



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

United States House of Representatives Committee on Energy and Commerce, Health Subcommittee Legislative Hearing on "Legislative Proposals to Support Patients and Caregivers."

February 14, 2024

The Alzheimer's Association and Alzheimer's Impact Movement (AIM) appreciate the opportunity to submit this statement for the record for the House Energy and Commerce, Health Subcommittee legislative hearing on "Legislative Proposals to Support Patients and Caregivers." The Association and AIM thank the Subcommittee for considering four key pieces of legislation that have been instrumental in prioritizing our nation's response to the widespread and growing impact of Alzheimer's disease on over 6 million Americans, their 11 million caregivers, and society as a whole. The Association and AIM are proud to support the **NAPA Reauthorization Act (H.R. 619/S. 133)**, the **Alzheimer's Accountability and Investment Act (H.R. 620/S. 134)**, the **BOLD Infrastructure for Alzheimer's Reauthorization Act (H.R. 7218/S. 3775)**, and the **Lifespan Respite Care Reauthorization Act (H.R. 6160)**. We are grateful to the Subcommittee and the champions leading these bipartisan bills for their timely consideration today. Congress must reauthorize these laws now to ensure our country continues to advance policies that improve the lives of people living with dementia, and their families.

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 advocacy affiliate, working in a 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 the development of approaches to reduce the risk of developing dementia.

As too many of us know from personal experience with family or friends, Alzheimer's is a progressive brain disease that damages and eventually destroys brain cells, leading to a loss of memory, thinking, and other cognitive functions. Ultimately, Alzheimer's is fatal. We have yet to celebrate the first survivor of this devastating disease. By 2050, an estimated 13 million Americans will be living with Alzheimer's, and total payments for all individuals with Alzheimer's or other dementia are projected to increase to more than \$1.1 trillion. These mounting costs threaten to bankrupt families, businesses, and our health care system. Unfortunately, our work is only growing more urgent.

The NAPA Reauthorization Act (H.R. 619/S. 133) and the Alzheimer's Accountability and Investment Act (H.R. 620/S. 134)

In 2011, Congress passed the bipartisan National Alzheimer's Project Act (NAPA) (P.L. 111-375), resulting in the landmark [*National Plan to Address Alzheimer's Disease*](#) (The National Plan). The National Plan, which is updated by the Department of Health and Human Services



(HHS) annually, continues to drive meaningful action, creating and address Alzheimer's and other dementia on both national and state the creation of the Advisory Council on Alzheimer's Research, Care, and Services, which is a panel of federal and non-federal experts that convene regularly to provide recommendations and annually update the coordinated strategic National Plan, including Dr. Joanne Pike, president and Chief Executive Officer of the Alzheimer's Association and Chief Executive Officer of the Alzheimer's Impact Movement.

While the National Plan has driven enormous progress in research, clinical and long-term care, and public awareness, we still have much work to do. For the first time, Alzheimer's patients have treatments that slow disease progression. The FDA's approval of these therapies was a historic moment for the Alzheimer's community and, as research continues, the scientific community expects better and more effective treatments. Patients are having difficulty accessing these new therapies, which only underscores the need for a clear, consistent, and updated national strategy to reflect the strides the field has made and the progress we need to protect.

The bipartisan NAPA Reauthorization Act (H.R. 619/S. 133) would extend this important work through 2035 and modernize the law to reflect strides the field has made in understanding the disease, such as including a new focus on promoting healthy aging and reducing risk factors. The bill would also add new federal representatives to the Advisory Council, including those from the Social Security Administration, Department of Justice, and Federal Emergency Management Agency. These representatives can provide unique insight and focus on timely issues, like Social Security Disability Insurance, elder abuse and law enforcement training, and disaster preparedness, for this vulnerable population. Adding these Agencies to the Advisory Council now is critical to ensuring the federal government addresses these issues in a coordinated way at the national level. Reauthorizing NAPA ensures the continuity of vital initiatives, fostering advancements in understanding, treatment, and care for individuals living with Alzheimer's disease and other dementia.

The 2015 Alzheimer's Accountability Act (P.L. 113-235) complements NAPA's efforts by ensuring the National Institutes of Health (NIH) receives the funding and resources essential to making meaningful research progress in the fight against Alzheimer's. The law requires the NIH to annually submit a professional judgment budget, or bypass budget, which is an estimate of the investment needed to reach the goals of the National Plan. Strong funding for Alzheimer's research is vital for advancing scientific research, developing effective diagnostics and treatments, and improving the quality of care and support available to those affected by the disease. This annual bypass budget has been a crucial blueprint for Congress, enabling historic increases in Alzheimer's research investments and leading to a more than seven-fold increase in Alzheimer's funding at NIH over the past decade.

The approval of new Alzheimer's treatments is amplifying the urgency of detecting the disease early. Blood biomarker tests will revolutionize the detection and diagnosis of Alzheimer's, and these funding increases over the past decade have enabled groundbreaking advancements, including improved blood biomarker test accuracy. These blood-based biomarkers indicate the likelihood of amyloid or tau accumulation in the brain and track changes in protein levels in response to treatment. NIH investment is also advancing researchers' understanding of the risk factors, genetics, and mechanisms of dementia, diversifying and de-risking the therapeutic



pipeline, and expanding research on dementia care and care part must continue as there is much farther to go and the population of the only continues to grow.

Reauthorizing this law through the bipartisan Alzheimer's Accountability and Investment Act (AAIA) (H.R. 620/S. 134) will reinforce Congress' commitment to prioritizing the resources needed to address the multifaceted challenges posed by Alzheimer's and other dementia. AAIA would ensure NIH continues to submit an Alzheimer's annual bypass budget to Congress and the President through 2035.

The NAPA Reauthorization Act and AAIA have strong bipartisan, bicameral support in Congress. Enacting these bills now would provide HHS the certainty and stability to continue both immediate and long-term planning for a strategic nationwide approach to Alzheimer's and other dementia. The Subcommittee action today builds upon Senate momentum, following the Senate Health, Education, Labor, and Pensions (HELP) Committee's June 2023 markup of the bills. During that process, NAPA was modified to highlight the importance of including representation from the Down syndrome community in Alzheimer's clinical, research and service efforts, given the increased prevalence of the disease in this population. According to the National Down Syndrome Society, individuals with Down syndrome have a lifetime risk of developing Alzheimer's disease that is higher than 90 percent. Scientists believe this increased risk of dementia results from the extra genes present. Today, people with Down syndrome are living longer than at any other time in the past. When NAPA was signed into law more than a decade ago, we did not know that individuals with Down syndrome were disproportionately at risk for developing Alzheimer's. We look forward to working with the Subcommittee on similar changes as these bills move through the legislative process in the House of Representatives.

The BOLD Infrastructure for Alzheimer's Reauthorization Act (H.R. 7218/S. 3775)

We are also grateful to Subcommittee Chairman Brett Guthrie and Committee member Congressman Paul Tonko for their leadership on the 2018 Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act (P.L. 115-406), and recent efforts to reauthorize this important law. The BOLD Act has enabled communities nationwide to implement public health strategies that promote brain health, increase early detection, address dementia, and support people living with dementia and their caregivers. The BOLD Act provides an avenue for the activation of advances in knowledge to be integrated into our public health infrastructure. Public health can integrate brain health messages into existing, relevant public health campaigns, acknowledging the growing evidence that healthy living can reduce the risk of cognitive decline and may reduce the risk of dementia. Public health can also undertake public awareness campaigns to promote early detection and diagnosis, and can educate medical professionals about assessment tools, which is critical to ensuring access to treatment. Public health can also increase access to care and services by ensuring providers are trained in evidence-based care guidelines, and people living with dementia and their caregivers have the support and resources they need in their communities.

Since its enactment, the CDC has made 66 awards to 45 state, local, and tribal public health departments. These award recipients are working to implement public health strategies tailored to local populations as well as create, update, and operationalize state plans to address Alzheimer's disease. The CDC has also awarded funding to three Public Health Centers of



Excellence each focusing on a priority public health area of need: de
detection of dementia, and dementia caregiving. Together, this infra
strategies from [The Healthy Brain Initiative: State and Local Road Map for Public Health](#) and
[Healthy Brain Initiative Road Map for Indian Country](#), which provide a framework for BOLD
award recipients to lead with urgency and act for impact in their communities to improve brain
health across the life course and support caregivers.

The BOLD Act continues to make a significant impact on communities across the country. For
example, in Kentucky, BOLD funding is increasing the state's capacity to operationalize its
Kentucky State Alzheimer's Plan. Kentucky's initial investment in Alzheimer's disease and other
dementia led to the creation of a full-time state agency Dementia Services Coordinator staff
position which was a catalyst for their application to the BOLD Program award. In September
2023, the Kentucky Department for Public Health was awarded a BOLD Public Health Program
Component 1 award to develop strategic statewide strategies to address Alzheimer's disease.
This funding is already allowing the state to support the work of Kentucky's Office of Dementia
Services.

Using the HBI Road Map, the state of Washington has expanded its public health infrastructure
to increase the populations served and discuss dementia throughout the continuum of disease,
from risk reduction to the late stages of the disease. For example, the Washington State
Department of Health released guidance to local health departments on effective ways to use
the HBI Road Map and conducted an internal agency evaluation to assess its ability and identify
potential gaps in addressing Alzheimer's and caregiving needs. The state has also allocated
funding to support the statewide expansion of dementia-specific public awareness efforts at the
Memory and Brain Wellness Center at the University of Washington and to other state-led public
awareness efforts aimed at reducing the stigma surrounding dementia as well as educating
physicians about the importance of the early detection and diagnosis of Alzheimer's. This work
led to the CDC awarding the Washington State Department of Health with the state's BOLD
Public Health Program Component 2 award in September 2023, which will allow the state to
expand upon these actions.

In September 2020, Wisconsin received a BOLD Public Health Program Component 1 award,
and, through this grant, the Wisconsin Department of Health Services is utilizing existing public
health infrastructure to increase early detection and diagnosis, reduce the risk of developing
dementia, and support dementia caregiving. Wisconsin is in the process of implementing the
Wisconsin State Dementia Plan: 2019–2023, its third state dementia plan. The current state
plan has four areas of focus: care provided in communities where people live; improving how
health care providers diagnose and care for people with dementia; responding to crises
involving people with dementia; and care provided in assisted living, nursing homes, and other
residential facilities. Further, a steering committee, led by the Department of Health Services,
was established to ensure the state plan is implemented with the assistance of four "leadership
teams" (work groups) that are responsible for assisting the Steering Committee in each of the
four focus areas: care in the communities, health care, crisis response, and facilities-based
care. The CDC awarded Wisconsin with its second BOLD award in September 2023, which will
allow the state to continue building upon the great progress made thanks to its first award in
2020.



California recognized its need for a comprehensive Alzheimer's public health approach and used the resources provided by the federally funded Healthy Brain Initiative (HBI) as a framework to establish the California Healthy Brain Initiative. For this, six local health departments across the state produced action plans, and educational outreach materials and conducted 101 media campaigns for the public. Furthering implementation of the actions in the [2018 HBI Road Map](#), California appropriated funds to the state Medicaid program to establish [Dementia Care Aware](#) in 2021, a statewide program providing primary care providers with the information and tools needed to successfully administer cognitive health assessments and determine the appropriate next steps for the patients. In 2020, the County of Los Angeles received a BOLD Public Health Program Component 1 award, and in September 2023, the county received a BOLD Public Health Program Component 2 award to continue this work. The California State Department of Public Health received its first BOLD Public Health Program Award in September 2023, when the CDC awarded the state with a BOLD Public Health Program Component 2 award to amplify its existing efforts to address Alzheimer's disease.

The Vermont Department of Health received a BOLD Public Health Program Component 2 award from the CDC in September 2020, and, in September 2021, the department launched a virtual Project ECHO series to help build capacity for dementia diagnosis and care. Over 80 participants joined the first session of this monthly telementoring program run through the Area Health Education Center at the University of Vermont's (UVM) Larner College of Medicine. The Department of Health also offers monthly "Dementia Corner Consults" for primary care providers and their teams, led by the medical director of the UVM Memory Program. Additionally, in October 2021, the Vermont Department of Health published a data brief on Risk Factors for Subjective Cognitive Decline in Vermonters. The CDC awarded Vermont with its second BOLD award in September 2023, which will allow the state to continue building upon the great progress made thanks to its first award in 2020.

Underscoring the importance of a public health approach to addressing Alzheimer's and dementia in our communities, while New Jersey does not currently receive BOLD funding, the state is active in developing Alzheimer's public health initiatives. For example, the New Jersey Alzheimer's Disease Study Commission was established in 2011 to study the current and future impact and incidence of Alzheimer's within the state. The New Jersey Alzheimer's Disease Study Commission Report was published in August 2016 and examined services within the state to meet the needs of those affected by Alzheimer's. Most recently in 2023, the New Jersey Department of Health participated in a public health program called Data for Action, a project of the HBI designed to support the integration of data on brain health and caregiving into public health planning efforts. This has allowed the health department to produce state-specific data on risk factors for Alzheimer's and other dementia as well as identify links between cognitive changes and other chronic conditions and health behaviors. New Jersey now plans to use their work to educate members of the public and inform key decision-makers on how to advance public health action on brain health.

These are just a few of the many examples of the innovation stemming from Alzheimer's investment across the country. BOLD has clearly led to great progress in building and



strengthening the Alzheimer's public health infrastructure nationwide program is set to expire this year. The bipartisan BOLD Infrastructure Reauthorization Act of 2024 (H.R. 7218/S. 3775), introduced by Subcommittee Chairman Brett Guthrie and Committee member Congressman Paul Tonko, would extend this important law until 2029 and authorize \$33 million annually for five years, to reflect the program's current appropriated level. It is vital that Congress passes this bill and continues to invest in a nationwide Alzheimer's public health response that will help further population-level improvements, achieve a higher quality of life for those living with the disease and their caregivers, and reduce associated costs.

The Lifespan Respite Care Reauthorization Act (H.R. 6160)

Finally, we thank the Subcommittee for considering ways to help support caregivers of people living with chronic conditions, such as Alzheimer's and other dementia. Eighty-three percent of the help provided to all older adults in the United States comes from family members, friends, or other unpaid caregivers. Compared with caregivers of people without dementia, caregivers of those with dementia indicate more substantial emotional, financial, and physical difficulties. In 2022, caregivers of people living with Alzheimer's or another dementia provided an estimated 18 billion hours of unpaid care, a contribution valued at \$339.5 billion. The Lifespan Respite Care Program, administered by the Administration for Community Living, continues to play a crucial role in helping support these caregivers and enhancing the overall quality of life for people with chronic conditions or disabilities. The program provides funding opportunities to states that offer caregivers a temporary break from the heavy physical, mental, and financial tolls associated with caregiving that, all too often, go unnoticed. The Lifespan Respite Care program has also been very valuable for dementia care by providing caregivers with Alzheimer's and dementia education and training sessions. This can, in turn, improve the quality of life for both caregivers and their loved ones living with chronic conditions.

The Lifespan Respite Care Reauthorization Act (H.R. 6160) would extend this important program until 2028, which is essential for sustaining a supportive infrastructure that has been shown to help alleviate caregiver stress and enhance care quality for people with chronic conditions.

Conclusion

The Alzheimer's Association and AIM appreciate the Committee's steadfast support and commitment to advancing issues important to the millions of individuals living with Alzheimer's and other dementia, as well as their caregivers. We look forward to working with the Subcommittee and other members of Congress in a bipartisan way to reauthorize and extend these laws through the BOLD Infrastructure for Alzheimer's Reauthorization Act (H.R. 7218/S. 3775), NAPA Reauthorization Act (H.R. 619), the Alzheimer's Accountability and Investment Act (H.R. 620), and the Lifespan Respite Care Reauthorization Act (H.R. 6160). The swift reauthorization of these four important laws will underscore Congress' sustained commitment to a strategic approach to combating Alzheimer's disease and supporting caregivers nationwide and will enable further strides in understanding, treating, and ultimately preventing Alzheimer's and other dementia. Doing so will provide much-needed hope for the millions of families affected by this devastating disease.