



**Testimony of Beth McMullen, Vice President, Government Affairs,
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**Fiscal Year 2019 Appropriations for Alzheimer's-Related Activities
at the U.S. Department of Health and Human Services**

March 9, 2018

The Alzheimer's Association and Alzheimer's Impact Movement (AIM) appreciate the opportunity to comment 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. 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 research toward methods of treatment, prevention 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. AIM is the Association's sister organization, 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.

The Minnesota-North Dakota Chapter works to support Minnesotans living with this disease, and their care partners. In FY 2017, we had nearly 6,500 local calls to our 24/7 Helpline, provided community and professional education to over 5,000 individuals, and supported nearly 1,800 people through Care Consultations from our social workers, giving individualized assistance with problem solving and planning. We recently hosted the largest dementia conference in the Midwest with Mayo Clinic in St. Paul, providing innovative education and powerful support to over 1,200 attendees.

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 currently living with Alzheimer's, including 92,000 Minnesotans aged 65 and older. Unfortunately, our work is only growing more urgent: the number of Minnesotans living with the disease is set to increase by over 30 percent by 2025, and the number of Americans living with Alzheimer's could nearly triple by 2050.

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, the cost of caring for people living with Alzheimer's will exceed \$1.1 trillion in 2050 (not adjusted for inflation).¹ In 2017 alone, Medicaid spent \$781 million caring for Minnesotans living with Alzheimer's. As the generation of baby boomers grows older, that number will increase by 35 percent by 2025.

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, in 2017, America spent \$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 higher 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 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, 251,000 Minnesotans provided unpaid care to their family members and friends living with the disease, valued at \$3.6 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 in Minnesota had \$186 million in additional health costs in 2016.

Changing the Trajectory of Alzheimer's

Until recently, there was no federal government strategy to address this looming crisis.

Congress unanimously passed the bipartisan National Alzheimer's Project Act (P.L. 111-375) in 2010. The law requires the Secretary of the Department of Health and Human Services (HHS) to create and annually update a National Plan to Address Alzheimer's Disease. The National

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

² *ibid*

Alzheimer's Plan, reported to Congress annually, must include recommendations for priority actions both to improve health outcomes for individuals and to lower costs to families and government programs.

In keeping with the National Plan, NIH convened research summits in 2012, 2015 and recently in 2018, which has resulted in the development and updating of milestones and timelines for meeting the goals outlined in the National Plan. 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.

To achieve the primary research goal of the National Alzheimer's Plan to prevent and effectively treating Alzheimer's by 2025, Congress has bolstered support for Alzheimer's research at the NIH. In May 2017, Congress appropriated an historic \$400 million increase for Alzheimer's research funding in FY 2017, bringing the annual allocation to nearly \$1.4 billion.

NIH funding is vitally important and has enabled promising research nationwide, some of which is happening right here in Minnesota. For example, the Mayo Clinic has received over \$70 million in NIH funding for the Alzheimer's Disease Biomarker Combinations in the Community Project. This study will use brain scans and cerebrospinal fluid testing to examine how brain health is affected by tau and beta-amyloid clumping, which are two hallmark brain changes of Alzheimer's disease. Results of this study could shed new light on how cognitive decline occurs at the molecular level, which is critical for detecting disease-related changes years before the symptoms of memory loss appear.

Congress is still working to finalize the FY 2018 appropriations bills, but we have seen important progress. In September, the full Senate Appropriations Committee approved a proposed \$414 million increase for Alzheimer's research at NIH and a few months earlier, the full House Appropriations Committee approved a proposed \$400 million increase. This significant increase is an important investment in research that will provide relief for millions of Americans and to federal spending. 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.

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 research 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 effectively treating and preventing Alzheimer's by 2025.

The Alzheimer's Association and AIM urge Congress to fund the promising research targets outlined in the Professional Judgment Budget by supporting an additional \$425 million for NIH Alzheimer's funding in FY 2019.

Conclusion

The Alzheimer's Association and AIM appreciate the steadfast support of Representative Betty McCollum and her important work on the House Appropriations Committee. We thank her and other bipartisan champions in Congress for supporting the historic \$400 million increase for Alzheimer's research activities at NIH in FY 2017, and the pending request of an additional \$414 million for Alzheimer's research funding for FY 2018. However, the current funding level is still short of the total funding scientists believe is needed to meet the goal of preventing and treating Alzheimer's by 2025. We look forward to continuing to work with Representative McCollum and her colleagues to address the growing Alzheimer's crisis. We ask Congress to continue 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.