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Written Testimony

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

February 14, 2024

Chairs McMorris Rodgers and Guthrie, Ranking Members Pallone and Eshoo, and members of the Subcommittee, my name is **Joanne Pike** and I am **the president and Chief Executive Officer of the Alzheimer's Association and Chief Executive Officer of the Alzheimer's Impact Movement**. Thank you for the opportunity to testify before you today to discuss four key pieces of bipartisan 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 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.

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 dementias 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.

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 implementing strategies to address Alzheimer's and other dementias on both national and state levels. NAPA also led to the creation of the Advisory Council on Alzheimer's Research, Care, and Services, on which I am honored to currently serve, which is a panel of federal and non-federal experts that convene regularly to provide recommendations and annually update the coordinated strategic National Plan.

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 partner support. This progress must continue as there is much farther to go and the population of those affected by this disease 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 dementias. 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 dementias. 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, about 30 percent of people with Down syndrome who are in their 50s have Alzheimer's dementia. About 50 percent of people with Down syndrome in their 60s have Alzheimer's dementia. 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.

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 activation of advances in knowledge to be integrated within 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: dementia risk reduction, early detection of dementia, and dementia caregiving. Together, this infrastructure helps implement 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.

To illustrate the real-world impact the BOLD Act is having in communities across the country, I would like to highlight a few examples. 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 dementias 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.

California recognized its need for a comprehensive Alzheimer's public health infrastructure 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.

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. 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.

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 dementias 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. However, this important program is set to expire this year. The bipartisan BOLD 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.

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.

The swift reauthorization of these four important laws through passage of the bipartisan NAPA Reauthorization Act (H.R. 619/S. 133), the Alzheimer's Accountability and Investment Act (H.R. 620/S.

134), the BOLD Reauthorization Act (H.R. 7218/S. 3775), and the Lifespan Respite Care Reauthorization Act (H.R. 6160) will underscore Congress' sustained commitment to a strategic approach to combating Alzheimer's disease and supporting caregivers nationwide. The timely passage of these bipartisan bills will enable further strides in understanding, treating, supporting, and ultimately preventing Alzheimer's and other dementias. Doing so will provide much-needed hope for the millions of families affected by this devastating disease. Thank you very much for the opportunity to testify before the Subcommittee today and I look forward to answering any questions you may have.