A comprehensive strategy to ensure brain health is included as an integral element of overall good health and cognitive decline is identified and addressed in a timely manner.
The Brain Health Partnership

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www.usagainstalzheimers.com
A Call to Action

The Second Inconvenient Truth of the 21st Century

Alzheimer’s disease and related dementias (ADRD) are among the twenty-first century’s greatest health, social, and economic challenges facing the United States and the world. Today, 5.7 million Americans are living with the disease, at a national cost of more than $275 billion.¹ As the population ages, this staggering impact will only grow. By 2050, prevalence is projected to soar to nearly 14 million, and costs are set to rise to more than $1 trillion.² If the U.S. continues on its current course, these devastating effects will reach levels that are unsustainable for our nation’s future.

5.7 million Americans live with the Alzheimer’s disease, at a national cost of over $275 billion. By 2050, prevalence is projected to soar to nearly 14 million, and costs to rise to over $1 trillion.

Despite the magnitude and urgency of this crisis, the U.S. has yet to adopt a comprehensive response. Most health care providers do not know how to address cognitive health, even when it is raised by their patients; payers and systems do not incentivize providers to assess cognition or provide coordinated care; and policymakers are missing opportunities to advance prevention and early detection in the absence of a cure. Consumers are afraid of Alzheimer’s and dementia and awareness of how to protect brain health is limited. Indeed, research is beginning to show that more than one-third of dementia cases could be prevented by addressing modifiable, lifestyle-based risk factors across the lifespan, such as regular physical activity, staying socially engaged, and maintaining good heart health.³

UsAgainstAlzheimer’s (UsA2) was founded to address the Alzheimer’s challenge, with a new vision for disruptive, urgent change that accelerates progress towards a cure. We now believe that achieving this vision will require transformation of the wider brain health landscape, as there is an emerging consensus that the risk and indications of Alzheimer’s begin as much as 20 years before symptoms. Meaningful progress will require a broader perspective that aligns a diverse group of stakeholders, takes a system-wide approach and engages individuals in brain health care long before symptoms appear.

Multiple organizations, advocates, and policymakers have dedicated themselves to finding a cure for Alzheimer’s, but the scale of this health epidemic, combined with a rapidly aging population, demand more coordinated and collaborative efforts. In short, there is not enough urgency, innovation, and disruption in this fight. We can and must do more. Together with our partners, UsAgainstAlzheimer’s is launching Brain Health Partnership to address these challenges and transform the broader landscape for brain health.

A New Frontier: Brain Health

Improving rates of early detection and diagnosis is essential to effectively fight and prevent Alzheimer’s. Scientific advances allow us to recognize the risk and indications of ADRD perhaps even decades before apparent symptoms—a window of opportunity to delay onset, improve overall health, lower costs, and increase clinical trial participation. Yet this opportunity is currently not being realized; instead of action, there is silence.

Seizing this opportunity will address a central barrier not just for those affected, but the entire landscape. Today, the estimated number of people over 65 with any cognitive impairment is between 25 and 40 percent, but 60 to 80 percent of these cases go unrecognized.⁴ Anecdotally, we know that well over three-quarters of all initial prescriptions of common Alzheimer’s medications are given without a formal diagnosis. Yet, according to the Value of Knowing study, most people say if they showed signs of the disease, they would want to see a physician to determine if the cause was Alzheimer’s.⁵ And it’s estimated that early diagnosis could realize cost savings of as much as $7.9 trillion in the U.S. by enabling better planning, management, and care.⁶

Therefore, early detection and diagnosis is a key missed opportunity that is enormously costly—both in terms of health outcomes and spending.
Our goal is to improve health outcomes for people living with or at risk of Alzheimer’s and other dementias. To accomplish this, we are embarking on a Brain Health Partnership, with others, to make a check-up from the neck up a routine aspect of clinical care, to encourage people to make lifestyle choices that reduce their risk, to accelerate the widespread availability of treatments and medicines, and to reduce health care costs.

Our Solution: Cultivating a Culture of Brain Health

The Brain Health Partnership is a comprehensive strategy to ensure people, providers, and policy-makers treat brain health as an integral element of overall good health and identify cognitive decline early. Our goal is to improve health outcomes for people living with or at risk of Alzheimer’s disease and related dementias.

Building on years of effective Alzheimer’s advocacy and policy work, we believe a broadened focus on brain health is the key to defeating stigma, increasing rates of early detection, and, ultimately, ending this disease. Together with our partners we must build a culture of brain health and a better healthcare ecosystem where:

- **Families and Communities** understand the importance of their brain health and view the brain as a vital organ—monitoring cognitive well-being, raising the topic of brain health with their loved ones and care providers, taking control of their own brain health and seeking out clinical research opportunities.

- **Providers, Payers and Health Systems** address brain health by discussing changes in cognition with patients, tracking cognitive baselines, and guiding patients to appropriate assessments, preventive measures, diagnosis, and collaborative care services. Payment systems support optimal brain health care services.

- **Policymakers** recognize the opportunity to maximize individual health outcomes, reduce total costs and minimize disruptions to the economy, as well as drive public health by advancing policies to support early and accurate detection and diagnosis, quality care, and aggressive research.

Our Plan: Building a Better Brain Health Ecosystem

We have developed a comprehensive approach to work collaboratively with each of these stakeholder groups. Grounded in research and partnerships, our plan for the initiative includes three pillars that are designed to work together to rethink and retool the way our system and culture address brain health as our population ages.
Over the first four years, collectively we will implement a thoughtful approach, beginning with a management and governance structure and creating clear measures of success. In Phase One, we are already gathering input, conducting research, advancing initial policy changes, engaging partners, and launching our public-facing outreach. In Phase Two, we will publish strategy papers with recommendations for high-impact change, implement pilots, and evaluate our public engagement efforts. In Phase Three, we will begin to scale our learnings.

A central, public-facing starting point for the initiative is our Campaign for Women’s Brain Health: a groundbreaking effort to transform how the public sees, thinks, and talks about brain health. Research shows that women play a pivotal role as “Chief Medical Officers” for their families, making not only their own health decisions, but also the health choices of their families. In addition to being key influencers in the health and wellness of their families and communities, women bear the burden of the disease. Almost two-thirds of Americans with Alzheimer’s are women, and more than 60 percent of Alzheimer’s and dementia caregivers are women. As such, our outreach efforts will begin with addressing women as advocates for themselves, their families, and their communities.

Join Us: Opportunities to Advance Brain Health

UsAgainstAlzheimers is raising $8 million in seed capital over four years to support our strategy, and we invite you to partner with us to address our nation’s brain health. With founding investments from the Alzheimer’s Drug Discovery Foundation (ADDF), an initiative started in 1998 by Leonard A. and Ronald S. Lauder and from the Vradenburg Foundation, we have begun in earnest. Our approach is to develop opportunities for collaboration with a wide range of founding partners including industry, advocacy groups, and influencers across the country to achieve a cultural shift in how we address cognition. Founding investors in this work have the opportunity to help guide the agenda and priorities, benefit from the tools and resources we develop, participate in roundtable discussions, and receive brand exposure on a national scale.

Contact Kelly O’Brien to learn more at: kobrien@usagainstalzheimers.org

What is Brain Health?

Brain health is about making the most of your brain and helping reduce risks to it as you age. Evidence is strong that people can reduce their risk of cognitive decline by making key lifestyle changes, including participating in regular physical activity, staying socially engaged, and maintaining good heart health.
C
ommitted advocates, organizations, and policymakers have driven important recent progress on Alzheimer’s—but there is still a pressing need to expand these efforts to create a broader brain health ecosystem. For example, funding for Alzheimer’s and dementia research at the National Institutes of Health has increased from $448 million in 2011 to more than $2.3 billion in 2019. In another sign of progress, Bill Gates has spoken out on Alzheimer’s and pledged to donate $100 million to research, including to develop tools for early detection. Despite many negative results, the private sector is investing in nearly one hundred potential drugs and trials and continues to push towards an effective means of treatment and prevention.

However, the slow pace of drug research and the scope of the disease’s impact mean broaden our efforts to prevent and cure Alzheimer’s through a wider brain health landscape. Effectively understanding, diagnosing, and fighting the disease will require engaging not just individuals and organizations already in the Alzheimer’s space, but a wider group of patients, providers, consumers, and leaders to understand and support brain health and prevention efforts.

Other disease areas show how broad-based efforts can drive cultural changes that effectively increase early detection and diagnosis, and change outcome for patients and their families. For example, in the 1980s, the creation of National Breast Cancer Awareness Month and organizations like The Susan G. Komen Breast Cancer Foundation brought awareness to a disease that impacts millions of women each year. What was once an uncomfortable, stigmatized topic has become normal and widely accepted, lifting rates of early detection, enabling earlier interventions, and extending and improving quality of life—even in the absence of a cure.

Now is the ideal time to apply this game-changing approach to brain health. Adults over 50 rank “staying mentally sharp” as a higher priority and concern than Social Security and physical health. Adults over 50 agree that addressing cognitive health should be a healthcare priority. The U.S. is also in the midst of a “wellness boom”—the largest piece of the $3.7 trillion global wellness market, growing at more than 10% each year. It’s clear that Americans are interested in the steps they can take to improve their wellness—a key opportunity for brain health.
The Transformative Value of the Brain Health Partnership

Building an effective brain health ecosystem in the U.S. will require engagement with key stakeholders: families and communities; providers, payers and systems; and policymakers. We have developed a comprehensive strategy for the Brain Health Partnership to reach, educate, and engage these groups.

Critically, we believe that this multi-pronged approach will have a combined impact greater than any one can accomplish in isolation. While we have specific objectives for each pillar, our overall goal is holistic and multi-dimensional. We aim to develop and launch a diverse set of interconnected programs that lead to important changes in how different stakeholders approach brain health.

For example, policy changes will influence providers' decisions, and provider efforts will influence how individuals see their brain health. The Partnership's activities will target different stakeholders, but share a common purpose: building a future where the U.S. approaches brain health as an integral element of ongoing preventive care and overall good health, and where cognitive decline is discussed openly, detected early, and treated appropriately.

For each pillar, we outline the current problems that are restraining effective brain health, our vision for the future, and the existing partnerships and programs that we are already pursuing to achieve these objectives.
Families and Communities: Leading with Women

By the Numbers

44% of Americans say they aren’t worried about getting Alzheimer’s, primarily because the disease doesn’t run in their family, even though risk is not entirely genetic and there are actions all people can take to reduce risk.\(^{12}\)

22% of Americans know Alzheimer’s disproportionately affects women.\(^{13}\)

66% of Americans want a family member to be their primary caregiver, but only 25% of older adults have discussed the matter with their children.\(^{14}\)

The Problem

Cognitive decline remains a misunderstood and taboo topic for most Americans. Brain health awareness is limited, and few individuals understand the lifestyle changes that reduce dementia risk. Stigma and fear undermine effective, proactive discussions between individuals, family members, and providers, leading to delays in detection and difficulty recruiting for clinical trials. Compounding these challenges, there is no consensus on the best publicly available resources for brain health, cognitive assessment, and research participation.

Our Solution

Women, families, and communities need information and access to tools to help them proactively take control of their brain health. Our Campaign for Women’s Brain Health will alert American women to the critical value of brain health and risk reduction strategies, empowering them to both pay attention to their cognition and drive system-wide change. New tools and resources will support consumers at every stage, from prevention and detection to care and clinical trials. As a result, we aim to ensure families and communities:

- **Discuss and track brain health**: Greater awareness of brain health will reduce stigma, spark conversations, and encourage cognitive assessment and tracking. Brain health will become an everyday topic for women, within their families, and between patients and providers. Informed about the importance of brain health, women will understand the steps recommended to protect brain health, and encourage their families to do the same, including physical activity.

- **Proactively seek cognitive assessment and screening**: Women and their families will seek cognitive assessments when there is a concern, and older adults will seek assessments for mild cognitive impairment. Families and communities will use emerging digital tools and other methods to understand their cognitive baseline, track changes, and drive early detection.

- **Search for trial opportunities**: People will be connected to and participate in appropriate trial opportunities. Whether pre-symptomatic or later in disease progression,
Our Initial Focus on Women

One of the first major efforts of our Brain Health Partnership will be the Campaign for Women’s Brain Health: a collaborative effort to empower women to drive fundamental change in the way we care for our brains.

Why focus on women? And why now?

Research we commissioned shows that women want to take action on brain health, but they don’t know where to begin. Our survey of more than 1,500 women found that 89% believe taking care of brain health is as important as other parts of the body, and 89% also believe that it’s something we should be talking about more.14 Yet few women act on brain health, and many are unsure what to do.

69% of women are interested in learning more about how to measure brain health and care for their brains.15

Current Partners and Progress

We have already launched activities that provide the foundation for the Partnership to achieve our vision for women, families, and communities. We have conducted nationwide research and outreach to understand the current consumer environment related to brain health. Based on this research, we have designed and tested brain health awareness messages that will be used in the public-facing work of the Brain Health Partnership and the new Campaign for Women’s Brain Health. We have also begun to develop partnerships with a broad, diverse set of advocacy partners for the Campaign, including influential media outlets, high-profile women leaders, and women executives from leading global companies.
Providers, Payers and Health Systems

By The Numbers

**Half** of Americans with Alzheimer’s are never told they have the disease.\(^{17}\)

**18.6 months** is the average wait time until treatment in 2020 if an Alzheimer’s therapy comes to market, according to RAND.\(^{18}\)

**18%** of nurse practitioners often raise the issue of memory and brain health; nearly 30% never raise the issue.\(^{19}\)

**86%** of Americans agree that healthcare professionals should discuss clinical trials with patients as part of their standard of care,\(^{20}\) yet 85-90% of trials have delayed recruitment.\(^{21}\)

Despite being at higher risk for Alzheimer’s and other dementias, Latinos and African Americans are underdiagnosed or diagnosed at later stages in the disease compared to non-Hispanic whites.

The Problem

Health systems currently lack the structure, incentives, and pathways to engage providers and patients to promote brain health and detect Alzheimer’s early. Providers are not proactively communicating about brain health and detecting, diagnosing, and treating cognitive decline in its early stages, constrained by time and resources. Referral networks are weak or nonexistent. Technological advances have not been fully applied to brain health, and while some quality measures exist, they are not impacting care. Care pathways and workflows are not maximized for efficiency or effectiveness, leaving the healthcare system unprepared for new therapies.

Our Solution

Providers, payers and systems require knowledge, infrastructure, and processes to implement prevention, early detection, and proactive, collaborative care. Our work will improve incentives in order to shift care approaches and give providers access to appropriate incentives will shift care approaches, and providers will have access to a full range of innovative diagnostics, screening tools, and biomarkers. We will work to develop and scale new, more efficient care models, leverage big data, and implement better workflow systems around an optimal brain health care plan. As a result, we aim to encourage providers and the healthcare system to:
• **Map an optimal brain health care plan.** The optimal brain health prevention and care pathway will be outlined and disseminated broadly to help clarify the way forward.

• **Identify and scale “shovel-ready” cost-effective systems changes with greatest impact on health outcomes.** Agenda-setting recommendations around systems changes that could make an immediate and measurable difference in brain health will be identified, implemented, and scaled.

• **Leverage technology and data to improve prevention and care.** Science-based, non-pharma brain health interventions and tools, including new technologies, will be widely available and utilized by families and providers. An Alzheimer’s “early warning system” utilizing big data will be available. Brain health data will be integrated into the standard EHR to support tracking of a cognitive baseline.

• **Prioritize prevention and early detection and diagnosis.** There will be broad consensus on cognitive assessment tools and best practices, and primary care physicians (PCPs), specialists, and other healthcare providers (HCPs) will take a proactive approach to brain health, cognitive assessment, early diagnosis, and care planning.

• **Advance equity and access in brain health for communities of color through our Alzheimer’s Disparities Engagement Network (ADDEN).** There will be community and health system capacity to identify, measure, and address disparities in Alzheimer’s impacting communities of color.

• **Improve care coordination and connections to clinical trials.** Providers will be connected and collaborate to detect and rapidly diagnose cognitive symptoms and underlying disease pathology. Care coordination and referral networks will effectively support patient-centered care and leverage technology interventions like telehealth. Providers will also direct patients to clinical trials along clear, well-established pathways. Quality measures around early assessment, detection and collaborative care for ADRD will be in place.

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**Current Partners and Progress**

We have already begun to engage providers and healthcare systems, and receive vital guidance to help build robust programs in this area. We have engaged professional organizations, such as the American Medical Women’s Association and the National Association of Nurse Practitioners, to seek and incorporate their input on our strategy, identify potential partners, and begin developing resources.
Policymakers

By the Numbers:

3X
Alzheimer's is a growing national crisis: the number of Americans with Alzheimer's will nearly triple by 2050, rising to almost 15 million.22

$7.9 trillion
is the estimated potential cost savings if all Alzheimer's cases were diagnosed early, during the MCI stage.23

$56,000
Alzheimer's currently costs between $40,000 and $56,000 per person per year, exceeding the cost of heart disease.24

4X
People with Alzheimer's have nearly 4x the rate of stays in skilled nursing facilities as other older people.24

The Problem
Policymakers have not implemented the changes to clinical care paradigms, public health efforts, and regulatory frameworks necessary to address the growing national impact of Alzheimer's. The cost to government, payers, and society overall are immense, but these are not fully captured or realized. This leads to missed opportunities to improve health outcomes and lower total costs by detecting and diagnosing the disease early and accurately, supporting care planning, and controlling the costs of Alzheimer's and the many comorbidities that exist in our aging population.

Our Solution
Significant policy change is needed to transform the current costly, reactive system into a cost-effective, proactive early detection and care system that clears the path to a cure. We see policy as a key lever to drive practical changes in care and medical practices. Policy efforts to provide support for those affected and enable rapid progress towards effective treatments include new reimbursement models, regulatory frameworks, clinical care paradigms, integrated research, and public health activities. As a result, we aim to work with policymakers to:

- Develop more effective reimbursement and regulatory frameworks to establish requirements and incentives for early detection and diagnosis: UsA2 will continue working as the leading advocate for the passage of the CHANGE Act (H.R. 4957 and S. 2387—Concentrating on High-Value Alzheimer's Needs to Get to an End), currently pending in Congress, which will create a new comprehensive care pathway for Alzheimer's. The policy change will call on the Centers for Medicare and Medicaid Innovation (CMMI) to advance delivery models that provide a continuum of care throughout the Alzheimer's and dementia spectrum. Model state legislation—based on new initiatives in states like Massachusetts, which recently passed a comprehensive overhaul of the state's approach to Alzheimer's—will be introduced to other states.
• **Prioritize brain health on the public health agenda:** The CDC and other state and local agencies will enhance the understanding of Alzheimer’s disease, the benefits of early and accurate diagnosis and care intervention, and the need to develop a culture of brain health. The U.S. Preventive Services Task Force will reevaluate new evidence to update its screening recommendation for cognitive impairment, currently under review.

• **Advance pilot programs within the Department of Veterans Affairs (VA):** The VA will capitalize on its access to populations that have unique risks for cognitive decline to develop, pilot, and implement innovative programs to alleviate the burden of Alzheimer’s and speed the path to a cure. These programs will provide data and incentives for broader adoption of such approaches.

• **Improve multi-stakeholder engagement and data usage:** Both policymakers and payers will incorporate multi-stakeholder input and new sources of data into their decisions, such as the perspectives of patients. Policymakers will engage with advocates and scientists to craft effective brain health responses, and payers will integrate real-world evidence to help develop a predictive, “early warning” evaluation system. Research institutions will leverage cross-institute funding and data to better understand, for example, relationships between cognitive health and chronic diseases.

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**Current Partners and Progress**

We are currently working with policymakers to lay the foundation for significant policy changes. We are focusing as the leading advocate for the Concentrating on High-Value Alzheimer’s Needs to Get to an End (CHANGE) Act: bipartisan legislation introduced in February 2018 that would implement changes to Medicare policies to support families affected by Alzheimer’s. Concurrently, we have developed a framework model to guide payer actions and promote innovation, with a particular focus on the the Centers for Medicare & Medicaid Services (CMS) through the Center for Medicare and Medicaid Innovation. To push towards the full commitment and leadership of CMS, we have developed a structural paradigm for a comprehensive continuum of care for individuals with Alzheimer’s and related dementias, based on the Program of All-Inclusive Care for the Elderly (PACE) and other tested models.
# Measuring Our Success

Initial milestones and metrics to measure the ongoing progress of the Brain Health Partnership are based on our existing baseline research, including several important goals for each key stakeholder pillar.

## Goal: Families and communities have access to and promote awareness of the information and tools needed to proactively take control of their brain health

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<tr>
<th>OBJECTIVES</th>
<th>KEY MILESTONES</th>
<th>METRICS AND RESULTS</th>
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<tbody>
<tr>
<td>Discuss and track their brain health</td>
<td>• Launch consumer research to understand the most impactful messages for engaging with women on the topic of brain health</td>
<td>• Change in women’s attitudes, knowledge, and behaviors on brain health</td>
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<tr>
<td>Proactively seek cognitive assessment and screening</td>
<td>• Launch targeted consumer awareness campaigns that elevate brain health as an important, actionable topic and routine evaluation</td>
<td>• Number of women tracking their cognitive baseline and following the optimal brain health care plan</td>
</tr>
<tr>
<td>Search for trial opportunities</td>
<td>• Develop and launch consumer cognitive health tools to assess and track brain health, particularly digital technologies</td>
<td>• Number of people using personal cognitive health tools</td>
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<td></td>
<td>• Create and promote resources to connect consumers to appropriate clinical trial opportunities</td>
<td>• Number of people raising cognitive health with HCPs</td>
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<td></td>
<td></td>
<td>• Share of people with ADRD who receive an early diagnosis</td>
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<td></td>
<td></td>
<td>• Number of people seeking information about clinical trials</td>
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<td>• Number of people enrolling in clinical trials</td>
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<td>• Number of people taking the Brain Health Challenge</td>
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<td>• Number of partners disseminating Brain Health Challenge messages</td>
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<td>• Reach of consumer-facing media properties</td>
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Goal: Providers, payers and systems have the knowledge, infrastructure, and processes in place to implement prevention, early detection, and proactive, collaborative care.

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<th>OBJECTIVES</th>
<th>KEY MILESTONES</th>
<th>METRICS AND RESULTS</th>
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<tr>
<td>Map optimal brain health care plan</td>
<td>Establish a Brain Health Partnership Steering Committee</td>
<td>Reimbursement for effective care coordination by private and public payers</td>
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<td>Identify and scale &quot;shovel-ready&quot; cost-effective systems changes with greatest impact on health outcomes</td>
<td>Publish optimal brain health care plan and key recommendations around specific components that should be implemented/scaled</td>
<td>Number of systems that implement optimal brain health care plan</td>
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<td>Prioritize prevention and early detection and diagnosis</td>
<td>With partners, build consensus around cognitive assessment tools and best practices</td>
<td>Number of systems integrating cognitive assessment module in EMR</td>
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<td>Leverage technology and data to improve prevention and care</td>
<td>Publish recommendations for best practices that strengthen care coordination and referral networks, including telehealth</td>
<td>Share of people with Alzheimer’s who receive an early diagnosis</td>
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<tr>
<td>Improve care coordination</td>
<td>Create and/or accelerate adoption of science-backed non-pharma brain health interventions and tools, including new technologies</td>
<td>Rate of Alzheimer’s diagnosis disclosure</td>
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<td></td>
<td>Promulgate of quality measures around early assessment, detection and collaborative care for ADRD</td>
<td>Number of providers who use brain health tools and cognitive assessments</td>
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<td></td>
<td>Integrate brain health data into the standard EHR to support tracking of a cognitive baseline.</td>
<td>Number of people referred to clinical trials</td>
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<td>Build and test an Alzheimer’s “early warning system” utilizing big data</td>
<td>Number of people tracking their cognitive baseline and following the optimal brain health care plan</td>
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<td>Cost savings from earlier diagnosis and better care management</td>
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<td>Decrease in number of hospital stays for people with Alzheimer’s</td>
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<td>Delays in transition to nursing facility</td>
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<td>Completion of phase II of Project Insight/testing feasibility of AI to create predictive model</td>
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Goal: Policymakers drive significant policy change to transform the current costly, re-active system into a cost-effective, proactive early detection and care system that clears the path to a cure.

**OBJECTIVES**

- Develop more effective reimbursement and regulatory frameworks to establish requirements and incentives for early detection and diagnosis
- Prioritize Brain Health on the public health agenda

**KEY MILESTONES**

- **CHANGE Act** (H.R. 4957 and S. 2387) passage
- **CMMI advances innovative delivery models**
- Launch pilot within the VA system within the VA
- **The US Preventive Services Task Force updates its screening recommendation** for cognitive impairment
- **Model legislation** based on innovative models created in states like Massachusetts enacted in other states
- **New analysis of total cost of Alzheimer’s** and identify potential savings from early and accurate diagnosis

**METRICS AND RESULTS**

- CMS implements payment reforms
- Increase diversity of and innovation in how NIH spends funds
- Passage of the CHANGE Act to address Alzheimer’s
- Implementation of key state policy changes targeting Alzheimer’s
- Cost savings from earlier diagnosis and better care management
Engagement Opportunities

Success will rely on a partnership approach. Collaboration opportunities for partners exist on many levels, from thought leadership to event sponsorship to media partnerships. Below are some of the opportunities that give partners and investors a chance to engage with us and benefit from brand alignment and exposure.

Thought Leadership

Steering Committee Companies providing founding level investment are invited to participate on the Steering Committee of the Brain Health Ecosystem. The Committee will be comprised of C-suite executives, thought leaders and experts from prominent public and private organizations with a goal of providing ongoing strategic input, counsel, and insight to guide this initiative.

Key Influencers Based on our consumer research, we will develop campaign collateral and engage key influencers from across communities and cultures to produce a series of high-impact communications and public-facing opinion pieces intended to catalyze more action at an earlier age begin to change behavior. This may include a partnership with key influencers and experts with actionable insights.

Advisory Groups/Expert Convenings Our execution plan is grounded in a collaborative approach—no one organization can advance such comprehensive goals. To get there, we will engage partners from across industry, advocacy, provider groups, payers, government, and academia.

Co-Published Strategy Papers Key to our collaborative agenda-setting approach is aligning the field and partners around strategies we can all get behind. We will seek partners to collaborate with us and to co-publish strategy papers.

Pilot Projects and Community-Based Efforts Initial implementation efforts will be pilot tested in healthcare systems and communities.

Events

Launch The Brain Health Partnership was publicly announced on November 6th, in New York City, with the launch of the Campaign for Women’s Brain Health, our consumer-focused effort to drive awareness and behavior change. Hosted by WomenAgainstAlzheimer’s and Woman’s Day Magazine, former First Lady, Mrs. Laura Bush, was in attendance, serving as the Honorary Chair of our Honorary Brain Trust.

Media Outreach

Social Media We will amplify the message of brain health with a unifying social media campaign targeted to American women. The Campaign will include calls to action for women to take control of their brain health, talk about their brains, and take steps to protect their brains. With effective visuals and thoughtful messaging, we will educate, empower, and engage women across America.

Women’s Engagement

Brain Health Challenge We will invite women to participate in the Brain Health Challenge—encouraging a daily practice of paying attention to the brain as a vital organ. The Brain Health Challenge will provide access to tips and ideas through our digital hub and via social media. We will encourage women to monitor their mood, memory, stress, and sleep on a daily basis and post their efforts with a unique hashtag.

Courageous Conversations Courageous Conversations is a traveling series of events that bring together women from diverse backgrounds to engage in open discussion focused on ways to raise the issue of brain health in their various networks and communities. Co-hosted with Woman’s Day Magazine, each Courageous Conversations event includes brief remarks from a Women’s Leadership Council member, perspective from a healthcare provider, and open dialogue.
Advocacy

Advocacy Engagement We are integrating our advocacy work into the brain health ecosystem with an initial focus on garnering support for a major piece of legislation, the CHANGE Act. The CHANGE Act will lay the groundwork for systems change by advancing the payment and care structures needed to build system capacity. We look forward to working with our Founding Partners on this work.

BrainSTORM, Powered by Alz Talks We will host a regular teleconference series, called BrainSTORM, which will feature scientists, advocates, entrepreneurs, and others to raise awareness about issues in brain health, unite advocates with researchers and policy leaders, and recruit more supporters. Alz Talks is our monthly podcast and teleconference series that has reached more than 10,000 listeners and downloads. These informational interactive calls (that run much like a radio talk show) provide caregivers, researchers, non-profit leaders, government officials, and other advocates direct access to the nation’s leading researchers.
# Timeline

<table>
<thead>
<tr>
<th>2018</th>
<th>2019</th>
<th>2020</th>
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<tbody>
<tr>
<td>Build Management Structure</td>
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<tr>
<td>Research – Landscape</td>
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<tr>
<td>Research – Consumer Attitudes, Knowledge, Beliefs</td>
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<tr>
<td>Research – Provider Attitudes, Knowledge, Beliefs</td>
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<tr>
<td>Research – Stakeholder Focus Groups</td>
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<tr>
<td>Develop Consumer Engagement Plan</td>
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<td>Host Public-Facing Launch</td>
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<tr>
<td>Initiate Consumer Engagement</td>
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<td>Launch Digital Hub</td>
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<td><strong>Develop Payment Model Recommendations</strong></td>
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<td></td>
<td>Convene Brain Health Partnership Steering Committee</td>
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<td>Issue Strategy Briefs</td>
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<td></td>
<td>Convene Influence/Expert Advisory Groups</td>
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<td></td>
<td>Activate Disparities Engagement Networks</td>
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<td></td>
<td>Advance Payment Model and Policy Recommendations</td>
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<tr>
<td></td>
<td>Grow Consumer-Facing Engagement</td>
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<td>Evaluate Impact and Adjust Strategy</td>
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<tr>
<td></td>
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<td>Advance Strategy Papers</td>
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<td></td>
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<td>Health-System Pilots</td>
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**Legend:**
- Blue: All Pillars
- Red: Consumer
- Orange: Policy
- Black: Systems
Funding Levels and Benefits

We are seeking private-sector founding investors for the Brain Health Partnership with the goal of raising $8 million in funding over four years. **Founding investors support this work with $250,000 or more each year.** We are pleased that the Alzheimer’s Drug Discovery Foundation (ADDF), an initiative started in 1998 by Leonard A. and Ronald S. Lauder are and the Vradenburg Foundation are anchoring this work as our initial founding investors.

Early investors will have the opportunity to be on the ground floor of our work and planning. We recognize supporters may have interest in one or more of the three pillars, and we will collaborate to ensure proper engagement and exposure.

Additional funding and sponsorship opportunities for $50,000-$100,000 per year with commensurate partnership opportunities for key parts of this work, particularly the Campaign for Women’s Brain Health, are available as are customized partnerships.

<table>
<thead>
<tr>
<th>2019 Brain Health Budget</th>
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<tbody>
<tr>
<td>Project direction and management</td>
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<tr>
<td>Campaign for women’s health/communications</td>
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<tr>
<td>Policy work</td>
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<tr>
<td>Systems work/research</td>
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UsA2’s Unique Contribution to the Solution

UsAgainstAlzheimer’s and its network are uniquely suited to accomplish the ambitious project of the Brain Health Partnership, given the depth and breadth of our organization. Our networks, partnerships, and knowledge of the Alzheimer’s space provide us both expertise and existing vehicles to effectively plan and execute towards our goals, including the Campaign for Women’s Brain Health.

UsA2 has already developed an unprecedented, diverse set of relationships and tools in the brain health and Alzheimer’s space, which can be leveraged to create the Brain Health Initiative. These vehicles—which we have already set in motion—will play vital roles in fostering the Initiative.

We have strong relationships and proven influence with the top healthcare stakeholders in the U.S., including researchers, payers, industry, government agencies, and policy-makers:

- **The Global CEO Initiative on Alzheimer’s Disease (CEOI)** brings together private-sector leaders, including Pfizer, Johnson & Johnson, GE, Bank of America, and others, to forge consensus on immediate action items and long-term strategies on Alzheimer’s.
- **The Global Alzheimer’s Platform Foundation (GAP)** is the only non-profit focused exclusively on accelerating Alzheimer’s clinical research, including through a one-of-a-kind network of up to 60 high-performance research sites.
- **ResearchersAgainstAlzheimer’s (RA2)** is a network of more than 500 respected Alzheimer’s researchers, which publishes landmark reports that have driven policy change.

It would be a privilege for our senior leadership and global staff to hear your [George’s] perspective and deep expertise on the topic of the global burden of Alzheimer’s disease … From your creation of the Global CEO Initiative on Alzheimer’s Disease—of which Roche is a proud member—to your leadership in keeping Alzheimer’s disease on the agenda among heads of state of G7, your work and dedication has motivated so many and fostered a spirit of collaboration. In addition, your work with UsAgainstAlzheimer’s directly impacts those affected by Alzheimer’s disease.

Severin Schwan
CEO, Roche Holding AG
• **WomenAgainstAlzheimer’s (WA2)** is a network of women leaders and advocates that has started the first-ever campaign to define Alzheimer’s as the 21st century’s primary economic justice issue and health crisis for women.

• **Alzheimer’s Disease Disparities Engagement Network** is a platform that engages and connects stakeholders across the health system and in communities to collect actionable data, develop and scale awareness programming, and build community capacity to address brain health disparities among people of color. This work is carried out through a deep bench of cross-sector stakeholders in the health disparities field and coordinated by UsAgainstAlzheimer’s minority-serving networks:
  - **AfricanAmericansAgainstAlzheimer’s** is a national network of local relationships that are increasing brain health awareness in African American communities.
  - **LatinosAgainstAlzheimer’s** works through a coalition of 50 cross-sector stakeholders to spearhead strategic convening, legislative advocacy, and culturally tailored education and brain health promotion efforts to address disparities in Alzheimer’s impacting Latino families.
  - **VeteransAgainstAlzheimer’s** is working to elevate the needs of our nation’s military families and veteran’s through partnerships with leading veterans service organizations (VSOs) across the country.

UsA2 has a track record of success—leveraging these networks, organizations, and relationships to achieve significant changes in the Alzheimer’s landscape since our founding in 2010:

• **Set the national target for effective treatments by 2025**, influencing leaders at the White House and Department of Health and Human Services to adopt this goal.

• **Pushed to dramatically increase NIH funding for Alzheimer’s research**, which rose from under $500 million in 2011 to almost $2.3 billion in 2019.

• **Advocating for the CHANGE Act**—ground-breaking, bipartisan legislation that would dramatically improve care paradigms for the millions of affected individuals and families.
Online engagement (social media, websites, email) is a key driver of USA2 network and partner reach.

<table>
<thead>
<tr>
<th>ORGANIZATION</th>
<th>AUDIENCE</th>
<th>VEHICLE</th>
<th>REACH</th>
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<tbody>
<tr>
<td>UsAgainstAlz</td>
<td>Advocates and researchers, global and domestic</td>
<td>Overall reach</td>
<td>230,000</td>
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<tr>
<td></td>
<td>General public, primarily women</td>
<td>Facebook</td>
<td>110,000</td>
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<td></td>
<td>Caregivers</td>
<td>Facebook Closed Group</td>
<td>4,200</td>
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<tr>
<td></td>
<td>Advocates and researchers, global and domestic</td>
<td>Twitter</td>
<td>10,000+ followers</td>
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<td></td>
<td></td>
<td>256,000 reach/mth</td>
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<tr>
<td>WomenAgstAlz</td>
<td>Advocates and researchers, global and domestic</td>
<td>Email distribution</td>
<td>2,500</td>
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<tr>
<td></td>
<td>Advocates, researchers, industry</td>
<td>Twitter</td>
<td>1,200</td>
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<td></td>
<td>Women's health and rights advocates</td>
<td>30 Partners</td>
<td>1M+</td>
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<td>ResearchersAgstAlz</td>
<td>Researchers</td>
<td>Email distribution</td>
<td>510</td>
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<td>LatinosAgstAlz and</td>
<td>Advocates</td>
<td>Email distribution</td>
<td>170</td>
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<td>AfricanAmericans-AgainstAlzheimer's</td>
<td>19 partners</td>
<td>Twitter followers</td>
<td>46,000</td>
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<td></td>
<td>19 partners</td>
<td>Facebook likes</td>
<td>98,000</td>
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<td>Advocates, researchers</td>
<td>27 advisory board members</td>
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<td>Faith and Clergy Networks</td>
<td>Advocates, people in faith based organizations</td>
<td>Email distribution</td>
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<td>3 partners</td>
<td>Twitter followers</td>
<td>35,500</td>
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<td></td>
<td>3 partners</td>
<td>Facebook likes</td>
<td>76,700</td>
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<tr>
<td>Alzheimer’s Talks</td>
<td>Email database of 230K</td>
<td>Overall reach</td>
<td>Up to 5,000</td>
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<tr>
<td></td>
<td></td>
<td>Live listeners and readers</td>
<td>2,000</td>
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Project Leadership

George Vradenburg
Chairman, UsAgainstAlzheimer's

George Vradenburg is Chairman of UsAgainstAlzheimer’s, which he co-founded in October 2010. He was named by US Health and Human Services Secretary Kathleen Sebelius to serve on the Advisory Council on Research, Care, and Services established by the National Alzheimer’s Project Act and has testified before Congress about the global Alzheimer’s pandemic. He is a member of the World Dementia Council. He and UsAgainstAlzheimer’s co-convene both the Leaders Engaged on Alzheimer’s Disease (LEAD) Coalition and the Global CEO Initiative on Alzheimer’s Disease. With his wife, Trish (1946-2017), George has long been a dedicated member of Washington’s civic and philanthropic community. George served as Chairman of The Phillips Collection for 13 years and is a member of the Council on Foreign Relations and The Economic Club of Washington. He has served in senior executive and legal positions at CBS, FOX, and AOL/Time Warner. George and Trish published Tikkun Magazine for 10 years.

Jill Lesser
President, WomenAgainstAlzheimer’s; Chief Strategy Officer, UsAgainstAlzheimer’s

Jill Lesser is President of WomenAgainstAlzheimer’s, a Network of UsAgainstAlzheimer’s. In that role, she leads a campaign to find, fund, and implement a cure for Alzheimer’s with a focus on the impact on women. Lesser also serves as Chief Strategy Officer and a member of the UsAgainstAlzheimer’s board. She is a co-founder of the Global Alliance on Women’s Brain Health and is in her 10th year as a caregiver for her mother, who suffers from Alzheimer’s. Previously, Lesser was Executive Director of the Center for Copyright Information. She collaborated with The Glover Park Group on strategic communications and government relations for clients and served as a Managing Director from 2010-11. She managed domestic policy for America Online until its merger with Time Warner. She was Senior Vice President, Domestic Public Policy for AOL Time Warner, Inc., leading the DC office.

Meryl Comer
Board Member, UsAgainstAlzheimer’s

Meryl Comer is President and CEO of Geoffrey Beene Foundation Alzheimer’s Initiative, which promotes early diagnosis, virtual innovation challenges, m-health technologies, and national public service campaigns. She is a Co-Founder of WomenAgainstAlzheimer’s and Founding Partner of the Global Alliance on Women’s Brain Health. Comer is also Co-Principal Investigator for the PCORI Alzheimer’s, Dementia, Patient & Caregiver Powered Research Network (funded by PCORI), a partnership of the Mayo Clinic, UCSF Brain Health Registry and UsAgainstAlzheimer’s. She is a veteran broadcast journalist. Her New York Times bestseller, Slow Dancing with a Stranger: Lost and Found in the Age of Alzheimer’s (HarperCollins) is an unflinching account of her husband’s early onset Alzheimer’s disease.

Kelly O’Brien
Executive Director, Brain Health

Kelly O’Brien is the Executive Director of the Brain Health Partnership at UsAgainstAlzheimer’s. In this role, she is the strategic lead and manager of the team implementing the project. Kelly’s unique combination of leadership, strategy, community engagement, partnership development, project management, sales/fundraising, and communications skills have resulted in an impressive record of raising the profile and impact for many organizations and initiatives. Previously, Kelly was the founding Executive Director of The Kennedy Forum Illinois, a mental health initiative led nationally by former Congressman Patrick Kennedy. Her service history includes leadership positions in the public, nonprofit and private sector, including CEO of the social impact consultancy Ideaction Corps, health aide to Senator Richard Durbin and Congressman Jerry Kleczka, Director of Government Affairs for Partnership for Prevention, Associate Executive Director for the American Public Health Association, Congressional Liaison for the Director of the Centers for Disease Control and Prevention.
Brooks Kenny  
**Executive Director, WomenAgainstAlzheimer’s**

Brooks Kenny oversees client projects in the public health arena, with specific emphasis on caregiving, women’s health, and aging. She supports the women’s network of UsAgainstAlzheimer’s, driving growth through strategic partnerships and marketing initiatives. Brooks brings to HLG more than 20 years of experience in the nonprofit sector, along with deep expertise in leadership and partnership development and media relations strategy. For five years, she was on the founding team and Executive Vice President of Lotsa Helping Hands, a technology company providing solutions for family caregivers. She led its worldwide branding and social media marketing efforts, developing partnerships and expanding its reach to more than 1.5 million members. For a decade, Brooks ran a boutique consulting agency in Washington, DC, where she trained national nonprofit organizations on communications, marketing, and partnership development.

Drew Holzapfel  
**Executive Director, Global CEO Initiative on Alzheimer’s Disease; Acting President, UsAgainstAlzheimer’s**

Drew serves as the Executive Director of The Global CEO Initiative on Alzheimer’s Disease, a coalition of leading corporations investing in Alzheimer’s disease research, treatment, and care. He is also a Partner at High Lantern Group, a healthcare consultancy focused on the intersection of business strategy and public policy. Drew brings nearly two decades of healthcare experience in government and corporate affairs, sales and marketing in global biotechnology, pharmaceuticals, and U.S. government organizations to a diverse client base. He has spent over 10 years working on Alzheimer’s disease in a range of positions. Prior to joining High Lantern Group, Drew was at Pfizer, where he most recently led efforts around the company’s Alzheimer’s program and advanced Alzheimer’s and aging issues through the development of commercial strategy and advocacy with international organizations, non-governmental organizations, nonprofits, and other key stakeholders.
<table>
<thead>
<tr>
<th>Name</th>
<th>Title and Affiliations</th>
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<tbody>
<tr>
<td>George Vradenburg</td>
<td>Chairman and Co-Founder</td>
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<tr>
<td>Trish Vradenburg</td>
<td>(In Memoriam) Co-Founder and Vice President</td>
</tr>
<tr>
<td>Meryl Comer</td>
<td>Board Member, Founding Member, WomenAgainstAlzheimer’s</td>
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<tr>
<td>John Dwyer</td>
<td>Board Member, President, GAP Foundation</td>
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<tr>
<td>Marilyn Glosserman</td>
<td>Board Member</td>
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<tr>
<td>Drew Holzapfel</td>
<td>Board Member and Acting President, Executive Director, The Global CEO Initiative on Alzheimer’s Disease</td>
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<tr>
<td>Peter L. Levin, PhD</td>
<td>Board Member, President and CEO, Amida Technology Solutions</td>
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<tr>
<td>Greg O’Brien</td>
<td>Board Member</td>
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<tr>
<td>Jill Lesser</td>
<td>Board Member</td>
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<tr>
<td>Stanley B. Prusiner, MD</td>
<td>Board Member, Professor of Neurology, Director, Institute for Neurodegenerative Diseases, University of California, San Francisco</td>
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<tr>
<td>David Satcher, MD, PhD</td>
<td>Board Member, Founder and Senior Advisor, Satcher Health Leadership Institute, Morehouse School of Medicine; 16th U.S. Surgeon General</td>
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<tr>
<td>Karen Segal</td>
<td>Board Member, Founding Board Member, Children’s Research Fund; North Suburban Board, Ann &amp; Robert Lurie Children’s Hospital of Chicago</td>
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<tr>
<td>Shawn Taylor</td>
<td>Founding Board Member, Founder &amp; President, VeteransAgainstAlzheimer’s; Founding Member, WomenAgainstAlzheimer’s</td>
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<tr>
<td>William Vega, PhD</td>
<td>Board Member, Founder, LatinosAgainstAlzheimer’s; Emeritus Provost Professor, University of Southern California</td>
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Endnotes

1 https://www.alz.org/alzheimers-dementia/facts-figures
2 https://www.alz.org/alzheimers-dementia/facts-figures
4 http://actonalz.org/sites/default/files/documents/02%20Compelling%20Case%20PDF.pdf
5 https://www.alzheimer-europe.org/Research/Value-of-Knowing
7 http://www.talentinnovation.org/_private/assets/PopHealthcare_ExecSumm-CTI.pdf
8 https://report.nih.gov/categorical_spending.aspx
9 https://www.reuters.com/article/us-health-dementia-gates/bill-gates-makes-100-million-personal-investment-to-fight-alzheimers-idUSKBN1DD0S3
15 UsA2 research conducted April/May 2018 in partnership with Healthy Women. Sample size = 1,001 women, 35 – 64 years of age, nationwide, margin of error associated with any individual statistic is plus or minus 3.1% at the 95% level of confidence.
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18 https://www.rand.org/content/dam/rand/pubs/research_reports/RR2200/RR2272/RAND_RR2272.pdf
21 http://globalalzplatform.org/background/