

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

United States Senate Committee on Health, Education, Labor & Pensions (HELP)
Hearing on Fiscal Year 2026 Department of Health and Human Services Budget

May 14, 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 Health, Education, Labor & Pensions (HELP) hearing on the Fiscal Year (FY) 2026 Department of Health and Human Services (HHS) budget. 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.

Just last Congress, this Committee renewed our nation's commitment to the Alzheimer's community by unanimously reauthorizing three critical, bipartisan bills: the NAPA Reauthorization Act (P.L. 118-92), the Alzheimer's Accountability and Investment Act (118-93), and the Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Reauthorization Act (P.L. 118-142). We also thank the Committee for reaffirming your commitment to the Alzheimer's and dementia community while sounding the alarm about the impact that cuts to HHS will have on the progress in the fight against Alzheimer's and other dementia. It is crucial for officials to understand 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, 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 in America will be 12.7 million, and total payments for all individuals 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, sustained federal commitment. The Alzheimer's Association is gravely concerned by the proposed FY2026 budget released by the Trump administration. The proposal, which includes substantial cuts to HHS, including a 40 percent cut to the National Institutes of Health (NIH), will limit our nation's ability to address the needs of people living with dementia and their caregivers, and set research advancements back decades.

Investing in policies that improve the lives of people impacted by dementia, including robust and sustained research into ways to address the condition, remains a bipartisan priority. Just recently, during the Senate Appropriations Committee hearing, members from both sides of the aisle spoke passionately about the role America — through the NIH — has played in advancing progress on treatments, detection, and diagnosis for Alzheimer's. The Alzheimer's

Association and AIM will continue to work with champions from all parties, our nationwide network of advocates, and our partners in the biomedical research community to highlight the value of biomedical research to all Americans.

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 resulting 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 and the Alzheimer's Accountability and Investment Act.

Since the passage of NAPA, Congress has worked in a bipartisan fashion to increase federal research funding more than sevenfold. Current investments at the NIH in Alzheimer's and dementia research are 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 greater momentum now than ever before, largely due to appropriately robust funding from Congress. Recent advances include approval of the first treatments approved by the Food and Drug Administration (FDA) 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 as pivotal as they have 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. More than 7 million Americans are 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 Research

While the NIH has conducted research to find treatments for Alzheimer's, the agency is also focused 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 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.

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. Recent actions targeting research funding and staffing — such as stalled funding to Alzheimer's Disease Research Centers (ADRCs) — will jeopardize scientific and medical progress. Funding and staffing capacity are critical to effectively and efficiently carry out research and public health programs. Delays and reductions have real consequences for the health of the American people. Alzheimer's Disease Research Centers are a rock solid foundation for the entire Alzheimer's and dementia research field. We are deeply concerned that stalled approval of funding to ADRCs will jeopardize scientific and medical progress. Additional delays to ADRC funding risk reducing or eliminating many research trials and scientific collaborations, training and advancement opportunities for researchers and clinicians, and dementia care throughout the region of each ADRC. We are at a critical moment for Alzheimer's research and treatment. More than ever, we must sustain the momentum we've created as a dementia research field.

As Congress continues to advance the FY2026 appropriations process, the NIH must continue to build upon promising research advances. An increase of \$113.485 million in Alzheimer's research funding at NIH in FY2026 would accelerate our ability to prevent and treat Alzheimer's and other dementia. This funding request is equal to the amount recommended in the FY2026 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.

Enabling Accurate and Timely Diagnosis

The 2025 Alzheimer's Association Facts & Figures Special Report, titled "American Perspectives on Early Detection in the Era of Treatment," reveals that four in five Americans consider early diagnosis very important. Nine in 10 Americans would want a simple test to allow for early treatment, and four in five Americans would want to know if they had Alzheimer's before symptoms appear or affect daily activities.

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. Recent research indicates as many as 40 percent 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 the Centers for Disease Control and Prevention (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 was passed with unanimous support in both chambers. The funding appropriated for BOLD's implementation over the years has allowed the 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 have been important steps forward, we are alarmed that the Cooperative Agreements for the Healthy Brain Initiative (HBI) and the three Dementia Public Health Centers of Excellence under the BOLD Act are set to expire at the end of September. These programs have been vital in supporting successful state and local public health efforts to address the growing dementia crisis in the United States. Congress recognized this by reauthorizing the BOLD Infrastructure for Alzheimer's Act through 2029. A funding forecast by the CDC indicated that the Notice of Funding Opportunity (NOFO) to continue the HBI and Centers of Excellence was to be issued in early 2025. But to date, no NOFO has been issued, even though the BOLD Act was just reauthorized and funding is available under the full-year continuing resolution passed by Congress in March. The Alzheimer's Association and

AIM urge Secretary Kennedy to ensure these programs continue to be effectively implemented, consistent with congressional intent.

In addition to ensuring that current funding is allocated for fiscal year 2025, the Alzheimer's Association and AIM also 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 FY2026 would enable state, local, and tribal public health agencies to implement the Healthy Brain Initiative 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 HBI and BOLD, both of which had staff placed on administrative leave as part of the reduction in workforce at HHS, have a meaningful impact on Americans every day. These public health programs are critical to Alzheimer's and related 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, and support they need. We remain concerned that continuing on a path of reducing staff and 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, and so is the need for health care professionals trained 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 diagnoses. In 85 percent 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 improve the capacity of providers, especially those in rural and underserved areas, to best meet the needs of people living with Alzheimer's, other dementia, and many other chronic diseases.

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 address the knowledge gaps shared 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 Congress' most important means to improve the lives of people in every community across the country. This research produces longer, healthier lives, a stronger economy, and continued global leadership. We face serious health challenges. 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. 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.