

Testimony of Robert Egge, Chief Public Policy Officer of the Alzheimer's Association
Fiscal Year 2018 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 House of Representatives

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The Alzheimer's Association appreciates the opportunity to comment on the Fiscal Year (FY) 2018 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. Our mission is to eliminate Alzheimer's 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. The Alzheimer's Association is the nonprofit with the highest impact in Alzheimer's research worldwide and 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 Alzheimer's 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. In partnership with its sister organization, the Alzheimer's Impact Movement (AIM), the Alzheimer's Association is committed to creating a world without Alzheimer's.

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. 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 16 million Americans will have Alzheimer's by 2050 and costs will exceed \$1.1 trillion (not adjusted for inflation), creating an enormous strain on the health care system, families and federal and state budgets.¹ 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 *2017 Alzheimer's Disease Facts and Figures* report released on March 7, 2017, in 2017, America will spend an estimated \$259 billion in direct costs for those with Alzheimer's, including \$175 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 23 times higher.²

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 comorbidities that complicate the management of the condition(s) and increase costs. For example, a senior with diabetes and Alzheimer's

¹ *2017 Alzheimer's Disease Facts and Figures*: http://www.alz.org/facts/downloads/facts_figures_2017.pdf

² *ibid*

costs Medicare 81 percent more than a senior who only has diabetes. Nearly 30 percent of people with Alzheimer's or other dementias who have Medicare also have Medicaid coverage, compared with 11 percent of individuals without Alzheimer's or other dementias. Alzheimer's is also extremely prevalent in nursing homes, where 64 percent of Medicare residents live with the disease.

With Alzheimer's, it is not just those with the disease who suffer - it is also their caregivers and families. In 2016, 15.9 million family members and friends provided unpaid care valued at over \$230 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 \$10.9 billion in additional health costs in 2016.³

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 (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. In addition, the National 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

³ ibid

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.

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, the most recent of which was released in August 2016. 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 National 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 research summits in 2012 and 2015, which resulted in the development and updating of research milestones and timelines for meeting the goal of effectively treating and preventing Alzheimer's by 2025. 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 continue to provide the resources the scientists need. 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 milestones established by the National Plan. This provides Congress with an account of the resources that NIH believes are needed to reach the critical goal of the National Plan: to effectively treat and prevent Alzheimer's by 2025. The latest professional judgment budget, released in August 2016, calls for an additional \$414 million for Alzheimer's research funding in Fiscal Year 2018.

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.⁴

Consistent with the Alzheimer's Professional Judgment Budget issued by the NIH for FY 2018, the Alzheimer's Association urges Congress to listen to the scientists at the NIH by supporting an additional \$414 million for research activities and priorities included in the National Alzheimer's Plan required under P.L. 111-375.

Conclusion

The Alzheimer's 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) with an additional \$414 million for Alzheimer's research activities in FY 2018.

⁴ *Changing the Trajectory of Alzheimer's Disease: How a Treatment by 2025 Saves Lives and Dollars:*
http://www.alz.org/documents_custom/trajectory.pdf