

UsAgainstAlzheimer's

2022 ANNUAL REPORT

*Change
Starts with*

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*Driving
meaningful*

change



— CHAIRMAN'S LETTER —

Dear Supporters and Stakeholders,

I am delighted to present to you the annual report for UsAgainstAlzheimer's, highlighting our remarkable journey in 2022, a historic year that has set us on a path toward a highly promising and successful 2023.

We are proud to be conveners, policy experts, vocal advocates, and visionary leaders on a mission to combat Alzheimer's disease. Our team's tireless dedication and unwavering commitment to this cause have yielded significant achievements and, together, we have made a substantial impact in the fight against this devastating illness.

One of the most significant moments of the past year was when Medicare announced its plans to deny coverage for Alzheimer's drugs. In response, we swiftly brought together patients, leading scientists, and other organizations in our field to pool our collective resources and fight for access to vital disease-modifying treatments.

In line with our commitment to empowering healthcare professionals and improving patient care, we took a major step forward by launching the Brain Health Academy. In partnership with other leaders in the field, we are equipping healthcare and wellness professionals with the essential resources they need to engage in meaningful conversations with their patients about Alzheimer's disease, including ways they can reduce their risk of developing dementia.

Our influence extended to the highest levels of government as we worked collaboratively with the administration and Congress to create ARPA-H (Advanced Research Projects Agency for Health). This pivotal initiative will accelerate

groundbreaking research and innovation in the field of Alzheimer's disease, bolstering our collective efforts to find effective treatments and, ultimately, a cure.

Maintaining our commitment to brain health equity, we successfully worked with members of Congress to pass a bill directing the National Institute on Aging (NIA) to work with the Alzheimer's Disease Research Centers and other stakeholders to promote clinical trial participation among underrepresented populations and lower the barriers for enrollment.

Furthermore, our persistent advocacy efforts led to a major increase in funding for Alzheimer's research. With an additional \$226 million, new research will drive forward scientific advancements and support innovative approaches to treat and end Alzheimer's.

Like all annual reports, this document was completed well after 2022 concluded, giving us an opportunity to look back and chronicle the year's biggest moments. But even as I write this letter, 2023 is already shaping up to be a pivotal year for our movement. The Food and Drug Administration granted full approval of Leqembi, a drug that slows the progression of Alzheimer's, and on the same day, Medicare agreed to cover it with some conditions. And Medicare also announced it will now cover more than one PET scan for Alzheimer's patients.

These accomplishments, though significant, only scratch the surface of what we have achieved together. Every step forward was possible because of the dedicated and passionate people who refused to accept defeat and remained united to pursue our common goal.

Change starts with *Us*. As we venture into 2023, we do so with renewed determination and hope.

On behalf of UsAgainstAlzheimer's, I extend my deepest gratitude for your unwavering support, dedication, and belief in our mission. Together, we have proven that change is not only possible but inevitable when we stand united against Alzheimer's.

With gratitude,

George Vradenburg

*Chairman and Co-Founder
UsAgainstAlzheimer's*



Making a lasting impact



- CHIEF OPERATING OFFICER'S LETTER -

Dear Supporters, Partners, and Friends,

As we reflect on the past year, it is with great enthusiasm that we share the progress and achievements of UsAgainstAlzheimer's. In the face of unprecedented challenges, 2022 has laid a strong foundation, positioning us to embrace future challenges with renewed determination and vigor. The contents of this annual report demonstrate our commitment to driving meaningful change, fostering innovation, and making a lasting impact on the lives of those affected by Alzheimer's disease.

This has been a pivotal year for our movement, and we are harnessing the lessons learned to inform the work ahead. To that end, we are thrilled to announce the development of a new strategic plan, set to be unveiled in 2023. This plan stands as a testament to our commitment to addressing the multifaceted nature of Alzheimer's disease head-on. Our focus will be threefold: prevention and risk reduction, early detection and diagnosis, and equitable access to treatments. By placing equity at the center of our strategy, we are building on one of our core values as an organization: ensuring no one is left behind in our pursuit of a world without Alzheimer's.

We are particularly proud of the strides made by BrainGuide and the Brain Health Academy. These initiatives have equipped individuals and communities with actionable information while fostering a proactive approach to brain health. Building on these achievements, we remain steadfast in our fight for patient access to promising new drugs. One of our highest priorities is securing Medicare coverage for these treatments, ensuring that the hope of these breakthroughs is not out of reach for those who need it most.

In the journey toward progress, we recognize our responsibility extends beyond merely keeping up the fight. Patients and their loved ones are counting on us to capitalize on the momentum we have generated. This is our moment – a pivotal juncture where our dedication, collaborations, and achievements have positioned us to effect transformative change.

In closing, we extend our heartfelt gratitude to each one of you – our dedicated supporters, partners, and friends. Your commitment fuels our progress and emboldens our mission. Together, we will continue to make a profound impact on the lives of those affected by Alzheimer's.

Sincerely,

Russ Paulsen
Chief Operating Officer
UsAgainstAlzheimer's



Prevention & Early Intervention

UsAgainstAlzheimer's is tackling Alzheimer's disease head-on. One of our key strategies is focusing on prevention and early intervention. **Alzheimer's disease is the sixth leading cause of death in the United States.** While there is no cure for Alzheimer's, there are disease-modifying treatments under development that slow its progression, particularly for patients in the early stages of the disease. At the same time, scientific evidence continues to grow that we can reduce our own risk of ever developing Alzheimer's. Our **Brain Health Academy™**, **BrainGuide**, and **Faith in Action** programs aim to provide health care providers, community leaders, and individuals themselves with real-world solutions to promote brain health and encourage good conversations between patients and their providers.



The Brain Health Academy™

Alzheimer's is not a natural part of aging, and there are things we can all do to reduce the risk of developing this terrible disease. In fact, studies show that reducing the number of people with Alzheimer's risk factors by 10-15% each decade could lower the number of people living with dementia by one million or more by 2050. Healthcare and wellness professionals play a key role in spreading the word to the public and the people they serve. That's why Brain Health Academy was launched in May 2022: to provide those professionals with expert-led video courses, written materials, and interactive tools that demystify the science behind Alzheimer's prevention. The emphasis is on promoting healthy lifestyle choices, including nutrition, exercise, sleep, and other interventions that have been scientifically proven to contribute to better brain health. More than 2,200 people participated in this year's six sessions.

Building on this success, UsAgainstAlzheimer's plans to offer six additional Brain Health Academy courses in 2023 covering obesity, diabetes, hearing loss, depression, smoking, and alcohol use.



BrainGuide

Last year, UsAgainstAlzheimer's launched BrainGuide as a tool to help people better understand and take control of their brain health. BrainGuide isn't just a passive repository of information; it actively engages users who may be concerned about their brain health, or that of a loved one, with a confidential memory questionnaire they can complete over the phone or online, in English or Spanish. Once complete, users are provided with tailored information and resources to help them determine what next steps they may want to take.

BrainGuide has received more than 510,000 pageviews by 228,000 web visitors, and nearly 130,000 questionnaires have been completed. Of the completed questionnaires, 81% were taken by the person listed, while 19% were completed for someone else.

Faith in Action

Faith leaders and organizations are important messengers in the fight against Alzheimer's, which is why UsAgainstAlzheimer's launched our Faith in Action program to reach Black Americans who are disproportionately impacted by the disease. This initiative mobilizes faith communities, fostering an environment of understanding, support, and action through direct outreach and partnerships.

Faith in Action equips faith leaders nationwide with the tools and resources they need to bring valuable brain health information to their congregations. Using a combination of webinars and physical resources like our 'Brain Health in a Box,' we help faith-based organizations raise Alzheimer's awareness, encourage conversations about brain health, and reduce stigma.



BRAIN HEALTH ACADEMY KEY PERFORMANCE INDICATORS (KPIs) 2022-2023

Participation			
KPI	2022 Target	2022 Results	2023 Target
Total number of unique person registrations for all sessions	n/a	3,100	3,400
Average number of registrants per seminar (not unique persons)	400	1,102	1,200
Number of Nurse Fellows recruited and trained	10	12	10
Number of healthcare professionals trained by Nurse Fellows	250	260	250

Satisfaction			
KPI	2022 Target	2022 Results	2023 Target
% of participants who agree or strongly agree that course content was current	70% or more	98.97%	95%
% of participants who agree or strongly agree that course material was presented efficiently	70% or more	98.08%	95%
% of participants who agree or strongly agree that course material was appropriate to education	70% or more	96.99%	95%
% of participants who agree or strongly agree that course material was relevant to practice	70% or more	92.40%	95%
Net Promoter Score (NPS above 50= Excellent; NPS above 80 = World Class)	Above 50	63.66	Above 60

Speeding Treatments

UsAgainstAlzheimer's is transforming the landscape of Alzheimer's disease through legislative advocacy, dedicated program work, and unwavering support for the patients and families impacted by this devastating condition. As we stand on the cusp of groundbreaking advancements in Alzheimer's treatment, our resolve to secure better funding and improved access to these life-changing therapies has never been stronger.

The emergence of new disease-modifying treatments has ignited a renewed sense of hope within our community. As these potential therapies come to the forefront, we are laser-focused on ensuring equitable

access to care, and that patients, caregivers, and their doctors are the ultimate decision makers in their treatment plans.

We have reached a pivotal moment. The horizon shines with new possibilities, and UsAgainstAlzheimer's remains steadfast in our pursuit of progress. Our work on Medicare coverage, the creation of the Advanced Research Projects Agency-Health (ARPA-H), and increased research funding reflects our dedication to creating a brighter future for those impacted by Alzheimer's.

Medicare Coverage of FDA-Approved Alzheimer's Treatments

This spring, the Centers for Medicare and Medicaid Services (CMS) issued a National Coverage Determination (NCD), effectively denying Medicare coverage not only for a single drug but for an entire drug class. As a result, only people participating in additional, CMS-approved clinical trials can access new treatments in this drug class—even if the drugs differ from the one Medicare reviewed. Individuals who cannot participate in trials because they live too far away from an approved trial site or are deemed ineligible for a trial are forced to pay out-of-pocket or go without treatment.

UsAgainstAlzheimer's continues to lead the charge against this overly broad NCD with a full-throated initiative including meetings with approximately 100 Congressional offices. We educated members of Congress about the negative impact of the NCD, particularly on Black and Latino people, those living in rural communities, and seniors on fixed incomes. UsAgainstAlzheimer's is also collaborating with other stakeholders as we demonstrate a united front and amplify the voices of the health community as a whole. This concerted action has even led to the introduction of a bill that would prohibit Medicare from refusing to cover drugs before they have seen the evidence.

Advanced Research Projects Agency for Health (ARPA-H)

Recognizing the need for transformative research and innovation in Alzheimer's disease, UsAgainstAlzheimer's worked alongside stakeholders to establish and fund the Advanced Research Projects Agency for Health (ARPA-H). UsAgainstAlzheimer's role in shaping legislative provisions paved the way for a \$1 billion allocation for ARPA-H in 2022.

Additional Legislative Accomplishments

Working with members of Congress, UsAgainstAlzheimer's played a key role in passing legislation important to speeding access to treatments, particularly for populations that are most heavily impacted. Specifically, we helped secure a \$226 million increase in research funding, promoted clinical trial diversity through legislation, and strengthened the Food and Drug Administration's (FDA) Accelerated Approval Program to help get groundbreaking treatments to patients faster.



2022 LEGISLATIVE ACHIEVEMENTS:

- :: Educated Members of Congress about the detrimental impact of denying Medicare coverage of Alzheimer's drugs.
- :: Helped create and secure \$1B in funding for ARPA-H.
- :: Legislation to increase racial and ethnic diversity in clinical trials.
- :: Strengthened FDA's Accelerated Approval Program.

Health Equity & Access

Women make up two-thirds of Alzheimer’s cases. Black Americans are twice as likely than whites to develop Alzheimer’s. Latinos are 1.5 times more likely to develop the disease. At the same time, these groups experience greater barriers to brain health care, including inadequate access to an early and accurate diagnosis that maximizes the effectiveness of treatments and participation in research.

As the U.S. population gets older and more diverse, it is more important than ever to focus on creating a healthcare system that works for everyone, regardless of who you are or where you live.

Addressing Public Health and Awareness

In 2021, UsAgainstAlzheimer’s established the Center for Brain Health Equity (the Center), supported in part by funding from the Centers for Disease Control and Prevention (CDC). 2022 was a pivotal year for the Center. Its accomplishments include:

- Creating a culturally tailored Brain Health Equity messaging guide and toolkit, cobranded with the CDC. These resources reached more than 300 partners dedicated to brain health equity on the local, state, and national levels, along with organizations focused on brain health equity and Alzheimer’s care.
- Reaching 1.6 million Latinos and African Americans to raise brain health awareness, promote risk reduction and early detection, and reduce stigma.
- Using data generated from the UsAgainstAlzheimer’s National Alzheimer’s Disease Index (NADEX), the Center created 82 customized congressional reports for members of the Congressional Black Caucus, Congressional Hispanic Caucus, and Congressional Alzheimer’s Task Force. Additionally, the insights from the NADEX data were prominently featured in a [congressional briefing](#) coordinated by the Center in September 2022.
- In June 2022, UsAgainstAlzheimer’s Brain Health Academy launched with its first seminar on “Understanding Inequities in Alzheimer’s and Other Dementias.” Working alongside the National Association of Hispanic Nurses (NAHN) and the National Black Nurses Association (NBNA), and the CDC, this seminar was viewed by 692 healthcare and wellness professionals.
- Partnering with NAHN and NBNA to launch UsAgainstAlzheimer’s Brain Health Equity Nurse Fellowship, aimed at addressing brain health disparities at the local level. Through a series of community conversations with peers, the first cohort of fellows reached an additional 300 nursing professionals in their communities.

UNDERSTANDING THE LANDSCAPE

- By 2030, nearly 40 percent of Americans living with Alzheimer’s will be Black or Latino.
- Medicare’s decision to effectively deny Medicare coverage of Alzheimer’s drugs exacerbates disparities as patients of color are already less likely to gain access to such treatments in clinical trials.
- Black Americans are twice as likely as whites to develop Alzheimer’s. Latinos are 1.5 times as likely to develop the disease.

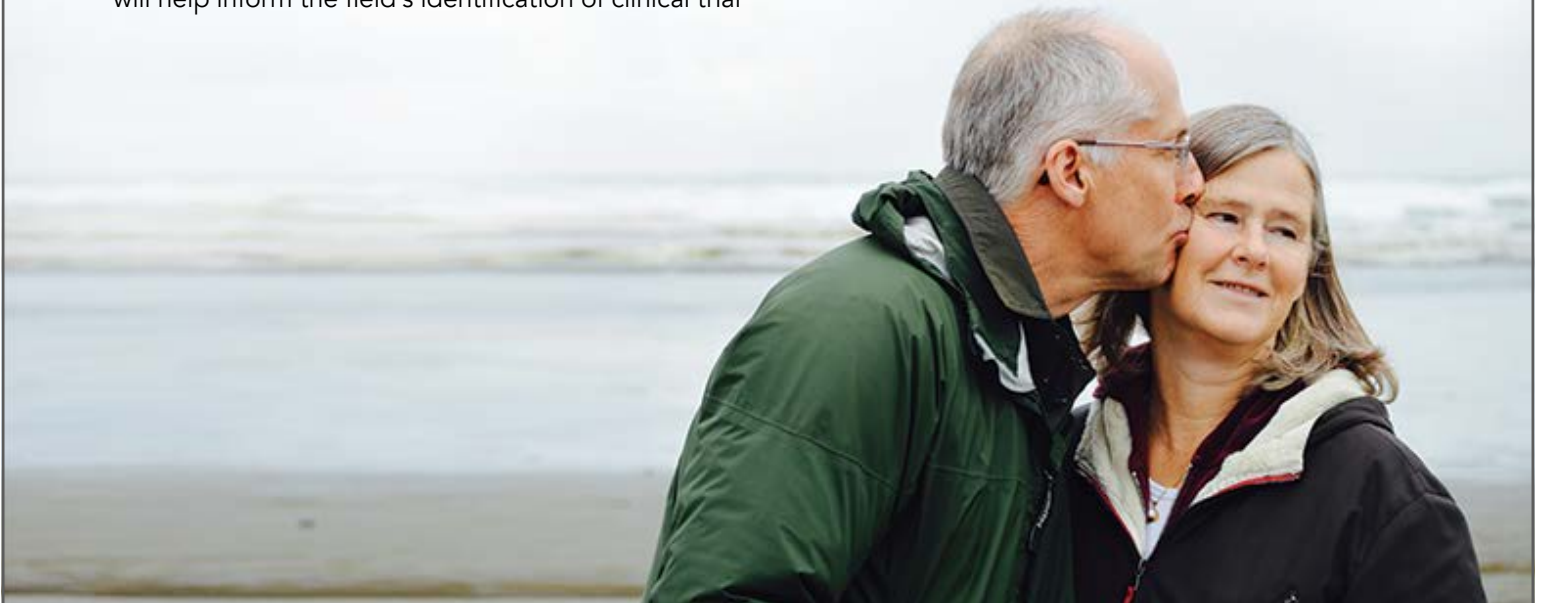
Patients & Caregiver Voices

The needs of people living with Alzheimer's, those who care about them, and those who want to avoid this disease drive our work. Throughout 2022, UsAgainstAlzheimer's continued to gather 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, and healthcare providers. These important efforts have informed and will continue to inform FDA and CMS decisions on approval and access to new therapies. Additionally, UsAgainstAlzheimer's has used these stories to advocate for a stronger understanding of the value of new treatment with organizations such as the Institute for Cost Effectiveness Research (ICER).

In 2022, the Alzheimer's Disease Patient and Caregiver Engagement (AD PACE) initiative continued to deliver new Alzheimer's patient experience data through the second round of the seminal What Matters Most® Research Program. Through this public-private partnership, UsAgainstAlzheimer's has continued to advance the understanding of the symptoms and impacts of Alzheimer's that are most concerning to patients and caregivers across the Alzheimer's lived experience. These first-of-their-kind data will be available in the AD PACE Data Commons, where they will help inform the field's identification of clinical trial

endpoints that capture clinically meaningful outcomes from the perspective of patients and caregivers. These accomplishments set the foundation for the second round of the What Matters Most™ (WMM) Research Program that will continue into the next two years.

UsAgainstAlzheimer's also connects with the Alzheimer's community directly through the A-LIST®, an online group of more than 11,000 people living with Alzheimer's disease and related dementias, current and former caregivers, and healthy adults concerned about brain health. Their needs, preferences, and insights are shared through frequent online surveys that are reported out as data for the A-LIST What Matters Most Insight Series Research Study. In 2022, the A-LIST expanded its partnerships with several third-party academic institutions (Mayo Clinic, Tufts University, Center for Brain Health, University of Dallas, and UsAgainstAlzheimer's Brain Health Academy) who find value in the A-LIST's agility to test theoretical designs, recruit for studies, and successfully collaborate in multi-year National Institutes of Health and National Institute on Aging grants and consortia. Current studies focus on a range of topics, including incidents of paradoxical lucidity, caregiver health-related quality of life, sibling-caregiver interactions, and brain health.



INDIVIDUAL DONOR SPOTLIGHT

The Honorable Ann Brown



In 2010, George and Trish Vradenburg, fueled by frustration over the slow progress in the Alzheimer's movement, founded UsAgainstAlzheimer's. They envisioned a grassroots momentum infused with passion and purpose, capable of propelling innovative solutions and fostering greater urgency and collaboration from government, industry, and the scientific community. Among the dedicated supporters who believed in and invested in their vision from the outset, the Honorable Ann Brown emerged as a crucial figure, becoming an integral part of the "Us" in UsAgainstAlzheimer's.

Ann's belief and investment were pivotal, especially since she was no stranger to the impact that grassroots advocacy organizations can make. Ann herself founded a nonprofit grassroots group to fight for consumer safety issues under the umbrella of Americans for Democratic Action. The organization worked with experts to conduct an annual toy safety survey, which gained nationwide awareness and helped keep countless kids safe from dangerous toys. As a successful and fierce consumer advocate, she served as vice president of the Consumer Federation of America and as chairman of the board of the consumer advocacy group Public Voice. During the Clinton administration, Ann served for over seven years as Chairman of the U.S. Consumer Product Safety Commission, leading numerous children's safety initiatives.

Ann has watched as many friends struggle with Alzheimer's or cared for someone living with it. But she believes that it is a disease that can be treated, prevented, and eventually cured. She says, "I want to do what I can to get to a victory. And I believe we can do it – together."

The growth and success of UsAgainstAlzheimer's would not have been possible without the early support and ongoing generosity of the Honorable Ann Brown. But the true honor belongs to UsAgainstAlzheimer's for her belief in the vision of a world where no one is lost to Alzheimer's.

DONOR SPOTLIGHT

Gates Ventures

Established in 2009, Gates Ventures' mission is to catalyze innovations that solve global problems and improve the lives of the world's poorest people. The organization works to craft investment approaches that help accelerate solutions in global health and development, connecting health and economic empowerment solutions with the people who need them most. These achievements occur by incubating products, advocating for important causes, engaging with global organizations, and managing venture investments.

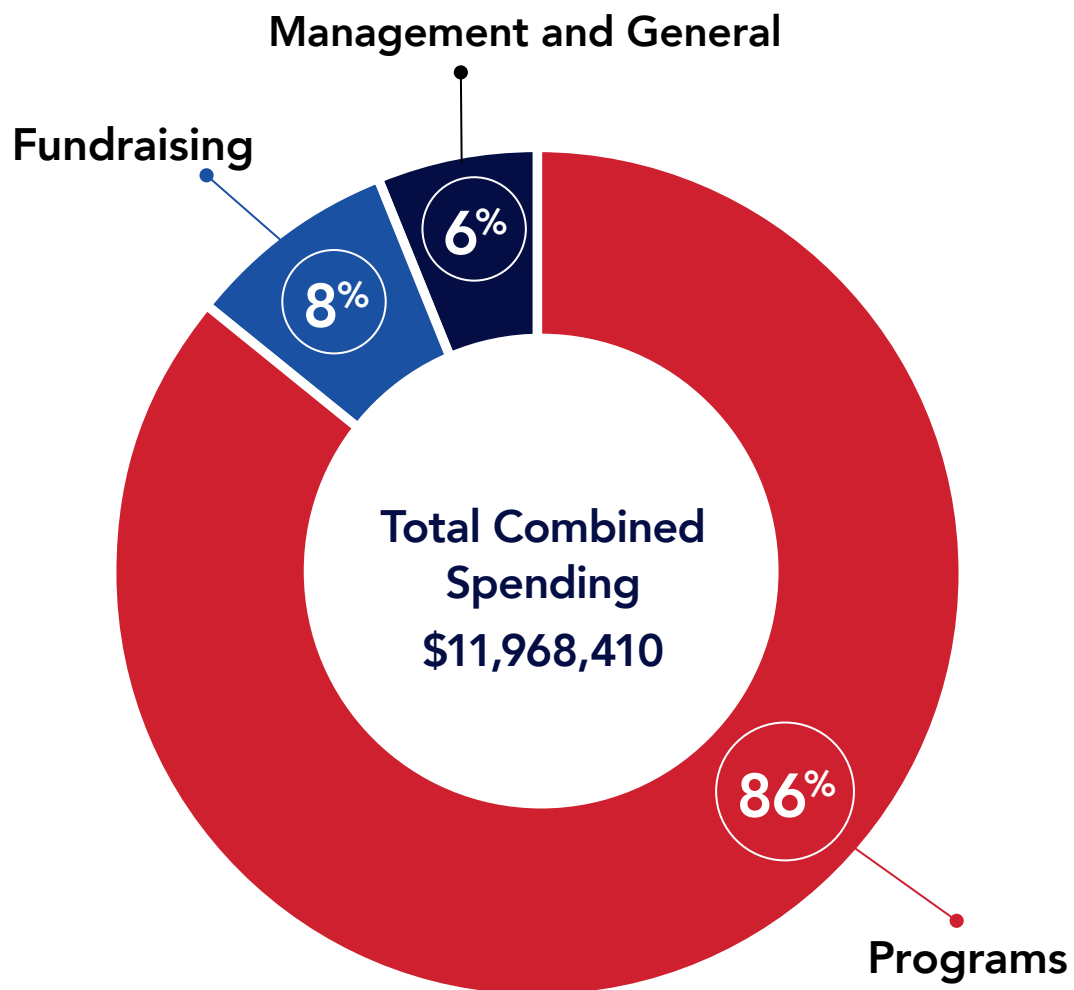
Beginning with an initial investment in 2020, Gates Ventures has graciously supported UsAgainstAlzheimer's by helping to expand our efforts across the three strategic pillars — prevention and brain health, early detection and diagnosis, and access to treatments — that guide our work. The partnership with Gates Ventures has led to some notable outcomes in our mission, including (1) making progress to increase early detection of

Alzheimer's disease by ensuring that older adults receive cognitive screening during their Medicare Annual Wellness Visit with a screening tool identified by the National Institute on Aging; (2) educating Capitol Hill champions to continue engaging with the Centers for Medicare & Medicaid Services; (3) encouraging further policy changes that favor early detection of Alzheimer's disease; and (4) increasing healthcare providers' awareness, knowledge, and capacity around early detection and risk reduction of the disease especially among Blacks, Latinos, and women through our Brain Health Academy.

UsAgainstAlzheimer's values its partnership with Gates Ventures. The impact of the work achieved through this partnership is a true testament to the alignment of shared values and goals, and for this, UsAgainstAlzheimer's is grateful.



FINANCIALS



COMBINED STATEMENT OF ACTIVITIES AND CHANGE IN NET ASSETS

For the Years Ended December 31, 2022, and 2021

	2022	2021
REVENUE AND SUPPORT	Total	Total
Contributions and Grants	\$ 11,346,292	\$ 11,238,115
Program Service Revenue	1,000,810	2,178,400
Special Events Revenue, Net of Expenses	101,871	90,206
Investment Income, net	24,991	(144)
Other Revenue	4,980	5,925
Total Revenue and Support	12,478,944	13,512,502
EXPENSES	Total	Total
Program Services	10,325,939	7,704,956
Supporting services:		
Fundraising	\$ 910,409	\$ 907,453
Management and General	732,062	941,834
Total Supporting Services	1,642,471	1,849,287
Total Expenses	11,968,410	9,554,243
OTHER ITEMS	Total	Total
Extinguishment of Debt	–	\$ 64,175
Transfer of Net Assets	–	(2,251,108)
CHANGE IN NET ASSETS	510,534	1,771,326
Net Assets at Beginning of Year	8,019,761	6,248,435
NET ASSETS AT END OF YEAR	\$ 8,530,295	\$ 8,019,761

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

National Alzheimer's Summit

Alzheimer's Prevention, Detection, and Treatment: The Power of Us

The 2022 National Alzheimer's Summit brought together international leaders working to end Alzheimer's to discuss solutions to the most pressing challenges facing our movement. The all-virtual event was an opportunity for participants to interact with thought leaders as we convened experts in advocacy, policy, research, and industry. Over the course of two half-days, our sessions covered the latest scientific developments in prevention, early detection, and treatment with a focus on ensuring more equitable access to innovations for everyone, especially women and people of color who are disproportionately affected by Alzheimer's. Highlights of the Summit included fireside chats with both Susan Collins, U.S. Senator from Maine, and Anna Eshoo, U.S. Representative from California. Special thanks to our sponsors, Biogen, Eisai, Eli Lilly, Edward Jones, Genentech, Alzheimer's Drug Discovery Foundation, Brain AMPM, Faegre Drinker, Home Instead, Lynda Everman and Don Wendorf, Corium, BrightFocus Foundation, Roche, Pathstone, Acadia, High Lantern Group, Lundbeck, Tetra and Creative Planning and all the donors and supporters who made this event possible.





2022 Dunk Alzheimer's Basketball Tournament

KidzEndAlz and Tru2Form Hoops hosted the 2022 Dunk Alzheimer's basketball tournament in Bethesda, Maryland. KidzEndAlz and the Dunk Alzheimer's basketball tournament were founded by teenagers Natalie and Max Veksler in 2019 to raise money and awareness for Alzheimer's disease. These two know the impact of Alzheimer's all too well, having seen more than one family member battle the disease. Through the Dunk Alzheimer's tournament, they bring families together to reduce stigma surrounding the disease, increase awareness about risk reduction and prevention, and raise money to fuel the battle to end Alzheimer's. Each year, the all-volunteer, community-driven event brings together kids and parents from around the Washington, DC area to play three-on-three basketball. After being sidelined for two years because of COVID-19, the event came back stronger than ever in 2022, drawing nearly 100 participants who helped raise almost \$25,000 to support UsAgainstAlzheimer's.



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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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 \$50 or more were made in honor or memory of the following:

Johnnie Ali
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Robert H. and Alice A. Wells
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Mildred Marie Williams
Pauline Harris Williams
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*Together, we have proven
that change is not only
possible but inevitable*



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