



10 years of *Us* being...

thought leaders

Activists and collaborators

risk takers

Champions of
health equity

change-makers
and doers

UsAgainstAlzheimer's

2020 Annual Report

Ten years.

In 2010, my wife, Trish, and I – along with John Dwyer and Meryl Comer – founded UsAgainstAlzheimer's to stop Alzheimer's disease. All of our families had been touched by this terrible disease. We formed this new organization to change the sluggish "business as usual" mindset of that time and to instill greater urgency, innovation, and collaboration in the battle to end Alzheimer's.

We set the ambitious goal of stopping Alzheimer's by 2020. To reach this goal, we knew that UsAgainstAlzheimer's had to be different and had to be disruptive. We entered the race with a new approach, believing that a patient/caregiver-led organization could rally a wide range of people, businesses, organizations, and government entities – all of "Us" – to a shared mission and thereby make a difference.

How did we do that? By forming an action-oriented organization that runs to the hardest issues in this fight and that uses the power of patient-caregiver leadership to bring together sectors and people to work collaboratively towards a common goal. We want every company to introduce wildly successful drugs, every scientist to get the Nobel Prize, and every nation to be the fastest in enabling access to innovative interventions for their citizens at risk for Alzheimer's.

The value of racial and gender justice has been a guiding principle since our founding, and we mobilized women, Blacks, and Latinos, the communities most disproportionately affected by Alzheimer's.

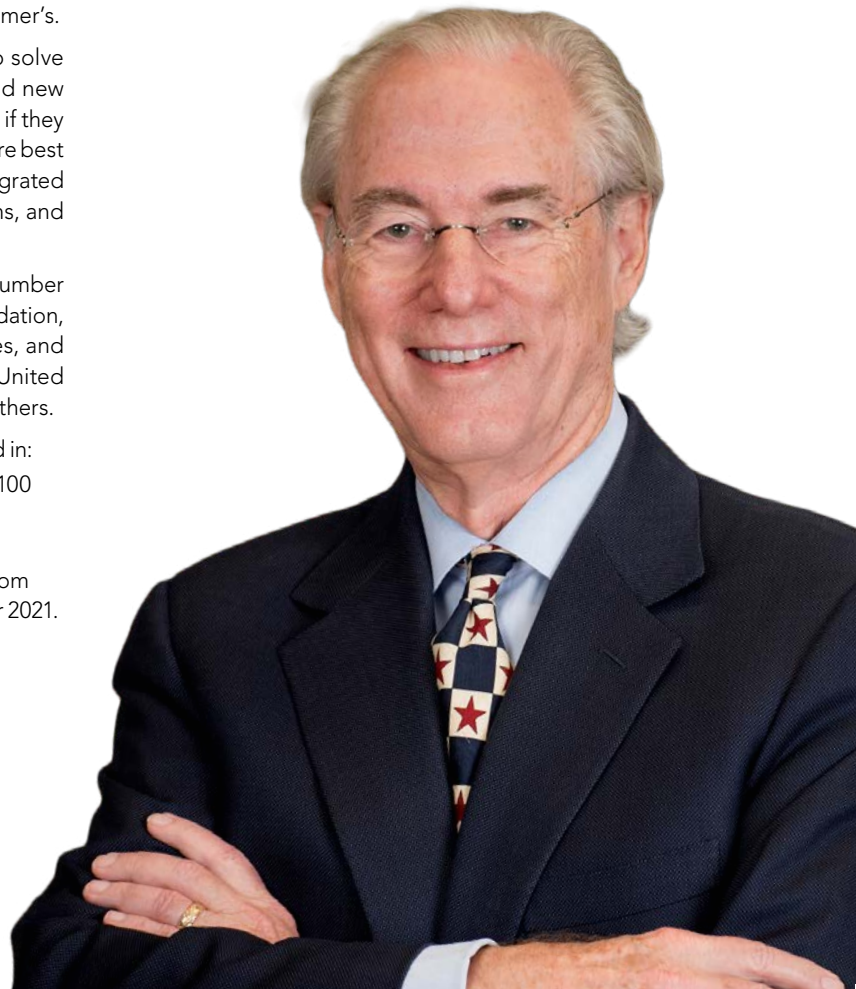
UsAgainstAlzheimer's constantly finds innovative ways to solve problems. We incubate and develop new approaches and new collaborations. As initiatives germinate and grow, we assess if they will be most effective on their own and spin them off. If they are best nurtured within our organization, we nest them inside an integrated program portfolio with common advocacy, communications, and finance support.

Venture philanthropists have invested with us to incubate a number of these innovative projects, including the Vradenburg Foundation, Alzheimer's Disease Discovery Foundation, Gates Ventures, and Dolby Foundation, as well as leading companies such as United Healthcare, Johnson & Johnson, Eli Lilly, Biogen, Eisai, and others.

Over the past decade, this pioneering approach has resulted in:

- // Creation of an independent advocacy coalition of over 100 Alzheimer's-serving organizations.
- // Stunning increases in the level of Alzheimer's research investments at the National Institutes of Health (NIH), from \$448 million in fiscal year 2011 to \$3.1 billion in fiscal year 2021.

- // Convening of a global corporate roundtable of major pharmaceutical and biotech companies with Alzheimer's programs, the Global CEO Initiative on Alzheimer's Disease (CEOi).
- // Incubation and spin-off of a North American clinical trials support platform, the Global Alzheimer's Platform Foundation (GAP).
- // A brain health partnership to develop a non-pharmacological approach to Alzheimer's prevention.
- // An initiative with United Healthcare to use artificial intelligence and machine learning technology to predict the onset of Alzheimer's symptoms from medical records.
- // The UsAgainstAlzheimer's Center for Brain Health Equity, which received multi-year funding from the Centers for Disease Control and Prevention.



Most recently, we launched this January a first-of-its-kind global initiative in partnership with the World Economic Forum – called the Davos Alzheimer’s Collaborative – to eradicate Alzheimer’s worldwide, much like previous global initiatives to end infectious diseases. This global mechanism will innovate new technologies to detect Alzheimer’s and develop new digital tools to enable researchers to link data worldwide from the racially and ethnically diverse populations that make up nearly 70 percent of the families touched by Alzheimer’s globally.

The past 10 years have seen victories, but also many disappointments in Alzheimer’s drug trials. Our founding families have experienced heartbreaking losses: In 2017 I lost Trish, my wife of 49 years, to a heart attack. Meryl Comer, one of our co-founders, lost both her husband and mother to Alzheimer’s. John Dwyer, our other co-founder, has lost a grandmother, his father, seven aunts/uncles, and now the first member of his generation to Alzheimer’s.

I wish Trish were here to see the progress we’ve all made. While we didn’t hit our goal of stopping Alzheimer’s by 2020, we are accelerating the pace of change towards the goal of eradicating Alzheimer’s. Trish would have been proud of our work.

We are thought leaders, risk takers, incubators of innovative approaches, politically engaged activists, champions of new technology and, most importantly, change-makers and doers.

UsAgainstAlzheimer’s consistently and constantly fights above its weight class. We have been able to do so by bringing people living with the disease, caregivers, researchers, and companies together to find ways to respond to what matters most to patients and caregivers in research, drug development, and regulation.

Our earned reputation for collaboration has garnered respect. More and more, companies working on disease-modifying treatments, therapies for dementia-related symptoms, or new tests to detect and

diagnose the disease want to work with us. It is hard to express the excitement I felt when the World Economic Forum approached us to partner and to convene international leaders in this global effort against Alzheimer’s.

When UsAgainstAlzheimer’s was created, Trish said: “A cure for Alzheimer’s: a fantasy, a wish, an impossible dream.” I believe that yesterday’s impossible dream is on the brink of reality today. More and more people are understanding that Alzheimer’s is not an inevitable and normal part of aging.

While I will always want the pace of progress against Alzheimer’s to be faster, I’ve never been as optimistic about the future as I am now. But our work is not done.

Alzheimer’s has had a multi-generational impact in my family, with three generations affected by this disease over 40 years, including Trish’s mother and grandmother. I hope that our work will reduce the chance this disease will touch my children and grandchildren.

I intend to spend the rest of my life striving to eradicate Alzheimer’s, whether as a philanthropist, as a servant leader, as a father and grandfather — whether through national or international mechanisms and always working with others. That is my goal in life – for Trish, for my family and for the 150 million families worldwide that are now or will be touched by this disease.

Thank you for your support and partnership.
We must never stop until we end this disease.

George Vradenburg
Chairman and Co-Founder
UsAgainstAlzheimer’s

KEY MILESTONES ACHIEVED SINCE 2010



- The United States sets a national goal of preventing and effectively treating Alzheimer’s by 2025.
- The G7 follows the United States in setting a goal of curing the disease or introducing a disease-modifying drug by 2025.



- Federal funding for Alzheimer’s research is now \$3.1 billion, up from \$448 million a year.

- “Brain Health Equity” enters the national conversation and becomes a recognized focus driving necessary change for communities of color when it comes to public health, research, and care in Alzheimer’s disease.



- People now are paying attention to brain health, not just brain disease. New research in 2020 shows that it may be possible to delay or prevent up to 40 percent of Alzheimer’s and dementia cases.

- What matters most to patients and caregivers for treatment outcomes is being included in decision-making by drug developers and regulators.



- Our fight against Alzheimer’s goes global in a major way with the World Economic Forum partnership to create the Davos Alzheimer’s Collaborative.
- The despair and disappointment of the past is being replaced by promise and hope for the days just ahead.

CHIEF OPERATING OFFICER'S LETTER

Changing the world in the fight against Alzheimer's.

This was our mindset when we started in 2010, and it shapes our approach today and as we move into the future.

We identify the toughest problems in the fight – and run towards them. In an ecosystem of researchers, companies, individual philanthropists, foundations, government leaders, and other nonprofit organizations, we bring all of us together to solve the seemingly unsolvable.

What do I mean by the toughest issues?

- // Countering the misimpression that dementia is an unavoidable condition of old age.
- // Taking on racism, sexism, and systemic inequities that have been barriers to clinical trials and health services for women and communities of color.
- // Providing a path forward for people in their search for information about memory loss and brain health.

Here are a few examples of what we've delivered.

Risk Reduction – Even as scientists were discovering that people could reduce their risk of getting Alzheimer's in the first place, prevention and risk reduction failed to get the kind of attention that would change behavior at the population level. We brought together a coalition of nearly 200 top leaders and nonprofits—including AARP, the American Heart Association, and the YMCA—to call for the federal government to set a national goal to prevent Alzheimer's and related dementias. There is more to do, but the narrative is shifting. Something CAN be done.

Brain Health Disparities – Women, Blacks, and Latinos get Alzheimer's at higher rates than men and Whites. Systemic inequities increase their risk and limit their access to care. Our National Alzheimer's Disease Index makes it easier for people to see the disproportionate impact of Alzheimer's on people of color. This

index, which uses Medicare fee-for-service data, shows where people with Alzheimer's live, and it overlays that with demographic information and Congressional district lines. Additionally, the UsAgainstAlzheimer's Center for Brain Health Equity, supported by the Centers for Disease Control and Prevention, is working on how

to deliver tailored messages about brain health to minority communities through our public health infrastructure.

Trusted Information – Accurate and easily accessible information is critical to helping people improve their brain health or talk with their doctors about memory concerns. At the end of 2020, we released the beta version of [BrainGuide](#), a free platform that equips people with trusted resources relevant to where they are on their brain health journey. Our equity agenda is embedded in the platform, with versions built from the ground up in Spanish as well as English, via the phone as well as on the Web.

Looking beyond today, we anticipate new trends and shape them. Where will the Alzheimer's movement be five years from now? How are the issues shifting? What can we do now to address future needs?

For example, as new drug therapies are approved to treat Alzheimer's or its symptoms, data will be needed to understand how the treatments work, how the disease progresses, how health outcomes vary among different people, and what factors may contribute to people developing Alzheimer's. UsAgainstAlzheimer's is beginning to create the kind of platform to collect and analyze these data.

Our approach, partnered with our supporters and collaborators, has realized true change in the fight against Alzheimer's. We can't wait to see what we accomplish together over our next decade.

Russ Paulsen
Chief Operating Officer
UsAgainstAlzheimer's



Stephanie Monroe

Executive Director
AfricanAmericansAgainstAlzheimer's

Q: How would you describe UsAgainstAlzheimer's to a new advocate? What are the key elements you highlight?

SM: UsAgainstAlzheimer's is a thought-generating, action-oriented organization whose mission is to meet and tackle Alzheimer's disease and prevention where it is, in all communities across America and not just for those who are privileged. We are the first organization to call out Alzheimer's health disparities, identifying challenges and barriers and developing and implementing effective strategies to confront it, including large health systems and gaps that have created the disparity. There is still much we need to learn, but one thing is clear: there is no reason Blacks should be twice as likely to develop Alzheimer's as non-Hispanic Whites.

Q: Being in the trenches everyday can take its toll. What do you do to personally take care of yourself and your brain health?

SM: That's a great question. As an advocate and a caregiver to my parents, including my father, who has dementia, I, like many thousands more, tend to burn the candle at both ends. I am trying to schedule in "me" time, literally as an appointment on my calendar for me, during which I will read, play word games and puzzles, and call friends. Scheduling the time in makes this work for me. Otherwise, I find myself taking second place to whatever needs to be done for others at the time. That is not healthy.

Q: You not only give of your expertise, talent, and time, but you are also a donor. Why is it important to you to give philanthropically to the organization?

SM: I was once told that the best way to determine what a person values is to look in his checkbook. Whether large or small, every gift matters. It's of course helpful to the organization's mission but more importantly, it allows individuals to feel proud that they are participating in making good things happen for a cause they believe in.

Q: Why did you choose to come to UsAgainstAlzheimer's?

SM: I was invited to attend the formal launch of UsAgainstAlzheimer's and had the privilege of listening to George Vradenburg and former Justice Sandra Day O'Connor. I learned more in that one hour about this dreadful disease than I had learned in my entire 25 years working on Capitol Hill. I was shocked by how little our government was invested in finding a cure for Alzheimer's and even more overwhelmed by its cost and toll on average Americans. I joined the fight to lend my public policy expertise. Little did I know that a few years after joining, my father would receive the diagnosis himself.

Q: What has been the biggest accomplishment that you've seen in the organization's first 10 years?

SM: I am convinced that without UsAgainstAlzheimer's, we would not have seen the federal government increasing its research commitment from nearly \$450 million a year to more than \$3 billion 10 years later. The funding is essential, but so too is the need for people of all races and ethnicity to participate in research. UsAgainstAlzheimer's has been calling out the need for diversity, equity, inclusion and access before it was a thing. We are using our voices and developing strategies to demand inclusion because we know that the first person cured of Alzheimer's will be in a clinical trial.



COVID-19 Pandemic

People living with Alzheimer's and their caregivers were hit especially hard by the COVID-19 pandemic. Many people with advanced Alzheimer's live in long-term care communities, which were devastated in the early days of the pandemic. People living at home had less support, as day programs shut down and in-home care became harder to find.

UsAgainstAlzheimer's sprang into action early, pushing hard for the government to require testing of residents and staff at nursing homes in order to stop the spread. While the federal government did not mandate testing, within a week of our outreach it was strongly urging states to do more testing in nursing homes. And when COVID-19 vaccines became available, we were pleased to see that the government took our advice and made nursing homes a top priority.

Along the way, we gathered data so that we could shine a light on how COVID-19 was affecting our community.

A series of seven A-LIST® surveys on the impact of COVID-19 on people living with dementia and caregivers documented the severe, persistent stress on caregivers during the pandemic, challenges created by nursing home restrictions, and declines in the memory and behaviors of loved ones with the disease because of the restrictions and isolations. We made those data available to policymakers in real time, and we are now making them available to researchers.

The pandemic also challenged UsAgainstAlzheimer's as an organization – and we met that challenge. At a time when a number of other nonprofit organizations made significant cuts in staff and programs because of declining revenues,

UsAgainstAlzheimer's finished 2020 in a solid financial position thanks to strong financial support from our donors. We made no staff reductions and no substantial cuts in programs. (See detailed financials on pages 13-14.)

We were agile and adaptable. When the pandemic struck in March and shut down most operations, we essentially closed our office and saved thousands of dollars on rent.

We switched all planned UsAgainstAlzheimer's events from in-person to virtual gatherings. Time and again, we delivered quality virtual events with important speakers.

Our two biggest events of the year – the National Alzheimer's Summit and Trish Vradenburg Gala – were held virtually and were home runs in terms of reach, impact, and fundraising results. In addition, we held a successful virtual workshop on the importance of patient perspectives in drug development and regulation that featured keynote addresses from U.S. Rep. Diana DeGette and Janet Woodcock, a top FDA regulator. The virtual Lausanne meeting of our Global CEO Initiative featured top-shelf speakers from across the world, including the CEOs of Eisai and Biogen.

With more people at home throughout the day, we developed new digital programming – called BrainStorms – to complement our Alzheimer's Talks webinars with additional discussions centered on brain health.

We are proud of how we were able to adapt to the pandemic-related changes, pivot to the virtual realm, and continue to keep our focus on our meaningful programs on behalf of those living with Alzheimer's.

EFFECTS OF COVID-19 PANDEMIC AND CLOSURES ON ALZHEIMER'S COMMUNITY

86%

of Alzheimer's caregivers reported having one or more stress symptoms typically found in people experiencing severe stress

- Top stressors include being "super alert," sleep problems, loss of interest in activities, and difficulty concentrating

20%

of caregivers said their care of their loved one has been affected by the pandemic-related mental and physical health changes on caregivers

70%

of caregivers reported seeing memory and behavior declines in their loved ones with Alzheimer's or another dementia during the pandemic

47%

of patient respondents – those diagnosed with mild cognitive impairment, Alzheimer's, or dementia – said they believe their cognition has declined

Source: UsAgainstAlzheimer's 2020 A-LIST® Surveys

UsA2 PROGRAMS MAKE A DIFFERENCE

Speeding Treatments

UsAgainstAlzheimer's makes sure that the patient voice is heard in the halls of Congress and within the agencies of the federal government. One way we "punch above our weight" is to focus on shaping federal policy.

With our partners in the Alzheimer's movement, we were successful in gaining a \$300 million increase in federal funding for Alzheimer's research at the National Institutes of Health, with the annual spending up to \$3.1 billion in FY21. This is a tremendous improvement from the \$448 million a year in research spending in FY11 when our organization was formed, and it sets the stage for breakthroughs that will help end the disease.

The Global CEO Initiative on Alzheimer's Disease (CEOi), which is convened by UsAgainstAlzheimer's, partnered with the World Economic Forum to create the Davos Alzheimer's Collaborative (DAC). It is a first-of-its-kind global effort to accelerate the discovery, testing, and delivery of precision interventions for Alzheimer's. After being incubated by UsAgainstAlzheimer's during its development throughout 2020, the Davos Alzheimer's Collaborative was launched in January 2021 in Davos, Switzerland.

DAC 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.

In the U.S., 2020 saw many signs of hope on the horizon, with indications that as many as three drug therapies for Alzheimer's could be on the market nationally in 2021, with more treatments in the pipeline. These included a new disease-modifying treatment that seeks to slow progression of the disease, a treatment for dementia-related insomnia, and a treatment for dementia-related hallucinations and delusions. In addition, a new blood test announced in late fall offered a more-accessible and more-affordable way to detect Alzheimer's pathology in the brain.

UsAgainstAlzheimer's leaders offered comments at a November meeting of a Food and Drug Administration (FDA) advisory committee that was reviewing the drug therapy aducanumab. In this 2020 meeting, UsA2 supported approval of the drug, which is developed by Biogen and Eisai, because of the promise and potential of what would be the first new treatment in nearly 20 years.

Niranjan Bose of Gates Ventures spoke at CEOi's 2020 Lausanne Workshop about the importance of speeding and scaling treatments and his support of the Davos Alzheimer's Collaborative.



Early Intervention

Cancer. Heart disease. Diabetes. Alzheimer's.

Potentially killer diseases, better caught early, best when prevented.

Yet research tells us that most cases of Alzheimer's are not diagnosed until they are at a late stage, and that very few doctors bring up brain health with their patients. For generations, people have thought of dementia as a normal part of aging, rather than a symptom of a potentially preventable disease.

UsAgainstAlzheimer's is leading work to change the status quo, by changing clinical practice, public perception, and public policy.

Changing Clinical Practice

In 2020, we brought together high-level representatives of national health provider organizations such as the American Medical Association, American Academy of Family Physicians, American Academy of Neurology, American College of Preventive Medicine, National Association of Hispanic Nurses, National Black Nurses Association, and American Psychiatric Association. All of these groups share our interest in improving clinical practice around dementia.

Our efforts seek to move the discussion from a place where many providers say they do not know what to tell patients about cognitive impairment and dementia to one where risk reduction, assessment, and early intervention are a routine part of primary care practice. This group is working to improve health outcomes for people with elevated risk of dementia or early symptoms of cognitive change by improving clinical practice nationally. It focused its 2020 work on how to implement dementia risk reduction in primary care, with outputs expected in 2021.

Changing Public Perception

UsAgainstAlzheimer's catalyzed a broad coalition that asked the federal government to create a national, measurable, time-bound goal to reduce the prevalence of Alzheimer's and related dementias. By the end of the year, more than 160 organizations and

leaders had signed onto a statement in support of a national goal. These supporters included AARP, American Heart Association, American Public Health Association, Gerontological Society of America, Hispanic Neuropsychological Society, Milken Institute Center for the Future of Aging, National Consumers League, National Kidney Foundation, National Urban League, and YMCA of the USA.

The government's Advisory Council on Alzheimer's Research, Care, and Services concurred and recommended to the Secretary of Health and Human Services that a goal be set. In addition, the Advisory Council established a new subcommittee – co-chaired by UsAgainstAlzheimer's – to address risk reduction and determine specific goals, metrics, and timelines.

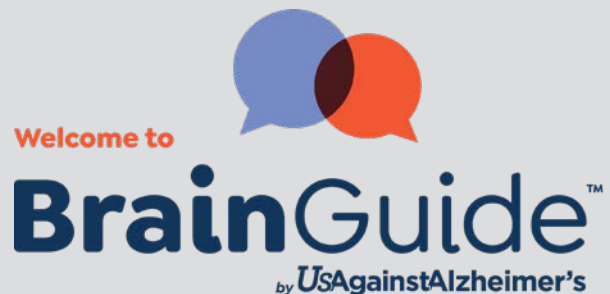
We also continued to expand our Be Brain Powerful® campaign and welcomed actress and advocate Mandy Moore as our National Ambassador. This new role for Moore, whose character in the television series *This Is Us* has dementia, received national media attention, boosted visibility for the campaign, and led to an increase in sign-ups.

The publicity surrounding the coalition recommendations, along with the efforts of Mandy Moore and others, has contributed to the long process of changing the public perception that nothing can be done to prevent Alzheimer's.

Changing Public Policy

A national goal to prevent Alzheimer's, which would cause significant change in federal policy, could be set as early as 2021.

In 2020, UsAgainstAlzheimer's Action was able to add cosponsors to the Concentrating on High-Value Alzheimer's Needs to Get to an End (CHANGE) Act. This legislation would require Medicare to expect doctors to use validated, objective tests to detect Alzheimer's, rather than the current "observation" approach, which we know misses about half of all Alzheimer's cases. We also made our case directly to senior officials in Medicare.



Brain Health Equity

Since our founding, UsAgainstAlzheimer's has recognized the role that systemic inequities play in Alzheimer's for women and communities of color. With the momentous social and racial justice demonstrations in 2020, the importance of our work to increase equitable access to Alzheimer's research and healthcare has never been more clear.

Addressing inequities in brain health is vital for families, communities, and the nation. By 2030, nearly 40 percent of all Americans living with Alzheimer's will be Black or Latino. Black Americans are twice as likely as non-Hispanic Whites to develop Alzheimer's; Latinos are 1.5 times as likely.

One way to address the problem is to make the inequities visible, which we did in 2020 by creating the National Alzheimer's Disease Index™ (NADEX), a tool that puts Medicare data about Alzheimer's on a map and then overlays demographic information. Using this NADEX, we released a [research report](#) with the Urban Institute that highlighted the importance of where people live to their brain health and found deep social, educational, environmental, and economic inequities in the 25 counties most highly impacted by Alzheimer's disease among Latino and Black Americans. The report was the centerpiece of a major *Wall Street Journal* story on the issue.

We created the UsAgainstAlzheimer's [Center for Brain Health Equity](#) in partnership with prominent national Black and Latino health provider associations to drive equity in our public health response to Alzheimer's. The Center is led by UsAgainstAlzheimer's in collaboration with the National Association of Hispanic Nurses, the National Black Nurses Association, Alzheimer's Los Angeles, and a network of community-based partners. Its work is supported in part by a five-year, \$1.5 million cooperative agreement with the Centers for Disease Control and Prevention. In 2020, the Center hosted a

series of digital events with community partners that generated more than 12 million impressions online.

Finally, UsAgainstAlzheimer's worked on the public policy front, mobilizing thousands of advocates to take action on inequities in our nation's response to COVID-19 testing and data reporting. Our Paid Leave Alliance for Dementia Caregivers organized 15 trainings for grassroots advocates to help them fight for families hit hard financially by the pandemic, making sure that COVID-related unemployment benefits covered caregivers of people with serious chronic conditions like Alzheimer's.

"We can make progress against deeply entrenched health disparities if we are purposeful and vigilant in our pursuit of equity. The Center will be critical to driving the coordinated and persistent efforts we need to deliver better brain health outcomes for all communities."

- **Dr. David Satcher**, former U.S. Surgeon General and former director of the CDC, who serves on the Center's expert advisory board

UsAgainstAlzheimer's began work in the final months of 2020 on a new easy-to-use platform to help people concerned about memory or brain health find resources and a path forward.

This work led to the successful launch in early 2021 of [BrainGuide™](#) in a major exclusive story on *Good Morning America* and extensive coverage in a segment on *Telemundo*.

UsAgainstAlzheimer's is committed to making BrainGuide relevant and accessible to all communities. The platform is free, available in English and Spanish, and can be used by phone or the Web. Additionally, we have been working with diverse partners and community groups that reach communities of color to share the BrainGuide platform. The technology is built on Amazon Web Services with in-kind and financial support from Biogen.

Voices of Alzheimer's

What matters most to people living with dementia and their care partners should drive policy, research, drug development, prevention, and access to care. In a complex disease like Alzheimer's, determining what actually matters most is not simple.

In 2020, results from the first phase of our multi-year research project were published in *Alzheimer's Research & Therapy*, a peer-reviewed publication. We and our collaborators met with the Food and Drug Administration (FDA) in February 2020 to share findings directly. We also presented three research posters at the Alzheimer's Association International Conference (AAIC), showcasing our groundbreaking findings for the field.

One real impact of this work came as the Institute for Clinical and Economic Review (ICER) developed its proposed framework to assess the comparative clinical effectiveness and value of Biogen's aducanumab therapy for the treatment of Alzheimer's disease. UsAgainstAlzheimer's included findings from the What Matters Most study and successfully urged ICER, as evidenced through several direct mentions and citations of our findings, to include real-life impacts and burden to caregivers in an updated valuation approach. This is a key win because ICER's framework will have long-lasting ramifications on how future Alzheimer's therapies are valued and reimbursed.

In addition, UsAgainstAlzheimer's, Acadia, and the Lewy Body Dementia Association jointly conducted a qualitative and quantitative study of people who have dementia with psychotic symptoms and their care partners. The results showed the unmet need for a treatment for patients with dementia-related psychosis, who have symptoms such as visual hallucinations, auditory hallucinations, and persecutory delusions. The research, highlighted in posters at the 2020 AAIC, found that these patients are unaware of what's happening or how to communicate what they are experiencing, which increases stress and anxiety and affects the daily lives of both patients and their caregivers. This research was integrated into a filing for FDA review and approval of a treatment for dementia-related psychosis.



2020 KEY ACCOMPLISHMENTS



SECURED A \$300 MILLION INCREASE IN FEDERAL FUNDING

for Alzheimer's research at the National Institutes of Health with research spending now up to more than \$3.1 billion.



HIGHLIGHTED THE IMPORTANCE

of where people live to their brain health. Issued research report, using the UsAgainstAlzheimer's National Alzheimer's Disease Index, which found deep social, educational, environmental, and economic inequities in counties most highly impacted by Alzheimer's disease among Latinos and Blacks.



PARTNERED WITH THE WORLD ECONOMIC FORUM to create the Davos Alzheimer's Collaborative (DAC) to drive a scaled global response to the Alzheimer's pandemic.



EXPANDED OUR BE BRAIN POWERFUL CAMPAIGN and welcomed actress and advocate Mandy Moore as our National Ambassador.



LED EFFORTS FOR BRAIN HEALTH EQUITY

in research and healthcare including the creation of the UsAgainstAlzheimer's Center for Brain Health Equity with funding from the Centers for Disease Control and Prevention.



BROUGHT TOGETHER NEARLY 180 ORGANIZATIONS AND LEADERS

to date - in support of a national Prevention Goal for Alzheimer's disease and related dementias.



RESEARCHED THE IMPACT OF COVID-19 ON THE ALZHEIMER'S COMMUNITY

through a series of seven A-LIST surveys. Results from these surveys led to our demanding action by the federal government and states to require COVID-19 tests for nursing home staff and residents.

NETWORKS AND COALITIONS -

Forget Me Not Play

When it comes to Alzheimer's disease, many communities – often those most at-risk – are left in the dark. The award-winning *Forget Me Not* play sheds light on confronting Alzheimer's disease head-on.

This award-winning stage play by Garrett Davis invites the audience into the life of an African American family and shows the immense impact of the disease on the primary caregiver, family, and friends. Meeting people where they are, *Forget Me Not* aims to raise awareness of brain health and the importance of intervening early to prevent and detect changes.

The *Forget Me Not* play has reached over 25,000 people across 27 communities since it was first premiered by UsAgainstAlzheimer's and Garrett Davis Productions in 2013. It is now being offered [via live stream](#) to the general public, research sites, and others hoping to draw attention to Alzheimer's disease among minority communities.

Forget Me Not has proven effective in reaching individuals, primarily those 65 and over, with information about brain health and Alzheimer's disease prevention, early detection and treatment, and the importance of minority participation in clinical trials, and even led to some signing up on the spot for a screening. Audience surveys show that more than 80 percent of play attendees requested more information about clinical trial participation and said they agreed or strongly agreed that they had gained an understanding of why older African Americans need to get involved in Alzheimer's research.



Health Equity Collaborative

UsAgainstAlzheimer's helped launch the Health Equity Collaborative – a coalition of 33 advocacy organizations fighting to advance health equity, diversity, and inclusion in healthcare. The Collaborative organized sign-on letters and digital actions to pressure the federal government to respond to the COVID-19 pandemic more equitably, generating coverage in *Newsweek* and *Politico*.

Latino Network

LatinosAgainstAlzheimer's and the USC Roybal Institute on Aging released the first-ever analysis of the economic impacts of Alzheimer's on the nation's 55 million Latino families. The seminal report *Latinos & Alzheimer's: New Numbers Behind the Crisis* found that the Alzheimer's will cost the Latino community a cumulative \$2.3 trillion by 2060. It was the most widely cited report ever issued by the USC Roybal Institute on Aging and has helped shape advocacy for culturally tailored Alzheimer's research and care supports.

In 2017, the LatinosAgainstAlzheimer's Network partnered with Disney-Pixar cultural consultant and animator Lalo Alcaraz to launch the [#WhoseYourCoco](#) campaign to promote brain health in high-risk communities. The campaign used the Oscar award-winning film *Coco* and its powerful themes around culture, memory loss, and caregiving to spark conversations in communities and online, reaching 1 million families digitally and through in-person events in Kansas City, Mo.



A DECADE OF IMPACTS

Living Well with Alzheimer's

Throughout much of the past decade, UsAgainstAlzheimer's has worked to help ensure the highest quality of life possible for those living with the disease while efforts continue to find effective treatments.

The Faith United Against Alzheimer's Coalition is a coalition of clergy, laity, and faith-based organizations promoting dementia-friendly faith communities through publication of books and educational materials that help congregations actively welcome members living with the disease and family caregivers. The Coalition's work has resulted in continued worship for those with dementia, improved caregiver support, and enabled faith communities across the country to become key sources for Alzheimer's and brain health education.

In 2015, UsAgainstAlzheimer's spurred creation of Dementia Friendly America (DFA), a national network of states, counties, cities, towns, and local programs that are ensuring people living with dementia can live full lives in their own communities. DFA provides tailored educational guides and technical assistance so that banks, financial and legal services, first responders, police, hospitals, libraries, small businesses, faith communities, and other important sectors of a community can support people with dementia.

Bringing Women's Voices to the Forefront

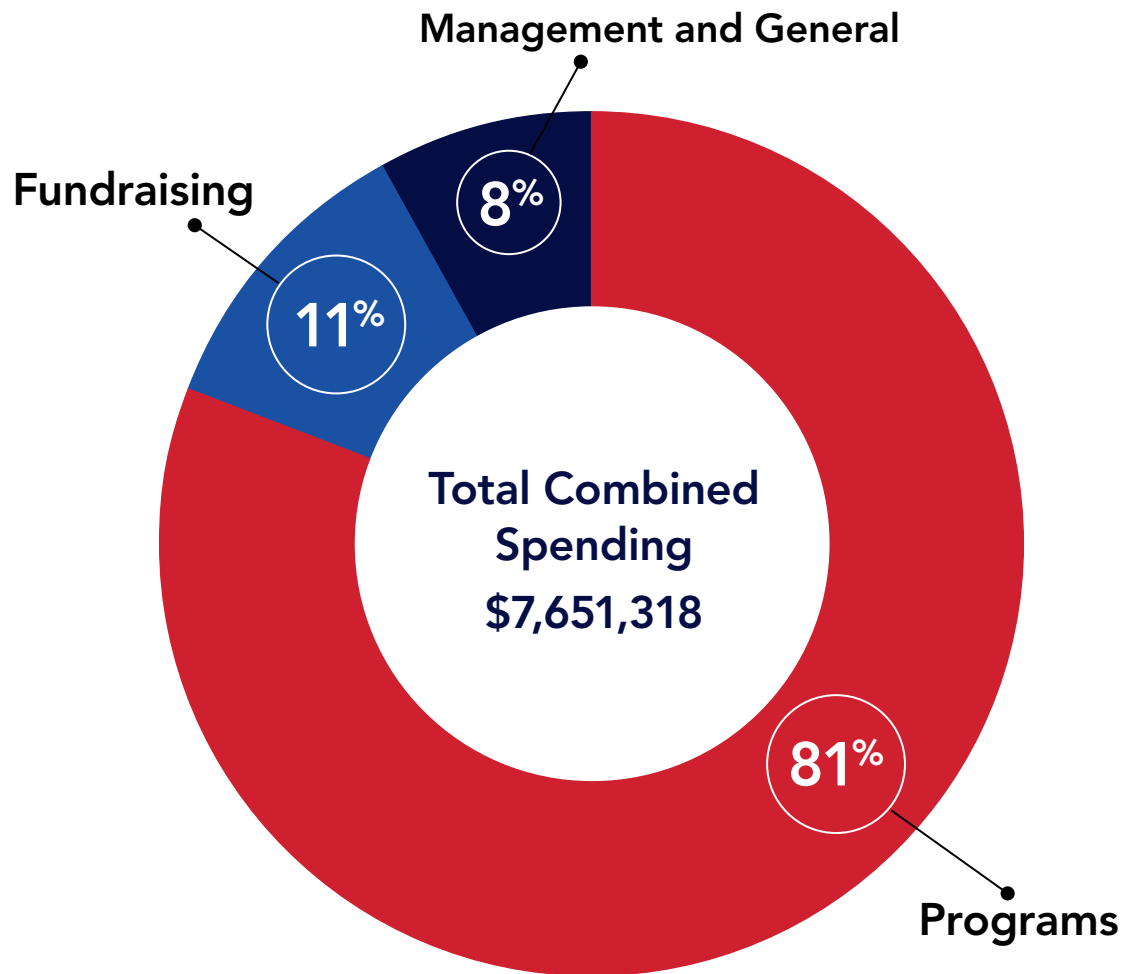
WomenAgainstAlzheimer's (WA2) has broken the silence on the disproportionate impacts of Alzheimer's disease on women. We have established WA2 as the premier voice on women and Alzheimer's – galvanizing two dozen women executives that speak out on brain health and an Honorary Committee of influential Brain Trust women, including Honorary Chair Laura Bush and brain health Ambassador, Mandy Moore, that use their platforms to raise awareness.

Our nationwide survey of women ages 34-65 revealed important data that fueled the creation of our Be Brain Powerful Campaign to empower women to start talking about their brain health. It found that 68 percent of women were interested in learning more about measures of brain health and the same percentage wanted to learn how to discuss the topic with their provider.

Since the launch of our campaign, more than 20,000 women have taken our 30-day brain health challenge. To date, post-survey results show 70 percent report talking to their doctor about brain health and 60 percent have increased focus on daily habits related to brain health.



FINANCIALS



COMBINED STATEMENT OF ACTIVITIES AND CHANGE IN NET ASSETS

FOR THE YEARS ENDED DECEMBER 31, 2020 AND 2019

	2020	2019
REVENUE AND SUPPORT	Total	Total
Contributions and grants	\$ 9,230,654	\$ 8,132,926
Special events revenue, net of expenses	99,138	54,553
Program service revenue	350,032	-
Investment income, net	8,392	9,425
Contributed services and materials	-	14,216
Total revenue and support	9,688,217	8,211,120
EXPENSES	Total	Total
Program services	6,167,115	7,401,235
Supporting services:		
Fundraising	850,462	702,008
Management and general	633,741	576,555
Total supporting services	1,484,203	1,278,563
Total expenses	7,651,318	8,679,798
Change in net assets	2,036,898	(468,678)
Net assets at beginning of year	4,211,536	4,680,214
NET ASSETS AT END OF YEAR	\$ 6,248,434	\$ 4,211,536

A complete copy of the financial statements audited by Gelman, Rosenberg & Freedman is available upon request by contacting stopalz@usagainstalzheimer.org.



**Changing the
world in the
fight against
Alzheimer's.**

Vint and Sigrid Cerf

Vint and Sigrid Cerf know all too well the effects of dementia and, given Vint's background as a scientist often called "a father of the Internet," they understand the value of research to find breakthroughs.

Vint's mother, Muriel, experienced dementia for the last 15 years of her life. Like many people, Muriel never had an official Alzheimer's diagnosis, but her memory loss steadily increased. When she passed away at 98, Muriel no longer recognized family, believed she was a young girl living in her native Montreal, and rejected any notion that she was married or had children of her own.

So, when UsAgainstAlzheimer's co-founder George Vradenburg asked Vint and Sigrid Cerf to get involved with UsAgainstAlzheimer's, "he did not need to push very hard," Vint recalled.

Vint and Sigrid are eager to understand the origins of this condition and whether it can be prevented. "I think most people would like to know whether they are at risk and whether there is anything therapeutic to be done to ward off onset or to blunt the worst-case scenarios," Vint said.

A renowned engineer and scientist, Vint understands that Alzheimer's is a complex problem that is hard to solve. Further research is necessary to help find answers to questions about the root cause of the disease including potential autoimmune interactions, and how advances in technology, like Functional Magnetic Resonance Imaging (fMRI) and Positron Emission Tomography (PET) scans, help to find early indicators of onset or to measure effectiveness of new therapies.

That's why the Cerfs believe it is important for UsAgainstAlzheimer's to continue advocating for increased research funding at the National Institutes of Health and other research institutions. And, because Alzheimer's is a global issue, the Cerfs are excited about the partnership between the UsAgainstAlzheimer's Global CEO Initiative on Alzheimer's Disease and the World Economic Forum to launch the Davos Alzheimer's Collaborative to attack the problem around the world.

Active donors since 2017, Vint and Sigrid admire the organization's dedication to the cause. They are proud to be Leadership Council members whose philanthropy helps UsAgainstAlzheimer's in its efforts to increase funding for research and to help families and caregivers access available resources until there are more effective treatments and, ultimately, a cure.



Mary Katie Ward and the Ward Family

Chris Ward greeted every day, arms wide open, with a smile on his face. It was part of his enthusiastic charm and love for life.

But in 2000, when Chris was 56, his wife, Katie, started to notice something was off. As a teacher for hearing-impaired students, she recognized slight differences in the language and behaviors of her husband, an intellectual and gregarious superintendent of a large public school district. While Katie internally processed what might lay ahead, it would take years to get a diagnosis of early onset Alzheimer's disease.

Katie did all she could to protect and guide, keeping Chris active in his retirement while working to educate herself on the possibilities of treatments and how to be active in the fight for a cure.

That is when Katie discovered UsAgainstAlzheimer's. She was inspired by the leadership of patient-service activists and drawn to our advocacy for government and science to work together to change the course of Alzheimer's. Katie made her first donation to UsAgainstAlzheimer's in 2016, and the Wards have been activists and supporters ever since.

Katie was particularly moved by Meryl Comer's experience as a caregiver. "Meryl is living my life," she reflected, and Meryl's work to keep the voice of those living with Alzheimer's – and their caregivers – front and center resonated with Katie.

Caregiving is an important role shared by the entire Ward family, including 13 grandchildren. Spending time with Papa is a gift none of them overlook. As granddaughter Maggie was earning her driver's permit, Katie saw the beauty in having Papa serve as the licensed adult. Maggie's college essay recounted those moments with Papa, running errands and watching him light up with recognition driving through old neighborhoods – yet not remembering if they had picked up the groceries they were sent to buy.

The Ward grandchildren celebrate Papa and each finds a personal way to remain part of his life. Whether it is visiting his care facility to build a snowman outside the window during the pandemic, hosting sports-oriented fundraisers for Alzheimer's, writing long handwritten letters across the miles, or fondly recalling Papa's amazing pancakes, Papa is with them.

Katie recognizes the essential role of professional caregivers at the facility where Chris now lives, and she makes a monthly contribution to UsAgainstAlzheimer's in their honor.

But the true honor belongs to UsAgainstAlzheimer's for the loyal support of the Ward family. We thank them for sharing their lives and stories with UsAgainstAlzheimer's.



AARP

UsAgainstAlzheimer's was thrilled to recognize AARP with our 2020 Corporate Champion Award during the Trish Vradenburg Annual Gala in recognition of its work on behalf of all people living with or concerned about dementia.

AARP is highly focused on reducing risks for cognitive decline and empowering people with, or at risk of, cognitive decline to choose how they live as they age.

During the 2020 virtual Gala, AARP collaborated with UsAgainstAlzheimer's to showcase a tribute wall of personal stories from around the country about whom people were fighting for and what gives them hope in the battle against Alzheimer's. These stories helped us honor all those engaged in the movement, especially those most vulnerable to the risk of cognitive decline.

AARP has been a long-standing partner of UsAgainstAlzheimer's; its leadership has been engaged in many areas of our work including membership on the Steering Committee of our Brain Health Partnership and Women's Leadership Council to advance our collective work in early intervention. We have partnered with AARP's Diversity, Equity, and Inclusion team to deliver culturally tailored brain health education to AARP's members and the public through tele townhalls and presentations at diversity conferences across the country.

Through AARP's stayingsharp.org website, the Global Council on Brain Health, the Women's Brain Trust chaired by First Lady Laura Bush and the Be Brain Powerful campaign, AARP continues to show its commitment to developing effective solutions and helping people live well with dementia.



TRISH VRADENBURG GALA



NATIONAL ALZHEIMER'S SUMMIT



THANK YOU TO OUR DONORS

UsAgainstAlzheimer's is grateful to the many generous donors whose philanthropy makes the work we do possible. In addition to the ongoing visionary support from our Founding Chairman George Vradenburg, we are proud to recognize the following supporters:

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This list reflects donors giving \$1,000 or more between January 1-December 31, 2020. If you have questions, please contact the Anne Staunton Adams in the Development Department at 202-796-3397.

Gifts in Tribute

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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Meryl Comer	Robert E. and Carol Hamilton	Daniel Nicholson	Robert and Alice Wells
Mollie I. Comer	Jim Heiselmann	Daniel E. Nyberg	Ralph Willey
Dementia Friendly Faith Village Connections; Mia Chester and Dr. Fayron Epps	James John Hoard	Lola O'Brien	Bill and Edie Wilson
Andrew P. Dickerson	Cye Jacobson	Liam Conor O'Clisham	Ken Winkler
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Meryl Comer

Meryl Comer, a founding Board member of UsAgainstAlzheimer's, has long advocated for people living with Alzheimer's disease and their caregivers. It is a role she knows intimately from her 24-year journey caring for her husband and her mother.



A LEGACY OF ADVOCACY LEADERSHIP

- Co-founder and chair of the Global Alliance on Women's Brain Health
- President and CEO of the Geoffrey Beene Foundation Alzheimer's Initiative (2007-19)
- Member, National Institutes of Health (NIH) National Advisory Council on Aging
- Member, 2009 bipartisan Alzheimer's Study Group, charged with presenting a National Strategic Plan to Congress that led to the creation of the national goal to effectively treat and prevent Alzheimer's by 2025

Dr. Harvey Gralnick, who had served as chief of hematology/oncology at the National Institutes of Health, was diagnosed with early onset Alzheimer's disease at age 58. Meryl spent more than two decades caring for him at home as the disease progressed until his death in February 2020. At the same time, Meryl cared for her mother, Mollie I. Comer, whose own battle with Alzheimer's ended in August 2019.

As a former broadcast journalist, Meryl was determined to set the record straight about Alzheimer's. In her 2014 *New York Times* best-seller, *Slow Dancing with a Stranger: Lost and Found in the Age of Alzheimer's*, she wrote: "No one deserves to be forgotten in life when their disease has no cure. I knew that no matter what I did for my husband and mother, Alzheimer's was going to ultimately win out at home. Advocacy saved my life."

Along with Trish Vradenburg, Meryl co-founded and launched WomenAgainstAlzheimer's with a global research challenge that posed the question "Does Sex Matter?" to explore why women are disproportionately twice as likely to get the disease. Today, the issue of sex-based research is widely viewed as the gateway to precision medicine.

Meryl led UsAgainstAlzheimer's in its engagement with the Patient-Centered Outcomes Research Institute (PCORI) Alzheimer's Patient-Caregiver Research Network. This work sought to validate the importance of tracking the caregiver's health as well as that of the patient to assess where interventions were most needed and supportive.

The PCORI work led UsAgainstAlzheimer's to establishing the A-LIST® in 2016. An active, online community of 8,000 people living with or caring for someone with the disease, A-LIST members respond to surveys on a range of topics, providing insights for researchers and health systems mapping the trajectory of the Alzheimer's journey. Everyone has a story to tell, but the power lies in the combination of evidence-based research and open commentary that produces what the A-LIST calls "data with soul."

Looking back, Meryl is proudest of how UsAgainstAlzheimer's built its networks to respect cultural diversity, its reputation for taking on the tough issues, and its record forging a number of "firsts" as a nonprofit whose power base and success she credits to leadership and collaborations.

"Once you have seen Alzheimer's up close and personal, you are changed forever," Meryl said. "The global COVID-19 pandemic gave the world a taste of the extreme challenges of isolation, vulnerability, and fear of the unknown that haunt the daily lives of every Alzheimer's family. It's also been a wake-up call to rethink our life priorities and commit to keeping our bodies and brains healthy until the science catches up. Our resilience has been tested and new disease-modifying therapies are on the horizon. Hope doesn't get us to a cure. That's why we're in this fight."

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