

2021

ANNUAL REPORT



Raising Awareness, Driving Action

UsAgainstAlzheimer's

CHAIRMAN'S LETTER

This past year was an exciting and consequential time in the fight against Alzheimer's. With breakthroughs in treatment, a remarkable step forward in prevention, and a new initiative to raise public awareness of the importance of brain health, there have been significant accomplishments in this movement. Many of these efforts were led by UsAgainstAlzheimer's (UsA2) and are detailed in this year's Annual Report.

These are the types of milestones we aspired to when we launched UsAgainstAlzheimer's more than a decade ago. They demonstrate what can be achieved when people and organizations work as partners to reach a common goal.

I am so proud of what we have accomplished together in the past year, taking on the toughest problems and making a meaningful difference for people with Alzheimer's and their caregivers. Major accomplishments in 2021 included:

- // Historic action by the federal government making **Alzheimer's prevention a national priority**. Establishing a new federally backed national commitment to risk reduction for Alzheimer's and related dementias was a direct result of advocacy and leadership by UsAgainstAlzheimer's.
- // We saw unmitigated success in continued **increases in federal Alzheimer's research funding** and played an important role in the creation of a new federal agency to advance breakthrough research, called the Advanced Research Projects Agency for Health (ARPA-H). Modeled after DARPA, which brought about innovations like the internet and GPS, ARPA-H is dedicated to incentivizing bold innovations in research for diseases like Alzheimer's.
- // Launch of **BrainGuide™ by UsAgainstAlzheimer's** to help people learn more about their personal brain health or that of a loved one, a major new initiative that earned national coverage, including on *Good Morning America* and the *Today Show*. In its first nine months, more than 160,000

people took the mybrainguide.org memory questionnaire and received trusted, tailored information to help them.

// Kickoff of a first-of-its-kind global initiative in partnership with the World Economic Forum – the **Davos Alzheimer's Collaborative** – to eradicate Alzheimer's worldwide, much like previous global initiatives to end infectious diseases. The collaborative, formed and incubated by UsA2, now stands as its own nonprofit.

FDA approval of the first-ever drug therapy to slow the progression of the disease gave hope to many people with mild cognitive impairment and early-stage Alzheimer's. The first in its class of treatments, Aduhelm was seen as opening the door for additional Alzheimer's medications currently in the pipeline. In a historic move, however, CMS determined it would only cover Aduhelm – and the entire class of anti-amyloid treatments – for Alzheimer's patients who participate in highly restrictive clinical trials. UsA2 is working aggressively to ensure access to treatments for all Medicare recipients who need them.

We fought to remove barriers preventing communities of color from accessing clinical trials and brain health resources. We highlighted the areas of the country with the highest Alzheimer's prevalence rates for Blacks and Latinos and demanded action by policymakers.

It was a year of tremendous progress and new hope. This is what we can achieve with the power of "Us."

Yet, we know that more work remains, and we must never stop until we end this disease.

Thank you
for your support and partnership.

George Vradenburg
Chairman and Co-Founder
UsAgainstAlzheimer's



People who get to know UsAgainstAlzheimer's often say that we "punch above our weight class," that our achievements exceed what would be expected of an organization of our size.

Thanks to our supporters, 2021 marks the year that UsAgainstAlzheimer's moved up to the next weight class. The accomplishments of our organization shown in this Annual Report bear that out.

A new national goal on reducing risk of Alzheimer's and dementia is a major advancement in the fight, as is the creation of a platform, BrainGuide, to help people learn more about their brain health – and talk with their doctors about it.

The National Institutes of Health (NIH) relied on data from our National Alzheimer's Disease Index to site a new Alzheimer's Disease Research Center in South Texas, an underserved region of the nation. Clinical trials are setting higher – and more appropriate – goals for participation of Black and Latino Americans. Federal regulators and companies are hearing the voices of people living with Alzheimer's and their caregivers about what matters most through A-LIST as well as robust advertising and media campaigns.

UsAgainstAlzheimer's is playing a greater role in helping shape federal legislation and policies such as creation of ARPA-H. And our efforts on behalf of patients and caregivers are earning significantly more attention from the news media and members of Congress.

As a patient-centered organization, we rely heavily on people living with Alzheimer's and caretakers to help inform what we do and make their voices heard everywhere from their communities to the halls of Congress. Throughout the year, UsAgainstAlzheimer's A-LIST researched and raised the voices of the Alzheimer's community about treatments, prevention, brain health, and the ongoing effects of the COVID-19 pandemic on our community.

Further, the Alzheimer's Disease Patient and Caregiver Engagement (AD PACE) initiative continues to make advances in bringing scientific rigor and breadth to the delivery of patient experience data in Alzheimer's. In 2021, AD PACE developed two manuscripts on findings from the What Matters

Most (WMM) Research Program to be submitted for publication in peer-reviewed journals, initiated the Next Generation of the WMM study, and established a strong working relationship with the Institute for Clinical and Economic Review.

With Black and Latino people disproportionately impacted by Alzheimer's, we are working diligently to change the healthcare system so it works for everybody. Our working relationship with the Centers for Disease Control and Prevention (CDC) has allowed us to make even greater investments in brain health equity while raising public awareness among communities of color.

Now, that greater impact and bigger weight class will mean even higher expectations for 2022 and beyond.

Over the next year, we'll need to answer some big questions:

How does UsAgainstAlzheimer's lead efforts to build on the new national goal on Alzheimer's risk reduction and prevention? It is a critical step forward for our early intervention work in our drive for changes in clinical practices to improve screening and earlier detection. It also is the foundation of our efforts to show that people can take steps to reduce their risk of getting Alzheimer's.

How do we continue to dismantle barriers to access for Black and Latino Americans and reduce the disproportionate burden they and women bear?

What are the best ways to support faster development of new diagnostics and treatments, and to ensure that they meet the greatest needs of patients and caregivers?

How can we build on the success of our BrainGuide platform to support all of these goals? And how can we keep our eye out for new needs and opportunities in the field, while maintaining focus on the current work?

Let us know what you think. It will take all of "Us" to answer these questions and to ultimately solve Alzheimer's. Thanks for being a part of the fight, a part of the team, and a part of the solution.



Russ Paulsen
Chief Operating Officer
UsAgainstAlzheimer's

Daphne Delgado

Project Director of Brain Health Partnerships
AmericansAgainstAlzheimer's



Q: What brought you to UsA2?

DD: The people! Before UsAgainstAlzheimer's, I spent a decade as a policy and government relations professional for several public health and nonprofit organizations. Through the interview and onboarding process at UsA2, I met many wonderful, smart, strategic, dedicated people; it further solidified my instinct that this was a good career move. I'm so glad that my first impressions were 100 percent spot on!

Q: Your role at UsA2 connects two essential programs – the Brain Health Partnership and the Center for Brain Health Equity – to ensure the organization is engaging with diverse communities in order to improve awareness and action on brain health. What does that look like day-to-day?

DD: I know it's absolutely cliché, but there is no typical day for me. Some days are focused on working with partners on public policy priorities. Others are focused on ensuring we are advancing the mission we share with the Centers for Disease Control and Prevention (CDC) to raise brain health awareness among people of color.

Some days are focused on building external relationships – meeting with our amazing partners, like the National Black Nurses Association or the National Association of Hispanic Nurses, to coordinate how we further our CDC work to empower Black and Latino nurses, or meeting with brand-new partners to help us build out or disseminate work we're launching, like Brain Health Academy.

The overall theme is working with others. Nothing I do is done in a silo, either internally or externally. We're working together to solve a really big problem!

Q: How does your background help you deliver on UsA2's mission?

DD: I'm a first-generation Cuban-American from a long line of immigrants. One of my core childhood memories is watching my great-grandmother, with whom I conversed in Spanish, develop Alzheimer's and lose her ability to speak Spanish. Instead, at the end of her life, she reverted to only speaking Arabic – the language of her childhood in Cuba with her Lebanese and Syrian immigrant parents. Watching a person I knew and loved my entire life lose a whole language was astounding to me. It is absolutely one of the reasons why I made a career in public health.

To be able to bring that experience full circle is incredibly fulfilling. I believe (and hope) that my background in policy and advocacy will help deliver UsA2's mission to take on the toughest problems in the fight to equitably end Alzheimer's.

Q: Can you share a story of an experience you've had since joining UsA2 that has really resonated with you and keeps you grounded as to why this is important work to be doing?

DD: My first day of work was June 1, 2021. Just five days later the FDA announced of its decision to approve aducanumab – the first disease-slowing Alzheimer's treatment ever.

I came from the world of chronic disease prevention, most recently at Trust for American's Health and YMCA of the USA. It is a world that still has work to do but where there is a plethora of behavioral and pharmacological interventions.

Being in a new workplace knowing I was with a great group of people making brave choices, doing hard work to make a difference for a disease that hasn't seen as much progress, reiterated that I was in the right place.



BrainGuide by UsAgainstAlzheimer's, developed and launched in 2021, showed the immense interest in an easy-to-use technology platform to help people concerned about memory or brain health find resources and a path forward. In the first nine months after the March 2021 kickoff, 283,000 people visited BrainGuide with nearly 160,000 people taking a memory questionnaire.

BrainGuide offers two memory questionnaires: one that can be taken for yourself and the other for a loved one you see often. Tailored resources are provided to each visitor to help them on their next step in their journey.

BrainGuide is free, available in English and Spanish, and can be used by phone or online. The technology is built on Amazon Web Services with initial financial support from Biogen.

Media outlets from across the country saw the value of this first-of-its-kind technology, producing more than 100 stories on BrainGuide in 2021. This extensive coverage started with a major exclusive story on the launch on *Good Morning America*, with additional stories on the *Today Show* and broadcast outlets in Chicago, Atlanta, and other major cities, as well as on Spanish-language media, including *La Opinion* and *Telemundo*.

UsAgainstAlzheimer's has worked continuously to add new features to BrainGuide since the launch. These include ways for people who take a BrainGuide questionnaire to get a summary of the results to show their doctor. We've also created several educational videos in [English](#) and [Spanish](#) to help describe BrainGuide.

User Surveys Show BrainGuide's Value

User surveys in 2021 showed that 79 percent of the people taking the BrainGuide questionnaires did so to assess their own memory or brain health; 21 percent said they took it on behalf of someone else.

Moreover, 90 percent of users reported finding the platform helpful, and 80 percent said they would recommend BrainGuide to a friend or colleague.

Raising Community Awareness of Brain Health and BrainGuide

BrainGuide was at the center of a community [Town Hall](#) in Atlanta in December that brought greater attention to brain health within the Black community as well as local [media coverage](#). The event was held in partnership with organizations including Alter, Black Health Matters, Emory University Goizueta Alzheimer's Disease Research Center, Black sororities and fraternities, and area memory and elder care groups.



Who We Are



Memory Questionnaires

155k+ Web Chats
1.3k+ Voice calls

Total Questionnaires

79% Taken for themselves
21% Taken for a Loved one
78% Female
77.2% age 60-90

Spanish Resource Update

- All content on site translated to Spanish
- 35+** External Spanish Resources
- Identified new Spanish Resources across all Evergreen Pages
- Fixed Broken Links

Take to my Doctor PDF



- Personalized User Score
 - 8 different PDF versions

“ BrainGuide™ is easy to use, science-based, and hopeful. I can answer a few questions, and it helps me determine what my next steps will be. It has a lot of facts and information, but I'm not overwhelmed by it. As a nurse recently diagnosed, BrainGuide™ reminds me of what my friend (a neurologist) did when she helped me understand I had a problem. And it can be used as a jumping off point for a physician visit.”

R. Doreen Monks
 Retired Nurse Practitioner living with Alzheimer's disease



“ As an expert in consumer engagement strategies in healthcare, I know that BrainGuide can be a gamechanger. It will make it so much easier for consumers to begin the journey towards better brain care in a healthcare system that too often leaves them with the impression that there is nowhere to turn. Alzheimer's disproportionately affects people of color, and BrainGuide empowers people from all communities to take action.”

Marsha Henderson, M.C.R.P.
 Former Associate Commissioner for Women's Health at FDA

Early Intervention

The past year saw the biggest strides forward in making prevention a higher priority and engaging healthcare providers with real steps to address brain health and reduce the risks of Alzheimer's.

In a milestone moment for the Alzheimer's movement, Health and Human Services Secretary Xavier Becerra made prevention a national priority when he updated the National Alzheimer's Plan in December by adding a new goal: *Accelerate Action to Promote Healthy Aging and Reduce Risk Factors for Alzheimer's Disease and Related Dementias (ADRD)*. The update calls for clear strategies to achieve this goal, including additional research, strengthening the public health infrastructure, and turning risk reduction research findings into clinical practice.

Adoption of the new prevention goal is the latest recognition of how reducing the burden of risk factors such as hypertension, physical inactivity, or depression may delay the onset or slow progression of ADRD and its symptoms.

The new national prioritization of risk reduction builds on the recommendation earlier in 2021 by the National Alzheimer's Project Act (NAPA) Advisory Council that the new goal seek a 15 percent reduction by 2030 in the prevalence of 10 key risk factors: depression, diabetes, hearing loss, midlife hypertension, physical inactivity, poor diet quality and obesity, poor sleep quality and sleep disorders, tobacco use, traumatic brain injury, and unhealthy alcohol use.

UsAgainstAlzheimer's played a key role in the development of the new national goal and the work of the NAPA Advisory Council.

This milestone was reached because UsAgainstAlzheimer's refused to accept what many believed – that Alzheimer's disease is an inevitable part of aging. We convened nearly 200 organizations and leading changemakers, conducted research, and led the effort in shifting the conversation around

Alzheimer's to more of a focus on brain health, general well-being, and the idea that people can minimize their risk of Alzheimer's.

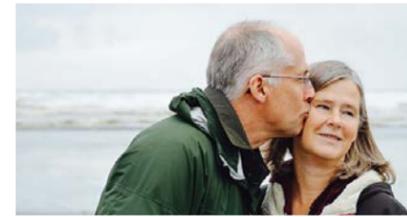
Helping Doctors Talk with Patients about Brain Health

In addition to changing government policy, throughout 2021 UsAgainstAlzheimer's convened experts to develop key recommendations and clinical practices to promote brain health.

This work resulted in a journal article by UsA2 staff and nine renowned clinicians and experts in Alzheimer's & Dementia: *The Journal of the Alzheimer's Association*. The article, [Primary Prevention Recommendations to Reduce the Risk of Cognitive Decline](#), presents six recommendations and associated strategies for prevention that primary care clinicians and general neurologists can use to initiate risk reduction conversations with their patients about cognitive decline. These focus on neurovascular risk management, physical activity, nutrition, sleep, social activity, and cognitive stimulation.

Conversations about risk reduction between healthcare providers and their patients are essential to promote brain health and fight Alzheimer's, and these recommendations provide primary care clinicians and general neurologists with a starting point from which to begin those conversations.

UsAgainstAlzheimer's has developed [resources](#) for healthcare providers about these recommendations and platforms such as BrainGuide that promote brain health and support early detection and intervention.



Follow the timeline of UsAgainstAlzheimer's work to make brain health, prevention, and Alzheimer's risk reduction a federal priority.

www.usagainstalzhimers.org/sites/default/files/timelineUsAgainstAlzhimers.pdf

"CDC is pleased to see the addition of this new goal focused on reducing the risk of Alzheimer's and related dementias. Many of the evidence-based activities we promote to support healthy aging, such as managing hypertension and promoting physical activity, also serve as potential strategies to achieve this goal."

- **Dr. Karen Hacker**, Director, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention

"Evidence suggests that the wear and tear of high blood pressure on the brain's blood vessels contributes to the loss of brain function with aging. The good news is that blood pressure can be controlled, and aggressive blood pressure control substantially reduces one's risk for cognitive impairment and dementia. We are excited by the new goal to use the knowledge we already have to make a difference."

- **Dr. Walter Koroshetz**, Director, National Institute of Neurological Disorders and Stroke, National Institutes of Health



Health Equity and Access

UsAgainstAlzheimer's and our network of partners are an ever-present force behind our nation's public health efforts to address dementia in communities of color. Using cutting-edge data, innovative digital strategies, and trusted partnerships with health providers, we reached millions of people with tailored messages and resources such as BrainGuide.

Health System Readiness and Delivery

In July 2021, we released a new analysis that spotlights areas with high unmet needs and policies that improve healthcare access, make prevention a national priority, and support family caregivers.

The [data brief](#) identifies the 41 congressional districts that overlap with the top 25 counties with the highest prevalence of Alzheimer's among Black and Latino Americans in the Medicare Fee for Service program. It highlights the social determinants of health and systemic inequities prevalent in these districts and makes recommendations for policymakers to advance brain health equity in hard-hit communities.

These counties – and the congressional districts that represent them – are home to families that are **less likely** to have health insurance, **less likely** to have access to exercise opportunities, and **less likely** to have a bachelor's degree or higher. At the same time, they are **more likely** to have lower incomes and **more likely** to report poor health than families living in counties with lower levels of Alzheimer's disease.

Our data and recommendations drew attention from key members of Congress, were highlighted in three congressional hearings, and earned media coverage nationally and regionally.

Public Health and Awareness

In support of our work to improve our nation's public health response to Alzheimer's, UsAgainstAlzheimer's helped connect more than 700,000 Latino and Black Americans to culturally tailored messages and resources about signs and symptoms of Alzheimer's, brain health, and risk reduction steps.

More than 5 million individuals were reached online with brain health messages about disparities and UsA2 resources using the hashtag #BrainHealthEquity, helping to spark a national conversation about brain health inequities.

In partnership with the National Black Nurses Association and the National Association of Black Nurses, we engaged more than 5,000 Black and Latino nurses with educational messages and resources on early detection and risk reduction strategies to improve their ability to promote brain health in their communities.

Paid Leave for Caregivers

UsAgainstAlzheimer's has been the leading voice in the fight for paid leave for dementia caregivers. We believe that economic policies such as paid leave are essential to helping caregivers provide quality care and to narrowing economic inequities experienced by caregivers of color, especially Black and Brown women.

The U.S. has roughly 53 million family caregivers – 16 million providing dementia care – who too often are caught in an unsustainable conflict between caregiving and work responsibilities. The lack of a uniform, national paid leave policy impacted millions of families and contributed to \$6.1 billion in lost productivity for Black families.

In support of this vision, we mobilized more than 26,000 advocates who sent more than 66,000 letters to Congress urging a national policy inclusive of dementia care. As a result, in a major step forward, the U.S. House of Representatives passed legislation that included paid family leave protections for dementia caregivers as well as emergency leave protection for individuals needing leave for COVID. As of early 2022, the U.S. Senate has yet to act on this legislation, and we continue to activate our growing grassroots and grasstops networks to ensure a national paid leave program becomes a reality.

A Growing Public Health Crisis

- Alzheimer's disease is a public health crisis; more than 6 million Americans are living with the disease, with nearly 14 million people expected to be diagnosed with Alzheimer's by 2050.
- Women and communities of color bear a disproportionate burden with women making up 2/3 of Alzheimer's cases. By 2030, nearly 40 percent of all Americans living with Alzheimer's will be Black or Latino.
- AD is the 4th leading cause of death for older Black Americans and 8th for Latino Americans.
- Alzheimer's not only takes an emotional and economic toll on patients and their families, but without early intervention and treatment it is projected to generate care costs exceeding \$20 trillion over the next 30 years.

Voices of Alzheimer's

Throughout 2021, UsAgainstAlzheimer's gathered the perspectives of people living with dementia and their care partners on vital issues, raising their voices about what matters most and sharing their insights with policymakers, researchers, regulators, payers, healthcare providers, and others. These important efforts are intended to inform policies, new treatments and access to those treatments, AD prevention, and support services.

And this work made an impact.

For example, the Alzheimer Disease Patient and Caregiver Engagement (AD PACE) team shared research findings on what matters most to people with AD and caregivers regarding Alzheimer's treatments with the Institute for Clinical and Economic Review (ICER), which was looking into ways to measure the impact of treatments. ICER's final report on the framework to evaluate Aduhelm included our AD PACE findings and information on the effect of Alzheimer's on the caregiver.

This was the first ICER report in any disease area that had a major focus on the consequences for the care partner.

The UsAgainstAlzheimer's A-LIST® is an online community of people living with Alzheimer's and other dementias, current and former caregivers, and those interested in brain health. In 2021, the ninth in a two-year series of COVID-19 A-LIST surveys captured the views of people living with the disease and caregivers on the continuing effects of the pandemic and related closures. Other key surveys examined caregiver burden and the importance of brain health and early detection.

A-LIST research results were featured regularly in the new podcast series [BrainStorm by UsAgainstAlzheimer's](#) which launched in the fall. This podcast – hosted by Meryl Comer, a UsA2 founding Board member and former broadcast journalist – explores the latest science and developments in the field and what they mean to people living with the disease and their caregivers.





Speeding Treatments

For the federal budget year 2022, we and others in the Alzheimer’s movement gained a \$289 million increase for Alzheimer’s research at the National Institutes of Health. This achievement boosted the annual spending for this important federal research to nearly \$3.5 billion. For comparison, when UsA2 was formed in 2010, this federal research funding was just \$448 million a year.

UsA2 took on a prominent leadership role to build support for the proposed new Advanced Research Projects Agency for Health (ARPA-H) to manage large-scale federal health research initiatives, and in March 2022 Congress approved \$1 billion to make ARPA-H a reality.

We believe that ARPA-H is the kind of bold idea our nation needs to drive innovation that will help develop the transformational therapies and technologies required to treat and prevent Alzheimer’s disease and related dementias.

In addition, we have been engaging on behalf of patients and caregivers as several promising drug therapies for Alzheimer’s advance in the research and regulatory pipeline, including disease-slowing treatments by Eli Lilly (Donanemab) and a joint therapy by Eisai and Biogen (Lecanemab).

Global Leadership on Alzheimer’s

Our work on speeding treatments to market includes global leadership on Alzheimer’s.

The Global CEO Initiative on Alzheimer’s Disease (CEOi), the corporate roundtable of UsAgainstAlzheimer’s, partnered with the World Economic Forum to create and launch the Davos Alzheimer’s Collaborative (DAC). DAC was officially formed in 2021 as a U.S. 501(c)3 organization and a Switzerland-based foundation. It has established a comprehensive approach to collecting diverse population data, conducting clinical trials, and supporting health system preparedness across high-, middle-, and low-resource countries. It aims to create a global innovation system to speed and scale up the global response, lower costs, and bring new treatments to market.

CEOi has also been working closely with the World Health Organization (WHO) to inform how ministries of health take action to stem the growing impact of dementia through involvement on new WHO sectoral plans and existing mechanisms such as the Global Dementia Observatory.

In addition, CEOi convened more than 500 stakeholders at its annual global Lausanne workshop held with Alzheimer’s Disease International, the Organization for Economic Cooperation and Development (OECD), and the World Economic Forum. At this workshop, held virtually again in 2021, we released an analysis on the lessons of COVID-19 for the Alzheimer’s community.

Aduhelm

The FDA’s approval in June 2021 of aducanumab, marketed as Aduhelm, was a seminal moment in the battle to end Alzheimer’s. This new medication was the first ever found by the FDA likely to slow the progression of Alzheimer’s for people with Mild Cognitive Impairment and in the early stages of Alzheimer’s. It holds the promise that many people would be able to live independently and perform daily activities longer.

The clinical trials for aducanumab took an unusual path, which led to some controversy as to how to interpret the results. UsAgainstAlzheimer’s very quickly took the position that any ambiguity should be decided in favor of giving individual patients and their doctors the ability to make an informed choice. We asked our A-LIST cohort their opinion, which confirmed our initial position: patients wanted the drug approved. We were heartened that the FDA heard the voices of patients and ultimately gave the drug approval.

At the same time, UsAgainstAlzheimer’s raised concerns in 2021 with the FDA and Biogen, Aduhelm’s manufacturer, about the cost of the drug to patients, the plans for the confirmatory clinical trials on the drug, and other aspects of the drug’s intended use.

We called for changes – and we made a difference in three areas.

- Affordability –** UsAgainstAlzheimer’s raised concerns that the \$56,000 yearly list cost of the treatment could reduce access for many patients who would not be able to afford the drug and diagnostic tests. In December 2021, Biogen announced it would cut the drug’s price in half, to \$28,000 a year.
- Faster and More Diverse Confirmatory Trial –** UsAgainstAlzheimer’s called on Biogen to speed up the timeline for completing the clinical trial necessary to confirm the clinical benefit of Aduhelm, and further demanded that Biogen include a more diverse population in that confirmatory trial. Biogen committed to completing the trial by 2026, four years faster than the nine years given by the FDA, and announced the goal of increasing Black and Latino trial participants to 18 percent.

- Focus on Patients Who Would Be Helped Most –** After FDA approval initially allowed Aduhelm to be prescribed for patients with mild, moderate, and severe Alzheimer’s, UsAgainstAlzheimer’s called for the drug to be prescribed only for patients in the early stages, the same group studied in the clinical trials. The FDA and Biogen quickly made this change to narrow the group of patients for whom the treatment could be prescribed.

The work by UsAgainstAlzheimer’s is part of our advocacy for accelerated development of drug therapies to effectively treat this disease.

Equally important is making these new treatments affordable and accessible to all patients who would benefit, regardless of income or race. That is why we have advocated for Medicare and private insurers to cover the costs of these treatments and the necessary diagnostics tests.

However, in early April 2022, Medicare announced it would deny coverage for Aduhelm – and the entire class of anti-amyloid drugs – except for a small number of people in clinical trials. This decision, vigorously opposed by UsA2, effectively reduces the potential patient population for this treatment from 2 million to a few thousand.





There have been significant accomplishments

BOARD MEMBER SPOTLIGHT

Jill Lesser



Jill Lesser is an Alzheimer’s caregiver and founding member of the UsAgainstAlzheimer’s Board of Directors.

At first, Jill hesitated when approached by George and Trish Vradenburg about joining their new organization in 2011. With her mother’s recent diagnosis, she weighed the time needed for this new organization while she was also raising three young

children and adapting to ongoing challenges of helping with her mother’s care.

But she realized the tremendous importance of stopping Alzheimer’s for society, for women, and for families just like hers. She was drawn to the vision of starting an organization that would change the trajectory of the disease and create the imperative for greater urgency to take on what was clearly a national emergency. And she realized this work and advocacy could give her an opportunity help bring about a brighter future, while living in the present with her mother.

“This has been a labor of love for my mother and a labor of love for George and Trish,” she said.

As she reflects on the past decade-plus, Jill is proud of being the co-founder – along with Meryl Comer and Trish Vradenburg – of UsA2’s work on the disproportionate impact of Alzheimer’s on women and its call for looking at the disease through a gender-based lens. Jill has led the organization to promote greater attention to health inequities, shine a light on the extraordinary work of women scientists in this field, and empower women to take charge of their brain health.

Jill also takes great pride helping to catalyze a much-needed focus on brain health and prevention. She recalls making a presentation on these issues to her Board colleagues in 2017, and after some additional discussions, saw brain health and prevention become part of UsA2’s expanded mission.

Since then, UsA2 has led efforts to raise awareness about brain health among consumers and healthcare providers and to seek improved screening and earlier detection. In 2018, it launched the [Be Brain Powerful™](#) campaign, which offered steps that people could take to strengthen their own brain health. The campaign also sought to empower women to have conversations with their doctors about brain health, and this helped lead to the launch of [BrainGuide](#).

Most importantly, in December 2021, with UsA2 in the lead, the federal government made prevention and risk reduction a national priority with a new risk reduction goal in the National Alzheimer’s Plan. This new national goal comes at a time of increased attention on the effects of risk factors and co-morbidities and effects on diseases such as Alzheimer’s, diabetes, heart disease, and COVID-19.

Looking ahead, Jill hopes to see dramatic improvements in disease-modifying treatments and risk reduction, propelled by research by both government and the private sector, especially innovations by tech companies. And she says that treatments, risk reduction steps, and efforts to engage consumers and doctors must be available to everyone, regardless of gender, race, or ethnic background.

Together, those will be keys to achieving the goal of ending Alzheimer’s disease. Jill wishes Trish were still on the journey with UsA2.



In Memoriam: Marilyn Glosserman

The UsAgainstAlzheimer’s community was deeply saddened by the passing of our board member Marilyn Glosserman in October 2021.

Nobody believed more in this cause than Marilyn, and the fight against Alzheimer’s would not be where it is without her.

Marilyn had a family connection to this disease, having lost her father to Alzheimer’s in 2004. She experienced firsthand how Alzheimer’s affects the person living with the disease and their family caregivers.

Marilyn, who joined the UsAgainstAlzheimer’s board of directors in 2018, was a strong supporter for more Alzheimer’s research, especially understanding how lifestyle and nutritional choices can impact neurological, cancer, and heart-related diseases.

Our organization’s work on strengthening brain health, risk reduction, and prevention is a testament to her leadership.

Her passing was a loss for all of us at UsAgainstAlzheimer’s and throughout the Alzheimer’s Movement.

Senator Mark Warner

Senator Mark Warner's commitment to Alzheimer's goes far beyond his work on Capitol Hill. It is personal. As a co-chair of the Congressional Task Force on Alzheimer's Disease, Sen. Warner works with his colleagues in Congress to increase research into Alzheimer's disease and to improve access and quality of medical care for patients. This focus of his public service is inspired by his mother, who lost her battle with Alzheimer's disease just before he became Governor of Virginia in 2001.

His mother's decade-long struggle helped shape Sen. Warner to be an even stronger leader who fights on behalf of our nation's most vulnerable patients. He also acknowledges that watching his mother suffer with Alzheimer's shed light on one of his greatest regrets: not getting her input on the kind of care she would have wanted while she was still able to make her wishes known.

"I know firsthand just how easy it is to put these conversations off because it's incredibly painful to imagine a loved one becoming so ill that he or she is unable to make decisions about her own medical care," Warner said. "Advanced care planning is never easy, but every family can benefit from having these conversations early."

After meeting George and Trish Vradenburg in 2009, Warner became aware of UsAgainstAlzheimer's and the work the co-founders were putting into motion. In 2017, Warner was honored at the UsAgainstAlzheimer's Annual Congressional Bipartisan Dinner and was pleased to see representatives from both sides of the aisle who care about Alzheimer's disease coming together for the common goal of beating this terrible disease.

In his role as a policymaker, Sen. Warner values the advocacy work of UsAgainstAlzheimer's. Knowing the challenges of this terrible disease firsthand, he also chose to provide personal philanthropic support for the critical work UsAgainstAlzheimer's does every day.

Warner notes, "It really runs the gamut, from caregiver resources, advocacy, prevention, and getting treatments to patients faster. I'm grateful for all the work the organization does on behalf patients and their families."

UsAgainstAlzheimer's is honored to turn Sen. Warner's generous contributions into action as we continue our work to support patients and caregivers, promote prevention and early detection, and end this disastrous disease.



Michael and Shari Ellenbogen

When Michael Ellenbogen was diagnosed with dementia, he and his wife, Shari, were relieved. At least now they knew what they were fighting.

For many years, Michael's symptoms were dismissed or attributed to stress or anxiety. When the diagnosis finally came, it was frightening, but it also steered them into action. They stopped putting off travel and other adventures and began to focus on doing things while still able to enjoy them.

They also set out to learn as much as possible about dementia. While many organizations were working toward a cure, Michael and Shari discovered few were engaging people living with the disease. Decisions were being made without input from the people they would impact most – those living with Alzheimer's and dementia. Michael and Shari committed to changing that, and their fight has been relentless. Michael has become a vocal and well-respected advocate for people living with dementia and their caregivers to policymakers, industry executives, researchers, clinicians, and the World Health Organization.

Michael and Shari have also been tremendous advocates for UsAgainstAlzheimer's, raising both awareness and financial support. Michael sees himself as a disruptor, just like UsAgainstAlzheimer's co-founder George Vradenburg. He

is proud to be part an organization that takes a leadership position on urgent matters and encourages others to join forces.

With limited personal resources, the Ellenbogens find ways to give and to encourage others to support UsAgainstAlzheimer's. As a patient advocate, Michael is in high demand as a speaker at conferences and events and frequently directs stipends and speaking fees directly to UsAgainstAlzheimer's. He has even secured a grant from his financial services firm. When they do make personal gifts, or raise funds for UsAgainstAlzheimer's, they do it with confidence those contributions are put to excellent use.

The Ellenbogens feel fortunate in many ways. Shari's work was flexible enough to allow them to travel. Michael is able to remain an active volunteer and, so far, his symptoms have progressed slowly. But he knows many others are not as lucky. Michael points out, "Cancer advocacy efforts are fueled by survivors. But Alzheimer's has no survivors." Those fighting the disease are often unable to speak out, unable to make themselves heard and seen. That's why Michael and Shari are committed to be vocal for as long as they are able. And UsAgainstAlzheimer's is grateful for it!



Alzheimer's Drug Discovery Foundation (ADDF)



Investors in Prevention

The Alzheimer's Drug Discovery Foundation (ADDF) makes investments in a diverse range of novel treatments and diagnostics that are altering the course of Alzheimer's research. Their early bets and out-the-box ideas frequently become guiding principles across the broader field of research and clinical trials. They serve as a significant driver of meaningful innovation and change not only in drug development, but also in dementia prevention through their funding of prevention studies and their educational resource, CognitiveVitality.org, which provides scientific evidence-based information on brain health.

Demonstrating their commitment to the power of prevention, in 2018 the ADDF provided seed funding to UsAgainstAlzheimer's multi-year effort to catalyze a new national landscape in risk reduction, early detection, and diagnosis. Over the past four years, with the ADDF's help, UsA2 has framed and advanced the national conversation around brain health and early intervention. Together, we have made a lasting impact on

our country's approach to ending Alzheimer's and related dementias, including mobilizing providers, developing risk-reduction guidelines and, most recently, successfully achieving the addition of a risk reduction goal to the National Alzheimer's Plan.

When the ADDF and UsA2 began our work together, brain health, risk reduction, and prevention were not widely discussed. There was little action and awareness in either the public or the private sector. Today, and thanks to the ADDF's foundational support, that has changed.

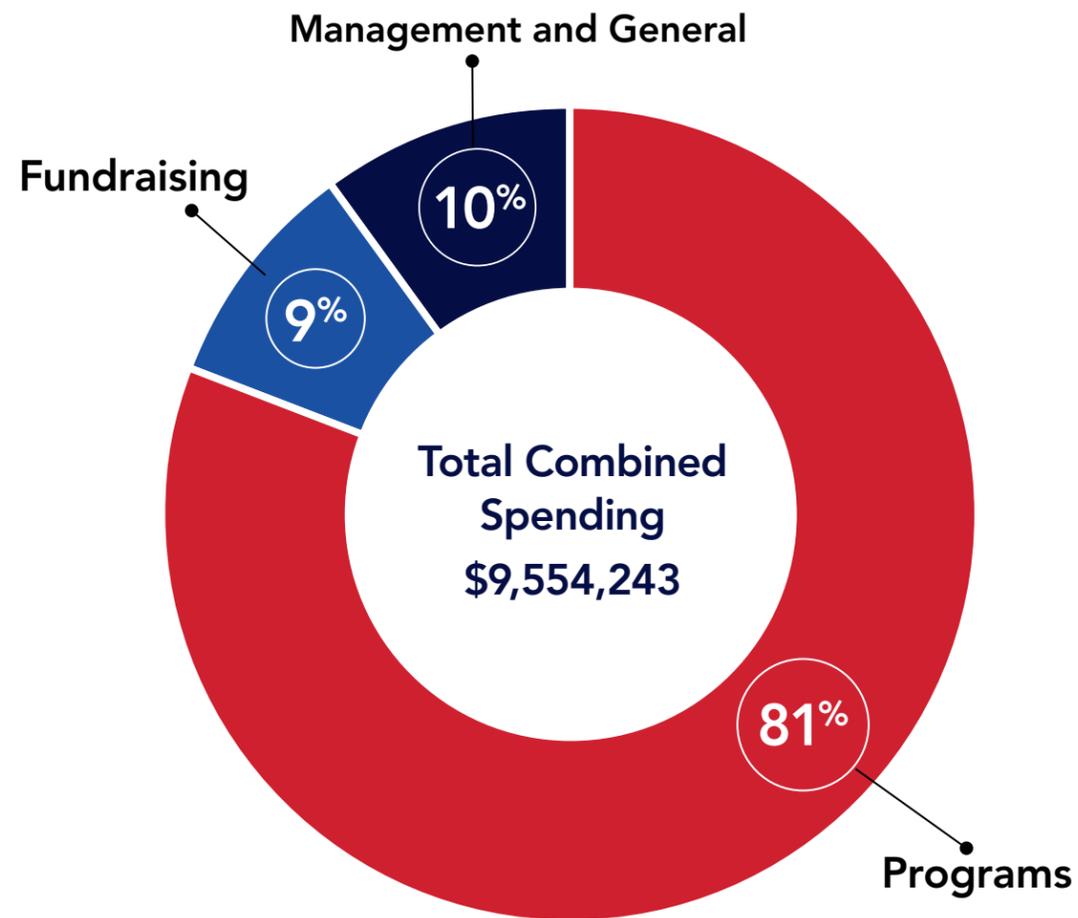
UsAgainstAlzheimer's is equally proud of and awed by the results and impact of our prevention work and our partnership with the ADDF. We are grateful to them for their vision, leadership, and support and for joining their formidable forces with ours to not only improve brain health but also propel the field to the ultimate goal of preventing Alzheimer's in the first place.

Howard Fillit, MD

Co-Founder and Chief Science Officer of the Alzheimer's Drug Discovery Foundation



FINANCIALS



COMBINED STATEMENT OF ACTIVITIES AND CHANGE IN NET ASSETS

For the Years Ended December 31, 2021 and 2020

	2021	2020
REVENUE AND SUPPORT	Total	Total
Contributions and Grants	\$ 11,244,040	\$ 9,230,655
Special Events Revenue, Net of Expenses	90,206	99,138
Program Service Revenue	2,178,400	350,032
Investment Income, net	(144)	8,392
Total Revenue and Support	13,512,502	9,688,217
EXPENSES	Total	Total
Program Services	7,704,956	6,167,115
Supporting services:		
Fundraising	\$ 907,453	\$ 850,462
Management and General	941,834	633,741
Total Supporting Services	1,849,287	1,484,203
Total Expenses	9,554,243	7,651,318
OTHER ITEMS	Total	Total
Extinguishment of Debt	\$ 64,175	-
Transfer of Net Assets	(2,251,108)	-
CHANGE IN NET ASSETS	1,771,326	2,036,899
Net Assets at Beginning of Year	6,248,435	4,211,536
NET ASSETS AT END OF YEAR	\$ 8,019,761	\$ 6,248,435

A complete copy of the financial statements audited by GRF CPAs and Advisors is available upon request by contacting stopalz@usagainstalzheimer.org.

TRISH VRADENBURG GALA



UsAgainstAlzheimer's



Seth & Lauren Rogen
Actors & Co-Founders of Hilarity for Charity



UsAgainstAlzheimer's

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Chief Executive Officer, Biogen



Marsha Henderson
Former Associate Commissioner for Women's Health, FDA



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UsAgainstAlzheimer's

Dr. David Satcher, MD, PhD
Founder and Senior Advisor, Satcher Health Leadership Institute, Morehouse School of Medicine, and U.S. Surgeon General



Billy Crystal



Lisa Genova
Author, Still Alice, Remember: The Science of Memory and the Art of Forgetting

NATIONAL ALZHEIMER'S SUMMIT AND OTHER EVENTS



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Caregiver



CONGRESSWOMAN LINDA SANCHEZ
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THANK YOU TO OUR DONORS

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Special thanks to all those who have made gifts in honor and memory of mothers, fathers, grandparents, family members, and caregivers. Gifts of \$100 or more were made in tribute to the following:

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