

## **Alzheimer's Association and Alzheimer's Impact Movement Statement for the Record**

### **United States Senate Committee on Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies Hearing on "Review of Coronavirus Response Efforts"**

**September 16, 2020**

The Alzheimer's Association and Alzheimer's Impact Movement (AIM) appreciate the opportunity to submit this statement for the record for the Senate Committee on Appropriations, Subcommittee on Labor, Health and Human Services, Education, and Related Agencies hearing entitled "Review of Coronavirus Response Efforts." The Association and AIM thank the Subcommittee for its continued leadership on issues important to the millions of people living with Alzheimer's and other dementia and their caregivers. This statement provides an overview of urgent policies that are needed now to protect this vulnerable population during the COVID-19 pandemic and beyond, including actions for the long-term care community, robust FY21 funding for Alzheimer's activities at the CDC and NIH, and efforts to expand capacity for health outcomes through Project ECHO.

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 dementia 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. 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.

#### **COVID-19 Impact on Long-Term Care**

Nursing homes and assisted living communities are on the frontlines of the COVID-19 crisis, where 48 percent of nursing home residents are living with dementia, and 42 percent of residents in residential care facilities have Alzheimer's or another dementia. Residents with dementia are particularly susceptible to COVID-19 due to their typical age, their significantly increased likelihood of coexisting chronic conditions, and the community nature of long-term care settings. Across the country these facilities, their staff, and their residents are experiencing a crisis due to a lack of transparency, an inability to access the necessary testing, inaccurate reporting, and more. According to some reports, nearly 70,000 residents and employees of nursing homes and long-term care facilities have died, representing more than 40 percent of the total death toll in the United States.

The Alzheimer's Association released policy recommendations, [\*Improving the State and Federal Response to COVID-19 in Long-Term Care Settings\*](#), to address both the immediate and long-term issues impacting these settings during the COVID-19 pandemic. These recommendations focus on four main areas: enhancing rapid, point-of-care testing in long-term care community

settings; implementing timely reporting; developing protocols to respond to a rise in cases; and ensuring all facilities have necessary support, like personal protective equipment (PPE) and televisitiation services.

It is absolutely imperative that each nursing home and residential care community have the onsite testing capability to verify that all residents, staff, and visitors are free of COVID-19 infection, whether or not they are symptomatic. We appreciate the Administration's recent purchase of 150 million rapid tests, a portion of which we expect will be directed to long-term care settings. We also appreciate the recent announcement by the Centers for Medicare and Medicaid Services (CMS) that certain nursing home workers should receive testing as frequently as twice a week. However these actions still fall woefully short of what is urgently needed to protect the vulnerable Americans living in long-term care communities. We continue to advocate for the "White House Standard" of daily rapid-response testing for all new individuals who come onsite, and retesting for returning individuals who enter the facility, in accordance with local guidance. We also support the immediate and accurate reporting of long-term care COVID-19 cases. These reports should be updated upon remission, death, transfer, or other appropriate status update. With all appropriate privacy safeguards for individuals, this reported data should be freely and immediately accessible to everyone, down to the facility level. Any reported cases should trigger careful, ongoing monitoring and, if conditions warrant, "strike teams" should be deployed to provide needed support until the outbreak is appropriately contained and eliminated. It is also essential that all nursing homes and residential living communities have full, timely access to all needed PPE, testing equipment, training, and external support to keep them COVID-19-free. Importantly, this includes requiring these settings to address social isolation and ensure people with Alzheimer's and other dementia are able to communicate with their family and friends.

### **FY2021 Alzheimer's Appropriations at CDC and NIH**

Now more than ever it is apparent how crucial it is to have an established infrastructure in place to respond to public health threats. 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. The Alzheimer's Association and AIM thank the Subcommittee for its leadership in providing the Centers for Disease Control and Prevention (CDC) \$10 million in FY20 to implement the first year of the BOLD Infrastructure for Alzheimer's Act (P.L. 115-406). This funding enabled CDC to recently award three Public Health Centers of Excellence, one focused on Dementia Risk Reduction, one on Dementia Caregiving and one on Early Detection of Dementia. CDC also awarded BOLD funding to 16 public health departments at the state, local and tribal level. While this funding is an important step forward, CDC must receive the full \$20 million authorized for FY21 to ensure the meaningful impact that Congress intended.

Furthermore, as the current pandemic has shown, continued investment in medical research is absolutely critical to understanding and responding to diseases. We thank the Subcommittee for its leadership in providing a \$350 million increase in Alzheimer's research funding at the National

Institutes of Health (NIH) in FY20. However, 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. Therefore we urge the Subcommittee to fund the research targets outlined in the Alzheimer's Professional Judgment Budget by supporting an additional \$354 million for NIH Alzheimer's funding in FY21.

### **Expanding Capacity for Health Outcomes (Project ECHO)**

Finally, we ask the Subcommittee to support provisions to expand the use of technology-enabled collaborative learning and capacity-building models. These education models, often referred to as Project ECHO, can improve the capacity of providers, especially those in rural and underserved areas, on how to best meet the needs of people living with Alzheimer's. During the COVID-19 pandemic, Project ECHO is helping primary care physicians in real-time understand how to use validated assessment tools appropriate for virtual use to make early and accurate diagnoses, educate families about the diagnosis and home management strategies, and help caregivers understand the behavioral changes associated with Alzheimer's, which can be heightened during isolation. Project ECHO is also helping long-term care providers understand in real-time how to train temporary staff that may not be familiar with how to best care for people with Alzheimer's, implement important health strategies such as hand-washing and social distancing for people with Alzheimer's, and effectively communicate with residents to help them understand the COVID-19 pandemic. In fact, the Alzheimer's Association developed a special topic [Project ECHO dementia series](#) to help assisted living communities during COVID-19 based on our guidelines, [Emergency Preparedness: Caring for persons living with dementia in a long-term or community-based care setting](#).

### **Conclusion**

The Alzheimer's Association and AIM appreciate the steadfast support of the Subcommittee and its priority setting activities, especially during this time. However, our nation must do more to support the millions of Americans living with Alzheimer's and other dementia, and their caregivers. We urge the Subcommittee and other members of Congress to work in a bipartisan way to advance policies that will help protect this vulnerable population during the COVID-19 pandemic and beyond, including actions for the long-term care community, robust FY21 funding for Alzheimer's activities at the CDC and NIH, and efforts to expand capacity for health outcomes through Project ECHO.