

UsA2's transformative programming is laser-focused on proactive brain health across the lifespan and understanding what matters most across the lived experiences of those affected by Alzheimer's in the service of preventing, treating and curing this disease. We are working to ensure that all communities have their voices heard, and get a chance to be brain healthy from the earliest years while building resistance to and resilience against potential cognitive decline.

Embracing a comprehensive Theory of Change.

UsAgainstAlzheimer's (UsA2) is a disruptive advocacy and research organization that has pushed for expanding treatments and accelerating towards a cure for Alzheimer's disease. No longer a concern simply for later years, proactive brain health across the lifespan requires understanding, attention and commitment to our body's most powerful organ. We need to know how to empower ourselves, our families and our communities to keep our brains healthy from the earliest years. UsA2 is here to help share this knowledge and understanding, to combat Alzheimer's from every angle and to continue the urgent work that will ultimately bring about a cure.

This means not only continuing to maintain and develop pharmacological approaches, and doing everything we can to accelerate clinical trials for new therapies and treat-

ments, but to also expand dramatically into preventative care while addressing critical, fundamental risks to brain health – beginning in the earliest years of life.

It also means doing everything we can to accelerate clinical trials for new therapies and treatments, while providing common tools to promote research engagement and brain health literacy.

Everything we do to attack and slow this disease must be implemented simultaneously and mature concurrently – so that when a cure does arrive, we're ready to fully integrate it into an existing health care infrastructure based on advanced pharmacological development, consumer and provider action and the latest thinking on brain health.



Empowering all communities impacted by Alzheimer's to demand action on proactive brain health across the lifespan.

Brain Health Partnership. Our goal is to increase awareness of and action around brain health across the lifespan in the service of preventing, treating and curing Alzheimer's. We also advocate fiercely for policies that expand access to treatments and reduce health care costs for all patients in all communities.

Alzheimer's Disease Disparities Engagement Network (ADDEN). We are a national learning network committed to curing Alzheimer's and eliminating brain health disparities for communities of color and women. This means developing culturally tailored awareness programming, research, community engagement strategies and policy solutions that promote brain health equity and access across diverse communities.

Alzheimer's Disease Patient and Caregiver Engagement (AD PACE) and A-LIST. We exist to give both patients and caregivers a collective voice and enable them to make their preferences heard on issues that span the entire scope of Alzheimer's disease. We aim to deliver the authentic voice of the patient and caregiver across lived experiences with Alzheimer's.

Focusing on brain health and brain health equity across all communities.

We work through collaboration, mobilizing the most deeply affected communities and forging important partnerships. United under UsA2, our networks are dedicated to engaging their constituents and partners around proactive brain health across the lifespan, stopping Alzheimer's and caring for those touched by it.

Our networks include:

AfricanAmericansAgainstAlzheimer's
 WomenAgainstAlzheimer's
 LatinosAgainstAlzheimer's
 VeteransAgainstAlzheimer's
 ClergyAgainstAlzheimer's & FaithUnitedAgainstAlzheimer's
 ResearchersAgainstAlzheimer's

Did you know?

Alzheimer's is the only top-ten disease in the U.S. **with no known current treatment or cure.**

There are more deaths in the U.S. annually from Alzheimer's than from breast cancer and prostate cancer combined.

5.8 million people living with Alzheimer's in the U.S.

Half of Americans with Alzheimer's are never told they have the disease.

By 2030, nearly half of all Americans living with Alzheimer's will be **African American or Latino.**

Women are twice as likely as men to have Alzheimer's.

\$290 billion in 2018 Including \$195 billion in Medicare and Medicaid payments. Annually, this is equivalent to the economic burden on our healthcare system caused by smoking.

Accelerating towards a cure.

Since its founding in 2010, UsA2 has worked collaboratively to:

Help drive U.S. investment in dementia research at the NIH from \$448 million in 2010 to nearly \$2.4 billion for FY 2018 (a fourfold increase), while prompting the U.K., Canada and Japan to commit to greater research investment

Forge industry and regulatory commitments to improve efficiencies in expedited drug discovery and to assure clarity in approval processes needed for innovative medicines to reach those in need

Create a nationwide, grassroots coalition of more than 90 organizations and corporations touching well over 3 million individuals

Help develop and introduce Congressional legislation, including the CHANGE Act, the EUREKA Act, the Alzheimer's Beneficiary and Caregiver Support Act and the 21st Century Cares Act

Successfully engage with the FDA to release revised guidance which recognizes the value of patient engagement in clinical trials and highlights the value of data sharing

Partnering to expand treatments and accelerate towards a cure.

13 State and Local Partners

A partial list of additional partners includes:

Alzheimer's Drug Discovery Foundation
 American Association of Retired Persons
 Balm in Gilead
 Centers for Disease Control and Prevention
 Centers for Medicare and Medicaid Services
 Curves
 Former First Lady, Mrs. Laura Bush
 U.S. Food and Drug Administration
 Joy of Mom
 National Black Nurse Practitioner Association
 National Hispanic Council on Aging
 National Institutes of Health
 National Minority Quality Forum
 Sunrise Senior Living
 The Vradenburg Foundation

THE CHANGE ACT OF 2019

CONCENTRATING ON HIGH-VALUE ALZHEIMER'S NEEDS TO GET TO AN END

UsAgainstAlzheimer's

Background

Alzheimer's is currently America's biggest healthcare crisis – economically, socially, and medically. While the latest emerging science – much of which is NIH-supported – indicates that proactive, risk-modifying measures exist that can strengthen brain health and increase resiliency against cognitive decline, Alzheimer's remains the sixth-leading cause of death in the United States and the only top-ten cause of death without an effective treatment or cure.

In 2019, Alzheimer's and other dementias will cost the United States an estimated \$290 billion, including \$195 billion in Medicare and Medicaid payments (Alzheimer's is Medicare and Medicaid's No. 1 cost driver). Annually, this is equivalent to the economic burden on our healthcare system caused by smoking, according to the CDC. Alzheimer's disease and related dementias will increase exponentially as the baby boom generation ages. At the current rate, the cost of Alzheimer's will reach \$1.1 trillion in 2050.

An estimated 5.8 million Americans are living with Alzheimer's in 2019. By 2050, the number of people age 65 and older with Alzheimer's may grow to a projected 14 million, in the absence of medical breakthroughs to prevent, slow, or cure the disease. We also know that communities of color and women face higher risk for the disease and experience barriers to treatment and research.

Unfortunately, while CMS has recognized the importance of dementia detection, the policies in place do not properly get those services to those with Alzheimer's. There are existing, evidence-based, reliable and NIH-identified cognitive impairment detection tools that must replace detection by direct observation in the Medicare Annual and Welcome to Medicare visits. The NIH-identified tools will allow for appropriate follow-up instead of delaying diagnosis or clinical trial participation. Studies consistently show that proper detection and diagnosis and active management of Alzheimer's can delay the onset of symptoms and improve quality of life through all stages of the disease for patients and their caregivers.

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| Alzheimer's is the only top-ten disease in the U.S. with no known current treatment or cure. | 5.8 million people living with Alzheimer's in the U.S. | Women are twice as likely as men to have Alzheimer's. |
| There are more deaths in the U.S. annually from Alzheimer's than from breast cancer and prostate cancer combined. | Half of Americans with Alzheimer's are never told they have the disease. | \$290 billion in 2018 Including \$195 billion in Medicare and Medicaid payments. Annually, this is equivalent to the economic burden on our healthcare system caused by smoking. |
| | By 2030, nearly half of all Americans living with Alzheimer's will be African American or Latino. | |

Bill Summary

The CHANGE Act is bipartisan and bicameral legislation that encourages early detection, diagnosis, and access to interventions.

Detection and Treatment: Directs the Centers for Medicare and Medicaid Services to require use of cognitive impairment detection tool or set of tools identified by the National Institutes of Health. Use of these tools will incentivize clinicians to detect and diagnose Alzheimer's and related dementias in their earliest stages. If cognitive impairment is detected, patients are to be referred for additional testing, to community-based support services, and to appropriate clinical trials.

Access to Care: Requires the Centers of Medicare and Medicaid Services to lead, create, adopt, and recognize quality measures and incentives to promote the detection and diagnosis of Alzheimer's disease or related dementias and appropriate care planning services, including potential for clinical trial participation.

We encourage you to co-sponsor H.R. 2283/S. 1126.



We can accelerate a cure for Alzheimer's

By George Vradenburg
April 11, 2019

Since the first cases were diagnosed in 1981, [1.8 million Americans have been diagnosed with HIV/AIDS](#). A positive diagnosis was once thought to be a death sentence and the disease was considered one of the greatest public health crises ever.

In response, the federal government poured massive resources into developing treatments and now, thanks to pharmacological and other research, HIV/AIDS is considered a chronic but no longer life-threatening condition.

By comparison, 5.8 million Americans today are battling Alzheimer's disease, with a new case being diagnosed every 65 seconds.

By 2050, the number of people age 65 and older with Alzheimer's will grow to a projected 14 million, in the absence of medical breakthroughs that would prevent, slow, treat, or cure the disease. Furthermore, we know that communities of color and women face higher risk for the disease and experience barriers to treatment, care and research.

Congress has joined us in the fight and demonstrated a commitment to funding research for a pharmacological cure by increasing NIH funding for Alzheimer's research from under \$450 million in 2011 to \$2.3 billion in 2019.

However, drug development has been more complicated than we could have ever predicted. As we work tirelessly to accelerate a cure, we are simultaneously doing everything we can to promote early detection, assessment, diagnosis and risk reduction. Congress has joined us on this mission too.

Last year, the BOLD Infrastructure for Alzheimer's Act passed both the House and Senate with broad support and was signed into law by President Trump. Just last month, the Younger-Onset Alzheimer's Disease Act was introduced.

Now, a group of leaders in the Congress have introduced a critical new piece of legislation – the Concentrating on High-Value Alzheimer's Needs to Get to an End (CHANGE) Act. The bill was introduced by Sens. Shelley Moore Capito (R-W.Va.), Robert Menendez (D-N.J.), Debbie Stabenow (D-Mich.) and Roger Wicker (R-Miss.), along with Reps. Linda Sanchez (D-Calif.), Darren Lahood (R-Ill.), Cathy McMorris Rodgers (R-Wash.) and Doris Matsui (D-Calif.).

The CHANGE Act takes a targeted approach to addressing our nation's Alzheimer's crisis by encouraging early detection, diagnosis and access to interventions.

We have learned a great deal in recent years about Alzheimer's disease. Most

notably, cognitive decline is no longer an inevitability of aging. In fact, [a recent study by the Lancet Commission found that](#) “around 35 percent of dementia is attributable to a combination of the following nine risk factors: education to a maximum age of 11-12 years, midlife hypertension, midlife obesity, hearing loss, late-life depression, diabetes, physical inactivity, smoking and social isolation.”

In other words, more than one-third of dementia cases may be preventable through proactive actions taken to promote brain health across the lifespan and build cognitive resilience.

Additionally, we know that Alzheimer’s can be diagnosed as many as 20 years before symptoms appear. Early diagnosis affords a critical window in which measures taken to promote brain health can delay the onset of symptoms and improve quality of life through all stages of the disease for patients and their caregivers.

Underscoring the importance of early diagnosis, the Centers for Medicare and Medicaid Services (CMS) recently announced plans for 2020 that include financial incentives to screen for and identify individuals with dementias.

While CMS has recognized the importance of dementia detection, without policies in place to implement these tools, they will never realize their full potential, which makes the CHANGE Act so critical. CHANGE would

incentivize and equip providers with the tools they need to accurately detect and diagnose Alzheimer’s at its earliest stages by directing CMS to require the use of cognitive impairment detection tools identified by the National Institutes of Health.

The bill would also direct CMS to incentivize the detection and diagnosis of Alzheimer’s disease or related dementias and promote care planning services, including the potential for clinical trial participation, which have historically had low levels of engagement, particularly within communities of color.

A shift in the provider system to focus heavily on brain health would spur a new understanding of its importance among Americans. More people will be aware that they may be able to minimize risk and delay the onset of Alzheimer’s and other dementias.

Moreover, with more Americans being diagnosed earlier and receiving education on the availability of clinical trials, we could see increased participation and diversity in trials, which may accelerate a pharmacological cure for Alzheimer’s.

I’m heartened that leaders in Congress are working together to solve what has become the greatest public health crisis of our time.

George Vradenburg is the co-founder and Chairman of [UsAgainstAlzheimer’s](#).



What helps prevent dementia? Try exercise, not vitamin pills

By Marilynn Marchione

May 14, 2019

If you want to save your brain, focus on keeping the rest of your body well with exercise and healthy habits rather than popping vitamin pills, new guidelines for preventing dementia advise.

About 50 million people currently have dementia, and Alzheimer's disease is the most common type. Each year brings 10 million new cases, says the report released Tuesday by the World Health Organization.

Although age is the top risk factor, "dementia is not a natural or inevitable consequence of aging," it says.

Many health conditions and behaviors affect the odds of developing it, and research suggests that a third of cases are preventable, said Maria Carrillo, chief science officer of the Alzheimer's Association, which has published similar advice.

Since dementia is currently incurable and so many experimental therapies have failed, focusing on prevention may "give us more benefit in the shorter term," Carrillo said.

Much of the WHO's advice is common sense, and echoes what the U.S. National Institute on Aging says.

That includes getting enough exercise; treating other health conditions such as diabetes, high blood pressure and high cholesterol; having an active social life, and avoiding or curbing harmful habits such as smoking, overeating and drinking too much

alcohol. Evidence is weak that some of these help preserve thinking skills, but they're known to aid general health, the WHO says.

Eating well, and possibly following a Mediterranean-style diet, may help prevent dementia, the guidelines say. But they take a firm stance against vitamin B or E pills, fish oil or multi-complex supplements that are promoted for brain health because there's strong research showing they don't work.

"There is currently no evidence to show that taking these supplements actually reduces the risk of cognitive decline and dementia, and in fact, we know that in high doses these can be harmful," said the WHO's Dr. Neerja Chowdhary.

"People should be looking for these nutrients through food ... not through supplements," Carrillo agreed.

The WHO also did not endorse games and other activities aimed at boosting thinking skills. These can be considered for people with normal capacities or mild impairment, but there's low to very low evidence of benefit.

There's not enough evidence to recommend antidepressants to reduce dementia risk although they may be used to treat depression, the report says. Hearing aids also may not reduce dementia risk, but older people should be screened for hearing loss and treated accordingly.



FOR IMMEDIATE RELEASE

UsAgainstAlzheimer's Applauds the Bipartisan Introduction of the CHANGE Act, Critical Legislation to Promote Early Diagnosis of Alzheimer's

The Concentrating on High-Value Alzheimer's Needs to Get to an End (CHANGE) Act Encourages Early Detection, Diagnosis, and Access to Interventions

Washington, D.C. (April 10, 2019) – UsAgainstAlzheimer's today applauded the bipartisan, bicameral introduction of the CHANGE Act by Sens. Shelley Moore Capito (R-WV), Robert Menendez (D-NJ), Debbie Stabenow (D-MI), and Roger Wicker (R-MS) and Reps. Darren Lahood (R-IL), Doris Matsui (D-CA), Cathy McMorris Rodgers (R-WA), and Linda Sanchez (D-CA).

The CHANGE Act would incentivize and equip providers with the tools they need to accurately detect and diagnose Alzheimer's at its earliest stages by directing the Centers for Medicare and Medicaid Services (CMS) to require the use of cognitive impairment detection tools identified by the National Institutes of Health.

The bill would also direct CMS to incentivize the detection and diagnosis of Alzheimer's disease or related dementias and promote care planning services, including potential for clinical trial participation, which have historically had low levels of engagement, particularly among communities of color.

"I thank this bipartisan group of legislators for their commitment and leadership in accelerating a cure for Alzheimer's," said George Vradenburg, chairman of UsAgainstAlzheimer's. "This is a critical step towards providing relief for the 5.8 million Americans living with this disease, their 16 million caregivers, and the tens of millions more who are at risk for cognitive decline but are unaware that they are at risk and the fact that they may be able to take actions to address that risk. We look forward to working with these legislators and their colleagues to advance the CHANGE Act through Congress and into law."

"We have always supported the work of developing a pharmacological cure, and will continue to do so, but drug development has proven to be more complicated than we could have ever predicted," added Vradenburg. "We must also focus on additional pathways for detection, assessment, and diagnosis, including leveraging the latest science around delaying and possibly even preventing Alzheimer's through various risk-modifying behaviors. The critically important CHANGE Act will equip and incentivize providers to do just this."

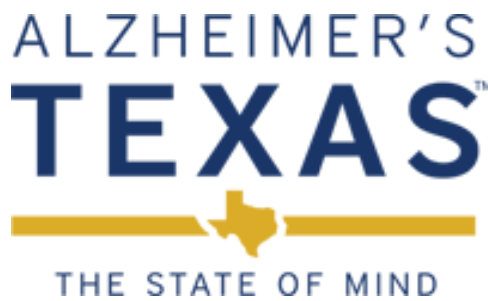
Last week, the CMS announced plans for 2020 that include financial incentives to screen for and identify individuals with dementias. While CMS has recognized the importance of dementia detection, without policies in place to implement these tools, they will never realize their full potential, which makes the CHANGE Act so critical.

The CHANGE Act would spur a new understanding of the importance of brain health among Americans. And with more Americans being diagnosed earlier and receiving education on the availability of clinical trials, we could see increased participation and diversity in trials, which may accelerate a pharmacological cure for Alzheimer's.

###

CHANGE Act 2019 Organizational Endorsements

The following organizations support the passage of the CHANGE Act:



Kid Caregivers



Minding Our Elders



June 14, 2018

Dear Member of Congress,

We sincerely thank you and your colleagues for recognizing and decisively responding to the challenges of Alzheimer's disease and other forms of dementia (including vascular, Lewy body dementia and frontotemporal degeneration). Congressional determination to make dementia a national priority has been evident, powerful, and effective. From passage of the National Alzheimer's Project Act, to historic funding increases for Alzheimer's research, and legislation that improves quality of life for those facing dementia while strengthening the scientific enterprise, Congress is changing the trajectory of Alzheimer's disease and other forms of dementia. We applaud your continued commitment to seize the enormous opportunities for America if we invest in the science, care, and support required to overcome these challenges and for recognizing the consequences if we fail to act. Doing so is a national priority, an economic and budgetary necessity, a health and moral imperative. In that same spirit, **we encourage House Committee on Ways and Means to pass the bicameral, bipartisan *Concentrating on High-Value Alzheimer's Needs to Get to an End (CHANGE) Act (H.R.4957/S.2387)*.**

The CHANGE Act will advance systemic changes required to strengthen care for millions of American families currently facing dementia while helping to maximize the value of our national investments in science to deliver prevention, disease modifying treatments and an eventual cure. In particular, the CHANGE Act makes clear that Medicare should adopt and cover uniformly accepted assessment and diagnostic tools for Alzheimer's disease and other forms of dementia. As research increasingly focuses on intervening at the earliest point in the disease trajectory, shortcomings in disease detection impede progress toward breakthrough therapies. The lack of uniform Alzheimer's tools delays cognitive impairment detection and diagnosis at the earliest possible point, resulting in decreased opportunities for people to access timely treatment options, including clinical trial participation.

When people receive a timely and accurate diagnosis, they are better able to make informed decisions about participating in research. They also have improved opportunities to make productive medical, financial, legal, and spiritual choices to improve both their own quality of life and that of their family caregivers. Delaying diagnosis or receiving an inaccurate diagnosis significantly complicates and all-too-often prevents research participation and undermines efficacy of quality of life decisions.

The CHANGE Act would encourage early assessment and diagnosis, improve care, and accelerate scientific progress:

- **Diagnosis / Clinical Research:** Would require the Centers for Medicare and Medicaid Services to identify a uniform, reliable cognitive impairment detection tool or set of tools and to incentivize clinicians to detect, refer, and diagnose Alzheimer's disease and other forms of dementia in their earliest stages. Earlier

diagnosis would allow for increased clinical trial participation and contribution by the patient in health care decision making, and validated tools would make it much easier for physicians to provide earlier diagnoses.

- **Care:** Would use Medicare authority to test a comprehensive continuum of care addressing care needs for people living with Alzheimer's disease and other forms of dementia along with their caregivers, modeled on the Programs of All-Inclusive Care for the Elderly (the PACE Program). It also would create a coverage and payment model that offers family caregivers evidence-based training and certification specific to dementia care that qualifies them to provide certain medically necessary services that society relies upon them to provide.

The CHANGE Act comes at a time of deepening urgency and expanding opportunity. While the need never has been greater, Congress and federal agencies are taking unprecedented action build comprehensive, integrated and transformative solutions.

Alzheimer's disease and other forms of dementia 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 recent 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

Today, more than 5.7 million Americans are living with dementia at an annual cost to our economy exceeding \$259 billion.^{iv} An estimated 16 million Americans provide unpaid care for someone with dementia, resulting in additional healthcare and economic costs for the family caregiver. Alzheimer's disease contributes to the deaths of approximately 500,000 Americans each year. Alzheimer's disease is the third leading cause of death in the United States^v and the only one among the top 10 for which there is no proven means of prevention, disease modification or cure.^{vi}

Today, another person develops the disease every 65 seconds; by 2050, someone in the United States will develop the disease every 33 seconds. This explosive growth will cause Alzheimer's costs to increase from an estimated \$277 billion in 2018 to \$1.1 trillion in 2050 (in 2018 dollars).^{vii} The federal government, through Medicare and Medicaid payments, shoulders an estimated 70 percent of all such direct care costs. These mounting costs threaten to bankrupt families, businesses and our health care system.

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 their most 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.^{viii} The Food and Drug Administration is encouraging new research avenues and clarifying regulatory approval pathways.^{ix} Your committee and NIH have moved mountains to create additional resources, public-private partnerships, and a culture of urgency. Across the NIH, institutes are supporting promising research into Alzheimer's disease and other forms of dementia to: understand genetic risk factors;^x

address health disparities among women,^{xi} African Americans,^{xii} Hispanics,^{xiii} and persons with intellectual disabilities;^{xiv} understand Down syndrome's relationship to Alzheimer's disease; and pursue cutting-edge trials aimed at preventing or substantially slowing disease progression by administering treatments much earlier in the disease process.^{xv} In the coming year, the National Institute on Aging (NIA) plans to increase its research focus on Molecular Pathogenesis and Pathophysiology of Alzheimer's Disease; Diagnosis, Assessment, and Disease Monitoring; Translational Research and Clinical Interventions; Epidemiology; and Care and Caregiver Support.^{xvi}

The CHANGE Act is essential to unlocking the transformative potential made possible by Congress and federal agencies. The CHANGE Act will improve access to timely and accurate diagnosis, in turn catalyzing better informed decisions about participating in research; simultaneously, the CHANGE Act will offer access to evidence-based care and services to improve quality of life for both the person living with dementia and family caregivers.

Please support passage of this important legislation to advance diagnosis, treatment, research progress, and support for individuals living with dementia and for family caregivers.

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 or other policy issues, please contact Ian Kremer, executive director of Leaders Engaged on Alzheimer's Disease (the LEAD Coalition),^{xvii} ikremer@leadcoalition.org or (571) 383-9916.

Sincerely,

Abe's Garden Alzheimer's Center of Excellence

ActivistsAgainstAlzheimer's Network

Aging Life Care Association®

African American Network Against Alzheimer's

Paul S. Aisen, MD (Keck School of Medicine of USC, Alzheimer's Therapeutic Research Institute*)

Alliance for Aging Research

Alliance for Patient Access

Alzheimer's & Dementia Alliance of Wisconsin

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

Alzheimer's Drug Discovery Foundation

Alzheimer's Foundation of America

Alzheimer's Greater Los Angeles

Alzheimer's Mississippi

Alzheimer's New Jersey

Alzheimer's Orange County

Alzheimer's San Diego

Alzheimer's Tennessee

Alzheimer's Texas

AMDA – The Society for Post-Acute and Long-Term Care Medicine

American Academy of Neurology

American Association for Geriatric Psychiatry

American Federation for Aging Research (AFAR)

American Medical Women's Association

Argentum | Expanding Senior Living

Laura D. Baker, PhD (Wake Forest University Health Sciences*)

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

Baylor Scott & White Health

Beating Alzheimer's by Embracing Science

Benjamin Rose Institute on Aging

Biogen

B'nai B'rith International

Soo Borson MD (Minnesota Brain Aging Research Collaborative*)

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

Bridge Builder Strategies

BrightFocus Foundation

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

Caregiver Action Network

Caregiver Voices United

CaringKind, The Heart of Alzheimer's Caregiving

Center for BrainHealth at The University of Texas at Dallas

Center to Advance Palliative Care

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

Joshua Chodosh, MD, MSHS, FACP (New York University*)

ClergyAgainstAlzheimer's Network

Cleveland Clinic Foundation

Cognition Therapeutics

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

Critical Path for Alzheimer's Disease (CPAD)

Jeffrey Cummings, MD, ScD (Cleveland Clinic Lou Ruvo Center for Brain Health*)

Darrell K. Royal Fund for Alzheimer's Research

Dementia Alliance International

Department of Neurology, Washington University School of Medicine

Drexel University College of Nursing and Health Professions

Duke (Alzheimer's) Family Support Program

Eisai Co., Ltd.

ElevatingHOME

Eli Lilly and Company

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

Faith United Against Alzheimer's Coalition

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

Joseph E. Gaugler, PhD (School of Nursing, Center on Aging, University of Minnesota*)

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

Georgetown University Medical Center Memory Disorders Program

Gerontological Society of America

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

Global Alzheimer's Platform Foundation

Global Coalition on Aging

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

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

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

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| Home Instead Senior Care | Minnesota Association of Area Agencies on Aging |
| Huffington Center on Aging | Minnesota Brain Aging Research Collaborative |
| Indiana University Center for Aging Research | David G. Morgan, PhD (Michigan State University*) |
| Janssen R&D | Darby Morhardt, PhD, LCSW (Northwestern University Feinberg School of Medicine*) |
| Kathy Jedrzejewski, PhD (University of Pennsylvania*) | Mount Sinai Center for Cognitive Health |
| The Jewish Federations of North America | National Alliance for Caregiving |
| Katherine S. Judge, PhD (Cleveland State University*) | National Asian Pacific Center on Aging |
| Keck School of Medicine of USC, Alzheimer's Therapeutic Research Institute | National Association of Activity Professionals |
| Keep Memory Alive | National Association of Area Agencies on Aging |
| Walter A. Kukull, PhD (School of Public Health, University of Washington*) | National Association of Chronic Disease Directors |
| Bruce Lamb, Ph.D. (Indiana University School of Medicine*) | National Association of Counties (NACo) |
| Latino Alzheimer's and Memory Disorders Alliance | National Association of Social Workers (NASW) |
| LatinosAgainstAlzheimer's | National Association of State Long-Term Care Ombudsman Programs (NASOP) |
| Layton Aging and Alzheimer's Disease Center, Oregon Health & Science University | National Association of States United for Aging and Disabilities |
| LeadingAge | National Certification Council for Activity Professionals |
| Lewy Body Dementia Association | National Committee to Preserve Social Security and Medicare |
| Allison Lindauer, PhD, NP (Layton Aging and Alzheimer's Disease Center, Oregon Health & Science University*) | National Consumer Voice for Quality Long-Term Care |
| Linked Senior, Inc | National Council for Behavioral Health |
| Lou Ruvo Center for Brain Health | National Down Syndrome Society |
| Lundbeck | National Hospice and Palliative Care Organization (NHPCO) |
| Medicare Rights Center | National Task Group on Intellectual Disabilities and Dementia Practices |
| Michigan State University Alzheimer's Alliance | Neurotechnology Industry Organization |
| Milken Institute Center for the Future of Aging | |

NFL Neurological Center
 Noah Homes
 NYU Langone Health
 Otsuka Pharmaceutical Development and Commercialization
 Planetree International, Inc.
 Prevent Alzheimer's Disease 2020
 Program to Improve Eldercare, Altarum
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 ResearchersAgainstAlzheimer's
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 Tatiana Sadak, PhD, PMHNP, ARNP (University of Washington School of Nursing*)
 Stephen Salloway, M.D., M.S. (The Warren Alpert Medical School of Brown University*)
 Quincy Miles Samus, PhD, MS (Johns Hopkins School of Medicine*)
 Second Wind Dreams, Inc./ Virtual Dementia Tour
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 Alan B. Stevens, PhD (Baylor Scott & White Health, Center for Healthcare Policy*)
 Rudolph Tanzi, PhD (Department of Neurology, MGH/Harvard Medical School*)
 The Association for Frontotemporal Degeneration

The Evangelical Lutheran Good Samaritan Society
 The Youth Movement Against Alzheimer's
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 University of Minnesota School of Nursing, Center on Aging
 USF Health Byrd Alzheimer's Institute
 UsAgainstAlzheimer's, LEAD Coalition co-convener
 VeteransAgainstAlzheimer's
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 Volunteers of America, LEAD Coalition co-convener
 Vradenburg Foundation
 Carol J. Whitlatch, PhD (Benjamin Rose Institute on Aging*)
 Nancy Wilson, MA LCSW (Baylor College of Medicine*)
 WomenAgainstAlzheimer's

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

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

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

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- iii <http://annals.org/article.aspx?articleid=2466364#>
- iv https://www.alz.org/documents_custom/2018-facts-and-figures.pdf
- v <http://www.neurology.org/content/early/2014/03/05/WNL.0000000000000240>
- vi <http://www.neurology.org/content/early/2014/03/05/WNL.0000000000000240>
- vii https://www.alz.org/documents_custom/2018-facts-and-figures.pdf
- viii <https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers>
- ix <https://www.fda.gov/downloads/Drugs/GuidanceComplianceRegulatoryInformation/Guidances/UCM596728.pdf>
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- xvii <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.