LEAD
Leaders Engaged on Alzheimer's Disease

July 7, 2025

The Honorable Susan Collins, Chair
The Honorable Patty Murray, Vice Chair
Senate Appropriations Committee
Washington, DC 20510

The Honorable Tom Cole, Chairman
The Honorable Rosa DeLauro, Ranking Member
House Appropriations Committee
Washington DC, 20515

by electronic delivery

Dear Chair Collins, Vice Chair Murray, Chairman Cole, and Ranking Member DeLauro:

We sincerely thank you for recognizing and decisively responding to the challenges of Alzheimer's disease and related disorders (AD/ADRD). We applaud your indispensable leadership and relentless determination to seize the enormous opportunities for America by investing in basic and clinical science, detection and diagnosis, care and support, and risk reduction research required to overcome these challenges and for recognizing the consequences if we fail to continue acting with urgency. Doing so is a national priority, economic and budgetary necessity, and health and moral imperative.

There are few more compelling or complex issues to confront our society, now and over the coming decades, than Alzheimer's disease and other forms of dementia. You and your colleagues clearly recognize the catastrophic human toll inflicted over many years as individuals gradually succumb to the cognitive, functional, and emotional consequences of these conditions. Ultimately, one third of older Americans die with Alzheimer's disease or another form of dementia.[i] These neurodegenerative conditions also impose enormous costs to our nation's health, prosperity, and social fabric. According to a 2015 analysis of data from the National Institute on Aging's Health and Retirement Study (HRS), the average per-person health care spending in the last five years of life for people with dementia was more than $250,000, or 57 percent greater than costs associated with death from other diseases including cancer and heart disease—and these costs are skyrocketing.[ii] Health and long-term care costs for people living with Alzheimer's and other dementias are projected to reach $384 billion in 2025,[iii] with a recent analysis estimating the total cost of dementia as $781 billion annually.[iv]

Without exception, and under Republican and Democratic congressional leadership, the federal government has advanced a consistently non-partisan commitment to a comprehensive approach to overcoming AD/ADRD. That commitment, embodied in the landmark National Alzheimer's Project Act (NAPA, enacted in 2010 and reauthorized in 2024) and in your wise appropriations investments, has delivered enormous and indispensable progress for the American people. For example, there are FDA-approved treatments to slow the progression of Alzheimer's disease, new tests available to diagnose dementia earlier, and services that support individuals living with dementia as well as their care partners. The NAPA Plan's six goals are America's goals and your catalytic investments to achieve these goals are working and paying off for all Americans.

Suddenly, transformative progress achieved and more essential progress soon to be realized now face an existential threat due to sweeping changes to public health, science, clinical care, social supports, and public service. Efforts to implement the National Plan have nearly idled – for example, the NAPA Advisory Council, which aids in coordinating federal and non-federal efforts to meet the Nation's six goals, has not met since January 2025. Several federal agencies have also been left without representatives on the Council given recent efforts to fire personnel and restructure HHS. This progress cannot be halted, and Congress must do everything in its power to ensure progress is not reversed. The seven million Americans who live with dementia and their 12 million unpaid family caregivers, along with all Americans who are at risk for developing dementia in the coming decades, need Congress to reassert our country's non-partisan national priority to overcome AD/ADRD by:

- **making robust appropriations for federal agencies to meet the NAPA goals and ensuring expenditure of those funds is completed in a full and timely manner for the Congressionally-designated purposes**
- **guaranteeing that the work of civil servants, research institutions, clinicians, and social service providers is not disrupted**
- **reauthorizing essential laws**

All Americans are depending on Congress to maintain and build upon the non-partisan national commitment to overcome AD/ADRD. In this letter, we describe ways in which Congress can meet this moment and ensure progress for all Americans.

Making Robust Appropriations & Ensuring Expenditure of Appropriated Funds

We are eager to work with everyone who shares your commitment to optimizing the value of public dollars. While some call for radical cuts in federal spending, we know there is collective consensus among Republicans and Democrats alike that sustained and robust AD/ADRD investments are necessary for fighting these diseases holistically and improving America's and Americans' health, wellbeing, and prosperity. These investments epitomize efficiency, advance U.S. global leadership, and drive vital progress for the health of all Americans. To achieve all six goals of the NAPA Plan and ensure progress is not reversed, we call on Congress to make robust appropriations for Fiscal Year 2026 for all federal agencies involved in implementing the NAPA Plan, including:

- **an $113,485,000 increase for AD/ADRD research at NIH as articulated in the Professional Judgement Budget[v]**

  The choice before our nation is not whether to pay for dementia – we are paying dearly. The question is whether we will emulate the sustained investment strategies that have led to remarkable progress in fighting other leading causes of death and achieve similar breakthroughs, or spend trillions to care for tens of millions of people. A modernized and more robust research portfolio supported by substantial federal investment can help America prevent this catastrophe and move us closer to achieving our national goal of preventing and effectively treating dementia.[vi] The NIH estimated the additional funds needed in FY2026 to advance AD/ADRD research progress as $113.5M and we implore Congress to provide NIH with these funds to enable scientific progress in the next fiscal year.

- **$51.3 billion for NIH, allowing its base budget to keep pace with the biomedical research and development price index (BRDPI) and maintaining meaningful growth of nearly 6%, with funding for ARPA-H supplementing (rather than supplanting) the essential foundational investment in the NIH. The FY2026 investment should include at least $4.75B for the National Institute on Aging (NIA) to provide adequate funding for continued progress on AD/ADRD research as well as research to improve the health and well-being of all older Americans.**

  This core NIH investment would continue a trajectory of steady and predictable annual increases – allowing meaningful base budget growth above inflation that would expand NIH's capacity to support promising science in all disciplines – and would ensure that the Innovation Account supplements the agency's base budget, as intended, through dedicated funding for specific programs. The FY2026 President's Budget calls for a radical 43% cut to NIH spending compared to FY2025 levels. A funding reduction of this magnitude would undo research progress enabled by bipartisan funding increases over the last 10 years, set back biomedical science and public health by decades, and ultimately cost American taxpayers an estimated $8.2 trillion.[vii] For example, with this proposed budget, the success rate of applications submitted to the NIA within the NIH would drop from nearly 20% to less than 4%, inevitably dismissing hundreds of new, meritorious AD/ADRD research applications and impeding the field's ability to make forward progress. Biomedical research does not have geographic barriers; research is being conducted in every state and should not be an issue to politicize in Washington, D.C. Congress must act now to protect the bipartisan foundational investment in the NIH or risk significant effects on the health and wellbeing of every American, especially the most vulnerable among us, as well as the economy of every state in this Nation.

- **restoration of the NIH BRAIN Initiative funding to $680 million**

  This groundbreaking program has been supported by the 21st Century Cures Innovation Fund and, with diminishing resources available from the fund, it is critical that Congress provide discretionary appropriations to allow the program to continue to make revolutionary advances that improve brain and overall health outcomes. Originally created in 2013, the BRAIN Initiative is revolutionizing our understanding of the human brain to better develop treatments and cures for neurologic diseases, including AD/ADRD. This multidisciplinary collaboration (including the NIH, FDA, DARPA and IARPA,[viii] along with private partners) is working to map circuits of the brain, measure electrical and chemical activity, and understand how their interplay creates unique cognitive and behavioral capabilities. Halting progress will undoubtedly slow the discoveries necessary to develop effective prevention and treatment strategies for AD/ADRD.

- **$60 million for the CDC's Alzheimer's Disease and Healthy Aging Program (ADHAP)**

  The ADHAP within CDC historically has been the only place within the federal government specifically dedicated to promoting the health of older adults through dementia risk-reduction interventions (e.g. smoking cessation, exercise, nutrition) and across chronic conditions that heighten risk for dementia (e.g. hypertension, hearing and vision loss, depression, traumatic brain injury, diabetes, obesity). Yet, total funding for the ADHAP's vital work represents only approximately 0.25% of the overall CDC budget.

Moreover, all ADHAP staff were removed from their positions on April 1, 2025 as part of the HHS reduction in force, so there are currently zero individuals to support this vital work.

We are calling for the reinstatement of CDC's ADHAP staff and encourage Congress to ensure a $60 million funding level to support ADHAP's work to:

- strengthen programs that reduce risk and support populations with a high burden of AD/ADRD
- build public health infrastructure through the BOLD Act and Healthy Brain Initiative
- expand capacity in state, tribal and territorial public health departments to promote the health of older adults within an age-friendly public health system
- expand healthy aging work to include coordinating healthy aging efforts across the agency and implementing a public-private initiative to reduce dementia risk
- fund applied research and translation for public health practice

As part of this overall ADHAP funding, we support $35 million for CDC to continue implementing the Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act (Pub. L. 115 – 406).[ix] Under the law, Congress directed CDC to strengthen the public health infrastructure nationwide by implementing effective Alzheimer's interventions focused on public health priorities including increasing early detection and diagnosis, reducing modifiable risk, and preventing avoidable hospitalizations. Increased funding also would support a significant increase for the CDC's long-standing and successful Healthy Brain Initiative, which is implementing its 2023-2027 Healthy Brain Aging Road Map (and companion Road Map for Indian Country) to ramp up the nation's public health capacity in addressing dementia.[x] The Road Map is advancing strategies to reduce lifestyle risk factors, improve detection and diagnosis, and strengthen community supports for people with dementia and their families.

- **an increase for the FDA to keep pace with its new scientific opportunities**

  Substantial additional funding is needed for FDA to fulfill its evolving responsibilities. Specific increases are sought for drug and device review, biologics, public health data modernization, facilities improvements, human and animal food safety programs, and other priority areas. Additional funding is also needed to attract the necessary staffing expertise who can adequately address FDA goals and meet performance metrics. This higher funding level is critical for FDA to protect public health given its oversight of 80% of the food supply and 100% of drugs, medical devices, and other regulated products.

- **an increase for Older Americans Act (OAA) and other aging programs and services (including the ACL Alzheimer's Disease Program and the DOJ Missing Alzheimer's Disease Alert Program) and $58.245 million for the HRSA geriatrics workforce programs to meet the needs of the rapidly growing number of Americans living with AD/ADRD**

  Until science delivers effective means to prevent, slow, or cure dementia for all, families and friends along with health care providers rely on programs to protect their own wellbeing as they help persons with dementia remain independent and in the community while delaying placement in institutional settings. OAA investments are relatively small yet crucial complements to vastly larger Medicaid and Medicare expenditures to protect and promote the wellbeing of people living with dementia and their caregivers along with

other older adults. As urgently as resources are needed to enable scientific breakthroughs, millions of Americans currently living with dementia and their family caregivers – who are the backbone of the health care system for older adults – deserve strengthened commitments to programs and services that protect and enhance their quality of life. In fact, dementia is among the leading causes of disability and dependence among older people.[xi] Federal initiatives and programs are vital in helping people receive a diagnosis so they know what they are facing, can begin disability and care planning processes, maintain independence as long as possible, and – for people with younger onset dementia – seek appropriate workplace accommodations. These programs also aid family caregivers in supporting older adults in their homes for as long as possible, thus reducing Medicaid costs for care in more expensive settings such as nursing facilities. In FY 2026, the reauthorization of the Older Americans Act and the expansion of investments in these aging programs and services will be instrumental to achieving the NAPA Plan's goals to enhance care quality, efficiency, and supports for people living with dementia and their caregivers.[xii]

For example, the ACL Alzheimer's Disease Program Initiative (ADPI) supports and promotes the development and expansion of dementia-capable home and community-based long-term services and support systems in states and communities. By funding efforts to develop dementia-capable services, implement evidence-based interventions, and offer training for both formal and informal caregivers, ADPI fills gaps and builds capacity to serve the growing number of Americans living with a dementia. ACL's National Alzheimer's and Dementia Resource Center (NADRC) provides technical assistance to ACL's grantees that build dementia-capable systems to better identify and support people with dementia living in the community and improve training for dementia caregivers who experience considerable stress and depression. Many of the programs are geared towards at-risk populations, such as the growing population of those who live alone, those with disabilities (including those with intellectual disabilities), and those who reside in rural and other underserved communities. NADRC also produces dementia-related toolkits and provides technical assistance and AD/ADRD webinars to the public.[xiii]

The Department of Justice (DoJ) Missing Alzheimer's Disease Patient Alert Program provides grants for training and technology that help first responders locate people living with AD/ADRD (or autism) who wander and become lost. The program saves lives, strengthens the capacity of search and rescue programs to respond to other community needs, and allows local first responders to conserve both time and money. The program's strong track record, along with rapid growth in the number of people living with dementia and the program's expansion to include services for people living with autism, merit and require substantial additional resources to better serve states and communities nationwide.

The Geriatrics Workforce Enhancement Program (GWEP) and the Geriatrics Academic Career Awards (GACAs), administered by HRSA, are the only federal mechanism for supporting the education and training of geriatrics health professionals and addressing the geriatrics workforce gap. Sustained and enhanced investment will ensure that critical resources are available to educate and engage the broader frontline workforce, including primary care, paid caregivers, and family caregivers, and improve the quality of care delivered to older adults nationwide. Increases for GACAs would ensure a larger and geographically more diverse pipeline of geriatrics research and training expertise with

needed incentives and resources for the current and future workforce that is essential for all of us as we age, especially those living with dementia.

While new FY 2026 investments are vitally important, it is equally critical that Congress enforce requirements reflected in the FY 2025 Appropriations Act. Congressional appropriations bills signed by the President are not suggestions, they are law; this includes the FY 2025 CR. Similarly, the Impoundment Control Act of 1974 requires that the Executive Branch obligate funds appropriated by Congress. As recognized by Republican and Democratic members alike during Congressional budget hearings this year, *de facto* impoundment is happening now. Congress has an obligation under law and through the Constitution's separation of powers to conduct oversight and take legal action as necessary to compel the full and timely expenditure of appropriated funds for their legislatively designated purposes.

Ensuring Progress is Not Disrupted

Congress along with administrations of both parties long have championed the productivity and efficiency of U.S. public-private partnerships – and our country's commitment to overcoming health challenges such as AD/ADRD relies on stable, predictable, and coherent public-private partnerships. This includes (among a multitude of other examples) CDC partnering with community-based organizations to promote brain health and address modifiable AD/ADRD risk factors, NIH partnering with research universities and science innovators to develop new medical products, ACL partnering with home and community-based service providers, Medicare and Medicaid partnering with clinicians and residential care communities to deliver care, and the CMS Innovation Center partnering with health care systems and entrepreneurs to better support dementia family caregivers.

You and your Congressional colleagues consistently and powerfully have spoken to the enormous and lasting impact of civil servants working at federal agencies to support such partnerships, and must agree that serious damage is being done by expansive purges of staff across HHS and the proposed reorganization and elimination of vital agencies and offices. For example, progress has been undermined when the entire CDC staff responsible for implementing the BOLD Act and related programs are fired and when approved NIH research grants are cancelled or otherwise terminated and when indirect research costs are capped in contravention of federal law.[xiv] and when there is a systematic effort to eliminate vast swaths of public and private sector work to understand and address health disparities and the distinct needs faced by Americans most disproportionately affected by AD/ADRD. The impacts of these decisions, if not reversed, will be even more catastrophic when coupled with other proposed actions, such as an egregious 40% reduction in funding for biomedical research, the dismantling of ACL and expertise required to administer the Older Americans Act, the slashing of Medicaid funding and potentially Medicare cuts, and the abandonment of support for critical clinical workforce development programs. As various Congressional hearings this year have made abundantly evident, these actions do not improve government efficiency and, in fact, undermine both the NAPA Plan goals and the needs of all Americans facing Alzheimer's disease and related disorders. Through the appropriations process and related oversight actions, Congress has the authority to take all necessary steps to restore competence, coherence, urgency, efficiency, rationality, and fundamental American civility to our nation's fight to overcome AD/ADRD.

Among other actions, we specifically implore you to ensure that the reorganization of federal agencies that contributed to the *National Plan to Address Alzheimer's Disease: 2024 Update*[xv] is

based on a transparent, inclusive and deliberative process with rigorous, thorough, and constructive participation by Congress and the Alzheimer's disease and related disorders community, and occurs only pursuant to a Federal Register notice and 180-day public comment period. We also urge you to establish processes that will provide the public with opportunities to engage with HHS on ways to increase efficiency across the Department and require the agencies — including, but not limited to, NIH, FDA, CMS, and CDC — to submit iterative updates to Congress and the public on how they are meeting performance metrics. Such oversight is essential for AD/ADRD progress to advance.

Reauthorizing Essential Laws

This Congress and the Administration also have the opportunity and responsibility to act swiftly to reauthorize laws essential to achieving the NAPA goals. As leaders of the Appropriations Committees and of the sustained non-partisan work by Congress to address holistically the myriad challenges for all Americans relating to AD/ADRD, you are ideally positioned to urge the Congressional committees of jurisdiction to complete passage of legislation to reauthorize the Older Americans Act and the FDA user fee agreements (specifically, the Prescription Drug User Fee Act and the Medical Device User Fee and Modernization Act are of particular importance to the AD/ADRD community). It is in the highest national interest for AD/ADRD experts – those with technical expertise who the LEAD Coalition would be happy to help identify, and those with lived experience from all walks of life across our country – to be at the center of any deliberations that have implications for implementation of the NAPA plan.

As you work to address AD/ADRD through the FY 2026 appropriations process, we also appreciate your attention to report language requests that have been and will be shared by various organizations committed to advancing progress for AD/ADRD.

Thank you again for your leadership and commitment to meeting the needs of all Americans facing AD/ADRD. For any questions or additional information, please contact Ian Kremer, executive director of Leaders Engaged on Alzheimer's Disease (the LEAD Coalition),[xvi] ikremer@leadcoalition.org or (571) 383-9916.

Sincerely,

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ACCSES – The Voice of Disability Service Providers

AC Immune

ACMCRM Arachnoiditis & Chronic Meningitis Collaborative Research Network

ADvancing States

AgeneBio

Aging and Memory Disorder Programs, Howard University

Alliance for Aging Research

Alliance for Patient Access

AlterDementia, LLC

Alzheimer's Association

Alzheimer's Disease Resource Center, Inc. (ADRC)

Alzheimer's Drug Discovery Foundation

Alzheimer's Foundation of America

Alzheimer's Impact Movement (AIM)

Alzheimer's Los Angeles

Alzheimer's New Jersey

Alzheimer's Orange County

Alzheimer's San Diego

Alzheon

American Academy of Neurology

American Association for Geriatric Psychiatry

American Federation for Aging Research (AFAR)

American Geriatrics Society

American Medical Women's Association

American Neurological Association

American Society of Consultant Pharmacists (ASCP)

American Society on Aging

Argentum | Expanding Senior Living

Association of California Caregiver Resource Centers (ACCRC)

Association of Population Centers

Autistic Women & Nonbinary Network — AWN

Axxam SPA

The Balm in Gilead, Inc.

Banner Alzheimer’s Institute

Banner Health

Benjamin Rose Institute on Aging

Biomarker Collaborative

B'nai B'rith International

Bone Health and Osteoporosis Foundation

The Brain Donor Project

Bridge Builder Strategies

Brigade Health

BrightFocus Foundation

Caregiver Action Network

CaringKind, The Heart of Alzheimer's Caregiving

Center for BrainHealth at The University of Texas at Dallas

Center for Healthy Aging

Center to Advance Palliative Care

Chambers-Grundy Center for Transformative Neuroscience, Department of Brain Health, University of Nevada, Las Vegas

Chronic Disease Coalition

CNS Innovations

Coalition of Wisconsin Aging and Health Groups

The Coelho Center for Disability Law, Policy and Innovation

Cognitive Dynamics Foundation

Cognito Therapeutics

Cure Alzheimer’s Fund

Cure MAPT FTD

CurePSP

Davos Alzheimer's Collaborative

Dementia Alliance International

Dementia Alliance of North Carolina

Eisai, Inc.

Eli Lilly and Company

Exon 20 Group

Family Caregiver Alliance

Genetic Alliance

Georgetown University Medical Center Memory Disorders Program

Gerontological Advanced Practice Nurses Association

Gerontological Society of America

Global Alzheimer's Platform Foundation

Global CEO Initiative on Alzheimer's Disease

Global Coalition on Aging

Hadassah, The Women’s Zionist Organization of America, Inc.

The Hartford Institute for Geriatric Nursing, NYU Rory Meyers College of Nursing

HealthyWomen

HFC

Hopkins Economics of Alzheimer’s Disease & Services Center

Huntington's Disease Society of America

Hypertrophic Cardiomyopathy Association

I AM ALS

ICAN, International Cancer Advocacy Network

International Association for Indigenous Aging

Iowa State Grange

Johns Hopkins Memory and Alzheimer's Treatment Center

Las Vegas HEALS

Latino Alzheimer’s and Memory Disorders Alliance

LeadingAge

Lewy Body Dementia Association

Lewy Body Dementia Resource Center

Life Molecular Imaging

Linus Health, Inc.

Lipitz Center to Advance Policy in Aging and Disability, Johns Hopkins Bloomberg School of Public Health

Long Term Care Community Coalition

Lorenzo's House

LuMind IDSC Foundation

Lupus and Allied Diseases Association, Inc.

Marymount University

Massachusetts Alzheimer's Disease Research Center (Harvard Medical School, Mass General Brigham)

Medicare Rights Center

MEI Micro, Inc.

Memory Care Home Solutions

MET Crusaders

Michigan State University Alzheimer's Alliance

Mindr

Minnesota Association of Area Agencies on Aging

Mount Sinai Center for Cognitive Health

National Adult Protective Services Association (NAPSA)

National Alliance for Caregiving

National Asian Pacific Center on Aging

National Association of Activity Professionals

National Association of Social Workers (NASW)

National Association of State Long-Term Care Ombudsman Programs (NASOP)

National Certification Council for Activity Professionals

National Consumers League

National Consumer Voice for Quality Long-Term Care

National Council of Dementia Minds

National Down Syndrome Society

National Hartford Center of Gerontological Nursing Excellence

National Hispanic Council on Aging (NHCOA)

National Menopause Foundation

National Minority Quality Forum

National Respite Coalition

National Task Group on Intellectual Disabilities and Dementia Practices

NCBA, Inc.

Nebraska AIDS Project

Neurogen Biomarking

Neurotech Network

Nevada Chronic Care Collaborative

NFL Neurological Center

Noah Homes

The Ohio Council for Cognitive Health

Organic Acidemia Association

Owl Therapeutics

Partnership to Fight Chronic Disease

Patients Rising Now

Pat Summitt Foundation

PD-L1 Amplifieds

Population Association of America

Positrigo, Inc.

Post-Acute and Long-Term Care Medical Association (PALTmed)

PrognosUs

Research Institute for Home Care

RetireSafe

The Richman Family Precision Medicine Center of Excellence in Alzheimer's Disease, Johns Hopkins Medicine

Scottish Brain Sciences

Second Wind Dreams, Inc./ Virtual Dementia Tour

Society of Behavioral Medicine

Society for Women's Health Research

Synthesis Brain Health

The Association for Frontotemporal Degeneration

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Tolion, Inc.

Toronto Memory Program

Trellis/ACT on Alzheimer's

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University of Miami, Miller School of Medicine, Comprehensive Center for Brain Health

University of Minnesota Center for Healthy Aging and Innovation (CHAI)

University of Rochester Alzheimer's Disease Care, Research and Education Program (AD-CARE)

UsAgainstAlzheimer's

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[xiv] https://www.congress.gov/118/plaws/publ47/PLAW-118publ47.pdf#page=219 (Section 224)

[xv] https://aspe.hhs.gov/sites/default/files/documents/dc2ff0be0e08df15971fce57cb8e5c7a/napa-national-plan-2024-update.pdf

[xvi] http://www.leadcoalition.org Leaders Engaged on Alzheimer's Disease (the LEAD Coalition) is a diverse national coalition of member organizations including patient advocacy and voluntary health non-profits, philanthropies and foundations, trade and professional associations, academic research and clinical institutions, and home and residential care providers, large health systems, and biotechnology and pharmaceutical companies. The LEAD Coalition works collaboratively to focus the nation's strategic attention on dementia in all its causes -- including Alzheimer's disease, vascular disease, Lewy body dementia, and frontotemporal degeneration -- and to accelerate transformational progress in detection and diagnosis, care and support, and research leading to prevention, effective treatment, and eventual cure. One or more participants may have a financial interest in the subjects addressed.