

The Honorable Nita Lowey
Chairwoman, House Appropriations Committee
H-307, The Capitol
Washington, DC 20515

May 14, 2020

Dear Chairwoman Lowey:

On behalf of the Alzheimer's Association and the Alzheimer's Impact Movement (AIM), including our nationwide network of advocates, thank you for your continued leadership on issues and legislation important to Americans living with Alzheimer's and other dementia, and to their caregivers. The Alzheimer's Association and AIM especially appreciate provisions in the Health and Economic Recovery Omnibus Emergency Solutions (HEROES) Act, which would help people living with Alzheimer's and other dementia during the coronavirus pandemic.

The COVID-19 pandemic continues to create additional challenges for people living with dementia, their families, and caregivers. These challenges are particularly being felt in long-term care settings. 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 estimates, more than 27,000 residents and workers have died from the coronavirus at nursing homes and other long-term care communities.

The Alzheimer's Association and AIM thank you for including numerous policies that would help protect this vulnerable population in nursing homes. These crucial provisions are consistent with the Alzheimer's Association's recently released policy recommendations, [*Improving the State and Federal Response to COVID-19 in Long-Term Care Settings*](#). These recommendations focus on enhancing testing in long-term care community settings, implementing necessary reporting, developing protocols to respond to a rise in cases, and ensuring all facilities have the necessary equipment, like personal protective equipment (PPE). As "hot spots" occur, they must be dealt with urgently and effectively. Any reported cases should trigger careful, ongoing monitoring and, if conditions warrant, "strike teams" should be deployed to the facility to provide needed support until the outbreak is contained and eliminated. This bill provides funding for States to establish and implement "strike teams" to deploy to nursing homes within 72 hours of three residents or employees being diagnosed with or who are suspected of having COVID-19. Additionally, we appreciate the prioritization of infection control in nursing facilities as well as data collection and reporting on COVID-19 in nursing homes. Our policy recommendations suggest all cases of COVID-19 at nursing homes and assisted living communities need to be reported immediately and accurately. 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 all down to the facility level.

The Alzheimer's Association and AIM also thank you for including crucial 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 in real-time understand 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.

We were also encouraged to see the inclusion of \$100 million for the Administration for Community Living to ensure continued access to direct services such as home-delivered and prepackaged meals, and supportive services for seniors and disabled individuals, and their caregivers.

The Alzheimer's Association and AIM also support provisions to extend paid leave for employees that are caring for a family member that is self-isolating, regardless of the size of their employer. These provisions include people engaged in caregiving for seniors whose place of care or direct care provider is unavailable. This could be especially beneficial in light of the 31 percent of individuals using adult day services that have Alzheimer's or other dementia. Providing paid leave to these caregivers would greatly help ease the financial and emotional burden placed on them during this particularly vulnerable time.

There are several additional policies that we hope you will consider for inclusion as you work to finalize and pass the HEROES Act. The *Promoting Alzheimer's Awareness to Prevent Elder Abuse Act* (H.R. 6813/S. 3703) would improve interactions between justice personnel and people with Alzheimer's and other dementia. With the current COVID-19 pandemic and given the growing population of persons with dementia, police, firefighters, emergency personnel, and social workers will increasingly encounter these vulnerable individuals, and working with them can be fundamentally different from working with other older victims of abuse or exploitation. For example, individuals living with dementia often have difficulty understanding or explaining situations. Common behaviors experienced by individuals living with Alzheimer's and other dementias could be viewed as uncooperative, disruptive, or combative unless professionals have training on the unique needs of someone living with dementia. This bipartisan bill is consistent with the *National Plan to Address Alzheimer's Disease* and will help ensure greater success for the Department of Justice's efforts to combat elder abuse, neglect, and financial fraud targeting seniors. This bill would require the Department of Justice to develop training materials to assist professionals supporting victims of abuse living with Alzheimer's and other dementia. Dementia-specific training materials for these professionals will improve the quality of their interactions with individuals living with Alzheimer's and other dementia, and will also help protect them from elder abuse.

We also ask that you include the bipartisan Improving HOPE for Alzheimer's Act (H.R. 1873/S. 880), which would educate clinicians on Alzheimer's and dementia care planning services available through Medicare. As the COVID-19 pandemic continues to challenge health systems worldwide, it raises many important issues including care planning in the presence of acute life-threatening illness, especially for patients with chronic diseases like Alzheimer's and other dementia. Robust care planning is the first step to learning about long-term care options and selecting the preferred, most appropriate services for persons with dementia, families, and caregivers. Analyses show dementia-specific care planning can lead to fewer hospitalizations, fewer emergency room visits, and better medication management. Alzheimer's and related dementia also complicate the management of other chronic conditions, so care planning is key to their management and better care coordination. The availability of CPT® code 99483, care planning for persons with cognitive impairment, is an important step in that direction; however we must ensure that clinicians are aware of this code. Nearly half of Congress has cosponsored this vital legislation.

Finally, we appreciate your work to improve access to credit for large nonprofits like the Alzheimer's Association and ask that you continue to refine the Paycheck Protection Program and the Main Street Lending Program. Nonprofits of all sizes are essential to the well-being of our communities, and communities are relying on nonprofits now more than ever. We have continued our mission during the pandemic, providing care consultations, caregiving tips, and 24/7 access to free, confidential support. But the financial impact of the crisis threatens our ability to continue to serve all those touched by Alzheimer's and dementia--a population that will only grow in the coming years. While the changes to the Paycheck Protection Program and the Main Street Lending Program in the bill are important steps, they do not go far enough for large charities like the Alzheimer's Association. We continue to support the *Help Charities Protect Communities Act* sponsored by Congresswoman Beatty. This legislation will help large nonprofits gain access to credit by requiring the Treasury Secretary to provide loans and loan guarantees through the mid-size lending program within the CARES Act and create a mechanism for loan forgiveness. This is critical, as each dollar spent on loan and interest repayment is a dollar diverted from our constituents.

Again, the Alzheimer's Association and AIM deeply appreciate your continued leadership on behalf of all Americans living with Alzheimer's and other dementia. If you have any questions about this or any other legislation, please contact Rachel Conant, Vice President of Federal Affairs, at rconant@alz-aim.org or at 202.638.7121.

Sincerely,



Robert Egge
Chief Public Policy Officer
Executive Vice President, Government Affairs
Alzheimer's Association