

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

# United States Senate Committee on Appropriations Hearing on "Biomedical Research: Keeping America's Edge in Innovation"

# April 30, 2025

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 hearing on "Biomedical Research: Keeping America's Edge in Innovation." We are grateful to the Committee and bipartisan champions in both chambers who have worked together to ensure our country continues to advance policies that improve the lives of people living with dementia and their families. We also thank you for reaffirming your commitment to the Alzheimer's and dementia community, while sounding the alarm about the impact cuts to the Department of Health and Human Services (HHS) will have on the progress in the fight against Alzheimer's and other dementia. It is crucial for officials to understand both the challenges of this fatal disease, the progress we have made, and the hope we have for the future in the fight to end Alzheimer's and all other dementia. Alzheimer's isn't a red or blue issue — it is purple. What unites us all is our shared vision of a world without Alzheimer's and all other dementia. We are at the moment when our knowledge and discoveries are changing the way we fight dementia. Now is the moment to do more, not less.

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. The Alzheimer's Impact Movement is the Association's separately incorporated advocacy affiliate, 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 and all other

dementia, including increased investment in research, improved care and support, and the development of approaches to reduce the risk of developing dementia.

Federally supported health research is a direct investment in the health, economy, and security of the United States. This research, conducted through partnerships involving federal agencies, academic institutions, and industry, produces discoveries that lead to longer, healthier lives, generates significant economic growth, and strengthens our nation's resilience against health threats. We have seen clear results: lower cancer death rates, life-saving vaccines, and effective treatments for many diseases. The National Alzheimer's Project Act (NAPA), enacted in 2011 and reauthorized unanimously in 2024 (P.L. 118-92), demonstrates how focused national commitment accelerates progress, particularly in Alzheimer's research.

However, major health challenges remain: Alzheimer's disease and related dementias (AD/ADRD), chronic diseases, the threat of pandemics, and health disparities. Alzheimer's disease illustrates the urgency. 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. According to the 2025 Alzheimer's Disease Facts and Figures, by 2050, the projected number of people age 65 and older living with Alzheimer's or other dementias are projected to increase to just under \$1 trillion. These mounting costs threaten to bankrupt families, businesses, and our health care system. Unfortunately, our work is only growing more urgent. Meeting these challenges and using new scientific opportunities requires a strong federal commitment. As we continue to understand more about the Department of Health and Human Services (HHS) reorganization we want to make certain that programs that are critical to those with Alzheimer's and other dementias and caregivers continue to be supported.

# **Progress Leads to Treatment**

The 2011 enactment of the landmark National Alzheimer's Project Act (P.L. 111-375) ushered in a new phase of progress, changing the way our nation addresses Alzheimer's and all other dementia — and resulted in unprecedented progress in Alzheimer's and dementia research, care, and support. In 2024, Congress renewed the nation's commitment with the

unanimous passage of the NAPA Reauthorization Act (P.L. 118-92) and the Alzheimer's Accountability and Investment Act (P.L. 118-93).

Since the passage of NAPA, Congress has worked in bipartisan fashion to increase federal research funding more than sevenfold. Current investments at the NIH in Alzheimer's and dementia research is more than \$3.8 billion annually. As a result of this increased investment, scientists have been able to work at a more rapid pace to advance basic disease knowledge, explore ways to reduce risk, uncover new biomarkers for early diagnosis and drug targeting, and develop potential treatments.

Alzheimer's and dementia research has momentum now more than ever, largely due to appropriately robust funding from Congress. Recent advances include approval of the first FDA-approved treatments to slow the progression of Alzheimer's disease and more tools for accurate detection and diagnosis, such as amyloid and tau PET imaging, cerebrospinal fluid assays and blood tests. These treatments change the course of the disease in a meaningful way for some people in the early stages. By slowing progression of the disease in the early stages of Alzheimer's, individuals will have more time to participate in daily life and live independently. Future treatments will need to address the underlying biology that drives all stages and symptoms of each neurodegenerative disease so that all individuals who are affected by Alzheimer's or another dementia have effective treatment options. Our progress must continue.

As Alzheimer's and other dementia science rapidly evolves, we all have a responsibility to ensure the information presented to people facing these conditions is accurate and grounded in the latest science. However, increasingly, influencers in the news media and a very small minority in the dementia field are perpetuating harmful myths about Alzheimer's, including the new FDA-approved Alzheimer's treatments. These inaccurate, highly distorted, and sensationalized attacks on scientific discoveries and the scientific community have begun to reach the patient community and are impacting their health care decisions and treatment options.

The Dementia Research Community is Strong, Collaborative, Science-Driven, and Exploring a Wide Variety of Pathways

Recently researchers and investigative journalists highlighted several dementia researchers who have engaged in fraud over the past two decades resulting in a small number of studies that cannot be relied upon. To be clear — research fraud is unacceptable and must not be tolerated. However, these studies in question were not pivotal as they have recently been portrayed, and subsequent research did not depend on them.

Over the past two decades, Alzheimer's research has included research into the "amyloid hypothesis" based on a robust body of scientific evidence. This research has been successful. Through the clearance of amyloid, the two treatments available to patients today have demonstrated their effectiveness in rigorous phase 3 clinical trials and FDA approval, bringing meaningful benefits to patients. Further important progress based on this line of research is currently in clinical trials and highly possible.

At the same time, the NIH, the Alzheimer's Association, and other stakeholders are funding many more projects addressing therapeutic targets such as tau, inflammation, and metabolic pathways. Claims that Alzheimer's research is focused on amyloid to the exclusion of other targets are simply wrong. For example, as of September 2024, the National Institute on Aging (NIA) has 68 active pharmacological trials, only 12 of which focus on amyloid.

Myths about dementia research are harming patients. There are more than 7 million Americans living with Alzheimer's disease. Another 11 million are providing unpaid care. On behalf of these individuals and the millions more who may develop Alzheimer's or another dementia in the years to come, the myths about Alzheimer's research must stop. For someone facing Alzheimer's disease, having accurate information and unbiased guidance can mean the difference between seeking care — including obtaining a diagnosis, getting access to treatment, or exploring participation in clinical trials — or not.

### Investing in Alzheimer's Treatments

While the NIH has conducted research to find treatments for Alzheimer's, there is also a large focus on advancing researchers' understanding of the risk factors, genetics, and biological mechanisms that drive dementia and expanding research on dementia care and care partner support. The NIA is currently conducting over 150 early and late stage clinical trials that are focused on non-pharmacological interventions, including exercise, brain stimulation, and cognitive training. Ongoing support also allows the NIH to further study the impact of blood

pressure control, hearing aids, and other non-pharmacological interventions on Alzheimer's prevention and care. As we work toward increased access to current and future treatments, we understand that there is still important work that needs to be done to move Alzheimer's research forward.

While recent NIH funding increases have laid the foundation for breakthroughs in diagnosis, treatment, and prevention, and enabled significant advances in understanding the complexities of Alzheimer's, there is still much left to be done. It is vitally important that NIH continues to build upon promising research advances. An increase of \$113.485 million in Alzheimer's research funding at NIH in fiscal year 2026 would go towards accelerating our understanding about the prevention and treatment of Alzheimer's and other dementia, including expanding research on how genetic traits influence the likelihood of developing Alzheimer's, and to what extent genetics play a role in being a risk factor for the disease. People who have family members with dementia may be at a higher risk of developing it themselves — and it is important to identify the cause of any predisposition. When individuals are able to identify that they are at a higher risk, they then have the knowledge to work to mitigate modifiable risk factors, and increase their overall health. This funding request is equal to the amount recommended in the fiscal year 2026 NIH Professional Judgement Budget for Alzheimer's Disease and Related Dementias Research: Advancing Progress in Dementia Research, as authorized by the unanimous passage of the Alzheimer's Accountability and Investment Act (P.L. 118-93).

## **Enabling Accurate and Timely Diagnosis**

An early diagnosis provides a range of benefits for individuals living with Alzheimer's or another dementia and their families, including better treatment. However, there is no single diagnostic test that can determine if a person has one of the diseases that cause dementia; instead, health care professionals use a variety of approaches and tools to make a diagnosis. Scientists are developing simple, inexpensive diagnostic tools that can be incorporated into the diagnostic process in a variety of clinical practice settings. With the newest approved treatments being limited to individuals in the early stages of Alzheimer's disease, early and accurate detection is even more critical.

Blood biomarker tests are beginning to revolutionize the detection and diagnosis of Alzheimer's. The 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. Sustained, robust 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.

## **Progress Toward Effective Means of Prevention Through Lifestyle Interventions**

Researchers in the United States and around the globe are working to uncover ways to prevent Alzheimer's and other dementia. Identifying methods of prevention could save millions of lives and greatly reduce health care costs for families, Medicare, and Medicaid. While we have no definitive means of preventing dementia, research has shown us that we can take action to reduce the risk of cognitive decline. Lifestyle interventions combining multiple behavior components show promise as a therapeutic strategy to protect brain health.

Many chronic diseases, including heart disease, stroke, diabetes, and dementia, share modifiable risk factors like hypertension, physical inactivity, and diet, and recent research indicates as many as 40% of dementia cases worldwide may be attributable to such risk factors. Research targeting these shared pathways offers broad benefits. In order to identify a more precise "recipe" to reduce a person's risk of cognitive decline and dementia, the Alzheimer's Association, along with partners, is leading the Protect Brain Health Through Lifestyle Intervention to Reduce Risk (U.S. POINTER) study. It is a two-year clinical trial to evaluate whether lifestyle interventions that simultaneously target many risk factors protect cognitive function in older adults who are at increased risk for cognitive decline. U.S. POINTER is the first such study to be conducted in a large group of Americans across the United States. With recruitment complete, more than 2,100 people were enrolled via study sites in Chicago (Advocate Health Care, Rush University Medical Center), Houston (Baylor College of Medicine in collaboration with Kelsey Seybold Foundation), Providence, Rhode Island (Butler Hospital in collaboration with LifeSpan), Sacramento, California (UC Davis School of Medicine), and Winston-Salem, North Carolina (Wake Forest School of Medicine). Data from the U.S. POINTER study is expected later in 2025, and we are looking forward to sharing the results with Congress.

### Addressing Alzheimer's as a Public Health Crisis

In 2018, Congress acted decisively to address Alzheimer's as an urgent and growing public health threat through the passage of the bipartisan BOLD Infrastructure for Alzheimer's Act (P.L. 115-406). This law directs CDC to build a robust Alzheimer's public health infrastructure across the country focused on public health actions that can allow individuals with Alzheimer's to live in their homes longer and delay costly long-term nursing home care. Congress solidified this commitment to addressing Alzheimer's as a public health threat when the BOLD Infrastructure for Alzheimer's Reauthorization Act of 2024 (P.L. 118-142) was passed with unanimous support in both chambers. The funding appropriated for BOLD's implementation over the years has allowed CDC to award funding to three Public Health Centers of Excellence and funding 66 awards to 43 state, local, and tribal public health departments. The Alzheimer's Association is grateful to be leading the Public Health Center of Excellence on Dementia Risk Reduction, focusing on community-level actions to reduce the risk of developing Alzheimer's and other dementia. Although risk factors like age, genetics, and family history cannot be changed, other risk factors can be modified to reduce the risk of cognitive decline and dementia. Examples of modifiable risk factors are physical activity, smoking, education, staying socially and mentally active, blood pressure, and diet.

While these BOLD implementation efforts are important steps forward, the Alzheimer's Association and AIM urge Congress to include \$35 million for BOLD's continued implementation at CDC in fiscal year 2026. Activities supported by the requested \$35 million in fiscal year 2026 would enable state, local, and tribal public health agencies to implement the Healthy Brain Initiative (HBI) Road Map, most recently released in Fall 2024. This funding will also help these jurisdictions create, update, and implement their strategic Alzheimer's plans by using the HBI Road Map. Programs like the Healthy Brain Initiative and BOLD, both of which had staff placed on administrative leave as part of the reduction in force at HHS, have a meaningful impact on Americans everyday. These public health programs are critical to Alzheimer's/dementia awareness and brain health in communities across the nation. Among other things, they ensure that people living with dementia, caregivers and health providers have the information, resources could cause irreversible damage. Without these programs, people may not have the information to make brain healthy choices to reduce their risk of Alzheimer's, and be

less likely to get a diagnosis or seek treatment.

### Investing in Accelerating Dementia Workforce Preparedness

As we enter a new era of Alzheimer's treatment, access to a timely and accurate diagnosis is more critical than ever, so is the need for healthcare professionals trained on how to meet the unique health needs of people living with Alzheimer's and other dementia. Today, only half of those living with Alzheimer's disease are diagnosed, and of those, only half are told of their diagnosis. In 85% of cases, primary care providers make the initial diagnosis of Alzheimer's. But because they are not dementia specialists, most report they do not feel prepared to provide care for these diagnosed individuals. Too often, overburdened primary care providers are unable to access the latest patient-centered dementia training.

Technology-enabled collaborative learning and capacity-building models, often referred to as Project ECHO, use a hub-and-spoke approach by linking expert specialist teams at a 'hub' with the 'spokes' of health providers in local communities to increase on-the-ground expertise. Using case-based learning, Project ECHO models can improve the capacity of providers, especially those in rural and underserved areas, on how to best meet the needs of people living with many chronic conditions, including Alzheimer's and other dementia. The Alzheimer's and Dementia Care ECHO program, led by the Alzheimer's Association, has trained more than 2,000 health care professionals since 2018. Ninety-five percent of those professionals made changes to the way they care for patients as a result of what they learned from ECHO. Quality care delivered by trained providers leads to better health outcomes for individuals and caregivers and puts less strain on health systems. Project ECHO programs have shown they can help address the knowledge gaps felt by many primary care providers. The Alzheimer's Association and AIM respectfully request \$10 million to provide full funding for the authorization contained in the Consolidated Appropriations Act, 2021 (P.L. 116-260) to expand the use of Project ECHO models.

### Conclusion

Investing in federal health research is one of the most important actions Congress takes. It produces longer, healthier lives, a stronger economy, and continued global leadership. We face serious health challenges, like Alzheimer's disease. Yet, progress, especially in Alzheimer's research fueled by past bipartisan Congressional action, shows what focused, sustained federal commitment can achieve. The cost of inaction — in lives, health care dollars, and competitiveness — is far greater than the cost of investment. By providing robust, predictable funding across the entire health research ecosystem, Congress empowers researchers, clinicians, and public health professionals working to solve our most pressing health problems. The Alzheimer's Association and AIM look forward to continuing our longstanding bipartisan collaboration with Congress to combat Alzheimer's and all other dementia, as well as with HHS leadership. Working together, we can support ongoing research, translate science into meaningful care and support, promote brain health, and ultimately find cures. We urge you to continue to make federal health research a top priority and enact the funding increases needed to accelerate discovery, improve health, and secure a better future for all Americans.