



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

United States House Committee on Energy and Commerce Subcommittee on Health Hearing on "Caring for America: Legislation to Support Patients, Caregivers, and Providers."

October 26, 2021

The Alzheimer's Association and Alzheimer's Impact Movement (AIM) appreciate the opportunity to submit this statement for the record for the House Committee on Energy and Commerce Subcommittee on Health hearing entitled "Caring for America: Legislation to Support Patients, Caregivers, and Providers." 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 and are glad to see today's consideration of the bipartisan *Alzheimer's Caregiver Support Act* (H.R. 1474/S.56).

The Alzheimer's Association is the world's leading voluntary health organization in Alzheimer's care, support, and research. It 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. AIM is the advocacy affiliate 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 is emotionally, physically, and financially draining for individuals and families. It is also creating an enormous strain on the health care system, as well as federal and state budgets. An estimated 6.2 million Americans age 65 and older are living with Alzheimer's dementia in 2021. Total payments for all individuals with Alzheimer's or other dementias are estimated at \$355 billion (not including unpaid caregiving) in 2021. Medicare and Medicaid are expected to cover \$239 billion, or 67 percent, of the total health care and long-term care payments for people with Alzheimer's or other dementias. Total payments for health care, long-term care, and hospice care for people with Alzheimer's and other dementias are projected to increase to more than \$1.1 trillion in 2050, not adjusted for inflation. These mounting costs threaten to bankrupt families, businesses, and our health care system.

Alzheimer's Caregiver Support Act

The burden of caring for an individual with Alzheimer's and other dementias extends to millions of Americans. In 2020, more than 11 million unpaid caregivers provided 15.3 billion hours of care valued at nearly \$257 billion. And while caregiving is often rewarding, the intense responsibilities that accompany it are often challenging. More than half of dementia caregivers report having no experience performing medical or nursing related tasks. Additionally, dementia caregivers are twice as likely as other caregivers to report these tasks are difficult. The

bipartisan *Alzheimer's Caregiver Support Act* (H.R. 1474/S.56) would provide grants for training and support services for families and unpaid caregivers of individuals living with Alzheimer's disease or another dementia.

Jakara Hubbard, an Alzheimer's Association advocate from Illinois, is a caregiver for her mother who is living with vascular dementia. Jakara's family has a history of dementia so the progression of the disease was familiar to her. However, Jakara and her father have experienced challenges while learning the day-to-day responsibilities of caring for a loved one with dementia. They have had difficulties receiving consistent in-home care for Jakara's mother, leaving them to do the primary physical tasks of caregiving. Jakara is a licensed therapist, and while she has a good foundation for the mental and emotional toll caregiving takes on families, she struggles with the practical aspects of caregiving, like having to change diapers and how best to assist someone who is combative or hesitant to receive help. Grants established by the *Alzheimer's Caregiver Support Act* could provide the much needed practical virtual training on the physical aspects of caregiving. The grants can also be used to make available online resources on different types of activities to do with someone with dementia, especially as the types of activities someone living with the disease can actively engage in changes over time. With so many things to consider, immediate access to educational resources and information for caregivers can become a reality through the grants established by this legislation.

Priority Legislation

The Association and AIM look forward to working with the Subcommittee on our priority legislation, the bipartisan *Comprehensive Care for Alzheimer's Act* (H.R. 2517/S. 1125), led by Reps. Brian Higgins, Darin LaHood, Paul Tonko, and Health Subcommittee Ranking Member Brett Guthrie, and the bipartisan *Equity in Neuroscience and Alzheimer's Clinical Trials (ENACT) Act* (H.R. 3085/S. 1548) led by Reps. Lisa Blunt Rochester, Jaime Herrera Beutler, John Curtis, Chris Smith, and Maxine Waters. Each of these bills is critical in the fight against Alzheimer's, and given the Subcommittee's jurisdiction over policies important to the Alzheimer's and dementia community, we ask for their consideration too.

Comprehensive Care for Alzheimer's Act

Caring for an individual living with Alzheimer's or another dementia is unique. Most families provide a large amount of care, which can be intrusive and exhausting, and more than 95 percent of individuals living with dementia have one or more chronic conditions, requiring them to seek multiple avenues of medical care. This forces those living with the disease to navigate a complicated health care maze. The *Comprehensive Care for Alzheimer's Act* (H.R. 2517/S. 1125) would ask the Center for Medicare and Medicaid Innovation (CMMI) to implement a dementia care management model to test the effectiveness of comprehensive care management services. Dementia care management has been proven to reduce health care costs while improving quality of life for those living with dementia and their families. However, a change in the payment structure under Medicare is necessary to allow this model to develop. The *Comprehensive Care for Alzheimer's Act* would help address that issue.

Equity in Neuroscience and Alzheimer's Clinical Trials (ENACT) Act

Alzheimer's and other dementia disproportionately affect older Black and Hispanic Americans compared to older Whites. Black Americans are twice as likely to develop Alzheimer's, and Hispanic Americans are one and a half times more likely to develop the disease. However, much of the Alzheimer's research to date has not included sufficient numbers of Blacks, Hispanics, Asian Americans/Pacific Islanders, and Native Americans to be representative of the U.S. population. This limits our understanding of these health disparities, and how an approved therapy or diagnostic may affect the population most likely to need the treatment. The bipartisan *ENACT Act* (H.R. 3085/S. 1548) would address underrepresentation in Alzheimer's and other dementia clinical trials by expanding education and outreach to these populations, through entities like Historically Black Colleges and Universities and Hispanic-Serving Institutions, and encouraging the diversity of clinical trial staff, through trainings, grants, and awards established through the National Institute on Aging. It would also reduce the participation burden to make it easier for underrepresented populations to participate in clinical trials by providing incentives for locating Alzheimer's clinical trial sites in areas with high concentrations of underrepresented populations.

Conclusion

Since its reintroduction earlier this year, the bipartisan *Alzheimer's Caregiver Support Act* continues to build support in both chambers but especially in the House, where more than 150 bipartisan members have signed on in support of the bill. The Alzheimer's Association and AIM appreciate the steadfast support of the Subcommittee and its continued commitment to advancing legislation important to the millions of families affected by Alzheimer's and other dementia, including the *Alzheimer's Caregiver Support Act*. Thank you for holding this important hearing, and we look forward to working with you and other members of Congress to ensure this bill and our other bipartisan legislative priorities are enacted into law.