannot gain access to NHSC providers due to insufficient funding for the program. We feel now, more than ever, is the time for sustainable investments by Congress in order for health centers to meet existing and future demands for care. We urge the Subcommittee to fund the National Health Service Corps at the President's Budget request of \$380 million, to provide scholarships and loan repayment to thousands more clinicians.

Of course, we are also looking towards the end of fiscal year 2017 when funding provided under MACRA for the Health Center Fund is set to expire again. Without Congressional action, health centers will once again face a 70 percent reduction of funding. A reduction in funding of that magnitude will directly impact every health center in nearly every Congressional district. When facing this potential reduction in 2015, we estimated 7.4 million patients would have lost access to care at their local health center and nearly 57,000 clinicians and other staff would have lost their jobs—given recent investments called for by Congress, these numbers would almost surely be higher if this funding were to expire next year. We strongly believe the Federal investments that support the health center system of care must be sustained and stabilized to ensure access to care is not disrupted. To that end, we look forward to working with the members of the Subcommittee to ensure the “Health Center Funding Cliff” will not occur. We urge Congress to take action well before the September 2017 expiration of the Health Center Fund to make the Health Centers Fund permanent and reduce the uncertainty caused by year-by-year renewals of this critical investment in access to care.

#### CONCLUSION

As the fiscal year 2017 appropriations process moves forward, we urge you to maintain current funding levels for our Nation's health centers. Despite the progress made in expanding the program in recent years, health centers continue to see unmet need in our communities and are experiencing increased demand. Though some health center patients have gained insurance, this doesn't automatically translate into meaningful access to care. Health centers are still serving a large number of under-insured patients, as well as those who remain uninsured. We are extremely grateful for your past support and ask for the Subcommittee's continued support for the Health Centers 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, National Association of Community Health Centers.]

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. City, county, metropolitan, district, and tribal health departments work to ensure the public's health and safety. On behalf of local health departments, NACCHO submits the following requests:

*Emergency Funding for Zika Virus*

NACCHO urges Congress to provide emergency supplemental funding without delay to respond to the Zika virus. Recently the Centers for Disease Control and Prevention (CDC) announced that evidence links the virus to serious health impacts, miscarriages and birth defects. With this funding, State and local health departments would be supported by CDC with increased virus readiness and response capacity; enhanced laboratory, epidemiology and surveillance capacity in at-risk areas to reduce the opportunities for Zika transmission and surge capacity through rapid response teams to limit potential clusters of Zika virus in the United States.

*Public Health Emergency Preparedness—CDC*

NACCHO urges the Subcommittee to provide \$675 million for the Public Health Emergency Preparedness (PHEP) cooperative agreements in fiscal year 2017. Sustained funding to support local preparedness and response capacity is needed to make sure that every community is prepared for emergencies including infectious diseases like Zika and mumps, as well as severe and frequent weather events causing natural disasters. CDC cut \$44 million from PHEP grants in fiscal year 2016 to transfer to the agency's response to the Zika virus. More than 55 percent of local health departments rely solely on Federal funding for emergency preparedness.

*Hospital Preparedness Program—Assistant Secretary for Preparedness and Response (ASPR)*

The Hospital Preparedness Program (HPP) provides grant funding to States and four directly funded cities to enhance regional and local hospital preparedness through regional healthcare coalitions (HCCs). NACCHO urges Congress to begin restoring HPP funding that was cut by a third (\$104 million) in fiscal year 2014 by increasing it to \$300 million in fiscal year 2017.

*Medical Reserve Corps—ASPR*

In 2002, the Medical Reserve Corps (MRC) was created after the terrorist attacks of 9/11 to establish a way for medical, public health, and other volunteers to address local health and preparedness needs. These highly skilled volunteers include doctors, dentists, nurses, pharmacists, and other community members. The program is comprised of 200,000 volunteers enrolled in 1,000 units in all 50 States and territories. Two-thirds of MRC units are coordinated by local health departments. NACCHO opposed the President's proposed cut to MRC in fiscal year 2016 and requests \$11 million in funding in fiscal year 2017 to restore funding to the fiscal year 2014 level.

*Section 317 Immunization Program—CDC*

In an effort to prevent and control the spread of infectious diseases, the promotion of vaccinations to reduce the spread of disease is needed more now than ever. In 2014, the United States experienced the greatest number of cases since measles elimination was documented in the U.S. in 2000. The 317 Immunization Program funds vaccine purchase for at-need populations and immunization program operations, including support for implementing billing systems. NACCHO opposes the President's \$50 million cut in fiscal year 2017 and supports the \$8 million included in the President's budget to build health department capacity for billing to provide reimbursement for services.

*Core Infectious Diseases, Including Antibiotic Resistance and Vector-Borne Diseases—CDC*

The Core Infectious Disease Program identifies and monitors the occurrence of known infectious diseases and new emerging diseases and respond to outbreaks. Funding for this program also addresses antibiotic resistance, emerging infections, healthcare-associated infections, infectious disease laboratories, high-consequence pathogens, and vector-borne diseases. NACCHO supports the President's \$40 million increase (\$428 million total) for fiscal year 2017.

*Prescription Drug (Opioid) Overdose Prevention—CDC*

The Prescription Drug (Opioid) Overdose Prevention Program provides States with the funding for prescription drug abuse and overdose prevention programs in the hardest hit communities, enhances prescription drug monitoring programs (PDMPs), implements insurer and health system interventions to improve prescribing practices, and collaborates with a variety of State entities such as law enforcement. The number of deaths due to opioid overdose has increased to 78 people per day. Thus, NACCHO supports the President's \$10 million increase (\$80 million total) for fiscal year 2017 and urges CDC to ensure that these funds reach local communities in order to respond effectively to this epidemic.

*Childhood Lead Poisoning Prevention—CDC*

NACCHO supports the restoration of childhood lead prevention funding to the fiscal year 2010 level of \$35 million in fiscal year 2017. The recent tragedy of lead poisoning in Flint, MI emphasizes the need to tackle this continuing public health threat. This program provides funding for 29 State and 6 city health departments to identify families with harmful exposure to lead, track incidence and causes, inspect homes and remove environmental threats, connect children with appropriate services, and provide education to healthcare providers as well as the public.

*Preventive Health and Health Services Block Grant—CDC*

NACCHO urges the rejection of the President's proposed elimination (a cut of \$160 million) of the Preventive Health and Health Services (PHHS) Block Grant. The PHHS Block Grant gives States the autonomy and flexibility to solve State problems and support similar issues in local communities, with accountability for demonstrating the impact of their investments. NACCHO also asks for report language asking CDC to report the amount of money going to the local level.

*Prevention and Public Health Fund—HHS*

In fiscal year 2017, 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 and continued allocation of the PPHF through the annual appropriations process.

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PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF NUTRITION AND AGING SERVICES PROGRAMS

Chairman Blunt, Ranking Member Murray: On behalf of the National Association of Nutrition and Aging Services Programs (NANASP), an 1,100-member nonpartisan, nonprofit, membership organization for national advocates for senior health and well-being, we thank you for the opportunity to offer testimony in support of the Department of Health and Human Services' proposed increase of \$13.8 million for Older Americans Act Title III(C) senior nutrition programs within the Administration for Community Living, and in support of, at a minimum, the President's request for level funding for the Senior Community Service Employment Program within the Department of Labor.

OLDER AMERICANS ACT TITLE III(C) SENIOR NUTRITION PROGRAMS

Older Americans Act congregate and home-delivered meals programs are provided in every State and congressional district in this Nation. Approximately 2.4 million seniors in 2014 received these services. Studies have found that 50 percent of all persons age 85 and over need help with instrumental activities of daily living, including obtaining and preparing food. Older Americans Act nutrition programs address these concerns. Thus, these meal recipients are able to remain independent in their homes and communities and are not forced into hospitals or nursing homes due to an inability to maintain a proper diet.

In addition, for participants in the congregate program, the nutrition programs provide a daily opportunity for socialization, preventing isolation and promoting health and wellness. For home-delivered meals recipients, their delivery driver may be the only person they see all day—therefore, this wellness check is also key to their health.

In fiscal year 2016, Older Americans Act Title III(C) programs received appropriations in the amount of \$835 million. Though we are thankful that this represents an increase from fiscal year 2015, unfortunately, this does not keep pace with the rising cost of food, inflation, and the growing numbers of older adults. In fact, year over year, the number of older adults receiving meals is shrinking even as the need is growing.

The additional \$13.8 million in funding for congregate and home-delivered meals will help to counteract inflation and provide more than 1.3 million additional meals. This does not keep up with the growing demand for services, but it would at least prevent further reductions in services. As we saw in fiscal year 2013 when sequestration was in effect, our programs had lengthy wait lists and some sites even closed for lack of funding. One NANASP program created its first wait list in over 90 years of operation.

Investing in these programs is cost-effective because many common chronic conditions such as hypertension, heart disease, diabetes, and osteoporosis can be effectively prevented and treated with proper nutrition. The Academy of Nutrition and Dietetics estimates that 87 percent of older adults have or are at risk of hypertension, high cholesterol, diabetes, or some combination of all of these. These seniors need healthy meals, access to lifestyle programs, and nutrition education and counseling to avoid serious medical care.

Older adults who are not receiving proper meals can also become malnourished and undernourished. This makes it harder for them to recover from surgery and disease, makes it more difficult for their wounds to heal, increases their risk for infections and falls, and decreases their strength that they need to take care of themselves. Malnourished older adults are more likely to have poor health outcomes and to be readmitted to the hospital—their health costs can be 300 percent greater than those who are not malnourished on entry to the healthcare system.

Access to Older Americans Act meals is essential to keeping these older adults out of costly nursing facilities and hospitals. On average, a senior can be fed for a year for about \$1,300. The cost of feeding a senior for a year is approximately the same as the cost of one day's stay in a hospital or less than the cost of 10 days in a nursing home. The cost savings to Medicare and Medicaid that this creates cannot be over-emphasized. One study estimates that for every dollar invested in the Older Americans Act nutrition programs, Medicaid saves \$50.

Further, these services are designed to target those in the “greatest social and economic need,” according to the Older Americans Act and to actual practice in the field. According to ACL's studies, approximately two-thirds of home-delivered meal recipients have annual incomes of \$20,000 or less. Sixty-two percent of these recipients report that these meals represent at least half their food intake each day. And yet, the Government Accountability Office found that only about 9 percent of low-income older adults are even receiving meals services. For a small investment, more at-risk older adults could receive nutritious meals.

#### SENIOR COMMUNITY SERVICE EMPLOYMENT PROGRAM

The Senior Community Service Employment Program (SCSEP), also known as Community Service Employment for Older Americans, is authorized by the Older Americans Act but administered and funded by the Department of Labor. SCSEP is the only Federal program targeted to serve specifically older adults seeking employment and training assistance; moreover, the Government Accountability Office has previously identified SCSEP as one of only three Federal workforce programs with no overlap or duplication.

SCSEP currently provides jobs for about 67,000 older adults in every State and territory, and in nearly every county in every State. Many of these jobs are in the service of other older adults—SCSEP participants may work as senior center staff members, transportation providers, or home-delivered meals cooks and drivers. The average age of a program participant is 62; according to the Department of Labor, 65 percent of all SCSEP participants in Program Year 2012 were women, 46 percent were minorities, and 88 percent were at or below the Federal poverty level.

NANASP has one SCSEP national grantee and approximately 80 SCSEP State and local sub-grantees who are NANASP members, as well as many nutrition providers among our membership who have SCSEP employees on staff.

SCSEP, as authorized by Title V of the Older Americans Act (OAA), has a dual purpose: “to foster individual economic self-sufficiency and to increase the number of participants placed in unsubsidized employment in the public and private sectors, while maintaining the community service focus of the program.”

By providing subsidized employment opportunities for this highly vulnerable and underemployed/unemployed segment of the population, SCSEP helps participants build their resumes and receive the training they need to transition into unsubsidized employment. These subsidized employment opportunities also provide staff members for other community programs that may lack funding for regular hires—not only senior centers, but also public libraries, schools, hospitals, and other community agencies.

Considering that other programs that received cuts during the fiscal year 2013 sequestration have not had their funding even partially restored, we are pleased that in fiscal year 2016, funding for SCSEP held level at \$434.4 million where it has remained since its partial restoration in fiscal year 2014. However, this is not enough to meet the growing need for SCSEP—both in participants and in wages.

Many States and localities are raising the minimum wage, and this dilutes SCSEP funding, which has to increase to match increasing wages. This decreases the number of participants SCSEP can handle, yet the older population is growing. The last time there was an increase in funding for SCSEP, other than under the fiscal years 2009–2010 stimulus package, was when the Federal minimum wage was increased. Though wages have not increased at the Federal level, they have increased in enough States and localities to the point that SCSEP is becoming strained.

With more than 10,000 seniors turning 65 every day, now is the time to provide an even greater investment in these proven and cost-effective programs for older adults.

Thank you for your past and future support.

[This statement was submitted by Ann Cooper, Chair, and Robert Blancato, Executive Director, National Association of Nutrition and Aging Services Programs.]

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PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF STATE HEAD INJURY ADMINISTRATORS

Dear Chairman Roy Blunt and Ranking Member Patty Murray: On behalf of the National Association of State Head Injury Administrators (NASHIA), thank you for the opportunity to submit testimony regarding the fiscal year 2017 appropriations for programs authorized by the Traumatic Brain Injury (TBI) Act within the U.S. Department of Health and Human Services (HHS). NASHIA, a non-profit organization, is comprised of 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 necessary to live and work in the community as independently as possible. My name is Susan L. Vaughn and I am the Director of Public Policy for NASHIA, having previously worked for almost 30 years for State agencies administering an array of disability and brain injury services, including serving as the co-project director for Federal grants awarded to our State through the Federal TBI State Grant Program authorized by the TBI Act.

The HHS Federal TBI State Grant Program is the only program that assists States in addressing the complex needs of individuals with TBI and their families. Currently, only 20 States receive grants to expand and improve service delivery, yet TBI is a leading cause of death and disability in the United States. To that end NASHIA supports increasing the State Grant Program by \$1.5 million to fund an additional four States. It is imperative that all States have access to resources to address this robust population.

Federal funding is necessary to offer incentives for States to direct attention to the needs of individuals with TBI. States which have not received funding for a number of years are finding it difficult to continue their previous work, even though the numbers of individuals with TBI are increasing, especially with regard to older adults; sports-related concussions and returning servicemembers with TBI.

In a 2015 survey completed by State governmental programs and State brain injury associations, survey respondents listed the following as the top three most pressing needs in their States:

- services/alternatives for individuals with behavioral issues;
- long-term services and supports; and
- post-acute rehabilitation services.

With limited State resources to address these needs, States often place people out of State or in State institutional settings. Unfortunately, many individuals, particularly those with behavioral issues, including addiction, and poor judgment will find themselves homeless or in correctional facilities. In fact, several States are now working with their juvenile justice and correctional systems to screen incidence of TBI within the incarcerated population and are finding alarming results. These States are now conducting training with corrections staff and law enforcement in order for them to understand how to address their behaviors and assist with identifying community resources upon release hoping for successful community re-entry. The Federal program has played a critical role in helping States to address these issues.

We are pleased that the HHS Secretary has transferred the Federal TBI Program from the Health Resources and Services Administration to the Administration for



Community Living (ACL) following the passage of the reauthorization of the TBI Act in 2014. NASHIA believes that the program transfer will align the program better with other disability programs offering services across the lifespan and to maximize resources accordingly, as well as benefit from research conducted by the TBI Model Systems funded by the National Institute on Disability, Independent Living and Rehabilitation Research also housed in the ACL. While our members are especially interested in Federal funding that assists States in providing services, members also support funding for injury prevention to reduce the incidence of TBI and research to further the field in providing appropriate and effective treatment and service delivery.

For fiscal year 2017, NASHIA supports an additional \$5,000,000 for the Centers for Disease Control and Prevention's (CDC) National Center for Injury Prevention and Control to establish and oversee a national concussion surveillance system to accurately determine the incidence of concussions, particularly among the children and youth. With the requested increase of \$5,000,000, CDC will launch a national surveillance system on concussions, making the agency fully responsive to the recommendations issued in a 2013 report by the National Academies of Sciences, Engineering, and Medicine (formerly known as the Institute of Medicine, or the IOM). The report specifically called on CDC to establish a surveillance system that would capture a rich set of data on sports- and recreation-related concussions among 5–21 year olds that otherwise would not be available.

As you are probably aware, all 50 States and the District of Columbia, have enacted return to play laws to address concussion management in youth athletics. The data gathered from the national surveillance system will help States and local educational systems by having data regarding the incidence, prevalence, and outcomes of sports-related concussions in order to carry out their policies according to their State law. Currently, data is only collected when injury occurs in a school athletic setting and through emergency room visits.

In closing, 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, however, vary in size and scope across the country and even within a State, creating a patchwork of services.

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. These laws vary significantly with regard to the amount of revenue generated, how the funds are used, and what the funds are used for. Twenty-three States have also implemented 27 brain injury Home and Community-Based Services (HCBS) Medicaid Waiver Programs to divert individuals from nursing and institutional care. At least twelve of these States have the advantage of administering both a trust fund for non-Medicaid eligible individuals or non-Medicaid services and Medicaid waiver programs for those individuals who are eligible and are in need of nursing level of care. Across the country, these programs are administered by State public health, Vocational Rehabilitation, mental health, Medicaid, intellectual disabilities, education or social services agencies within the States. As no two brain injuries are alike, no two States are alike with regard to how services are provided and funded.

Yet, through the TBI Act Programs, Federal funding has provided an avenue for States to assess needs, develop State plans; and to implement strategies for coordinating and maximizing resources across State and local agencies and to build partners to sustain these efforts. We ask that you continue to fund and increase this important program, as well as to establish the CDC national concussion surveillance system to address this critical issue.

Should you wish additional information, please do not hesitate to contact Rebecca Wolfkiel, Governmental Consultant, at [rwolfkiel@ridgepolicygroup.com](mailto:rwolfkiel@ridgepolicygroup.com). You may also contact Susan L. Vaughn, Director of Public Policy, at [publicpolicy@nashia.org](mailto:publicpolicy@nashia.org) or William A.B. Ditto, Chair of the Public Policy Committee, at [williamabditto@aol.com](mailto:williamabditto@aol.com). Thank you.

[This statement was submitted by Susan L. Vaughn, Director of Public Policy, National Association of State Head Injury Administrators.]

## PREPARED STATEMENT OF THE NATIONAL COALITION OF STD DIRECTORS

## CDC's DIVISION OF STD PREVENTION FUNDING HISTORY

Fiscal Year	(\$ millions)
2017 Funding Request .....	* 165.4
2017 President's Budget Request .....	157.3
Funding Level:	
2016 .....	157.3
2015 .....	157.3
2014 .....	157.7
2013 .....	154.9
2012 .....	163

\* A requested increase of \$8.1 million.

On behalf of the members of the National Coalition of STD Directors (NCSDD), I am writing to request an additional \$8.1 million for the Division of STD Prevention in fiscal year 2017 funding. The Division of STD Prevention is part of the National Center for HIV/AIDS, Viral Hepatitis, STD and TB Prevention at the Centers for Disease Control and Prevention (CDC). NCSDD members represent sexually transmitted disease (STD) programs in all fifty Nations, seven cities counties and eight U.S. territories.

STDs remain major epidemics in the United States. Each year, there are nearly 20 million new cases of STDs, approximately half of which go undiagnosed and untreated. These new STDs cost the U.S. healthcare system \$16 billion every year—and cost individuals even more in immediate and life-long health consequences, including infertility and a higher risk of certain cancers. In addition, having other STDs increases the likelihood of contracting HIV, and in turn, having HIV also increases the likelihood of contracting and spreading STDs. Investments in STD prevention and treatment further the National HIV/AIDS Strategy's goal of reducing new HIV infections.

CDC's Division of STD Prevention (DSTDP) guides national efforts to prevent and control STDs. DSTDP invests most of its Federal funding in Nation, territorial, and large city or county health departments who carry out on-the-ground efforts to control STDs. State, territorial, and local public health STD programs are the backbone of our national STD infrastructure, not only monitoring and controlling STD epidemics, but responding to emergency outbreaks of all kinds, from Ebola to food-borne illnesses to flu. However, the current public health infrastructure has been continually strained by budget reductions at the Federal, Nation, and local levels and is currently not sufficiently prepared for the reality of rising rates of STDs, particularly syphilis, and other outbreaks.

Today, STD programs in these departments across the country are facing skyrocketing syphilis rates, including increases in congenital syphilis. In fact, last year, for the first time since 2006, rates for chlamydia, gonorrhea, and syphilis all increased concurrently. DSTDP and these health departments across the country need additional Federal resources to reverse the alarming and costly trends of STDs. Flat funding will not address these growing needs for outreach, treatment assurance and surveillance. In fiscal year 2017 funding, please support an urgent funding increase of \$8.1 million to the CDC's Division of STD Prevention to ensure those on the front lines of STD prevention have funding to respond to the rising STD rates, particularly syphilis, and prepare for other unforeseen outbreaks.

#### *Increasing Syphilis Rates, Including Congenital Syphilis*

Additional funding is needed to address our syphilis epidemic and to ensure the needs of hard to reach populations are addressed. In 2014, for the third year in a row, reported cases of primary and secondary syphilis—the stages where the infection is most likely to spread—have increased by double digits. In 2012, primary and secondary syphilis increased by 11 percent, in 2013, by 10 percent, and in 2014, by a shocking 15 percent. There was not a single demographic that escaped these increases. Males and females, LGBT persons and heterosexuals, and even newborns experienced increases in syphilis.

In fact, between 2012 and 2014, congenital syphilis, which can be a disabling, and often life-threatening infection for infants, increased by 38 percent, to the highest rate in almost 15 years. While syphilis is primarily a sexually transmitted disease, it may be passed on by an infected woman during pregnancy. Passing on the infection during gestation or at birth may lead to serious health problems including premature birth, stillbirth, and in some cases, death shortly after birth. Sadly, un-

treated syphilis in pregnant women results in infant death in up to 40 percent of cases. Untreated infants who survive will often develop problems in multiple organs, including the brain, eyes, ears, heart, skin, teeth, and bones.

Increases have also occurred in cases of ocular syphilis that are resulting in significant eyesight and vision problems, including instances of complete and irreversible blindness. Between December 2014 and March 2015, 12 cases of ocular syphilis were reported from two major cities, San Francisco and Seattle. Subsequent case finding indicated more than 200 cases over the past 2 years from 20 Nations.

#### *Strained Public Health Infrastructure*

Responding to these ever-increasing STDs is a strained public health infrastructure. Since 2003, Federal investments in STD prevention have been stagnant when adjusted for inflation. In fact, due to mostly flat funding, the real buying power of Federal funding has plummeted 38 percent. State, territorial and local health departments across the country that spearhead STD prevention and control have charged forward with STD prevention and control, but the weight of the work is being overburdened by a lack of national investment in these efforts and in public health.

According to Trust for America's Health, combined Federal, Nation and local public health spending is currently below pre-recession levels. Adjusting for inflation, public health spending is currently 10 percent lower in 2013 than in 2009. At the same time, Nation and local investments, largely as a result of the recession budget crunch, have equally collapsed. At the height of the recession, the National Association of County and City Health Officials reports that up to 45 percent of local health departments reported budget cuts; one in four is still affected by budget cuts today. Since 2008, 51,700 jobs have been lost at local health departments. As a result, when it comes to STDs, we are in the midst of true genuine crisis.

#### *A New Response is Needed*

Due to these infrastructure losses, our STD public health infrastructure is in a state of crisis and additional resources are needed to combat our growing STD epidemics. If fully funded, this request would go to two distinct but complimentary needs, which are outlined below.

#### *Additional Workforce Needs: \$5.1 million*

- Funding would be disseminated to public health departments for more boots on the ground.
- This could include trained epidemiology staff, more staff to ensure positive cases are tracked down and treated, or medically trained staff to best respond to each health department's needs for dealing with their epidemics.

#### *Program Science Activities: \$3 million*

- Our current system of prevention and control careens from one emergency outbreak to another, and this cannot continue.
- Improved data is needed to show, empirically, what is causing this surge in STDs and which evidenced-based interventions work to best to reduce STDs in the U.S.
- Additional program science evidence is also needed to better understand how to reach communities hardest hit by STD increases.
- This would result in evidence-based interventions that can be scaled up across the country to respond to these ever-rising rates.

In fiscal year 2017 funding, please support an urgent funding increase of \$8.1 million to the Division of STD Prevention to ensure those on the front lines of STD prevention have funding to respond to the rising rates of all STDs, particularly syphilis, and prepare for other foreseen outbreaks. For more information, please contact the National Coalition of STD Director's Director of Policy and Communications, Stephanie Arnold Pang at [sarnold@ncsddc.org](mailto:sarnold@ncsddc.org).

[This statement was submitted by William Smith, Executive Director, National Coalition of STD Directors.]

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#### PREPARED STATEMENT OF THE NATIONAL CONGRESS OF AMERICAN INDIANS

The National Congress of American Indians (NCAI) is the intergovernmental body for American Indian and Alaska Native tribal governments. NCAI is the oldest and largest national tribal organization in the United States that is dedicated to protecting the rights of tribal governments to achieve self-determination and self-sufficiency. For over 60 years tribal governments have come together as a representative Congress through NCAI to consider issues of critical importance to tribal govern-

ments and endorse consensus policy positions. NCAI appreciates the opportunity to offer the following testimony on tribal programs in the Departments of Labor, Education, and Health and Human Services.

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

NCAI supports investments in tribal health and well-being across the Department of Health and Human Services (HHS) agencies.

*Substance Abuse Mental Health Services Administration*

NCAI appreciates the funding increases made to Tribal Behavioral Health Grants in the fiscal year 2016 appropriations bill. NCAI requests continued funding of at least \$30 million, which includes \$15 million in the Mental Health appropriation and \$15 million in the Substance Abuse Prevention appropriation. These funds are essential in the promotion of mental health and prevent substance activities for high-risk American Indian/Alaska Native (AI/AN) youth and their families.

*Administration for Community Living (ACL)*

Native American Nutrition and Supportive Services: NCAI recommends \$31 million for this program. This program provides nutrition and other direct supportive services to American Indian, Alaska Native, and Native Hawaiian elders. These programs help to reduce the need for costly nursing home care by supporting adult day care, meal delivery and transportation.

*Head Start*

Head Start funds provide early education to over 24,000 Native children. This vital program combines education, health, and family services to model traditional Native education, which accounts for its success rate. NCAI recommends the Subcommittee to provide \$9.6 billion total funding for Head Start, which includes Indian Head Start. Head Start has been and continues to play an instrumental role in Native education.

*Administration for Children and Families*

NCAI supports start-up funding for tribal IV-E programs and improving of tribal access to Promoting Safe and Stable Families.

*Start-up Funding and Increase Match for Tribal IV-E Programs.*—NCAI urges Congress to improve tribes' capacity to operate title IV-E programs by providing start-up funding and an increased match for tribal IV-E. The President's budget includes a proposal that allows Indian tribes, tribal organizations, or consortia that are approved to operate a title IV-E program to apply for start-up funding to assist with the implementation of the program requirements in title IV-E of the Social Security Act. A second proposal would amend title IV-E to develop the tribal child welfare workforce by increasing the match rate for tribal case work activities and increasing the Federal financial participation to 90 percent for training tribal case-workers.

*Increasing Tribal Access to Promoting Safe and Stable Families (PSSF).*—NCAI supports an increase of \$20 million in the discretionary PSSF appropriation from the fiscal year 2016 enacted level to improve tribal capacity to administer child welfare services. American Indian and Alaska Native children are disproportionately represented at two times their population in State child welfare systems nationally. Among individual State foster care systems they are overrepresented at as much as 10 times their population rate. NCAI urges Congress to help address the disproportionality affecting Native children by investing in tribal child welfare systems.

Many tribes lack infrastructure and stable funding. While tribes may directly administer title IV-E programs, many tribes still need to build their child welfare programs. With this increase, total funding reserved for formula grants for tribes will be \$31 million, including \$22 million discretionary and \$9 million mandatory.

*Tribal Court Improvement.*—A \$2.75 million increase is proposed for this program to allow ACF to fund a total of 25 tribal court improvement grants. The expansion of the Tribal Court Improvement Program would continue to strengthen the tribal court's capacity to exercise jurisdiction in Indian Child Welfare Act cases and to adjudicate child welfare cases in tribal court.

*Low-Income Home Energy Assistance Program (LIHEAP).*—Provide \$4.7 billion for LIHEAP, with \$51 million allocated to tribes and tribal organizations. The LIHEAP is intended to assure that low-income families will not be forced to choose between food and heat. With high unemployment and long-standing barriers to economic development, much of Indian Country cannot afford the rising costs of heat and power. Alaska Native villages are experiencing some of the highest costs for energy with

fuel prices recently reaching \$7 per gallon. In fiscal year 2011, LIHEAP was appropriated \$4.7 billion total, with \$51 million allocated to tribes and tribal organizations. Full funding is crucial to address the extreme need for heating assistance in Indian Country. Accordingly, funding for fiscal year 2017 should be \$51 million for tribes.

#### U.S. DEPARTMENT OF EDUCATION

*Title I Part A Local Education Agency Grants.*—Title I of the Every Student Succeeds Act (ESSA) provides critical financial assistance to local educational agencies (LEAs) 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 public schools in rural and urban locations. A drastic increase in funding to counter annual inflation and sequestration, as well as to match the amount appropriated under the American Reinvestment and Recovery Act (ARRA), is necessary to meet the needs of Native students and students from low-income families. NCAI recommends funding of \$25 billion for Title I, Part A.

*Impact Aid.*—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, Impact Aid provides essential funding for schools serving Native students. Funding for Impact Aid must not be less than this requested amount. Furthermore, Impact Aid should be converted to a forward-funded program to eliminate the need for cost transfers and other funding issues at a later date. NCAI requests the Subcommittee to provide \$2 billion in funding for Impact Aid, Title VII funding under the Every Student Succeeds Act.

#### TITLE VI-INDIAN EDUCATION

*Grants to Local Education Agencies (Title VI, Part A).*—Increases are needed as this critical 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 parity with their non-Native peers. Title VI funds support early-childhood and family programs, academic enrichment programs, curriculum development, professional development, and culturally-related activities. These grants provide much needed resources to Native communities to invest in the success of their students. NCAI recommends funding of \$198 million for LEA grants.

*Native American and Alaska Native Language Immersion Schools and Programs (Title VI, Part A, Subpart 3).*—Native American and Alaska Native Language Immersion Schools and Programs would strengthen tribal sovereignty, while protecting the cultural and linguistic heritage of Native students in education systems. In years past, funding for Title VI only reached 500,000 Native students leaving over 100,000 without supplementary academic and cultural programs in their schools. As Native students lag behind their non-Native peers in educational achievement, increased funding is necessary to address this substantial gap. NCAI urges the Subcommittee to fund immersion programs at \$6.6 million for fiscal year 2017.

*Alaska Native Education Program (Title VI, Part C).*—This essential 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 programs and Head Start programs, family literacy services, and dropout prevention programs. NCAI recommends the Alaska Native Education Equity Assistance Program be funded at \$35 million for fiscal year 2017.

*Native Hawaiian Education Program (Title VI, Part B).*—Increases are needed as this critical grant program funds the development of curricula and education programs that address the unique needs of Native Hawaiian students to help bring equity to this Native population. The Native Hawaiian Education Program empowers innovative culturally appropriate programs to enhance the quality of education for Native Hawaiians. These programs strengthen the Native Hawaiian culture and improve educational attainment, both of which are correlated with positive economic outcomes. NCAI recommends funding of \$35 million for Native Hawaiian Education Program for fiscal year 2017.

#### *Tribal Colleges and Universities: Supporting Financially Disadvantaged Students*

Titles III and V of the Higher Education Act, known as Aid for Institutional Development programs, support institutions with a large proportion of financially disadvantaged students and low cost-per-student expenditures. Tribal Colleges and

Universities (TCUs) clearly fit this definition. The Nation's 37 TCUs serve Native and non-Native students in some of the most impoverished areas in the Nation. Congress recognized the TCUs as emergent institutions, and, as such, authorized a separate section of Title III (Part A, Sec. 316) specifically to address their needs. Additionally, a separate section (Sec. 317) was created to address similar needs of Alaska Native and Native Hawaiian institutions. NCAI urges this Subcommittee to appropriate \$60 million (\$30 million in discretionary funding and \$30 million in mandatory funding) for Title III-A grants under the Higher Education Act for Tribal Colleges and Universities.'

*Tribally Controlled Post-Secondary Career and Technical Institutions*

Section 117 of the Carl Perkins Career and Technical Education Improvement Act authorizes funding for operations at tribally controlled postsecondary career and technical institutions. Vocational education/training programs are very expensive to conduct, but are vital to preparing a future workforce that will operate safely and efficiently contributing greatly to the global economy. Currently, two TCUs participate in this funding program: United Tribes Technical College in Bismarck, North Dakota, and Navajo Technical College in Crownpoint, New Mexico. NCAI recommends \$10 million for tribally controlled postsecondary career and technical institutions program funds under the Carl Perkins Career and Technical Education Improvement Act.

*Native American-Serving, Non-Tribal Institutions (Higher Education Act Title III-F)*

As the primary Federal funding for non-tribal, Native-serving institutions of higher education, the current funding levels are insufficient. With nearly 100 institutions potentially qualifying as Native-serving, non-tribal institutions, this strains the small amount of available funding. Increasing the funding will provide the opportunity for more Native-serving institutions to better serve their students and increase graduation rates among Native students. NCAI urges the Subcommittee to fund \$10 million for non-tribal, Native-serving institutions of higher education.

In conclusion, NCAI appreciates the opportunity to share these recommendations with the Subcommittee. The needs in Indian Country are great and we thank this Subcommittee for working to honor the Federal Indian trust responsibility.

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PREPARED STATEMENT OF THE 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 2017 Appropriation. NCSSMA respectfully requests that Congress consider full funding of the President's fiscal year 2017 budget request for SSA, which includes \$13.067 billion for SSA's Limitation on Administrative Expenses (LAE) account.

NCSSMA is a membership organization of approximately 3,200 SSA managers and supervisors who provide leadership in nearly 1,250 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 46 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 paramount to be good stewards of the taxpayers' monies and the Social Security programs we administer.

NCSSMA respectfully requests that Congress consider full funding of the President's fiscal year 2017 budget request, which includes \$13.067 billion for SSA's Limitation on Administrative Expenses (LAE) account. This level of funding will allow SSA to improve and modernize customer service, enhance program integrity efforts, deter and detect fraud and errors, and continue to address high volumes of work.

SSA's fiscal year 2016 LAE account funding is \$12.162 billion. Although greatly appreciated, this level of funding did not fully cover the agency's inflationary costs. At the same time, SSA is experiencing an increase in visitors to field offices as members of the baby boom generation retire or file for disability benefits. Nearly 3 million cases are currently pending in the agency's Program Service Centers (PSCs), of which the average case is nearly 4 months old. Many cases involve a dire need for funds, resulting in hardship for the people involved, often including the inability to get Medicare coverage. Over 1.114 million people are waiting for a hearing decision. The number of pending hearings has reached an all-time high. Of serious concern is that this wait is now a record setting 535 days. The processing time for hearings has now increased for 36 consecutive months.

*LAE Funding History*

## FISCAL YEAR 2017—SSA BUDGET FORECAST

(Dollars in millions)

	Fiscal Year				
	2013 Enacted	2014 Enacted	2015 Enacted	2016 Enacted	2017 President's Budget
SSA's LAE Funding .....	\$11,046	\$11,697	\$11,806	\$12,162	\$13,067

Adequate resources for SSA have a positive impact on delivering vital services to the American public and in fulfilling the agency's stewardship responsibilities. Full funding is critical to maintain staffing in SSA's front-line components, cover inflationary costs, increase deficit-reducing program integrity work, and to address the significantly increased hearings backlog. It is important to note that the fiscal year 2017 budget request includes inflationary increases of over \$319 million in fixed costs, including rent, guards, postage, and employee salaries and benefits.

*Program Integrity Initiatives*

Program integrity initiatives save taxpayer dollars and contribute to reducing the Federal budget and deficit. To address program integrity, the President's fiscal year 2017 SSA budget request includes \$1.819 billion for the two most cost-effective tools to reduce improper payments—Medical Continuing Disability Reviews (CDRs) and SSI Redeterminations. It is important to note that in fiscal year 2015, the same SSA field office employees who answered telephone calls, took initial claim applications, and developed and adjudicated benefit claims, also processed the following program integrity workloads:

- 799,000 Medical CDRs; and
- 2.267 million SSI Redeterminations.

In fiscal year 2016, SSA projections indicate the agency will complete 850,000 Medical CDRs and 2.522 million SSI Redeterminations. The fiscal year 2017 budget request calls for SSA to process 1,100,000 Medical CDRs, which is an increase of 38 percent over fiscal year 2015 and 2.822 million SSI Redeterminations, which is an increase of 25 percent over fiscal year 2015. In order to process this large increase in volume of Medical CDRs and SSI Redeterminations, the field offices and Disability Determination Services (DDSs) will need to have adequate staffing levels in fiscal year 2017, or there could be delays in processing initial disability claims and reconsiderations, and degradation of other services field offices provide.

CDRs conducted in fiscal year 2017 will yield net Federal program savings, on average over the next 10 years, of \$8 for every \$1 budgeted from dedicated program integrity funding including OADSI, SSI, Medicare and Medicaid program effects. SSI Redeterminations conducted in fiscal year 2017 will yield a return on investment (ROI) averaging about \$3 of net Federal program savings over 10 years per \$1 budgeted for dedicated program integrity funding, including SSI and Medicaid program effects.

*Funding for Fiscal Year 2017*

SSA's fiscal year 2017 budget request includes \$301.4 million for over 2,800 work years to handle the additional program integrity workloads, address the massive hearings backlog, increases in other workloads, visitors, and telephone calls in field offices, teleservice centers and Program Service Centers.

The budget request also includes funding of \$352.2 million for Information Technology (IT) Modernization. SSA's database systems are over 40 years old and include more than 60 million lines of COBOL coding. Additional IT funding will allow SSA to modernize its computer language, database and infrastructure, including moving its data to the cloud. The budget request also contains a proposal for additional mandatory IT funding through fiscal year 2020. SSA also plans to spend \$87 million on cybersecurity.

Again, 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's TSCs, hearing offices, PSCs, DDSs, and the nearly

1,250 field offices are in grave need of adequate resources to address their growing workloads. Without adequate funding, SSA will not be able to provide the high-quality customer service Americans deserve, and have paid for. Examples of decreased levels of customer service include inordinately long wait times when visiting SSA field offices or difficulty reaching those same offices by telephone. These very same field offices will also be unable to process program integrity workloads, which save taxpayers billions of dollars and reduce the Federal budget and deficit.

We realize the fiscal year 2017 funding level of \$13.067 billion for SSA's LAE account requested above is not insignificant, particularly in this difficult Federal budget environment; however, Social Security serves as the largest and most vital component of the social safety net of America and is facing unprecedented challenges. The American public expects and deserves SSA's assistance and support.

In fiscal year 2017, SSA's programs are projected to pay a combined total of \$1.0 trillion in Federal benefits to 68.4 million recipients. Spending on administrative costs for these programs is projected to be only about 1.3 percent of benefit outlays.

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 Richard E. Warsinskey, President, National Council of Social Security Management Associations.]

#### PREPARED STATEMENT OF THE NATIONAL COUNCIL ON INDEPENDENT LIVING

Dear Chairman Blunt, Ranking Member Murray, and Members of the Subcommittee, my name is Kelly Buckland, and I am the Executive Director of the National Council on Independent Living (NCIL). I am writing to you on behalf of the Nation's Centers for Independent Living (CILs). I would like to start by thanking you for your commitment to enabling people with disabilities to participate fully in their communities by investing in the Independent Living Program. I write today to ask that you reaffirm your commitment to the over 57 million Americans with disabilities by increasing funding for CILs by \$200 million, for a total of \$301 million for the Independent Living line item in fiscal year 2017.

NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide. NCIL is the oldest cross-disability, national grassroots organization run by and for people with disabilities. NCIL's membership includes people with disabilities, Centers for Independent Living, Statewide Independent Living Councils, and other disability rights organizations. NCIL advances independent living and the rights of people with disabilities, and we envision a world in which people with disabilities are valued equally and participate fully.

Centers for Independent Living are non-residential, community-based, non-profit organizations that are designed and operated by individuals with disabilities and provide five core services: advocacy, information and referral, peer support, independent living skills training and transition services that facilitate the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services. Also included are assistance to individuals with significant disabilities who are at risk of entering institutions so that the individuals may remain in the community, and the transition of youth with significant disabilities to postsecondary life.

CILs are unique in that they operate according to a strict philosophy of consumer control, in which people with any type of disability, including people with mental, physical, sensory, cognitive, and developmental disabilities, of any age, directly govern and staff the Center. Each of the 365 federally funded Centers are unique because they are run by people with disabilities and reflect the best interest of each community individually.

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

NCIL estimates that to meet the current demand- including the addition of a fifth core service as authorized by WIOA-and overcome years of devastating funding cuts, appropriations for the IL Program will need to increase by \$200 million. In fiscal



year 2010 funding for the IL Program was \$103,716,000, and in fiscal year 2016 funding for the IL Program is \$101,183,000. That equals a loss of \$2.5 million, not including adjusting for inflation. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream of society.

According to data collected by the Rehabilitation Services Administration, during fiscal years 2012–2014, Centers for Independent Living:

- Attracted over \$2.26 Billion through private, State, local, and other sources;
- Moved 13,030 people out of nursing homes and institutions, saving States and the Federal Government over \$500 million, not to mention improving people's quality of life, and;
- Provided the four core services, including: advocacy to 233,230 consumers, information and referral to 4,189,922 consumers, peer support to 172,287 consumers, and independent living skills training to 274,991 consumers.

In that same period, CILs provided other services to hundreds of thousands of individuals with disabilities in their respective communities that included:

- Services to 35,137 youth with disabilities;
- Assistance to 145,937 people in securing accessible, affordable, and integrated housing;
- Transportation services to 103,175 people with disabilities;
- Personal assistance services to 184,240 people with disabilities;
- Vocational and employment services to 96,492 people with disabilities; and
- Assistance with Assistive Technology for 171,441 people with disabilities.

Beyond the direct services they provide, CILs seek ways to broadly change traditional service delivery in their communities and throughout the Nation, including reform of the long term care system. For over 40 years, CILs have sought community based programs to assist people with all types of disabilities, across the lifespan, to remain in or return to their family and friends, in their homes and communities. When such services are delivered in an individual's home, rather than a costly nursing facility or other institution, the result is tremendous cost savings to Medicaid, Medicare and States, while enabling people with disabilities to become more independent, financially self-sufficient, and less reliant on long term government supports. And research has found that community-based services are significantly less expensive than nursing home placements.

In 2015 alone, CILs have had major successes in increasing access and equality for people with disabilities. The DIAL Center for Independent Living in Clifton, New Jersey joined a local wheelchair user in efforts to work with the city of Montclair, and those efforts will result in accessible parking spaces outside schools, parks, and other public parking areas, as well as the hiring of an ADA Coordinator for the city. The Montana Independent living Project collaborated on a snow ordinance policy for the city of Helena that requires sidewalks, ADA ramps, corners, bulb-outs, and driveway and alley aprons used for pedestrian travel to be cleared within 24 hours, with enforcement and penalties for non-compliance. Access Living in Chicago, Illinois conducted phone-based fair housing tests and used the results to draw attention to the issue of discrimination against home seekers who are Deaf or hard of hearing. And the Disabled Resource Services CIL (DRS) in Fort Collins and Loveland, Colorado conducted its first Women's Empowerment Group, which has led to ongoing efforts by DRS staff to create an empirical research design model that can be used in future groups to quantitatively measure the concept of "empowerment," an area of study in which little research exists.

Additionally, CILs have been extremely effective in helping people remain in or transition back into the community. The Whole Person's Money Follows the Person program completed 32 consumer transitions from institutions to apartments/homes in the Kansas City, Missouri metro area. Tri-County Patriots for Independent Living in Washington, Pennsylvania transitioned 54 people from nursing homes and other institutions into their own homes, saving the State and Federal Government \$2,268,000. The Houston Center for Independent Living in Texas transitioned 186 nursing home residents into community-based living, saving the State of Texas and the Federal Government approximately \$8,779,200. And the Center for Disability Rights in Rochester, New York was instrumental in achieving introduction of the Disability Integration Act by Senator Schumer, which has the potential to provide access to community services and supports to people with disabilities all across the country.

As previously mentioned, the Workforce Innovation and Opportunity Act created a fifth core service for Centers: transition. NCIL strongly supported the addition of this fifth core service, but additional funding is sorely needed to effectively carry it out. Funding these transition services will be critical to promoting effective employment outcomes, successful nursing home transition, and increased community par-

ticipation for transitioning students. Current funding levels barely sustain day-to-day operations. CILs struggle to meet the demands of the community and provide leadership and common sense solutions. Without increased funds our vision to achieve full integration of people with disabilities in society will be undercut and taxpayers will continue to pay for costly Medicaid nursing homes and bear the economic impact of negative employment outcomes and continued dependence on programs that disincentive work and community involvement. CILs are an excellent service and a bargain for America. They keep people active and engaged in their communities, and they save taxpayer money.

Thank you for the opportunity to provide testimony. We welcome any questions you may have. We also welcome each of you to visit your local Center for Independent Living so you can see first-hand their contributions to your Congressional Districts. We look forward to working with you to ensure that Americans with disabilities have the opportunity become active members of society.

[This statement was submitted by Kelly Buckland, Executive Director, National Council on Independent Living.]

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PREPARED STATEMENT OF THE NATIONAL ENERGY AND  
UTILITY AFFORDABILITY COALITION

The Low Income Home Energy Assistance Program (LIHEAP) is America's cornerstone energy safety net program. Since its inception nearly 35 years ago, LIHEAP has assisted low-income families, those on a fixed income and seniors, to ease energy burdens, especially in the cold winter and hot summer months. LIHEAP is federally administered by the U.S. Department of Health and Human Services, Administration of Children and Families, Office of Community Services. It is presently funded at \$3.39 billion. The President's fiscal year 2017 budget proposes a cut of \$390 million to LIHEAP's discretionary appropriation. The National Energy and Utility Affordability Coalition (NEUAC) urges you to reject that proposed cut and instead restore LIHEAP funding to earlier levels of at least \$4.7 billion for fiscal year 2017.

Why the need for more funding? In fiscal year 2015 LIHEAP served about 18 percent of qualifying U.S. households. In other words, 82 percent of LIHEAP-eligible households received no assistance. (National and State by State fact sheets about LIHEAP can be found at <http://neuac.org/wp-content/uploads/2015/10/2016LADStateSheetsFINAL.pdf>).

Federal eligibility rules governing LIHEAP require that household income may not exceed 150 percent of the Federal poverty level or 60 percent of the State's median income. Simply stated, a family of three would only qualify if they made less than \$30,000 annually. However, most LIHEAP recipients fall well under that requirement; according to HHS the typical family receiving assistance in fiscal year 2014 had a median income of 83.5 percent of the Federal poverty guidelines—about \$16,000.<sup>1</sup>

Families who rely on LIHEAP are truly the most vulnerable among us. State LIHEAP administrators report that nearly 73 percent of LIHEAP recipient households had at least one vulnerable person, that is a senior age 60 or older, a child age 5 and under, or an individual with a disability.<sup>2</sup>

LIHEAP is not an entitlement, it must come before Congress every year and no one is assured of assistance, not even households in crisis. Since 2009, LIHEAP funding has been reduced by one third, but the need has not fallen by a similar measure.

NEUAC notes that while the Administration seeks a cut in the discretionary LIHEAP funding in fiscal year 2017, it did include a "a contingency fund providing additional mandatory funds to respond to increases in the number of low-income households, spikes in the price of natural gas, electricity, or oil, and extreme cold at the beginning of winter."

Additionally, the Administration proposes allowing States to "use up to 40 percent" of its LIHEAP appropriation for weatherization "without regard to the waiver process." Currently, a State is not required to spend any LIHEAP money on weatherization. Further, States are limited to not more than 15 percent to be used for weatherization without a waiver, and with a waiver, States may spend a maximum of 25 percent on weatherization. There is already a Federal block grant for low-in-

<sup>1</sup>HHS FY 2017 Budget Justification; [https://www.acf.hhs.gov/sites/default/files/olab/final\\_cj\\_2017\\_print.pdf](https://www.acf.hhs.gov/sites/default/files/olab/final_cj_2017_print.pdf).

<sup>2</sup>NEADA 2014 LIHEAP Household Report <http://neada.org/wp-content/uploads/2015/06/State-Table-FY14-Households-Served.pdf>.

come weatherization, funded in the Energy and Water Development Appropriations bill.

NEUAC's position is that while both proposals are well-intentioned; they have the practical effect of reducing the commitment of core LIHEAP resources to States and Tribes. Thus, NEUAC opposes both proposals, and urges the Subcommittee to maximize its commitment to LIHEAP, to concentrate all resources into the program's base block grants, and to enable the program to focus upon the core mission Congress established it to accomplish.

Thank you for the opportunity to express the views of the National Energy and Utility Affordability Coalition on this important matter. We thank you for consideration of our request to fund LIHEAP at an amount no lower than \$4.7 billion in fiscal year 2017.

NEUAC is national, broad-based and diverse. Its mission is to heighten awareness of the energy needs of low- and moderate-income Americans. NEUAC members—including non-profits, fuel funds, energy providers, charitable organizations, Tribes, and many others—are working to reduce the energy burden of vulnerable households through advocacy, policy improvements and partnerships.

[This statement was submitted by Mary Thompson Grassi, Interim Executive Director, the National Energy and Utility Affordability Coalition.]

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PREPARED STATEMENT OF THE NATIONAL ENERGY ASSISTANCE DIRECTORS'  
ASSOCIATION

The members of National Energy Assistance Directors' Association (NEADA), representing the State directors of the Low Income Home Energy Assistance Program (LIHEAP) would like to first take this opportunity to thank the members of the Subcommittee for considering our funding request for fiscal year 2017. For fiscal year 2017 we are requesting the Committee restore program funding to the fiscal year 2011 level of \$4.7 billion.

The funding request would allow States to increase program services to the level provided in fiscal year 2011 and allow us to increase the number of households served from 6.7 million to 8 million and the percentage of households served from about 19 percent in fiscal year 2016 to about 22 percent and fund about 50 percent of the cost of home heating for eligible households.

In addition, 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. We are concerned that States will be hampered in their ability to administer their programs efficiently due to the lack of advanced funding. In order to address this concern, we are requesting advance appropriations of \$4.7 billion for fiscal year 2018.

LIHEAP is the primary source of heating and cooling assistance for some of the poorest families in the United States. In fiscal year 2016, the number of households receiving heating assistance is expected to remain at about 6.7 million or about 19 percent of eligible households, with an average grant size of about \$425. In addition, the program is expected to reach about 1 million households for cooling assistance, the same level that received assistance in fiscal year 2015.

Program funding for LIHEAP has been significantly cut from \$5.1 billion in fiscal year 2010 to the current level of \$3.3 billion. As a result, States have had to reduce the number of households receiving assistance by 1.3 million, from 8 million to the current level of 6.7 million. Program cuts have hurt the ability of States to help the Nation's poorest households pay their energy bills. The average grant has further been reduced from \$520 in fiscal year 2010 to the current level of about \$425.

At the same time, LIHEAP is in a period of transition. Along with the Administration for Children and Families, the Department that oversees the program, LIHEAP offices are working to enhance current program integrity measures including developing modernized web-based intake systems, and instituting external verification of applicant-submitted data. In addition, they are developing nationwide performance measures that will give Congress and the public a clear picture of the effectiveness of LIHEAP in helping low income households. NEADA believes these efforts will lead to a more responsive and more cost-effective program.

LIHEAP IN THE PRESIDENT'S BUDGET

The Obama Administration released its fiscal year 2017 budget on February 9, 2016. This budget would reduce core block grant funding for LIHEAP from \$3.39 billion to \$3.0 billion. This represents a cut of \$390 million or about 12 percent. The

budget did not provide a rationale for the cut. We urge the Committee to reject this proposal.

*Weatherization.*—Current law allows States to set aside up to 15 percent of their allocation for Weatherization and up to 25 percent with a waiver. The Administration's proposal would allow States to set-aside up to 40 percent without a waiver. We are recommending that the Committee reject this proposal. The current law provides States with sufficient flexibility to design their weatherization programs in context of other resource that might be available for this purpose, allowing States to strike the proper balance between bill payment assistance and efficiency. In addition, we believe that increasing the ceiling for Weatherization within the block grant would undermine the primary purpose of LIHEAP which is to help poor families pay their home energy bills.

One aspect of the budget is potentially very positive for LIHEAP. It would add a new contingency fund of \$560 million. We urge the Committee to consider this proposal assuming it would not detract from providing full funding for the base program.

#### 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 have someone age 60 or older
- 72 percent have a family member with a serious medical condition
- 26 percent use medical equipment that requires electricity
- 37 percent went without medical or dental care
- 34 percent did not fill a prescription
- 85 percent of people with a medical condition are seniors

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.

#### ENERGY PRICES AND THEIR IMPACT ON LOW INCOME HOUSEHOLDS

While energy prices have stabilized in some cases declined from previous year highs they remain unaffordable for millions of low income households. According to the U.S. Energy Information Administration, the cost of home heating this winter with natural gas was \$525, electricity \$903, heating oil, \$1,033, propane \$1,696 in the Northeast and \$1,015 in the Midwest. EIA also reported that the average summer electricity expenditures is expected to remain at an unaffordable \$407, about the same as last year.

Energy prices fall hardest on lower income households. In fiscal year 2014, mean burden for low-income was 10 percent almost four times the rate for non-low income households (2.4 percent). Of even greater concern about one-third of lower income households have energy burden greater than 15 percent of income and one in six have an energy burden greater than 25 percent of income.

Source: Fiscal Year 2014 Home Energy Notebook, Administration for Children and Families.

#### FACES OF LIHEAP

*Alabama:* A single mother in Alabama supporting three children on minimum wage was often forced to decide whether to pay utility bills or rent. She received LIHEAP to help pay her bill and was enrolled in an energy education class to help manage her energy usage. In addition to the LIHEAP benefit, she was able to bring down her energy bill from about \$570 a month to \$495 month, a savings of \$75, as a result of the class.

*California:* A young mother of three lived in an older all-electric home and had their electricity shut off due to a past-due bill of about \$800. She worked full time making minimum wage and her husband worked as a seasonal laborer. With no electricity, the family could not heat their home, access hot water, or operate appliances. LIHEAP was able to assist the family by paying their past due bill to get the electricity turned back on. She was also referred to the County's Weatherization Program, which assists families in making their homes more energy efficient.

*Connecticut:* A single mother of two facing the challenges of being homeless came to the State for help. Through Connecticut's connected services, she received a housing subsidy, \$505 in LIHEAP funds, and was enrolled in the utility company's Matching Payment Program.

*Georgia:* A 77 year-old disabled senior living on SSI was facing shut-off due to unaffordable winter energy bills. During the winter months every year her heating bills peaked as the result of having to maintain a consistent home heating temperature due to her disability and other illnesses. Her gas bill was in danger of disconnection with a balance of \$612 and an additional past due portion of \$355. With the senior meeting the eligibility requirement for both the LIHEAP maximum benefit \$350 and Home Energy Assistance Team (H.E.A.T) program funds of \$350 the program was able to successfully assist this senior to bring her home heating bill current which resulted in the senior maintaining home heating throughout the remainder of winter.

While visiting the home of a senior citizen to take a LIHEAP application, the Program Coordinator noticed the oven and top burners of her stove were on, as well as that she was wearing a heavy over wrap. During the intake process it was discovered that her home heating furnace was not working. Based on the her income she received the maximum LIHEAP benefit of \$350 and was referred to the Weatherization Assistance Program (WAP) to have her heating season evaluated. The Weatherization Program Coordinator came out and confirmed that the furnace needed to be replaced. A WAP team was dispatched to the senior home to install a new furnace, the senior could immediately feel the difference in the heating of the home and was extremely grateful.

*Idaho:* A 90 year-old woman in rural Idaho was referred by LIHEAP to Weatherization after she indicated that she had a broken furnace. Weatherization staff found that she was using a coffee can to carry wood pellets from an outdoor shed to a pellet stove in her living room, because she was not able to carry an entire bag. With no other backup heat source, she would have to leave her home if the unreliable stove broke. Because of the referral from LIHEAP, the Weatherization program was able to install a new high efficiency furnace and weatherize her home. This saved her money on her monthly heating bill and allowed her to stay in her home.

*Illinois:* A single man who had been living in a tent was able to afford an apartment for the first time in years when he discovered he had an old bill with the utility and would not be able to get utilities in his new home. LIHEAP was able to get him connected and help him get up-to-date on his bills.

*Oklahoma:* A young single woman with medical issues was working part time as a cashier and taking care of her elderly grandmother. She was able to use LIHEAP to maintain service while she was between jobs, preventing her and her mother from entering a shelter. She was also able to use LIHEAP emergency assistance to prevent disconnect of her electricity when her new salary was not enough to cover the bill.

*Pennsylvania:* A disabled cancer patient lost her home through foreclosure but was still in the residence pending eviction. Her furnace was shut down for safety reasons after the State weatherization team discovered it was leaking carbon monoxide. The property was acquired by an out-of-state corporation that refused to allow the weatherization team to repair the furnace. The State LIHEAP office was able to use LIHEAP weatherization funds to provide space heaters for the woman until she was able to make other living arrangements, saving her from making the choice of living in a house made hazardous from carbon monoxide or in freezing temperatures.

*Tennessee:* A woman who is bed ridden and paralyzed from the waist down had to cut back on other necessities to pay her medical bills. At the beginning of last winter, she saved energy by only turning on the lights when her nurse came to visit. She also kept her thermostat at 60 degrees and asked her nurse to layer her clothing and put extra blankets on her before she left. Since receiving LIHEAP, she has been able to leave a light on at night to make her feel more secure and to keep the home a comfortable temperature.

*Wyoming:* An elderly woman was facing eviction because she got behind on her utility bills. She was having trouble stretching her social security check to cover her utilities, her cancer treatments, and the cost of travel to receive treatment. LIHEAP helped her out with her bill, ensuring she could stay in her home. "We might not be able to eat very well or pay for medicines, but at least we can be warm in our own homes with the help of LIHEAP".

PREPARED STATEMENT OF THE NATIONAL FAMILY PLANNING & REPRODUCTIVE  
HEALTH ASSOCIATION

## SUMMARY

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Requesting \$327 million in funding for fiscal year 2017 for the national family planning program (Title X of the Public Health Service Act).

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My name is Clare Coleman; I'm the President & CEO of the National Family Planning & Reproductive Health Association (NFPRHA), a membership 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 committee works on the fiscal year 2017 appropriations bill, NFPRHA respectfully requests that you make a significant investment in Title X by including \$327 million, which would help make progress to restore the capacity of the program to serve those in need.

NFPRHA was pleased to see that the administration acknowledged Title X's integral role in healthcare delivery by including \$300 million for the program in the President's fiscal year 2017 Budget Request, a \$13.5 million increase over the fiscal year 2016 appropriated level. However, that amount is insufficient to meet the well-documented demand for publicly funded family planning services. A recent analysis published in the *American Journal of Public Health* found that in order for all low-income, uninsured women of reproductive age to access family planning services, the program would need to be supported with approximately \$737 million. The fiscal year 2016 appropriated level of \$286.5 million, therefore, represents only a fraction of what is needed to serve low-income, uninsured women across the country.

Even as more individuals benefit from insurance coverage through the Affordable Care Act (ACA) and as additional States expand Medicaid, the Title X network continues to play an essential role in our Nation's service delivery framework. "Churning" and confidentiality issues, for example, play a role in keeping some individuals uninsured or unable to use the coverage they have for the full range of their family planning needs. More importantly, Title X-funded health centers, because of the quality and specialty care they provide, remain in demand even as low-income women gain access to health insurance. If the Massachusetts health reform experience were to prove representative of what could be expected as the ACA continues into its third full year of implementation, there will be a strong increase in demand for services at publicly funded family planning centers. 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 \$16,242 a year for an individual in 2016)—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, 19 States have not expanded their Medicaid eligibility under the ACA. Of those, only 1 State (WI) have full-benefit Medicaid eligibility for childless adults. For working parents, 16 of the 19 States have Medicaid eligibility equal to or less than 75 percent of FPL (an income of \$8,910 a year); 12 have eligibility at or below 50 percent (an income of \$5,940 a year). Six States have eligibility set at less than 25 percent of FPL—that means individuals making more than \$2,970 are too "rich" for Medicaid.

Furthermore, emerging public health threats highlight the importance of the publicly funded family planning safety net and the need for robust Title X funding. The CDC recently reported a causal link between babies born with microcephaly and pregnant women infected with the Zika virus, and public health experts expect the Zika virus to continue to spread domestically. Because of the potentially devastating impact of the virus on the health of the developing fetus, it is imperative that women have the tools and resources to prevent unplanned pregnancies. In a time of public health emergency, women will turn to the Title X program for thorough counseling, risk assessment, and access to family planning services, and the pro-

gram should be funded in a manner that allows the publicly funded family planning safety net to respond to this threat.

Similar to other publicly funded health programs, Title X has suffered budget cuts despite rising patient need. Between fiscal year 2010–fiscal year 2014, the Title X family planning program was cut a net \$31 million (-10 percent). During the same period, approximately 1.1 million patients were lost from the program. These findings are very disturbing given that four in ten women who utilize a publicly funded family planning center say that it is their only source of care.

As appropriators grapple with how best to distribute limited Federal resources, NFPRHA encourages the Committee to 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 \$7.09 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.

Moreover, appropriators should invest in programs, such as Title X, that focus on outcomes and increasing service efficiency. Title X has long set the standard for high-quality family planning and sexual health service provision and recently doubled down on its efforts to lead the field by advancing best practices for clinical care. In April 2014, the program issued “Providing Quality Family Planning Services—Recommendations of CDC and the U.S. Office of Population Affairs,” that outlines the most up-to-date clinical recommendations for all providers of family planning care, including Title X-funded providers, to help define patient-centered, high-quality care in a family planning visit. Such efforts reinforce the network’s dual role as safety-net providers and centers of excellence for family planning and sexual healthcare.

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.

Millions of low-income women and men depend on the Title X program for affordable access to family planning and reproductive health services that help them stay healthy. However, politically motivated attacks are jeopardizing the Title X program’s ability to help these vulnerable individuals and families. NFPRHA urges the Committee to reverse this trend by making a significant investment in the Nation’s safety-net family planning health services and requests funding for Title X at \$327 million in fiscal year 2017.

[This statement was submitted by Clare Coleman, President & CEO, National Family Planning & Reproductive Health Association.]

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#### PREPARED STATEMENT OF THE NATIONAL HEAD START ASSOCIATION

Dear Chairman Blunt, Ranking Member Murray, and Members of the Committee, on behalf of the National Head Start Association (NHSA), thank you for the opportunity to submit written testimony regarding funding for Head Start and Early Head Start in fiscal year 2017. For more than 50 years, Head Start has created opportunities for disadvantaged children and families to succeed by providing the highest quality early childhood education, including health, nutrition, parent engagement, family support and child development services. NHSA is grateful for the Subcommittee’s tradition of strong bipartisan support for early childhood education. In fiscal year 2017, NHSA respectfully requests the Subcommittee allocate \$9,601,724,000 for Head Start and Early Head Start. This amount is in line with the President’s fiscal year 2017 request and represents a \$434,000,000 increase over fiscal year 2016 enacted levels.

Head Start and Early Head Start directors nationwide remain appreciative of your leadership in preventing the return of sequestration in fiscal years 2016 and 2017, as well as providing a significant increase in funding for Head Start in fiscal year 2016. The fiscal year 2016 funds will expand infant-toddler access, strengthen quality through increased duration of services, and help enable Head Start programs to keep pace with rapidly rising operating costs. They will also allow the Head Start field to prepare for and begin implementation of new Head Start Program Performance Standards, which the Administration proposed in June 2015 and

are expected to be made final in 2016. The entire Head Start field sincerely appreciates the additional investment and commitment Congress continues to make in our Nation's future by supporting youth and families in our most underserved communities.

NHSA recognizes the restrictions and challenges of the fiscal year 2017 budget and the top-line discretionary spending limits. However, as we strongly believe in continuous quality improvement and are intent on implementing new Head Start Program Performance Standards with minimal impact to the number of children and families served nationwide, we strongly encourage you to consider the funding needs and priorities necessary to strengthen and grow Head Start, as identified by the Head Start community. An investment of \$9.6 billion will allow Head Start centers to continue services to the nearly one million children and their families from birth through age five currently enrolled in Head Start and Early Head Start, as well as continue to strengthen quality through the expanded duration of services, improved teacher retention, and direct quality improvement funds as identified in the 2007 Head Start Act.

NHSA urges the Subcommittee to continue to build on last year's investments. Should the Committee have the flexibility to invest in Head Start programs above the fiscal year 2016 enacted level, we offer the following prioritized funding recommendations:

*Supporting Quality Workforce Retention:* Within the sum provided, NHSA recommends \$141,629,000 be allocated for Workforce Investments through a cost-of-living adjustment. Nearly every Head Start provider struggles to retain quality staff due to non-competitive salaries. Furthermore, high staff turnover rates directly impact quality of services to young children. Investing in workforce quality is the most important and pressing need for programs across the country. Recent Program Information Report (PIR) data strongly suggest that when Head Start grantees receive a Workforce Investment, there is less teacher turnover. For example, in the 2008–2009 school year, when there was not a Workforce Investment 26.5 percent of teachers who left Head Start cited salary as the main reason for their departure. The next 2 years, when Congress made a significant Workforce Investment through the Recovery Act and annual appropriations, that number dropped to 20.9 percent in 2009–2010 and 19.3 percent in 2010–2011. The next year, 2011–2012, turnover increased back to 26.2 percent when there was not a Workforce Investment. Teacher turnover has a direct impact on the quality and stability of programs and we strongly encourage Congress to do everything possible to help mitigate this growing concern.<sup>1</sup>

*Supporting Duration Expansion:* Within the overall sum, NHSA recommends \$292,000,000 be allocated for flexible Quality Improvement funding (QIF), without restrictions, to support the preparation and implementation of the new Head Start Performance Standards. Authorized in the 2007 Head Start Act, QIF may be used for increasing duration of instruction time, staff training, improving community-wide planning and classroom environments, strengthening transportation safety, and increasing hours of program operation. The QIF offers local centers flexibility to prepare their communities for duration expansion and other policies to strengthen quality as part of the new standards.

NHSA largely concurs with the goals outlined in the proposed standards of ensuring continuous quality improvement, strengthening evidence-based practices, and expanding duration of Head Start programming. However, not every Head Start center and community is ready to immediately expand their programs—some centers require additional community-wide planning, classroom improvements, and safer transportation systems before they can increase the hours of services. By allocating funding through the Quality Improvement Fund, Congress will allow those Head Start centers who are fully prepared to expand services immediately, while also providing sufficient flexibility to assist those centers that require additional preparation before they can expand with quality. An increase in the Quality Improvement Fund will ensure that duration expansion does not come at the expense of the number of children and families served.

*Head Start Returns the Public's Investment:* Given the constrained fiscal environment in fiscal year 2017, NHSA recognizes the need to prioritize programs with demonstrable returns on the investment in public dollars. Studies have proven that for every one dollar invested in a Head Start child, society earns at least seven dollars back through increased earnings, employment, and family stability;<sup>2</sup> as well as

<sup>1</sup>U.S. Department of Health and Human Services. (2015, November). 2008–2015 Head Start Program Information Reports.

<sup>2</sup>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



decreased welfare dependency,<sup>3</sup> healthcare costs,<sup>4</sup> crime costs,<sup>5</sup> grade retention,<sup>6</sup> and special education.<sup>7</sup> The latest science in brain development shows that the ages of zero to five are the most critical in a child's life. Head Start and Early Head Start ensure that children from the most disadvantaged communities receive the nurturing, engaging, and healthy education necessary for an equal opportunity to succeed later in life. In 2014–2015, there were 4,770,452 children in poverty under age five.<sup>8</sup> Of those, only 41 percent of three and 4 year olds had access to Head Start. And only 4 percent of children under age three had access to Early Head Start. Investments in Head Start are investments in the success of our Nation's future generations and, while we have made significant strides the past several years, we could do more.

Again, the Head Start community understands the pressure the Subcommittee faces in fiscal year 2017 and we are grateful for the commitment shown by Congress and the President to keep early learning, and Head Start in particular, a priority. We urge the Subcommittee to build on investments to Head Start and Early Head Start in fiscal year 2017 in order to increase workforce retention, provide continuous quality improvement, and expand duration or services. Thank you for your time and consideration.

[This statement was submitted by Yasmina Vinci, Executive Director, National Head Start Association.]

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#### PREPARED STATEMENT OF THE NATIONAL INDIAN CHILD WELFARE ASSOCIATION

The National Indian Child Welfare Association (NICWA), located in Portland, Oregon, has over 35 years of experience advocating on behalf of American Indian and Alaska Native (AI/AN) children in child welfare and children's mental health systems. Thank you for the opportunity to provide fiscal year 2017 budget recommendations for child welfare and children's mental health programs administered by the Department of Health and Human Services (DHHS). Our recommendations and priorities are listed below.

#### CHILD WELFARE RECOMMENDATIONS

A recent report from the Attorney General's Advisory Committee on American Indian/Alaska Native Children Exposed to Violence provided the following recommendation:

Congress and the executive branch shall direct sufficient funds to AI/AN Tribes to bring funding for tribal criminal and civil justice systems and tribal protection systems into parity with the rest of the United States (U. S. Department of Justice [USDOJ], 2014, p. 51).

Tribes, like States, rely on the Federal Government for the majority of their child welfare funding. Child safety and family stability are Tribal Governments' highest priorities, yet their programs remain drastically underfunded by the Federal Government. This underfunding has contributed to the increased risk for child maltreatment of AI/AN children and has stymied efforts to heal victims of child maltreatment and rehabilitate their families. Congress must prioritize the safety and well-

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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.

<sup>3</sup>Meier, J. (2003, June 20). Kindergarten Readiness Study: Head Start Success. Interim Report. Preschool Services Department of San Bernardino County.

<sup>4</sup>Frisvold, D. (2006, February). Head Start participation and childhood obesity. Vanderbilt University Working Paper No. 06-WG01; Currie, J. and Thomas, D. (1995, June). Does Head Start Make a Difference? *The American Economic Review*, 85 (3): 360; Anderson, K.H., Foster, J.E., & Frisvold, D.E. (2009). Investing in health: The long-term impact of Head Start on smoking. *Economic Inquiry*, 48 (3), 587–602.

<sup>5</sup>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.

<sup>6</sup>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.

<sup>7</sup>NHSA Public Policy and Research Department analysis of data from a Montgomery County Public Schools evaluation. See Zhao, H. & Modarresi, S. (2010, April). Evaluating lasting effects of full-day prekindergarten program on school readiness, academic performance, and special education services. Office of Shared Accountability, Montgomery County Public Schools.

<sup>8</sup>Kids Count Data Book. (2015). Children in poverty by age group. The Annie E. Casey Foundation. Retrieved from <http://datacenter.kidscount.org/data>.

being of these children and families in the budget process. NICWA provides the following recommendations:

Agency	Program	Fiscal year 2016 enacted	Fiscal year 2017 recommendation
DHHS ACF/CB	Promoting Safe and Stable Families-Disc. (tribal)	\$59.7m (\$1.8m)	\$79.7m (\$21.8m with \$20m tribal capacity funds)
DHHS ACF/CB	Child Abuse Discretionary Activities (tribal)	\$33.0m (unknown)	\$43.7m (unknown)
DHHS ACF/CB	Community-Based Child Abuse Prevention (tribal)	\$39.7m (\$416k)	\$50m (\$500k)
DHHS ACF/CB	Child Welfare Services (tribal)	\$268.7m (\$6.3m)	\$280m (-\$7.1m)
DHHS ACF/CB	Payments for Foster Care and Permanency	\$0.0m for tribal start-up funds	\$37m for tribal Title IV-E start-up funds
DHHS HRSA	Maternal Infant & Early Childhood Home Visiting Program (tribal)	\$400m (\$12m)	\$400m (\$12m)

#### PRIORITY RECOMMENDATIONS

##### *Payments for Foster Care and Permanency*

##### *DHHS, Administration for Children and Families*

**Budget Recommendation.**—Increase this program’s funding by \$37 million to specifically support tribal Title IV-E program start-up for Tribes with approved Title IV-E plans.

The Fostering Connections to Success and Increasing Adoptions Act (Public Law 110–351) provided Tribal Governments with historic new opportunities to access foster care and permanency funding and technical assistance under the Title IV-E program—an area of child welfare services where Tribes are woefully underfunded.

As described in a recent GAO report (2015), more Tribes are not running Title IV-E programs because Title IV-E does not provide the funding or support needed by many Tribes to actually begin implementation of the program. Essential to Title IV-E implementation is the ability to provide a substantial non-Federal match and support initial caregiver payments and program costs with tribal funds. Yet, Tribes interested in operating Title IV-E do not have the same access to general revenue as States. Also essential to Title IV-E implementation is the staffing and infrastructure necessary to support expanded services, additional requirements, and new accounting systems. Tribes—who have been chronically underfunded and only reassumed control over their child welfare services in 1978—do not have the same child welfare infrastructure or capacity as States.

The President’s fiscal year 2017 budget requests an increase of \$37 million to the Payments for Adoption and Permanency Program to allow for Tribes that have approved Title IV-E plans to apply for start-up funding. For Tribes to successfully access Title IV-E and children to have safe and supported foster homes this program must be funded.

##### *Promoting Safe and Stable Families (Social Security Act Title IV-B, Subpart 2)*

##### *DHHS, Administration for Children and Families*

**Budget Recommendation.**—Increase discretionary funding in this program to \$89.75 million to support the President’s \$20 million initiative to increase tribal capacity and rural child welfare.

The Promoting Safe and Stable Families Program (PSSF) provides funds to Tribes for coordinated child welfare services that include family preservation, family support, family reunification, and adoption support services. There is a 3 percent set-aside for Tribes based on a formula, however if a Tribe would qualify for less than \$10,000 then it is not eligible to receive any funding under this program. This means that many Tribes, typically those Tribes with the most need, cannot access PSSF funding because the overall appropriation is currently too low and affects the individual tribal allocation. This means that Tribes are providing intensive family preservation and family reunification services in spite of inadequate funding and in-

sufficient staffing. This puts incredible strain on individual workers and programs. This strain stands in the way of Tribes' ability to build capacity, expand programs, coordinate services with States, and help reduce disproportionate placement of AI/AN children in both State and tribal foster care systems.

The President's fiscal year 2017 budget includes a \$20 million increase to PSSF discretionary funds for a tribal child welfare capacity building initiative. This initiative would provide Tribes with the resources necessary to support the staff time, infrastructure, and development of child welfare departments and services, as well as assist States in reducing foster care rates of AI/AN children in their systems. NICWA recommends that this initiative be funded.

#### CHILDREN'S MENTAL HEALTH

The Attorney General's Advisory Committee on American Indian/Alaska Native Children Exposed to Violence provided the following recommendation:

The Secretary of Health and Human Services should increase and support access to culturally appropriate behavioral health services in all AI/AN communities (USDOJ, 2014, p. 88).

In order to effectively serve AI/AN children and communities, funding must provide flexible opportunities that allow Tribes to integrate culturally appropriate comprehensive mental and behavioral health services. NICWA provides the following recommendations:

Agency	Program	Fiscal year 2016 enacted	Fiscal year 2017 recommendation
DHHS SAMHSA	Programs of Regional and National Significance— Children and Family Programs (includes Circles of Care)	\$6.4m	\$8.5m (Reserve \$6.5m for Circles of Care)
DHHS SAMHSA	Children's Mental Health Services Program— Systems of Care	\$117m	\$117m
DHHS SAMHSA	GLS State/Tribal Youth Suicide Prevention	\$35.4m	\$40.5m
DHHS SAMHSA	GLS Campus Suicide Prevention Program	\$6.5m	\$9.1m
DHHS SAMHSA	AI/AN Suicide Prevention	\$2.9m	\$3.2m
DHHS SAMHSA	Tribal Behavioral Health Grant (divided equally between substance abuse prevention and mental health services)	\$30m	\$50m
DHHS SAMHSA	Project LAUNCH	\$34.5m	\$34.5m

#### PRIORITY RECOMMENDATIONS

##### *Tribal Behavioral Health Program*

##### *DHHS, Substance Abuse Mental Health Services Administration*

*Budget Recommendation.*—Increase funding of this program to \$50 million to make this funding available across Indian Country.

The Consolidated Appropriations Act of 2015 recommended that \$5 million be allocated to Tribal Behavioral Health Grants in the form of the Native Connections grant program appropriating this funding for the first time. These are competitive grants designed to target tribal entities with the highest rates of suicide per capita over the last 10 years. These funds must be used for effective and promising strategies to address the problems of substance abuse and suicide, and to promote mental health and well-being among AI/AN young people.

As originally conceptualized, the fiscal year 2012 budget request sought \$50 million for a new Behavioral Health-Tribal Prevention Grant. Approximately half of the funding was to be allocated as a "base level" to federally recognized Tribes that applied for these funds. Originally, the base amount that each Tribe would be eligible for was at least \$50,000. As eventually passed by Congress in the 2015 budget, funding for what is now known as the Native Connections grant program, focuses more specifically on youth and, due to the level of funding, are competitive grants

available to approximately 20 Tribes. The President's fiscal year 2017 budget request includes a \$20 million increase, \$10 million additional dollars in the Mental Health Services appropriations, and \$10 million new dollars in the Substance Abuse appropriations. This additional funding is still not enough to provide the program with adequate support to fulfill its initial conceptualization. To make it available across Indian Country NICWA recommends this program be funded at \$50 million, as suggested by the initial conceptualization of the program.

If you have any questions about this testimony please contact NICWA Government Affairs Director David Simmons at [desimmons@nicwa.org](mailto:desimmons@nicwa.org).

*References:*

U. S. Department of Justice, Office of Justice Programs, Office of Juvenile Justice and Delinquency Prevention. (2014). Attorney General's Advisory Committee on American Indian/Alaska Native Children Exposed to Violence: Ending violence so children can thrive. Retrieved from <http://www.justice.gov/sites/default/files/defendingchildhood/pages/attachments/2014/11/18/finalaianreport.pdf>.

PREPARED STATEMENT OF THE NATIONAL INDIAN HEALTH BOARD

Chairman Blunt, Ranking Murray and Members of the Subcommittee, thank you for the opportunity to offer this testimony for the record. On behalf of the National Indian Health Board (NIHB) and the 567 federally recognized Tribes we serve, I submit this testimony on fiscal year 2017 budget for the Department of Health and Human Services (HHS).

The Federal promise to provide Indian health services was made long ago. Since the earliest days of the Republic, all branches of the Federal Government have acknowledged the Nation's obligations to the Tribes and the special trust relationship between the United States and Tribes. The United States assumed this responsibility through a series of treaties with Tribes, exchanging compensation and benefits for Tribal land and peace.<sup>1</sup> In 2010, as part of the Indian Health Care Improvement Act, Congress reaffirmed the duty of the Federal Government to American Indians and Alaska Natives (AI/ANs).

Devastating consequences from historical trauma, poverty, and a lack of adequate treatment resources continue to plague Tribal communities. AI/ANs have a life expectancy 4.2 years less than other Americans, but in some areas, the life expectancy is far worse. For instance, in Montana, "white men . . . lived 19 years longer than American Indian men, and white women lived 20 years longer than American Indian women."<sup>2</sup> In South Dakota, in 2014, "for white residents the median age [at death] was 81, compared to 58 for American Indians."<sup>3</sup> These statistics reflect the shocking disparity that exists in per capita spending of the Indian Health Service (IHS) and other Federal healthcare programs. In 2015, the IHS per capita expenditures for patient health services were just \$3,136, compared to \$8,097 per person for healthcare spending nationally.

The obligation to provide healthcare to AI/ANs does not extend only to the IHS. The Federal trust responsibility is the responsibility of all government agencies, including others within HHS. Agencies like the Centers for Disease Control and Prevention (CDC); Substance Abuse and Mental Health Services Administration (SAMHSA); and Centers for Medicare and Medicaid Services (CMS) all must play a crucial role in ensuring that Indian Country receives both preventative and direct access to health services. Tribes may be eligible to apply for Federal grants that address public health and other issues, however, many of these programs have little penetration into Indian Country because Tribes have difficulty meeting the service population requirements, match requirements, or are under resourced to even competitively apply for the grants. Unlike State health departments which employ teams of people to write grants, few Tribes have enough staff to conduct basic programming, let alone work on competitive grant applications.

NIHB respectfully requests that the committee consider providing additional direct funding to Tribal communities through the use of "set asides" for Indian Country to ensure that Indian Country is not left out of Federal funding opportunities. Without direct funding, Tribes are unable to develop sustainable infrastructure for public health and behavioral health programs, leading to an inconsistent and unreliable service delivery system.

<sup>1</sup>The Snyder Act of 1921 (25 U.S.C. 13) legislatively affirmed this trust responsibility.

<sup>2</sup>"The State of the State's Health: A Report on the Health of Montanans." Montana Department of Public Health and Human Services. 2013. p. 11.

<sup>3</sup>"2014 South Dakota Vital Statistics Report: A State and County Comparison of Leading Health Indicators." South Dakota Department of Health. 2014. P. 62.

## CENTERS FOR DISEASE CONTROL AND PREVENTION

*Public Health Services Block Grant.*—Public health infrastructure in Indian Country is one of the most severely underfunded and under developed areas of the health service delivery system. IHS services are largely limited to direct patient care, leaving little, if any, funding available for public health initiatives. Our communities are therefore more vulnerable to increased health risks and sickness. As independent, sovereign nations, Tribal Governments do not operate within the State regulatory structure, and often must compete with their own State Governments for resources. Tribes are regularly left out of statewide public health plans and Federal funding decisions for public health programs. A complex public health system exists in the U.S. that includes a funding stream between the Federal and State Governments that largely support the national public health infrastructure—Tribes were excluded from this system. Tribes do not receive the Federal funding that allows State health departments to function. It is time to examine how Tribes can be integrated into the U.S. public health system, and redress this wrong.

Tribal communities must cobble together public health funding from a variety of Federal, State, local and private funding sources. State Governments receive base operational systems and programmatic funding through the large flagship Federal grants and the Public Health and Health Services Block (PHHS) grant program, while Tribes are either not eligible to compete for the funding or are woefully underrepresented in the grantee pool. This leads to rampant unpredictability and inconsistency among Tribal public health initiatives. Consequently, significant gaps exist when it comes to health education, emergency preparedness, community healthcare services and basic healthcare screenings. Therefore, NIHB requests that, in fiscal year 2017, Congress create base funding for Tribal communities through the PHHS grant program by allocating at least 5 percent to Indian Tribes directly. This will enable public health systems in Indian Country to access consistent, sustainable, public health infrastructure dollars so that Tribal communities can begin to catch up to other Americans when it comes to public health.

*Hepatitis C Treatment in Indian Country.*—According to the CDC's most recent surveillance report on hepatitis C, in 2013, AI/ANs were the population with the highest hepatitis C-related mortality rate at 12.2 deaths per 100,000 people. This is 46 percent higher than the next highest population death rate. And between 2009 and 2013, the hepatitis C-related mortality rate among American Indians and Alaska Natives increased by 23.2 percent. The hepatitis C (HCV) scourge among AI/AN communities continues to grow out of control with no substantial dedication of resources or commitment by HHS to provide for targeted prevention, capacity building, and treatment. Treatment, that very nearly mirrors a cure, is readily available; however, community members may not be sure how to access the treatments, and Tribes have competing priorities and are reticent to utilize scarce IHS resources to secure the treatment. Even more so, prevention efforts to promote HCV screening have not been bolstered in Tribal communities, service providers have not been trained to talk to their patients about hepatitis risks and testing options, nor have efforts existed to educate the community and high risk populations about their ability to minimize their risks for exposure to HCV.

Therefore, NIHB recommends that Congress direct the CDC to create a grant program specifically for AI/ANs that will provide monies for community-based prevention and screening efforts for HCV. Furthermore, we request that CDC be instructed to work with IHS to construct a targeted action plan for promoting the prevention of hepatitis C, increasing screening efforts and increasing access to treatment.

*Public Health Emergency Preparedness.*—The Public Health Emergency Preparedness (PHEP) Cooperative Agreements at CDC provide base funding to States, territories and major cities to upgrade their ability to respond to a public health crises. But again, Tribal communities do not receive this funding directly, see little support from their State programs. Without federally-supported infrastructure support for prevention and rapid response to natural disasters, bioterrorism and outbreaks in Indian Country, the impacts on American Indians and Alaska Natives (and others) could be enormous. And with the looming threat of the Zika Virus, this is even more urgent—as a significant percentage of Tribes occupy those lands projected to be in danger due to the habitat of the mosquito that transmits the virus. Failure to fund Tribal communities and reservations could mean that large land areas of this country are not covered for emergency infrastructure support, causing a domino effect throughout the rest of the Nation when it comes to disease outbreaks or natural disasters. NIHB requests that Congress direct 5 percent of PHEP funds to Tribes so that they can develop serious and achievable response plans for public health crises.

## SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION

Nowhere is the issue of lack of solid infrastructure support more acute than mental and behavioral health services. AI/AN children and communities grapple with complex behavioral health issues at higher rates than any other population. Destructive Federal Indian policies and unresponsive or harmful human service systems have left AI/AN communities with unresolved historical and generational trauma.<sup>4</sup> But access to behavioral health services is limited. In a study of 514 IHS and Tribal facilities, 82 percent report providing some type of mental health service such as psychiatric services, behavioral health services, substance abuse treatment, or traditional healing practices, and to improve access 17 percent (87) have implemented telemedicine for mental health services.<sup>5</sup> However, none provide inpatient psychiatric services.<sup>6</sup> Without access to care, persons in psychiatric distress often end up at the hospital emergency room.<sup>7</sup>

*Tribal Behavioral Health Grants and Zero Suicide.*—At the Substance Abuse and Mental Health Services Administration, several programs specifically target Tribal communities. NIHB was pleased to see that Tribal Behavioral Health Grants (TBHG) received a substantive increase in the final fiscal year 2016 appropriation. This critical program is designed to address the high incidence of substance use and suicide among AI/AN populations and it is a vital component of ensuring that behavioral health challenges are addressed across Indian Country. In fiscal year 2017, NIHB requests funding of \$50 million for the TBHG program. NIHB also supports the Administration's fiscal year 2017 request for \$5.2 million in a Tribal set-aside to implement the Zero Suicide Initiative.

*Circles of Care.*—NIHB continues to support the Circles of Care Program which offers 3-year infrastructure/planning grants and seeks to eliminate mental health disparities by providing AI/AN communities with tools and resources to design and sustain their own culturally competent system of care approach for children. Behavioral health infrastructure is one of the key challenges for many Tribal communities when it comes to creating sustainable change for their communities. Circles of Care represents a critical part of this work. In fiscal year 2017, we recommend increasing Circles of Care funding by \$2 million for a program total of \$8.5 million.

## CENTERS FOR MEDICARE AND MEDICAID SERVICES

*Definition of Indian in the Affordable Care Act.*—The Affordable Care Act (ACA) (PL 111–148) contains several important provisions for American Indians and Alaska Natives including permanent reauthorization of the Indian Health Care Improvement Act. However, certain portions of healthcare reform contain different definitions of “Indian” which led to conflicting interpretations of eligibility for benefits and requirements for coverage. These definitions are different than those used by IHS and the Centers for Medicare and Medicaid Services and require that an individual be a member of a federally recognized Tribe. NIHB requests a legislative fix to streamline these definitions. Specifically, we request that Congress insert the text of S. 2114 into the fiscal year 2017 Labor, HHS, Education and Related Agencies Appropriations bill. Despite efforts by Congress to provide instructions to the agency in fiscal year 2016, the Administration has refused to correct this inconsistency through regulation. This fix will not change who is eligible to receive IHS services, but will ensure that the benefits and protections in the law are provided to those for whom they were intended. Without a fix, the Federal Government will essentially create class of “sometimes Indians” who are eligible for some benefits (e.g. IHS) but not others (those in the ACA). This fix is also supported in the fiscal year 2017 President's Budget request to Congress.

*American Indian/Alaska Native Call Center for the Health Insurance Marketplace.*—AI/ANs continue to experience poor assistance when contacting the marketplace call center for help. Issues range from technicians having no knowledge of the Indian-specific protections like exemptions and tax credits, to technicians being rude and having no patience to walk elderly consumers through the troubleshooting process. Because AI/AN consumers continue to receive such poor customer service that exhibit little or no knowledge about AI/AN-specific provisions in the ACA, NIHB has

<sup>4</sup> Braveheart, M. Y. A., & DeBruyn, I. M. (1998). The American Indian Holocaust: healing historical unresolved grief. American Indian and Alaska Native Mental Health Research, 8(2).

<sup>5</sup> Urban Indian Health Institute. (2012). Addressing depression among American Indians and Alaska Natives: A literature review. Seattle, WA: Urban Indian Health Institute.

<sup>6</sup> Indian Health Service. (2011). Inpatient mental health assessment. Retrieved from [http://www.ihs.gov/newsroom/includes/themes/newihstheme/display\\_objects/documents/FINAL\\_IHCIA\\_InpatientMH\\_Assessment\\_Final.pdf](http://www.ihs.gov/newsroom/includes/themes/newihstheme/display_objects/documents/FINAL_IHCIA_InpatientMH_Assessment_Final.pdf).

<sup>7</sup> Ibid.

requested that the Center for Consumer Information and Insurance Oversight establish an Indian-specific call center to respond to questions and provide technical assistance to AI/ANs. NIHB recommends that Congress provide funding, as detailed in the President's Request, for the Tribal Resource Center at the Center for Medicare and Medicaid Services at \$500,000 as requested by CMS.

#### CONCLUSION

Thank you again for the opportunity to offer this written statement. As noted above, the Federal trust responsibility for health extends beyond the IHS to all agencies of the Federal Government. While Tribes have made important gains in recent years in terms of funding, consultation and increased awareness throughout all of HHS, there is still a long way to go before health systems in Indian Country are on par with those enjoyed by other Americans.

[This statement was submitted by Lester Secatero, Chairman, National Indian Health Board.]

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#### PREPARED STATEMENT OF THE NATIONAL KIDNEY FOUNDATION

The National Kidney Foundation (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. NKF works with volunteers to offer the scientific, clinical and kidney patient perspective on what needs to be done to prevent kidney disease, delay progression, and better treat kidney disease and kidney failure. In addition, NKF has provided evidence-based clinical practice guidelines for all stages of chronic kidney disease (CKD), including transplantation since 1997 through the NKF Kidney Disease Outcomes Quality Initiative (NKF KDOQI). NKF has local division and affiliate offices serving our constituents in all 50 States.

NKF is pleased to submit testimony regarding the impact of Chronic Kidney Disease (CKD), and steps that can be taken by Congress to build upon the success of the existing programs at the National Institutes of Health, Centers for Disease Control, and Health Resources and Services Administration to improve early detection and treatment of the disease.

#### ABOUT CKD

Chronic Kidney Disease (CKD) is a condition characterized by a gradual loss of kidney function over time. CKD impacts 26 million American adults, while 1 in 3 (73 million) American adults are at risk for kidney disease. Diabetes and high blood pressure are responsible for up to two-thirds of all cases of irreversible kidney failure (end stage renal disease). Kidney disease can be detected through a simple urine test, yet the disease can go undetected until very advanced because kidney disease often has no symptoms. When kidney disease progresses, it may lead to kidney failure, which requires dialysis or a kidney transplant to maintain life. Rates of kidney failure are higher among minorities, with African Americans developing ESRD at a rate of 3 to 1 compared to Whites and Hispanic Americans developing it at a rate of 2 to 1.

#### THE IMPORTANCE OF EARLY DETECTION OF CKD

Only 10 percent of individuals with CKD are aware they have it.<sup>1</sup> CKD is often asymptomatic—especially in the early stages—and therefore goes undetected without laboratory testing. Some people are not diagnosed until they have reached end-stage renal disease (ESRD) and must begin dialysis immediately.

At the end of 2014, 661,648 Americans had End Stage Renal Disease (ESRD), including 468,386 dialysis patients and 193,262 kidney transplant recipients. Complicating the cost and human toll is the fact that it is a disease multiplier, with patients very likely to be diagnosed with cardiovascular disease. ESRD was present in less than 2 percent of Medicare beneficiaries but responsible for nearly 6 percent of Medicare expenditures.

Cost-effective early identification and treatment options exist which can slow the progression of kidney disease, delay complications, and prevent or delay kidney failure. Intervention at the earliest stage is vital to improving outcomes, lowering healthcare costs, and improving patient experience, yet in a recent clinical study

<sup>1</sup> Tuot DS, Plantinga LC, Hsu CY, et al. Chronic kidney disease awareness among individuals with clinical markers of kidney dysfunction. *Clin J Am Soc Nephrol*. Aug 2011;6(8):1838–1844.

only 12 percent of primary care clinicians were properly detecting CKD in their patients with diabetes who are at the highest risk of kidney disease.<sup>2</sup> There often is a misconception that once someone is diagnosed with CKD, there must be a referral to a nephrologist. However, it is not necessary in most instances for referral to a nephrologist in early stages.

#### THE CKD INTERCEPT INITIATIVE

NKF is moving forward on an initiative we announced 2 years ago to help improve early detection and diagnosis of CKD by primary care practitioners (PCP). Our CKD Intercept initiative aims to transform PCP detection and care of the growing numbers of Americans with CKD by deploying evidence based clinical guidelines into primary care settings through education programs, symposia and practical implementation tools.

In support of this effort, NKF is advocating for Congress to enact legislation to remove the reimbursement barriers to earlier, better CKD care management by directing the Secretary of Health and Human Services to create a Medicare bundled payment demonstration for CKD management to primary care practitioners and nephrologists. Given the high costs and comorbidities associated with late diagnosis of CKD, this demonstration is expected to improve patient outcomes, lower hospitalizations and result in savings to Medicare. NKF commissioned a study to develop a cost estimate model on improving earlier detection and management of CKD. Through early intervention, Medicare could reduce spending by \$4.8 billion in year 10 and \$8.2 billion in year 20, for a total reduction in spending of \$93 billion over 20 years.

While progression of CKD can lead to ESRD, CKD patients are at a greater risk of death, cardiovascular events and adverse drug events. In a most recent study conducted by The Johns Hopkins University, testing for kidney disease—in those with the disease—may be a stronger risk predictor of heart attack and stroke than tobacco use, blood pressure, or high cholesterol.<sup>3</sup> Testing for kidney disease in at-risk populations provides the opportunity for interventions to foster awareness, foster adherence to medications and control risk factors. Therefore, NKF's initiatives address three priorities in the National Strategy for Quality Improvement in Health Care, including (1) making care safer by reducing harm caused in the delivery of care, (2) promoting the most effective prevention and treatment of the leading causes of mortality, starting with cardiovascular disease, and (3) working with communities to promote widespread use of best practices to enable healthy living.

With the continued support of Congress, NKF is confident a feasible detection, surveillance and treatment program can be advanced to as a first step to slow the progression of kidney disease. These initiatives will help build on the CDC's investment in the Chronic Kidney Disease Program.

#### CDC CHRONIC KIDNEY DISEASE PROGRAM

NKF urges the Committee to provide \$2.31 million for the CKD program for fiscal year 2017, an increase of \$200,000. Prior to the creation of the Chronic Kidney Disease Program at CDC in fiscal year 2006, no national public health program focusing on early detection and treatment of CKD existed. The CDC CKD 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.

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 objectives. However, increas-

<sup>2</sup>Szczzech LA, et al. Primary Care Detection of Chronic Kidney Disease in Adults with Type-2 Diabetes: The ADD-CKD Study (Awareness, Detection and Drug Therapy in Type 2 Diabetes and Chronic Kidney Disease), PLOS One November 26, 2014.

<sup>3</sup>Matsushita, Kunihiro, Estimated glomerular filtration rate and albuminuria for prediction of cardiovascular outcomes: a collaborative meta-analysis of individual participant data. *Lancet Diabetes Endocrinol.* Published online May 29, 2015, [http://dx.doi.org/10.1016/S2213-8587\(15\)00040-6](http://dx.doi.org/10.1016/S2213-8587(15)00040-6).



ing the proportion of persons with CKD who know they are affected requires acquiring additional data sources beyond Medicare claims and NHANES survey analyses to identify the undiagnosed population and assess the burden of CKD across the country to better understand the CKD impact at a State and local level. This momentum will be stifled and CDC's investment in CKD to date jeopardized if line-item funding is not increased.

A study published by researchers leading the program shows that the burden of kidney disease is increasing and that over half of U.S. adults age 30–64 are likely to develop CKD.<sup>4</sup> Congressional support for an increase in funding to the CDC program will benefit kidney patients and those 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. Agency priorities going forward include assessing disparities among racial and socioeconomic populations and adding new and local data on CKD including additional risk factors.

#### NIDDK

NKF supports the Friends of NIDDK request of \$2.16 billion for the Institute in fiscal year 2017. Medicare spent \$99 billion in 2014 caring for patients with kidney disease, \$68 billion of which was for individuals who do not have kidney failure, yet NIH funding for kidney disease research is only about \$600 million annually. Many research proposals with the potential to lead to improved treatments, including reconstructing the kidney to restore function, remain unfunded. Patients deserve better and we cannot allow these opportunities to slip away.

In March, NKF hosted the Third Annual Kidney Patient Summit that included participation from nearly 100 advocates from NKF and four other kidney patient organizations. Increased Federal support for kidney disease research was a top priority in meetings with the advocates' congressional delegations. This is particularly important for individuals whose kidney disease is the result of genetic factors. 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, CKD research has the potential to provide cost savings to the Federal Government like that of no other chronic disease. We urge Congress to again provide strong bipartisan support for NIH to continue building on the success of the fiscal year 2016 efforts, and fund NIDDK at this requested level.

#### HRSA ORGAN TRANSPLANTATION

NKF urges the Committee to provide \$28.5 million for organ donation and transplantation programs in the HRSA DoT. This request is broadly supported by patient and professional members of the transplant community to restore the program's purchasing power to the fiscal year 2010 level. Activities supported by DoT include initiatives to increase the number of donor organs, and the National Donor Assistance Program which helps individuals obtain a transplant by assisting living organ donors with expenses such as travel and subsistence that are not reimbursed by insurance, a health benefit program, or any other State or Federal program.

As of April 8, 2016, the kidney transplant wait list consisted of 100,269 individuals plus an additional 1,927 waiting for a combined kidney/pancreas donation. Transplantation remains the treatment of choice for most patients with kidney failure yet few will be given this opportunity. 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 \$29,920 per year on a kidney recipient after the year of transplant, compared to more than \$84,450 annually on a dialysis patient.

In 2014, NKF established an organ donation task force to review the state of organ donation and identify opportunities to expand the number of transplants. While the task force continues to develop its recommendations, some activities are being implemented, one example of which is NKF's "The Big Ask/The Big Give" campaign. This initiative, currently in the pilot phase, promotes and supports awareness of living kidney donation. It is designed for both those waiting for a kidney transplant who have trouble asking somebody to consider donation (The Big Ask) and potential kidney donors (The Big Give). The Big Ask/The Big Give provides the necessary education and platform to take the misconceptions and confusion out

<sup>4</sup>Hoeger, Thomas, et al. The Future Burden of CKD in the United States: A Simulation Model for the CDC CKD Initiative, *Am J Kidney Dis.* 2015;65(3):403–411.

of what can be a very complex process. We intend to offer the program nationwide in transplant centers, dialysis centers and nephrology practices.

Thank you for your consideration of our funding requests for fiscal year 2017.

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#### PREPARED STATEMENT OF THE NATIONAL LEAGUE FOR NURSING

The NLN promotes excellence in nursing education to build a strong and diverse nursing workforce to advance the health of the Nation and the global community. The League represents more than 1,200 nursing schools, 40,000 members, and 25 regional constituent leagues. The NLN urges the subcommittee to fund the Health Resources and Services Administration's (HRSA) Title VIII nursing workforce development programs at \$244 million in fiscal year 2017. This amount is equal to the fiscal year 2010 funding level for the Title VIII programs.

#### NURSING EDUCATION

Health inequities, inflated costs, and poor healthcare outcomes are intensifying because of today's shortfall of appropriately prepared registered nurses (RNs) and licensed vocational/practical nurses (LVN/LPNs). With 4.6 million active, licensed RNs/LPNs, nurses are the primary professionals delivering quality healthcare in the Nation. According to the Bureau of Labor Statistics (BLS), the RN workforce is projected to grow by 16 percent from 2014–2024, resulting in 1,088,400 job openings due to growth and replacement needs. BLS also calculates the LVN/LPN workforce will grow by 16.3 percent resulting in 322,200 job openings during the same time-frame. This increase is fueled by an increased demand for healthcare services for the aging population. Nurses will also be needed to educate and care for patients with various chronic conditions, such as arthritis, dementia, diabetes, and obesity. The situation is further affected by the needed replacement of some 439,300 jobs vacated by RNs and 117,000 vacated by LVN/LPNs who will leave the profession and/or retire by 2024.

The nursing shortage continues to outpace the level of Federal resources allocated by Congress to help alleviate it. Appropriations for nursing education are inconsistent with the healthcare reality facing our Nation today. For the last 50 years, the Title VIII nursing workforce development programs have provided training for entry-level and advanced practice registered nurses (APRNs) to improve the access to, and quality of, healthcare in underserved communities. The Title VIII 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 health policy that provides high-value care for every dollar invested in capacity building for a 21st century nurse workforce. Insufficient Federal investments in the nursing workforce are a shortsighted course of action that further jeopardizes access to, and the quality of, the Nation's healthcare delivery. Absent consistent support, slight boosts to Title VIII programs 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. As the United States tackles the workforce shortage that exacerbates the stress in the healthcare system, nursing programs across the country are rejecting qualified candidates because there is not enough faculty to teach them. The percentage of LPN/LVN pre-licensure programs that turned away qualified applicants dropped by 11 percent according to the NLN's survey of schools of nursing for academic year 2013–2014. The percentage for BSN programs remained unchanged between 2012 and 2014, while the percentage for BSRN (RN to BSN), masters, and doctorate programs increased by 6 percent, 8 percent, and 4 percent, respectively. If BSN programs remain the same as from 2012 to 2014, this could have a potential impact on the Institute of Medicine's (IOM) recommendation in *The Future of Nursing: Leading Change, Advancing Health* (2011) for an increase in the proportion of nurses with baccalaureate degrees from 50 to 80 percent by 2020.

While the proportion of programs that turn away qualified applicants in prelicensure programs is declining, the NLN survey still indicates that a number of qualified applications are being rejected due to various constraints encountered by nursing programs. A lack of clinical placement settings continues to be a critical

constraint as well as lack of faculty to expanding the capacity of nursing programs in almost all programs. NLN research on America's nearly 60,000 nurse educators shows that a core cause of the shortage is an aging and overworked faculty who earn less than nurses entering clinical practice. Sixty percent of all full-time nurse faculty members are 45- to 60-years old. Fifty-five percent of nurse faculty say they are likely to leave academic nursing by 2020. BLS projects a need of 25,400 new nursing instructors by 2024 due to the expected increase in demand as well as the expected retirement of 12,200 current faculty members.

#### EQUALLY PRESSING IS LACK OF DIVERSITY

Besides representing an untapped talent pool to remedy the nationwide nursing shortage, diversity in nursing is essential to developing a healthcare system that understands and addresses the needs of our rapidly changing population. Our Nation is enriched by cultural complexity—37 percent of our population identify as racial and ethnic minorities. Yet diversity eludes the nursing student and nurse educator populations. Minorities only constitute 28 percent of the student population and males only 15 percent of pre-licensure RN students. 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. 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, loans, scholarships, and services that enable students to overcome obstacles to completing their nursing education programs. HRSA's Title VIII data below from the agency's fiscal year 2017 budget justification of estimates provide a perspective on current Federal investments.

The *Advanced Nursing Education (ANE)* program supports infrastructure grants to schools of nursing for advanced practice programs preparing nurse-midwives, nurse anesthetists, nurse practitioners, clinical nurse specialists, nurse administrators, nurse educators, public health nurses, or other advanced level nurses. In academic year 2014–2015, ANE program grantees trained 8,735 nursing students and produced 2,148 graduates. In addition, 30 percent of students trained were underrepresented minorities and/or from disadvantaged backgrounds.

*Nursing Workforce Diversity (NWD)* grants increase educational opportunities for individuals from disadvantaged backgrounds (including racial and ethnic minorities underrepresented in nursing) through scholarship or stipend support, pre-entry preparation, and retention activities. In academic year 2014–2015, the number of nursing program students trained was 4,400.

*Nurse Education, Practice, Quality, and Retention Grants (NEPQR)* address the critical nursing shortage via projects to expand the nursing pipeline, promote career mobility, provide continuing education, and support retention. The NEPQR program funded the Veterans' Bachelor of Science in Nursing (VBSN) program and made awards to 17 schools. Four hundred seventy-two veterans were enrolled in BSN degree programs and 82 graduated with a BSN degree. It is estimated that 33 percent of participating veterans were underrepresented minorities in the field of nursing, and 24 percent reported coming from a financially and/or educationally disadvantaged background.

The *Nurse Faculty Loan Program (NFLP)* supports the establishment and operation of a loan fund at participating schools of nursing to assist nurses in completing their graduate education to become qualified nurse faculty. In academic year 2014–2015, the NFLP supported 2,399 students pursuing faculty preparation. Twenty percent of students who received a loan reported coming from a disadvantaged background and nearly 25 percent of students are considered underrepresented minorities in their prospective professions.

The *NURSE Corps Scholarship and Loan Repayment Program (NURSE Corps)* offers to individuals, who are enrolled or accepted for enrollment as full-time or part-

time nursing students, the opportunity to apply for funds. The NURSE Corps repays up to 85 percent of nursing student loans in return for at least 3 years of practice in a designated nursing shortage area. In fiscal year 2015, the NURSE Corps loan repayment program made 590 loan repayment awards and 319 continuation awards. The NURSE Corps scholarship program made 257 new scholarship awards and 12 continuation awards during the same time period.

The NLN urges the subcommittee to fund the Title VIII nursing workforce development programs at the fiscal year 2010 funding level of \$244 million in fiscal year 2017.

[This statement was submitted by Anne R. Bavier, PhD, RN, FAAN, President, and Beverly Malone, PhD, RN, FAAN, Chief Executive Officer, National League for Nursing.]

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PREPARED STATEMENT OF THE NATIONAL MINORITY CONSORTIA

The National Minority Consortia (NMC) submits this statement on fiscal year 2019 advance appropriations for the Corporation for Public Broadcasting (CPB). We represent a coalition of five national organizations, who, with modest support from CPB, bring authentic stories of diversity to the Nation. We bring unique voices and perspectives from America's diverse communities into all aspects of public broadcasting and other media, including content transmitted digitally over the Internet. Our requests are two: (1) That Congress direct CPB to meaningfully increase its commitment to diverse programming and serving underserved communities; and (2) that at least \$445 million be provided in advance fiscal year 2019 funding for CPB. We ask the Committee to:

—Direct CPB to increase its efforts for diverse programming with a commitment for minority programming and for organizations and stations located within underserved communities. We urge Congress in bill and/or report language to recognize that CPB, while it has enabled diversity in public broadcasting, still has very far to go. We suggest language such as:

The Committee recognizes the importance of the partnership CPB has with the National Minority Consortia, which helps develop, acquire, and distribute diverse content to Public Media entities to serve underrepresented communities. These stories of diversity transcend statistics and bring universal American stories to all U.S. citizens. As populations of diverse ethnic backgrounds are increasing in cities and towns across the Nation, Public Media entities, TV and Radio stations and digital platforms must strive to meet this audience's needs. The Committee encourages CPB to support and expand this critical partnership, including instituting funding guidelines that encourage and reward public media that represent and reach a diverse American public.

CPB has a big responsibility with regard to diversity, yet the five NMC organizations combined receive only \$6.5 million in discretionary funds from CPB, an amount less than 2 percent of the CPB budget. A previous amount of \$7.5 million had been decreased by 10 percent in 2013 due to the sequestration and was never reinstated.

—Provide fiscal year 2019 advance appropriation for CPB of \$445 million, in order to develop content that reaches across traditional media boundaries, such as those separating television and radio.

While public broadcasting continues to uphold strong ethics of responsible journalism and thoughtful examination of American history, life and culture, it has not kept pace with our rapidly changing demographics. Members of minority groups continue to be underrepresented on programming and oversight levels within and in content production. This is unacceptable in America today, where minorities comprise 34.7 percent of the population. This becomes more urgent now that racial and ethnic minorities make up more than half of all children born in the United States today.

Public broadcasting has the potential to be particularly important for our growing minority and ethnic communities, especially as we transition to a broadband-enabled, 21st century workforce that relies on the skills and talent of all of our citizens. While there is a niche in the commercial broadcast and cable world for quality programming about our communities, it is in the public broadcasting sphere where minority communities and producers should have more access and capacity to produce diverse high-quality programming for national audiences. We therefore, urge Congress to insert strong language in this act to ensure that this is the case and that these opportunities are made available to minorities and other underserved communities.

## ABOUT THE NATIONAL MINORITY CONSORTIA

The NMC is made up of five separate and distinct organizations that address the need for programing that reflects American's growing ethnic and cultural diversity. With primary funding from the CPB, the NMC serves as an important component of Public Media content—on air and/or digitally. By developing and funding diverse content, training and mentoring the next generation of minority media makers, as well as brokering relationships between content creators and content aggregators, we are in a position to ensure the future strength and relevance of Public Media content from and to our communities.

Each Consortia organization is engaged in cultivating ongoing relationships with the independent producer community by providing technical assistance and program funding, support and distribution. Often the funding we provide is the initial seed money for a project, that is matched by other public and private sources, providing true economic development. We also provide numerous hours of programming to individual Public Television and Radio stations—programming that is beyond the reach of most local stations. To have a real impact, we need funding that recognizes and values the full extent of minority participation in public life. Below is information regarding each of the five NMC organizations.

*Center for Asian American Media (CAAM).*—CAAM's mission is to present stories that convey the richness and diversity of Asian American experiences to the broadest audience possible. They do this by funding, producing, distributing and exhibiting works in film, television and digital media. CAAM's award-winning public TV programs are seen by millions of viewers a year across the United States, including 47 documentary shows in the last 4 years. Since launching the groundbreaking Asian American anthology series *Silk Screen* (1982–1987) on PBS, CAAM has continued to bring works to millions of viewers nationwide. CAAM is widely recognized for its artistic and programmatic excellence. Films supported by CAAM include, *Jake Shimabukuro: Life on Four Strings* winner of the Gotham Audience Award and Peabody Award winner *American Revolutionary: The Evolution of Grace Lee Boggs* (2014) by Grace Lee. These and other CAAM supported films have formed the canon of Asian American studies programs and virtually defined the development and evolution of a distinctive Asian American voice in the media for over three generations.

CAAM presents the annual CAAMFest (formerly known as the San Francisco International Asian American Film Festival) and distributes Asian American media to schools, libraries and colleges. CAAM's newest department, Digital Media, is becoming a respected leader in bringing innovative content and audience engagement to public media.

*Latino Public Broadcasting (LPB).*—Latino Public Broadcasting (LPB) is the leader in the development, production, acquisition and distribution of non-commercial educational and cultural media that is representative of Latino people, or addresses issues of particular interest to Latino Americans. These programs are produced for dissemination to public broadcasting stations and other public telecommunication entities. Between 2009 and 2015, LPB programs won 85 awards, including the prestigious George Foster Peabody Award, two Emmys, two Imagen Awards and the Sundance Film Festival Award for Best Director, Documentary. In addition, LPB has been the recipient of the Norman Lear Legacy Award and the NCLR Alma Award for Special Achievement—Year in Documentaries.

Latino Public Broadcasting provides a voice to the diverse Latino community throughout the United States. Latinos have helped shape the Nation over the last 500-plus years and have become, with more than 50 million people, the largest minority group in the Nation.

*National Black Programming Consortium/Black Public Media (NBPC)* works to increase capacity in diverse communities to create, distribute and use public media. Throughout its history, its mission has been two-fold: building capacity in new generations of creators of social issue media and broadening the pool of stakeholders in public media institutions. NBPC is dedicated to developing black digital authorship and distributing unique stories of the black experience in the new media age. Since 1979 NBPC has invested over \$7 million dollars in iconic documentary productions for public television; trained, mentored, and supported a diverse array of producers who create content about contemporary black experiences; and emerged as a leader in the evolving next-media landscape through its annual New Media Institute and New Media Institute: Africa programs. NBPC also distributes engaging content online through its social media portal BlackPublicMedia.org, an online home for enlightening black digital content and engagement.

*Pacific Islanders in Communications (PIC).*—PIC's mission is to support, advance, and develop Pacific Island media content and talent that results in a deeper understanding of Pacific Island history, culture, and contemporary challenges. In keeping

with the mission, PIC helps Pacific Islander stories reach national audiences through funding support for productions, training and education, broadcast services, and community engagement. Last year alone, PIC provided 17.5 hours of Pacific Islander content to Public Media. In the past 10 years, PIC has produced over 100 hours of programming for national broadcast, trained over 400 Pacific Islander filmmakers, and have had over 200 community screenings worldwide reaching more than 60,000 people in attendance. This summer, PIC will present their new, Emmy award winning, six- part series Family Ingredients on PBS. In the last 2 years PIC has had two films in the award-winning series Independent Lens, Kumu Hina and In Football We Trust. PIC's seminal series Pacific Heartbeat, reached over 24 million households last year, and will begin its fifth season in May.

*Vision Maker Media (VMM)* (formerly Native American Public Telecommunications) empowers and engages Native People to tell stories. They serve Native producers and Indian country in partnership with public television and radio by working with Native producers to develop, produce and distribute educational telecommunications programs for all media including public television and public radio. Vision Maker Media supports training to increase the number of American Indians and Alaska Natives producing quality public broadcasting programs, which includes advocacy efforts promoting increased control and use of information technologies and the policies to support this control by American Indians and Alaska Natives. A key strategy for this work is the development of strong partnerships with Tribal nations, Indian organizations and Native communities. Reaching the general public and the global market is the ultimate goal for the dissemination of Native produced media that shares Native perspectives with the world.

In the past 2 years, VMM has presented over 20 hours of programming to Public Media. 90 percent of public television stations utilized their content for programming needs. The Medicine Game was released in April 2015 and stations continue to use this program to inspire students, teachers and parents. Two brothers from the Onondaga Nation pursue their dreams of playing lacrosse for Syracuse University. Their dream nearly in reach, the boys are caught in a constant struggle to define their Native identity, live up to their family's expectations and balance challenges on and off the Reservation. Stories of hope, like The Medicine Game, can shine light in dark places, helping solve some of the toughest issues Native Americans face.

Thank you for your consideration of our recommendations. We see new opportunities to increase diversity in programming, production, audience, and employment in the new media environment, and we thank Congress for support of our work on behalf of our communities.

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PREPARED STATEMENT OF THE NATIONAL NETWORK TO END DOMESTIC VIOLENCE

Labor, Health and Human Services Appropriations Subcommittee Chairman Blunt, Ranking Member Murray, Chairman Cochran, Vice Chairwoman Mikulski and distinguished members of the Appropriations Committee, thank you for this opportunity to submit testimony on the importance of investing in Family Violence Prevention and Services Act (FVPSA) and Violence Against Women Act (VAWA) programs. I sincerely thank the Committee for its ongoing support of these life-saving programs.

I am the President and CEO of the National Network to End Domestic Violence (NNEDV), the Nation's leading voice for domestic violence survivors and their advocates. We represent the 56 State and territorial domestic violence coalitions, their nearly 2,000 member domestic violence and sexual assault programs, and the millions of victims they serve. Our direct connection with victims and victim service providers gives us a unique understanding of their needs and the vital importance of continued Federal investments. I am submitting this testimony to request a targeted investment of \$260 million in Family Violence Prevention and Services Act (FVPSA), Violence Against Women Act (VAWA) and related programs administered by the U.S. Department of Health and Human Services fiscal year 2017 Budget (specific requests detailed below).

*Incidence, Prevalence, Severity and Consequences of Domestic and Sexual Violence.*—The crimes of domestic and sexual violence are pervasive, insidious and life-threatening. Recently, the Centers for Disease Control and Prevention (CDC) released the first-ever National Intimate Partner and Sexual Violence Survey (NISVS) which found that domestic violence, sexual violence, and stalking are widespread. Domestic violence affects more than 12 million people each year and nearly three in ten women and one in four men have experienced rape, physical, violence, or stalking in his or her lifetime. Female victims of rape, physical violence, or stalking

by an intimate partner experienced severe impacts such as fear, concern for their safety, need for medical care, injury, need for housing services, and missing work or school.

The CDC has estimated that 854,000 women in Missouri and 1,094,000 women in Washington State have experienced rape, physical violence, or stalking by an intimate partner in their lifetime.<sup>1</sup> The terrifying conclusion of domestic violence is often murder, and every day in the United States, an average of three women are killed by a current or former intimate partner.<sup>2</sup> The cycle of intergenerational violence is perpetuated as children are exposed to violence. Approximately 15.5 million children are exposed to domestic violence every year.<sup>3</sup> One study found that men exposed to physical abuse, sexual abuse and witnessing adult domestic violence as children were almost 4 times more likely than other men to have perpetrated domestic violence as adults.

In addition to the terrible cost domestic and sexual violence has on the lives of individual victims and their families, these crimes also cost taxpayers and communities. The cost of intimate partner violence exceeds \$5.8 billion each year, \$4.1 billion of which is for direct healthcare services.<sup>4</sup> Translating this into 2016 dollars, based on the Bureau of Labor Statistics Consumer Price Index, the annual cost to the Nation is over \$9 billion per year. Domestic violence costs U.S. employers an estimated \$3 to \$13 billion annually.<sup>5</sup>

Despite this grim reality, we know that when a coordinated response is developed and immediate, and essential services are available, victims can escape from life-threatening violence and begin to rebuild their lives. To address unmet needs and build upon its successes, FVPSA and VAWA programs should receive significant increases in the fiscal year 2017 Labor, Health and Human Services Appropriations bill.

*Family Violence Prevention and Services Act (FVPSA) (Administration for Children and Families)—\$175 million request.*—Since its passage in 1984 as the first national legislation to address domestic violence, FVPSA has remained the only Federal funding directly for shelter programs. Now in its 32nd year, FVPSA has made substantial progress toward ending domestic violence. Despite the progress and success brought by FVPSA, an unconscionable need remains for FVPSA-funded victim services.

There are more than 2,000 community-based domestic violence programs for victims and their children (approximately 1,500 of which are FVPSA-funded through State formula grants). These programs offer services such as emergency shelter, counseling, legal assistance, and preventative education to millions of adults and children annually and are at the heart of our Nation's response to domestic violence. A 2008 multi-State study conclusively shows that the Nation's domestic violence shelters are addressing victims' urgent and long-term needs and are helping victims protect themselves and their children.

This same study found that, if shelters did not exist, the consequences for victims would be dire, including "homelessness, serious losses including [loss of] children [or] continued abuse or death."<sup>6</sup> Additionally, non-residential domestic violence services are essential to addressing victims' needs. Such programs provide a wide variety of services to victims including counseling, child care, financial support, and safety planning. Without the counseling services she received from her local domestic violence program, one victim said, "I would not be alive, I'm 100 percent certain about that."<sup>7</sup>

<sup>1</sup>Black, M.C., Basile, K.C., Breiding, M.J., Smith, S.G., Walters, M.L., Merrick, M.T., Chen, J., & Stevens, M.R. (2011). The National Intimate Partner and Sexual Violence Survey (NISVS): 2010 Summary Report. Atlanta, GA: National Center for Injury Prevention and Control, Centers for Disease Control and Prevention.

<sup>2</sup>Bureau of Justice Statistics (2008). Homicide Trends in the U.S. from 1976–2005. U.S. Dept. of Justice.

<sup>3</sup>McDonald, R., et al. (2006). "Estimating the Number of American Children Living in Partner-Violence Families." *Journal of Family Psychology*, 30(1), 137–142.

<sup>4</sup>National Center for Injury Prevention and Control. Costs of Intimate Partner Violence Against Women in the United States. Atlanta (GA): Centers for Disease Control and Prevention; 2003.

<sup>5</sup>Bureau of National Affairs Special Rep. No. 32, Violence and Stress: The Work/Family Connection 2 (1990); Joan Zorza, Women Battering: High Costs and the State of the Law, *Clearinghouse Rev.*, Vol. 28, No. 4, 383, 385.

<sup>6</sup>Lyon, E. & Lane, S. (2009). Meeting survivors' needs: A multi-State study of domestic violence shelter experiences. Harrisburg, PA: National Resources Center on Domestic Violence.

<sup>7</sup>Lyon, Eleanor, Bradshaw, Jill, Menard, Anne. Meeting Survivors' Needs through Non-Residential Services & Supports: Results of a Multi-State Study. Harrisburg, PA: National Resource Center on Domestic Violence. November, 2011.

*The Increased Need for Funding: to Maintain Programs and Bridge the Gap.* — Many programs across the country use their FVPSA funding to keep the lights on and their doors open. We cannot overstate how important this funding is: victims must have a place to flee to when they are escaping life-threatening violence. As increased training for law enforcement, prosecutors and court officials has greatly improved the criminal justice system's response to victims of domestic violence, there is a corresponding increase in demand for emergency shelter, hotlines and supportive services. Additionally, demand has increased as a result of the economic downturn, and victims with fewer personal resources become increasingly vulnerable. Since the economic crisis began, eight out of ten domestic violence shelters have reported an increase in women seeking assistance from abuse.<sup>8</sup> As a result, shelters overwhelmingly report that they cannot fulfill the growing need for these services.

Each year NNEDV releases a report entitled Domestic Violence Counts: A 24-hr National Census of Domestic Violence Services (Census). The report revealed that in just one day in 2015, while 71,828 victims of domestic violence received services, over 12,197 requests for services went unmet, due to lack of funding and resources. Of those unmet requests, 63 percent were for safe shelter. In 2015, domestic violence programs reported that they had laid off nearly 1,235 staff positions in addition to reducing or eliminating 1,936 services in the past year, including prevention services, therapy, and child welfare advocacy. I strongly encourage you to read NNEDV's DV Counts Census ([www.nnedv.org/census](http://www.nnedv.org/census)) to learn more about the desperate needs of victims State-by-State and nationally.

In 2013, domestic violence programs funded by the Family Violence Prevention & Services Act (FVPSA) provided shelter and nonresidential services to more than 1.3 million victims. Due to lack of capacity, however, an additional 186,552 requests for shelter went unmet. Since 2011, at least 19 local domestic violence programs across the country have been forced to close entirely.

For those individuals who are not able to find safety, the consequences can be extremely dire, including continued exposure to life-threatening violence or homelessness. It is absolutely unconscionable that victims cannot find safety for themselves and their children due to a lack of adequate investment in these services. In order to help meet the immediate needs of victims in danger and to continue this work to prevent and end domestic violence, FVPSA funding must be increased to its authorized level of \$175 million.

#### ADDITIONAL REQUESTS

National Domestic Violence Hotline (Administration for Children and Families)—\$12 million; DELTA Prevention Program (Centers for Disease Control and Injury Prevention)—\$6 million; Rape Prevention and Education (RPE) (Centers for Disease Control and Injury Prevention)—\$50 million; Preventative Health and Health Services Block Grant, Rape Set-Aside—\$7 million; Violence against Women Health Initiative, (Office On Women's Health)—\$10 million.

[This statement was submitted by Kim Gandy, President and CEO, National Network to End Domestic Violence.]

#### PREPARED STATEMENT OF THE NATIONAL RESPITE COALITION

Mr. Chairman, I am Jill Kagan, Chair of the National Respite Coalition (NRC), a network of State respite coalitions, respite providers, family caregivers, and national, State and local organizations that support respite. The NRC also facilitates the Lifespan Respite Task Force, a coalition of over 100 national, State and local groups. The NRC is requesting that the Subcommittee include \$5.0 million for the Lifespan Respite Care Program in the fiscal year 2017 Labor, HHS, and Education Appropriations bill as recommended in the President's fiscal year 2017 budget. 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

<sup>8</sup>Mary Kay's Truth About Abuse Report. Mary Kay Inc. (2012).



—Greater consumer direction by providing family caregivers with training and information on how to find, use and pay for respite services.

*Who Needs Respite?*—More than 43 million adults in the U.S. are family caregivers of an adult or a child with a disability or chronic condition (National Alliance for Caregiving (NAC) and AARP Public Policy Institute, 2015). The estimated economic value of family caregiving of adults alone is approximately \$470 billion annually (AARP Public Policy Institute, 2015). Eighty percent of those needing long-term services and supports (LTSS) are living at home. Two out of three (66 percent) older people with disabilities who receive LTSS at home get all their care exclusively from family caregivers (Congressional Budget Office, 2013). This percentage will only rise in the coming decades with greater life expectancies of individuals with disabling and chronic conditions living at home 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.

Immediate concerns about how to provide care for a growing aging population are paramount. However, caregiving is a lifespan issue with the majority of family caregivers caring for someone between the ages of 18 and 75 (53 percent) (NAC and AARP, 2015). The most recent National Survey of Children with Special Health Care Needs found that 11 million children under age 18 have special healthcare needs<sup>1</sup> (Health Resources and Services Administration, 2013).

National, State and local surveys have shown respite to be the most frequently requested service by family caregivers (The Arc, 2011; National Family Caregivers Association, 2011). Yet, 85 percent of family caregivers of adults are not receiving respite services at all (NAC and AARP, 2015). Nearly half of family caregivers of adults (44 percent) identified in the National Study of Caregiving were providing substantial help with healthcare tasks. Of this group, despite their high level of care, fewer than 17 percent used respite (Wolff, J., et al. 2016).

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 remains high for all veterans and their family caregivers. A 2014 Rand Corporation report prepared for the Elizabeth Dole Foundation, *Hidden Heroes: America's Military Caregivers*, recommended that respite care should be more widely available to military caregivers (Ramchand, et al., 2014). The Dole Foundation's Respite Impact Council found that traditional respite services do not address the needs of military caregivers and the Lifespan Respite Care program should be fully funded to help meet those needs.

*Respite Barriers and the Effect on Family Caregivers.*—While most families want to care for family members at home, research shows that family caregivers are at risk for serious emotional stress and mental and physical health problems (NAC and AARP, 2015; American Psychological Association, 2012; Spillman, et al., 2014). 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). 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 children (McBean, A, et al., 2013).

Respite, that has been shown to ease family caregiver stress, is too often out of reach or completely unavailable. Restrictive eligibility criteria preclude many families from receiving services. Many children with disabilities age out of the system when they turn 21 and lose services, such as respite. A survey of nearly 5000 caregivers of individuals with intellectual and developmental disabilities (I/DD) found the vast majority of caregivers report physical fatigue (88 percent), emotional stress (81 percent) and emotional upset or guilt (81 percent); 1 out of 5 families (20 percent) report that someone in the family quit their job to provide care; and more than 75 percent of family caregivers could not find respite services (The Arc, 2011). Despite their higher burden of care, caregivers of persons with dementia are more prone to underutilizing and/or delaying respite. The 2013 Johns Hopkins Maximizing Independence at Home Study, in which researchers surveyed persons with

<sup>1</sup>The U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau (MCHB) defines children with special healthcare needs (CSHCN) as "...those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."

dementia residing at home with their informal caregivers, found that nearly half of the caregivers had unmet needs for mental healthcare and most of these, according to the researchers, needed emotional support or respite care (Black, B, et al., 2013). Respite may not exist at all for individuals with conditions such as ALS, MS, spinal cord or traumatic brain injuries, or children with serious emotional conditions or autism.

Barriers to accessing respite include fragmented and narrowly targeted services, cost, and the lack of information about respite or how to find or choose a provider. A critically short supply of well-trained respite providers may prohibit a family from making use of a service they so desperately need. Lifespan Respite is designed to help States eliminate barriers through improved coordination and capacity building.

*Respite Benefits Families and is Cost Saving.*—Respite has been shown to help reduce the stress that can lead poor health among family caregivers. In turn, respite helps avoid or delay out-of-home placements, minimizes precursors that can lead to abuse and neglect, and strengthens marriages and family stability. While limitations in respite research exist, these findings were recently corroborated by a review of the literature conducted by an Expert Panel on Respite Research, convened by ARCH with support from ACL (Kirk, 2015). For example, a study of parents of children with autism found that respite was associated with reduced stress and improved marital quality (Harper, et al., 2013). A U.S. Department of Health and Human Services report found that reducing key stresses on caregivers through services such as respite would reduce nursing home entry (Spillman and Long, USDHHS, 2007). In a survey of caregivers of individuals with Multiple Sclerosis, two-thirds said that respite would help keep their loved one at home. When the care recipient with MS also has cognitive impairment, the percentage of those saying respite would be helpful to avoid or delay nursing home placement jumps to 75 percent (NAC, 2012).

Compelling budgetary benefits accrue because of respite. Delaying a nursing home placement for one person with Alzheimer's or avoiding hospitalization for a child with autism can save Medicaid and other government programs thousands of dollars. Researchers at the University of Pennsylvania studied the records of 28,000 children with autism enrolled in Medicaid in 2004. They concluded that for every \$1,000 States spent on respite, there was an 8 percent drop in the odds of hospitalization (Mandell, D., et al., 2012). In the private sector, U.S. businesses lose from \$17.1 to \$33.6 billion per year in lost productivity of family caregivers (MetLife Mature Market Institute, 2006). Higher absenteeism among working caregivers costs the U.S. economy an estimated \$25.2 billion annually (Witters, D., 2011). Respite for working family caregivers could improve job performance, saving employers billions.

*Lifespan Respite Care Program Helps.*—The Federal Lifespan Respite program, administered by the Administration for Community Living (ACL) provides competitive grants to eligible State agencies. Congress appropriated \$2.5 million each year from fiscal year 2009—fiscal year 2012 and slightly less in fiscal year 2013—fiscal year 2015. Since 2009, 33 States and DC have received Lifespan Respite Grants. In fiscal year 2016, the program received \$3.3 million. While current or past grantees will receive no new funding this year, an additional 2–3 new States are expected to be funded. 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 respite access. Lifespan Respite helps States maximize use of limited resources across age and disability groups and deliver services more efficiently. Increasing funding, even slightly, for the program in fiscal year 2017 could allow funding of several new States and help current grantees complete their ground-breaking work.

*How is Lifespan Respite Program Making a Difference?*—With limited funds, Lifespan Respite grantees are engaged in innovative activities such as:

- Alabama, Arizona, Delaware, Montana, Nebraska, Nevada, North Carolina, Oklahoma, Rhode Island, South Carolina, Tennessee, Virginia, and Washington have successfully used consumer-directed respite vouchers for serving underserved populations, such as individuals with MS or ALS, adults with intellectual or developmental disabilities (I/DD), or those on waiting lists for services.
- Idaho, Illinois, Iowa, and Nebraska offer emergency respite support.
- Alabama, Arizona, Colorado, Massachusetts, Nebraska, New York, Ohio, Pennsylvania, South Carolina and Tennessee are providing new volunteer or faith-based respite.
- Innovative and sustainable respite services, funded in Colorado, Massachusetts, North Carolina and Ohio through mini-grants to community-based agencies, have documented benefits to family caregivers.

—Respite provider recruitment and training are priorities in New Hampshire, Virginia, and Wisconsin.

Additional partnerships between State agencies are changing the landscape. The AZ Lifespan Respite program housed in Aging and Adult Services partnered with AZ's Children with Special Health Care Needs Program to provide respite vouchers to families across the age and disability spectrum. The OK Lifespan Respite program partnered with the State's Transit Administration to develop mobile respite to serve isolated rural areas of the State. States are building respite registries and "no wrong door systems" in partnership with Aging and Disability Resource Centers to help family caregivers access respite and funding sources. Funding must be maintained to help sustain these innovative State efforts. States are developing long-term sustainability plans, but without Federal support, many of the grantees will be cut off before these initiatives achieve their full 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 \$5 million in the fiscal year 2017 Labor, HHS, and Education appropriations bill. This will allow Lifespan Respite Programs to be replicated and sustained. Families, with access to respite, will be able to keep their loved ones at home, saving Medicaid and other Federal programs, billions of dollars.

*Complete references available upon request. Please contact the NRC for more information.* [Http://archrespite.org/national-respite-coalition](http://archrespite.org/national-respite-coalition).

[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 Senate Subcommittee on Labor, Health and Human Services, Education and Related Agencies with a statement for the record on fiscal year 2017 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.

Funding for the rural health safety net is more important than ever as rural Americans are facing a hospital closure crisis. Seventy-one rural hospitals have closed, 10,000 rural jobs lost and 1.2 million rural patients have lost access to their nearest hospital since 2010. Even more concerning is that 673 rural hospitals are at risk of closure, meaning sustained Medicare cuts threaten the financial viability of 1 in 3 rural hospitals. The loss of these hospitals would mean 11.7 million patients would lose access to care in their community.

Important rural health programs supported by NRHA are outlined below.

The *National Health Service Corps (NHSC)* plays an important role in maintaining the healthcare safety net by placing primary healthcare providers in the most undeserved rural communities. NHSC is a network of 8,000 primary healthcare professionals, and 10,000 sites (September 2010). However, the demand for primary care providers far exceeds the supply, and the needs of rural communities continue to grow. Rural communities must have the resources necessary to hire primary care, dental and behavioral health providers. *Request: \$278.3 million.*

*Rural Health Outreach and Network Grants* provide capital investment for planning and launching innovative projects in rural communities that will become self-sufficient. These grants are unique Federal grants in that they allow a great deal of flexibility for the community to build a program around their community's specific needs. Grant funds are awarded for communities to develop needed formal, inte-

grated networks of providers that deliver primary and acute care services. The grants have led to successful projects including information technology networks, oral screenings, and preventative care. Due to the community nature of the grants and the focus on sustainability after the grant term has run out—85 percent of the grantees continue to deliver services a full 5 years after Federal funding ends. *Request: \$69 million.*

*Rural Health Research and Policy Grants* form the Federal infrastructure for rural health policy. These grants provide policy makers with policy-relevant research on problems facing rural communities in providing access to quality affordable care and to improving population health in rural America. By funding rural health research centers across the country these grants produce a mix of health services research, epidemiology, public health, geography, medicine, and mental health. These funds allow rural America to have a coordinated voice in the Department of Health and Human Services (HHS), in addition to providing expertise to agencies such as the Centers for Medicare and Medicaid Services. As a part of this request, 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* provide State specific infrastructure for rural health policy. These State offices are the counterpart to the Federal rural health research and policy framework. State offices form an essential link between small rural communities and the State and Federal resources to develop long term solutions to rural health problems. These funds provide necessary capacity to States for the administration of critical rural health programs, assist in strengthening rural healthcare delivery systems, and maintaining rural health as a focal point within each State. 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. State offices form an essential connection to other State agencies and local communities; allowing Federal resources to best address the unique needs of rural communities. *Request: \$15 million.*

*Rural Hospital Flexibility Grants* fund quality improvement and emergency medical service projects at Critical Access Hospitals (CAHs). These grants allow rural communities to improve access to care, develop increased efficiencies, and improved quality of care by leveraging the services of CAHs, Emergency Medical Services (EMS), clinics, and health practitioners. These grants serve an important function in increasing information technology activities in rural America. 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 improve business operations, focus on quality improvement, and ensure compliance with health information privacy regulations. *Request: \$46 million.*

*Rural and Community Access to Emergency Devices Grants* help communities afford the purchase of emergency devices, such as defibrillators, and the necessary training for community members and first responders in the proper use of these devices. The proper and timely use of a defibrillator following a sudden cardiac arrest doubles a victim's change of survival. Placement of devices within the community where cardiac arrest is likely to occur allows for greater success. Such immediate intervention are particularly important in rural America where follow on medical care may require longer wait times due to long distances to a hospital, mountainous terrain, or inclement weather. *Request: \$4.5 million.*

The *Office for the Advancement of Telehealth (OAT)* supports the provision of clinical services at a distance, reduces rural provider isolation, fosters integrated delivery systems through network development, and tests a broad range of telehealth applications. Long-term, telehealth promises to improve the health of millions of Americans, save money by reducing unnecessary office visits and hospital stays, and provide continuing education to isolated rural providers. The OAT coordinates and promotes the use of telehealth technologies by fostering partnerships between Federal and State agencies and private sector groups. Since telehealth is still an emerging field with new approaches and technologies; continued investment in the infrastructure and development is needed. *Request: \$18.5 million.*

*Title VII Health Professions Training Programs (with a significant rural focus):*

—Area Health Education and Centers (AHECs) encourage and provide financial support to those training to become healthcare professionals in rural areas. Without this experience and support in medical school, far fewer professionals would be aware of the needs of rural communities and even fewer would make the commitment to practice in rural areas. AHECs support the recruitment and

retention of physicians, students, faculty and other primary care providers in rural and medically underserved areas. It has been estimated that nearly half of AHECs would shut down without Federal funding, placing future access to healthcare in rural communities at risk. *Request: \$40 million.*

—Rural Physician Pipeline Grants help medical colleges develop rural specific curriculum and to recruit students from rural communities that are 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: \$5.3 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 our Nation’s elderly and is more likely to have physician shortages than urban locations. Without this program, rural healthcare provider shortages would grow. *Request: \$42 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 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 2017 budget request for NTID, one of nine colleges of RIT, in Rochester, N.Y. Created by Congress by Public Law 89–36 in 1965, NTID provides a university-level 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. NTID students study at the associate, baccalaureate, master’s and doctoral levels as part of a university (RIT) that includes more than 17,000 hearing students. NTID also provides baccalaureate and graduate-level education for hearing students in professions serving deaf and hard-of-hearing individuals.

BUDGET REQUEST

On behalf of NTID, for fiscal year 2017 I would like to request \$70,712,000 for Operations. NTID has worked hard to manage its resources carefully and responsibly. NTID actively seeks alternative sources of public and private support, with approximately 28 percent of NTID’s Operations budget coming from non-Federal funds, up from 9 percent in 1970. Since fiscal year 2006, NTID raised more than \$22.5 million in support from individuals and organizations. NTID has also recognized that construction funding is limited and planned for critical and long overdue renovations using existing Federal and non-Federal funds.

NTID’s fiscal year 2017 request of \$70,712,000 in Operations would allow NTID to admit all qualified students for Fall 2017 enrollment, keep the fiscal year 2017 tuition increase relatively low (3.9 percent), and continue to offer Grants in Aid to more students. With this funding, NTID can support new academic programs, add staff (sign language interpreters and captionists) in student access services to meet unprecedented demand, and complete much needed capital and renovation projects.

ENROLLMENT

Truly a national program, NTID has enrolled students from all 50 States. In Fall 2015 (fiscal year 2016), NTID’s enrollment was 1,413 students. For fiscal year 2017, NTID anticipates an enrollment near 1,400. NTID’s enrollment history over the last 10 years is shown below:

NTID ENROLLMENTS: FISCAL YEAR 2007—FISCAL YEAR 2016

Fiscal Year	Deaf/Hard-of-Hearing Students				Hearing Students			Grand Total
	Undergrad	Grad RIT	MSSE	Sub-Total	Interpreting Program	MSSE	Sub-Total	
2016 .....	1,167	53	15	1,235	151	27	178	1,413
2015 .....	1,153	44	16	1,213	146	28	174	1,387

## NTID ENROLLMENTS: FISCAL YEAR 2007—FISCAL YEAR 2016—Continued

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
D2012 .....	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 provides transfer associate degree programs to better serve our student population seeking bachelor's, master's, and doctoral degrees. These transfer programs provide seamless transition to baccalaureate and graduate 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 (e.g., sign language interpreting, real-time speech-to-text captioning, 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 assignment 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. Last year, 235 students 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

NTID deaf and hard-of-hearing students persist and graduate at higher rates than the national persistence and graduation rates for all students at 2-year and 4-year colleges. For NTID deaf and hard-of-hearing graduates, over the past 5 years, an average of 93 percent have found jobs commensurate with their education level. Of our fiscal year 2014 graduates (the most recent class for which numbers are available), 94 percent were employed 1 year later, with 61 percent employed in business and industry, 28 percent in education and 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 (SSA), and Cornell University examined earnings and Federal program participation data for more than 16,000 deaf and hard-of-hearing individuals who applied to NTID over our entire history. The study showed that NTID graduates, over their lifetimes, are employed at a higher rate and earn more (therefore paying more in taxes) than students who withdraw from NTID or attend other universities. NTID graduates also participate at a lower rate in SSI and SSDI programs 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 and 69 percent of deaf and hard-of-hearing graduates from other universities. 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 and \$21,000 for deaf and hard-of-hearing graduates from other universities.

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

Access services include sign language interpreting, real-time captioning, classroom notetaking services, captioned classroom video materials, and assistive listening 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. Historically, NTID has followed a direct instruction model for its associate-level classes, with limited need for sign language interpreters, captionists, or other access services. However, the demand for access services has grown recently as associate-level students request communication based on their preferences.

Higher enrollments have also increased the demand for access services. During fiscal year 2015, 140,230 hours of interpreting were provided—an increase of 20 percent compared to fiscal year 2010. During fiscal year 2015, 22,241 hours of real-time captioning were provided to students—a 14 percent increase over fiscal year 2010. The increase in demand is partly a result of the increase in the number of students enrolled in programs at RIT and the number of students with cochlear implants. In fiscal year 2016, there were 596 deaf and hard-of-hearing students enrolled in baccalaureate or graduate programs at RIT, a 16 percent increase compared to fiscal year 2010, and 432 students with cochlear implants, a 58 percent increase over fiscal year 2010.

As a result, NTID's fiscal year 2017 funding request recognizes the need to invest in additional access services staff and in research on technologies that might serve as an alternative to traditional access services.

#### SUMMARY

It is extremely important that NTID's fiscal year 2017 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 students persist and graduate at higher rates than national rates for all students. NTID graduates have higher salaries, pay more taxes, and are less reliant on Federal SSI/SSDI programs. NTID's employment rate is 93 percent over the past 5 years. Therefore, I ask that you please consider funding our fiscal year 2017 request of \$70,712,000 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 an outstanding educational record of service to 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, Vice President and Dean, Rochester Institute of Technology.]

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#### 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 2017 funding level to \$25 million to allow for nationwide expansion of the NVDRS program including all 50 States, District of Columbia and U.S. territories. fiscal year 2016 NVDRS funding is \$16 million.

## BACKGROUND

Each year, about 57,000 Americans die violent deaths.<sup>1</sup> In addition, an average of 117 people<sup>2</sup> (22 of which are military veterans<sup>3</sup>) take their own lives each day. Violence-related death and injuries cost the United States \$107 billion in medical care and loss in productivity.<sup>4</sup>

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 32 States<sup>5</sup> with 9 additional States having expressed an interest in joining once new funding becomes available. While NVDRS is beginning to strengthen violence and suicide prevention efforts in the 32 participating States, non-participating States continue to miss out on the benefits of this important public health surveillance program.

## NVDRS IN ACTION

Opioid deaths are a serious public health issue. Drug overdose deaths are the leading cause of injury deaths in American.<sup>6</sup> It is important to invest in surveillance of opioid addiction to determine the extent of the problem and implement treatment options and community-based prevention strategies. NVDRS has already proven to be an invaluable tool in many States like Alaska, Indiana and Utah that collect information, through toxicology reports, about prescription-opioid overdose associated with violent deaths. Combined 2010 NVDRS data showed that 24 percent of violent deaths tested were positive for opiates.<sup>7</sup> Importantly, surveillance is included as one of the primary recommendations in a report published by Johns Hopkins Bloomberg School of Public Health that promotes an evidence-based response to the prescription-opioid epidemic.<sup>8</sup>

Children are often the most vulnerable as they are 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 17 of the 32 States that currently participate in NVDRS, showed that African American children aged 4 years and under are more than three times as likely to be victims of homicide than Caucasian children,<sup>9</sup> and that homicides of children aged four and under are most often committed by a parent or caregiver in the home. The data further notes that household items, or “weapons of opportunity,” were most commonly used, suggesting that poor stress responses may be factors in these

<sup>1</sup>Centers for Disease Control and Prevention . (2015, June 18 ). Injury Prevention & Control: Division of Violence Prevention. Retrieved April 14, 2016, from <http://www.cdc.gov/violenceprevention/nvdrs/>.

<sup>2</sup>Americans for Suicide Prevention. (n.d.). Suicide Statistics. Retrieved April 14, 2016, from Americans for Suicide Prevention: <http://afsp.org/about-suicide/suicide-statistics/>.

<sup>3</sup>Kemp, J., & Bossarte, R. (2013, February). Suicide Report 2012. Retrieved April 14, 2016, from Department of Veterans Affairs: <http://www.va.gov/opa/docs/suicide-data-report-2012-final.pdf>.

<sup>4</sup>Centers for Disease Control and Prevention . (2015, June 18). National Violent Death Reporting System—An Overview. Retrieved 14 2016, April , from National Violent Death Reporting System: [http://www.cdc.gov/violenceprevention/pdf/nvdrs\\_overview-a.pdf](http://www.cdc.gov/violenceprevention/pdf/nvdrs_overview-a.pdf).

<sup>5</sup>Centers for Disease Control and Prevention. (2015, December 15). National Violent Death Reporting System—State Profiles. Retrieved April 14, 2016, from A CDC website: <http://www.cdc.gov/violenceprevention/nvdrs/stateprofiles.html>.

<sup>6</sup>U.S. Department of Health and Human Services . (2016, April 8). The U.S. Opioid Epidemic. Retrieved April 14, 2016, from U.S. Department of Health and Human Services: <http://www.hhs.gov/opioids/about-the-epidemic/>.

<sup>7</sup>Centers for Disease Control and Prevention. (2014, January 17). Surveillance for Violent Deaths—National Violent Death Reporting System, 16 States, 2010. Retrieved April 14, 2016, from Morbidity and Mortality Weekly Report-Surveillance Summaries/Volume 63/No.1: <http://www.cdc.gov/mmwr/pdf/ss/ss6301.pdf>.

<sup>8</sup>Alexander GC, F. S. (2015). The Prescription Opioid Epidemic: An Evidence-Based Approach. Baltimore: Johns Hopkins Bloomberg School of Public Health. <http://www.jhsph.edu/research/centers-and-institutes/center-for-drug-safety-and-effectiveness/opioid-epidemic-town-hall-2015/2015-prescription-opioid-epidemic-report.pdf>.

<sup>9</sup>Center for Disease Control and Prevention. (2013). National Violent Death Reporting System . Retrieved April 14, 2014, from A Web-based Injury Statistics Query and Reporting System (WISQARS) Database: <https://wisqars.cdc.gov:8443/nvdrs/nvdrsDisplay.jsp>.



deaths. Knowing the demographics and methods of child homicides 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. An analysis of intimate partner homicide based on NVDRS data from 16 States shows that intimate partners represented 80 percent of intimate partner violence-related homicides victims and corollary victims (family members, police officers, friends etc . . . ) represented the remaining 20 percent of victims.<sup>10</sup>

Despite being in its early stages in several States, NVDRS is already providing critical information that is helping law enforcement and public health officials target their resources to those most at risk of 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 or members of the suspect's family. 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.<sup>7</sup>

#### NVDRS & VA SUICIDES

Although it is preventable, every year more than 42,773 Americans die by suicide and another one million Americans attempt it, costing more than \$42 billion in lost wages and work productivity.<sup>2</sup> 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—the program can be used to develop effective suicide prevention plans at the community, State, and national levels.

A 2015 study showed that 19.9 percent of all veteran deaths between 2001 and 2007 were suicide, with male veterans three times as likely as female veterans to commit suicide.<sup>11</sup> The central collection of such data can be of tremendous value for organizations such as the Department of Veterans Affairs that are working to improve their surveillance of suicides. 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.

In addition to veteran suicides, NVDRS data has been crucial in many States like Oregon, Utah, New Jersey and North Carolina in understanding the circumstances surrounding elder suicide. This has allowed the States to collaborate locally and implement programs that target those populations at greatest risk.

#### 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 2017

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. The program received an additional \$4.7 million in fiscal year 2016 for a total of \$16 million. The additional \$5 million will allow for as many as seven new States to join the current 32 States that participate in NVDRS. The time is now to complete the nation-wide expansion of NVDRS by providing an appropriation of \$25 million in fiscal year 2017 to place NVDRS in all 50 States and U.S. territories.

We thank you for the opportunity to submit this statement for the record. The investment in NVDRS has already begun to pay off, as NVDRS-funded States are adopting effective violence prevention programs. We believe that national implemen-

<sup>10</sup>Smith, S. G., Fowler, K. A., & and Nolon, P. H. (March 2014). Intimate Partner Homicide and Corollary Victims in 16 States—NVDRS 2003–2009. *American Journal of Public Health*, 461–466.

<sup>11</sup>Kang, H., Bullman, T. A., & Smolenski, D. J. (2015). Suicide risk among 1.3 million veterans who were on active duty during the Iraq and Afghanistan wars. *Annals of Epidemiology*, 96–100.

tation 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 affect communities around the country. We look forward to working with you to complete the nationwide expansion of NVDRS by securing an fiscal year 2017 appropriation of \$25 million.

[This statement was submitted by Paul Bonta, Chair, National Violence Prevention Network.]

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#### PREPARED STATEMENT OF THE NATIONAL VIRAL HEPATITIS ROUNDTABLE

The National Viral Hepatitis Roundtable (NVHR) respectfully submits this testimony to the U.S. Senate Appropriations Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies (LHHS) regarding the fiscal year 2017 Appropriations bill. As a broad national coalition representing approximately 350 public and private organizations committed to fighting, and ultimately ending, the hepatitis B (HBV) and hepatitis C (HCV) epidemics domestically, we are gravely concerned about the many missed opportunities and negative public health consequences resulting from the lack of urgency and resources available to adequately address these two communicable viruses in the United States.

We therefore urge the Subcommittee to increase the appropriation for the Division of Viral Hepatitis (DVH) at the Centers for Disease Control and Prevention (CDC) to no less than \$62.8 million in fiscal year 2017, an increase of \$28.8 million over fiscal year 2016. Further, particularly due to the dramatic rise in HCV and, increasingly, HBV cases that are interconnected with the opioid and heroin addiction crisis, we also urge the Subcommittee to maintain modified language regarding the use of Federal funds as outlined in Sec.520 of the fiscal year 2016 LHHS Appropriations Bill, given the critical role syringe services programs (SSPs) play in viral hepatitis prevention and linkage to healthcare, social services, and drug treatment. NVHR further encourages the committee to appropriate additional funds specifically to support SSPs in fiscal year 2017 given the current crises driven by the syndemic of opioid and heroin addiction, overdose death, and chronic viral hepatitis infection (which may additionally serve as an early harbinger of an HIV outbreak, as seen in Scott County, Indiana in early 2015).

This request is both timely and urgent, given: (1) distressing and preventable health disparities seen among many communities; (2) the vital need for a robust surveillance infrastructure; (3) the role of HBV and HCV infection in the rising incidence of liver cancer; and (4) the current state of the hepatitis C epidemic, with unique challenges in addressing prevalence and incidence among two distinct generations, and tremendous opportunity created by new curative HCV treatment.

#### SCOPE OF THE EPIDEMICS

Despite a safe, effective vaccine for HBV, and revolutionary curative treatments for HCV, CDC conservatively estimates that approximately 1.2 million Americans are living with chronic HBV, and 3.2 million are living with chronic HCV.<sup>1</sup> These are likely underestimates however, as surveillance systems across the Nation are disjointed at best, with only five States and two jurisdictions (Florida, Massachusetts, Michigan, New York, Washington, Philadelphia, and San Francisco) federally funded for such activities.<sup>2</sup> Some experts place estimates of prevalence at approximately 2.2 million for chronic HBV alone and up to 5 million Americans chronically infected with HCV.<sup>3</sup> Of primary concern is that of the nearly 4.5 million individuals conservatively thought to be living with HBV and/or HCV, at least 50–66 percent do not know they are infected with a potentially life-threatening, communicable virus, as both HBV and HCV most often present with no symptoms until the liver is already significantly damaged.<sup>4</sup> On average, HBV and/or HCV will shorten one's lifespan by 15–20 years.<sup>5</sup>

#### HEALTH INEQUITY

There are alarming and unacceptable disparities among various communities for both of these viruses as well. While comprising less than 5 percent of the U.S. population, Asian American and Pacific Islander (AAPI) communities comprise over 50

<sup>1</sup> [Http://www.cdc.gov/hepatitis/abc/index.htm](http://www.cdc.gov/hepatitis/abc/index.htm).

<sup>2</sup> [Http://www.cdc.gov/hepatitis/statistics/2013surveillance/commentary.htm](http://www.cdc.gov/hepatitis/statistics/2013surveillance/commentary.htm).

<sup>3</sup> [Http://onlinelibrary.wiley.com/doi/10.1002/hep.28026/epdf](http://onlinelibrary.wiley.com/doi/10.1002/hep.28026/epdf).

<sup>4</sup> [Http://www.cdc.gov/hepatitis/abc/index.htm](http://www.cdc.gov/hepatitis/abc/index.htm).

<sup>5</sup> [Http://cid.oxfordjournals.org/content/58/8/1047.full.pdf+html](http://cid.oxfordjournals.org/content/58/8/1047.full.pdf+html).

percent of domestic HBV prevalence.<sup>6</sup> As HBV is also endemic in many regions of the world, particularly in Asia and Africa, the foreign-born and their children are also at high risk.<sup>7</sup> Many diverse communities are highly and disproportionately impacted by HCV compared to the general population, including veterans, especially Vietnam-era service members; the “baby boomer” birth cohort (born 1945–1965); communities of color, particularly Tribal communities; the incarcerated/returning citizens; and people who inject drugs.

#### STRENGTHENING SURVEILLANCE

Surveillance is the core public health service driving effective interventions, particularly for infectious disease. The current system of surveillance for HBV and HCV is woefully underfunded, and as such the available data provides merely a snapshot of the epidemics, albeit an alarming one. Without significantly bolstering States’ ability to leverage existing systems of surveillance, these epidemics will remain ahead of our efforts to eliminate them—a goal achievable in the coming decades with dedicated resources. Of particular concern is that, despite a dearth of surveillance resources, increases in perinatal transmission of HCV are being identified, potentially due to the equalizing gender balance of people who inject drugs.<sup>8,9</sup>

#### HEPATITIS B, HEPATITIS C, AND LIVER CANCER

Liver cancer is one of several potential long-term consequences of chronic HBV and HCV infection, and is one of the most aggressive and deadliest cancers with a devastatingly low 15 percent 5-year survival rate for all stages combined.<sup>10</sup> Despite a downward trend in incidence of various cancers, unfortunately liver cancer rates are increasing faster than any other cancer site.<sup>11</sup> The 2016 Annual Report to the Nation on the Status of Cancer further found that HCV infection alone accounts for 22 percent of the liver cancer burden in the United States.<sup>12</sup> Not only can the debilitating consequences of HBV and HCV be avoided with effective intervention—including vaccination and treatment for HBV and curative treatment for HCV—addressing these epidemics can serve the secondary purpose of preventing a substantial proportion of primary liver cancer cases. Indeed, treatment for HBV and HCV is associated with 50–80 percent and 75 percent reductions in the risk of developing liver cancer, respectively. Continuing the tragic effects of preventable health disparities, outcomes also show that the AAPI community historically has been most affected by liver cancer, and African Americans and Latinos are the youngest to die from liver cancer (median age).<sup>13</sup> Further, entirely preventable perinatal transmission of HBV stubbornly remains—a particular danger as about 90 percent of infected infants will develop chronic infection and experience these devastating consequences far earlier in life.<sup>14</sup>

<sup>6</sup> [Http://www.cdc.gov/hepatitis/Populations/api.htm](http://www.cdc.gov/hepatitis/Populations/api.htm).

<sup>7</sup> *Ibid.*

<sup>8</sup> [Http://slideplayer.com/slide/8867285/](http://slideplayer.com/slide/8867285/).

<sup>9</sup> [Http://mcaap.org/wp2013/wp-content/uploads/2014-MIAP-Conference-PM-session4\\_HCV-among-infants-in-MA\\_Kerri-Barton.pdf](http://mcaap.org/wp2013/wp-content/uploads/2014-MIAP-Conference-PM-session4_HCV-among-infants-in-MA_Kerri-Barton.pdf).

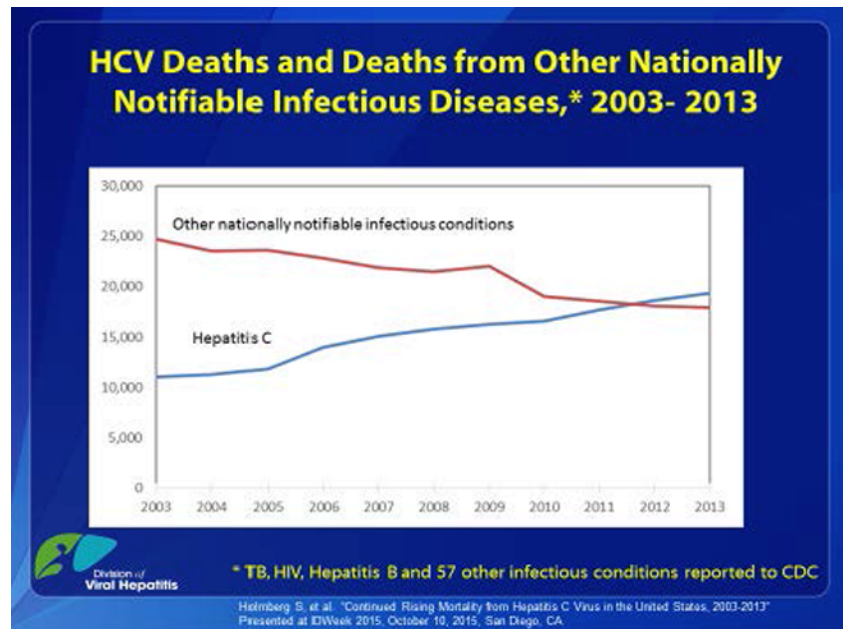
<sup>10</sup> [Http://www.cancer.org/cancer/livercancer/detailedguide/liver-cancer-survival-rates](http://www.cancer.org/cancer/livercancer/detailedguide/liver-cancer-survival-rates).

<sup>11</sup> [Http://onlinelibrary.wiley.com/doi/10.1002/cncr.29936/pdf](http://onlinelibrary.wiley.com/doi/10.1002/cncr.29936/pdf).

<sup>12</sup> *Ibid.*

<sup>13</sup> *Ibid.*

<sup>14</sup> [Https://blog.aids.gov/wp-content/uploads/Perinatal\\_HBV\\_Report\\_FINAL\\_12-21-15-508.pdf](https://blog.aids.gov/wp-content/uploads/Perinatal_HBV_Report_FINAL_12-21-15-508.pdf).



The HCV epidemic presents in two fairly distinct waves. First is the majority of prevalence, existing among the baby boomer birth cohort which comprises about 75 percent of those currently living with HCV. While this population by and large is not continuing to transmit the virus, the majority do not know they are infected and have likely been living with HCV for decades. As this community ages, the long term impacts of the disease are going to become more apparent as patients increasingly present with cirrhosis (scarring) of the liver, end-stage liver disease, liver cancer, and the need for liver transplantation. A recent study suggests that nearly half of individuals in this birth cohort already have severe liver scarring and are in need of immediate treatment.<sup>15</sup> As baby boomers rapidly age into Medicare, it is vital to identify those living with HCV and link them to appropriate care and treatment. Strikingly, as indicated in the chart above, CDC data indicate that as of 2012, mortality attributable to HCV alone now surpasses that of all other 59 nationally notifiable infectious diseases combined.

Of equal concern is the issue of current and ongoing transmission of HCV. As Americans across the Nation have been devastated by the crises of opioid and heroin addiction and overdose death, there have been parallel increases in HCV, with CDC reporting a 151 percent increase in new infections from 2010–2013 (still likely a significant underestimate due to lack of surveillance infrastructure), predominantly among young people and increasingly in rural and suburban areas of the country.<sup>16</sup> Further, HBV has also been introduced into some of these networks, with early 2016 CDC data indicating a 114 percent increase in acute cases from 2009–2013 in Kentucky, West Virginia, and Tennessee.<sup>17</sup>

Despite the many challenges currently facing us in attempting to catch up to this epidemic, this is also a time of tremendous opportunity for those living with HCV. In just the past several years, new direct-acting antivirals have entered the market that offer cure rates of over 90 percent, as well as much shorter regimens and few to no side effects compared to previous treatments. With this medical innovation has come hope for millions, and an effective intervention can be offered to those who test positive.

<sup>15</sup> <http://www.hivandhepatitis.com/hepatitis-c/hepatitis-c-topics/hcv-disease-progression/5086-croi-2015-liver-disease-progression-is-common-among-baby-boomers-with-hepatitis-c>.

<sup>16</sup> <http://www.cdc.gov/hepatitis/statistics/2013surveillance/commentary.htm#hepatitisC>.

<sup>17</sup> <http://www.cdc.gov/mmwr/volumes/65/wr/mm6503a2.htm>.

Although these new options have revolutionized HCV treatment, and there is a safe and effective vaccine and treatment to successfully control HBV, there are a number of natural barriers to treating everyone who needs it; most significantly, the majority of those living with HBV and HCV are unaware of their status, there is a significant lack of provider capacity particularly in rural areas and those serving immigrant and refugee communities, and surveillance is still piecemeal at best.

Again, we strongly urge the Subcommittee to increase the appropriation for CDC's DVH to no less than \$62.8 million for fiscal year 2017, to maintain language permitting use of Federal funding under specific circumstances for syringe services programs as outlined in the fiscal year 2016 LHHS Appropriations bill, and to further appropriate additional funds specifically to support SSPs in fiscal year 2017. We thank Chairman Blunt, Ranking Member Murray, and members of the Subcommittee for their thoughtful consideration of our request.

[This statement was submitted by Ryan Clary, Executive Director, National Viral Hepatitis Roundtable.]

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PREPARED STATEMENT OF THE NEPHCURE KIDNEY INTERNATIONAL  
SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2017

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- Provide \$34.5 billion for the National Institutes of Health (NIH)
  - Provide a corresponding Increase to the NIH Institutes and Centers
  - Support the 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
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Thank you for the opportunity to present the views of NephCure Kidney International 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. Researchers continue to study the pathogenesis of these variants.

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. NephCure works closely with NIH and has partnered with NIH on two large studies that will advance the pace of clinical research and support precision medicine. These studies are the Nephrotic Syndrome Study Network and the Cure Glomerulonephropathy Network.

With collaboration from other Institutes and Centers, ORDR established the Rare Disease Clinical Research Network. This network provided an opportunity for NephCure Kidney International, the University of Michigan, and other university research health centers to come together to form the Nephrotic Syndrome Study Network (NEPTUNE). Now in its second 5-year funding cycle, NEPTUNE has recruited over 450 NS research participants, and has supported pilot and ancillary studies utilizing the NEPTUNE data resources. NephCure urges the subcommittee to continue its support for RDCRN and NEPTUNE, which has tremendous potential to facilitate advancements in NS and FSGS research.

NIDDK recently initiated the Cure Glomerulonephropathy Network (Cure GN), a multicenter 5-year cohort study of glomerular disease patients. Participants will be followed longitudinally to better understand the causes of disease, response to therapy, and disease progression, with the ultimate objective to cure glomerulonephropathy. NephCure recommends that the subcommittee encourage NIDDK to continue to support CureGN as well as other primary glomerular disease program announcements.

It is estimated that annually there are 20 new cases of ESRD per million African Americans due to FSGS, and 5 new cases per million Caucasians. This disparity is largely due to variants of the APOL1 gene. Unfortunately, the incidence of FSGS is rising and there are no known strategies to prevent or treat kidney disease in individuals with the APOL1 genotype. NIMHD began supporting research on the APOL1 gene in fiscal year 2013. Due to the disproportionate burden of FSGS on minority populations, it remains appropriate for NIMHD to continue to advance this research. NephCure asks the subcommittee to encourage NIMHD to continue to study FSGS/NS, including the APOL1 gene.

## PATIENT PERSPECTIVE

Mac was originally diagnosed with Childhood Nephrotic Syndrome after his 5-year-old well-child checkup. Our pediatrician noticed that Mac had elevated blood pressure and checked his urine, which was positive for protein (3+). Because he seemed so healthy, it was hard to believe that our spunky little boy was really sick. We were completely shocked and devastated by the news. Being a physician, Mac's dad knew enough about this disease to know that it would be life changing for all of us. How could Mac look so normal and healthy and be so sick? This is a question we continue to ask.

After a referral to a pediatric nephrologist, we were relieved to hear that Mac most likely had Minimal Change Disease and should respond to steroid treatment. He was started on steroids and other medications to control the symptoms of the disease. In Mac's words, his kidneys were "silly" and he was a trooper through all of the tests and appointments. To our dismay, the steroids did not induce a remission, but he was greatly affected by the side-effects of the prednisone. This was the first time that he had ever appeared to be unhealthy. He was extremely swollen and his blood pressure was even further elevated, despite significantly restricting his salt intake and taking an anti-hypertensive (not to mention the personality changes, hyperactivity, mood swings, etc). It was around this time that we realized that Mac's cholesterol was alarmingly high, so a statin was added to his daily meds.

After failing to respond to several months of steroid treatment, our nephrologist recommended a kidney biopsy to get more information. Again, we were encouraged because his kidney tissue appeared normal (no evidence of FSGS) and the Minimal Change Disease diagnosis still seemed most likely, although our nephrologist always reminded us that FSGS was still a possibility. With this news, we were still holding out hope for a remission and moved to another course of treatment: cyclosporine.

Again, while experiencing multiple unpleasant side effects (mood swings, fatigue, significant facial/body hair growth), Mac's kidneys did not stop spilling protein and his albumin (level of protein in his blood) remained significantly low. It was at this time that we decided to have some genetic testing and move to a different medication. The testing would tell us if Mac has one of the known genetic mutations that is linked with Nephrotic Syndrome (and will be highly unlikely to respond to treatment. While waiting on the results from the University of Michigan, Mac started

taking Prograf (tacrolimus). Six months later, Mac still failed to show any response to treatment, but seemed to be tolerating the Prograf relatively well (other than some problems with sleep).

The results from the genetic testing came back and we were thrilled to hear that Mac did not have any of the known genetic mutations. This restored hope for a response to treatment and relieved some of the fear that our other child could also be predisposed to Nephrotic Syndrome. Before deciding on our next step, our nephrologist recommended a second biopsy because he was suspicious that our original biopsy may have missed FSGS. As we feared, this biopsy did find the scarred tissue that confirmed a diagnosis of FSGS. Additional scarring caused by medication was also found. With this new information, we investigated the available studies that were examining the efficacy of Galactose, which is actually a naturally occurring sugar. We were hopeful that Galactose would be a great match for Mac, as he was found to be positive for the FSGS permeability factor, which Galactose is suspected of binding to, preventing the factor from doing its dirty work. Additionally, Galactose was a good next step for us because it is naturally occurring and should not cause additional scarring to the kidneys. Unfortunately, after several months of treatment, Galactose did not work for Mac.

Discouraged, but not defeated, we made the decision, upon recommendation from our nephrologist, to give Mac's little body a break from the medications that are attempting to put the disease in remission. We decided to simply treat the side-effects of the disease (blood pressure, cholesterol, frequent vitamin imbalances, etc). It has been over a year now that we have been proceeding this way, and Mac has appeared to be healthier than ever. His body has been more effective at fighting sicknesses (common cold, flu, stomach viruses, etc) and he finally got his energy and appetite back! Although we are always looking for a new and promising treatment option for Mac, we are enjoying this period of time in which Mac feels well and can focus on just being a boy. We realize that things could change at any time.

Now, more than 6 years into our fight against NS and FSGS, we continue to be amazed by Mac's physical and emotional strength through this process; however we are frustrated that he has neither been in remission nor responded positively to medication.

Thank you for the opportunity to present the views of the FSGS/NS community. Please contact NephCure Kidney International if additional information is required.

[This statement was submitted by Irving Smokler, Ph.D., President and Founder, Nephcure Kidney International.]

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#### 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 2017 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, NIMH, NCATS, and NEI. Children and adults with NF are at significant risk for the development of many forms of cancer; the Committee encourages NCI to increase its NF research portfolio in fundamental basic science, translational research and clinical trials focused on NF. The Committee also encourages the NCI to support NF centers, NF clinical trials consortia, NF preclinical mouse models consortia and NF-associated tumor sequencing efforts. Because NF causes brain and nerve tumors and is associated with cognitive and behavioral problems, the Committee urges NINDS to continue to aggressively fund fundamental basic science research on NF relevant to nerve damage and repair. Based on emerging findings from numerous researchers worldwide demonstrating that children with NF are at significant risk for autism, learning disabilities, motor delays, and attention deficits, the Committee encourages NINDS, NIMH and NICHD to expand their investments in laboratory-based and clinical investigations in these areas. 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. NF1 can cause vision loss due to optic gliomas, the Committee encourages NEI to expand its investment in NF1 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 part 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 Cystic Fibrosis, hereditary Muscular Dystrophy, Huntington's disease and Tay Sachs 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 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. Researchers have gained deep knowledge on how mast cells promote tumor growth, and this research has led to ongoing clinical trials to block this signaling, resulting in slower tumor growth. As researchers learn more about blocking mast cell signals in NF, this research can be translated to the management of mast cells in wound healing.

#### *Cancer*

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 per-



cent of all human cancers. Some of these tumor types are benign and some are malignant, hard to treat and often fatal. Previous studies have found a high incidence of intracranial glioblastomas and malignant peripheral nerve sheath tumors (MPNSTs), as well as a six fold incidents of breast cancer compared to the general population. One of these tumor types, malignant peripheral nerve sheath tumor (MPNST), is 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 \$22 million in fiscal year 2016. 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.

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#### PREPARED STATEMENT OF NEW LEADERS

Thank you for the opportunity to provide testimony regarding the fiscal year 2017 Labor, Health and Human Services, Education, and Related Agencies Appropriations bill. New Leaders is a national nonprofit organization dedicated to providing all children with a high-quality education that prepares and inspires them to be successful in college, career, and citizenship. To achieve this critical goal, we develop transformational school leaders to serve the Nation's highest-need communities and we advance the policies and practices that allow great leaders across the country to be successful. Since 2001, we have developed 2,500 leaders who are currently supporting 450,000 students, most of whom are students of color and come from low-income backgrounds.

New Leaders is committed to making every school a place where great teachers love to teach and all students love to learn. We can reach this goal by paying more attention to how our schools—not just individual classrooms, but all classrooms within a school—are organized and led. We were pleased that the Every Student Succeeds Act (ESSA), passed by Congress in December 2015 to reauthorize the Elementary and Secondary Education Act (ESEA), maintains and strengthens several programs that provide critical support for school leadership. In addition, the authorizing language repeatedly emphasizes the important role of principals and school leaders, clearly demonstrating that Congress understands the relationship between strong school leadership and student success.

The current appropriations process is an opportunity for Congress to solidify its support for school leaders and show its commitment to improving student outcomes by making meaningful investments in the programs that will enable and empower great principals to create schools where teachers can thrive and students can excel.

As you consider fiscal year 2017 appropriations legislation, we urge you to provide robust funding for two programs specifically dedicated to fostering highly-effective school leaders: the School Leadership Retention and Support Program (SLRSP) and an updated Teacher Quality Partnerships (TQP) program.

—*The School Leadership Recruitment and Support Program (SLRSP) was authorized under ESSA with bipartisan support. SLRSP updates the School Leadership program (SLP, the program included in the previous version of ESEA) and will give high-poverty districts resources to develop and support dynamic leaders who have a measurable, positive impact on student achievement. The program empowers eligible entities—including State or local educational agencies—to pursue a range of activities in support of school leadership, including the development and implementation of leadership training programs, the provision of ongoing professional development for school leaders, and the dissemination of best practices regarding the recruitment and retention of highly effective school leaders. In addition, eligible entities may carry out projects in partnership with nonprofit organizations and institutions of higher education (IHEs). Finally, under priorities set forth in the reauthorized statute, SLRSP incentivizes eligible entities to focus on principal preparation and professional*

development practices for which there is evidence of effectiveness as demonstrated through rigorous research.

As implementation of ESSA moves to the State, local, and school levels, it is more important than ever that we ensure every school is led by an outstanding principal—a focus that can lead to incredible results for kids. For example, Oakland Unified School District started partnering with New Leaders shortly after the passage of No Child Left Behind to strengthen leadership in its lowest-performing schools. New Leaders' growth in the district was made possible by an SLP grant. With leadership as a key district initiative, Oakland achieved the status of most-improved urban district for 8 years in a row, outpacing the State's Academic Performance Index (API) growth by as much as 25 percent annually. While there's more work to be done, today Oakland schools are vastly different from what they were before the district decided to prioritize school leadership and rethink its approach to principal preparation and support—a reality truly made possible by strategic, timely Federal SLP support. We strongly recommend that Congress allocate at least \$30 million for SLRSP in fiscal year 2017, in line with the Administration's budget request and sufficient to carry out a new school leadership competition during the critical planning year before full ESSA implementation takes place in SY2017–18.

—*The Teacher Quality Partnerships Grant Program (TQP)* funds partnerships among IHEs and high-need LEAs to create model teacher and principal preparation programs. We support the goals of the TQP program—increasing student achievement by improving the quality of new prospective teachers—and encourage continued funding for this program at \$125 million. However, we also believe Federal lawmakers should take steps to strengthen the program and, in particular, ensure that it reflects the importance of school leaders. First, TQP should fund partnerships among high-performing educator preparation programs (including those run by both IHEs and nonprofit organizations) and high-need LEAs. Current law needlessly restricts eligibility and prevents proven, non-university-based programs from applying—doing a significant disservice to high-need LEAs that wish to partner with an alternative program that best meets its talent needs. In addition, TQP should allow grantees to use funds to support programs that prepare teacher leaders and principals, regardless of whether the partnership also intends to prepare teachers. Finally, to strengthen our collective understanding of the types of programs that prepare highly effective educators, TQP should require grantees to report on key outcomes measures, including those related to graduates' placement and retention in relevant positions and their influence on student achievement, among other potential measures. Ideally, the recommendations listed above would be incorporated into the reauthorization of the Higher Education Act. Given the limited time left to legislate this year, we believe that the President's proposed Teacher and Principals Pathway program could serve as an opportunity to update and replace TQP. We support \$125 million in funding for the Teacher and Principal Pathways program proposed in the Administration's fiscal year 2017 budget request, including \$35 million dedicated specifically to principals.

In addition to SLRSP and TQP, there are a number of other programs that have the potential to positively impact school leadership.

The Education Innovation and Research (EIR) program provides support and creates a framework for developing, validating, and scaling up effective, innovative interventions for addressing persistent education challenges. Therefore, EIR can play a key role in identifying and expanding school leadership development programs that truly have a positive effect on student achievement and school performance, especially in predominantly low-income districts. New Leaders recommends funding EIR at a level of \$180 million, the amount requested by the Administration.

In addition, the Teacher and School Leader Incentive Program (TSLIP) provides for the development and implementation of sustainable, performance-based compensation systems for teachers, principals, and other personnel in high-need schools in order to increase educator effectiveness and student achievement. This program has been instrumental in helping schools and districts move from a pay system based primarily on seniority to one that focuses on student outcomes. New Leaders recommends at least \$250 million in funding for TSLIP in fiscal year 2017—the amount requested by the Administration—and a continued focus on improving broader human capital systems in schools.

Finally, the Supporting Effective Educator Development program (SEED) makes grants to national nonprofit organizations for projects that recruit, select, prepare, or provide professional development activities for teachers or principals. The importance of recruiting, training, and retaining effective principals and other school leaders cannot be overstated. School leaders account for 25 percent of a school's effect

on a student achievement,<sup>1</sup> and 97 percent of teachers say that the principal is responsible for determining whether a school can attract and retain great teachers.<sup>2</sup> It is imperative that we make the necessary investments in evidence-based programs that help develop and retain outstanding leaders. New Leaders recommends that SEED be funded at \$100 million in fiscal year 2017, as recommended in the Administration's budget request.

Thank you for the opportunity to provide the views of New Leaders on the fiscal year 2017 appropriations. If you would like to discuss our recommendations, please do not hesitate to contact our Chief Policy Officer, Jackie Gran, at [policyteam@newleaders.org](mailto:policyteam@newleaders.org).

[This statement was submitted by Jean Desravines, CEO, New Leaders.]

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PREPARED STATEMENT OF THE NORTH AMERICAN SOCIETY FOR PEDIATRIC  
GASTROENTEROLOGY, HEPATOLOGY AND NUTRITION

We are pleased to offer testimony on the need for a public/private safety registry for pediatric patients with inflammatory bowel disease (IBD). Specifically, we request on behalf of the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN) and the Pediatric IBD Foundation Subcommittee consideration of the following report language to the fiscal year 2017 Labor, Health and Human Services, Education and Related Agencies Appropriations bill:

*Pediatric IBD Safety Registry:* The vast majority (an estimated 80 percent) of medications prescribed by physicians to treat children with inflammatory bowel disease (IBD) are prescribed "off-label" without any mechanism to monitor safety. The Committee recognizes the need for a national pediatric IBD population-based database to capture information on evidence-based health outcomes related to specific therapies and interventions, including concomitant medications and adverse events, and to make data accessible to physicians, patients, industry, researchers, and Federal agencies. The Secretary, acting through the National Institutes of Health, in consultation with the Food and Drug Administration, is encouraged to enter into cooperative agreements with public or private entities for the collection, analysis and reporting of data on pediatric IBD.

*Prevalence of Inflammatory Bowel Disease*

An estimated 1.6 million Americans are living with IBD (Crohn's disease and ulcerative colitis), with nearly one in four patients diagnosed under 20 years of age. IBD is a chronic inflammatory disorder of the intestines that does not have an identifiable cause (such as infection). Pediatric IBD causes the immune system to become inappropriately active, causing injury to the intestines. IBD does not have a medical cure but can be managed effectively through medication or other treatments. When IBD is not effectively managed, children do not grow normally because of a lack of absorption of nutrients. Many suffer constant intestinal pain causing them to miss school, have chronic diarrhea, multiple surgeries and, in some instances, wear colostomy bags.

*Treating Inflammatory Bowel Disease*

Treatment of a child with active Crohn's disease typically involves an induction regimen that includes a potent therapy with a rapid onset of action. If a remission is achieved, the patient can be transitioned to a maintenance regimen, typically involving medications with a slower onset of action and fewer side effects. The selection of drugs for induction and maintenance depend on age, disease severity, location, and clinical course. In general, very young children with IBD are more likely to have severe or refractory disease, and to have an identifiable genetic cause of the disease (monogenic IBD).

The ideal goal of treatment is clinical and laboratory remission with mucosal healing, not just symptomatic improvement. However, achieving this goal must be balanced against the risks of IBD therapies. Patients who achieve clinical, laboratory, and endoscopic remission may have better long-term outcomes. Optimal care therefore typically includes one of the following approaches:

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<sup>1</sup>Leithwood, K., Louis, K. S., Anderson, S., & Wahlstrom, K. (2004). *How Leadership Influences Student Learning*. New York, NY: Wallace Foundation.

<sup>2</sup>Scholastic Inc. (2012). *Primary Sources: America's Teachers on the Teaching Profession*. New York, NY: Scholastic and the Bill and Melinda Gates Foundation.

- Accelerated “step-up” therapy for most patients—Initiate treatment with the least potent drug predicted to be effective, promptly step-up therapy to more potent drug if response is incomplete.
- “Top-down” therapy for selected high-risk patients and often minority children—Early treatment with a highly potent immunosuppressant (e.g., anti-tumor necrosis factor antibody) for patients with high risks of complicated disease.

With either approach, close monitoring of patients is important to assess for remission (including upper endoscopy and colonoscopy) and to monitor for drug toxicities.

*Why a Pediatric IBD Registry is Needed*

There are many pediatric diseases and conditions for which great benefit could be derived through coordinated data collection. However, the creation of a pediatric IBD registry, which could serve as a model for other condition-based registries, should be more immediately supported by Congress for the following reasons:

*Monitoring the Safety of Off-Label Prescribing.*—When medications are prescribed for the treatment of IBD in children, the vast majority of these medications (an estimated 80 percent) are not approved by the Food and Drug Administration (FDA) for the indication at the time they are given—meaning, they are not approved by the FDA for use in children and are therefore used “off-label.” Medications used to treat IBD are first approved in adults and approval for children may come many years later, if at all, for a variety of reasons which we believe must also be addressed by Congress and the FDA. When medications, often found to be highly effective, are prescribed off-label to children, there is no mechanism to monitor safety, including potential side-effects and contra-indications. For example, a medication approved for treatment of Crohn’s disease in adults was recently found to cause a rare but fatal lymphoma in boys who received the medication in combination with another Crohn’s treatment. A national registry might have identified this problem much earlier.

*Expediting the Approval of Drugs for Pediatric Indications.*—When medications are prescribed off-label, such is the case with medications to treat pediatric IBD, families frequently incur significant out-of-pocket costs. This is because insurers will not cover medications for indications that are not FDA-approved, even though they are prescribed by physicians and are essential to properly and effectively treat these children, for whom there are few FDA-approved options. A pediatric IBD registry would help expedite drug approvals and encourage drug companies to pursue pediatric indications for FDA-approved drugs by allowing them to access a central data repository rather than establishing cost-prohibitive, proprietary, drug-specific registries for safety monitoring. Moreover, a registry would greatly enhance global pediatric drug development so medications that carry serious side-effects to treat IBD disease can be avoided and prescribed in more thoughtful evidence-based ways or replaced with better therapies.

*Informing Physician Decision-Making.*—A public-private pediatric IBD registry would be accessible to physicians and patients to aid in treatment decisionmaking. The need for better data to inform treatment decisionmaking is of particular importance when caring for minority populations. Recent epidemiologic studies describe incidence rates of IBD among African American children have approached and even surpassed those in Caucasians. Furthermore, studies have shown that African American children are diagnosed later, when compared to Caucasian children. This could be for a variety of reasons, although it is speculated that the older age of IBD diagnosis among African American children may be due in part to a low index of suspicion for IBD in minority children among medical providers because IBD has traditionally been viewed as a disease of Caucasians and adults. Furthermore, under-represented minorities often have decreased access to medical care or different patterns of healthcare seeking behavior thereby leading to much longer delays in diagnosis of IBD in African American children than in Caucasian children and, more importantly, the initiation of critically needed IBD therapy.

Studies continue to show that the disease natural history in African American children is more aggressive, prone to more complications, and requires more interventions, including more powerful medications (i.e., biologics) at earlier stages of the disease after initial diagnosis (i.e., top-down therapy). Top down therapy (starting with an immune system suppressing biologic) has also been shown to be more commonly employed in African American pediatric populations with IBD, thus putting these children even more at risk for long-term use of these medications. Additionally, reporting adverse effects and safety monitoring is presently voluntary in the United States—a factor which further contributes to the difficulties facing underserved populations.

IBD in minority populations—African American, Hispanic, African Caribbean—is clearly and substantially increasing in its frequency, and, represents a more aggressive type of IBD. Therefore, it is paramount that a mechanism be in place to monitor safety of the medications used to treat children with IBD, including minority populations.

*Maintaining a Central IBD Data Repository.*—The goal of the aforementioned report language is the creation of a central data repository, which would supplement proprietary, drug-specific registries. Children being treated with IBD medications benefit from FDA-mandated registries, but these registries are often single product and proprietary. Since children are often on multiple products, these registries do not monitor the safety of drug interactions. In addition, most pediatric IBD therapies (approximately 80 percent) are off-label and manufacturers are not required to collect data on off-label use. Furthermore, significant safety data captured on a competitor's medication may not be made public, and these registries lack uniformity of data collection.

*Building on Previous Federal Investments.*—We envision that existing IBD registries would share data points with the public IBD registry which would connect to an existing registry for pediatric rheumatology (CARRA—Childhood Arthritis and Rheumatoid Research Alliance). Connection to the CARRA registry would benefit both pediatric IBD and rheumatology patients because these auto-immune diseases are often treated with the same medications. CARRA was started with a \$7.5 million grant to the National Institutes of Health (NIH) in 2009 as a result of funding through the American Recovery and Reinvestment Act. Building on this federally-funded registry would encourage data sharing, extend the government's return on investment, and allow Federal regulators and researchers to access data without having to rely on proprietary registries. Presently CARRA is the only registry that meets Federal data sharing requirements per 21CFR-11. We appreciate the interest by many in Congress of a post-marketing data sharing system that could facilitate drug approval for treating rare diseases like pediatric IBD, particularly in diseases where many products are used off-label, thus relieving manufacturers from the obligation of collecting data. Fulfilling the vision of such a post-marketing data sharing system would require each component (i.e., each registry) to meet compliance with 21CFR-11. Therefore the development of a pediatric IBD registry that meets 21CFR-11 requirements and its interconnectivity with the CARRA registry, which already meets these requirements, would offer an excellent demonstration of registry interconnectivity.

#### *Conclusion*

A number of organizations have previously joined NASPGHAN and the Pediatric IBD Foundation in calling for a pediatric IBD registry, including the American Medical Association, the American Academy of Pediatrics and the American Gastroenterological Association.<sup>1</sup> We believe report language specifying the need for a pediatric IBD registry is necessary for the initiation of a public-private partnership. Indeed, this language provides flexibility to the NIH and the FDA to initiate collaborative arrangements with other public and private entities as they did with the CARRA registry, which is an independent 501(c)(3). In this way, the registry is supported with a minimal outlay of Federal resources.

On behalf of the thousands of children with IBD, their families, and pediatric gastroenterologists, we thank you for your consideration of our request.

[This statement was submitted by Carlo Di Lorenzo, MD, Nationwide Children's Hospital, Columbus, OH, President, North American Society for Pediatric Gastroenterology, Hepatology and Nutrition; Benjamin Gold, MD, Children's Center for Digestive Healthcare, Atlanta, GA, Member, North American Society for Pediatric Gastroenterology, Hepatology and Nutrition, Public Affairs and Advocacy Committee; Eric Zuckerman, DO, Bloomfield Hill, MI, Board Chairman, Pediatric IBD Foundation.]

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#### PREPARED STATEMENT OF THE NURSING COMMUNITY

The Nursing Community is a coalition comprised of 62 national professional nursing associations that builds consensus and advocates on a wide spectrum of healthcare issues surrounding education, research, and practice. These organizations are committed to promoting America's health through the advancement of the nursing profession. Collectively, the Nursing Community represents over one million Registered Nurses (RNs), Advanced Practice Registered Nurses (including certified

<sup>1</sup>Letter to Sen. Llamar Alexander and Sen. Patty Murray, September 9, 2015.

nurse-midwives (CNMs), nurse practitioners (NPs), clinical nurse specialists (CNSs), and certified registered nurse anesthetists (CRNAs), nurse executives, nursing students, faculty, researchers, and other nurses with advanced degrees. For fiscal year 2017, our organizations respectfully request \$244 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.]) and \$157 million for the National Institute of Nursing Research (NINR), one of the Institutes and Centers within the National Institutes of Health (NIH).

TITLE VIII PROGRAMS: RESPONDING TO THE NEEDS OF AMERICA'S PATIENTS THROUGH NURSING CARE

As integral members of the healthcare team, nurses collaborate with other professions and disciplines to improve the quality of America's healthcare system. The reach of their care is vast: they offer essential patient care in a variety of settings, including hospitals, long-term care facilities, community centers, State and local health departments, schools, workplaces, and patient homes. RNs comprise the largest group of health professionals with over three million licensed providers in the country.<sup>1</sup> A constant focus must be placed on education, recruitment, and retention to ensure a stable workforce, particularly in geographic regions that will continue to experience health provider shortages in the coming years. A significant investment must be made in the education of new nurses to provide the Nation with the services it demands. For over 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. 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 ensuring the demand for nursing care is met. Title VIII programs target specific aspects of America's nursing workforce and patient populations that require Federal support in order to ensure efficient and effective delivery of healthcare services.

For example, according to HRSA, there were over 61.2 million individuals living in primary care Health Professional Shortage Areas as of December 2015.<sup>2</sup> Title VIII programs provide graduate students and practicing nurses exposure to caring for underserved communities such as these, thus helping to bolster recruitment and retention in these areas. In academic year 2014–2015, the Title VIII Advanced Education Nursing Traineeships supported 3,008 students, of which 72 percent were trained in primary care,<sup>3</sup> and the Title VIII Nurse Anesthetist Traineeships supported 3,229 students, of which 64 percent were trained in Medically Underserved Areas.<sup>4</sup> Moreover, the U.S. Bureau of Labor Statistics' projection that employment of CRNAs, CNMs, and NPs is expected to grow 31 percent between 2012 and 2022.<sup>4</sup> These programs strengthen the supply of these clinicians.

Additionally, the Title VIII NURSE Corps Loan Repayment and Scholarship Programs assist students who agree to serve at least 3 years in facilities experiencing a critical shortage of providers.<sup>4</sup> Last year, 55 percent of the Loan Repayment Program recipients extended their service contracts to work in these facilities beyond the required 3 years.<sup>4</sup> Clearly, these programs are instrumental to connecting current and future providers to patient populations most in need.

America's aging population is another sector that will require additional providers. According to the U.S. Census Bureau, it is estimated that by year 2050, the number of people in the U.S. age 65 and older will reach 83.7 million (nearly one-quarter of the projected population).<sup>5</sup> Rising rates of chronic illness, coupled with an expanding population, will necessitate a cadre of nurses to care for these individuals. The Title VIII Comprehensive Geriatric Education program is designed to meet this call. In academic year 2014–2015 alone, there were 22,743 students and trainees supported through these grants. These individuals are the future caregivers

<sup>1</sup> National Council of State Boards of Nursing. (2016). Active RN Licenses: A profile of nursing licensure in the U.S. as of January 23, 2016. Retrieved from: <https://www.ncsbn.org/6161.htm>.

<sup>2</sup> U.S. Health Resources and Services Administration. (2016). Designated Health Professional Shortage Areas Statistics. Retrieved from: [https://ersrs.hrsa.gov/ReportServer?/HGDW\\_Reports/BCD\\_HPSA/BCD\\_HPSA\\_SCR50\\_Qtr\\_Smry\\_HTML&rc:Toolbar=false](https://ersrs.hrsa.gov/ReportServer?/HGDW_Reports/BCD_HPSA/BCD_HPSA_SCR50_Qtr_Smry_HTML&rc:Toolbar=false).

<sup>3</sup> U.S. Department of Health and Human Services. (2016). Health Resources and Services Administration Fiscal year 2017 Justification of Estimates for Appropriations Committees. Retrieved from: <http://www.hrsa.gov/about/budget/budgetjustification2017.pdf>.

<sup>4</sup> U.S. Bureau of Labor Statistics. (2014). Occupational Outlook Handbook. Registered Nurses. Retrieved from: <http://www.bls.gov/ooh/healthcare/registered-nurses.htm>.

<sup>5</sup> U.S. Census Bureau. (2014). An Aging Nation: The Older Population in the United States. Retrieved from: <https://www.census.gov/prod/2014pubs/p25-1140.pdf>.

to elderly Americans. Funding through this program was utilized to prepare faculty members, develop and disseminate geriatric curriculum, and provide traineeships for students pursuing advanced education nursing degrees in gero-psychiatric nursing, long-term care, and other nursing specialties centered on caring for elderly populations.

—*The Nursing Community respectfully requests \$244 million for the Nursing Workforce Development programs in fiscal year 2017.*

NATIONAL INSTITUTE OF NURSING RESEARCH: FOUNDATION FOR EVIDENCE-BASED CARE

The care that nurses provide must be rooted in evidence. As one of the 27 Institutes and Centers at the NIH, NINR funds research that lays the groundwork for evidence-based nursing practice. NINR examines 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. NINR addresses these challenges through its Strategic Plan, which includes the themes of: symptom science for patients with chronic illness and pain; wellness to prevent illness across conditions, settings, and the lifespan; patient self-management to improve quality of life; and end-of-life and palliative care science.<sup>6</sup>

In addition, NINR recognizes the need for improving global health and promotes research to reduce communicable diseases and improve public health and wellness such as maternal-newborn care. Moreover, NINR allots a generous portion of its budget towards training new nursing scientists, thus helping to sustain the longevity and success of nursing research. 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 \$157 million for the NINR in fiscal year 2017.*

The Ad Hoc Group for Medical Research requests at least \$34.5 billion for NIH in 2017, and the request level of \$157 million for NINR denotes the same percentage increase for NIH applied to NINR.

MEMBERS OF THE NURSING COMMUNITY SUBMITTING THIS TESTIMONY

Academy of Medical-Surgical Nurses	American Organization of Nurse Executives
American Academy of Ambulatory Care Nursing	American Pediatric Surgical Nurses Association
American Academy of Nursing	American Psychiatric Nurses Association
American Assembly for Men in Nursing	American Society for Pain Management Nursing
American Association of Colleges of Nursing	American Society of PeriAnesthesia Nurses
American Association of Critical-Care Nurses	Association for Radiologic and Imaging Nursing
American Association of Heart Failure Nurses	Association of Community Health Nursing Educators
American Association of Neuroscience Nurses	Association of Nurses in AIDS Care
American Association of Nurse Anesthetists	Association of Pediatric Hematology/Oncology Nurses
American Association of Nurse Assessment Coordination	Association of Public Health Nurses
American Association of Nurse Practitioners	Association of Rehabilitation Nurses
American Association of Occupational Health Nurses	Association of Women's Health, Obstetric and Neonatal Nurses
American College of Nurse-Midwives	Commissioned Officers Association of the U.S. Public Health Service
American Nephrology Nurses' Association	Dermatology Nurses' Association
American Nurses Association	Emergency Nurses Association

<sup>6</sup>National Institutes of Health. National Institute of Nursing Research. Implementing NINR's Strategic Plan: Key Themes. Retrieved from: [http://www.ninr.nih.gov/aboutninr/keythemes#.VRVhGWZ\\_Ssu](http://www.ninr.nih.gov/aboutninr/keythemes#.VRVhGWZ_Ssu).

Gerontological Advanced Practice Nurses Association	National Gerontological Nursing Association
Hospice and Palliative Nurses Association	National League for Nursing
Infusion Nurses Society	National Nursing Centers Consortium
International Association of Forensic Nurses	National Organization of Nurse Practitioner Faculties
International Society of Psychiatric-Mental Health Nurses	Nurses Organization of Veterans Affairs
National Association of Clinical Nurse Specialists	Oncology Nursing Society
National Association of Neonatal Nurse Practitioners	Organization for Associate Degree Nursing
National Association of Neonatal Nurses	Pediatric Endocrinology Nursing Society
National Association of Nurse Practitioners in Women's Health	Preventive Cardiovascular Nurses Association
National Association of Pediatric Nurse Practitioners	Public Health Nursing Section, American Public Health Association
National Black Nurses Association	Society of Urologic Nurses and Associates
National Council of State Boards of Nursing	The Quad Council of Public Health Nursing Organizations
	Wound, Ostomy and Continence Nurses Society

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PREPARED STATEMENT OF OPEN HAND ATLANTA

We are pleased to submit this testimony to the Members of this Subcommittee on the urgency of continuing to support the Ryan White Program through the Appropriations process and increasing funding for the domestic HIV/AIDS portfolio in fiscal year 2017. This support and funding will be decisive for achieving the goals of the National HIV/AIDS Strategy (NHAS) 2020, the AIDS Free Generation and halting the devastating effects of the HIV Treatment Cascade.

Open Hand Atlanta is part of a nationwide coalition, the Food is Medicine Coalition, of over 80 food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PWH) and other chronic illnesses. In our service area, we provide 1.5 million medically tailored, home delivered meals annually. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

*Why Food and Nutrition Services (FNS) Matter for PWH*

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PWH at any stage of their illness. For those who are most mobile, there are walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals, home-delivered grocery bags, and supplements complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective core medical service in the Ryan White Program. These services play a critical role in ensuring that PWH enter and continue in pri-



mary medical care, adhere to their medications, and ultimately achieve viral suppression.

*FNS as a Care Completion Service Unique to Ryan White*

Social and economic interventions, most often in the form of care completion services like food and nutrition services, are fundamental to making healthcare work for PWH. Support services for PWH are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PWH are poised to remain connected to care and treatment.

*Access to FNS and the Triple Aim*

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PWH.

*Better Health Outcomes*

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines.<sup>1</sup> Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections<sup>2</sup> and the resulting decreases in their healthcare costs. Compare these outcomes to PWH who are food insecure, who have:

- Lower CD4 counts & lower likelihoods of having undetectable viral loads<sup>3</sup>
- More ER visits<sup>4</sup> & increased morbidity and mortality<sup>5</sup>
- More missed primary care appointments & reduced use of antiretroviral therapy.<sup>6</sup>

*Lower Healthcare Costs*

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PWH. A recent study comparing participants in a medically-tailored FNS program vs. a control group within a local managed care organization found that average monthly healthcare costs for PWH fell 80 percent in first 3 months after receiving FNS.<sup>7</sup> If hospitalized, nourished clients' costs were 30 percent lower, their hospital length of stay was cut by 37 percent and they were 20 percent more likely to be able to be discharged to their homes rather than a more expensive institution.<sup>8</sup> Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

*Improved Patient Satisfaction*

Studies show nutrition counseling improves quality of life.<sup>9</sup> Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

<sup>1</sup> Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at [https://www.health.ny.gov/diseases/aids/ending\\_the\\_epidemic/docs/key\\_resources/housing\\_and\\_supportive\\_services/chain\\_factsheet3.pdf](https://www.health.ny.gov/diseases/aids/ending_the_epidemic/docs/key_resources/housing_and_supportive_services/chain_factsheet3.pdf).

<sup>2</sup> Academy of Nutrition and Dietetics (formerly American Dietetic Association). HIV/AIDS Nutrition Evidence Analysis Project at [http://www.adaevidencelibrary.com/conclusion.cfm?conclusion\\_statement\\_id=250707](http://www.adaevidencelibrary.com/conclusion.cfm?conclusion_statement_id=250707) Accessed 29 July 2012.

<sup>3</sup> Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011); Singe AW, Weiser SD McCoy, SI. Does Food Insecurity Undermine Adherence to Antiretroviral Therapy? A Systematic Review. *AIDS Behav* (2015) 19:1510–1526.

<sup>4</sup> Ibid.

<sup>5</sup> Anema A, Chan K, Yip B, Weiser S, Montaner JSG, Hogg RS. Impact of food insecurity on survival among HIV-positive injection drug users receiving antiretroviral therapy in a Canadian cohort. 141st APHA Annual Meeting, Nov. 2–6, 2013. Boston, MA. Abstract #: 290277.

<sup>6</sup> Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).

<sup>7</sup> Gurvey J, Rand K, Daugherty S, Dinger C, Schmeling J, Laverty N. Examining Health Care Costs Among MANNA Clients and a Comparison Group. *J Prim Care Community Health*. (2013) 4:311–317.

<sup>8</sup> Ibid.

<sup>9</sup> Rabeneck L, Palmer A, Knowles JB, Seidehamel RJ, Harris CL, Merkel KL, Risser JMH, Akrabawi SS. A randomized controlled trial evaluating nutrition counseling with or without oral supplementation in malnourished HIV-infected patients. *J Am Diet Assoc*. (1998) 98: 434–438; Schwenk A, Steuck H, Kremer G. Oral supplements as adjunctive treatment to nutritional counseling in malnourished HIV-infected patients: randomized controlled trial. *Clinical Nutrition* (1999) 18(6): 371–374.

*FNS and the National HIV/AIDS Strategy (NHAS)*

Access to FNS for PWH is fundamental to fulfilling the goals of the NHAS.

- NHAS Goal: Reducing new HIV infections: PWH who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96 percent of the time,<sup>10</sup> thus, FNS is key to prevention.<sup>11</sup>
- NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV: PWH who receive effective FNS are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines.<sup>12</sup>
- NHAS Goal: Reducing HIV-related disparities and health inequities: By providing FNS to PWH who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities.<sup>13</sup>
- NHAS Goal: Achieving a more coordinated national response to the HIV epidemic: There remains a tremendous variation by State in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White HIV Program all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including Ryan White and the ACA.

*Conclusion*

We are deeply aware of the difficult decisions that face the members of the Subcommittee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PWH live healthy and productive lives, produces better overall health outcomes and reduces healthcare costs.

Along with our colleagues, we appreciate the opportunity to offer this testimony regarding the fiscal year 2017 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you.

[This statement was submitted by Matthew Pieper, Executive Director, Open Hand Atlanta, Inc.]

## PREPARED STATEMENT OF ORAL HEALTH AMERICA

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 drive access to care, increase health literacy and advocate for policies that improve overall health through better oral health for all Americans, especially those most vulnerable; is requesting fiscal year 2017 funding for all programs administered under the Older Americans Act (OAA) (U.S. Department of Health and Human Services, Administration on Aging) be restored to at least fiscal year 2010 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, health promotion, and disease prevention programs provide to the system. Since fiscal year 2012, Title III-D funding has remained stagnant at \$19,848,000.

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

<sup>10</sup>M. S. Cohen et al., Prevention of HIV-1 Infection with Early Antiretroviral Therapy. *N. Engl. J. Med.* (2011) 365, 493–505 . HPTN 052.

<sup>11</sup>Palar K, Laraia B, Tsai A, Weiser SD Food insecurity is associated with sexually transmitted infections and HIV serostatus among low income adults in the National Health and Nutrition Examination Survey (NHANES) (1999–2010). Presented at the American Public Health Association 141st Annual Meeting, Boston, MA, November 5, 2013.

<sup>12</sup>Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014.

<sup>13</sup>Available at Weiser SD, Frongillo EA, Ragland K, Hogg RS, Riley ED, Bangsberg DR. Food insecurity is associated with incomplete HIV RNA suppression among homeless and marginally housed HIV-infected individuals in San Francisco. *J Gen Intern Med.* (2009) 24(1):14–20.

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 that 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. This core belief applies throughout the lifespan and especially with older adults.

#### 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.<sup>1</sup>

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.<sup>2</sup>

*Dental Health and Disparities.*—Oral health data reveals that many older adults experience adverse oral health associated with chronic and systemic health conditions. For example, associations between heart disease, periodontitis and diabetes have emerged in recent years, as well as oral conditions such as xerostomia associated with the use of prescription drugs.<sup>3,4</sup> 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.

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.<sup>5</sup>

As examples of these disparities, older African American adults are 1.88 times more likely than their white counterparts to have periodontitis;<sup>6</sup> low-income older adults suffer more than twice the rate of gum disease than their more affluent peers (17.49 versus 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.

*Aging in Place.*—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.<sup>7</sup> Today, many older adults benefit from healthy aging associated with the retention of their natural teeth, improvements in their ability to chew, and the ability to enjoy a variety of food choices not previously experienced by earlier generations of their peers.

<sup>1</sup>Administration on Aging. (2013). Aging Statistics. Retrieved from [http://www.aoa.gov/Aging\\_Statistics/](http://www.aoa.gov/Aging_Statistics/).

<sup>2</sup>Consumer Survey, National Association of Dental Plans. 2012.

<sup>3</sup>Ira 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*.

<sup>4</sup>Fox, 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](http://www.colgateprofessional.com.hk/LeadershipHK/ProfessionalEducation/Articles/Resources/profed_art_access-supplement-2008-xerostomia.pdf).

<sup>5</sup>U.S. Department of Health and Human Services. (2000). Oral Health in America: A Report of the Surgeon General. Retrieved from <http://silk.nih.gov/public/hck10cv.www.surgeon.fullrpt.pdf>.

<sup>6</sup>Borrel, 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>.

<sup>7</sup>Dolan, 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>.

Nearly 90 percent of older adults want to stay in their own homes as they age, often referred to as “Aging in Place.” Today’s older adults are living more independently than previous generations. In fact, only 9 percent of older adults live in a long term care setting. Maintaining a healthy mouth is one of the keys to independence as we age, however resources for oral health remain conspicuously absent from home and community-based services and are largely disconnected and difficult to access.

*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. 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’s 2016 A State of Decay, Vol. III report 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:

- Tooth loss continues to be a signal of suboptimal oral health. There are eight States with a 20 percent or more rate of edentulism, with West Virginia still notably having an older adult population that is 33.6 percent edentate.
- Communities without fluoridated water ignore opportunities for prevention. While States have increased the rates of communities with fluoridated water since 2010, five States (10 percent) still have 60 percent or more of their residents living in communities unprotected by fluoridated water. Hawaii (89.2 percent) and New Jersey (85.4 percent) have the highest rates of unprotected citizens, representing an unnecessary public peril 70 years after Community Water Fluoridation (CWF) was introduced and since named a public health best practice.
- Persistent shortage of oral health coverage. Sixteen percent (8 States) cover no dental services through Medicaid and only four States (8 percent) cover the maximum possible dental services in Medicaid.
- Critical lack of a strategic plan to address the oral health of older adults. Eighty-four percent (42 States) lack a State Oral Health Plan that both mentions older adults and includes SMART objectives. Of the 42 States, 14 lack any type of State Oral Health Plan.
- Inadequate surveillance of the oral health condition of older adults persists. Forty-six percent (23 States) have never completed a Basic Screening Survey of older adults and have no plan to do so.

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.<sup>8</sup> 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.

<sup>8</sup>Wall, Thomas and Nasseh, Dr. Kamyar, “Dental-Related Emergency Department Visits on the Increase in the United States,” Health Policy Institute, ADA, May 2013, [http://www.ada.org/media/ADA/Science%20and%20Research/HPI/Files/HPIBrief\\_0513\\_1.ashx](http://www.ada.org/media/ADA/Science%20and%20Research/HPI/Files/HPIBrief_0513_1.ashx).



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 Wisdom Tooth Project achieves these goals through five strategies: our web portal, regional symposia, communications, advocacy and demonstration projects.

In addition to the A 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 vigorously applauds Congress for passing the bipartisan-supported Older Americans Act reauthorization, S.192. The 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 at least fiscal year 2010 levels would greatly assist the Aging Network to conduct the screenings. More succinctly, the reauthorization 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 2017 funding for all OAA programs to at least fiscal year 2010 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, health promotion, and disease prevention 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 PATH

PATH is appreciative of the opportunity afforded by Chairman Blunt, Ranking Member Murray, and members of the Subcommittee on Labor, Health and Human Services, Education and Related Agencies to submit written testimony regarding fiscal year 2017 funding for global health programs within the U.S. Department of Health and Human Services (HHS). PATH acknowledges the strong leadership the Committee has shown in supporting HHS' work in this area, and recommends that this support continue. This testimony is submitted on behalf of PATH, a leader in global health innovation. As an international nonprofit organization, PATH saves lives and improves health, especially among women and children. Accelerating innovation across five platforms—vaccines, drugs, diagnostics, devices, and system and service innovations—PATH harnesses its entrepreneurial insight, scientific and public health expertise, and passion for health equity. By mobilizing partners around the world, PATH takes innovation to scale, working alongside countries primarily in Africa and Asia to tackle their greatest health needs. With these key partners, PATH delivers measurable results that disrupt the cycle of poor health. Therefore, we respectfully request that this Subcommittee ensure robust funding for global health programs within HHS in fiscal year 2017—including \$224 million for the Center for Disease Control and Prevention's (CDC's) global immunization programs, \$25.5 million for CDC's malaria programs, \$65.2 million for CDC's Division of Global Public Health Protection and Security, and \$33.1 billion for the National Institutes of Health (NIH)—which capitalize on the agency's technical expertise to improve health and increase security, while bolstering the ability of partner countries to lead in the future.

## THE VITAL ROLE OF HHS IN GLOBAL HEALTH AND SECURITY

Recent outbreaks of Zika, Ebola, and measles have demonstrated that the health of U.S. citizens is inherently connected to the health of people living around the globe. Global pandemics and increasing international travel only intensify Americans' vulnerability to diseases that have historically impacted communities outside our borders. For these and other reasons, HHS has been active in global health programs for decades. For example, within HHS, agencies such as CDC collaborate with partner governments to build public health infrastructure and expertise to track and combat diseases worldwide, while conducting research to support the development of new and improved technologies to better help us fight disease threats in the future.

HHS's Global Health Strategy (2011), currently being revised for 2016 and beyond, articulates the department's international role in guiding efforts to safeguard health globally. This role was further strengthened in HHS' central role in the Global Health Security Agenda, launched in 2014. These efforts—such as addressing antimicrobial resistance, and improving laboratory safety and workforce development in more than 34 countries—help to better protect Americans' health and security, while increasing partner countries' ability to contain outbreaks and provide for the health of their citizens.

With continued funding for these activities, the department will be able to continue to strengthen health systems around the world, improve access to proven

health interventions in communities where they are needed most, and invest in solutions to tomorrow's health and security challenges.

#### USING COST-EFFECTIVE STRATEGIES TO SAVE LIVES

One key strategy for achieving HHS' global health and security goals is immunization, with the majority of activities to ensure vaccine delivery overseen by CDC's Global Immunization Division, NIH and BARDA. Vaccines are one of the most impactful and cost-effective public health interventions available today. They have played an outsized role in the reduction—by half—of the number of child deaths since 1990. Worldwide, polio cases have dropped by more than 99 percent since 1988; measles deaths declined by 79 percent from 2000 through 2014; and 2 to 3 million deaths are averted each year through immunization. HHS has contributed significantly to this achievement. For example, thanks in part to HHS' role in global polio immunization efforts, including as a leading partner in the Global Polio Eradication Initiative, Southeast Asia, including India, was certified polio-free in March 2014. Nigeria has not had a case of polio in a year and half, and is expected to be certified polio-free next year if no further cases are reported. Only two countries (Afghanistan and Pakistan) remain endemic, down from more than 125 in 1988.

Globally, programs to immunize populations against a range of vaccine preventable diseases have been built on the foundation of polio vaccination efforts. In fact, polio and routine immunization programs have been a driving force behind strengthening public health systems in many of the world's least developed countries. As polio nears eradication, it is critical to maintain investment—in some cases transitioning funds that have previously been allocated under the heading of polio—to support activities that maintain and expand routine immunization and strengthen public health infrastructure.

Infrastructure and expertise created to address polio have not only reduced cases of that disease and expanded immunization to prevent other diseases, but have also been leveraged to address epidemics. For example, Nigeria was able to rapidly adapt its polio infrastructure and emergency operating center, built with CDC input and support, to respond to and contain an importation of Ebola in October 2014 in Lagos. Continued funding will enable HHS to further extend the delivery of life-saving vaccines to where they are needed most, which will save lives and reduce the burden of disease globally.

Additionally, 2015 marks the halfway point of the Decade of Vaccines, an initiative which established a global framework (2010–2020) endorsed by the United States and 192 other nations with the aim of expanding access to immunization. While some progress has been made toward the goals outlined in the framework, and individual achievements in countries have demonstrated what is possible with focused efforts, we are off track to meet many of the milestones outlined in the plan, and the delay means more lives lost. The U.S. Government is positioned to lead the way in accelerating progress toward the framework's goals, if coordination of efforts continues across various agencies. We are pleased to see HHS making strides toward strengthening the collective impact of its agencies engaged on global immunization, including the CDC and the NIH, among others, as well as across other departments of the U.S. Government. We urge the committee to continue to fully fund these efforts and encourage stronger coordination.

#### FIGHTING TO ELIMINATE MALARIA

In addition to its critical work in immunization, HHS has a long history in controlling and eliminating malaria. CDC, in particular, played a critical role in eliminating malaria from the United States. As a joint implementer of the President's Malaria Initiative (PMI), CDC continues to play a leading role in global control and elimination efforts alongside the U.S. Agency for International Development. These efforts have made a significant impact. Between 2001 and 2015, an estimated 6.2 million lives were saved as a result of scaled-up malaria interventions. While incredible progress has been made, progress is fragile, and investments must be sustained to prevent reemergence of malaria in communities that have succeeded in controlling it. Last year, PMI set forth a 5-year strategy, which includes an ambitious agenda to reduce malaria mortality by one-third from 2015 levels in PMI-supported countries, thereby achieving a greater than 80 percent reduction from PMI's 2000 baseline. The strategy also looks toward elimination of the disease regionally, in order to shrink malaria's footprint across the globe. Robust funding is required to execute on this goal.

With evidence of growing insecticide and drug resistance, CDC's Parasitic Diseases and Malaria program also plays a key role in malaria monitoring and surveillance, evaluation, and its work to ensure we have the new tools necessary to fight

this ever-changing disease. Examples of CDC's contributions include evaluations of the impact of improved nets, insecticides, and strategic use of antimalarial drugs, as well as field trials of promising malaria vaccines, such as RTS,S, the malaria vaccine candidate furthest along in development globally, and recently recommended by the World Health Organization for pilot implementations in Africa.

While CDC's mandate has grown, their budget for malaria has been flat. Increased funding would better equip the agency to track the spread of drug and insecticide resistance, develop and deploy new tools, and ensure the more timely surveillance that is necessary for ultimate malaria elimination.

#### PROTECTING U.S. LEADERSHIP IN GLOBAL HEALTH R&D

While access to existing, proven health interventions—whether vaccines, bed nets, or drugs—must be extended, it is also critical to support research and development (R&D) into future technologies that can prevent existing and emerging global health threats. Investments made by the U.S. Government, including through the NIH, FDA, and CDC over the past three decades, have enabled many partners, including PATH, to advance innovations that have improved health and saved lives around the world. These innovations include new and improved vaccines, such as an effective, low-cost vaccine against meningitis A, which historically caused devastating outbreaks each year in Africa's Meningitis Belt. Zero cases of meningitis A have occurred among the more than 235 million Africans vaccinated since 2010. We also leveraged U.S. support to pioneer safe injection technologies that have helped to prevent millions of blood-borne infections. Thanks to a discovery made by scientists at NIH, PATH was able to develop a simple, rapid test for exposure to river blindness, a disease that affects 25 million people. This test was launched commercially last year and is an important tool in the fight to eliminate river blindness in Africa.

The promise of new global health technologies can only be realized when products are developed, tested, licensed, and scaled up for use globally. Investment in these activities at NIH, CDC, and FDA should continue. Furthermore, strengthened collaboration and coordination between HHS operating divisions and other U.S. agencies funding new and improved drugs, diagnostics, vaccines, and devices will be critically important to better align R&D investments and global health program priorities across the U.S. Government to maximize the impact of U.S. taxpayer dollars.

#### AN INVESTMENT IN HEALTH, AT HOME AND AROUND THE WORLD

With strong funding for global health programs within HHS, the department will be able to improve access to proven health interventions in the communities where they are needed most, while at the same time investing in solutions to tomorrow's challenges. By fully funding the global health and immunization-related accounts, the U.S. can protect the health of Americans while ensuring that people everywhere have the opportunity to lead healthy lives and reach their full potential.

[This statement was submitted by Brandon Ball, Policy & Advocacy Officer, PATH.]

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#### PREPARED STATEMENT OF ANN D. PEEL

##### AMYLOIDOSIS

Mr. Chairman, amyloidosis is a rare and often fatal disease. I ask that you include language in the subcommittee's report for fiscal year 2017 recommending that the National Institutes of Health (NIH) expand its research efforts into amyloidosis, a rare disease characterized by abnormally folded protein deposits in tissues. I also request that the report language for fiscal 2017 directs NIH to keep the subcommittee informed on the steps taken to increase the understanding of the causes of amyloidosis and the measures taken to improve the diagnosis and treatment of this devastating group of diseases.

There is no known cure for amyloidosis. Current methods of treatment are risky and unsuitable for many patients. I have endured two stem cell transplants in order to fight the deadly disease amyloidosis and have survived the disease for 13 years due to the intensive, life-saving treatment that I have received. I want to use my experience with this rare disease to help save the lives of others.

Amyloidosis can cause heart, kidney, or liver dysfunction and failure and severe neurologic problems. Left untreated, the average survival is about 15 months from the time of diagnosis. Amyloidosis can literally kill people before they even know that they have the disease.



More research needs to be funded for various types of amyloidosis. Researchers have not been able to determine the root cause of the disease or an effective low-risk treatment. The patients with amyloidosis who are able to obtain treatment face challenges that can include high dose chemotherapy and stem cell transplantation or organ transplantation.

Amyloidosis is vastly under-diagnosed. Thousands of people die because they were diagnosed too late to obtain effective treatment. Thousands of others die never knowing they had amyloidosis.

#### AMYLOIDOSIS

Amyloidosis occurs when unfolded or misfolded proteins form amyloid fibrils and are deposited in organs, such as the heart, kidney and liver. These misfolded proteins clog the organs until they no longer are able to function—sometimes at a very rapid pace. I have been treated for primary (AL) amyloidosis, a blood or bone marrow disorder.

In addition to AL amyloidosis, there are also thousands of cases of inherited (familial) and age-related amyloidosis. The most common familial type of amyloidosis was found to be caused by mutations in a protein made in the liver. This is the form of amyloidosis that may be present in a significant number of African-Americans.

Older Americans are susceptible to heart disease due to amyloidosis formed from the non-mutated form of the same protein. Another type of amyloidosis, secondary or reactive amyloidosis, occurs in patients with chronic infections or inflammatory diseases.

It was not until the 1980s that research identified the most common amyloid proteins and rationales for treatment began being discussed. The first clinical trial using oral chemotherapy for primary amyloidosis was begun 27 years ago, and high dose chemotherapy with stem cell transplantation was developed in 1994. The first liver transplant in the United States for familial amyloidosis was performed in 1992.

All of these types of amyloidosis, left undiagnosed or untreated, are fatal. There is no explanation for how or why amyloidosis develops. Although progress has been made in developing alternate forms of treatment for amyloidosis, there is still no known reliable cure.

#### AMYLOIDOSIS TREATMENT

The Amyloidosis Center at Boston University School of Medicine and Boston Medical Center, and other centers for amyloidosis treatment, have found that high dose intravenous chemotherapy followed by stem cell transplantation is an effective treatment in selected patients with primary amyloidosis. Abnormal bone marrow cells are killed through high dose chemotherapy, and the patient's own extracted blood stem cells are replaced in order to improve the recovery process.

The high dose chemotherapy and stem cell rescue and other new drugs have increased the remission rate and long-term survival dramatically. However, this treatment can also be life threatening and more research needs to be done to provide less risky forms of treatment.

#### RESEARCH

Although it has been 13 years since my initial stem cell transplant for amyloidosis, I, like most patients, am faced with recurring amyloidosis. Fortunately, due to research, there are new forms of treatment that are options for me and patients with recurring amyloidosis. These were not available 13 years ago. This is evidence that funding through Health and Human Services can make a difference.

The limited research and equipment funding through HHS and NIH has been helpful in developing new treatment alternatives for some patients with amyloidosis. Although funding is severely limited, researchers are moving forward to develop targeted treatments that will specifically attack the amyloid proteins.

The current funding for amyloidosis research shows what might be possible with increased funding and emphasis on the disease—but it does not go far enough.

Additional funding for research and equipment is needed to accomplish this task. Only through more research is there hope of further increasing the survival rate and finding additional treatments to help more patients.

#### DIAGNOSIS

Timely diagnosis is also of great concern. Although I was diagnosed at a very early stage of the disease, many people are diagnosed after the point that they are physically able to undertake treatment.

Early diagnosis and treatment are the keys to success. More needs to be done in these areas to alert health professionals to identify this disease.

#### CURRENT INITIATIVES

Through the leadership of this Committee and the further involvement of the U.S. Government, a number of positive developments have occurred.

- The National Institutes of Health has substantially increased its interest in amyloidosis. The NIH, particularly the Office of Rare Diseases, participates in meetings and symposia and works closely with organizations doing research and outreach on amyloidosis. The Amyloidosis Research Consortium (ARC), a network of clinical centers caring for amyloidosis patients, has developed and is working with the Food and Drug Administration and pharmaceutical companies to more rapidly test new therapies for amyloidosis.
- Research supported by the National Institute of Neurologic Disorders and Stroke at NIH and the Office of Orphan Products Development at the Food and Drug Administration led to successful repurposing of a generic drug that markedly slows progression of familial amyloidosis. This was the first drug treatment for this disease and worked by stabilizing the precursor protein. In partnership with pharmaceutical companies, new types of treatment, RNA interference, that work by decreasing production of the precursor protein are now in clinical trials. There is also hope, with increased funding for research, to expand the range of treatment to other categories of amyloidosis.
- There has been increased basic and clinical research at the Boston University Amyloidosis Center: models of light chain (AL) amyloid disease have been developed; serum chaperone proteins that cause amyloid precursor protein misfolding are being identified; imaging techniques for the diagnosis of amyloid disease are being investigated, and new clinical trials for AL and familial amyloidosis are underway. A study of the age-related form of amyloid heart disease has provided natural history data indicating a shorter survival than had been previously appreciated for this under recognized form of amyloidosis. The National Institute of Aging has been supporting this work.
- Federal funding for research, equipment and treatment has been an important element in progress to date. Further funding is essential to speed the pace of discovery for basic and clinical research.

#### REQUEST FOR FISCAL YEAR 2017

Mr. Chairman, I ask that the subcommittee take the following actions to help address this deadly disease:

- First, include in the fiscal year 2017 subcommittee report language recommending that NIH expand its research efforts into amyloidosis, a group of rare diseases characterized by abnormally folded protein deposits in tissues.
- Second, direct the NIH to keep the subcommittee informed on the steps taken to increase the understanding of the causes of amyloidosis and the measures taken to improve the diagnosis and treatment of this devastating group of diseases.

Help me turn what has been my own life-threatening experience into hope for others.

Thank you for your consideration.

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#### PREPARED STATEMENT OF THE PHYSICIAN ASSISTANT EDUCATION ASSOCIATION

On behalf of the 199 accredited physician assistant (PA) education programs in the United States, the Physician Assistant Education Association (PAEA) is pleased to submit this statement on the fiscal year 2017 appropriations. PAEA supports funding of at least \$280 million in fiscal year 2017 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 that \$12 million of that funding support PA programs operating across the country. This relatively small investment will reinforce the capacity of physician assistant education, and will greatly enhance PA educational programs. Title VII funding is the only designated source of Federal funding for PA education. This funding is crucial to the U.S. PA education system's ability to meet the demand for PAs and produce highly skilled PAs ready to enter the healthcare workforce in an average of 27 months.

### *Need for Increased Federal Funding*

The unmet need for primary care services in the United States is well documented. In fact, the need for primary care services is expected to grow as the population ages and requires more healthcare services especially as formerly uninsured patients gain access. Healthcare systems are rapidly evolving; amidst this change; the need for qualified healthcare providers in numbers sufficient enough to meet the demand remains a constant concern. Primary care has been clearly identified as the critical entry point into the healthcare system where access must be guaranteed. The PA profession was created specifically to address a shortage of primary care physicians almost 50 years ago. Today's PAs continue this tradition and stand ready to help address the challenges our Nation faces in primary care and other specialties. The effectiveness of physician assistants is seen in better patient access, especially for Medicaid patients; high patient satisfaction; and healthcare outcomes similar to physicians. Importantly, PAs could play an even larger role in high-quality, cost-effective care with stronger Federal support and through innovations in the PA education system.

Like physicians, the PA profession 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 8,000 PA graduates annually, these shortages will persist, particularly in the rural and underserved communities where care is most needed.

### *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. 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.

### *PA Education: The Pipeline for Physician Assistants*

There are currently 199 accredited PA education programs in the United States. Together these programs graduate close to 8,000 PA students each year. PAs are educated as generalists in medicine, which gives them the flexibility to practice in more than 60 medical and surgical specialties. Approximately one third of PAs are working in primary care. The average PA education program is 27 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 55 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, the Centralized Application Service (CASPA) used by most programs grew from 4,669 applicants to over 20,000. As of March 2015, there were 22,997 applicants to PA education programs, which represents more than a 40 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 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 PA professions critical needs, especially as we continue to foster the growing demand for an increased primary care workforce. The PA teaching profession faces large numbers of retirements in the next 10-15 years

as nearly half of PA program faculty are 50 years or older. An interest in education must be developed early in the educational process to ensure a continuous stream of educators. Furthermore, the significant loan burdens that prevent many physician assistants from entering academia must be alleviated. 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. 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 the demand for qualified and highly trained practitioners. 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 (preceptors) willing to teach students as they are cycling through their clinical rotations, and a lack of sites with the physical space to teach. Cutbacks in Federal and State funding of Area Health Education Centers (AHECs) has also contributed to reduced access to clinical training for PA students, particularly in rural and underserved communities. Federal funding can help incentivize practicing clinicians to both offer their time as preceptors, and volunteer their clinical operations as training grounds for interprofessional training opportunities with PAs and other members of the health professional.

#### *Enhancing Diversity*

The Physician Assistant Education Association is committed to enhancing the diversity of the PA education community, workforce diversity, and practice in underserved areas. It is increasingly important for patient care 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. PA programs are looking for unique ways to recruit diverse individuals into the profession, and sustain them as leaders in the education field and within their communities. PAEA recognizes the need to recruit diverse faculty, as a diverse faculty pool with a broad perspective of experiences, enhances the educational setting and is beneficial to students. 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 funding for the Health Careers Opportunity Program (HCOP), and increased funding for the Scholarships for Disadvantaged Students and National Health Service Corps. 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 can serve as a solution and a remedy to many of the PA profession's areas of need, including faculty development, clinical site expansion and diversification of the primary care workforce. 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 needs.

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 future PAs, 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 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 New York program is using its PA training grant to operate a mobile health vehicle to provide health education and initial health screenings to local underserved communities. The direct exposure achieved by utilizing a mobile health vehicle provides the communities with medical and preventive education and health screenings while also addressing the students' awareness of cultural competency and health literacy. Equally as important, the experience has motivated students to specialize in primary care.
- A Virginia program uses its PA training grant to support transitioning veterans, while increasing the placement of graduates in primary care and medically underserved communities. The grant allows the PA program to provide scholarship to incoming physician assistant students who are veterans, and who dedicate the beginning of their careers to a primary care setting.

*Recommendations on Fiscal Year 2017 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 2017. 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.

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.

[This statement was submitted by Anthony Miller, M.Ed., PA-C, Chief Policy and Research Officer, Physician Assistant Education Association.]

PREPARED STATEMENT OF THE POPULATION ASSOCIATION OF AMERICA/ASSOCIATION OF POPULATION CENTERS

INTRODUCTION

Thank you, Chairman Blunt, Ranking Member Murray, 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 2017, we urge the Subcommittee to adopt the following funding recommendations: \$34.5 billion for the NIH, consistent with the level recommended by the Ad Hoc Group for Medical Research; \$170 million for the NCHS, consistent with the Friends of NCHS recommendation; and \$640.9 million, for the BLS, consistent with the Administration's request.

The PAA and APC are two affiliated organizations that together represent over 3,000 social and behavioral scientists and approximately 40 population research centers nationwide that conduct research on the implications of population change. Our members, which include demographers, economists, sociologists, and statisticians, who 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, retirement, and labor. Population scientists compete for discretionary grant funding from the NIH and rely on data from the Nation's statistical agencies to conduct research and research training activities.

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).

PAA and APC thank the subcommittee for supporting a \$2 billion increase for the NIH in fiscal year 2016 and look forward to working with the Congress to ensure

NIH can continue to receive sustainable, steady increases in fiscal year 2017 and beyond.

NATIONAL INSTITUTE ON AGING

By 2030, there will be 72 million Americans aged 65 and older. 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 population aging research.

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, accessible surveys. For example, the Health and Retirement Study (HRS), provides unique information about economics transitions in work, income, and wealth, allowing scientists to study how the domains of family, economic resources, and health interact. Since 1992, the HRS has collected data, including, most recently, biomarkers, from a representative sample of more than 27,000 Americans over the age of 50 every 2 years. These data are accessible to researchers worldwide and have informed numerous scientific findings.

In 2015, NIA grantee using vital statistics data as well as data from the HRS, published findings confirming rising mortality rates among middle aged, white, non-Hispanic Americans. This change reversed decades of progress in mortality and was unique to the United States. The study found increasing death rates resulted largely from “diseases of despair”—drug and alcohol poisonings, suicide, and chronic liver diseases and cirrhosis. The most dramatic increases in mortality occurred among the poorly educated. The findings point to alarming trends in populations previously thought to be healthy and underscore the need for broad public health strategies to combat their causes.

With additional support in fiscal year 2017, the Institute can sustain and expand its investment in population aging research, including contributing to the Institute’s efforts to address the scourge of dementia and Alzheimer’s disease. The BSR division is also eager to support research and data collection on the causes of widening disparities in health and longevity at older ages, and the role of social factors, such as education and income, in the health and well-being of older people. As members of the Friends of NIA, we urge the Committee to provide the NIH with an additional \$500 million in fiscal year 2017 to support aging research activities not only at the NIA, but also across the agency.

EUNICE KENNEDY SHRIVER NATIONAL INSTITUTE ON 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 research 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. The Add Health study received a 2016 Golden Goose Award, recognizing its significant and unique scientific contributions and innovations.

In 2015, scientists, using data from these large-scale data sets published numerous findings. For example, scientists, used data from the Fragile Families and Child Wellbeing Survey, found a negative association between father engagement and children’s behavioral problems, independent of the mother’s characteristics and her level of engagement. Using data from the Add Health study, scientists determined that social relationships affect individual’s physical health, including chronic disease and longevity. (<http://www.populationassociation.org/wp-content/uploads/PAAAPC-Advances-in-Population-Research.pdf>).

In addition to supporting individual research grants and surveys, NICHD supports the Population Dynamics Centers Research Infrastructure Program. These highly productive centers, based at U.S. universities and private research institutions nationwide, have advanced U.S. science by fostering groundbreaking interdisciplinary research on human health and development, and increased the scientific pipeline by nurturing the careers of junior researchers. With additional funding in fiscal year 2017, the Institute will be able to maintain its strong commitment to these centers of research excellence. As members of the Friends of NICHD, PAA

and APC request that the Institute receive a funding level of \$1.441 billion in fiscal year 2017.

#### NATIONAL CENTER FOR HEALTH STATISTICS

The National Center for Health Statistics (NCHS) is the Nation's principal health statistics agency, providing data on the health of the U.S. population and backing essential data collection activities. Most notably, NCHS funds and manages the National Vital Statistics System (NVSS), which contracts with the States to collect birth and death certificate information. NCHS also funds a number of complex large surveys to help policy makers, public health officials, and researchers understand the population's health, influences on health, and health outcomes. These surveys include the National Health and Nutrition Examination Survey and National Survey of Family Growth. The wealth of data NCHS collects makes the agency an invaluable resource for population scientists.

In recent years, NCHS has made significant progress toward modernizing the NVSS, moving many States from paper-based to electronic filing of birth and death statistics and expediting the release of these data to the user community. However, persistent flat funding levels in recent years, and the loss of funds from the Prevention and Public Health Fund, are hampering the agency's ability to enact additional innovations and make necessary survey redesigns and system improvements. That is why as members of the Friends of NCHS, PAA and APC request that NCHS receive \$170 million in budget authority in fiscal year 2016, an amount \$10 million above the Administration's request. Among other things, NCHS could use this additional money to support ongoing implementation of electronic death records nationwide to provide faster, better vital statistics and to pursue a thoughtful, well-conducted redesign of the National Health Interview Survey.

#### BUREAU OF LABOR STATISTICS

BLS produces essential economic information for public and private decision-making. Population scientists who study and evaluate labor and related economic policies and programs use its data extensively. The agency also supports the National Longitudinal Studies program and the American Time Use Survey, which are invaluable datasets that the population sciences use to understand how complex factors, such as changes in work status, income, and education, interact to affect health and achievement outcomes in children and adults.

PAA and APC joins other organizations comprising the Friends of Labor Statistics in thanking the subcommittee for providing BLS with a \$17 million increase in fiscal year 2016. However, the agency is still struggling to overcome years of insufficient support. Between fiscal year 2009 and fiscal year 2015, the absolute value and/or the purchasing power of BLS appropriations decreased every year. As a result, the agency eliminated several programs in fiscal year 2013 and fiscal year 2014 and in fiscal year 2015 had to rely on a one-time transfer from the Department of Commerce to maintain BLS' Export Price Program. The agency also cut back its rate of replacement of staff and staff training and development to unsustainable levels in 2015.

Given the importance and unique nature of BLS data, we urge the Subcommittee to support the Administration's request, \$640.9 million, an increase of \$31.9 million above the fiscal year 2016 funding level. This funding would allow BLS to support its core programs and surveys and to conduct other postponed activities, including a supplement to the Current Population Survey and changes to the Consumer Expenditure Survey to support development of a supplemental statistical poverty measure.

Thank you for considering our organization's positions on these agencies under your subcommittee's jurisdiction.

[This statement was submitted by Mary Jo Hoeksema, Director, Government and Public Affairs, Population Association of America/Association of Population Centers.]

#### PREPARED STATEMENT OF PREVENT BLINDNESS

##### FUNDING REQUEST OVERVIEW

Prevent Blindness appreciates the opportunity to submit testimony to the Subcommittee and respectfully requests the following allocation and support in fiscal year 2017 to help promote eye health and prevent eye disease and vision loss:

—Provide \$1,500,000 to strengthen the Vision Health at the Centers for Disease Control and Prevention (CDC).

—Support the Maternal and Child Health Bureau’s (MCHB) National Center for Children’s Vision and Eye Health.

#### INTRODUCTION AND OVERVIEW

Prevent Blindness—the Nation’s leading non-profit, voluntary organization committed to preventing blindness and preserving sight—maintains a long-standing commitment to working with policymakers at all levels of government, organizations and individuals in the eye care and vision loss community, and other interested stakeholders to develop, advance, and implement policies and programs that prevent blindness and preserve sight.<sup>1</sup>

Vision-related conditions affect people across the lifespan. Good vision is an integral component to health and well-being. It 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 National Eye Institute (NEI) reports that “the number of Americans with age-related eye disease and the vision impairment that results is expected to double within the next three decades.”<sup>2</sup>

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, 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 \$1,500,000 in fiscal year 2017 to strengthen vision and eye health efforts of the CDC.* This funding level would allow the VHI to increase vision impairment and eye disease surveillance efforts, apply previous CDC vision and eye health research findings to develop effective prevention and early detection interventions, and begin to incorporate vision and eye health promotion activities into State and national public health chronic disease initiatives, with an initial focus on early detection of diabetic retinopathy.

In addition, the CDC engaged the Institute of Medicine (IOM) at the National Academies of Sciences, Engineering, and Medicine to study public health approaches to reduce vision impairment and improve eye health. The IOM will release a report in fiscal year 2016 that captures findings from the study, and funding within this request would be allocated to support the implementation of the Academy’s recommendations for CDC.

<sup>1</sup>For more information about Prevent Blindness and our Federal Government relations and public policy efforts, please visit [www.preventblindness.org](http://www.preventblindness.org).

<sup>2</sup>“Vision Problems in the U.S.: Prevalence of Adult Vision Impairment and Age-Related Eye Disease in America,” Prevent Blindness America and the National Eye Institute, 2008.



## INVESTING IN THE VISION OF OUR NATION'S MOST VALUABLE RESOURCE—CHILDREN

While the risk of eye disease increases after the age of 40, eye and vision problems in children are of equal concern. If left untreated, they can lead to permanent and irreversible visual loss and/or cause problems socially, academically, and developmentally. Although more than 12.1 million school-age children have some form of a vision problem, only one-third of all children receive eye care services before the age of six.<sup>3</sup> Vision disorders are among the leading cause of impaired health in childhood as 1 in 4 school-aged children has a vision problem significant enough to affect learning. But early detection can help prevent vision loss and blindness and understands many serious ocular conditions in children are treatable if diagnosed at an early stage.

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 address issues surrounding children's vision screening.

The Center has established a National Advisory Committee to provide recommendations toward national guidelines for quality improvement strategies, vision screening and developing a continuum of children's vision and eye health. With this support the Center, will continue to: (1) provide national leadership in dissemination of best practices, infrastructure development, professional education, and national vision screening guidelines that ensure a continuum of vision and eye healthcare for children; (2) advance State-based performance improvement systems, screening guidelines, and a mechanism for uniform data collection and reporting; and (3) provide technical assistance to States in the implementation of strategies for vision screening, establishing quality improvement measures, and improving mechanisms for surveillance.

Therefore, Prevent Blindness encourages the Subcommittee to support the work of the Center which, through partnerships, sound science, and targeted policy initiatives, promotes vision and eye health for the Nation's children.

## 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 2017 funding for the CDC Vision Health Initiative, and the MCHB National Center for Children's Vision and Eye Health. 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 PROJECT ANGEL FOOD

We are pleased to submit this testimony to the Members of this Subcommittee on the urgency of continuing to support the Ryan White Program through the Appropriations process and increasing funding for the domestic HIV/AIDS portfolio in fiscal year 2017. This support and funding will be decisive for achieving the goals of the National HIV/AIDS Strategy (NHAS) 2020, the AIDS Free Generation and halting the devastating effects of the HIV Treatment Cascade.

Project Angel Food is part of a nationwide coalition, the Food is Medicine Coalition, of over 80 food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PWH) and other chronic illnesses. In Los Angeles County, we provide over 500,000 medically tailored, home delivered meals annually. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses .

<sup>3</sup>“Our Vision for Children's Vision: A National Call to Action for the Advancement of Children's Vision and Eye Health, Prevent Blindness America,” Prevent Blindness America, 2008.

*Why Food and Nutrition Services (FNS) Matter for PWH*

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PWH at any stage of their illness. For those who are most mobile, there are congregate meals, walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective core medical service in the Ryan White Program. These services play a critical role in ensuring that PWH enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

*FNS as a Care Completion Service Unique to Ryan White*

Social and economic interventions, most often in the form of care completion services like food and nutrition services, are fundamental to making healthcare work for PWH. Support services for PWH are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PWH are poised to remain connected to care and treatment.

*Access to FNS and the Triple Aim*

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PWH.

*Better Health Outcomes*

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines.<sup>1</sup> Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections<sup>2</sup> and the resulting decreases in their healthcare costs. Compare these outcomes to PWH who are food insecure, who have:

- Lower CD4 counts & lower likelihoods of having undetectable viral loads<sup>3</sup>
- More ER visits<sup>4</sup> & increased morbidity and mortality<sup>5</sup>

<sup>1</sup>Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at [https://www.health.ny.gov/diseases/aids/ending\\_the\\_epidemic/docs/key\\_resources/housing\\_and\\_supportive\\_services/chain\\_factsheet3.pdf](https://www.health.ny.gov/diseases/aids/ending_the_epidemic/docs/key_resources/housing_and_supportive_services/chain_factsheet3.pdf).

<sup>2</sup>Academy of Nutrition and Dietetics (formerly American Dietetic Association). HIV/AIDS Nutrition Evidence Analysis Project at [http://www.adaevidencelibrary.com/conclusion.cfm?conclusion\\_statement\\_id=250707](http://www.adaevidencelibrary.com/conclusion.cfm?conclusion_statement_id=250707) Accessed 29 July 2012.

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<sup>5</sup>Anema A, Chan K, Yip B, Weiser S, Montaner JSG, Hogg RS. Impact of food insecurity on survival among HIV-positive injection drug users receiving antiretroviral therapy in a Canadian cohort. 141st APHA Annual Meeting, Nov. 2–6, 2013. Boston, MA. Abstract #: 290277.

—More missed primary care appointments & reduced use of antiretroviral therapy.<sup>6</sup>

#### *Lower Healthcare Costs*

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PWH. A recent study comparing participants in a medically-tailored FNS program vs. a control group within a local managed care organization found that average monthly healthcare costs for PWH fell 80 percent in first 3 months after receiving FNS.<sup>7</sup> If hospitalized, nourished clients' costs were 30 percent lower, their hospital length of stay was cut by 37 percent and they were 20 percent more likely to be able to be discharged to their homes rather than a more expensive institution.<sup>8</sup> Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

#### *Improved Patient Satisfaction*

Studies show nutrition counseling improves quality of life.<sup>9</sup> Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

#### *FNS and the National HIV/AIDS Strategy (NHAS)*

Access to FNS for PWH is fundamental to fulfilling the goals of the NHAS.

—NHAS Goal: Reducing new HIV infections: PWH who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96 percent of the time,<sup>10</sup> thus, FNS is key to prevention.<sup>11</sup>

—NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV: PWH who receive effective FNS are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines.<sup>12</sup>

—NHAS Goal: Reducing HIV-related disparities and health inequities: By providing FNS to PWH who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities.<sup>13</sup>

—NHAS Goal: Achieving a more coordinated national response to the HIV epidemic: There remains a tremendous variation by State in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White HIV Program all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including Ryan White and the ACA.

#### *Conclusion*

We are deeply aware of the difficult decisions that face the members of the Subcommittee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are se-

<sup>6</sup>Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).

<sup>7</sup>Gurvey J, Rand K, Daugherty S, Dinger C, Schmeling J, Laverty N. Examining Health Care Costs Among MANNA Clients and a Comparison Group. *J Prim Care Community Health.* (2013) 4:311–317.

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<sup>9</sup>Rabeneck L, Palmer A, Knowles JB, Seidehamel RJ, Harris CL, Merkel KL, Risser JMH, Akrabawi SS. A randomized controlled trial evaluating nutrition counseling with or without oral supplementation in malnourished HIV-infected patients. *J Am Diet Assoc.* (1998) 98: 434–438; Schwenk A, Steuck H, Kremer G. Oral supplements as adjunctive treatment to nutritional counseling in malnourished HIV-infected patients: randomized controlled trial. *Clinical Nutrition* (1999) 18(6): 371–374.

<sup>10</sup>M. S. Cohen et al., Prevention of HIV-1 Infection with Early Antiretroviral Therapy. *N. Engl. J. Med.*(2011) 365, 493–505 . HPTN 052.

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<sup>13</sup>Available at Weiser SD, Frongillo EA, Ragland K, Hogg RS, Riley ED, Bangsberg DR. Food insecurity is associated with incomplete HIV RNA suppression among homeless and marginally housed HIV-infected individuals in San Francisco. *J Gen Intern Med.* (2009) 24(1):14–20.

verely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PWH live healthy and productive lives, produces better overall health outcomes and reduces healthcare costs.

Along with our colleagues, we appreciate the opportunity to offer this testimony regarding the fiscal year 2017 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

[This statement was submitted by Richard Ayoub, Executive Director, Project Angel Food.]

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PREPARED STATEMENT OF PROJECT ANGEL HEART

We are pleased to submit this testimony to the Members of this Subcommittee on the urgency of continuing to support the Ryan White Program through the Appropriations process and increasing funding for the domestic HIV/AIDS portfolio in fiscal year 2017. This support and funding will be decisive for achieving the goals of the National HIV/AIDS Strategy (NHAS) 2020, the AIDS Free Generation and halting the devastating effects of the HIV Treatment Cascade.

Project Angel Heart is part of a nationwide coalition, the Food is Medicine Coalition, of food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PWH) and other chronic illnesses. In our service area, we provide 318, 665 medically tailored, home delivered meals annually. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

*Why Food and Nutrition Services (FNS) Matter for PWH*

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PWH at any stage of their illness. For those who are most mobile, there are congregate meals, walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective core medical service in the Ryan White Program. These services play a critical role in ensuring that PWH enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

*FNS as a Care Completion Service Unique to Ryan White*

Social and economic interventions, most often in the form of care completion service like food and nutrition services, are fundamental to making healthcare work for PWH. Support services for PWH are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PWH are poised to remain connected to care and treatment.

### *Access to FNS and the Triple Aim*

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PWH.

#### *Better Health Outcomes*

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines.<sup>1</sup> Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections<sup>2</sup> and the resulting decreases in their healthcare costs. Compare these outcomes to PWH who are food insecure, who have:

- Lower CD4 counts & lower likelihoods of having undetectable viral loads<sup>3</sup>
- More ER visits<sup>4</sup> & increased morbidity and mortality<sup>5</sup>
- More missed primary care appointments & reduced use of antiretroviral therapy.<sup>6</sup>

#### *Lower Healthcare Costs*

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PWH. A recent study comparing participants in a medically-tailored FNS program vs. a control group within a local managed care organization found that average monthly healthcare costs for PWH fell 80 percent in first 3 months after receiving FNS.<sup>7</sup> If hospitalized, nourished clients' costs were 30 percent lower, their hospital length of stay was cut by 37 percent and they were 20 percent more likely to be able to be discharged to their homes rather than a more expensive institution.<sup>8</sup> Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

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- NHAS Goal: Achieving a more coordinated national response to the HIV epidemic: There remains a tremendous variation by State in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White HIV Program all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including Ryan White and the ACA.

#### *Conclusion*

We are deeply aware of the difficult decisions that face the members of the Subcommittee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PWH live healthy and productive lives, produces better overall health outcomes and reduces healthcare costs.

Along with our colleagues, we appreciate the opportunity to offer this testimony regarding the fiscal year 2017 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you.

[This statement was submitted by Erin Pulling, President & CEO, Project Angel Heart.]

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PREPARED STATEMENT OF THE PULMONARY HYPERTENSION ASSOCIATION  
THE ASSOCIATION'S FISCAL YEAR 2017 L-HHS APPROPRIATIONS RECOMMENDATIONS

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- \$7.48 billion in discretionary budget authority for the Health Resources and Services Administration (HRSA).
- \$7.8 billion in program level funding for the Centers for Disease Control and Prevention (CDC), which includes budget authority, the Prevention and Public Health Fund, Public Health and Social Services Emergency Fund, and PHS Evaluation transfers.
- A proportional fiscal year 2016 funding increase for CDC's National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP).
- At least \$34.5 billion in program level funding for the National Institutes of Health (NIH).
- Proportional funding increases for NIH's National Heart, Lung, and Blood Institute (NHLBI); the National Institute of Child Health and Human Development (NICHD), and the National Center for Advancing Translational Sciences (NCATS).

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Chairman Blunt 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 2017 L-HHS Appropriations Bill.

#### ABOUT PULMONARY HYPERTENSION

Pulmonary hypertension (PH) is a disabling and often fatal condition simply described as high blood pressure in the lungs. It affects people of all ages, races and

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<sup>12</sup> Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014.

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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 the heart has to pump against to push blood through the lungs; and a strain on the right side of the heart due to the increased work that it has to do. If this increased pressure is not treated, the right side of the heart can become overworked, become very weak and may possibly fail. Because blood has difficulty getting through the lungs to pick up oxygen, blood oxygen level may be lower than normal. This can put a strain not only on the heart, but also decrease the amount of oxygen getting to the 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.

#### THE PATIENT PERSPECTIVE

##### *The Hicks Family*

Carl Hicks is a former Army Ranger and a retired Colonel who led the first battalion into Iraq during the first Iraq war. Every member of his family was touched by pulmonary hypertension after the diagnosis of his daughter Meghan in 1994. I share their story here, in Carl's own words:

We're sorry Colonel Hicks, your daughter Meaghan has contracted primary pulmonary hypertension. She likely has less than a year to live and there is nothing we can do for her.

"Those words were spoken in the spring of 1994 at Walter Reed Army Medical Center. They marked the start down the trail of tears for a young military family that, only hours before, had been in Germany. My family's journey down this trail hasn't ended yet, even though Meaghan's fight came to an end with her death on January 30th, 2009. She was 27.

Pulmonary hypertension (PH) struck our family, as it so often does, without warning. One day, we had a beautiful, healthy, energetic 12-year old gymnast, the next, a child with a death sentence being robbed of every breath by this heinous disease. The toll of this fight was far-reaching. Over the years, every decision of any consequence in the family was considered first with regards to its impact on Meaghan and her struggle for breath.

The investment made by our country in my career was lost, as I left the service to stay nearer my family. The costs for Meaghan's medical care, spread over the nearly 14 years of our fight, ran well into the seven figures. Meghan even underwent a heart and dual-lung transplant. These challenges, though, were nothing compared to the psychological toll of losing Meaghan who had fought so hard for something we all take for granted, a breath of air."

##### *Jessica Armstrong*

In 2011, at the age of 29, GS12 Human Terrain Analyst Jessica (Puglisi) Armstrong who was serving in Afghanistan as Department of the Army Civilian began experiencing progressive shortness of breath dizziness, and exercise intolerance. Jessica reported her symptoms multiple times. The first time she was told that she needed to eat more, then she was diagnosed with dehydration. As her symptoms continued to progress, as is the case with many PH patients, she was told she had asthma and given a series of inhalers. Two months later, she fainted for no apparent reason. A CT scan 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 given a clean bill of health and orders to return to Afghanistan. Not feeling better she sought a second opinion at a civilian hospital where she was finally given a complete work up and diagnosed with chronic thromboembolic pulmonary hypertension.

Jessica 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, UCSD has only completed about 3,000 surgeries. The procedure that saved Jessica's life was developed in her lifetime.

Jessica was terminated from Army employment and spent more than \$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 obtain 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 Senior Manager 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.

#### 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 2017.

#### 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, however, 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 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.

#### NHLBI

PHA's Research Program has committed more than \$15 million for PH research by leveraging partnerships with the National Heart, Lung, and Blood Institute (NHLBI) and the American Thoracic Society (ATS). We have supported 70 promising researchers through four independently reviewed, cutting-edge research programs.

Through a career development award partnership with the National Heart, Lung, and Blood Institute (NHLBI), the Pulmonary Hypertension Association is pleased to provide supplemental funding to individuals who receive an NHLBI Mentored Clinical Scientist Research Career Development Award (K08) or a Mentored Patient-Oriented Research Career Development Award (K23) for research on pulmonary hypertension. The K23 award is focused on patient oriented research where clinicians interact directly with patients in their studies. The K08 award provides support to researchers through supervised research career development in the fields of biomedical and behavioral research, including translational research but whose studies do not include direct interaction with patients.

This program's award recipients are active in the PH community and PHA is proud to have provided support to 11 researchers to date.



The NHLBI-funded Centers for Advanced Diagnostics and Experimental Therapeutics in Lung Diseases Stage II program, which began in fiscal year 2014, provides a mechanism to accelerate the development of therapies for lung diseases, including pulmonary fibrosis and pulmonary arterial hypertension.

[This statement was submitted by Mr. Rino Aldrighetti, President and CEO, Pulmonary Hypertension Association.]

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PREPARED STATEMENT OF ANDREW REAMER

Chairman Blunt, Ranking Member Murray, and members of the Subcommittee, I am writing in support of the President's budget request for \$641 million for the Bureau of Labor Statistics (BLS) in fiscal year 2017.

As a research professor at the George Washington Institute of Public Policy, I focus on policies that promote U.S. economic competitiveness. From this perspective, I believe that a fully-funded BLS is essential to the health of the Nation's economy. I offer three reasons:

- Congress has given the BLS a number of specific mandates that require adequate resources to fulfill. I summarize these mandates in an appendix to this testimony.
- BLS data—particularly data on employment, unemployment, prices, and productivity—are essential for sound Federal macroeconomic policies.
- BLS data enable efficient U.S. labor markets by enabling participants—workers, students, educators, and employers—to make more informed decisions. Better decisions in labor markets will result in employers finding workers with desired skills, workers with high value credentials, and reduced Federal expenditures for education and workforce development grants.

Since 2010, however, real appropriations for the BLS have fallen by 9 percent and staff capacity by eight percent. As a result, the agency has not been able to fully carry out its mandated responsibilities, to the detriment of the U.S. economy. I encourage the Subcommittee to understand that a relatively small amount of taxpayer funds invested in current, reliable statistics will lead to substantial increases in economic activity as measure by jobs and income.

The value of cutting-edge BLS efforts can be seen in its release today of a new data series on the attainment of industry-recognized certifications and occupational licenses among adults. Subcommittee members may see these data at <http://www.bls.gov/cps/certifications-and-licenses.htm>.

I encourage the Subcommittee to approve the two BLS budget initiatives to greatly enlarge our understanding of two important dimensions of economic activity—contingent work and employer-provided training. To the extent that workers receive training through employers, Federal expenditures for workforce development can decline.

I very much appreciate the opportunity to provide this testimony, hope the Subcommittee finds it of value, and look forward to the Subcommittee's decision with regard to the BLS.

BLS MANDATES FROM CONGRESS

*Nationwide Workforce and Labor Market Information System.*—The Secretary of Labor is directed to develop, maintain, and continuously improve, in cooperation with the States, a nationwide workforce and labor market information system that facilitates Federal, State, and local policy and program design, implementation, and evaluation; labor market research; and informed decisionmaking by employers, workers, students, educational agencies, and workforce investment boards.<sup>1</sup> The U.S. Code gives BLS five more focused mandates that fit inside this broader one:

- Collect, collate and report at least once each year full and complete statistics on the conditions of labor;<sup>2</sup>
- Collect, collate, report, and publish monthly and annual employment and wage statistics by detailed industry and geography;<sup>3</sup>
- Operate statistical programs essential for development of . . . national statistical series, including those related to employment and unemployment;<sup>4</sup>

<sup>1</sup> 29 USC 491–2 and 29 USC 2864(d)(2)(E)).

<sup>2</sup> 29 USC 2.

<sup>3</sup> 29 USC 2.

<sup>4</sup> 29 USC 491–1.

—Develop methods for estimating Hispanic unemployment;<sup>5</sup> and

—Conduct an annual study of veterans' unemployment.<sup>6</sup>

*Determination of Federal Pay by Locality.*—Congress declares a policy that: Federal pay for employees under the General Schedule be based on equal pay for equal work; Federal pay distinctions be maintained in line with work and performance distinctions; within any local pay area, Federal pay rates be compatible with non-Federal pay rates for the same levels of work; and pay disparities between Federal and non-Federal employees should be eliminated.<sup>7</sup> In line with these principles, Federal pay rates are to be determined on the basis of a number of specified data sources, including these BLS products:

—Employment Compensation Index (national)

—National Compensation Survey (pay to non-Federal workers by occupation and work level, by pay locality)

—Unemployment rate (national)

—Consumer Price Index (national)

—Producer Price Index (national)

*Reports on Industrial Production and Productivity.*—BLS is directed to:

—Collect, collate and report at least once each year full and complete statistics on the products of the Nation's labor force and the distribution of these products;<sup>8</sup>

—At intervals of not less than 2 years, . . . report the general conditions of production of the Nation's leading industries;<sup>9</sup> and

—Make continuing studies of productivity and labor costs in the manufacturing, mining, transportation, distribution, and other industries.<sup>10</sup>

*Imports Monitoring.*—The Secretary of Labor and the Secretary of Commerce are directed to monitor imports of goods and services to identify changes in volume of imports and the impacts on production and employment, by geography.<sup>11</sup>

*Occupational Health and Safety Statistics.*—The Secretary of Labor is directed to develop and maintain an effective program of collection, compilation, and analysis of occupational safety and health statistics. The program should provide accurate statistics on work injuries and illnesses that include all disabling, serious, or significant injuries and illnesses, whether or not involving loss of time from work, and which involve medical treatment, loss of consciousness, restriction of work or motion, or transfer to another job.<sup>12</sup>

*Price Statistics.*—While the U.S. Code does not require BLS to produce the Consumer Price Index (CPI), it mandates the use of the CPI over 200 times.

In addition to its congressional mandates, the BLS is charged by the Office of Management and Budget with calculating and publishing seven Principal Federal Economic Indicators (PFEIs):<sup>13</sup>

1. Employment Situation (unemployment rate and nonfarm payroll employment)
2. Producer Price Indexes (PPI)
3. Consumer Price Index (CPI)
4. Real Earnings
5. Labor Productivity and Costs
6. Employment Cost Index
7. Import and Export Price Indexes<sup>14</sup>

[This statement was submitted by Andrew Reamer, Research Professor, George Washington Institute of Public Policy, George Washington University.]

#### PREPARED STATEMENT OF RESEARCH!AMERICA

On behalf of Research!America, the Nation's largest not for profit education and advocacy alliance working to accelerate medical progress and strengthen our Nation's public health system, thank you for this opportunity to share our views on

<sup>5</sup> 29 USC 8.

<sup>6</sup> 38 USC 4110A.

<sup>7</sup> 5 USC 5301.

<sup>8</sup> 29 USC 2.

<sup>9</sup> 29 USC 4.

<sup>10</sup> 29 USC 2b.

<sup>11</sup> 19 USC 2393(a).

<sup>12</sup> 29 USC 673(a).

<sup>13</sup> OMB, Statistical Policy Directive No. 3: Compilation, Release, and Evaluation of Principal Federal Economic Indicators, September 25, 1985.

<sup>14</sup> OMB, "Schedule of Release Dates for Principal Federal Economic Indicators for 2016," September 2015, p. 3.

fiscal year 2017 appropriations under the jurisdiction of the Subcommittee on Labor, Health and Human Services, Education, and Related Agencies.

*The National Institutes of Health (NIH) Drives the Discovery of New Treatments and Cures*

NIH is the world's leading funder of basic biomedical research, and Americans appreciate the value this research delivers. Since 1992, Research!America has commissioned national and State-level surveys to gauge public sentiment on issues related to health research and innovation. One of the most consistent findings over time has been Americans' support for basic research. In a survey commissioned in January 2015, 70 percent of respondents agreed that "even if it brings no immediate benefits, basic scientific research that advances the frontiers of knowledge is necessary and should be supported by the Federal Government."

More than 80 percent of NIH funding is awarded through almost 50,000 competitive grants to 300,000 researchers at more than 2,500 universities, medical schools, and other research institutions in every State and around the world. Research supported by NIH is typically at the early, non-commercial stages of the research pipeline; therefore, NIH funding complements critical private sector investment and development. The NIH also plays an essential role in educating and training America's future scientists and medical innovators. In 2015, NIH sponsored over 5,000 training grants and fellowships for biomedical- and health-focused graduate and medical students, postdoctoral researchers and young investigators— a pivotal investment in America's future research workforce.

We believe it is in the strategic interests of the United States to increase funding for NIH by at least 10 percent in fiscal year 2017. To achieve this increase, it is crucial to continue your successful efforts to rebuild annual appropriations for NIH, growing the Institutes' base budget in fiscal year 2017 by at least \$2.4 billion or 5 percent after inflation is taken into account. Research!America believes this increase is merited by the magnitude of our health challenges, the cost of inaction and the extraordinary return on medical progress.

*The Centers for Disease Control and Prevention (CDC) Safeguards the Nation's Health*

CDC is tasked with safeguarding the Nation's health, and over the past 70 years it has worked diligently to thwart deadly outbreaks, costly pandemics and debilitating disease. Moreover, CDC plays a key role in research that leads to life-saving vaccines, bolsters defenses against bioterrorism and improves health tracking and data analytics. CDC's work has hastened many health and safety improvements, such as lowering teen pregnancy rates, reducing deaths from motor vehicle accidents, lowering tobacco use and preventing millions of hospitalizations.

Ebola, Zika, Dengue fever and other emerging health threats have shown just how critical CDC is to our Nation, and have also revealed the enormity of the challenge the agency faces as it works to safeguard American lives. To protect Americans, CDC needs to have a global reach; CDC scientists must be on the ground fighting public health challenges wherever and whenever they occur. But there is an imbalance between the funding provided to CDC and its increasingly growing mission demands. We request that CDC receive at least \$7.8 billion in fiscal year 2017 to carry out its crucially important responsibilities.

*AHRQ Maximizes the Return on Medical Progress*

AHRQ is the lead Federal agency responsible for ensuring medical progress translates into better patient care. Medical discovery, development and delivery are intertwined: the value of discovery and development hinge on smart healthcare delivery. That's where AHRQ comes in. AHRQ-funded research is used to ensure patients receive the right care at the right time in the right settings. This research serves many critical purposes, from ensuring information about new medical discoveries reaches doctors and patients as quickly as possible, to deploying health IT to address challenges in healthcare access and delivery, to cutting the number of deadly—and preventable—medical errors.

If we underinvest in AHRQ, we are inviting unnecessary healthcare spending and squandering the opportunity to ensure patients receive the quality care they need. We ask that you commit to investing in life and cost-saving health services research by funding AHRQ at \$364 million in fiscal year 2017.

*Conclusion*

There are few Federal investments that convey benefits as important and far-reaching as funding for NIH, CDC and AHRQ: new cures, new businesses, new jobs; innovative solutions that improve healthcare delivery and optimize the use of limited health dollars; and a public health system nimble and sophisticated enough to meet daunting challenges to the health and safety of the American people. We ap-

preciate your consideration of our funding requests and thank you for your stewardship over such critically important Federal spending priorities.

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PREPARED STATEMENT OF RESULTS FOR AMERICA

Chairman Blunt and Ranking Member Murray: Results for America (RFA) is pleased to present our recommendations for fiscal year 2017 to the Senate Appropriations Subcommittee on the Departments of Labor, Health and Human Services and Education. RFA and our partners are requesting support for evidence-based programs that will improve outcomes for young people, their families and communities by helping to drive Federal resources towards results-oriented solutions. The attached letter and table outlines our requests for fiscal year 2017.

Results for America is improving outcomes for young people, their families and communities by shifting public resources toward practices, policies, and programs that use evidence and data to improve quality and get better results. In a climate of constrained resources and mounting demands, we know that public funds must increasingly be invested in “what works.”

Over the past few years, all levels of government have taken an interest in improving the way taxpayer dollars are invested to ensure that limited resources are spent in the most efficient manner possible, but with that efficiency comes the responsibility of getting the most for each dollar. This can be achieved by investing these dollars in evidence-based solutions. 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.

By identifying how to “invest in what works” this approach becomes the new norm for allocating public dollars and can be used as a catalyst for, and funder of, effective and innovative solutions that produce greater social impact, that will help drive public resources toward programs that are evidence-based, performance-driven and competitively selected and away from programs that consistently fail to achieve results.

On February 29, 2016, the following 133 organizations sent a letter to Chairmen Rogers and Cochran, and Vice Chairwoman Mikulski and Ranking Democratic Member Lowey, requesting bill and report language to achieve the goal of investing in what works. To provide you with a complete picture of our evidence and evaluation agenda, we have also included bill and report language requests for other departments and agencies and mandatory programs outside of the Appropriations Committees jurisdiction.

INVEST IN WHAT WORKS

Dear Chairmen Cochran and Rogers, Vice Chairwoman Mikulski and Ranking Democratic Member Lowey: We are writing to urge you to include the attached Invest in What Works provisions in the Appropriations Committees’ fiscal year 2017 bills and reports for the Departments of Labor, Health and Human Services, Education, and, Related Agencies; the Departments of Commerce, Justice, Science, and Related Agencies; the Departments of Transportation, Housing and Urban Development, and Related Agencies; and the Department of State, Foreign Operations, and Related Agencies. We have also included some information regarding our mandatory funding requests in order to provide you with a complete picture of the data and evidence provisions we support.

America continues to face severe budget constraints at all levels of government as well as enormous social and economic shifts. These factors, combined with an increasingly globally competitive workforce, require us to invest taxpayer dollars in the most effective and efficient manner possible. The recently enacted Consolidated Appropriations Act, 2016 includes an unprecedented commitment to evidence-based, results-driven solutions, but more needs to be done. While we applaud the Administration’s fiscal year 2017 budget, which proposes an increased focus on data and evidence, we must continue to ensure that scarce Federal resources are invested in what works.

We thank you for the positive steps you have taken toward building a strong evidence-based, results-driven policy agenda, and we ask you to incorporate the attached Invest in What Works recommendations in the fiscal year 2017 appropriations bills and committee reports.

Thank you for your consideration of our requests.

Achieve! Minneapolis	LIFT
Achievement Network (ANet)	Literacy Design Collaborative
AdvancED	Local Initiatives Support Corporation (LISC)
America Forward	March of Dimes
America's Promise Alliance	McREL International
American School Health Association	Mental Health Partners
AppleTree Institute for Education Innovation	MENTOR: The National Mentoring Partnership
Atlanta Neighborhood Charter School	Methodist Healthcare Ministries of South Texas
Be The Change	Mile High United Way
Blue Engine	Montgomery County Schools (NC)
Boston Plan for Excellence	Morino Institute
Building Educated Leaders for Life (BELL)	The National Campaign to Prevent Teen and Unplanned Pregnancy
California League of Middle Schools	National Center for Learning Disabilities
CASA de Maryland	National Center for Teacher Residencies
Cascade Philanthropy Advisors	National Council on Crime and Delinquency
Center for Employment Opportunities	National Forum to Accelerate Middle Grades Reform
Center for Research and Reform in Education, Johns Hopkins University	National Prevention Science Coalition (NPSC)
Challenger Center for Space Science Education	Nebraska Children and Families Foundation
Charitable Assistance to Community's Homeless (CATCH)	New Classrooms
Children's Literacy Initiative	New Leaders
Citizen Schools	New Profit
City of Boise	New Schools for New Orleans
City of Las Vegas	New Teacher Center
City Year	Nonprofit Finance Fund
College Possible National	Nurse Family Partnership
College Summit	Opportunity Nation
Communities In Schools	PACE Center for Girls, Inc.
Community Supervision Alternatives	Parents as Teachers
Community Training and Assistance Center (CTAC)	Peace Alliance
Congreso de Latinos Unidos	Public Counsel
ConnCAN	REDF
CSH	Research Institute for Key Indicators (RIKI)
Democrats for Education Reform	Results for America
The Dibble Institute	RMC Research Corporation
EDGE Consulting Partners	Saint Paul Promise Neighborhood
Education Analytics	Seneca Family of Agencies
Education Development Center	ServeMinnesota
Education Reform Now	Silicon Valley Community Foundation
Education Northwest	Social Finance
The eMINTS National Center	Society for Adolescent Health and Medicine
Forum for Youth Investment	Sorensen Impact Center, University of Utah
Greater Twin Cities United Way	South Carolina Campaign to Prevent Teen Pregnancy
GreenLight Fund	Spurwink Services
Green and Healthy Homes Initiative	StriveTogether
Green Dot Public Schools	Student Peace Alliance
Healthy Teens Coalition of Manatee County	Success for All Foundation
IDEA Public Schools	Teach For America
Infusing INnovative STEM Practices Into Education (INSPIRE)	Teach Plus
Institute for Child Success	The Policy & Research Group
Internationals Network for Public Schools	Third Sector Capital Partners
Jobs for the Future	TNTP
Kentucky Valley Educational Cooperative	Turnaround for Children
KIPP	United Way for Southeastern Michigan
Knowledge Alliance	United Way of Greenville County
Leading Educators	
Leaps and Bounds Family Services	

United Way of Lane County	Sandra Domingcil, Teen Parent
The University of Missouri College of Education	Program, Salinas Union High School District (CA)
University of North Carolina at Greensboro	Michael Greenstone, Milton Friedman Professor in Economics, University of Chicago and Director, Energy Policy Institute at Chicago
Uplift Education	Rebecca Maynard, Professor of Education & Social Policy, University of Pennsylvania
Urban Alliance	Diane Schanzenbach, Associate Professor, School of Education and Social Policy, Northwestern University and Director, The Hamilton Project, The Brookings Institution
U.S. Soccer Foundation	Matt Segneri, Director, Social Enterprise Initiative, Harvard Business School
Venture Philanthropy Partners	Martin West, Associate Professor of Education, Harvard Graduate School of Education
Voices for National Service	
Way to Grow	
WestEd	
Workforce Data Quality Campaign	
Wyman Center	
Year Up	
YES Prep Public Schools	
Youth Villages	
Paul Carttar, former Director, Social Innovation Fund and Senior Advisor, The Bridgespan Group	
Lynn Cominsky, Director, Education and Public Outreach Group, Sonoma State University	

INVEST IN WHAT WORKS  
SUMMARY OF FISCAL YEAR 2017 APPROPRIATIONS REQUESTS

DEPARTMENT OF LABOR

Language—*WIOA Pay for Performance*: provide technical assistance for Pay for Performance

Language—*Evaluation Set-Aside*: set aside 1 percent of discretionary appropriations for evaluations

\$40,000,000—*Workforce Data Quality Initiative*: build State and local data capacity for tracking employment and educational outcomes of WIOA program participants

DEPARTMENT OF HEALTH AND HUMAN SERVICES

\$25,000,000—*Head Start Designation Renewal System (DRS)*: use evidence to determine if Head Start and Early Head Start agencies deliver high-quality and comprehensive services

\$104,790,000—*Teen Pregnancy Prevention*: continue a tiered-evidence approach to scaling-up proven programs and developing, testing, and evaluating innovative programs

Language—*Maternal, Infant, and Early Childhood Home Visiting Program*: encourage HRSA and ACF to continue collaboration to improve outcomes for at-risk pregnant women and families through evidence-based home visiting programs

Language—*Community Mental Health Services Block Grant*: set aside 10 percent of funds to support evidence-based mental health prevention and treatment practices

Language —*Modernizing Senior Nutrition Programs*: set aside up to 1 percent of nutrition funds to expand evidence-based models, and set aside 1 percent for evaluations

\$15,000,000—*Children's Research and Technical Assistance*: develop and evaluate approaches to reducing welfare dependency and increasing well-being of minor children

Language—*Statistical Access to National Directory for New Hires (NDNH)*: allow select access to the NDNH dataset, consistent with privacy and confidentiality protections

DEPARTMENT OF EDUCATION

\$180,000,000—*Education Innovation and Research*: support a tiered-evidence approach to creating, replicating, scaling-up, and evaluating evidence-based innovations

\$100,000,000—*Replication and Expansion of High-Quality Charter Schools*: support competitive grants to charter management organizations with proven track records of success

\$100,000,000—*First in the World*: support the implementation and evaluation of evidence-based strategies to improve college completion, particularly for high need students

Language—*Evaluation Set Aside*: set aside 1 percent of all discretionary appropriations, except for Pell Grants, for program evaluations

\$100,000,000—*Supporting Effective Educator Development Grants (SEED)*: support evidence-based educator support by applicants with a track record of success

Language—*TRIO*: support the Secretary's use of evidence in awarding competitive grants

\$15,000,000—*InformEd*: collect, analyze, and release data and evaluation studies, for internal users and the public, to answer pressing education questions

\$75,000,000—*American Technical Training Fund*: support a tiered-evidence approach to developing, implementing, scaling-up, and evaluating job-training models

#### CORPORATION FOR NATIONAL AND COMMUNITY SERVICE

\$70,000,000—*Social Innovation Fund*: support evidence-based approaches that demonstrate measurable outcomes, including a 20 percent set aside for Pay for Success

\$386,010,000—*AmeriCorps State and National*: support community-based organizations and programs that implement evidence-informed and evidence-based solutions

#### GENERAL PROVISIONS—DEPARTMENTS OF LABOR, HHS AND EDUCATION

Language—*Performance Partnership Pilots*: support establishing up to 10 Performance Partnership Pilots

#### DEPARTMENT OF JUSTICE

*Second Chance Act Offender Re-entry Programs*: set aside \$20,000,000 for Pay for Success, of which \$10,000,000 shall be for implementing the Permanent Supportive Housing Model

Language—*Performance Partnership Pilots (P3)*: allow participation with other agencies in carrying out P3

#### DEPARTMENT OF COMMERCE

*Ryan-Murray Evidence-Based Policy Commission*: create a commission to make administrative data widely available, while ensuring data security, privacy, and confidentiality

#### DEPARTMENT OF HOUSING AND URBAN DEVELOPMENT

Language—*Performance Partnership Pilots*: permit HUD to partner with other Federal agencies in carrying out Performance Partnership Pilots

Language—*Office of Policy Development and Research—Transfer Authority*: authorize the transfer of up to \$120 million to integrate evidence throughout program policy and management

#### DEPARTMENT OF STATE

\$22,400,000—*USAID—Development Innovation Ventures*: support a tiered-evidence approach to testing, developing, implementing, scaling-up, and evaluating global development solutions

#### SUPPORT FOR MANDATORY PROGRAMS

\$400,000,000—*Maternal, Infant, and Early Childhood Home Visiting Program*: encourage HRSA and ACF to continue collaboration to improve outcomes for at-risk pregnant women and families through evidence-based home visiting programs

\$300,000,000—*Pay for Success (PFS)*: authorize a new PFS program within the Department of Treasury for State and local governments to establish PFS projects

Language—*Social Services Block Grant Program (SSBG)*: set aside-up to 1.5 percent of SSBG funds for research and program evaluation.

[This statement was submitted by Michele Jolin, CEO, Results for America.]

## PREPARED STATEMENT OF ROTARY INTERNATIONAL

Chairman Blunt, 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 2017 request of \$174 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

Thanks to this committee's funding for the fiscal year 2016 polio eradication activities of the CDC:

- There were fewer cases of polio in fewer places than in any point in history. Only 74 cases were confirmed for the entire year of 2015—a decrease of more than 80 percent over 2014 levels. Only two countries—Pakistan and Afghanistan—confirmed cases of wild polio in 2015.
- There have been no cases of polio on the African continent since August of 2014.
- Nigeria was removed from the list of endemic countries in September 2015 following more than a year without a case of wild polio.
- Polio immunization campaigns reaching more than 400 million children were conducted in more than 30 countries, primarily in Africa, South Asia and the Middle East.
- Polio outbreaks in the Middle East, Horn of Africa, and Central Africa, which accounted for roughly 60 percent of all cases in 2013, have been brought under control. All polio free countries remain at risk for outbreaks until the wild poliovirus has been eradicated in the remaining places where it persists.
- The Global Polio Eradication Initiative is cautiously optimistic that type 3 polio may have been eradicated. There have been no cases of type 3 polio since November 2012.
- While the program works to ensure no child is ever paralyzed again by wild polio, it is also taking steps to stop rare instances of vaccine-derived polio cases by beginning the withdrawal of the oral polio vaccine and the global introduction of the inactivated polio vaccine, which carries no risk of paralysis.

The United States has been the leading public sector donor to the Global Polio Eradication Initiative. Rotary International appreciates the United States' generous support and recognizes increased funding provided by Congress in fiscal year 2016 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 ensure the necessary human and financial resources are made available to polio-endemic and at risk countries to certify the world polio free.

Global polio eradication is Rotary International's top priority. Rotary's global membership of over 1.2 million business and professional leaders (more than 336,000 of which are in the U.S.) has contributed more than U.S.\$1.5 billion toward a polio free world. 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.

## CDC'S VITAL ROLE IN GLOBAL POLIO ERADICATION PROGRESS

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 has used the Congressional support to make the following significant programmatic contributions:

*Globally:*

*With funding from fiscal year 2015, CDC provided:*



- \$33.9 million to UNICEF for approximately 100 million doses of oral polio vaccine, 6.9 million doses of inactivated polio vaccine, and \$6.3 million for operational costs for NIDs in all polio-endemic countries and other high-risk countries in Asia, the Middle East and Africa. Most of these NIDs would not take place without the assurance of CDC's support.
- \$52.2 million to WHO for surveillance, technical staff and immunization activities' operational costs, primarily in Africa.
- CDC Atlanta-based staff spent 2,360 person-days during 295 deployments providing technical assistance to global headquarters of partners, countries and regional offices on polio. Through April 2016, CDC Atlanta-based staff provided 1,352 person-days of technical assistance on 169 deployments to global headquarters of partners, countries and regional offices on polio.
- CDC's Stop Transmission of Polio (STOP) program trains and deploys public health professionals to improve vaccine-preventable disease surveillance and to help plan, implement, and evaluate vaccination campaigns. STOP places staff resources in countries of higher-risk for poliovirus transmission to support critical national immunization functions. STOP has trained and deployed more than 1,800 public health professionals to work on polio surveillance, data management, campaign planning and implementation, program management, and communications in high-risk countries. In 2015, the STOP program sent 247 professionals on 379 assignments to 42 countries.
- The CDC Director serves as the Chair of the Polio Oversight Board (POB), the top governance body for the Global Polio Eradication Initiative. The CDC also houses the Secretariat for the POB in support of the Director's role as POB Chair. This involves coordination across the highest levels of the Global Polio Eradication Initiative partnership.
- The CDC led efforts to coordinate the switch from trivalent oral polio vaccine to bivalent vaccine, scheduled to occur in April 2016. At the same time, CDC continues to work with partners to help all countries introduce one dose of inactivated polio vaccine to their routine schedules by the last quarter of 2017.
- The CDC also supports global polio eradication by participating in technical advisory groups, EPI manager and other key global meetings. The CDC also published 27 articles on the progress toward polio eradication in the *Morbidity and Mortality Weekly Report* (MMWR) and in peer-reviewed journals.
- Build Capacity in Nigeria.*— The National Stop Transmission of Polio (N-STOP) program, adapted from the original STOP Program, has provided Nigeria with an accessible, flexible, and culturally competent workforce at the front lines of public health. N-STOP includes participatory training for public health workers composed of ten modules covering poliomyelitis, vaccine management and monitoring, program management, and problem-solving practices. CDC's National STOP program for Nigeria trained 219 staff at the Local Governing Area level in the highest risk States, playing a key role in interrupting transmission of wild polio. Nigeria's polio legacy planning will transition those workers to build lasting improvements in Nigeria's immunization system.
- Build capacity in Pakistan.*—In collaboration with the Pakistan Ministry of Health and in coordination with WHO and the USAID's mission in Islamabad, 64 national epidemiologists from CDC's Field Epidemiology Training Program (FETP) were trained and deployed to the highest risk districts for circulation of wild polio virus to help improve the quality of surveillance and immunization activities.

*Improve Program Management and Efficiency:*

- Based on best practices developed in India and Nigeria, CDC established several important benchmarks to improve the performance of polio programs and to achieve greater efficiency. These benchmarks streamline decisionmaking for program officials, by making clear who is accountable for achieving results while empowering program officials to respond rapidly to events on the ground.
- CDC also guided the establishment of Emergency Operations Centers (EOCs) and guided use of CDC-developed dashboards through the country and State levels. These have directly contributed to the dramatic turnaround in program quality in Nigeria and Pakistan.

*Ensure High Quality Global Surveillance:*

*CDC provided (and continues to provide):*

- expertise in virology, diagnostics, and laboratory procedures, including quality assurance, and genomic sequencing of samples obtained worldwide.

- training for virologists from around the world in advanced poliovirus research and public health laboratory support. CDC's Atlanta laboratories serve as a global reference center and training facility.
- the largest volume of operational (poliovirus isolation) and technologically sophisticated (genetic sequencing of polio viruses) lab support to the 145 laboratories of the global polio laboratory network. CDC has the leading specialized polio reference lab in the world.
- scientific and technical expertise to WHO on research issues regarding: (1) laboratory containment of wild poliovirus stocks following polio eradication, and (2) when and how to stop or modify polio vaccination worldwide following global certification of polio eradication.

*Foster the Effective Transition of Global Polio Eradication Assets*

- CDC is leading the efforts to raise awareness of the importance and urgency of transition planning amongst donors, country governments and other stakeholders to begin polio legacy planning to ensure that key polio functions, including immunization, surveillance, outbreak response and bio containment, will be in place post-eradication. Presently, the global polio eradication staff is the single largest source of external technical assistance for immunization and surveillance in low-income countries, and polio eradication efforts are responsible for reaching the world's most vulnerable children with vaccines and other health interventions.

FISCAL YEAR 2017 BUDGET REQUEST

For fiscal year 2017, we request this subcommittee to provide \$174 million for the CDC's polio eradication activities, the level that was requested in the President's budget. This will allow CDC to provide to continue to build capacity to support intense supplementary immunization activities in polio-affected and at-risk countries, to develop leadership on data management and evidence-based decisionmaking, and to implement for effective management and accountability. These funds will also help maintain essential certification standard surveillance. Finally, continued funding will enable CDC to capitalize on polio eradication efforts to strengthen immunization systems and protect the gains made in polio free and at-risk countries. Every year delayed eradicating this disease will require \$800 million to continue this fight.

Since 1988, 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 infectious diseases and will do so beyond polio eradication.

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 over the next 20 years. As many as 200,000 children could be paralyzed annually in the next 10 years if we do eradicate polio now. 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 CAROLE AND DAVID ROWE

Dear Chairman Cochran, Vice Chairwoman Mikulski, Chairman Blunt and Ranking Member Murray:

We write to express our strong disapproval for Senator Gillibrand and her colleagues' request for increased OCR funding. We respectfully ask that this subcommittee deny this and any other request for increased funding that will enable OCR to continue to enforce directives issued in violation of the Administrative Procedure Act.

In its effort to protect and propel the claims of those who file reports of sexual harassment, OCR has created a system whereby the accused of such allegations have been stripped of their right to due process. We are personally aware of scores of students (all male) who have been unjustly suspended or expelled from their college or university as a result of these unjust policies and procedures. We cannot express strongly enough the damage that such undeserved punishments cause to the accused. They suffer emotional distress, depression, rejection, isolation, and unwarranted shame. Their lives and futures are ripped out from beneath them.

Instead of increasing OCR's funding, we need to step back and take a look at the injustices occurring as a result of the current policies in place; policies adopted by colleges and universities as a direct result of the Dear Colleague Letter of 2011. The

lower preponderance standard of proof has eroded due process on campuses all over the country.

Respectfully submitted,

CAROLE AND DAVID ROWE

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PREPARED STATEMENT OF THE RYAN WHITE MEDICAL PROVIDERS COALITION

My name is Dr. Alice C. Thornton, and I serve as Medical Director of the Bluegrass Care Clinic (BCC) at the University of Kentucky Medical Center in Lexington, Kentucky. I write to submit testimony on behalf of the Ryan White Medical Providers Coalition (RWMP), which I Co-Chair. RWMP 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 Resources and Services Administration (HRSA). I thank the Subcommittee for its \$4 million funding increase for Ryan White Part C Programs in fiscal year 2016. And while I am very grateful for this support, and understand that times are hard, I request \$225.1 million, or a \$20 million increase, for Ryan White Part C programs in fiscal year 2017. While I know that this is a lot of funding, it is in fact well below the estimated need—in 2015, my clinic alone enrolled 179 new patients into care—a 14 percent increase in 1 year. These funds help Ryan White clinics identify, engage, and effectively treat persons living with HIV/AIDS in a way that saves both lives and money.

My Ryan White-funded clinic, the BCC, has served as the source for HIV primary care in the 63 counties of central and eastern Kentucky for the past 25 years. Over half of the counties served are federally recognized as economically distressed, and BCC cares for 74 percent of the people living with HIV in the region. Since the BCC received its first Part C grant in 2001, the number of patients has increased by almost 300 percent. To help fund these enormous patient and cost increases, the University incurs an annual deficit of approximately \$1.2 million.

Most Part C clinics, including BCC, also receive support from other parts of the Ryan White Program (RWP) that help us provide medications; additional medical care, such as dental services; and support services, such as case management and transportation—all essential components of the effective Ryan White HIV care model that results in excellent outcomes.

*Ryan White Part C Programs Support Comprehensive, Expert, and Effective HIV Care*

Part C of the Ryan White Program directly funds comprehensive and effective HIV care and treatment—services that are 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 achieve key outcomes that improve individual health and help prevent the transmission of HIV. 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 living with HIV, but also reduces HIV transmission risk to near zero—proving that HIV treatment is also HIV prevention.

The comprehensive, HIV care model that is supported by the Ryan White Program has been highly successful at achieving positive clinical outcomes with a complex patient population.<sup>1</sup> In a convenience sample of eight Ryan White-funded Part C programs ranging from the rural South to the Bronx, retention in care rates ranged from 87 to 97 percent. However, estimates from the Centers for Disease Control and Prevention (CDC) show that only 40 percent of all people with HIV are engaged in care nationally.<sup>2</sup> Once in care, patients served at Ryan White clinics do very well—more than 81 percent of Ryan White patients achieved viral suppression in 2014. BCC is doing even better than this national average for Ryan White clinics—in 2015, 92 percent of BCC patients had an undetectable viral load. Additionally, many BCC patients continue to work and remain active community members.

*Investing in Ryan White Part C Programs Saves Both Lives and Money*

Early and reliable access to HIV care and treatment both helps patients with HIV live relatively healthy and productive lives and is more cost effective. One study from the Part C Clinic at the University of Alabama at Birmingham found that patients treated at the later stages of HIV disease required 2.6 times more healthcare

<sup>1</sup>See Improvement in the Health of HIV-Infected Persons in Care: Reducing Disparities at <http://cid.oxfordjournals.org/content/early/2012/08/24/cid.cis654.full.pdf+html>.

<sup>2</sup>See CDC’s HIV in the United States: The Stages of Care, <http://www.cdc.gov/nchstp/newsroom/docs/HIV-Stages-of-Care-Factsheet-508.pdf>, November 2014.

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. This is a bargain when compared to the high cost of hospital and emergency care.

*Fully Funding and Maintaining Ryan White Part C Programs Is Essential*

Because of both the inadequacy of insurance coverage for people with complex conditions such as HIV and the fact that some individuals will remain uncovered, fully funding and maintaining the Ryan White Program is essential to providing comprehensive, expert and effective HIV care nationwide. However, RWMPC is concerned about the proposal to consolidate Ryan White Part D funding into Part C. RWMPC's specific concerns include:

- Parts C and D programs both provide comprehensive, effective care and treatment for women, infants, children and youth living with HIV/AIDS. However, Part D programs have cultivated special expertise for engaging and retaining women (including pregnant women) and young people in care and Part D allows funding for key services not covered by Part C. With adolescents accounting for 26 percent of new HIV infections in the U.S., it is still critical to target resources to support the effective, comprehensive services that Part D programs provide to these vulnerable populations and not enact this significant structural change outside of a broader reauthorization of the program.
- 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 already is a Part C program serving that community; and loss of that Part D program could reduce the community's overall access to HIV and treatment.
- It is unclear exactly how the proposed consolidation would impact grantees. More detail outlining how the consolidation process would actually impact grantees and access to HIV care and treatment in specific communities is needed before instituting a program change that could reduce community 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 and keeps patients engaged and working, it is essential to maintain overall funding levels 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.

*Continue to Permit the Use of Federal Funds for Syringe Access Programs that Help to Advance Public Health and Address Drug Use in Kentucky and Nationwide*

RWMPC commends Congress for leading the Nation by modifying the ban on Federal funding for syringe access programs. RWMPC is committed to evidence-based public health interventions that both increase access to healthcare and decrease transmission of HIV, viral hepatitis, and other blood-borne pathogens. Injection drug use is a major transmission route for these infections, and increasing access to syringe access programs through Federal funding will help decrease the spread of hepatitis C and HIV, as well as help connect individuals to critical healthcare and support services, including overdose prevention, substance use treatment, and medical care for hepatitis C, HIV, and other life-threatening infections.

Kentucky has one of the highest rates of acute hepatitis C in the country. We have seen a dramatic increase in hepatitis C infections with a majority of infections occurring in young persons who live in non-urban areas with a history of injection drug use, and previously used opioid agonists such as oxycodone.<sup>3</sup> In University of Kentucky's infectious diseases practice, hepatitis C and infections such as endocarditis, have compromised the lives of too many Kentuckians, and we have been frustrated by our inability to employ the full range of effective tools available to prevent infections and help patients address their addiction. These problems also have

<sup>3</sup> Centers for Disease Control and Prevention. Surveillance for Viral Hepatitis—United States, 2012. Online at: <http://www.cdc.gov/hepatitis/Statistics/2012Surveillance/Commentary.htm>.

been seen in West Virginia, Ohio, and many other States and communities, including Scott County, Indiana, where new HIV infections reached 168 in just the first 6 months of 2015 in a small, rural area that beforehand had under 10 HIV infections each year.

Last year, Kentucky legislators acted decisively to improve public health and the lives of residents by passing into law a comprehensive set of medical interventions, including expanded access to opioid overdose medication and substance use treatment. The law also included a syringe exchange program provision that allows local jurisdictions to establish syringe access programs that provide clean syringes and other critical services, including referral to substance use treatment and other needed medical care. My clinic worked with the local public health department to establish the syringe access program in Lexington, and we are pleased that Federal funds now could help support the budget of this and other syringe access programs nationwide.

Data from the Centers for Disease Control and Prevention (CDC) highlighting links between HIV infection and injection drug use illustrate the importance of syringe access programs. Data, published in CDC's Morbidity and Mortality Weekly Report, were gathered from 20 U.S. cities in 2012 and showed that of more than 10,000 injecting drug users tested for HIV, 11 percent are infected with HIV. Of those who answered interview questions, 30 percent reported injecting themselves with a syringe that was shared with other people.

We urge Congress to maintain the fiscal year 2016 omnibus appropriations language that allows access to syringe services in jurisdictions that are experiencing or are at risk for an increase in hepatitis infections or an HIV outbreak due to injection drug use as a key element of infectious disease prevention and as a way to identify and engage individuals in critical medical care, including substance use treatment. And again, we urge you to please fully fund the Ryan White Program this year. Thank you so much for your time and consideration of these requests.

[This statement was submitted by Alice Thornton, MD, Medical Director, Bluegrass Care Clinic and Co-Chair, Ryan White Medical Providers Coalition.]

#### PREPARED STATEMENT OF SAC AND FOX NATION

Chairman Blunt and esteemed members of the Committee, on behalf of the Sac and Fox Nation I thank you for the opportunity to present our requests for the fiscal year 2017 Budgets and matters for consideration for Health and Human Services and Education. The Sac and Fox Nation is home of Jim Thorpe, one of the most versatile athletes of modern sports who earned Olympic gold medals for the 1912 pentathlon and decathlon.

Each of our suggestions and requests for your budgets this year is contained in more detail below. I am so pleased to be able to provide you this testimony and hope that it helps you in your many deliberations regarding the budgets for fiscal year 2017. The Sac and Fox Nation looks forward to building a positive relationship with your committee and enhancing the future of our people and our youth.

#### NATIONAL REQUESTS—EDUCATION

*Increase in Funding Directly to Education Departments to Leave More Money for Programs.*—The fiscal year 2017 budget identifies funding directly for education departments and this is a priority for the Sac and Fox Nation. Having direct funding for the administration would leave more money for programs which are seriously underfunded. Right now, we receive only \$84,000 per year in higher education and vocational education funds. With the increase in demand among Native Students entering College, we are able to accommodate only about half of the requests we receive every year. An increase in this area and funding to leave more money in the program would be a significant benefit to all our Tribal students. With the adoption of the every student succeeds act, we are looking for more funding and more flexibility in programs that would allow us to target the best areas to put our funding on these issues.

*Support the President's Budget Fiscal Year 2017 Funding Investing in Tribally Driven Education.*—The President's Proposed Budget for fiscal year 2017 provides for a significant increase in funding, \$450 million dollars over the amount allocated last year, for the ED's Title I Program. This program is the largest K-12 grant program serving the Tribal Youth in Communities all across the United States. We at the Sac and Fox Nation feel that approval of this funding increase is critical to provide the support that low income schools need to bring their systems and the education of our youth into the future. It is especially important to us because Okla-

homa has so many rural and small schools who struggle to provide their students with books and materials let alone high speed Internet or access to research systems which can be critical to a well-rounded education. There has long been a disparity between the educations these rural schools can provide students. There is no reason for that disparity to exist. Those funds will also provide for supplies, books and materials that are currently unavailable in these rural communities because of funding concerns. With such a large portion of the Tribal Youth of the United States attending rural schools it is imperative that the funding levels reflect the needs that exist today.

*Increase Funding to Early Development and Preschool Services.*—The Budget presented by the President is bold in its provision for \$350 million dollars for preschool development grants, \$100 Million over the levels from fiscal year 2016. This increase is both needed and forward thinking. As it has been said over and over, the youth are our future and if we cannot provide for them we will not be able to move forward. The Sac and Fox Nation is proud to offer early childhood development and head start programs to our Tribal Children throughout our jurisdiction. However, these programs are consistently underfunded and cannot provide for all of the demands that exist. Especially in Oklahoma communities which can be very rural there are not a lot of options for preschool or early education. We are proud of our programs, but they are located in major areas like Shawnee, Norman and Cushing Oklahoma. More funding and more opportunities in this area would allow programs like ours to grow and expand to make sure that all Tribal youth are being served when it comes to early education.

#### NATIONAL REQUESTS—HEALTH AND HUMAN SERVICES

*Authorize Mandatory Funding and Fully Fund Contract Support Costs (CSC) for IHS.*—The President's fiscal year 2017 Budget proposal fully funds the estimated need for CSC for Indian Health Services at \$800 million, a significant increase over the levels of funding from fiscal year 2016. The estimated increase includes funding for new and expanded contracts and compacts. The Budget also requests that CSC be reclassified to a mandatory appropriation beginning in fiscal year 2018. We at the Sac and Fox Nation strongly urge you to consider allocating all the requested funds in this area and making these appropriations mandatory and separate in the future. Our health and the access of our Native People to healthcare is a serious and major concern all around Indian Country. It is always prominent for us because we have so many people in rural communities who need greater access to medical care. Fully funding contract support costs and making them mandatory serves to take pressure off Tribal Nations who have a lack of certainty in their medical services when they are not sure if the funding will be there or not. When there is certainty, it allows programs like ours to expand both services and locations to provide better care within reach of our people.

*Increase Funding to Social Services in Indian Country Through Health and Human Services.*—The President's fiscal year 2017 Budget provides robust funding for the desperately needed social services in Indian Country. That budget is calling for a \$204 million dollar increase of the funding level from 2016. These funds are being dedicated to the most critical issues currently facing Indian Country including \$916 Million for HHS's Administration for Children and Families, \$231 Million for Head Start Programs (which I previously addressed), \$194 Million for Tribal TANF, \$55 Million for Child Support, \$212 Million for Child Care Programs, \$106 Million for Child Welfare Programs, \$53 Million for the Administration of Native Americans, and \$55 million in SAMHSA to help reduce the ever worrisome increases in suicide among native youth. There is no shortage of things to say regarding each of these issues and why increasing their funding levels is critical. However, in order to be brief, I will simply say that these main issues are the ones we deal with every day on the ground in Tribal Governments. Tribal members are in desperate need of aid in these areas just to make their lives work. Our children are a critical resource that we must protect and the great work that is done by the Administration of Children and Families and all the Indian Child Welfare departments across the Nation should be properly funded. With the expansion of Indian Child Welfare, the BIA Guidelines and possible regulations these programs are in dire need of funding to ensure that they are running at the best capacity and efficiency possible. Protecting our Native youth from birth, through school and their trying years of finding themselves and their purpose is something that is paramount in our eyes. We strongly encourage you to consider this increase and to help us fight to make sure that critical services are reaching those who are most in need.

*Increase the Level of Funding for Programs Like the Title VI Elders Program Food Delivery.*—At the Sac and Fox Nation we are seeing a great increase in the number

of elders who need help getting meals. However, not all of those elders are medically homebound. Some don't have transportation or vehicles, some have issues with being able to drive properly and others are too far from the kitchens where we serve are meals. We would like an increase in funding to this program and implementation of more flexibility or another program to include increasing issues like those we are seeing. With an increase in funding to these programs, more kitchens or meals centers could be opened to provide for the care of our growing population of elders. While this may seem small compared to the other major issues we know you are dealing with, it is no small issue to us. For a lot of our elder population, who may live in rural areas or communities, a meal delivery may provide them the only opportunity with human interaction on any given day. Moreover, it allows them to have a good, nutritious meal which is not a possibility for a lot of them on their own. Our meal delivery staff is critical to the health of our elders to make sure they are eating, taking care of themselves and can get help when it is needed. In a rural community, a meal delivery could save a life.

Thank you for allowing me to submit these requests on these fiscal year 2017 Budgets.

[This statement was submitted by Hon. Kay Rhoads, Principal Chief, Sac and Fox Nation.]

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#### PREPARED STATEMENT OF 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 injury and violence prevention programs at the Centers for Disease Control and Prevention (CDC) and Health Resources and Services Administration (HRSA). Safe States Alliance requests that as you craft the fiscal year 2017 Labor, Health and Human Services and Education Appropriations bill, you consider including the following priorities:

- \$20 million to expand the State Core Violence and Injury Prevention Program;
- \$5 million to pursue a traumatic brain injury (TBI) surveillance program;
- \$25 million for nationwide expansion of the National Violent Death Reporting System;
- Preserve the Prevention and Public Health Fund and allocate resources to support injury and violence prevention efforts;
- Maintain funding for the Preventive Health and Health Services Block Grant at \$180 million and provide \$650 million to HRSA for the Maternal and Child Health Block Grant;
- \$19 million to increase youth violence prevention-related investments across all Federal agencies, including restoration of funding for youth violence prevention activities;
- \$10 million to research the causes and prevention of firearm-related violence and injuries; and,
- \$18 million for the Injury Control Research Centers for interdisciplinary research and train future injury and violence prevention practitioners and researchers.

#### BACKGROUND

*Injuries and violence are serious public health problems. Areas include:*

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 1985, the Institute of Medicine (IOM) first called attention to the lack of recognition and funding for injury and violence prevention (IVP) as a public health

issue in the United States.<sup>1</sup> Although some progress has been made, 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.<sup>2</sup>

In fact, in 2013 injury and violence resulted in more than 27 million visits to emergency departments, three million hospitalizations, and roughly 193,000 deaths—one person every three minutes.<sup>2</sup> Furthermore, in 2013 injuries and violence cost \$671 billion in medical costs and lost productivity.<sup>3</sup> Yet, today 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 3 percent of the CDC/Agency for Toxic Substances and Disease Registry budget to address the significant burden of injuries and violence nationwide.

#### CORE VIOLENCE AND INJURY PREVENTION PROGRAM

Given its limited budget, the CDC Injury Center currently provides small capacity building grants of approximately \$250,000 to only 20 State health departments (SHDs) through the Core Violence and Injury Prevention Program (VIPP). The Core VIPP is comprised of multiple components including: Basic Prevention (20 States); Regional Network Leaders (five States); Surveillance Quality Improvement (four States); Older Adult Falls Prevention (three States); and Motor Vehicle/Child Injury Prevention (four States).

Opioid pain relievers are now involved in more overdose deaths than cocaine and heroin combined. From 2000 to 2014 nearly half a million people died from drug overdoses. 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. Due to limited funding, a small number of Core VIPP States support promising surveillance and prevention strategies. 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.

*Safe States Alliance recommends an allotment of \$20 million for the Core VIPP to support injury and violence prevention programs in ALL States and territories and full funding for the Preventive Health and Health Services Block Grant at \$180 million.*

#### NATIONAL VIOLENT DEATH REPORTING SYSTEM

NVDRS (National Violent Death Reporting System) 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 cir-

<sup>1</sup>National Research Council. *Injury in America: A Continuing Public Health Problem*. Washington, DC: The National Academies Press, 1985.

<sup>2</sup>Centers for Disease Control and Prevention, National Center for Injury Prevention and Control. *Web-based Injury Statistics Query and Reporting System (WISQARS)* [online] (2007) [accessed 2013 Feb 15]. Available from URL: <http://www.cdc.gov/injury/wisqars>.

<sup>3</sup>Centers for Disease Control and Prevention, National Center for Injury Prevention and Control. *Web-based Injury Statistics Query and Reporting System (WISQARS)* [online] (2007) [accessed 2013 Feb 15]. Available from URL: <http://www.cdc.gov/injury/wisqars>.



cumstances 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 32 States to implement NVDRS and received an approximately \$5 million increase in fiscal year 2016 to expand number of participating States.

In Oregon, the Oregon Older Adult Suicide Prevention Advisory Work Group and the Oregon Department of Human Services used NVDRS to develop and focus suicide prevention programs for older adults. NVDRS found that 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. As a result, the suicide rates among males ages 65 and older in Oregon decreased approximately 8 percent from 2007 to 2010.

*Safe States Alliance supports an increase of \$7.5 million to complete nationwide expansion of NVDRS.*

#### PREVENTIVE HEALTH AND HEALTH SERVICES BLOCK GRANT

For more than 30 years, the PHHS (Preventive Health And Health Services) 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 and is the only source of funding for States without Core VIPP that supports local IVP prevention efforts. 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.<sup>4</sup> 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 SAVE THE CHILDREN ACTION NETWORK

Chairman Blunt, Ranking Member Murray, and honorable Members of the Subcommittee, thank you for the opportunity to provide testimony about the critical investments that must be made in early childhood education. My name is Mark Shriver and I am the President of Save the Children Action Network (SCAN). SCAN is a national, non-profit organization that aims to mobilize all Americans to support critical investments in early childhood education.

For the fiscal year 2017 Labor, Health and Human Services, Education and Related Agencies Appropriations bill, SCAN supports:

- \$3.4 billion for Child Care and Development Block Grants (CCDBG)
- \$10.1 billion of Head Start and Early Head Start
- \$350 million for Preschool Development Grants
- \$1.3 billion for 21st Century Community Learning Centers
- \$27 million for Innovative Approaches to Literacy

#### BACKGROUND

Early Childhood Education (ECE) programs are critical for children. During the first 5 years of life, a child develops many of the skills necessary to become successful. It is during these years that they build the foundation for reading, math, science and academics, as well as the skills necessary for character building, social-emo-

<sup>4</sup>State of the States: 2011 Report. Atlanta, GA: Safe States Alliance; 2013.

tional growth, gross-motor development, and executive functioning—including everything from impulse control to problem solving.

Unfortunately, two out of five American children are not enrolled in preschool. Without access to high quality early learning programs, children fall behind. Many never catch up. By age five, more than half of all American children are not prepared for school.<sup>1</sup>

Early education—starting at birth and continuing until a child’s first day in kindergarten—is a critical window for ensuring future academic achievement. This window, however, closes quickly, and children who enter kindergarten unprepared are more likely to experience serious negative social impacts. Disadvantaged children who don’t participate in high quality early education programs are:

- 70 percent more likely to be arrested for a violent crime; and
- 60 percent more likely to never attend college;
- 50 percent more likely to be placed in special education;
- 40 percent more likely to become a teen parent.<sup>2</sup>
- 25 percent more likely to drop out of school;

Additionally, there are strong social and economic benefits to high quality ECE programs, including improved social skills and significant gains in literacy, language and math and a return on investment of \$7 for every \$1 invested.<sup>3,4</sup> It is critical to ensure that access to high-quality preschool and comprehensive early education and family engagement programs are available for all children regardless of their income.

#### SAVE THE CHILDREN’S WORK ON EARLY CHILDHOOD EDUCATION

Save the Children has long been a part of the movement to improve early childhood education in the United States. To advance early learning, Save the Children supports education programs for children at home and in the classroom. Our child experts work to ensure that our Nation’s most underserved children have the best chance for success. Every day, we help children get ready to learn and succeed in school and live healthy, active lives.

#### *Save the Children’s Early Steps to School Success (ESSS)*

ESSS has been serving children in the United States since 2006. In 2014, more than 7,200 children and their families across 14 States and the District of Columbia participated in Save the Children’s Early Steps to School Success program. The vast majority of these children are growing up in poverty and facing many hurdles to success. Despite their challenges, more than 80 percent of the children in the program score at or above the normal range for vocabulary acquisition and enter kindergarten on par with their middle-income peers, ready to succeed in school and in life.

#### *Save the Children Early Head Start and Head Start Programs*

Children who participate in federally-funded Head Start and Early Head Start have a higher likelihood of graduating high school and a lower likelihood of being charged with a crime than similar children who do not participate in Head Start.<sup>5</sup> Furthermore, participation in Head Start has been shown to close over one-third of the gap in test scores between children who participate in Head Start and their more advantaged peers.<sup>6</sup> Three-year olds who participate in Early Head Start perform significantly better on cognitive, language and social-emotional measures than their peers.<sup>7</sup> In 2015, through these programs, Save the Children reached tens of thousands of American children with early education services.

<sup>1</sup>Julia B. Isaacs, “Starting School at a Disadvantage: The School Readiness of Poor Children,” Center on Children and Families at Brookings, (March 2012).

<sup>2</sup>“Early Childhood Education in the U.S.,” Save the Children USA, (2015), Print.

<sup>3</sup>James Heckman, Seong Hyeok Moon, Rodrigo Pinto, Peter Savelyev, and Adam Yavitz, “A New Cost-Benefit and Rate of Return Analysis for the Perry Preschool Program: A Summary,” NBER Working Paper Series, (2010), [http://jenni.uchicago.edu/papers/Heckman\\_Moon\\_etal\\_2010\\_NBER\\_wp16180.pdf](http://jenni.uchicago.edu/papers/Heckman_Moon_etal_2010_NBER_wp16180.pdf).

<sup>4</sup>Investing in Our Future: The Evidence Base on Preschool Education, Foundation for Child Development & Society for Research in Child Development, (Oct. 2013), <http://fcd-us.org/sites/default/files/Evidence%20Base%20on%20Preschool%20Education%20FINAL.pdf>.

<sup>5</sup>Eliana Garces, Duncan Thomas, and Janet Currie, “Longer-Term Effects of Head Start,” The American Economic Review, 92.4, (Sept. 2002), [http://www.jstor.org/stable/3083291?seq=1#page\\_scan\\_tab\\_contents](http://www.jstor.org/stable/3083291?seq=1#page_scan_tab_contents).

<sup>6</sup>Janet Currie and Duncan Thomas, “Does Head Start Make a Difference?” The American Economic Review, (1995): 359, <http://www.econ.ucla.edu/people/papers/Currie/Currie14.pdf>.

<sup>7</sup>Early Head Start Benefits Children and Families, Early Head Start National Resource Center, An Office of the Administration for Children and Families, (June 2015),

A recent review of programs operated under Maternal, Infant and Early Childhood Home Visiting Program (MIECHV) found various positive outcome measures.<sup>8</sup> Research shows that high quality, rigorous home visiting programs result in improved child development and school readiness as well as improved family economic self-sufficiency.<sup>9</sup> A leading model shows significant outcomes in reducing rates of State-verified reports of child abuse and neglect.<sup>10</sup>

#### APPROPRIATIONS PRIORITIES

##### *Child Care and Development Block Grant (CCDBG)*

The bipartisan reauthorization of CCDBG was a crucial moment for children and their families. Unfortunately, without significant new funding, States may be forced to make difficult decisions such as cutting the number of children receiving child care assistance or reducing payments to already low-paid child care providers.

Making matters worse, Federal and State child care spending has fallen to an 11-year low and the number of children receiving assistance is at a 16-year low. Between 2006 and 2014, more than 364,000 children lost Federal child care assistance. Only Oregon reimburses child care providers who serve children receiving child care assistance at the federally recommended level. Without the requested, new funding for CCDBG, fewer families will be able to receive the help they need affording child care, providers will be further deprived of the resources they need to support high-quality care, and the goals of the CCDBG reauthorization will go unfulfilled.

##### *Head Start and Early Head Start*

Head Start and Early Head Start are key to providing and expanding comprehensive early care and education to our poorest children. At the current level of funding, Head Start is only able to serve roughly two out of every five eligible preschoolers. Proposals for more Head Start programs to provide full-day, full-year services would help ensure our lowest-income children receive a strong early learning experience. This change, however, will require additional investments so that the additional hours and days of programming do not result in cuts in the number of children participating in Head Start, the number of staff employed by programs, or impact the quality of programming provided. Additionally, while the very early years of a child's life are critical to their development, Early Head Start serves less than 5 percent of eligible infants and toddlers. The increased funding request is required to expand access to this life changing program.

##### *Preschool Development Grants*

Currently, fewer than three in ten four-year-olds participate in a high-quality preschool program. Funding to encourage States to establish or expand their own pre-kindergarten programs to serve more children and bolster the quality of these programs is critical. This program has already served over 70,000 children who otherwise would not have had access to pre-school. In the next 2 years, it is estimated that an additional 100,000 children will gain access to these vital programs. States' commitment to increasing access to high-quality preschool opportunities is extremely strong, as is their eagerness to partner with the Federal Government in this endeavor. Congress should match their enthusiasm and provide States with the resources they need.

##### *21st Century Community Learning Centers (CCLC)*

The CCLC program supports the creation of community learning centers that provide academic enrichment opportunities during non-school hours for children, particularly students who attend high-poverty and low-performing schools. The pro-

<http://www.hhs.gov/2Fhslc/2Ftta-system/2Fehsnrc/2Fabout-ehs/23benefits>.

<sup>8</sup>Sarah Avellar, Diane Paulsell, Emily Sama-Miller, Patricia Del Grosso, Lauren Akers, and Rebecca Kleinman, "Home Visiting Evidence of Effectiveness Review: Executive Summary," Office of Planning, Research and Evaluation, Administration for Children and Families, U.S. Department of Health and Human Services, (2014): 9, [http://homvee.acf.hhs.gov/HomVEE\\_Executive\\_Summary\\_2014-59.pdf](http://homvee.acf.hhs.gov/HomVEE_Executive_Summary_2014-59.pdf).

<sup>9</sup>Kimberly Boller, Deborah Daro, Patricia Del Grosso, Russell Cole, Diane Paulsell, Bonnie Hart, Brandon Coffee-Borden, Debra Strong, Heather Zaveri, and Margaret Hargreaves, Making Replication Work: Building Infrastructure to Implement, Scale-up, and Sustain Evidence-Based Early Childhood Home Visiting Programs with Fidelity (Princeton, NJ: Mathematica Policy Research, 15 June 2014), <http://www.mathematica-mpr.com/our-publications-and-findings/publications/making-replication-work-building-infrastructure-to-implement-scaleup-and-sustain-evidence>.

<sup>10</sup>"Evidentiary Foundations of Nurse-Family Partnership," Nurse Family Partnership, (2011), [http://www.nursefamilypartnership.org/assets/PDF/Policy/NFP\\_Evidentiary\\_Foundations.aspx](http://www.nursefamilypartnership.org/assets/PDF/Policy/NFP_Evidentiary_Foundations.aspx).

gram helps students meet State and local student standards in core academic subjects, such as reading and math, and offers students a broad array of enrichment activities that can complement their regular academic programs. Additionally, the program offers literacy and other educational services to the families of participating children. Under the Every Student Succeeds Act, funds can also be used to pay for additional time, support and enrichment activities during the school day.

Every day 11.3 million children are alone after school and are unsupervised for an average of seven hours per week. Parents of more than 19.4 million youth say their children would participate in an afterschool program if one were available in their community. Programs like CCLC help working families, keep young people safe during the hours after school when juvenile crime peaks, and improve academic achievement. These programs also provide children with physical activity and engage them in their learning. Without funding for afterschool and summer learning programs, students will lose out on essential learning opportunities that help them prepare for school, college and careers.

*Innovative Approaches to Literacy (IAL)*

The IAL program supports high-quality programs designed to develop and improve literacy skills for children and students from birth through 12th grade in high-need schools and underserved communities. These innovative programs promote early literacy for young children, motivate older children to read, and increase student achievement by using school libraries, pediatricians, and national nonprofit organizations as partners to improve childhood literacy.

IAL is the primary source of Federal funding for school libraries and childhood literacy programs. Focusing on low income communities, these funds help many schools bring their school libraries up to standards and provide at-risk children with access to literacy programs. This money is not enough to help every child, but it does provide some support for disadvantaged schools to update materials and equipment, allowing children to have school library services and gain skills to become college and career ready.

CONCLUSION

On behalf of Save the Children Action Network, and our advocates across the country, I want to thank the subcommittee for its continued leadership on early childhood education programs and its demonstrated bipartisan support for these priority programs in the fiscal year 2016 appropriations process, and ask that you make a robust investment in early childhood education in fiscal year 2017. We appreciate the subcommittee's support for programs that are essential to giving children opportunity for success. We ask for your continued partnership in investing in children, increasing access to opportunity, and ensuring a more prosperous America for generations to come.

[This statement was submitted by Mark Shriver, President, Save the Children Action Network.]

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PREPARED STATEMENT OF THE SCLERODERMA FOUNDATION

THE FOUNDATION'S FISCAL YEAR 2017 L-HHS APPROPRIATIONS RECOMMENDATIONS

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- \$7.8 billion in program level funding for the Centers for Disease Control and Prevention (CDC), which includes budget authority, the Prevention and Public Health Fund, Public Health and Social Services Emergency Fund, and PHS Evaluation transfers.
  - A proportional fiscal year 2017 funding increase for CDC's National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP).
  - At least \$34.5 billion in program funding for the National Institutes of Health (NIH).
  - Proportional funding increases for NIH's National Heart, Lung, and Blood Institute (NHLBI); National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS); National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK); National Institute of Allergy and Infectious Diseases (NIAID); National Center for Advancing Translational Sciences (NCATS).
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Chairman Blunt 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 2017 L-HHS Appropriations Bill.

## ABOUT SCLERODERMA

Scleroderma, or systemic sclerosis, is a chronic connective tissue disease generally classified as one of the autoimmune rheumatic diseases.

The word "scleroderma" comes from two Greek words: "sclero" meaning hard, and "derma" meaning skin. Hardening of the skin is one of the most visible manifestations of the disease. The disease has been called "progressive systemic sclerosis," but the use of that term has been discouraged since it has been found that scleroderma is not necessarily progressive. The disease varies from patient-to-patient.

It is estimated that about 300,000 Americans have scleroderma. About one third of those people have the systemic form of scleroderma. Since scleroderma presents with symptoms similar to other autoimmune diseases, diagnosis is difficult. There may be many misdiagnosed or undiagnosed cases.

Localized scleroderma is more common in children, whereas systemic scleroderma is more common in adults. Overall, female patients outnumber male patients at a ratio of 4-to-1. Factors other than gender, such as race and ethnic background, may influence the risk of getting scleroderma, the age of onset, and the pattern or severity of internal organ involvement. The reasons for this are still unknown. Although scleroderma is not directly inherited, some scientists feel there is a slight predisposition to it in families with a history of rheumatic or autoimmune diseases. While, scleroderma can develop in every age group from infants to the elderly, its onset is most frequent between the ages of 25 to 55.

Currently, there is no cure for scleroderma. Treatments are based on a patient's particular symptoms. For instance, heartburn can be controlled by medications called proton pump inhibitors or medicine to improve the motion of the bowel. Some treatments are directed at decreasing the activity of the immune system. Due to the fact that there is so much variation from one person to another, there is great variation in the treatments prescribed.

Any chronic disease can be serious. The symptoms of scleroderma vary greatly for each person, and the effects of scleroderma can range from mild to life threatening. The seriousness will depend on which organ systems of the body are affected, and the extent to which they are affected. A mild case can become more serious if not properly treated. Prompt and proper diagnosis and treatment by qualified physicians may minimize the symptoms of scleroderma and lessen the chance for irreversible damage.

## ABOUT THE FOUNDATION

The non-profit Scleroderma Foundation is the national organization for people with scleroderma and their families and friends. It was formed January 1, 1998, by a merger between the West Coast-based United Scleroderma Foundation and the East Coast-based Scleroderma Federation. The national office is headquartered in Danvers, Massachusetts. The Foundation has a three-fold mission of support, education, and research.

*Support*

The Scleroderma Foundation offers the following tools and resources in support of people living with scleroderma and their families:

- A nationwide network of 24 chapters and more than 150 support groups
- A toll-free helpline providing information and referrals to callers
- Educational materials, including a quarterly magazine called "Scleroderma Voice"
- Offer a variety of brochures, booklets and newsletters, along with our informative website

Additionally, the Foundation hosts an annual National Patient Education Conference. The conference offers various educational and networking opportunities for people living with scleroderma, their caregivers, family members and friends. Workshops, panel discussions and other educational sessions are led by the leading scleroderma researchers and healthcare professionals.

*Education*

As part of our education mission, we not only perform all the functions mentioned above, we also work with our Medical Advisory Board of internationally known scleroderma experts to provide patient education programs as well as education for physician/healthcare professionals.

*Research*

The Scleroderma Foundation budgets at least \$1 million a year for research funding, its single largest budgeted expense. The Scleroderma Foundation takes its fidu-

ciary responsibility to donors very seriously, especially with regard to our research grant program.

#### 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.

#### 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 is a systemic fibrotic disease it is inexorably linked to other manifestations of fibrosis such as cirrhosis and pulmonary fibrosis that occurs during a heart attack. Scleroderma is a prototypical manifestation of fibrosis as it impacts multiple organ systems. In this way, it is important to promote cross-cutting research across such Institutes as NIAMS, NHLBI AND NIDDK.

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, which 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. 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. The scleroderma community urges you to weigh in with your colleagues on the Appropriations Committee to actively work to see that scleroderma is continues to be listed as a condition eligible

for study through the PRMRP within the Committee Report accompanying the fiscal year 2017 Defense Appropriations Bill.

Thank you again for your time and your consideration of the scleroderma community's requests.

[This statement was submitted by Mr. Robert J. Riggs, Chief Executive Officer, Scleroderma Foundation.]

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PREPARED STATEMENT OF THE SOCIAL SECURITY VOCATIONAL EXPERT OF  
INTERNATIONAL ASSOCIATION OF REHABILITATION PROFESSIONALS

The International Association of Rehabilitation Professionals' Social Security Vocational Expert (SSVE) Section is the only professional organization section with a focus on serving SSVEs. Our more than 600 members are experienced vocational rehabilitation professionals who assist individuals with disabilities to find and maintain competitive employment across the country. We are writing to express our extreme concern about the integrity and the future of the Social Security disability determination process. We request that the Subcommittee address an urgent issue that is affecting the ability of both disability claimants and taxpayers to continue to rely on an accurate, informed determination process going forward.

Like most VR professionals, SSVEs are small-business owners or employees of local small businesses. We work directly with clients, we testify in court, and we consult on workers compensation and private-insurance cases. In addition, on certain days each month, we offer our expertise to the Social Security Administration (SSA) as independent contractors providing vocational expert testimony in Social Security Disability hearings. Last year, VEs offered expert testimony in 800,000 of the one million hearings held.

As SSVEs, we provide information concerning the existence of jobs in the national economy as well as an individual's ability to perform job functions based on work capacity. Administrative Law Judges draw on our impartial expert opinions to provide a factual basis for determining whether a claimant meets Social Security's strict definition of disability and therefore is eligible to receive disability benefits. This is a crucial component of the disability-determination process that helps to assure that ALJs reach a correct decision that is supported by evidence.

And yet, the rate SSA pays for SSVE services through a fixed-rate Blanket Purchase Agreement has remained essentially unchanged for 37 years! In May 2012, the SSA Inspector General in an audit report (A-12-11-11124) raised concerns about the quality and availability of SSVEs and recommended that SSA conduct a compensation study to determine whether SSVE fees are reasonable and consistent with VE fees paid in the national economy or by other government entities. Despite the IG's concerns and recommendations, SSA has declined to conduct any market research to establish fair market value, and recently extended the current BPA through March of 2018 without any rate increase. This rate is less than half of what VEs earn on average for case management and less than one-third of what we are paid for other VE testimony. It is affecting our ability, and that of other experienced, qualified SSVEs, to continue to provide VE services to SSA in the future.

Current evidence suggests that fewer practicing vocational rehabilitation professionals are willing to take time out of their schedules to participate in SSA disability hearings. We also are concerned that a growing number of SSVEs are no longer actively providing vocational rehabilitation services, but instead are using their work as SSVEs to supplement their retirement incomes. Of even greater concern, anecdotal evidence suggests that some individuals who have neither the education nor the professional experience to qualify as VEs are none-the-less receiving BPAs and participating in hearings.

SSA has indicated that it plans to move to a competitive bidding process for VE services beyond 2018. While we have significant reservations about this new approach, our immediate concern is that even 2 more years at the current, 37-year-old rates could have a devastating impact on the integrity of the disability-determination process. We urge Congress to direct SSA to act now to conduct a compensation study of VE rates as recommended by the IG, and then promptly take steps to adjust its rates to reflect the results of that study. We respectfully request that Congress provide adequate funding in SSA's Limitation on Administrative Expenses to compensate SSVEs at a fair market rate.

Thank you for the opportunity to provide our comments to the Subcommittee.

[This statement was submitted by Maria Vargas, Chair, Social Security Vocational Expert Section, International Association of Rehabilitation Professionals.]

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: within the Centers for Disease Control and Prevention (CDC) National Center for Emerging and Zoonotic Infectious Diseases: \$427.9 million for Core Infectious Diseases including \$200 million for the National Strategy and Action Plan for Combatting Antibiotic Resistant Bacteria (CARB), \$21 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 \$4.7 billion for the National Institutes of Health/ National Institute of Allergy and Infectious Diseases (NIAID).

According to the CDC, some AR infections are already untreatable. Without immediate intervention, minor infections may become life-threatening and put at risk our ability to perform routine medical procedures or treat diseases. The CDC conservatively estimates that over two million illnesses and about 23,000 deaths are caused by AR infections. In addition, almost 453,000 people each year require hospital care for *Clostridium difficile* (*C. difficile*) infections. In most of these infections, the use of antibiotics was a major contributing factor leading to the illness.

CENTERS FOR DISEASE CONTROL AND PREVENTION

SHEA and APIC request \$427.9 million for Core Infectious Diseases for fiscal year 2017, which includes funding for the National Strategy and Action Plan for CARB, HAI prevention, AR prevention, and the Emerging Infections Program (EIP). This investment will allow CDC to expand and build upon existing AR and HAI prevention efforts across healthcare settings to reduce the emergence of AR pathogens and improve antibiotic use in the community. CDC will develop evidence-based infection prevention guidelines, work with Federal and private sector partners on programming to prevent HAIs and AR, and redesign and expand hand hygiene awareness and educational materials for different healthcare settings.

In fiscal year 2017, CDC will expand the EIP, which helps States, localities and territories protect the public from known infectious disease threats in their communities, maintain our Nation's capacity to identify new threats as they emerge, and identify and evaluate prevention strategies. CDC will strengthen the EIP program's infrastructure in the States and with their partners to ensure successful coordination and implementation of tracking and studies. CDC will also expand the scope of AR activities in current EIP sites and potentially add 1-2 additional EIP sites to the network.

We urge you to support \$200 million for the National Strategy and Action plan for CARB, currently in year two of implementation. CDC's funding request will allow full implementation of the tracking, prevention, and stewardship activities to reach the goals and prevention targets outlined in the CARB National Strategy. The fiscal year 2017 increase will expand the enacted fiscal year 2016 HAI/AR prevention efforts as part of the CARB initiative from 25 States to up to 50 States, six large cities, and Puerto Rico, investing in direct action to implement proven interventions that reduce emergence and spread of AR pathogens and improve appropriate antibiotic use. The CDC will award the majority of the fiscal year 2017 funding increase to States to effectively address the AR threats facing our country. It will also expand the National Healthcare Safety Network (NHSN) Antibiotic Use and Resistance (AUR) reporting option from 130 facilities in 30 States to more than 750 facilities in all 50 States, the Department of Defense, and the Department of Veterans Affairs. This investment will support better understanding and prevention of the spread of potentially preventable and untreatable infections in these settings.

We urge you to support \$21 million for CDC's National Healthcare Safety Network (NHSN). The CDC estimates that HAIs cost the healthcare system up to \$45 billion annually; at any given time, one in 25 hospitalized patients has a HAI. The CDC provides national leadership and expertise in HAI prevention and protects patients across the healthcare continuum through outbreak detection and control. These activities complement and are informed by the NHSN. This request represents level funding with the fiscal year 2016 enacted level for the NHSN to support HAI prevention and reporting efforts, and will support in fiscal year 2017 reporting on AR infections in up to 20,000 healthcare facilities across the continuum



of care. This investment will target prevention efforts and support assessment of antibiotic prescribing for healthcare facilities, and support of the National Action Plan for CARB. These funds will also enable CDC to continue to provide data for national HAI elimination, guide prevention to targeted healthcare facilities to enhance prevention efforts, and decrease HAI rates. This support will also provide NHSN infrastructure and critical user support and provide innovative HAI prevention approaches. In support of the HHS National Action Plan to Prevent HAIs, CDC will continue to track Central Line-Associated Blood Infections (CLABSI), Catheter-Associated Urinary Tract Infections (CAUTI), Surgical Site Infections (SSI), methicillin-resistant staphylococcus aureus (MRSA), and *C. difficile* infections through NHSN reporting in more than 6,000 hospitals, and bloodstream infection reporting in more than 7,000 dialysis facilities.

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. CDC needs continued resources to support improvements realized to date, and to succeed in the long run beyond its initial success.

AGENCY FOR HEALTHCARE RESEARCH AND QUALITY

We request your support of the proposed investment of \$34 million for AHRQ's HAI research activity. The HAI support includes a total of \$11 million for three projects using the Comprehensive Unit-based Safety Program (CUSP): CAUTI and CLABSI in Intensive Care Units (ICUs); Antibiotic Stewardship in Ambulatory and Long-Term Care Settings and Hospitals; and Enhanced Recovery Protocol for Surgery. The CUSP for Antibiotic Stewardship project is designed to support the National Action Plan for CARB and will extend the use of CUSP to promote the implementation of antibiotic stewardship programs, which seek to reduce inappropriate antibiotic use in ambulatory and long-term care settings as well as hospitals.

NATIONAL INSTITUTES OF HEALTH (NIH)/NATIONAL INSTITUTE OF ALLERGY AND INFECTIOUS DISEASES

SHEA and APIC support the \$4.7 billion requested for the National Institutes of Allergy and Infectious Diseases (NIAID) within NIH. NIAID plays a key role in advancing the goals of the National Action Plan for CARB through research to understand how microbes develop resistance and studies to identify novel ways to combat them; translation of laboratory findings into potential treatments, vaccines, and new diagnostic tests, clinical validation of diagnostic tests, and clinical trials to evaluate vaccines and new and existing therapies against drug-resistant microbes.

We thank you for the opportunity to submit testimony and greatly appreciate your leadership in the effort to eliminate preventable HAIs, combat antibiotic resistance and improve patient safety and outcomes.

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PREPARED STATEMENT OF THE SOCIETY FOR NEUROSCIENCE

Mr. Chairman and members of the Subcommittee, my name is Hollis Cline and I am privileged to offer this testimony in support of increased funding for NIH for fiscal year 2017. I offer this testimony in my capacity as president of the Society for Neuroscience (SfN). I am also the Chair of the Department of Molecular and Cellular Neuroscience and the Director of the Dorris Center for Neuroscience, as well as Hahn Professor of Neuroscience in the departments of Molecular and Cellular Neuroscience, and Chemical Physiology at The Scripps Research Institute in La Jolla, CA. My research focuses on determining how the mechanisms of sensory experience affect the brain's structure, development, and function.

SfN believes that discoveries in basic science that will lead to needed breakthroughs can occur only through strong, consistent, and reliable funding to NIH. The Society stands with others in the research community in requesting at least \$34.5 billion in discretionary funding, as part of a 10 percent overall increase, for NIH in the fiscal year 2017 Labor/HHS appropriations bill. This level of support builds on 2016 and pushes research forward. It is time to return research to a trajectory of sustained growth that recognizes its promise and its importance for health and that will serve as a springboard for economic development. Fiscal year 2016 was a great first step and we cannot back away from its potential now.

On behalf of the nearly 40,000 members of SfN, thank you for your tremendous support of both the NIH and neuroscience research in the past, and especially in fiscal year 2016. The two billion dollar increase in Federal support for NIH significantly contributes towards getting the agency back on a path of robust, sustained and predictable funding to fuel a future of great discovery. Thank you also for your support and investment in the NIH portion of the Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative. As one crucial part of the overall Federal investment in neuroscience, NIH-funded BRAIN programs promote future discoveries across many areas of neuroscience and other research disciplines. As you will see below, BRAIN continues to burst with potential and has already borne fruit in the field of scientific tool development. For the reasons below, continuing your strong and consistent support of NIH is critically important.

SfN's mission is to advance the understanding of the brain and nervous system. We believe this understanding occurs through a better and deeper grasp of basic science. By its nature, basic science is more curiosity-driven than translational research, allowing for greater experimentation. By employing the wide range of experimental systems and animals models not used elsewhere in the drug development pipeline, basic scientists have the ideal platform for making unexpected discoveries that lead to greater knowledge of biological processes. Increasing our basic understanding of the human brain and the diseases that affect it affords neuroscientists the best opportunity to identify new biological targets and then find and test compounds to treat brain disorders affecting countless people around the world.

SfN leads efforts to disseminate and discuss emerging neuroscience discoveries, hosting one of the world's largest annual scientific meetings and publishing two leading scientific journals. SfN is also committed to actively educating the public about the brain, both in health and in illness, and to engaging policymakers regarding the tremendous progress and potential of brain research.

#### CROSS-DISCIPLINARY NEUROSCIENCE

Now entering its third year, the Brain Research through Advancing Innovating Neurotechnologies (BRAIN) Initiative continues to push cross-disciplinary research in neuroscience. Drawing on knowledge from the life sciences, physical sciences, and engineering, brain research is among the most promising and productive areas of science today. Combining the talents of chemists, engineers, computational scientists and neuroscientists, the basic research funded by NIH at universities and hospitals across the Nation leads to discoveries that will inspire scientific and medical progress for generations. Past NIH-supported projects helped neuroscientists make tremendous strides that led to advances in the diagnosis and treatment of neurological and psychiatric disorders. The following examples are just a small selection of the many success stories made possible by brain research funded by investment in NIH.

##### *Repairing the Brain*

My own NIH-funded research investigates how an injured brain can be repaired to address conditions such as glaucoma and brain damage. I look to mechanisms involved in brain growth and development for possible answers and treatments. In order to understand how the brain grows and matures, I study how input from the body's senses affects the development of the brain's structures and their function. For example, my work looks at the visual systems in tadpoles to see how sensory system stimulation can help trigger the birth of new cell growth, which can change the growing brain and help the injured brain recover function. Future research in this field will attempt to use genes and pathways related to neuronal growth to better understand how the brain may be able to heal itself.

##### *Affecting Behavior at the Cell Level*

How neurons interact with each other is the basis of all our thoughts and behaviors. One key to understanding the brain is studying the communication between neurons. DREADD 2.0, an upgrade of a widely-used technology (also called DREADD—Designer Receptors Exclusively Activated by Designer Drugs), developed in part with long-term NIH funding, allows researchers to turn neurons “on” and “off”. Using DREADD 2.0, researchers are able to both change the activity of neurons and learn how neuron communication changes when they are active or silent. This new technology brings specific neurons under the direct control of a scientist, who can then test the function of those neurons and the behaviors they produce like never before. Currently limited to mice, DREADD 2.0 and other technologies set the stage for a deeper and more thorough exploration of the brain and behavior. This research will help seed discovery of potential treatments for disorders of the nervous

system, like Alzheimers Disease and schizophrenia, which are thought to occur when neuron communication breaks down.

*High Resolution Reconstruction of Mouse Cortex on a Nanometer Scale*

A collaboration of several researchers funded by the BRAIN Initiative produced a database of information about the cells in a small part of the mouse cerebral cortex. Using this database as a digital model for the larger brain, researchers are able to explore the physical properties of neurons and learn more about how brain cells interact and communicate. This new knowledge will help researchers understand a wide range of neurological diseases in which this communication suffers. The approaches used in this work, and the results it has produced thus far, address multiple goals of the NIH BRAIN Initiative, including cross-disciplinary efforts to develop technologies to better characterize different types of cells and their connections throughout the brain. This fundamental knowledge is essential in order to understand how the brain differs between healthy people and those with brain diseases.

NEUROSCIENCE: AN INVESTMENT IN OUR FUTURE

Sustained investment to stimulate and speed these discoveries is essential to American healthcare and economic well-being. 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 NIH's budget funds extramural research in communities located in every State.

Moreover, 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 one billion people worldwide. There are more than 1,000 debilitating neurological and psychiatric diseases that strike over 100 million Americans each year. This, in turn, produces severe hardship for millions of families and costs the U.S. economy at least \$760 billion a year, with future expenses reaching the trillions looming for several conditions. Advances made possible by publicly-funded research will help us maintain, and perhaps someday restore, healthy brain function. With funding from NIH, researchers are working towards lifesaving breakthroughs.

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 growing philanthropic support, the 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.

CONCLUSION

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. Thank you for this opportunity to testify.

[This statement was submitted by Hollis Cline, President, Society for Neuroscience.]

PREPARED STATEMENT OF THE SOCIETY FOR WOMEN'S HEALTH RESEARCH

The Society for Women's Health Research (SWHR®) is pleased to submit the following testimony to the Committee urging a renewed investment in scientific and medical research within the National Institutes of Health (NIH). For over 25 years, SWHR has been widely considered the thought-leader in promoting research on biological differences in disease; dedicated to transforming women's health through science, advocacy, and education. We believe that Congress has a duty to appropriately fund a Federal research agenda inclusive of women's health and sex differences research. To accomplish this goal, we ask for a minimum of \$34.5 billion for NIH appropriations in fiscal year 2017 including specific funding for the following Institutes and Offices:

- Office of Research on Women's Health (ORWH)-\$43 million
- National Institute on Minority Health and Health Disparities (NIMHD)-\$302 million
- National Institute of Environmental Health Sciences (NIEHS)-\$732.2 million

—Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)—\$1.441 billion

*Replace the BCA Spending Caps and Sequestration.*—SWHR was pleased to see an increase to the spending caps as outlined in the Budget Control Act of 2015 and would like to thank the Committee for their hard work to ensure the topline sequestration levels were raised. One of the Federal Government’s primary responsibilities is protecting the health of the public and investing in basic biomedical research to spur the way to the next generation of cures and therapies. Therefore, SWHR strongly disapproves of both the President’s budget as well as the one recently released by Chairman Price of the House Budget Committee. Each of these budgets propose significant cuts to nondefense discretionary programs; including the life-saving programs supported by the NIH. This means fewer research grants, less opportunities for young scientists to enter the field, and fewer innovative discoveries. While reducing the Federal deficit is incredibly important, we remain deeply concerned with the extent of these cuts and believe these policies should be replaced with a consistent and balanced approach to deficit reduction. This approach would place equal value on the roles of both nondefense and defense discretionary programs in keeping Americans healthy, safe, and secure.

*National Institutes of Health.*—The NIH is America’s premier medical research agency; serving as the largest source of funding for biomedical and behavioral research in the world. NIH works to promote the overall health and wellbeing of Americans through fostering creative discoveries and innovative research, train and support researchers to ensure continued scientific progress, and expand the scientific and medical knowledge base. Over 80 percent of its funding is awarded through competitive grants to researchers across the United States and around the world. Another 10 percent of funding supports the work of researchers within the NIH. Its storied history includes providing financial support for the Human Genome Project, without which the U.S. would not be able to embark on the Precision Medicine Initiative and newly announced “Cancer Moonshot.” To foster the next generation of cures, SWHR recommends that Congress set, at a minimum, a budget of \$34.5 billion for NIH for fiscal year 2017.

*Office of Research on Women’s Health (ORWH).*—ORWH is the focal point for coordinating sex differences research at NIH and supports innovative mentored career development initiatives such as the Building Interdisciplinary Research Careers in Women’s Health (BIRCWH) as well as supplemental grant funds to assist women and men returning to the scientific workforce. In addition, it provides funding through its Specialized Centers of Research (SCOR) on Sex Differences and Administrative Supplements for Research on Sex/Gender Differences. In 2015, NIH released a new policy for all pre-clinical research; requiring investigators to submit proposals that balance the use of male and female cells, animals, and tissues in all funded studies. ORWH has been tasked to coordinate and lead data collection on this effort. Each of these programs are designed to use interdisciplinary approaches to explore sex/gender differences across diseases and disorders. To allow ORWH’s programs and grants to continued emphasis of sex and gender research, Congress must direct NIH continue its support of ORWH through continued funding of \$42 million.

*National Institute on Minority Health and Health Disparities (NIMHD).*—NIMHD serves as the leader in scientific research dedicated to improving minority health and reducing health disparities. NIMHD funds Centers of Excellence and a Research Endowment Program; each of which are designed to support research opportunities and build capacity within academic institutions to address health disparities. In addition, it supports a Community-Based Participatory Research (CBPR) initiative to engage the community in research activities. One example includes a collaborative effort between Suquamish and Port Gamble S’Klallam Tribes and University of Washington researchers to develop a culturally-appropriate substance abuse prevention program for Native youth. NIMHD is deeply engaged with training young minorities to become part of the future scientific workforce through its Minority Health and Health Disparities International Research Training (MHIRT) and other training programs. As a result, SWHR requests \$302 million for NIMHD in fiscal year 2017—an increase of \$21 million over the fiscal year 2016 level and President’s budget request.

*National Institute of Environmental Health Sciences (NIEHS).*—NIEHS is the leading institute conducting research to understand the environmental influences on health and development; giving it a unique role within NIH. The diseases studied by NIEHS scientists and grantees range from ADHD to Lupus to Uterine Fibroids; all of which can be affected by the air we breathe, food we eat, or environment in which we work or play. NIEHS has provided scientific leadership in public health emergencies, such as the current water crisis in Flint, Michigan. In this case,

NIEHS is coordinating research efforts to understand how to prevent such occurrences in the future and plans to have a long-term role in areas such as supporting health and safety training for pipe workers through the NIEHS Worker Training Program. NIEHS is poised to generate new discoveries that can protect all Americans from toxic environmental exposures. To facilitate such research, we ask that you to provide \$732.2 million for NIEHS in fiscal year 2017.

*Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD).*—Throughout its 50+ year history, NICHD has achieved great successes in research on child development, maternal and child health, and women's health and reproductive biology among others. Recent studies include understanding the long-term impacts of childhood sexual abuse, prenatal exposure to marijuana abuse, and research to prevent mother-to-child HIV transmission. NICHD is leading the field in supporting clinical trials in pregnant women, who have historically been excluded even in studies that would advance knowledge of medical conditions and treatments in pregnancy. The development of the crowd-sourcing application, PregSource, to be unveiled in 2016 will allow pregnant women to track their health data from gestation to early infancy as well as access evidence-based information about healthy pregnancies. Unique to this project will be the ability for researchers to connect with NICHD staff to access aggregate data and provide information on clinical trials accepting pregnant participants. In order to continue the innovative work that NICHD is developing for women and children, SWHR asks that Congress appropriate \$1.441 billion to NICHD in fiscal year 2017.

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 Andrea Lowe, Health Policy and Public Health Liaison, Society for Women's Health Research.]

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#### PREPARED STATEMENT OF 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 to provide written testimony on TFAH's funding priorities. As this subcommittee works to develop a fiscal year 2017 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.

Every American should have the opportunity to be as healthy as he or she can be, but today this is not the case. The effects of sequestration and years of funding cuts as a result of discretionary budget caps under the Budget Control Act and related law have fundamentally eroded our ability to respond to disasters, prevent chronic diseases, reduce health disparities, and ensure the health of all Americans. Preventable chronic diseases such as cancer, diabetes, lung disease, heart disease and stroke are responsible for seven out of 10 deaths and cost \$1.3 trillion in healthcare and lost productivity costs every year. While funding for some community prevention remains, notably the Racial and Ethnic Approaches to Community Health (REACH) program, we were disappointed that Congress has indicated that the Partnerships to Improve Community Health (PICH) program will not be funded following fiscal year 2016.

In 2015 and early 2016, the Nation experienced the first domestic cases of Zika virus, and increasingly severe cold and drought, wildfires, tornados, and mudslides. These events illustrated persistent gaps in the country's preparedness for diseases, disasters, and bioterrorism. Each of these required a public health and healthcare response, but Federal, State, and local budget cuts have threatened more than a decade of progress.

Finally, prescription drug abuse has quickly grown into a full-blown epidemic, with more than 6.1 million Americans abusing or misusing prescription drugs. Prescription drug related deaths now outnumber those from heroin and cocaine combined and drug overdose deaths exceed motor vehicle-related deaths in a majority of States. Addressing this epidemic requires investments in prevention and treatment of those suffering from substance abuse addiction. Building a public health system prepared to meet the challenges of protecting Americans from natural and man-made threats and preventing disease can only occur with a strong and steady baseline of funding. Below are TFAH's recommendations for meeting that challenge.

*The Prevention and Public Health Fund (PPHF)*

TFAH was pleased to see Congress continue to exercise its authority to allocate the Prevention and Public Health Fund in fiscal year 14–16, and we urge the Committee to do so again in the fiscal year 2017 appropriations bill. To date, PPHF has invested more than \$6 billion to support State and local efforts to transform communities, build epidemiology and laboratory capacity, address healthcare associated infections, train the Nation’s public health and health workforce, screen for and prevent cancer, expand access to vaccines, reduce tobacco use, and help control the obesity epidemic.

*Centers for Disease Control and Prevention (CDC)*

From fiscal year 10–13, the CDC saw its budget authority cut by 18 percent. The fiscal year 2016 Omnibus Appropriations measure provided CDC with an increase of just over \$277 million, including \$892.3 million from the Prevention and Public Health Fund, but included a \$22 million decrease for chronic disease programs. The President’s fiscal year 2017 budget cuts that number by nearly an additional \$60 million. Scarce resources means CDC will be forced to make extremely difficult choices. We urge the Committee to oppose the overall \$164 million program level decrease included in the President’s budget for fiscal year 2017 and appropriate \$7.8 billion for CDC programs.

*National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP)—CDC*

We must continue to engage not only health systems but other sectors of society, such as education, housing, business, planning, and faith-based institutions, to help communities to make the healthy choice the easy choice for everyone. CDC’s 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. We encourage the Committee to fund the Chronic Disease Center’s Division of Nutrition, Physical Activity, and Obesity at \$61 million. This increase of \$11.08 million would permit CDC to increase enhanced support to State health departments in the remaining 18 States and the District of Columbia. TFAH also recommends that the Racial and Ethnic Approaches to Community Health (REACH) program be funded at \$51 million to fund new 3-year cooperative agreements to eligible grantees. This investment would ensure the continued success of this community-based program aimed at reducing health disparities amongst minority populations.

*National Center for Environmental Health (NCEH)—CDC*

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. The Center’s Health Tracking Program funds 25 States and one city to collect and share data for cancer, reproductive health outcomes, birth defects and demographics and socioeconomic status, outdoor air quality, drinking water quality, hospitalizations for asthma, cardiovascular disease, carbon monoxide poisoning, childhood lead poisoning, community design, and developmental disabilities. The Flint, Michigan water crisis underscores the need for a stronger environmental health surveillance program. We recommend that you fund the Health Tracking Program at \$50 million in fiscal year 2017. This amount would represent a down payment towards fully funding the Network within the next 3 years.

*Public Health Emergency Preparedness (PHEP) Cooperative Agreements—CDC*

The Public Health Emergency Preparedness (PHEP) program, administered by CDC, is the only Federal program that supports the work of State and local health departments to prepare for all types of disasters, including bioterror attacks, natural disasters, and infectious disease outbreaks. The grants fund all 50 States, as well as territories and cities, to develop core capabilities like laboratory testing, surveillance and epidemiology, and incident management. TFAH recommends that the Public Health Emergency Preparedness Cooperative Agreements continue to be funded at \$675 million in fiscal year 2017 to help States and localities address vulnerabilities in their preparedness capabilities.

*Hospital Preparedness Program—ASPR*

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 grants support nearly 500 healthcare coalitions with 24,000 participating facilities from across the health system, an increase of 47 percent in membership since 2013.

ASPR supports coalitions to develop key capabilities, including health system preparedness and recovery, emergency operations coordination, information sharing, medical surge and responder safety. Most jurisdictions receive no other Federal or State support for health system preparedness. TFAH recommends \$300 million for fiscal year 2017 for HPP, as it marks the beginning of the new project period which will shift the focus of the program from supporting establishment of healthcare coalitions to ensuring they are ready to respond to emergencies.

#### *Global Health Protection*

The CDC's Division of Global Health Protection (DGHP) protects Americans and people around the world from the leading public health threats. The Division builds the capacities of local, national and regional public health to detect emerging threats, prevent disease and prepare for and respond to public health emergencies. The centerpiece of the division is the Global Disease Detection (GDD) program, which supports GDD Centers in 10 countries (Bangladesh, China, Egypt, Georgia and the South Caucasus, Guatemala and Central America, India, Kazakhstan and Central Asia, Kenya, South Africa and Thailand) to conduct outbreak response, pathogen discovery, training and surveillance. The regional center in Guatemala has been assisting with the Zika response, including surveillance and outbreak investigation support. TFAH recommends \$65.2 million for the Division of Global Health Protection, including a \$5 million increase for Global Disease Detection to establish a new GDD center.

#### *Combating Opioid Abuse—CDC & SAMHSA*

Over the past several years, the overuse and misuse of opioids, both prescribed and illicit, has become a public health epidemic. Deaths from prescription painkillers have quadrupled since 1999, killing more than 28,000 people in the U.S. in 2014. TFAH supports the President's budget request for \$80 million for the CDC Injury Center's Injury Prevention Activities line. The \$10 million increase in fiscal year 2017 will allow the CDC to disseminate opioid prescribing guidelines for chronic pain, which are currently under development. These guidelines will be an important tool for prescribers to make informed decisions about when opioid treatment is necessary, with the understanding that some patients suffering from chronic pain do need access to these medications. This will also allow the Injury Center to continue their work supporting support drug overdose prevention programs in all 50 States.

TFAH also recommends \$20 million for the Substance Abuse and Mental Health Services Administration (SAMHSA) to continue the Grants to Prevent Prescription Drug/Opioid Overdose Related Deaths (PDO) program, an increase of \$8 million, which will allow SAMHSA to expand the reach of this program to at least eight additional States which are heavily impacted by opioid abuse and help equip and train State and local health departments, drug treatment and recovery programs, community-based overdose prevention programs and first responders with devices that rapidly reverse the effects of opioids.

TFAH supports \$50 million (a \$25 million increase) for SAMHSA to expand access to medication assisted treatment, which is currently unavailable for many Americans who desperately need it. Additionally, TFAH recommends a \$50 million increase for the Substance Abuse Prevention and Treatment Block Grant (SAPTBG) to help expand access to substance abuse treatment. While there has been more than a five-fold increase in treatment admissions in the past decade, millions more are going untreated. While SAPTBG received a much needed increase in fiscal year 2016, it had been flat funded for the past several years and has not kept up with inflation.

#### *Conclusion*

Approximately seventy-five percent of the CDC's annual budget flows to States, communities, Tribes, and territories in the form of grants and contracts to State and local public health departments, and community partners to give them the tools they need to conduct critical public health and prevention activities, such as protecting us from infectious diseases by combating healthcare-associated infections by delivering immunizations, ensuring adequate public health emergency preparedness, and conducting nonstop disease surveillance. Investing in disease prevention is the most effective, common-sense way to improve health and address our long-term deficit. Thank you for your consideration.

[This statement was submitted by Richard Hamburg, Interim President and CEO, Trust for America's Health.]

## PREPARED STATEMENT OF THE TUBERCULOSIS ROUNDTABLE

The TB Roundtable, a coalition of over 15 research, public health and health professional associations working to support global and domestic tuberculosis (TB) control and research, thanks Chairman Blunt and Ranking Member Murray and fellow members of the committee for this opportunity to provide written testimony to discuss important health threats to our country and opportunities that lie within government to address them. Our testimony will outline the importance of TB research and development dollars to domestic public health preparedness. We recognize that you face many challenging decisions about expenditures but given the urgent need to address drug-resistant TB (DR-TB), we are writing to encourage you to prioritize anti-TB efforts. Specifically, we request that in any final version of fiscal year 2017 appropriations language, you strongly urge BARDA to include TB in their new emerging infectious disease efforts and invest in the development of new TB diagnostics, drugs and vaccines as part of the Combating Antibiotic Resistant Bacteria (CARB) initiative and the Emerging Infectious Disease program at BARDA.

TB causes more deaths than any other single infectious disease agent, with 9.6 million new illnesses and 1.5 million deaths in 2014. Approximately 480,000 of those cases were multidrug-resistant (MDR), including 9.7 percent that were extensively drug-resistant (XDR). Only about 10 percent of people with MDR-TB in 2014 were successfully treated, according to the World Health Organization.<sup>1</sup> While these statistics are alarming, even more concerning is the lack of research funding going towards new, improved tools and treatments for one of humanity's oldest diseases.

While Zika and Ebola have captured headlines and funding commitments, TB's domestic and global health impact is much more costly and deadly. Because TB is airborne, TB can be contracted by inhaling the bacteria when a person with active TB disease of the lungs or throat coughs or sneezes—it's only necessary to inhale a few of these germs to become infected. The only available vaccine for TB, Bacille Calmette-Guérin (BCG), is only moderately effective in preventing TB in infants and young children—and it doesn't adequately protect teens and adults who suffer most of the disease burden. Current treatment regimens are long, expensive, and difficult to implement. Treatment side effects are serious and long-lasting, including permanent hearing loss. Even our current diagnostics are inadequate, with rapid, accurate drug susceptibility testing only available for just one TB drug out of the several required for an effective regimen.

TB does not just impact the rest of the world. Every State in the U.S. continues to report cases of TB each year and cases of TB occasionally make the news when diagnosed, with recent examples in Sturgis, Michigan;<sup>2</sup> Marion, Alabama;<sup>3</sup> El Paso, Texas;<sup>4</sup> or DeKalb County Georgia.<sup>5</sup> In March 2015, 27 people tested positive for TB in a high school located in Olathe, Kansas, prompting the testing of more than 300 students and staff.<sup>6</sup> Last year, an individual with XDR-TB was treated at the National Institutes of Health after traveling to and through the U.S. These travels included a long flight from India to Chicago, and then driving through Illinois, Tennessee, and Missouri, visiting friends and relatives, while infectious with a drug-resistant strain of this deadly airborne disease.<sup>7</sup> Just a few weeks ago, the CDC released figures showing the first increase in TB cases domestically in 23 years.<sup>8</sup> We know that TB anywhere can be TB everywhere.

Although the medical community has made strides to combat TB, the threat of this epidemic is growing, in part because of the spread of dangerous strains of MDR-TB and XDR-TB around the world, which we are trying to fight with 20th century

<sup>1</sup>The World Health Organization, 2015 Global Tuberculosis Report, Executive Summary, Page 1.

<sup>2</sup>Sturgis Journal, Case of Tuberculosis Treated in Sturgis, Oct. 23, 2015, <http://www.sturgisjournal.com/article/20151023/NEWS/151029514>.

<sup>3</sup>The New York Times, In Rural Alabama, Longtime Mistrust of Medicine Fuels a TB Outbreak, Jan. 18, 2016, [http://www.nytimes.com/2016/01/18/us/in-rural-alabama-a-longtime-mistrust-of-medicine-fuels-a-tuberculosis-outbreak.html?\\_r=0](http://www.nytimes.com/2016/01/18/us/in-rural-alabama-a-longtime-mistrust-of-medicine-fuels-a-tuberculosis-outbreak.html?_r=0).

<sup>4</sup>KKTV, El Paso County Jail Inmate Tests Positive for Latent TB, Oct. 22, 2015, <http://www.kktv.com/home/headlines/El-Paso-County-Jail-Inmate-Tests-Positive-For-Latent-Tuberculosis-335346171.html>.

<sup>5</sup>11 Alive, Student Tests Positive for TB at Dekalb Co. School, Oct. 22, 2015, <http://legacy.11alive.com/story/news/local/brookhaven/2015/10/22/student-tests-positive-tb-dekalb-co-school/74414390/>.

<sup>6</sup>CBS News, Tuberculosis Infects Dozens at Kansas High School, March 28, 2015, <http://www.cbsnews.com/news/tuberculosis-infects-dozens-at-kansas-high-school/>.

<sup>7</sup>NBC News, Exclusive: Patient With Extreme Form of TB Sent to NIH, June 9, 2015, <http://www.nbcnews.com/health/health-news/exclusive-patient-extreme-form-tb-sent-nih-n371806>.

<sup>8</sup>Centers for Disease Control and Prevention (CDC), Weekly Mortality and Morbidity Report, March 25, 2016, <http://www.cdc.gov/mmwr/volumes/65/wr/pdfs/mm6511a2.pdf>.



technologies. While MDR-TB is resistant to at least two of the key front-line drugs used to treat TB, XDR-TB is resistant to nearly all current drug options. The costs to treat MDR- and XDR-TB are enormous. In the U.S., a case of MDR-TB costs about 15 times the amount that is needed to treat drug sensitive TB, often requiring 20–26 months of treatment. And treating a single case of XDR-TB could cost more than half a million dollars—enough to wipe out a city’s total public health budget for a year.<sup>9</sup> Underscoring the urgent need for new tools to combat this disease, the CDC cited MDR and XDR-TB as serious antibiotic resistant threats in its 2013 report on antibiotic resistance in the U.S.

Efforts at BARDA are currently underway to establish an Emerging Infectious Disease Division to focus on naturally occurring infectious diseases. Including TB in BARDA’s new emerging infectious disease efforts to invest in the development of a TB vaccine and new TB drugs and diagnostics as part of the CARB initiative and the Emerging Infectious Disease program will be a critical step to ensuring that new vaccine, treatment and diagnostic options are developed and available for use. We respectfully urge Congress to place more attention on the threat of TB and invest more time and resources in developing 21st century solutions to an age-old problem. As fortunate as we are to live in a nation that has the adequate infrastructure and resources to combat a host of disease threats, with TB we are leaving American and global citizens with outdated treatment to an ever-changing threat.

[This statement was submitted by Nuala Moore, Associate Director of Government Relations, American Thoracic Society.]

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#### PREPARED STATEMENT OF TULSA CARES

We are pleased to submit this testimony to the Members of this Subcommittee on the urgency of continuing to support the Ryan White Program through the Appropriations process and increasing funding for the domestic HIV/AIDS portfolio in fiscal year 2017. This support and funding will be decisive for achieving the goals of the National HIV/AIDS Strategy (NHAS) 2020, the AIDS Free Generation and halting the devastating effects of the HIV Treatment Cascade.

Tulsa CARES is part of a nationwide coalition, the Food is Medicine Coalition, of food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PWH) and other chronic illnesses. In our service area, we provide nutrition, farmer’s market, and food pantry services to 475 individuals annually. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

#### *Why Food and Nutrition Services (FNS) Matter for PWH*

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient’s overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PWH at any stage of their illness. For those who are most mobile, there are congregate meals, walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

<sup>9</sup> CDC, Take on Tuberculosis Infographic, 2015. <http://www.cdc.gov/tb/publications/infographic/default.htm>.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective core medical service in the Ryan White Program. These services play a critical role in ensuring that PWH enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

*FNS as a Care Completion Service Unique to Ryan White*

Social and economic interventions, most often in the form of care completion services like food and nutrition services, are fundamental to making healthcare work for PWH. Support services for PWH are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PWH are poised to remain connected to care and treatment.

*Access to FNS and the Triple Aim*

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PWH.

*Better Health Outcomes*

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines.<sup>1</sup> Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections<sup>2</sup> and the resulting decreases in their healthcare costs. Compare these outcomes to PWH who are food insecure, who have:

- Lower CD4 counts & lower likelihoods of having undetectable viral loads<sup>3</sup>
- More ER visits<sup>4</sup> & increased morbidity and mortality<sup>5</sup>
- More missed primary care appointments & reduced use of antiretroviral therapy.<sup>6</sup>

*Lower Healthcare Costs*

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PWH. A recent study comparing participants in a medically-tailored FNS program vs. a control group within a local managed care organization found that average monthly healthcare costs for PWH fell 80 percent in first 3 months after receiving FNS.<sup>7</sup> If hospitalized, nourished clients' costs were 30 percent lower, their hospital length of stay was cut by 37 percent and they were 20 percent more likely to be able to be discharged to their homes rather than a more expensive institution.<sup>8</sup> Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

*Improved Patient Satisfaction*

Studies show nutrition counseling improves quality of life.<sup>9</sup> Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

<sup>1</sup>Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at [https://www.health.ny.gov/diseases/aids/ending\\_the\\_epidemic/docs/key\\_resources/housing\\_and\\_supportive\\_services/chain\\_factsheet3.pdf](https://www.health.ny.gov/diseases/aids/ending_the_epidemic/docs/key_resources/housing_and_supportive_services/chain_factsheet3.pdf).

<sup>2</sup>Academy of Nutrition and Dietetics (formerly American Dietetic Association). HIV/AIDS Nutrition Evidence Analysis Project at [http://www.adaevidencelibrary.com/conclusion.cfm?conclusion\\_statement\\_id=250707](http://www.adaevidencelibrary.com/conclusion.cfm?conclusion_statement_id=250707) Accessed 29 July 2012.

<sup>3</sup>Aidala A, Yomogida M., and the HIV Food & Nutrition Study Team (2011); Singe AW, Weiser SD McCoy, SI. Does Food Insecurity Undermine Adherence to Antiretroviral Therapy? A Systematic Review. *AIDS Behav* (2015) 19:1510–1526.

<sup>4</sup>Ibid.

<sup>5</sup>Anema A, Chan K, Yip B, Weiser S, Montaner JSG, Hogg RS. Impact of food insecurity on survival among HIV-positive injection drug users receiving antiretroviral therapy in a Canadian cohort. 141st APHA Annual Meeting, Nov. 2–6, 2013. Boston, MA. Abstract #: 290277.

<sup>6</sup>Aidala A, Yomogida M., and the HIV Food & Nutrition Study Team (2011).

<sup>7</sup>Gurvey J, Rand K, Daugherty S, Dinger C, Schmeling J, Laverty N. Examining Health Care Costs Among MANNA Clients and a Comparison Group. *J Prim Care Community Health*. (2013) 4:311–317.

<sup>8</sup>Ibid.

<sup>9</sup>Rabeneck L, Palmer A, Knowles JB, Seidehamel RJ, Harris CL, Merkel KL, Risser JMH, Akrabawi SS. A randomized controlled trial evaluating nutrition counseling with or without oral supplementation in malnourished HIV-infected patients. *J Am Diet Assoc*. (1998) 98: 434–438; Schwenk A, Steuck H, Kremer G. Oral supplements as adjunctive treatment to nutritional coun-

*FNS and the National HIV/AIDS Strategy (NHAS)*

Access to FNS for PWH is fundamental to fulfilling the goals of the NHAS.

- NHAS Goal: Reducing new HIV infections: PWH who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96 percent of the time,<sup>10</sup> thus, FNS is key to prevention.<sup>11</sup>
- NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV: PWH who receive effective FNS are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines.<sup>12</sup>
- NHAS Goal: Reducing HIV-related disparities and health inequities: By providing FNS to PWH who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities.<sup>13</sup>
- NHAS Goal: Achieving a more coordinated national response to the HIV epidemic: There remains a tremendous variation by State in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White HIV Program all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including Ryan White and the ACA.

*Conclusion*

We are deeply aware of the difficult decisions that face the members of the Subcommittee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PWH live healthy and productive lives, produces better overall health outcomes and reduces healthcare costs.

Along with our colleagues, we appreciate the opportunity to offer this testimony regarding the fiscal year 2017 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you.

[This statement was submitted by R. Shannon Hall, Executive Director, Tulsa CARES.]

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 PREPARED STATEMENT OF U.S. ACTION WORKING GROUP
 

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We request:

- CDC: Restore funding for ME/CFS in fiscal year 2017 budget—\$6 million
- HHS/Assistant Secretary for Health—Office of Women's Health: Continue funding for Chronic Fatigue Syndrome Advisory Committee—\$300,000
- NIH: Follow through on recent statements to patients by providing significant and specific funding for ME/CFS research, including RFA's

I present this testimony on behalf of the members listed below of the U.S. Action Working Group, a coordinating committee for a number of non-profit organizations and patient/advocates working to advance research on the disease Myalgic

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seling in malnourished HIV-infected patients: randomized controlled trial. *Clinical Nutrition* (1999) 18(6): 371–374.

<sup>10</sup>M. S. Cohen et al., Prevention of HIV-1 Infection with Early Antiretroviral Therapy. *N. Engl. J. Med.*(2011) 365, 493–505 . HPTN 052.

<sup>11</sup>Palar K, Laraia B, Tsai A, Weiser SD Food insecurity is associated with sexually transmitted infections and HIV serostatus among low income adults in the National Health and Nutrition Examination Survey (NHANES) (1999–2010). Presented at the American Public Health Association 141st Annual Meeting, Boston, MA, November 5, 2013.

<sup>12</sup>Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014.

<sup>13</sup>Available at Weiser SD, Frongillo EA, Ragland K, Hogg RS, Riley ED, Bangsberg DR. Food insecurity is associated with incomplete HIV RNA suppression among homeless and marginally housed HIV-infected individuals in San Francisco. *J Gen Intern Med.* (2009) 24(1):14–20.

Encephalomyelitis/Chronic Fatigue Syndrome (known as ME/CFS). ME/CFS affects up to 2.5 million people in the U.S., according to the Institute of Medicine, and approximately 17 million more around the world and has been reported in people younger than 10 years of age and the elderly (over 70 years). We represent organizations which provide information on governmental and other programs to patients and advocates; educate government officials, medical professionals, and patients about ME/CFS; and provide direct services to patients.

#### ABOUT ME/CFS

Two major reports, both funded by government agencies, were published in 2015, the NIH's Pathways to Prevention (P2P) report, "Advancing the Research on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome," and the Institute of Medicine (IOM) report, "Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness."

Myalgic encephalomyelitis/chronic fatigue syndrome, commonly referred to as ME/CFS, is a disease characterized by profound fatigue, cognitive dysfunction, sleep abnormalities, autonomic manifestations, pain, and other symptoms that are made worse by exertion of any sort. ME/CFS can severely impair patients' ability to conduct their normal lives, yet many struggle with symptoms for years before receiving a diagnosis. Fewer than one-third of medical school curricula and less than half of medical textbooks include information about ME/CFS. Although many healthcare providers are aware of ME/CFS, they may lack essential knowledge about how to diagnose and treat it.

The Institute of Medicine report states:

"Myalgic encephalomyelitis (ME) and chronic fatigue syndrome (CFS) are serious, debilitating conditions that impose a burden of illness on millions of people in the United States. At least one-quarter of ME/CFS patients are house- or bed-bound at some point in their lives. The direct and indirect economic costs of ME/CFS to society have been estimated at \$17 to \$24 billion annually . . . High medical costs combined with reduced earning capacity often have devastating effects on patients' financial status." (IOM, pp. 1μ092)

"Patients with ME/CFS have been found to be more functionally impaired than those with other disabling illness, including type 2 diabetes mellitus, congestive heart failure, hypertension, depression, multiple sclerosis, and end-stage renal disease." (IOM, p. 31)

This devastating disease is not limited to adults. Children and adolescents also get ME/CFS, but there are almost no existing trained medical professionals to give them proper care. One mother writes:

"Both of my children have ME/CFS. As a parent, it has been heartbreaking to watch them suffer from this debilitating illness. My son, now age 20, became sick when he was 12. He missed most of junior and senior high school because he was too sick to physically attend school. My daughter, now age 17, also became sick at the age of 12 and is also too sick to attend school. My children have lost an enormous amount—their health, the social experience of high school, and the ability to participate in things they love like sports and music. It took years of doctor visits and consultations with specialist to receive a diagnosis, and the utter lack of treatments for ME/CFS is incredibly frustrating."

For most of the last 30 years, patients with this disease have received little support from the Federal agencies with the most power to help them—NIH and CDC; only very small amounts of funding have been dedicated to researching or finding treatments for the disease or educating the medical community about it. In addition, some of the treatment recommendations provided by the CDC were based on research that is now under review, and have been harmful to patients.

Because of the lack of medical care providers who are properly educated about ME/CFS, and the lack of medical research leading to better understanding of the disease and effective treatments, patients with ME/CFS are often stigmatized or "treated with skepticism, uncertainty, and apprehension" (P2P, p. 4). As a result, most patients are not able to obtain adequate medical care for their illness, either not getting an accurate diagnosis or receiving inappropriate or no treatment, thereby leaving more than 2 million citizens largely disabled for decades.

#### CDC

The patient community was very disturbed to see that the already tiny allocation of \$5.4 million for the CDC's ME/CFS program was zeroed out in the President's budget for fiscal year 2017, a year in which the CDC is scheduled to complete its 4-year multi-site study and begin a new initiative to educate medical professionals about ME/CFS based on the recent findings of Institute of Medicine. The multi-site

study will provide a tremendous amount of new information regarding this disease and it is critical that it be completed.

We, therefore, join in asking this Committee to recommend a restoration of the CDC budget for ME/CFS at a level of no less than \$6 million and urge the CDC to use that to complete its multi-site study, and leverage the recommendations from both the Institute of Medicine and the Chronic Fatigue Advisory Committee to provide to develop and execute a new, broad-based medical education campaign.

To address the lack of access to clinical care, we also ask the Committee to urge the CDC to work with the NIH and other agencies within the Department of Health and Human Services to find creative ways to fund multiple Centers of Excellence (there are none now) and include in them a clinical care component so that patients nationwide might have improved access to expert ME/CFS medical professionals.

#### NIH

There are NO FDA-approved drugs to treat this disease. In 2014, there were at least 32 FDA-approved drugs to treat HIV/AIDS and nine for Multiple Sclerosis. Why is this? Because essentially no research dollars are going toward finding new treatments, new drugs, and other useful symptom-reducing interventions.

Today, research funding from NIH for ME/CFS is far below funding for similarly disabling illnesses with similar or lower prevalence:

—ME/CFS (2 million patients): Only \$3 per patient in NIH funding—\$6 million in 2015

—Multiple sclerosis (400,000 patients): About \$235 per patient; \$94 million 2015

—HIV/AIDS (1.2 million patients): About \$2500 per patient (\$3 billion in 2015)

ME/CFS patients are cautiously hopeful to see the recent focus on this disease at the National Institutes of Health, with support from Dr. Francis Collins, Director, and Dr. Walter Koroshetz, Director of the National Institute of Neurological Diseases and Stroke. A Trans-NIH Working Group has been established for this disease, and NIH has also begun planning for an intramural study to begin in the summer of 2016. We recognize the intention of the NIH to expand the extramural research program and applaud the goal of bringing new researchers into the field. However, this will not happen without funding allocated specifically to this disease.

We join in asking this Committee to recommend that the NIH make funding for ME/CFS research commensurate with disease burden. This funding is necessary to jump-start the field through a set of intramural and extramural investments that include Requests for Applications (RFAs) for biomarkers and treatment trials, set-aside funding for investigator initiated studies (including for hypothesis generation), regional Centers of Excellence, and support for a network of researchers to develop a research strategy with defined milestones and to reach consensus on a research case definition and research standards.

We further ask that NIH act aggressively to implement these required actions and to collaborate with disease researchers, clinicians, and patients and their advocates in doing so with full transparency for best results.

#### DEPARTMENT OF HEALTH AND HUMAN SERVICES (HHS) AND ASSISTANT SECRETARY FOR HEALTH

The Chronic Fatigue Syndrome Advisory Committee is a Federal Advisory Committee with 11 members of the public, including one patient representative, and non-voting representatives from 7 agencies within HHS. In addition there are up to 3 non-voting “liaison members” from ME/CFS patient or research organizations. It is an important vehicle by which patients can communicate face-to-face and engage in discussions with the agencies. Its charter must be renewed every 2 years, or it will cease to exist.

We join in asking this Committee to urge HHS and the Assistant Secretary for Health to continue support of the Chronic Fatigue Syndrome Advisory Committee (CFSAC) with a budget of \$300,000 including direct expenses and staff support, to renew its charter in September, 2016, and to accelerate progress on CFSAC’s recommendations to strengthen research, education, training, care, and services to better address the needs of two million Americans living with ME/CFS. Further, to address the gaps in medical care highlighted by the recent Institute of Medicine Report, we ask the Committee to urge HHS to find creative ways to fund regional Centers of Excellence that include both a research component and direct clinical care component.

We close with Cheryl’s story.

“CFS is an invisible disability. When you look at me, you won’t see my broken aerobic metabolism that has cost me my muscle strength, flexibility and endurance. You won’t see that taking a shower or preparing a simple meal causes me to exceed

my anaerobic threshold, creating lactic acid build-up, exhaustion and pain. You won't see how my sleep is disrupted every night, restless and unrefreshing. You won't see the chronic and debilitating muscle and joint pain, headaches, sore throat, or the intolerance to noise, bright lights, chemicals and foods that were easily tolerated before CFS. You won't see my lost sense of productivity, accomplishment and contribution that I got from career that I loved and was so much of my identity. Or my lost sense of connection with others because socializing exceeds my energy limits. Or that I can no longer be counted on to help family or friends in need, or be an equal partner and companion to my husband. You can't see my uncertainty about the future. You can't see my heart yearning to live fully, while my body and brain deteriorate. But it's real, and it's my CFS story."

On behalf of Cheryl and all other ME/CFS patients, we urge this Committee to take the actions we have outlined above. Thank you.

MEMBERS OF THE U.S. ACTION WORKING GROUP

Massachusetts CFIDS/ME & FM Association  
 New Jersey ME/CFS Association, Inc.  
 Solve ME/CFS Initiative  
 Adriane Tillman, California  
 Claudia Goodell, Race to Solve ME/CFS, New Mexico  
 Denise Lopez-Majano, Speak Up About ME, Pennsylvania  
 Erica Verrillo, Executive Director, American Myalgic Encephalomyelitis and  
 Chronic Fatigue Syndrome Society, Massachusetts  
 Gail Cooper, JD, California  
 Jean Harrison, Mothers Against ME, Massachusetts  
 Lily Chu, MD, MSHS, California  
 Lori Chapo-Kroger, RN, Pandora Org, Michigan  
 Margaret Lauritson-Lada, Cambridge, Massachusetts  
 Mary Dimmock, Connecticut  
 Meghan-Morgan Shannon MS, Medical Professional with ME and CFSIDS, Penn-  
 sylvania  
 Nansy Mathews, Maryland  
 Robert and Courtney Miller, 30-year patient and advocate, Reno, Nevada  
 Sonya Heller Irey, MPIA, Patient-Advocate, Arizona  
 Terri L. Wilder, ME Advocate/Person living with ME, New York

PREPARED STATEMENT OF THE U.S. HEREDITARY ANGIOEDEMA ASSOCIATION

SUMMARY OF FISCAL YEAR 2017 RECOMMENDATIONS

- 
- Provide \$34.5 billion for the National Institutes of Health (NIH)
  - Support the NIH hereditary angioedema research portfolio
  - Encourage the Centers for Disease Control and Prevention (CDC) to advance hereditary angioedema education and awareness
- 

Thank you for the opportunity to present the views of the U.S. Hereditary Angioedema Association (U.S. HAEA) regarding fiscal year 2017 funding for the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC). On behalf of U.S. HAEA, I urge Congress to support hereditary angioedema research and public awareness.

U.S. HAEA is a non-profit patient advocacy organization dedicated to serving the estimated 6,000 HAE sufferers in the U.S. We provide a support network and a wide range of personalized services for patients and their families. We are also committed to advancing clinical research designed to improve the lives of HAE patients and ultimately find a cure.

Hereditary angioedema (HAE) is a painful, disfiguring, debilitating, and potentially fatal genetic disease that occurs in about 1 in 30,000 people. Symptoms include episodes of swelling in various body parts including the hands, feet, face and airway. Patients often have bouts of excruciating abdominal pain, nausea and vomiting that is caused by swelling in the intestinal wall. The majority of HAE patients experience their first attack during childhood or adolescence. Approximately one-third of undiagnosed HAE patients are subject to unnecessary exploratory abdominal surgery. About 50 percent of patients with HAE will experience laryngeal edema at some point in their life. This swelling is exceedingly dangerous because it can lead to death by asphyxiation. The historical mortality rate due to laryngeal swelling is 30 percent.

## RESEARCH THROUGH THE NATIONAL INSTITUTES OF HEALTH

U.S. HAEA recommends that Congress provide an overall funding level of \$34.5 billion for NIH in fiscal year 2017. In addition, U.S. HAEA urges Congress to include recommendations in accompanying committee reports emphasizing the importance of advancing HAE research per the findings of the October 2014 scientific conference, Expanding Boundaries of our HAE Knowledge.

In October 2014, the NIH National Institute of Allergy and Infectious Diseases (NIAID), the National Center for Advancing Translational Sciences (NCATS), and U.S. HAEA partnered on the state-of-the-science conference, Expanding Boundaries of our HAE Knowledge. This conference brought together top HAE researchers as well as other medical researchers across disciplines in order to identify promising avenues for future research. NIH should capitalize on this conference by issuing requests for applications or other opportunities for HAE research based on the findings of the conference.

As a rare disease community, HAE patients are also stakeholders of the Office of Rare Diseases Research (ORDR) and may benefit from programs like the Therapeutics for Rare and Neglected Diseases (TRND) program. U.S. HAEA also urges Congress to robustly support NCATS and the NIH rare disease portfolio in fiscal year 2017.

## CDC PUBLIC AWARENESS AND EDUCATION TO PREVENT HAE DEATHS

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 2017.

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, patients are able to piece together a family history of mysterious deaths and episodes of swelling that previously had no name. In some families, this condition has come to be accepted as something that must simply be endured. Increased public awareness is crucial so that these patients understand that HAE often requires emergency treatment, and disabling attacks no longer need to be passively accepted. While HAE cannot yet be cured, the use of available treatments can help patients lead a productive life. Education and awareness is needed to reach patients and providers with this message.

Thank you for the opportunity to present the views of the HAE patient community. I hope Congress will support research and education on HAE.

## ADDITIONAL MEDICAL RESEARCH ACTIVITIES

For many years (including fiscal year 2016), Congress has included HAE as a condition eligible for study through the Department of Defense Peer-Reviewed Medical Research Program. This opportunity has led to many researchers successfully competing for funding with meritorious research projects that have advanced our scientific understanding of HAE. Further, emerging research has linked HAE episodes to Post-Traumatic Stress Disorder (PTSD) and general anxiety disorder, both of which have a higher prevalence in military service member populations. To capitalize on recent progress and opportunities in this area, please work with your colleagues on the Appropriations Committee to ensure HAE is once again recognized as a condition eligible for study in fiscal year 2017.

[This statement was submitted by Anthony Castaldo, President, U.S. Hereditary Angioedema Association.]

## PREPARED STATEMENT OF UNITED SPINAL ASSOCIATION

I am Alexandra Bennewith, Vice President, Government Relations with United Spinal Association and I am writing to support the National Council on Independent Living's request for Congress to reaffirm your commitment to the more than 57 million Americans disabilities by increasing funding in the HHS appropriations for Centers for Independent Living (CILs). I am asking that you increase funding by \$200 million, for a total of \$301 million for the Independent Living line item in fiscal year 2017.

United Spinal Association is the largest disability-led national non-profit organization founded by paralyzed veterans in 1946 and has since provided service pro-

grams and advocacy to improve the quality of life of those across the life span living with spinal cord injuries and disorders (SCI/D) such as multiple sclerosis, amyotrophic lateral sclerosis (ALS), post-polio syndrome and spina bifida. United Spinal represents over one million individuals with spinal cord injuries and disorders, 50 chapters, 103 rehabilitation hospital members and close to 200 support groups nationwide. Throughout its history, United Spinal Association has devoted its energies, talents and programs to improving the quality of life for these Americans and for advancing their independence. United Spinal Association is also a VA-recognized veterans service organization (VSO) serving veterans with disabilities of all kinds.

CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. Each of the 365 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services, which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012–2014, CILs provided the core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals. During this same period, prior to transition being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community.

Transition services were added as a fifth core service with the 2014 reauthorization of the Rehabilitation Act within the Workforce Innovation and Opportunity Act. Transition services include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

Every day, CILs are fighting to ensure that people with disabilities gain and maintain control over our own lives. We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions from 2012–2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and States. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In 2016, the Independent Living Program is receiving \$2.5 million less in funding than it was in 2010. It is simply not possible to meet the increasing demand for services and effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony.

If you have any questions, please contact me at [abennewith@unitedspinal.org](mailto:abennewith@unitedspinal.org).  
Sincerely,

[This statement was submitted by Alexandra Bennewith, MPA, Vice President, Government Relations with United Spinal Association.]



## PREPARED STATEMENT OF THE UNITED TRIBES TECHNICAL COLLEGE

United Tribes Technical College (UTTC) has for 47 years, and with the most basic of funding, provided postsecondary career and technical education and family services to some of the most impoverished high risk Indian students from throughout the Nation. Despite such challenges we have consistently had excellent retention and placement rates and are fully accredited by the Higher Learning Commission. We are proud to be preparing our students to participate in the energy economy in North Dakota and to be part of building a strong middle class in Indian Country by training the next generation of law enforcement officers, educators, medical providers, and administrators. We are governed by the five Tribes located wholly or in part in North Dakota. We are not part of the North Dakota University System and do not have a tax base or State-appropriated funds on which to rely. The funding requests of the UTTC Board for fiscal year 2017 are:

- \$10 million for base funding authorized under Section 117 of the Carl Perkins Act for the Tribally Controlled Postsecondary Career and Technical Institutions program. This is \$1.7 million above the fiscal year 2016 level. These funds are awarded competitively and distributed via formula. We are seeking a change to the formula that is not so reliant on Indian Student Count in order to avoid dramatic swings in annual awards.
- \$30 million in discretionary funds as requested by the American Indian Higher Education Consortium for Title III–A (Section 316) of the Higher Education Act, \$2.4 million above the fiscal year 2016 level.
- Support the scheduled proposed \$1.8 billion increase in the Pell Grant program and the reinstatement of Year-Round Pell Grant eligibility.

*Section 117 Perkins Funding.*—Tribally Controlled Career and Technical Institutions. We appreciate the \$500,000 increase for Section 117 Perkins in fiscal year 2016. This funding level finally brought Section 117 Perkins back to its fiscal year 2012 pre-sequestration level. Funding for other programs authorized under the Perkins Act was restored several years ago. Perhaps Section 117 was overlooked as a source of career readiness and job training because it had been moved to the Higher Education portion of the budget, rather than staying in the Career and Technical Education account. 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.

Acquisition of additional base funding is critical. We struggle to maintain course offerings and services to adequately provide educational services at the same level as our State counterparts. Perkins funds are central to the viability of our core post-secondary 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.

We highlight several relatively recent updates of our curricula to meet job market needs. Indeed, the ramifications of the North Dakota Bakken oil boom are apparent as we have seen faculty and students leave education in pursuit of jobs in the Bakken region. At the certificate level, UTTC recognized the need for more certified welders and heavy equipment operators in relation to the oil boom and expanded these programs in response to the workforce need. UTTC is now the only welding test site in a multi-State region approved by the American Welding Society. The hospital facilities in the regions were unable to hire certified Medical Coding & Billing personnel so we developed and currently offer this certificate as one of our on-line offerings. We are now able to train students for good paying in-demand employment with a focus on career rather than just a job. Lastly, we recently received Higher Learning Commission approval to offer a Bachelor's Degree in Environmental Science that will provide experiential research opportunities for our students.

Funding for United Tribes Technical College is a good investment. We have:

- Renewed unrestricted accreditation from the Higher Learning Commission for July 2011 through 2021, with authority to offer all of our full programs on-line. We offer 16 Associate degrees, 5 Certificates, and 3 Bachelor degree programs of study (Criminal Justice; Elementary Education; Business Administration). Six of the programs are offered online.
- Services including a Child Development Center, family literacy program, wellness center, area transportation, K–6 elementary school, tutoring, counseling, family and single student housing, and campus security.
- A projected return on Federal investment of 20–1 (2005 study).

- A semester retention rate of 58 percent and a graduate placement rate of 82 percent.
- Students from 37 Tribes represented at UTTC.
- Our students are very low income, and 67 percent of our undergraduate students receive Pell Grants.
- An unduplicated count of 536 undergraduate degree-seeking students: 828 continuing education students; and 24 dual credit enrollment students for a total of 1,283 students for 2014–2015.
- A dual-enrollment program targeting junior and senior high school students, providing them an introduction to college life and offering high school and college credits.
- A critical role in the regional economy. Our presence brings at least \$34 million annually to the economy of the Bismarck region. A North Dakota State University study reports that the five Tribal colleges in North Dakota made a direct and secondary economic contribution to the State of \$181,933,000 in 2012.

*Title III–A (Section 316) Strengthening Institutions.*—The Title III–A Strengthening Institutions funding is very important for all the Tribal colleges and we support American Indian Higher Education Consortium’s request of \$30 million for discretionary funding, \$2.4 million above fiscal year 2016. This is in addition to the \$30 million in (Part F) mandatory funding. While these are not operational funds, they are critical for developmental activities and provide an opportunity for a modest amount of construction funding. Funds are distributed via a formula with up to 30 percent of funds authorized to be set-aside for competitive funding for facility construction and maintenance. We share with the other Tribal colleges serious issues of inadequate physical infrastructure.

We are constantly in need of additional student housing, including family housing. Some of our students have to utilize private housing in Bismarck, and an offshoot of the oil boom in North Dakota is that housing prices have gone sky high. A two bedroom apartment in Bismarck rents for \$1,200–\$1,400 per month. 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.

Title III funds provide much needed support to strengthened academic offerings. Specifically, Title III has been instrumental in the College’s efforts to provide baccalaureate programs, online Associate programs, and increase the technology infrastructure necessary to support student learning and campus management functions. Professional development activities has been supported by Title III, increasing the intellectual and technical capacity of faculty and staff. Additional activities carried out with support of Title III funding have been associated with increasing the College’s Institutional Resources capabilities in order to strengthen relationships with alumni and forming relationships with organizations and individuals who may become supporters of the College. With the current Title III award, the College is anticipating expanding academic offerings through the development of a Master’s level program. The support of Title III will be critical for attaining accreditation approval, program development, and acquiring highly qualified faculty.

*Pell Grants.*—We support the proposed \$30 billion for the Pell Grant program (a \$1.8 billion increase), including the proposal to reinstate year-round Pell Grant eligibility, thus allowing students the opportunity to earn a third semester of Pell Grant funding during an academic year if they have already completed a full-time course load of 24 credit hours. As noted above, 67 percent of our undergraduate students receive Pell Grants. This resource makes all the difference in whether many of our students can attend college.

*The Duplication or Overlapping Issue.*—As you know in March 2011, the Government Accountability Office issued two reports regarding Federal programs which may have similar or overlapping services or objectives (GAO–11–474R and GAO–11–318SP). Funding from the Bureau of Indian Education and the Department of Education’s Carl Perkins Act for Tribally Controlled Postsecondary Career and Technical Education were among the programs listed in the reports. The full GAO report did not recommend defunding these programs; rather, it posed the possibility of consolidation of these programs to save administrative costs. We are not in disagreement about possible consolidation of our funding sources, as long as program funds are not cut.

The Perkins funds supplement, but do not duplicate, the BIE funds. Both sources of funding are necessary to the frugal maintenance of our institution. We actively seek alternative funding to assist with academic programming, deferred maintenance, and scholarship assistance, among other things. The need for career and technical education in Indian Country is so great and the funding so small that there is little chance for duplicative funding. United Tribes Technical College and Navajo Technical University, who focus on career and technical education, received combined only \$15.1 million in fiscal year 2016 Federal operational funds (\$8.2 million from Perkins; \$6.9 million from the BIE). That is not an excessive amount for two campus-based institutions who offer a broad array of programs geared toward the educational and cultural needs of their students and who teach job-producing skills.

We invite the Chair, Ranking Member and all members of this Subcommittee to visit United Tribes Technical College—we are in close proximity to the Bismarck airport. We would be honored and pleased to arrange such a visit.

Thank you for your consideration of our requests.

[This statement was submitted by Leander “Russ” McDonald, PhD, President, United Tribes Technical College.]

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PREPARED STATEMENT OF THE USHER SYNDROME COALITION

My name is Anne Croy and my daughter’s name is Maliea Croy. Maliea lives in New York City and works as an assistant art gallery director. Her stepfather and I reside in St. Louis, Missouri. As a very concerned parent and a member of the Usher Syndrome Coalition, I write on behalf of the Usher syndrome community to respectfully request this committee support the inclusion of report language prioritizing research into treatment of Usher syndrome at the National Institutes of Health (NIH).

The Usher syndrome community across the country is aware of and appreciates your support since our report language first appeared in the 2014 omnibus spending bill. But as I am sure you agree, Usher syndrome needs to become a higher priority at NIH until we have viable human treatments. Despite 3 years of appropriations language urging NIH to make Usher syndrome a higher priority, spending on Usher actually decreased by 11.6 percent from 2014 to 2015.

As you prepare the fiscal year 2017 Labor, Health and Human Services, Education bill, we respectfully request that you include the following report language with the objective of better defining the plan and measurements for the delivery of vision loss treatments for those with Usher syndrome:

—*Usher syndrome.*—The Committee continues to urge the NIH to prioritize Usher syndrome research at NEI and NIDCD. The Committee requests an update in the fiscal year 2017 budget request on steps NIH has taken to date and future plans to accelerate treatment options and improve patient outcomes for those with Usher syndrome. The update should include a description of the criteria in use by NIH to evaluate Usher syndrome related grant submissions to ensure the prioritization of those that accelerate human treatment options. The update should also include a timeline and deliverables that will be used to evaluate the progress made towards viable treatments for those with Usher syndrome.

Usher syndrome is the most common genetic cause of combined deafness and blindness. In the United States, it is estimated that nearly 50,000 people have this rare genetic disorder. Maliea is one of those people. She was born with a moderate to severe hearing loss and has worn digital hearing aids in both ears since the age of 1 1/2 years. It is imperative that she be constantly fitted with improved aids to maintain her level of hearing and this is a cost not covered by insurance. Our last pair of aids was \$6500.

At the age of 20 years and while attending college, Maliea began struggling with vision issues. Multiple tests revealed an Usher syndrome diagnosis. It was devastating to her and our family, but after much research, counseling and renewed family solidarity, we determined that our only choice was to begin planning and move forward as a strong unit. Maliea has lost a donut shape of vision in each eye. Her peripheral vision is dim and cloudy at best. She travels by subway to work in NYC with cane in hand. She is determined, but knows her limitations. She knows her days in the art field are limited due to reliance on visual accuracy. She is making plans to change careers next fall and has been accepted to Columbia University to earn a Master’s degree in Social Work. She wants to be a counselor.

We know that the progression of this disease can cut those dreams short and this is why we plead for your help. Not just for our daughter, but for every individual

with Usher syndrome, that their dreams at living a productive and rewarding life may not be squelched.

People with Usher syndrome share the same range of intelligence and work ethic as any American. Yet they suffer from an 82 percent unemployment rate. People with Usher syndrome are born with the same emotional strength as any other. Yet they have a suicide rate that is 2 ½ times greater than the general population. People with Usher syndrome not only have the capacity to contribute to America's future, they thirst for it. They want to be active members of society. Yet our country spends an estimated \$139 billion annually in direct and indirect costs for people with eye disorders and vision loss. That doesn't even include the costs associated with hearing impairment.

Excellent, timely and promising research on Usher syndrome is happening worldwide. As a country, we need to make the work of these dedicated scientists and doctors both plausible and meaningful in their progression. It is the future of many at stake.

Last year, my husband and I started a small company where a portion of the proceeds will be dedicated yearly to the Usher Syndrome Coalition. There are many independent groups at work to support those with the disease and help drive research. Now we need the support of the National Institutes of Health to fine-tune our directives. 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.

Until very recently, there was no way of knowing how much money NIH invested in Usher syndrome research. Through the efforts of the Usher Syndrome Coalition, this rare disease has been added as a new category in the NIH Categorical Spending list, the Estimates of Funding for Various Research, Condition, and Disease Categories (RCDC). Through the RCDC system, we now have visibility into the total dollars spent on Usher syndrome, as well as the specific grants that were funded. More important to us than increasing the dollars invested in Usher syndrome research is ensuring those dollars are invested in the most impactful manner.

We would like to see a strategic plan put forth by the National Institutes of Health developed with both internal and external expertise containing clear measurements of progress. NIH investment should target those research areas that will most quickly bring about viable human treatments for the vision loss phenotype in Usher syndrome. There are technologies and techniques available today to manage the hearing loss and vestibular issues faced by those with Usher syndrome. These are not perfect and more investment is needed, but the priority should be to provide treatments that allow people with Usher syndrome to manage the vision loss as well as they currently manage the hearing and vestibular losses.

The dollars invested in Usher syndrome research are precious to all of us. We want to make sure they are spent as wisely as possible. The researchers are there, waiting to discover what now is just a dream. All we are asking for is a chance; a chance at the sight most of us take for granted.

Thank you very much.

[This statement was submitted by Anne Croy, Member, Usher Syndrome Coalition.]

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PREPARED STATEMENT OF THE WASHINGTON STATE LONG-TERM CARE  
OMBUDSMAN PROGRAM

I am pleased to present this testimony on behalf of residents residing in Washington State's licensed long-term care facilities in collaboration with the National Association of State Long-Term Care Ombudsman Programs (NASOP). Thank you for your past support of the Long-Term Care Ombudsman Program (LTCOP) and all the vulnerable citizens that it serves. This statement and the following funding recommendations are submitted for the fiscal year 2017 for the Long-Term Care Ombudsman Programs administered through the Administration for Community Living (ACL).

Thank you for your recent support of the Older American Act reauthorization. The bill is awaiting the President's signature. This legislation, which had strong bipartisan support, does several important things to strengthen and improve the Long-Term Care Ombudsman Program, including:

- Mandating the program to serve all residents of long-term care facilities, including those individuals with disabilities, which expands our services to residents under the age of 60;

- Enabling the program to advocate for residents who cannot provide informed consent and have no resident representative—the Ombudsman can now advocate for the best interests of the resident;
- Improving our ability to advocate for residents who are victims of guardianship abuse.

In addition, Congress' reauthorization of the Older Americans Act continues to encourage regular, non-compliant facility visits, which are a cost effective vehicle to identify and resolve problems, avoiding the more costly regulatory system.

In addition, new Federal regulations for the Long-Term Care Ombudsman Program reinforce the reauthorized Older Americans Act. All of these tools will increase our ability to serve residents in the growing number of assisted living facilities caring for the baby boomer generation. In order to adequately serve the growing number of long-term care facility residents, NASOP asks for the following:

First, we request \$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. To date, no EJC funds have been provided for the LTCOP.

Second, we request \$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.

Third, we 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.

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 fiscal year 2014, nearly 8,200 volunteers, including individuals certified to investigate complaints, and 986 staff (full-time equivalent) served in the LTCOP. Ombudsman representatives investigated and worked to resolve 188,599 complaints made by 125,642 individuals. Ombudsmen were able to resolve or partially resolve 76 percent, or more than three out of every four complaints investigated. In addition, Ombudsman representatives provided information or consultation on rights, care and related services approximately 490,000 times.

The Washington State LTCOP (WA-LTCOP) is the first line of protection for thousands of individuals living in licensed long-term care facilities. The Washington State Long-Term Care Ombudsman Program is responsible for advocating for residents residing within the State's 3,548 long-term care facilities. Our State Program consists of the State Long-Term Care Ombudsman, an Assistant State Ombudsman and one Program Administrator. However, we subcontract with several Area Agencies on Aging, Community Action Programs and other private not-for-profits to deliver local ombudsman services to thousands of vulnerable adults living across the State. Currently the program has 16 full-time equivalent paid Ombudsman staff, working in fourteen local Regional LTC Ombudsman Programs. The local programs oversee an amazing corps of approximately 320 volunteers who are trained and certified as ombudsmen. Many of our volunteers are retirees who wish to "give back" to their communities by donating their time and skills to improving the lives of vulnerable adults. In Federal fiscal year 2015, WA-LTCOP investigated 4,500 complaints made by or on behalf of residents. Last Federal fiscal year, ombuds volunteers and staff made 16,652 in-person visits to care facilities and provided 53,773 consultations to residents, facility staff, resident family members and others. We are a vital direct service for the frail and isolated living in facilities.

Although we have a great team of regional ombuds and volunteers, our program has not been able to visit every one of the 3,548 facilities in Washington. Nearly 48 percent of facilities do not have routine Ombudsman visits which are the hallmark of the program and important to building trusting relationships and con-

fidence with residents and caregiving staff. As one of the first demonstration States of the ombudsman program in the mid 1970's, funding levels throughout the decades has never been sufficient to meet the Federal and State mandates. The program advocates for thousands of residents in facilities and we do this with a small number of paid staff. We are grateful for the staffing that we do have, and believe that our successes are just a drop in the bucket. According to two national studies about the Long-Term Care Ombudsman Program from the Institute of Medicine and the Bader Report, best practice is for States to have one full-time long-term care ombudsman for every 2,000 long-term care beds or residents. To meet this recommendation, Washington State needs to more than double the number of full-time paid staff from 16, to 34. Currently our ratio of ombudsmen to beds is 1 to 4,300 (total number of licensed beds is 68,818). With an increase in paid ombudsmen, we would increase our numbers of ombudsmen volunteers to strengthen coverage of all care facilities. An increase 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 long-term care residents in 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, State veteran's homes 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 put strain on ombudsman daily operations and overall resources.

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, Washington's Office of the State Long-Term Care Ombudsman and NASOP supports the aforementioned funding levels.

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. 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).

Thank you for your ongoing support.

[This statement was submitted by Patricia Hunter, Member, National Association of State Long-Term Care Ombudsman Programs.]

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PREPARED STATEMENT OF WESTCARE FOUNDATION

WestCare Foundation respectfully submits this testimony to the U.S. Senate Appropriations Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies (LHHS) regarding fiscal year 2017 funding for the Center for Disease Control (CDC), and Substance Abuse and Mental Health Services Administration (SAMHSA) to address the opioid and prescription drug epidemic.

Each day, 46 people in the United States die from overdose of prescription painkillers.<sup>1</sup> According to the CDC, people in rural communities are nearly twice as likely to overdose on prescription pain medications as people in cities.<sup>2</sup> Prescription drug and opioid abuse is a public health crisis of significant proportion, in which underserved, rural areas are hit the hardest. Offering a full continuum of services to individuals with substance use disorders (SUD), including evidence-based prevention, early intervention and treatment efforts, is a necessary and comprehensive approach to combatting prescription drug overdose and sustaining recovery.

WestCare Foundation provides a wide array of health and human services in both outpatient and residential environments in nearly 20 States and the Pacific and Caribbean Islands. The Foundation provides comprehensive, wrap-around substance abuse and mental health services for children, adolescents, adults, and families, with a focus on underrepresented populations in rural areas. WestCare programs have shown significant outcomes in treating veteran and criminal justice populations returning to their communities through recovery supports such as housing, education, employment and other transitional services.

As a national substance use disorder provider, WestCare Foundation recognizes the magnitude of the prescription drug and opioid public health crisis our Nation faces, and emphasizes the collaborative role of States, local communities, and service providers in preventing prescription drug overdoses, in addition to the importance of a continuum of care in effectively curbing substance use and mental health disorders through affordable, timely and accessible care.

#### CENTER FOR DISEASE CONTROL

WestCare Foundation supports the Administration's fiscal year 2017 request for \$80 million for prescription drug overdose prevention programming at the Centers for Disease Control (CDC), \$10 million above fiscal year 2016 enacted levels.

The Center for Disease Control's (CDC) Prescription Drug Overdose Prevention for States Program (Prevention for States) is an initiative implemented in 2015 to provide State health departments with resources and support needed to advance interventions for preventing prescription drug overdoses. Due to the effectiveness of the program and the rising need, CDC received substantial increases in fiscal year 2015, of \$20 million, and in fiscal year 2016, of \$50 million dollars, to expand State prevention activities to a national scale. To ensure accountability, CDC is undergoing an evaluation of the program in order for measures to inform program improvements to achieve the highest public health impact possible as this program continues to grow and expand.

In fiscal year 2017, the President's budget requests \$80 million for prescription drug overdose prevention to promote opioid prescribing guideline dissemination and uptake. The Administration's budget proposal includes funding to continue and expand State support for Prescription Drug Overdose Prevention for States Programs in all 50 States, and to continue to allow rigorous monitoring and evaluation and improvements in data quality.

In fiscal year 2017, WestCare Foundation supports the Administration's appropriations request for prescription drug overdose prevention of \$80,000,000. This investment will increase accountability for States and allow States to advance and expand interventions for preventing prescription drug overdoses.

Given the prevalence of prescription drug and opioid abuse in rural areas throughout the Nation, WestCare recommends CDC outline a new strategic goal within the Prescription Drug Overdose Prevention for States Program dedicated to rural outreach, engaging underserved communities through the existing U.S. Department of Agriculture (USDA) Cooperative Extension Service program (Extension Program).

By utilizing existing infrastructure such as Extension Programs, we can build on and connect services already underway such as SAMHSA Block Grants, SAMHSA Drug Free Communities, CDC Prevention for States, and HRSA grantees and streamline Federal efforts to increase local and Federal collaboration. Lack of local-Federal and interagency coordination has impeded efficient, collaborative efforts among local stakeholders.

In February 2016, Secretary Tom Vilsack of USDA announced the "Rural America Opioid Initiative" to address the shortage in substance abuse services in rural areas. This interagency initiative has potential to serve as an effective vehicle in coordinating Federal efforts. Through interagency coordination between the CDC and USDA, States and local communities can capitalize on existing programs like the

<sup>1</sup> Center for Disease Control (CDC): [http://www.cdc.gov/vitalsigns/opioid-prescribing/\(2014\)](http://www.cdc.gov/vitalsigns/opioid-prescribing/(2014)).

<sup>2</sup> Center for Disease Control (CDC): [http://www.cdc.gov/vitalsigns/painkilleroverdoses/\(2011\)](http://www.cdc.gov/vitalsigns/painkilleroverdoses/(2011)).

USDA Extension Program and the CDC Prevention for States Program. Specifically, WestCare recommends that the CDC Prevention for States Program require grantees to provide Extension Offices with the resources, best practices, and technical expertise necessary to guide and assist local communities and rural SUD treatment providers in expanding treatment capacity and coordinating Federal, State, and local opioid initiatives and funding streams at the local level.

WestCare respectfully recommends the following report language be inserted into the fiscal year 2017 Labor, Health and Human Services, Education, and Related Agencies Appropriations Bill: “the Committee directs the agency [CDC] to offer a new Prescription Drug Overdose Prevention for States Program competition [in fiscal year 2017] that incorporates a strategic goal to implement effective prescription drug overdose prevention in underserved rural areas, provided that up to 2 percent of funds under the program may be retained for an annual national summit on opioid treatment in rural communities.”

#### SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION

In fiscal year 2017, WestCare Foundation supports increased investment to address prescription opioid abuse and heroin use, and is encouraged by the significant attention to substance use disorder treatment expansion, provided that medication-assisted-treatment is coupled with the full continuum of behavioral therapy and recovery support services. As physicians become gate keepers, it is imperative that they are qualified to diagnose behavioral health disorders, treat addiction as a disease, properly prescribe pain, provide person-centered recovery, and make appropriate referrals to behavioral specialists as they would for another health disorder.

WestCare Foundation applauds the Administration’s and Congress’ attention to the opioid and heroin epidemic, but recommends that any investment in medication-assisted treatment provide flexibility for individualized, patient-centered behavioral and recovery support. Substance addiction is a chronic, relapsing disease with prescribed care regimens that are often comparable to diabetes or heart disease, requiring patient education, treatment, rehabilitation, and consistent management of the disease upon recovery. Treatment modality, length of stay and service provisions must be taken into consideration and will vary depending on the duration, dose and type of substance use, as well as the age of first initiation, experience with trauma, and other physical and mental health co-occurring disorders. SUDs are present on a wide spectrum of severity, often with co-occurring mental health and primary care health issues. To address the range of issues, WestCare provides differentiated programs across the continuum of care—services to accompany medication-assisted treatment. WestCare’s services consist of outpatient and residential treatment programs that include assessment, individual and group counseling, and case management; family and transitional education; vocational education; recreational therapy; holistic health promotion; permanent and temporary supportive housing; and other community and peer supports.

One of the most pressing barriers to comprehensive services is workforce capacity and access to treatment. People seeking treatment are usually at their lowest point and impressionable. When forced to wait for treatment service, hopelessness can manifest and increase the likelihood for relapse. Unfortunately, the existing community-based system of care for heroin and opioid disorders is restricted by the Institute of Mental Disease (IMD) Exclusion at a time when greater capacity is an essential respond to the crisis.

Medication-assisted-treatment has been shown to improve patient survival, increase retention in treatment, decrease illicit opiate use and other criminal activity among people with substance use disorders, increase patients’ ability to gain and maintain employment, improve birth outcomes among women who have substance use disorders and are pregnant.<sup>3</sup>

Despite this evidence-based approach and proven effectiveness, medication-assisted-treatment is greatly underused. According to SAMHSA, the number of heroin admissions with treatment plans that included receiving medication-assisted opioid therapy fell from 35 percent in 2002 to 28 percent in 2010.<sup>3</sup> Slow adoption of these treatment options is partly due to misconceptions about substituting one drug for another and lack of training for physicians. Now, medication-assisted treatment is being looked to as a primary and sustainable method to provide comprehensive treatment.

The CDC Guideline for Prescribing Opioids for Chronic Pain released in March of 2016 recommends clinicians “offer or arrange evidence-based treatment (usually

<sup>3</sup> SAMHSA Treatment Episode Data Set (TEDS) 2002–2010: <http://store.samhsa.gov/product/2000-2010-National-Admissions-to-Substance-Abuse-Treatment-Services/SMA12-4701>.



medication-assisted treatment with buprenorphine or methadone in combination with behavioral therapies) for patients with an opioid use disorder.”<sup>4</sup> As an extension, the CDC points to studies that suggest using behavioral therapies, in combination with treatments like methadone maintenance therapy or buprenorphine, can reduce opioid misuse and increase retention during maintenance therapy and improve compliance after detoxification.

As both providers and policy-makers look to medication-assisted treatment models, the importance of behavioral therapy and full recovery support cannot be overstated. Therefore, WestCare Foundation respectfully requests that any funding appropriated by Congress for medication-assisted treatment include report language explicitly stating “medication-assisted treatment in conjunction with behavioral and recovery support services” as an allowable use of medication-assisted treatment funds. The intention is to provide sufficient flexibility to allow substance use disorder treatment providers to meet local needs of their individual communities and target vulnerable populations such as pregnant women and veterans.

In closing, WestCare Foundation recognizes the fiscal realities of the Federal budget but remains encouraged by Congress’ strong commitment to addressing our Nation’s public health crisis. We support the highest possible funding for mental health and substance use disorder treatment in fiscal year 2017, and believe that through greater coordination of existing programs we can improve and better document treatment outcomes. We strongly encourage the Subcommittee not to overlook the need of coordination, capacity-building, and the break-down of Federal funding silos at the most local levels. We further urge the Subcommittee not to view medication-assisted treatment as a “silver bullet,” quick solution to the opioid public health crisis—medication must be paired with complementary behavioral support to achieve sustainable recovery. We look forward to collaborating on the fiscal year 2017 appropriations process as Congress looks to invest and direct resources to this critical, national issue.

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PREPARED STATEMENT OF THE WOMEN’S HEART ALLIANCE

Women’s heart disease is the number one killer of women in the United States and is responsible for the deaths of one in every three women in the United States.<sup>1</sup> Even though a woman’s heart is different than a man’s and the disease affects women differently, for the last 50 years, the treatment of women’s hearts has largely been based on medical research on men.

In fact, despite the sex differences in physiology and in the manifestation of cardiovascular disease, only 35 percent of participants in all heart-related studies are women.<sup>2</sup> Therefore, far too many women are dying from a largely preventable disease and not enough is being done to recognize the differences and appropriately treat heart disease in women.

Women are dying at high and often unrecognized rates from the disease. Consider:

- Heart diseases claims more than 400,000 women’s lives each year. That’s nearly one death every 80 seconds.<sup>3</sup>
- Although slightly more men (402,851) than women (398,086) died from heart disease and stroke in 2013 (the most recent year for which data are available), women fare worse than men in a number of critical ways.<sup>4</sup>

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<sup>4</sup> CDC Guideline for Prescribing Opioids for Chronic Pain—United States, 2016: <http://www.cdc.gov/mmwr/volumes/65/rr/rr6501e1.htm>.

<sup>1</sup> Heron M. Deaths: Leading Causes for 2013. National vital statistics reports. Hyattsville, MD: National Center for Health Statistics. 2016;65(2):22. Available from: [http://www.cdc.gov/nchs/data/nvsr/nvsr65/nvsr65\\_02.pdf](http://www.cdc.gov/nchs/data/nvsr/nvsr65/nvsr65_02.pdf).

<sup>2</sup> Melloni C, Mark DB, Douglas PS, et al. Representation of Women in Randomized Clinical Trials of Cardiovascular Disease Prevention. *Circulation: Cardiovascular Quality and Outcomes*. 2010;3:135–142. Available at: <http://circoutcomes.ahajournals.org/content/3/2/135.long>.

<sup>3</sup> Mozaffarian D, Benjamin EJ, Go AS, Arnett DK, Blaha MJ, Cushman M, et al.; on behalf of the American Heart Association Statistics Committee and Stroke Statistics Subcommittee. Heart disease and stroke statistics—2016 update: a report from the American Heart Association. *Circulation*. 2016;133:e148. Available from: <http://circ.ahajournals.org/content/early/2015/12/16/CIR.0000000000000350.full.pdf>.

<sup>4</sup> Ibid.

- For example, women are at greater risk of dying in the year following a heart attack than are men. Indeed, 1 in 4 women will die within 1 year of their heart attack, compared to 1 in 5 men.<sup>5</sup>
- Nearly half of African American women ages 20 and older (48.3 percent) have heart disease<sup>6</sup>, yet only 1-in-5 thinks she is personally at risk, and just half are aware of the signs and symptoms of a heart attack.<sup>7</sup>
- Breast cancer kills one in 32 women, while heart disease kills one in three, yet only a small fraction (\$246 million) of the National Institutes of Health budget is spent on women's heart disease research.<sup>8</sup>
- Blacks develop high blood pressure more often, and at an earlier age, than whites and Hispanics. More black women than men have high blood pressure.<sup>9</sup>
- Sixty-four percent of women who die suddenly of coronary heart disease have no prior symptoms.<sup>10</sup>
- Obesity, diabetes, high blood pressure, stress, lack of exercise, and other factors put young women at risk of dying from heart disease. Recent data show that CVD rates and the prevalence of CVD risk factors are increasing among young women.<sup>11</sup>

Increasing investment in research to discover why sex differences occur in heart disease must be a priority in the National Institutes of Health (NIH) budget. An October 2015 Government Accountability Office (GAO) report highlights the desperate need to close the gender gap in research and to improve our understanding of the impact of disease on women.

The Women's Heart Alliance requests that Congress appropriate sustained funding for NIH and the Centers for Disease Control and Prevention (CDC) to improve cardiovascular disease research, prevention and treatment and reduce the unnecessary suffering and death from cardiovascular disease in both women and men.

*Capitalize on Investment for the National Institutes of Health (NIH) and the National Heart, Lung, and Blood Institute (NHLBI)*

As was emphasized in our recently submitted letter from the NHLBI Constituency Group, of which we are a member organization, we are grateful for the significant funding increase for the National Institutes of Health during the fiscal year 2016 congressional appropriations process. In the fiscal year 2017 Labor-HHS-Education Appropriation bill, we request at least \$34.5 billion for the National Institutes of Health and \$3.4 billion for NIH's National Heart, Lung, and Blood Institute.

A funding level of this amount would allow the NIH to continue to restore its purchasing power. Despite the fiscal year 2016 funding increase for NIH, the agency's purchasing power is 19 percent less than in fiscal year 2003 (constant 2015 dollars). An fiscal year 2017 appropriation of at least \$34.5 billion for the NIH, including \$3.4 billion for NHLBI would permit the NIH to capitalize on its ability to enhance health, create jobs, boost economic growth and innovation and promote science. Stable and sustained funding will help secure a solid return on Congress' investment in NIH.

It is critical that, as the GAO recommended, stronger steps are taken to understand the impact of sex and gender on disease in NIH-funded clinical research trials. When medical research, analysis and reporting takes into account differences between men and women, new findings translate into better diagnosis and treat-

<sup>5</sup> CDC Feature: Women and Heart Disease [Internet]. Atlanta: CDC; c2015. [Updated: 2 February 2015; cited: 31 August 2015]. Available from <http://www.cdc.gov/features/wearred/index.html>.

<sup>6</sup> Mozaffarian D, Benjamin EJ, Go AS, Arnett DK, Blaha MJ, Cushman M, et al.; on behalf of the American Heart Association Statistics Committee and Stroke Statistics Subcommittee. Heart disease and stroke statistics—2016 update: a report from the American Heart Association. *Circulation*. 2016;133:e151.

<sup>7</sup> Heart Disease in African American Women [Internet]. Dallas American Heart Association—Go Red For Women; Available from: [https://www.goredforwomen.org/about-heart-disease/facts\\_about\\_heart\\_disease\\_in\\_women-sub-category/african-american-women/](https://www.goredforwomen.org/about-heart-disease/facts_about_heart_disease_in_women-sub-category/african-american-women/).

<sup>8</sup> Mozaffarian D, Benjamin EJ, Go AS, Arnett DK, Blaha MJ, Cushman M, et al.; on behalf of the American Heart Association Statistics Committee and Stroke Statistics Subcommittee. Heart disease and stroke statistics—2016 update: a report from the American Heart Association. *Circulation*. 2016;133:e148.

<sup>9</sup> Mozaffarian D, Benjamin EJ, Go AS, Arnett DK, Blaha MJ, Cushman M, et al.; on behalf of the American Heart Association Statistics Committee and Stroke Statistics Subcommittee. Heart disease and stroke statistics—2015 update: a report from the American Heart Association. *Circulation*. 2015;131:e98-e110.

<sup>10</sup> Roger VL, Go AS, Lloyd-Jones DM, Benjamin EJ, Berry JD, Borden WB, et al. Heart disease and stroke statistics—2012 update: a report from the American Heart Association. *Circulation*. 2012;125(1):e2—220.

<sup>11</sup> Lee et al., Ogden et al., Geiss et al., and Pope et al.

ment for women. Improvements in reporting and interpreting subgroup analysis and in clinical trial design are needed to give statistically meaningful results for men and for women.

We request the Committee invest money, as deemed appropriate, to enforce GAO recommendations, including policies that:

- Require women to be represented in clinical trials in proportion to the number of women affected by the disease being studied.
- As part of NIH's regular biennial report to Congress on the inclusion of women and minorities in research, include specific detailed reporting by institute, by disease category and by study. Such reporting should include an analysis of the number of women included in each clinical trial in proportion to the number of women affected by the disease being studied.
- As part of NIH's regular biennial report to Congress on the inclusion of women and minorities in research, NIH should track and report where we have made discoveries on sex differences and where gaps still exist.

In particular, more work is needed on the areas of persistent increased risk for heart disease in younger women; the higher procedural complications and bleeding complications in women; and the social determinants of cardiovascular health across the lifespan. A multi-Institute, multidisciplinary collaborative effort in this area that may include support for centers of excellence should also be strongly considered.

Recognizing the need for continued groundbreaking research on heart disease and particularly new discoveries on women's heart disease, we appreciate and support NHLBI as the lead research institution on heart disease.

The NHLBI has a long history of achievements in improving the health of your constituents. Over the past 68 years, the NHLBI has made important progress in the treatment and prevention of heart disease, stroke, asthma, emphysema, sickle cell disease, Cooley's anemia, diabetes, sleep disorders and other diseases.

However, challenges remain because heart, lung, blood, and blood vessel diseases account for more than 40 percent of all deaths in the United States. These diseases kill more than 1 million Americans each year and cost our Nation an estimated \$441 billion in medical expenses and lost productivity in 2012–2013.<sup>12</sup>

As the worldwide leader in research on heart, lung, blood and blood vessel diseases as well as sleep disorders, the NHLBI effectively translates research results to the American public. An fiscal year 2017 appropriation of \$3.4 billion for the NHLBI would allow the Institute to enhance current programs and pursue promising planned innovative basic, clinical, translational and prevention research initiatives to better diagnose, treat and prevent these diseases.

#### *Increase Funding for the Centers for Disease Control and Prevention*

According to the CDC's Division for Heart Disease and Stroke Prevention, cardiovascular disease (CVD) costs the United States \$320 billion in annual healthcare costs and lost productivity.<sup>13</sup> Unfortunately, the toll is only growing. By 2030, more than four in 10 Americans are projected to have cardiovascular disease, with total costs expected to triple to more than a trillion dollars.<sup>14</sup>

Heart disease is 80 percent preventable.<sup>15</sup> And it's clear the benefits of putting more resources into prevention far outweigh the costs.

We join the CDC Coalition in requesting \$7.8 billion for the agency and \$37 million for WISEWOMAN for expansion to additional and currently-funded States. WISEWOMAN provides low-income, under-insured or uninsured women with chronic disease risk factor screening, lifestyle programs and referral services in an effort to prevent cardiovascular disease and stroke. Scaling up programs like this would only help rein in the costs associated with heart disease. We also ask for \$5 million for Million Hearts™, a national initiative with an ambitious goal to prevent 1 million heart attacks and strokes by 2017, of which WHA is a member. This will allow Million Hearts to enhance efforts to prevent, detect, treat, and control blood pressure—a key reason for heart attack and stroke.

<sup>12</sup>National Heart, Lung, and Blood Institute. Unpublished tabulation. April 2016.

<sup>13</sup>Business Pulse [Internet]. Atlanta: CDC Foundation; c2015 [cited 22 Dec 2015]. Available from: <http://www.cdcfoundation.org/businesspulse/heart-health-infographic>.

<sup>14</sup>Heidenreich PA, Trogdon JG, Khavjou OA, Butler J, Dracup K, Ezekowitz MD, et al. Forecasting the future of cardiovascular disease in the United States: a policy statement from the American Heart Association. *Circulation*. 2011;123(8):933–44.

<sup>15</sup>Akesson A, Larsson SC, Discacciati A, Wolk A. Low-Risk Diet and Lifestyle Habits in the Primary Prevention of Myocardial Infarction in Men: A Population-Based Prospective Cohort Study. *J Am Coll Cardiol*. 2014;64(13):1299–1306. doi:10.1016/j.jacc.2014.06.1190. Available from: <http://content.onlinejacc.org/article.aspx?articleid=1909605>.

## CONCLUSION

Cardiovascular disease and its precursors are an unnecessary and heavy burden on America's people and budget. Boosting funding for the prevention, research and treatment of women and heart disease through NIH and CDC is not only an effective step toward improving the health of American women, but also a smart economic move for the country. We respectfully ask the Committee to approve these recommendations that will foster the health and wellbeing of the American people.

[This statement was submitted by British Robinson, Chief Executive Officer, Women's Heart Alliance.]

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