

Testimony of Robert Egge, Executive Vice President of Government Affairs of the Alzheimer's Association  
Fiscal Year 2016 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  
United States Senate

April 29, 2015

The Alzheimer's Association appreciates the opportunity to comment on the Fiscal Year (FY) 2016 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 federal and state budgets. 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.

Alzheimer's is the most expensive disease in America. In fact, a study funded by the National Institutes of Health (NIH) in the *New England Journal of Medicine* confirmed that Alzheimer's is the most costly disease in America, with costs set to skyrocket at unprecedented rates. If nothing is done, as many as 16 million Americans will have Alzheimer's disease by 2050 and costs will exceed \$1.1 trillion (not adjusted for inflation), creating an enormous strain on the healthcare system, families and the federal budget.<sup>1</sup> As the current generation of baby boomers age, near-term costs for caring for those with Alzheimer's will balloon, as Medicare and Medicaid will cover more than two-thirds of the costs for their care.

Caring for people with Alzheimer's will cost all payers - Medicare, Medicaid, individuals, private insurance and HMOs -- \$20 trillion over the next 40 years. In 2015, America will spend an estimated \$226 billion in direct costs for those with Alzheimer's, including \$153 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.<sup>2</sup>

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.

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<sup>1</sup> 2015 Alzheimer's Disease Facts and Figures: [http://www.alz.org/facts/downloads/facts\\_figures\\_2015.pdf](http://www.alz.org/facts/downloads/facts_figures_2015.pdf)

<sup>2</sup> ibid

With Alzheimer's, it is not just those with the disease who suffer - it is also their caregivers and families. In 2014, 15.7 million family members and friends provided unpaid care valued at over \$217 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. Nearly 60 percent of Alzheimer's and dementia caregivers rate the emotional stress of caregiving as high or very high, with nearly 40 percent reporting symptoms of depression. Caregiving may also have a negative impact on health, employment, income and family finances. Due to the physical and emotional toll of caregiving on their own health, Alzheimer's and dementia caregivers had \$9.7 billion in additional health costs in 2014.<sup>3</sup>

### **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 must 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. . Through its annual review process, NAPA has enabled, for the first time, Congress and the American people to assess whether the nation is meeting the challenges of this disease for families, communities and the economy.

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<sup>3</sup> ibid

As mandated by NAPA, the Secretary of Health and Human Services, in collaboration with the Advisory Council on Alzheimer's Research, Care and Services, released the first-ever *National Plan to Address Alzheimer's Disease* in May of 2012 and released annual updates in 2013 and 2014. 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.

In keeping with the National Plan, NIH convened a research summit in 2012, which resulted in the development of research milestones and timelines for meeting the goal of effectively treating and preventing Alzheimer's disease by 2025. NIH held a second summit in February of this year to review the progress being made on those milestones and to develop updates on them. Having a plan with measurable outcomes is important. But unless there are resources to implement the plan and the will to abide by it, we cannot hope to make adequate progress. If we are going to succeed in the fight against Alzheimer's, Congress must provide the resources the scientists need. Understanding this and following the recommendation of scientists at NIH, Congress passed the *Consolidated and Further Continuing Appropriations Act of 2015* (P.L. 113-235) which included a \$25 million increase for Alzheimer's research. The law also included the *Alzheimer's Accountability Act* (S.2192/H.R. 4351), which requires NIH to develop a professional judgment budget focused on the milestones established by the National Plan. This will provide Congress with an account of the necessary resources that NIH believes are needed to reach the critical goal of the National Plan, to effectively treat and prevent Alzheimer's disease by 2025.

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 2025 that delayed onset of Alzheimer's for five years (a treatment similar in effect to anti-cholesterol drugs), savings would be

seen almost immediately, with Medicare and Medicaid saving a cumulative \$535 billion in the first ten years.<sup>4</sup>

Today, despite the federal investment in Alzheimer's research, for every \$26,000 Medicare and Medicaid spend caring for individuals with Alzheimer's, 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.

**The Alzheimer's Association urges Congress to support an additional \$300 million for research activities and priorities included in the National Alzheimer's Plan required under P.L. 111-375.**

## **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 enactment of the Alzheimer's Accountability Act (P.L. 113-235), and with a commitment equal to the scale of the crisis.

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<sup>4</sup> *Changing the Trajectory of Alzheimer's Disease: How a Treatment by 2025 Saves Lives and Dollars:*  
[http://www.alz.org/documents\\_custom/trajectory.pdf](http://www.alz.org/documents_custom/trajectory.pdf)