

**Testimony of Robert Egge, Chief Public Policy Officer, Alzheimer's Association and Alzheimer's Impact Movement**  
**Fiscal Year 2019 Appropriations for Alzheimer's-Related Activities**  
**at the U.S. Department of Health and Human Services**

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

**April 26, 2018**

The Alzheimer's Association and Alzheimer's Impact Movement (AIM) appreciate the opportunity to testify on the Fiscal Year (FY) 2019 appropriations for Alzheimer's 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. The Alzheimer's Association is the nonprofit with the highest impact in Alzheimer's research worldwide and is committed to accelerating research toward methods of treatment, prevention and, ultimately, a cure. The Alzheimer's Impact Movement (AIM) is the advocacy arm of the Alzheimer's Association, working in strategic partnership to make Alzheimer's a national priority. Together, the Alzheimer's Association and AIM advocate for policies to fight Alzheimer's disease, including increased investment in research, improved care and support, and development of approaches to reduce the risk of developing dementia.

**Alzheimer's Impact on the American People and the Economy**

The most important reason to address Alzheimer's is because of the human suffering it causes to millions of Americans. 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. According to recent data from the National Center for Health Statistics, deaths from Alzheimer's disease increased 123 percent between 2000 and 2015.

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.

In addition to the human suffering caused by the disease, however, Alzheimer's is also creating an enormous strain on the health care system, families, and federal and state budgets. 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 14 million Americans will have Alzheimer's by 2050 and costs will exceed \$1.1 trillion (not adjusted for inflation).<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 insurers and HMOs – \$20 trillion over the next 40 years. As noted in the 2018 Alzheimer's Disease Facts and Figures report, in 2018 America will spend an estimated \$277 billion in direct costs for those with Alzheimer's, including \$186 billion in costs to Medicare and Medicaid. Average per person Medicare costs for those with Alzheimer's and other dementias are more than three times higher than those without these conditions. Average per senior Medicaid spending is 23 times higher.<sup>2</sup>

### **Changing the Trajectory of Alzheimer's**

Until recently, the federal government did not have a strategy to address this looming

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<sup>1</sup> 2018 Alzheimer's Disease Facts and Figures: [https://www.alz.org/documents\\_custom/2018-facts-and-figures.pdf](https://www.alz.org/documents_custom/2018-facts-and-figures.pdf)

<sup>2</sup> *ibid*

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 Plan to Address Alzheimer's Disease (National Plan) to help those with the disease and their families today and to change the trajectory of the disease for the future. The National Plan must include an evaluation of all federally-funded efforts in Alzheimer's research, care and services – along with their outcomes.

If America is going to succeed in the fight against Alzheimer's, Congress must continue to provide the resources scientists need to do their work. Understanding this, in 2014 Congress passed the Consolidated and Further Continuing Appropriations Act of 2015 (P.L. 113-235), which included the Alzheimer's Accountability Act (S. 2192/H.R. 4351). The Alzheimer's Accountability Act requires NIH to develop a Professional Judgment Budget focused on the research milestones established by the National Plan. This provides Congress with an account of the resources that NIH has confirmed are needed to reach the lead goal of the National Plan: to effectively treat and prevent Alzheimer's by 2025.

Recent funding increases have been critical to accelerate progress toward the National Plan's 2025 goal. Among other advances, this additional funding has already enabled important research advances into new biomarkers to detect the disease before the onset of symptoms, help to build better animal models to replicate the disease and enable preclinical testing of promising therapeutics, and has increased data sharing.

For example, the Alzheimer's Disease Neuroimaging Initiative (ADNI), which tracks how neuroimaging and fluid biomarkers change with disease onset and progression, has moved into a critical new phase of discovery with ADNI3. ADNI3 focuses on brain scans that detect the amount and location of tau protein tangles, one of the hallmark brain changes of Alzheimer's

disease. The discovery of novel biomarkers for Alzheimer's disease is critically needed for detection of disease-related changes years before the symptoms of memory loss appear.

Additionally, increased NIH funding has enabled the Accelerating Medicines Partnership-Alzheimer's Disease (AMP-AD) knowledge portal, a vibrant public-private partnership bringing together the NIH, pharmaceutical companies, and non-profits like the Alzheimer's Association. This important data portal allows the researcher community to access and analyze data on a scale that would not be possible by individual research teams, academic institutions, or pharmaceutical companies. This broad and rapid sharing of biological data and analytical results has already allowed researchers to discover more than 100 novel candidate targets.

Another exciting development is the publication this month of a new research framework developed between the National Institute on Aging (NIA) and the Alzheimer's Association, "NIA-AA Research Framework: Towards a Biological Definition of Alzheimer's Disease." This new framework shifts the definition of Alzheimer's disease in a research context from one based on cognitive changes and behavioral symptoms with biomarker confirmation, to a strictly biological construct as we have for other major diseases. This framework provides researchers a roadmap that circumvents many of the pitfalls that have crippled so many high-profile clinical trials in recent years. By recognizing the onset of Alzheimer's disease many years before the presentation of symptoms, it directs the research community's focus on overcoming specific hurdles to faster progress in addressing this disease.

**It is vitally important that NIH continues to build upon these and many other promising advances. The Alzheimer's Association and AIM urge Congress to fund the research targets outlined in the Professional Judgment Budget by supporting an additional**

## **\$425 million for NIH Alzheimer's funding in FY 2019.**

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>3</sup>

## **Conclusion**

The Alzheimer's Association and AIM appreciate the steadfast support of the Subcommittee and its priority setting activities. We thank the Subcommittee and Congress for including an historic \$414 million increase for Alzheimer's research activities at NIH in FY 2018. However, the current funding level is still short of the total funding scientists believe is needed to meet the goal of finding a treatment or cure for Alzheimer's and other dementias by 2025. 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) with an additional \$425 million for Alzheimer's research activities at NIH in FY 2019.

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<sup>3</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)