



June 28, 2023

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

The Honorable Kay Granger, Chairwoman
The Honorable Rosa DeLauro, Ranking
Member
House Appropriations Committee
Washington DC, 20515

by electronic delivery

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

As you continue the essential work to develop and pass Fiscal Year 2024 (FY24) appropriations bills, we write to reiterate support for priorities communicated earlier this year by 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 widespread access to the first 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 even more effective treatments for Alzheimer's disease and related disorders along with strengthening the programmatic supports imperative to improving quality of life for people with dementia and their caregivers.

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 2023 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, care, and support 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 FY24 appropriations bills include at least the following minimum levels:**

- **a \$321 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 FY24**

- a \$3.5 billion increase (to \$51 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
- A \$372 million increase for the FDA, in addition to funds included in the 21st Century Cures Act for targeted initiatives
- Double funding for Older Americans Act (OAA) and other aging programs and services
 - a \$6.5 million increase for the ACL Alzheimer’s Disease Program
 - a \$35 million increase for the HRSA geriatrics workforce programs
 - a \$5 million increase for the DoJ Missing Alzheimer’s Disease Alert Program
- \$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 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.ⁱⁱ 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.ⁱⁱⁱ Those costs continue to climb and are unsustainable for families, public and private insurers, and our nation’s economy.

Currently, more than 6.7 million Americans are living with dementia, with combined healthcare and long-term care costs of \$345 billion.^{iv} Taxpayers foot about 64% of that bill -- \$222 billion -- directly through the Medicare and Medicaid programs. Individuals with dementia and their families pay out of pocket 25% of the cost, \$87 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 nearing \$690 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 \$345 billion in 2023 to approximately \$1 trillion in 2050 (in 2022 dollars) and the hidden costs of uncompensated caregiving to become even more staggering.^v

Alzheimer's disease contributes to the deaths of more than 500,000 Americans each year. Alzheimer's disease is the third leading cause of death in the United States^{vi} and — despite a powerful body of evidence for risk-reduction strategies,^{vii} which is being expanded with significant NIH investments^{viii} — the only one among the top 10 for which there is not yet a proven means of prevention, disease modification or cure.^{ix} One third of older Americans dies with Alzheimer's disease or another form of dementia.^x

Advancing Science

We support a \$321 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 FY24 Bypass Budget.^{xi} 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 by 2025.^{xii}

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.^{xiii} The Food and Drug Administration (FDA) is encouraging new research avenues, clarifying regulatory approval pathways,^{xiv} 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, 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.^{xv} NIH is demonstrating strong progress as reflected in the AD+ADRD (Alzheimer's Disease and Alzheimer's Disease-Related Dementias) Research Implementation Milestones database.^{xvi} NIH and its partners are hard at work implementing the *National Strategy for Recruitment and Participation in Alzheimer's and Related Dementias Clinical Research*,^{xvii} engaging broad segments of the public in the Alzheimer's and related dementias research enterprise, with a particular focus on making research participants more accurately reflect 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 FY24, 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.^{xviii}

We support the recommendation from the Ad Hoc Group on Medical Research to appropriate at least \$51 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 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 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,^{xix} 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. To date, the BRAIN Initiative has supported more than 1,300 awards totaling more than 3 billion,^{xx} resulting in research that has made significant advances in important technologies such as brain imaging.^{xxi} The ongoing commitment to fund this program will continue the roll out of three large transformative projects that will build a comprehensive atlas of cell types in the human brain, develop and scale up the tools necessary to complete a micro-connectivity map of an entire mammalian brain, and provide tools for precision access to the identified cell types to allow interrogation and modulation of neural circuits. Together, these tools will enable the eventual development of novel interventions—including molecular and gene-editing therapies—for human circuit disorders.^{xxii}

We support the recommendation from the Alliance for a Stronger FDA for a \$372 million increase for the FDA to meet the most pressing needs in medical products and food safety programs.^{xxiii} Funding would strengthen FDA systems that guide and support agency decision-making and stimulate innovation for medical products, including improvements in drug and device manufacturing, advances in the use of real-world evidence in medical product development, revisions to the regulatory framework for digital health technology, enhancements to research on rare diseases such as less common forms of dementia, and new systems that could speed the introduction of cost-saving generic drugs.

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 recommendation from the Leadership Council of Aging Organizations (LCAO) to double funding for Older Americans Act (OAA) and other aging programs and services. These 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.^{xxiv} 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 FY24, 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.^{xxv}

We support a \$6.5 million increase for the ACL Alzheimer’s Disease 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,^{xxvi} 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 minority communities. NADRC also produces dementia-related toolkits and provides technical assistance and webinars on Alzheimer’s and other form of dementia to the public.^{xxvii}

We support a \$35 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.

We support a \$5 million increase for the Department of Justice (DoJ) Missing Alzheimer's Disease Patient Alert Program, which 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).^{xxviii} 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. Congress authorized \$100 million over five years so that CDC would have the necessary resources to establish Alzheimer's and Related Dementias Public Health Centers of Excellence, provide funding to state, local, and tribal public health departments, and increase data analysis and timely reporting.

Increased funding also would support a significant increase for the CDC's long-standing and successful Healthy Brain Initiative, which is implementing its 2018-2023 Healthy Brain Aging Road Map (and companion Road Map for Indian Country) to ramp up the nation's public health capacity in addressing dementia.^{xxix} 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. The next Healthy Brain Aging Road Map is anticipated to be released this summer and will launch an even more ambitious phase of our nation's public health response but to reduce the risk of dementia and to improve quality of life for those who are living with dementia.

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:

- **Health Resources and Services Administration (HRSA), Community Health Centers (CHC)**

Unfortunately, little is known about people with Alzheimer's disease and related forms of dementia served by CHCs and look-alikes in the CHC program due to the lack of available data. Data is essential to understanding the level of need, resources, training and challenges needed to keep people currently served in the CHC programs to continue as they age. The Committee strongly encourages HRSA to include Alzheimer's and related Dementia I-10 codes in the Uniform Data Collection System.

- **Health Resources and Services Administration (HRSA)**

The Committee urges HRSA to establish a Brain Health Equity initiative to help drive the integration of brain health services into the workflow of primary care delivery that reaches underserved populations served by Federally Qualified Health Centers and look-alikes.

- **Centers for Disease Control and Prevention (CDC) Alzheimer's Disease and Healthy Aging Program**

The Committee is encouraged by research demonstrating the positive impact of risk reduction on dementia prevalence and commends the Secretary for updating the National Alzheimer's Plan to reflect the latest science. To ensure high burden populations are reached, the Committee directs CDC to increase capacity to reach populations disproportionately burdened by Alzheimer's Disease — including, but not limited to Black/African American, Latino/Hispanic, American Indian/Native Alaskan, Down Syndrome, and rural populations — through public health promotion and workforce development by increasing Healthy Brain Initiative grants from \$5.5 million to \$10 million.

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),^{xxx} ikremer@leadcoalition.org or (571) 383-9916.

Sincerely,

Abe's Garden Community	Aging and Memory Disorder Programs, Howard University
Acadia Pharmaceuticals Inc	Aging Life Care Association®
Accelerate Cure/Treatments for Alzheimer's Disease (ACT-AD)	Paul S. Aisen, MD (Keck School of Medicine of USC, Alzheimer's Therapeutic Research Institute*)
ACCSES – The Voice of Disability Service Providers	Benedict C. Albeni, PhD, BCMAS, CRQM (Nova Southeastern University*)
ACMCRM Arachnoiditis & Chronic Meningitis Collaborative Research Network	Ricardo F. Allegri MD, PhD (School of Medicine, Universidad de Buenos Aires*)
ActivistsAgainstAlzheimer's Network	Alliance for Aging Research
ADvancing States	Alliance for Patient Access
African American Network Against Alzheimer's	Michael L. Alosco, PhD (Alzheimer's Disease Research Center, Boston University Chobanian & Avedisian School of Medicine*)
Nimit Agarwal MD (University of Arizona, Department of Medicine, Division of Geriatric Medicine*)	Alzheimer's Association
AgeneBio	Alzheimer's Disease Resource Center, Inc. (ADRC)
AgeWell Collaboratory of Drexel University	Alzheimer's Drug Discovery Foundation
Neelum T. Aggarwal, MD (Rush University Medical Center*)	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

Alzheimer's Tennessee

Takashi Amano, PhD, MSW (Rutgers University Newark*)

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

Halima Amjad, MD, PhD, MPH (Johns Hopkins University*)

Edward F. Ansello, Ph.D. (Virginia Commonwealth University*)

Brian S. Appleby, M.D. (Case Western Reserve University School of Medicine*)

María Aranda, PhD (USC Edward R. Roybal Institute on Aging*)

Argentum | Expanding Senior Living

Jalayne J. Arias, JD, MA (Georgia State University, School of Public Health*)

Association of California Caregiver Resource Centers (ACCRC)

Association of Population Centers

Athira Pharma, Inc.

Alireza Atri, MD, PhD (Banner Sun Health Research Institute*)

Rhoda Au, Ph.D. (Boston University Chobanian & Avedisian School of Medicine and Public Health*)

Autistic Women & Nonbinary Network — AWN

Laurie Badzek, LLM, JD, MS, RN, FNAP, FAAN (Penn State Ross and Carol Nese College of Nursing, Tressa Nese and Helen Diskevich Center of Geriatric Nursing Excellence*)

Laura D. Baker, PhD (Wake Forest University School of Medicine*)

The Balm In Gilead, Inc.

Banner Alzheimer's Institute

Banner Health

David M. Bass, PhD (Benjamin Rose Institute on Aging*)

Baylor Scott & White Health

Maryam Beigi, MD (Mary S. Easton Center for Alzheimer's Disease Research at UCLA*)

Andrew R. Bender, Ph.D. (Michigan State University*)

Benjamin Rose Institute on Aging

Tammie L.S. Benzinger, M.D., Ph.D. (Washington University School of Medicine in St. Louis*)

Biogen

B'nai B'rith International

Marie Boltz, PhD, GNP-BC, FGSA, FAAN (Penn State College of Nursing*)

Soo Borson MD (USC Keck School of Medicine*)

Nicole Bouranis PhD (Drexel University College of Nursing and Health Professions*)

Malaz A. Boustani MD, MPH, Indiana University Center for Health Innovation and Implementation Science*)

Adam L. Boxer, MD, PhD (Department of Neurology, University of California, San Francisco*)

Andrea Bozoki, MD, FAAN (University of North Carolina, Chapel Hill*)

The Brain Donor Project

James Brewer, M.D., Ph.D. (UC San Diego and Alzheimer's Disease Cooperative Study*)

Bridge Builder Strategies

BrightFocus Foundation

Brookdale Senior Living Inc.

Danielle Goldfarb Cabral, MD (University of Arizona College of Medicine*)

Ismael Calandri MD (University of Buenos Aires*)

Christopher M. Callahan, MD (Indiana University Center for Aging Research*)

Caregiver Action Network

CARE Research Center, Massachusetts General Hospital

CaringKind, The Heart of Alzheimer's Caregiving

Maria Torroella Carney, MD, FACP (Northwell Health and Zucker School of Medicine at Hofstra/Northwell*)

Centene

Center for Alzheimer Research and Treatment, Harvard Medical School

Center for BrainHealth at The University of Texas at Dallas

Center to Advance Palliative Care

Chambers-Grundy Center for Transformative Neuroscience, Department of Brain Health, UNLV

Marianne Chanti-Ketterl, PhD, MSPH (Duke-UNC Alzheimer's Disease Research Center*)

Sandra Bond Chapman, PhD (Center for BrainHealth at The University of Texas at Dallas*)

Joshua Chodosh, MD, MSHS, FACP (NYU Grossman School of Medicine*)

Urvika Choksey, MD (Yale School of Medicine*)

ClergyAgainstAlzheimer's Network

Cleveland Clinic Lou Ruvo Center for Brain Health, Nevada

Carolyn K Clevenger, DNP, GNP-BC, AGPCNP-BC, FAANP, FGSA, FAAN (Emory University*)

CNS Innovations

Coalition of Wisconsin Aging and Health Groups

The Coelho Center for Disability Law, Policy and Innovation

Cognitive Dynamics Foundation

Ann D. Cohen, PhD (Department of Psychiatry, University of Pittsburgh, School of Medicine*)

Corium

Tara A. Cortes PhD, RN, FAAN, FGSA (NYU Rory Meyers College of Nursing, The Hartford Institute for Geriatric Nursing*)

Suzanne Craft, PhD (Wake Forest School of Medicine*)

Creutzfeldt-Jakob Disease Foundation

Jeffrey Cummings, MD, ScD (University of Nevada Las Vegas*)

Lenise Cummings-Vaughn, MD (Washington University School of Medicine*)

Cure Alzheimer's Fund

CurePSP

Kirk R. Daffner MD, FAAN (Brigham and Women's Hospital, Harvard Medical School*)

Darmiyan

Walter Dawson, Dphil (Oregon Health & Science University*)

Steven T. DeKosky, MD, FACP, FANA, FAAN (University of Florida College of Medicine*)

Dementia Alliance International

Dementia Alliance of North Carolina

Dementia Palliative Education Network

DigiCARE Realized Inc.

Elizabeth Disbrow, PhD (LSU Health Shreveport Center for Brain Health*)

Michael C Donohue, PhD (Keck School of Medicine of USC *)

N. Maritza Dowling PhD (The George Washington University School of Nursing*)

Drexel University College of Nursing and Health Professions

Easterseals

Eisai, Inc.

The Emory Goizueta Alzheimer's Disease Research Center

Fayron Epps, PhD, RN, FGSA, FAAN (Emory University, Nell Hodgson Woodruff School of Nursing*)

Gary Epstein-Lubow, MD (Alpert Medical School of Brown University & Brown University School of Public Health*)

Anne Fabiny, MD (University of California, San Francisco*)

Faith United Against Alzheimer's Coalition

Family Caregiver Alliance

D. Luke Fischer, MD, PhD (Weill Institute for Neurosciences, University of California, San Francisco*)

Concetta Forchetti MD, PhD (Department of Neurology, Northwestern University Feinberg School of Medicine*)

Brent P. Forester, MD, MSc (Tufts University School of Medicine*)

Richard H. Fortinsky, PhD (UConn Center on Aging, University of Connecticut School of Medicine*)

Frank & Barbara Broyles Legacy Foundation

Fujirebio

Seth A. Gale, M.D. (Brigham and Women's Hospital, Harvard Medical School*)

Michela Gallagher, PhD (Johns Hopkins University School of Medicine*)

Sam Gandy, MD, PhD (Icahn School of Medicine at Mount Sinai*)

Joseph E. Gaugler, PhD (School of Public Health, University of Minnesota*)

David S. Geldmacher, MD, FACP (University of Alabama at Birmingham School of Medicine*)

Genentech

Genetic Alliance

Daniel R. George, Ph.D, M.Sc (Penn State College of Medicine*)

Georgetown University Medical Center Memory Disorders Program

Gerontological Advanced Practice Nurses Association

The Gerontological Society of America

Thomas M. Gill, M.D. (Yale School of Medicine*)

Laura Gillen, MS (McDaniel College*)

Meredith Gilliam MD MPH (University of North Carolina*)

Laura N. Gitlin, PhD (Drexel University, College of Nursing and Health Professions*)

G. Peter Gliebus, MD, FAAN (Drexel University College of Medicine*)

Global Alzheimer's Platform Foundation

Global CEO Initiative on Alzheimer's Disease

Global Coalition on Aging

Global Neurosciences Institute

Jürgen Götz, PhD, Dr. habil, FAHMS, GAICD (Queensland Brain Institute, The University of Queensland*)

Barry D. Greenberg, Ph.D. (Johns Hopkins University School of Medicine*)

Lisa P. Gwyther, MSW, LCSW (Duke University Medical Center*)

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

Duke Han, PhD (Keck School of Medicine of USC*)

Christian Haass Ph.D.(Ludwig Maximilians University Munich*)

Healthcare Leadership Council

HealthMatters Program

HealthyWomen

J. Neil Henderson, PhD (University of Minnesota Medical School*)

Victor Henderson, MD (Stanford University*)

Patricia C. Heyn, PhD, FGSA, FACRM (Marymount University*)

HFC

Nikki L. Hill, PhD, RN (The Pennsylvania State University, Ross and Carol Nese College of Nursing*)

Annie Hiniker MD, PhD (Alzheimer's Disease Research Center, University of California San Diego*)

Nancy A. Hodgson, RN, PhD, FAAN (University of Pennsylvania School of Nursing*)

David M. Holtzman, MD (Washington University School of Medicine, Department of Neurology*)

Home Instead Senior Care

William Hu MD, PhD, FAAN (Rutgers University*)

Huffington Center on Aging, Baylor College of Medicine

Huntington's Disease Society of America

Ula Hwang, MD, MPH (Yale University School of Medicine*)

Hypertrophic Cardiomyopathy Association

ICAN, International Cancer Advocacy Network

International Association for Indigenous Aging

Iona Senior Services

Jonathan Jackson, PhD (Harvard Medical School*)

Shannon Jarrott, Ph.D. (Ohio State University, College of Social Work*)

Kathy Jedrzewski, PhD (University of Pennsylvania*)

Lee A. Jennings, MD, MSHS (University of Oklahoma Health Sciences Center*)

Johns Hopkins Memory and Alzheimer's Treatment Center

The Jona Goldrich Center for Alzheimer's and Memory Disorders, Cedars-Sinai Medical Center

Katherine S. Judge, PhD (Cleveland State University*)

Nicholas Kanaan, PhD (Michigan State University*)

Kejal Kantarci, MD, MS (Mayo Clinic*)

Anumantha Kanthasamy, Ph.D. (Department of Physiology and Pharmacology, University of Georgia College of Veterinary Medicine*)

Jason Karlawish, MD (Penn Memory Center, University of Pennsylvania*)

Jeffrey Kaye, MD (Layton Aging & Alzheimer's Disease Research Center, Oregon Health & Science University*)

Keck School of Medicine of USC, Alzheimer's Therapeutic Research Institute

Ara S. Khachaturian, PhD (University of Nevada Las Vegas*)

Zaven S. Khachaturian, PhD (Johns Hopkins University*)

Vikram Khurana, MD, PhD (Brigham and Women's Hospital, Harvard Medical School*)

Amy J.H. Kind, MD, PhD (University of Wisconsin School of Medicine and Public Health*)

William E. Klunk, M.D., Ph.D. (University of Pittsburgh*)

Rada Koldamova MD, PhD (School of Public Health, University of Pittsburgh*)

Walter A. Kukull, PhD (School of Public Health, University of Washington*)

Latino Alzheimer's and Memory Disorders Alliance

LatinosAgainstAlzheimer's

Layton Aging and Alzheimer's Disease Center, Oregon Health & Science University

LeadingAge

Edward B. Lee, M.D., Ph.D. (Perelman School of Medicine at the University of Pennsylvania*)

Cynthia A. Lemere, PhD (Brigham & Women's Hospital; Harvard Medical School)*

Allan Levey, MD, PhD (Emory University School of Medicine*)

Lewy Body Dementia Association

Life Molecular Imaging

Jennifer Lingler PHD, MA, CRNP, FAAN (University of Pittsburgh, School of Nursing*)

Linked Senior, Inc

Lei Liu, MD PhD, (Brigham and Women's Hospital, Harvard Medical School*)

Livpact Inc.

Marissa Natelson Love, MD (Division of Memory Disorders and Behavioral Neurology, University of Alabama at Birmingham*)

LuMind IDSC Foundation

Lundbeck Pharmaceuticals, LLC

Lupus and Allied Diseases Association, Inc.

Kostas Lyketsos, M.D., M.H.S. (Johns Hopkins Memory and Alzheimer's Treatment Center*)

Yannick Marchalant, Ph.D. (Central Michigan University*)

Beth Marks, PhD, RN, FAAN (University of Illinois at Chicago*)

David X. Marquez, PhD (Department of Kinesiology and Nutrition, University of Illinois at Chicago*)

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

Donovan Maust, MD, MS (University of Michigan Medical School*)

Eric McDade, DO (Washington University School of Medicine*)

Medicare Rights Center

Michigan State University Alzheimer's Alliance

Milken Institute Alliance to Improve Dementia Care

Brienne Miner, MD MHS (Yale University School of Medicine*)

Minnesota Association of Area Agencies on Aging

MLD Foundation

Vincent Mor, PhD (Brown University, School of Public Health*)

David G. Morgan, PhD (Michigan State University*)

Darby Morhardt, PhD, LCSW (Northwestern University Feinberg School of Medicine*)

Mount Sinai Center for Cognitive Health

Catherine Mummery, MBBS PhD (University College London*)

Aanand Naik, MD (University of Texas Health Houston*)	Rik Ossenkoppele PhD (Alzheimer center Amsterdam University Medical Center*)
National Alliance for Caregiving	Otsuka America Pharmaceutical Inc.
National Asian Pacific Center on Aging	Miguel A. Pappolla, MD, PhD (University of Texas Medical Branch*)
National Association of Activity Professionals	Van Ta Park, PhD, MPH (University of California, San Francisco*)
National Academy of Elder Law Attorneys	Monica W. Parker, MD (Goizueta Alzheimer's Disease Research Center, Emory University*)
National Association of Social Workers (NASW)	Partnership to Fight Chronic Disease
National Association of State Long-Term Care Ombudsman Programs (NASOP)	Patients Rising Now
National Caucus and Center on Black Aged, Inc. (NCBA)	Pat Summitt Foundation
National Certification Council for Activity Professionals	Penn Program on Precision Medicine for the Brain (P3MB)
National Committee to Preserve Social Security and Medicare	Penn State Ross and Carol Nese College of Nursing, Tressa Nese and Helen Diskevich Center of Geriatric Nursing Excellence
National Consumers League	Pentara Corporation
National Consumer Voice for Quality Long-Term Care	Planetree International, Inc.
National Council for Behavioral Health	Population Association of America
National Down Syndrome Society	Anton P. Porsteinsson, M.D. (University of Rochester School of Medicine and Dentistry*)
National Hartford Center of Gerontological Nursing Excellence	Positrigo AG
National Hispanic Council On Aging (NHCOA)	Katherine Possin, PhD (University of California San Francisco, Memory and Aging Center*)
National Indian Council on Aging (NICOA)	Daniel C. Potts, MD, FAAN (University of Alabama College of Community Health Sciences*)
National Minority Quality Forum	Melinda C. Power, ScD (Milken Institute School of Public Health, George Washington University*)
National Prion Disease Pathology Surveillance Center	Daniel Z. Press, MD (Harvard Medical School*)
National Task Group on Intellectual Disabilities and Dementia Practices	Prevent Alzheimer's Disease 2020
NFL Neurological Center	PXE International
Noah Homes	
Thomas O. Obisesan, MD, MPH (Howard University Hospital*)	
The Ohio Council for Cognitive Health	
Organic Acidemia Association	

Vanessa Rayment, MBChB, MSc,
MRCPsych (University of Oxford*)

Peter Reed, PhD (Sanford Center for
Aging, University of Nevada Reno*)

Eric Reiman, MD (Banner Alzheimer's
Institute*)

Dorene M. Rentz, PsyD (Brigham and
Women's Hospital, Harvard Medical
School*)

ResearchersAgainstAlzheimer's

RetireSafe

David B. Reuben, MD (David Geffen
School of Medicine at UCLA*)

Emma Rhodes, PhD (University of
Pennsylvania, Department of Neurology,
Frontotemporal Degeneration Center*)

Craig W Ritchie, MD, PhD (University of
Edinburgh*)

Roche Diagnostics Corporation

Emily Rogalski, PhD (Northwestern
University, Mesulam Center for
Cognitive Neurology & Alzheimer's
Disease*)

Theresa Rohr-Kirchgraber, MD, FACP,
FAMWA (Augusta University/University
of Georgia Medical Partnership*)

Tatiana Sadak, PhD, PMHNP, ARNP
(University of Washington School of
Nursing*)

Carl H. Sadowsky, MD, FAAN (Nova
Southeastern University*)

Takaomi C Saido, PhD (RIKEN Center for
Brain Science*)

Stephen Salloway, M.D., M.S. (The
Warren Alpert Medical School of Brown
University*)

Quincy Miles Samus, PhD, MS (Johns
Hopkins School of Medicine*)

Sanford Health

Andrew J. Saykin, PsyD, ABCN (Indiana
Alzheimer's Disease Research Center,
Indiana University School of Medicine*)

Suzanne Schindler MD, PhD (Washington
University School of Medicine,
Department of Neurology*)

Julie A. Schneider, MD, MS (Rush
Alzheimer's Disease Center, Rush
University*)

Michael Schöll PhD (University of
Gothenburg*)

Second Wind Dreams, Inc./ Virtual
Dementia Tour

Dennis J. Selkoe, MD (Brigham and
Women's Hospital, Harvard Medical
School*)

Leslie M Shaw, PhD (Perelman School of
Medicine at the University of
Pennsylvania*)

Jasmina Sisirak, PhD (University of Illinois
at Chicago*)

Gary Small, MD (Hackensack Meridian
School of Medicine*)

Amanda G. Smith, M.D. (USF Health Byrd
Alzheimer's Institute*)

B. Joy Snider, MD, PhD (Washington
University School of Medicine*)

Peter J. Snyder, Ph.D. (Albert Medical
School of Brown University*)

Society for Women's Health Research

Reisa A. Sperling, MD, MMSc (Center for
Alzheimer Research and Treatment,
Harvard Medical School*)

Alan B. Stevens, PhD (Baylor Scott &
White Health, Center for Healthcare
Policy*)

Donald Sullivan, MD, MA, MCR (Oregon
Health and Science University*)

Russell H. Swerdlow, M.D. (University of
Kansas School of Medicine*)

Malú Gámez Tansey, Ph.D. (College of
Medicine, University of Florida*)

Rudolph Tanzi, PhD (Department of
Neurology, MGH/Harvard Medical
School*)

Pierre N. Tariot, MD (University of Arizona College of Medicine*)

Carmela Tartaglia, M.D., FRCPC (Tanz Centre for Research in Neurodegenerative Diseases, University of Toronto*)

David B. Teplow Ph.D. (Department of Neurology, David Geffen School of Medicine at UCLA*)

Texas Rare Alliance

The Association for Frontotemporal Degeneration

The Evangelical Lutheran Good Samaritan Society

The Memory Impairment and Neurodegenerative Dementia (MIND) Center, University of Mississippi Medical Center

Megan Thomas Hebdon, PhD, DNP, RN, NP-c (University of Texas at Austin School of Nursing*)

Trellis/ACT on Alzheimer's

Geoffrey Tremont, Ph.D., ABPP-CN (Alpert Medical School of Brown University*)

Elena Tsoy, PhD (Department of Neurology, University of California, San Francisco*)

R. Scott Turner, MD, PhD (Georgetown University Memory Disorders Program*)

UCLA Mary S. Easton Center for Alzheimer's Disease Research, David Geffen School of Medicine

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, LEAD Coalition co-convener

USAging

USC Edward R. Roybal Institute on Aging

Ipsit Vahia, MD (Mclean Hospital, Harvard Medical School*)

Lawren VandeVrede, MD/PhD (University of California, San Francisco*)

Christopher H. van Dyck, MD (Alzheimer's Disease Research Center, Yale School of Medicine*)

Linda J. Van Eldik, PhD (Sanders-Brown Center on Aging and Alzheimer's Disease Research Center, University of Kentucky*)

VeteransAgainstAlzheimer's

Virginia Center on Aging

Anand Viswanathan, MD, PhD (Massachusetts General Hospital and Alzheimer's Disease Research Center*)

Voices of Alzheimer's

Stella L. Volpe, PhD, RDN, ACSM-CEP, FACSM (Virginia Tech*)

Volunteers of America, LEAD Coalition co-convener

Keith Vessel, MD, MSc (Mary S. Easton Center for Alzheimer's Disease Research, David Geffen School of Medicine at UCLA)

Victoria Walker, MD CMD (Sanford School of Medicine, University of South Dakota*)

Qing Wang Ph.D. (Washington University in St. Louis, School of Medicine*)

David A. Weidman, MD, FAAN (Banner Alzheimer's Institute*)

Carol J. Whitlatch, PhD (Benjamin Rose Institute on Aging*)

Nancy Wilson, MA LCSW (Baylor College of Medicine*)

Jennifer Wolff, PhD (Johns Hopkins Bloomberg School of Public Health*)

David A. Wolk, MD, FAAN (Alzheimer's Disease Research Center, Perelman School of Medicine at the University of Pennsylvania*)

Benjamin Wolozin, M.D., Ph.D. (Boston University Chobanian & Avedisian School of Medicine*)

WomenAgainstAlzheimer's

Women's Brain Project

World Molecular Imaging Society

Hyun-Sik Yang, MD (Brigham and Women's Hospital, Harvard Medical School*)

Julie M. Zissimopoulos, Ph.D. (University of Southern California, Price School of Public Policy*)

** Affiliations of individual researchers are for identification purposes only and do not necessarily represent the endorsement of affiliated institutions.*

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xxix <https://www.cdc.gov/aging/healthybrain/roadmap.htm>

xxx <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.