

Testimony of Rachel Conant, Senior Director of Federal Affairs, Alzheimer's Association and Senior Political Director of the Alzheimer's Impact Movement

The Alzheimer's Association and Alzheimer's Impact Movement (AIM) appreciate the opportunity to testify on the Fiscal Year (FY) 2020 appropriations for Alzheimer's research and public health activities at the U.S. Department of Health and Human Services. Specifically, we respectfully request a \$350 million increase for Alzheimer's research at the National Institutes of Health (NIH) and \$20 million for implementation of the Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act (P.L. 115-406) at the Centers for Disease Control and Prevention (CDC).

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 American Families and the Economy

The most important reason to address Alzheimer's is because of the suffering it causes to millions of Americans and their families. 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. We have yet to celebrate the first survivor of this devastating disease.

In addition to the 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. According to an NIH-funded study published in the *New England Journal of Medicine*, Alzheimer's is the most expensive disease in America, with costs set to skyrocket at unprecedented rates. While there are over 5 million Americans currently living with the disease, without significant action, as many as 14 million Americans will have Alzheimer's by 2050 and costs will exceed \$1.1 trillion (in 2019 dollars). 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 *2019 Alzheimer's Disease Facts and Figures* report, in 2019 America will spend an estimated \$290 billion in direct costs for those with Alzheimer's, including \$195 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.

Investing in Alzheimer's Treatments

Congress unanimously passed the National Alzheimer's Project Act (NAPA) (P.L. 111-375) in 2010, 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. The primary research goal of the National Plan is to prevent and effectively treat the disease by 2025.

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 2025 goal. **The Alzheimer's Association and AIM urge Congress to fund the research targets outlined in the Professional Judgment Budget by supporting an additional \$350 million for NIH Alzheimer's funding in FY 2020.**

Recent funding increases have been critical to progress toward the primary research goal to effectively treat and prevent Alzheimer's by 2025 – including advances into new biomarkers to detect the disease; building better animal models to enable preclinical testing of promising therapeutics; and bolstering the Alzheimer's research workforce to enable the expertise, experience, and new thinking needed to understand the complex causes of Alzheimer's disease and related dementias.

However, Alzheimer's continues to be the only leading cause of death in the United States without a way to prevent, cure, or even slow its progression. The primary reason this remains true is that investment in Alzheimer's research is still only a fraction of what's been applied over time to address other major diseases. Between 2000 and 2017, the number of people dying from Alzheimer's increased by 145 percent while deaths from other major diseases have decreased significantly or remained approximately the same.

It is vitally important that NIH continues to increase the investment in Alzheimer's research so we can see the same promising advances that other major diseases have realized with sustained, robust funding. An increase of \$350 million in FY 2020 would allow scientists to target a precision medicine approach to deliver the right treatments at the right stage of the disease; enable NIH to follow up on successful Phase I drug trials by initiating more Phase II trials focused on new therapeutic targets; and support the inclusion of Alzheimer's phenotype and environmental exposure measures in non-Alzheimer's cohorts, like cardiovascular disease and cancer, which have a wealth of data that could unlock new discovery research and accelerate cross-validation of discoveries made in Alzheimer's cohorts.

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.

Addressing Alzheimer's as a Public Health Crisis

As scientists continue to search for a way to cure, treat, or slow the progression of Alzheimer's through medical research, public health plays an important role in promoting cognitive function and reducing the risk of cognitive decline. Investing in a nationwide Alzheimer's public health response will help create population-level improvements, achieve a higher quality of life for those living with the disease and their caregivers, and reduce associated costs.

Last year, Congress acted decisively to address Alzheimer's as an urgent and growing public health crisis through the passage of the BOLD Infrastructure for Alzheimer's Act (P.L. 115-406). This strong bipartisan law authorizes \$100 million over five years for the CDC to build a robust Alzheimer's public health

infrastructure across the country. **The Alzheimer's Association and AIM urge Congress to include the full \$20 million for the first year of BOLD's implementation at CDC in FY 2020.**

With this important funding, CDC will establish Alzheimer's and Related Dementias Public Health Centers of Excellence across the country and fund state, local, and tribal public health departments to increase early detection and diagnosis, reduce risk, prevent avoidable hospitalizations, reduce health disparities, support the needs of caregivers, and provide care planning for people living with the disease. These important public health actions can allow individuals with Alzheimer's to live in their homes longer and delay costly long-term nursing home care. The law also aims to increase the analysis and timely reporting of data. This data is critical to identifying opportunities for public health interventions, helping stakeholders track progress in the public health response, and enabling state and federal policymakers to make informed decisions when developing plans and policies.

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 previous increases in Alzheimer's research activities at NIH, but the current funding level is still short of the total investment needed to meet the National Plan's primary research goal of finding a treatment or cure for Alzheimer's and other dementias by 2025. We ask Congress to continue to address Alzheimer's with the bipartisan collaboration demonstrated in previous years by providing an additional \$350 million for Alzheimer's research activities at NIH and \$20 million for implementation of the BOLD Infrastructure for Alzheimer's Act at CDC in FY 2020.