



May 3, 2024

The Honorable Patty Murray, Chair
The Honorable Susan Collins, 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 Murray, Vice Chair Collins, Chairman Cole and Ranking Member DeLauro:

As you continue the essential work to develop and pass Fiscal Year 2025 (FY25) appropriations bills, we write to reiterate support for priorities communicated earlier this year by our allies across the health, aging, and science advocacy community.

Since well prior to passage of the landmark National Alzheimer's Project Act in 2010, advocates have implored Congress that Alzheimer's disease was the only cause of death among the top 10 without an effective means of prevention or treatment. Thanks to sustained, robust, and effective investments by Congress and the private sector, as soon as this summer, there may be access to a second disease-modifying treatment to slow the progression of Alzheimer's disease. **Your pivotal investments are working.** Now there is even greater urgency to build on this watershed moment with an unrelenting commitment of essential funding to advance the science to deliver even more effective treatments for Alzheimer's disease and related disorders, improve access to timely and accurate diagnosis, strengthen programmatic supports imperative to quality of life for people with dementia and their caregivers, and expand public health capacity to reduce incidence and prevalence of these diseases.

We sincerely thank you for recognizing and decisively responding to the challenges of Alzheimer's disease and other forms of dementia (e.g. cerebrovascular disease, Lewy body dementia, frontotemporal degeneration, and Creutzfeldt-Jakob disease) by passing Fiscal Year 2024 appropriations with a historic funding increase for Alzheimer's research. We applaud your continued determination to seize the enormous opportunities for America by investing in the science, detection and diagnosis, care and support, and risk reduction required to overcome these challenges and for recognizing the consequences if we fail to continue acting with the required urgency. Doing so is a national priority, economic and budgetary necessity, health and moral imperative.

We respectfully encourage you to continue the momentum toward the National Alzheimer's Plan goals and your own commitment to advancing science, care and support, and public health. **Specifically, we request that the FY25 appropriations bills include, at minimum:**

- a \$318 million increase for National Institutes of Health (NIH) research on Alzheimer's disease and other forms of dementia to accelerate progress as articulated in the Bypass Budget Proposal for FY25
- a \$3.579 billion increase (to \$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 5%. Funding for ARPA-H should supplement, rather than supplant, the essential foundational investment in the NIH.
- a \$60 million increase for the BRAIN Initiative over the FY 2023 level (providing at least \$740 million in FY 2025)
- a \$391 million increase for the FDA
- double funding for Older Americans Act (OAA) and other aging programs and services, including the ACL Alzheimer's Disease Program, the HRSA geriatrics workforce programs, and the DoJ Missing Alzheimer's Disease Alert Program
- a \$33.8 million increase for the geriatrics education and training programs under Title VII of the Public Health Services (PHS) Act
- \$60 million for the CDC's Alzheimer's Disease and Healthy Aging Program (ADHAP) to continue BOLD Act implementation, expand the CDC Healthy Brain Initiative road map for state and national partnerships, and reduce dementia risk through brain health promotion

Additionally, we support sustained and robust funding for Federally Qualified Health Centers (FQHCs).

We also support appropriations report language to advance accomplishing goals of the National Alzheimer's Plan.

There are few more compelling or complex issues to confront our aging society, now and over the coming decades, than Alzheimer's disease and other forms of dementia. These neurodegenerative conditions impose enormous costs to our nation's health, prosperity, and social fabric, costs that are skyrocketing.ⁱ 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.ⁱⁱ

Based on the National Institute on Aging's Health and Retirement Study (HRS), we know that the health system costs of caring for people with dementia in the United States are comparable to, and perhaps greater than, those for heart disease and cancer.ⁱⁱⁱ A 2015 analysis of HRS data revealed that average per-person health care spending in the last five years of life for people with dementia was more than \$250,000 -- 57 percent greater than costs associated with death from other diseases including cancer and heart disease.^{iv} Those costs continue to climb and are unsustainable for families, public and private insurers, and our nation's economy.

Currently, more than 6.9 million Americans are living with dementia, with combined healthcare and long-term care costs of \$360 billion.^v Taxpayers foot about 64% of that bill -- \$231 billion -- directly through the Medicare and Medicaid programs. Individuals with dementia and their families pay out of pocket 25% of the cost, \$91 billion. More than 11 million Americans provide unpaid care for someone with dementia, resulting in additional healthcare and economic costs. Today, as another person develops the disease every 65 seconds, Alzheimer's and other forms of dementia impose an economic cost over \$706 billion in public and private expenditures along with uncompensated caregiving. By 2050, someone in the United States will develop the disease every 33 seconds with as many as 12.7 million Americans living with dementia. This explosive growth will cause direct costs to increase from \$360 billion in 2024 to approximately \$1 trillion in 2050 (in 2024 dollars) and the hidden costs of uncompensated caregiving to become even more staggering.^{vi}

Advancing Science

We support a \$318 million increase for National Institutes of Health (NIH) research on Alzheimer's disease and other forms of dementia to accelerate progress as proposed in the NIH FY25 Bypass Budget.^{vii} 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 can help America prevent this catastrophe and move us closer to achieving our national goal of preventing and effectively treating dementia.^{viii}

Due to leadership and direction from Congress, the Department of Health and Human Services (HHS) continues to increase prioritization of Alzheimer's disease and other forms of dementia. The publicly appointed members of the Advisory Council on Alzheimer's Research, Care, and Services have generated thoughtful and catalytic recommendations for the annual update to the National Plan to Address Alzheimer's Disease. There is heightened focus on improving care for people with advanced dementia.^{ix} The Food and Drug Administration (FDA) is encouraging new research avenues, clarifying regulatory approval pathways,^x and reviewing products to modify disease pathology, clinical progression, and the most heart-breaking symptoms of dementia. Congressional appropriations committees and NIH have moved mountains to create additional resources, public-private partnerships, and a culture of urgency. Across NIH, institutes are advancing promising research into Alzheimer's disease and other forms of dementia to: understand genetic risk factors; address health disparities among women, communities of color, rural and other medically underserved areas, and persons with intellectual and developmental disabilities; understand Down syndrome's relationship to Alzheimer's disease; pursue cutting-edge trials aimed at preventing or substantially slowing disease progression by administering treatments much earlier in the disease process; and improve quality of life for people with dementia and their caregivers.^{xi} NIH is demonstrating strong progress as reflected in the AD+ADRD (Alzheimer's Disease and Alzheimer's Disease-Related Dementias) Research Implementation Milestones database.^{xii} NIH and its partners are hard at work implementing the *National Strategy for Recruitment and Participation in Alzheimer's and Related Dementias Clinical Research*,^{xiii} engaging broad segments of the public in the Alzheimer's and related dementias research enterprise, with a particular focus on making research participants more representative of intended beneficiaries of breakthroughs. The progress has been important but incomplete in diversifying the scientific workforce, the pool of clinical

trial participants, and the nature of the specific research projects to remedy the deep and disturbing health disparities that drive Alzheimer's disease and other forms of dementia. In FY25, the National Institute on Aging (NIA) plans to advance research to improve the diagnosis, treatment, and care of those living with dementia by identifying and testing new drug candidates, advancing comprehensive models of care, developing novel biomarkers for use as screening tests and to monitor treatment response, exploring disease risk and protective factors, and improving the understanding of the role of genetics and other disease mechanisms.^{xiv}

We support the recommendation from the Ad Hoc Group on Medical Research to appropriate at least \$51.3 billion for the NIH's base program level, with funding for the Advanced Research Projects Agency for Health (ARPA-H) to supplement, rather than supplant, this core investment in NIH. This \$51.3 billion 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.

We support the recommendation from the American Brain Coalition for a \$60 million increase over the FY 2023 level (providing at least \$740 million in FY 2025) for the Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative. 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 Alzheimer's and other forms of dementia. This multidisciplinary collaboration (including the NIH, FDA, DARPA and IARPA,^{xv} 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.

We support the recommendation from the Alliance for a Stronger FDA for a \$391 million funding increase for the FDA to meet the most pressing needs in medical products and food safety programs.^{xvi} The Alliance requests \$3.918 billion in total budget authority for the FDA in FY 2025. This represents an increase of \$391 million over FDA's FY 2024 enacted level. Substantial additional funding is needed for FDA to fulfill its expanding responsibilities. Specific increases are sought for drug and device review, biologics, public health data modernization, inspector staffing, facilities improvements, human and animal food safety programs, and other priority areas. 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. **We also support the recommendation from the American Brain Coalition to increase funding for the FDA's Neurology Drug Program from the FY 2024 level of \$2 million to a FY 2025 level of \$5 million.**

Strengthening Quality of Life

Until science delivers effective means to prevent, slow, or cure dementia, families and friends along with health care providers rely on programs to protect their own well-being as they help persons with dementia to remain independent and in the community while delaying placement in institutional settings.

We support recommendations from the Leadership Council of Aging Organizations (LCAO) to double funding for Older Americans Act (OAA) and other aging programs

and services. OAA investments are relatively small but 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 deserve strengthened commitments to programs to protect and enhance their quality of life. The World Health Organization has noted that dementia is among the leading causes of disability and dependence among older people.^{xvii} Federal initiative and programs have a vital role 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. We commend your work to ensure that OAA programs and services were sustained during the worst of the pandemic. In FY25, expansion of aging programs and services would be instrumental to achieving the National Plan's goals to enhance care quality, efficiency, and supports for people living with dementia and their caregivers.^{xviii}

Among many vital aging programs and services, we highlight the urgent need for increased investments in the ACL Alzheimer's Disease Program, geriatrics education and training programs under Title VII of the Public Health Services (PHS) Act, and the Department of Justice (DoJ) Missing Alzheimer's Disease Patient Alert Program.

The Administration for Community Living (ACL) Alzheimer's Disease Program Initiative (ADPI) supports and promotes the development and expansion of dementia-capable home and community-based service long-term services and support systems in states and communities. As American Indians and Alaska Natives communities experience higher rates of dementia,^{xix} we applaud the recent ADPI grant specific to development of dementia capability in Indian Country. We encourage its funding and continuation in future years. ADPI delivers cutting-edge programs that meet the needs of individuals and caregivers managing dementia. Part of those resources support ACL's National Alzheimer's and Dementia Resource Center (NADRC). 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 dementia populations, such as those who live alone, those with disabilities (including those with intellectual disabilities), and those who reside in rural, poor, and minoritized communities. NADRC also produces dementia-related toolkits and provides technical assistance and webinars on Alzheimer's and other form of dementia to the public.^{xx}

We support a \$33.8 million increase for the geriatrics education and training programs under Title VII of the Public Health Services (PHS) Act. The Geriatrics Workforce Enhancement Program (GWEP) and the Geriatrics Academic Career Awards (GACAs), administered by the Health Resources and Services Administration (HRSA), are the only federal mechanism for supporting geriatrics health professions education and training. Sustained and enhanced investment will ensure that these critical resources are maximally deployed to serve older adults nationwide. GWEP awardees educate and engage the broader frontline workforce, including family caregivers, and focus on improving quality of care delivered to older adults. An important GWEP component is developing academic-primary care- community-based partnerships to address gaps in older adults' health care while transforming clinical training environments into integrated geriatrics and primary care sites/systems that become age-friendly health systems and dementia-friendly communities. An essential complement to the GWEP, the GACA program builds a pipeline of individuals

with academic and research expertise who become leaders in their fields and enhance the educational or research capacity at the grantee's institution. The proposed increases would enable every state to have a GWEP program and ensure that more rural and underserved areas of the country have access to geriatrics training and expertise to expand the capacity of the existing health care delivery and caregiving workforce. The increases for GACAs would ensure a larger and geographically more diverse pipeline of geriatrics research and training expertise with needed incentives and resources to grow the field.

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 Alzheimer's disease 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 addition resources to better serve states and communities nationwide.

Promoting Public Health

We support \$60 million for the CDC's Alzheimer's Disease and Healthy Aging Program (ADHAP) to continue BOLD Act implementation, expand the CDC Healthy Brain Initiative roadmap for state and national partnerships, and reduce dementia risk through brain health promotion.

The ADHAP is the only place within the CDC specifically dedicated to promoting the health of older adults through dementia risk-reduction interventions (e.g. smoking cessation, exercise, education) and across chronic conditions that heighten risk for dementia (e.g. hypertension, hearing loss, depression, traumatic brain injury, diabetes, obesity). The ADHAP also is the central locus for addressing health equity challenges across chronic conditions that share these common risk factors. Yet, last year, total funding for the ADHAP's vital work represented only approximately 0.25% of the overall CDC budget.

Specifically, the \$60 million funding level would support the CDC ADHAP's work to:

- strengthen programs that reduce risk, promote health equity, and support populations with a high burden of Alzheimer's disease and related forms of dementia
- 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
- support public health strategies addressing the social determinants of health that contribute to disparities in healthy aging and brain health.

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).^{xxi} 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. We commend your work to fund CDC's ADHAP its BOLD Act work to support implementation of the Healthy Brain Aging Road Map.

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.^{xxii} The Road Map is advancing strategies to reduce lifestyle risk factors, improve detection and diagnosis, strengthen community supports for people with dementia and their families, and redress health disparities.

We support sustained and robust funding for Federally Qualified Health Centers (FQHCs). The FQHCs help address cultural, linguistic, and other barriers to care by delivering coordinated and comprehensive primary and preventive services – helping to reduce health disparities in medically-underserved communities across the nation. Leveraging the capacity of these innovative, high quality, community-based, and trusted providers is an important way to advance health equity while reducing the burden of dementia on the individuals, families, communities, the healthcare system, the federal budget and national economy.

Appropriations Report Language

We also support appropriations report language to advance accomplishing goals of the National Alzheimer's Plan and request that the following be included:

- **Centers for Medicare and Medicaid Services (CMS)**

The Committee directs the Centers for Medicare and Medicaid Services to identify, within 180 days of enactment of this Act, actions the agency can take within existing authorities to improve early detection of mild cognitive impairment (MCI) under the Medicare Annual Wellness Visit (AWV) and the annual Initial Preventive Physical Exam (IPPE). This review should include opportunities to improve early detection of MCI during the AWV and IPPE by ensuring use of evidence-based, reliable, cognitive impairment detection tools identified by the National Institute on Aging.

The Committee is encouraged by innovations in diagnostic tools along with treatments for the underlying biology of Alzheimer's disease and some of its most serious symptoms. The Committee acknowledges that potential benefits of early diagnosis include timely access to treatments and lifestyle interventions, enhanced opportunities participate in research studies, lower costs of care, and more time for care and quality of life planning. Integration of evidence-based diagnostic tools into clinical practice will ensure that people facing these conditions can have the earliest possible opportunities to benefit from community-based services and clinical interventions, which may include symptomatic and disease-modifying therapies. The Committee urges CMS to recognize its role in facilitating timely and equitable beneficiary access to these diagnostic tools and services, and we encourage continued collaboration between CMS and other federal agencies in their collective efforts to shift standard of care towards timely and accurate detection and diagnosis.

- **Department of Health and Human Services (HHS)**

The Committee is encouraged that the Secretary announced in 2021 that the National Alzheimer's Plan would include a sixth goal to reduce risk factors for Alzheimer's disease and related disorders. The Committee directs the Secretary to compile a report on progress made toward meeting the goal. The report should focus on evaluating funding allocated toward achieving Goal Six; detail about how progress against the goal is being measured and tracked; the level of spending on Alzheimer's disease and related disorders across federal agencies; and an analysis of how HHS and other federal agencies are implementing risk reduction strategies and working with non-governmental organizations to meet Goal Six.

The Committee encourages HHS to develop a process – modeled on the CDC's Special Diabetes Program -- by which tribes, tribal serving organizations, and urban Indian organizations can be awarded non-competitive grant funding from the Centers for Disease Control and Prevention (CDC) and the Indian Health Service (IHS) to address dementia, including public health approaches and direct-care programs. All 574 federally recognized tribes should have access to all funding opportunities. Federal funding should support tribal sovereignty by making funds directly available to tribes, tribal serving organizations, and urban Indian organizations. Most tribes are disadvantaged by competitive funding due to limited capacity (e.g., not having in-house grant writers), the need for longer response time due to tribal nations' governance processes, and other factors.

Thank you for considering our views and for your commitment to overcoming Alzheimer's disease and other forms of dementia. For any questions or additional information about this legislation or other policy issues, please contact Ian Kremer, executive director of Leaders Engaged on Alzheimer's Disease (the LEAD Coalition),^{xxiii} ikremer@leadcoalition.org or (571) 383-9916.

Sincerely,

Abe's Garden Community

Acadia Pharmaceuticals Inc

Accelerate Cure/Treatments for
Alzheimer's Disease (ACT-AD)

ACCSES – The Voice of Disability Service
Providers

ACMCRM Arachnoiditis & Chronic
Meningitis Collaborative Research
Network

ActivistsAgainstAlzheimer's Network

ADvancing States

African American Network Against
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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
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Alzheimer's San Diego
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AMDA – The Society for Post-Acute and Long-Term Care Medicine
American Academy of Neurology
American Association for Geriatric Psychiatry
American Brain Coalition
American College of Preventive Medicine (ACPM)
American Federation for Aging Research (AFAR)
American Geriatrics Society
American Medical Women's Association
American Society for Biochemistry and Molecular Biology
American Society of Consultant Pharmacists (ASCP)
American Society on Aging

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Association of Population Centers
Athira Pharma, Inc.
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B'nai B'rith International

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The Brain Donor Project

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Bridge Builder Strategies

BrightFocus Foundation

Brookdale Senior Living Inc.

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CARE Research Center, Massachusetts General Hospital

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Center for BrainHealth at The University of Texas at Dallas

Center for Innovation: The Green House Project and Pioneer Network

Center to Advance Palliative Care

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The Coelho Center for Disability Law, Policy and Innovation

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Cure Alzheimer's Fund

CurePSP

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Danaher Diagnostics

Darmiyan, Inc.

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Dementia Palliative Education Network

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Eisai, Inc.

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Global Alzheimer's Platform Foundation

Global CEO Initiative on Alzheimer's Disease

Global Coalition on Aging

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Healthcare Leadership Council

HealthMatters Program

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ICAN, International Cancer Advocacy Network

International Association for Indigenous Aging

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National Asian Pacific Center on Aging

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National Association of Social Workers (NASW)

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

National Caucus and Center on Black Aged, Inc. (NCBA)

National Certification Council for Activity Professionals

National Coalition for Hospice and Palliative Care

National Committee to Preserve Social Security and Medicare

National Consumers League

National Consumer Voice for Quality Long-Term Care

National Council for Behavioral Health

National Down Syndrome Society

National Hartford Center of Gerontological Nursing Excellence

National Hispanic Council On Aging (NHCOA)

National Indian Council on Aging (NICOA)

National Minority Quality Forum

National Prion Disease Pathology Surveillance Center

National Task Group on Intellectual Disabilities and Dementia Practices

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Penn State Ross and Carol Nese College of Nursing, Tressa Nese and Helen Diskevich Center of Geriatric Nursing Excellence

Pentara Corporation

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Population Association of America

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Positrigo AG

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The Evangelical Lutheran Good Samaritan Society

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UsAgainstAlzheimer's, LEAD Coalition co-convenor

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VeteransAgainstAlzheimer's

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WomenAgainstAlzheimer's

Women's Brain Project

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ⁱ <http://www.nejm.org/doi/full/10.1056/NEJMsa1204629>

ⁱⁱ <https://alz.org/media/Documents/alzheimers-facts-and-figures.pdf>

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- xxi <https://www.congress.gov/bill/115th-congress/senate-bill/2076>
- xxii <https://www.cdc.gov/aging/healthybrain/roadmap.htm>
- xxiii <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.