



Testimony of Harry Johns, President and CEO of the Alzheimer's Association
Fiscal Year 2014 Appropriations for Alzheimer's-related Activities
at the U.S. Department of Health and Human Services

Subcommittee on Labor, Health and Human Services, Education and Related Agencies
Committee on Appropriations
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The Alzheimer's Association appreciates the opportunity to comment on the Fiscal Year (FY) 2014 appropriations for Alzheimer's disease research, education, outreach and support at the U.S. Department of Health and Human Services.

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

Alzheimer's Impact on the American People and the Economy

In addition to the human suffering caused by the disease, Alzheimer's is creating an enormous strain on the health care system, families and the federal budget. Alzheimer's is a progressive brain disorder that damages and eventually destroys brain cells, leading to a loss of memory, thinking and other brain functions. Ultimately, Alzheimer's is fatal. Currently, Alzheimer's is the sixth leading cause of death in the United States and the only one of the top ten without a means to prevent, cure or slow its progression. Over five million Americans are living with Alzheimer's, with 200,000 under the age of 65. While deaths from other major diseases, including heart disease, stroke and HIV continue to experience significant declines, those from Alzheimer's have increased 68 percent between 2000 and 2010.

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

the compassion to care, the leadership to conquer

more and more Americans living with Alzheimer's - as many as 16 million by 2050, when there will be nearly one million new cases each year. Due to these projected increases, the graying of America threatens the bankrupting of America. Caring for people with Alzheimer's will cost all payers - Medicare, Medicaid, individuals, private insurance and HMOs -- \$20 trillion over the next 40 years, enough to pay off the national debt and still send a \$10,000 check to every man, woman and child in America. In 2012, America will have spent an estimated \$200 billion in direct costs for those with Alzheimer's, including \$140 billion in costs to Medicare and Medicaid. Average per person Medicare costs for those with Alzheimer's and other dementias are three times higher than those without these conditions. Average per senior Medicaid spending is 19 times higher.

A primary reason for these costs is that Alzheimer's makes treating other diseases more expensive, as most individuals with Alzheimer's have one or more co-morbidity that complicate the management of the condition(s) and increase costs. For example, a senior with diabetes and Alzheimer's costs Medicare 81 percent more than a senior who only has diabetes. Nearly 30 percent of people with Alzheimer's or another dementia who have Medicare also have Medicaid coverage, compared with 11 percent of individuals without Alzheimer's or dementia. Alzheimer's disease is also extremely prevalent in nursing homes, where 64 percent of Medicare residents live with the disease. Unless something is done, the costs of Alzheimer's in 2050 are estimated to total \$1.1 trillion (in today's dollars). Costs to Medicare and Medicaid will increase nearly 500 percent and there will be a 400 percent increase in out-of-pocket costs.

With Alzheimer's, it is not just those with the disease who suffer - it is also their caregivers and families. In 2011, 15.2 million family members and friends provided unpaid care valued at over \$210 billion. Caring for a person with Alzheimer's takes longer, lasts longer, is more personal and intrusive, and takes a heavy toll on the health of the caregivers themselves. More than 60 percent of Alzheimer's and dementia caregivers rate the emotional stress of caregiving as high or very high, with one-third reporting symptoms of depression. Caregiving may also have a negative impact on health, employment, income and family finances. Due to the physical and emotional toll of caregiving on their own health, Alzheimer's and dementia caregivers had \$8.7 billion in additional health costs in 2011.

Changing the Trajectory of Alzheimer's

Until recently, there was no federal government strategy to address this looming crisis. In 2010, thanks to bipartisan support in Congress, the National Alzheimer's Project Act (NAPA) (P.L. 111-375) passed unanimously, requiring the creation of an annually-updated strategic National Alzheimer's Plan (Plan) to help those with the disease and their families today and to change the trajectory of the disease for the future. The Plan is required to include an evaluation of all federally-funded efforts in Alzheimer's research, care

and services -- along with their outcomes. In addition, the Plan must outline priority actions to reduce the financial impact of Alzheimer's on federal programs and on families; improve health outcomes for all Americans living with Alzheimer's; and improve the prevention, diagnosis, treatment, care, institutional-, home-, and community-based Alzheimer's programs for individuals with Alzheimer's and their caregivers. NAPA will allow Congress to assess whether the nation is meeting the challenges of this disease for families, communities and the economy. Through its annual review process, NAPA will, for the first time, enable Congress and the American people to answer this simple question: *Did we make satisfactory progress this past year in the fight against Alzheimer's?*

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

Having a plan with measurable outcomes is important. But unless there are resources to implement the plan and the will to abide by it, we cannot hope to make much progress. If we are going to succeed in the fight against Alzheimer's, Congress must provide the resources the scientists need. Understanding this, the President's FY 2013 budget request included \$80 million for Alzheimer's research and \$20 million for education, outreach and support. These funds are a critically needed down payment for needed research and services for Alzheimer's patients and their families.

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

Today, despite the federal investment in Alzheimer's research, we are only just beginning to understand what causes the disease. Americans are growing increasingly concerned that we still lack effective treatments that will slow, stop, or cure the disease, and that the pace of progress in developing breakthrough discoveries is much too slow to significantly impact on this growing crisis. For every \$31,000 Medicare and Medicaid spends caring for individuals with Alzheimer's, the National Institutes of Health (NIH) spends only \$100 on Alzheimer's research. Scientists fundamentally believe that we have the ideas, the technology and the will to develop new Alzheimer's interventions, but that progress depends on a prioritized scientific agenda and on the resources necessary to carry out the scientific strategy for both discovery and translation for therapeutic development.

For too many individuals with Alzheimer's and their families, the system has failed them, and today we are unnecessarily losing the battle against this devastating disease. Despite the fact that an early and documented formal diagnosis allows individuals to participate in their own care planning, manage other chronic conditions, participate in clinical trials, and ultimately alleviate the burden on themselves and their loved ones, as many as half of the more than five million Americans with Alzheimer's have never received a formal diagnosis. Unless we create an effective, dementia-capable system that finds new solutions to providing high quality care, provides community support services and programs, and addresses Alzheimer's health disparities, Alzheimer's will overwhelm the health care system in the coming years. For example, people with Alzheimer's and other dementias have more than three times as many hospital stays as other older people. Furthermore, one out of seven individuals with Alzheimer's or another dementia lives alone and up to half do not have an identifiable caregiver. These individuals are more likely to need emergency medical services because of self-neglect or injury, and are found to be placed into nursing homes earlier, on average, than others with dementia. Ultimately, supporting individuals with Alzheimer's disease and their families and caregivers requires giving them the tools they need to plan for the future and ensuring the best quality of life for individuals and families impacted by the disease. It is vital that we make the investments in Alzheimer's that were laid out in the President's FY 2013 budget. While the President's budget requested \$100 million for research and support services, the needs of the Alzheimer's community has grown. **The Alzheimer's Association urges Congress to fully fund the research, education, outreach and support activities and the priorities included in the National Alzheimer's Plan required under P.L. 111-375.**

Additional Alzheimer's programs

National Alzheimer's Call Center: The National Alzheimer's Call Center, funded by the AoA, provides 24/7, year-round telephone support, crisis counseling, care consultation, and information and referral services in 140 languages for persons with Alzheimer's, their family members and informal caregivers. Trained professional staff and master's-level mental health professionals are available at all times. In the 12 month period ending July 31, 2011, the Call Center handled over 300,000 calls through its national and local partners, and its online message board received over 40,000 visits a month. Additionally, the Association provides a two-to-one match on the federal dollars received for the call center. **The Alzheimer's Association urges Congress to support \$1.3 million for the National Alzheimer's Call Center.**

Healthy Brain Initiative (HBI): The Centers for Disease Control and Prevention's (CDC) HBI program works to educate the public, the public health community and health professionals about Alzheimer's as a public health issue. Although there are currently

no treatments to delay or stop the deterioration of brain cells caused by Alzheimer's, evidence suggests that preventing or controlling cardiovascular risk factors may benefit brain health. In light of the dramatic aging of the population, scientific advancements in risk behaviors, and the growing awareness of the significant health, social and economic burdens associated with cognitive decline, the federal commitment to a public health response to this challenge is imperative. The FY2013 Senate Labor-HHS bill included report language commending HBI for its leadership in bringing attention to the public health crisis of Alzheimer's disease and for its work on cognitive impairment data collection in 45 states, the District of Columbia and Puerto Rico. Additionally, the committee noted that developing a population-based surveillance system with longitudinal follow-up is a key recommendation in the National Public Road Map to Maintaining Cognitive Health, which was developed jointly by the CDC and the Alzheimer's Association. The bill increased funding for HBI by \$10 million in order to further develop this system and to develop effective public health messages to promote cognitive health in older adults. **The Alzheimer's Association urges Congress to support \$11.8 million for the Healthy Brain Initiative.**

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

Conclusion

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