

### President's Letter

Dear friends,

In challenging times like these, we are profoundly grateful to you, our most generous and committed supporters. In the wake of the coronavirus (COVID-19) crisis. which we know is impacting all of our constituents and comes with special concerns for those facing dementia, we have taken steps to protect the health and safety of those we serve, our volunteers and our staff. We have successfully transitioned our programs and services to online and telephone delivery, and have enabled most of our 24/7 Helpline staff to work remotely — adaptations made quickly and comprehensively thanks to the resources you provide.

While the majority of those who experience changes in memory, thinking and behavior are over 65, we work on behalf of people affected by any kind of dementia at any age. In the coming pages, you'll read about Joel Berman's late wife, Sandy Rosenbaum, who lived with frontotemporal dementia, and Alzheimer's Association<sup>®</sup> National Early-Stage Advisor Bonnie Erickson, who was diagnosed with vascular dementia at age 57. Longtime supporter Leslie Lawson has witnessed the devastation of younger-onset Alzheimer's: her husband, David.

and his seven siblings all developed the disease before their 65th birthdays.

Stories like theirs are why the Alzheimer's Association and the Alzheimer's Impact Movement (AIM), a separately incorporated advocacy affiliate of the Association, led the charge for the Younger-Onset Alzheimer's Disease Act. The key elements of the bill were part of the Older Americans Act reauthorization. which was signed into law in March. This vital legislation will improve the lives of those under the age of 60 who are living with dementia by providing access to nutritional programs, transportation, and legal and respite services that were previously denied because of their age. We are grateful to our advocates nationwide — and especially those generous annual donors who make up the AIM Leadership Society — who fought tirelessly until the bill was enacted.

As the number of people affected by Alzheimer's and all other dementia grows, we are partnering with an increasing variety of stakeholders to ensure all those affected receive the quality care and support they need and to advance research toward effective treatment and prevention.



We were honored to welcome Bill Gates into our community of supporters, and CVS Health increased its support dramatically.

Those partnerships are a great vote of confidence in the work we do every day. It is work that you have made possible. In these challenging times, we'll continue to need your support to do that ongoing work and to continue our advances together.

Best wishes of health and safety to you and your loved ones.

Thank you!

Sincerely,

Harry Johns
President and CEO
Alzheimer's Association

Philanthropy in Action

Better Care for Caregivers

Private philanthropy is the

driving force behind the care,

support and research efforts

and you are a valued and instrumental partner in our

fight against this disease.

us achieve.

**COVER PHOTO** 

at the Alzheimer's

Mary Joy and Jerre Stead

Association International Conference® (AAIC®)

of the Alzheimer's Association —

We are committed to investing your contributions efficiently and effectively, while connecting you with the outcomes you help

**ALZ** Updates

Help for Families Facing Younger-Onset Alzheimer's

Joel Berman: Cycling for Sandy

"Imagine" Delights and Inspires

Donors Plan for Bigger Impact

Music Stars Rally for Alzheimer's Research

John and **Crystal Beuerlein:** Funding a Future

Without Alzheimer's

**Bonnie Erickson:** My Alzheimer's Story

Add-On Studies Accelerate Research Progress

**Upcoming Events** 

Lawson Family: Hope Runs in the Family

## Philanthropy in Action

### **BILL GATES FUNDS \$10 MILLION MATCH** CHALLENGE FOR PART THE CLOUD



Last fall, Bill Gates made a personal \$10 million gift in support of the Alzheimer's Association Part the Cloud global research grant program to stimulate an additional \$20 million in private funding. The \$30 million goal has been met and gifts continue to be received.

Led by visionary philanthropist Michaela "Mikey" Hoag, Part the Cloud has funded \$30 million in grants to 39 state-of-the-art research projects since 2012. The Gates Match Challenge will double the program's total investment in clinical research to \$60 million.

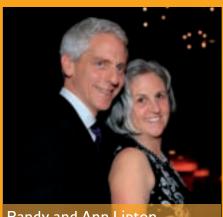
"Like millions of others, I have witnessed the devastating effects of Alzheimer's disease firsthand." says Gates. "Finding a treatment or cure is an enormous scientific challenge that needs increased and continued research investments. The Alzheimer's Association Part the Cloud program is impressive in accelerating early clinical phases of drug development to

slow, stop and, ultimately, cure the disease."

Part the Cloud awards are specifically designed to accelerate the transition of findings from the laboratory into possible therapies — filling the gap in Alzheimer's drug development by providing essential support for early-phase clinical studies. Grant recipients have gone on to receive more than \$259 million in additional funding from the National Institutes of Health, the National Institute on Aging, venture capital firms and other sources.

"Bill Gates and Mikey Hoag's commitment to the Alzheimer's Association demonstrates the urgency with which we must pursue innovative ideas that could be game changers for the tens of millions affected by Alzheimer's disease worldwide," says Maria Carrillo, Ph.D., Alzheimer's Association chief science officer.

#### **MATCHING GIFTS** MAXIMIZE IMPACT



Randy and Ann Lipton

Every gift to the Alzheimer's Association provides fuel for the mission, but some have a turbocharging effect. Matching gift challenges increase the impact of individual contributions by inspiring others to give.

Four Zenith Society and seven Aspire Society members recently gave nearly \$3 million to fund challenges that yielded more than four times the value of the original gifts.

"These matching funds, through the capable hands of the Alzheimer's Association, allow us to help more families and advance more research." says **Randy Lipton**, who funded a challenge this past winter and is funding a second challenge this spring. "My wife, Ann, and I are always happy to leverage our contributions to the Association because, with every additional dollar generated, we are that much closer to ending Alzheimer's."

If you would like to fund a matching gift challenge, email leadershipgiving@alz.org.

#### ZENITH SOCIETY MEMBERS ADVANCE KEY INITIATIVES

#### **ASSOCIATION ENGAGES HEALTH SYSTEMS**

More primary care physicians will be able to better diagnose cognitive impairment and provide care-planning support thanks to partnerships between the Alzheimer's Association and health systems nationwide. The Association is working with health systems to accelerate the adoption of best practices, helping them to determine which of several evidence-based, quality improvement programs are most suitable for them and facilitating those programs' implementation.

"As the incidence of dementia increases with the aging of the population, we must extend our reach to maximize early diagnosis, quality care and support for all affected," says Joanne Pike, Dr.P.H., the Association's chief strategy officer. "Working with health systems that employ a large number of physicians is an efficient and effective way to improve health outcomes, increase patient satisfaction and reduce costs for more people."

Alzheimer's Association Zenith Society members Dagmar Dolby and Mary Barton Smith made generous gifts to advance health systems engagement in Northern California. The Zenith Society sets the bar for philanthropic leadership, engagement and impact.



"Alzheimer's is a big part of my family's medical history, but I wasn't asked anything about memory during my most recent check up," says Smith. "If doctors knew when and how to ask targeted questions and how to address their patients' fears, so many people could be helped to deal with what is ahead or be put at ease if no problems are identified."

### PARTNERSHIPS ADVANCE TAU RESEARCH

The Alzheimer's Association is partnering with the Rainwater Charitable Foundation to advance the development of clinical interventions to prevent, reduce or stop tau protein build up in the brain. Toxic tau is associated with more than 20 brain diseases including Alzheimer's, frontotemporal dementia, Parkinson's and Pick's disease. With funding support from Zenith Society member Robert Thistle and seven other major donors, five translational research teams were collectively awarded nearly \$3 million in grants via the Tau Pipeline Enabling Program (T-PEP) in 2018. Earlier this year, the Association and the Tau Consortium awarded eight more T-PEP awards totaling \$3.9 million.

"There is a considerable gap between academic researchers and the pharmaceutical companies that are looking for drug candidates to be taken into human trials," says Heather Snyder, Ph.D., Alzheimer's Association vice president of Medical and Scientific Relations. "This funding will help shorten the timeline from bench science to clinical studies that test effectiveness."

### **ALZ Updates**



### CONCERN AND AWARENESS



"Discussing Alzheimer's is challenging for families, and this campaign tackles the issue directly... Initiating conversations sooner can enable early diagnosis and (provide) diagnosed individuals a voice in their future care."

-MICHAEL CARSON

### ASSOCIATION PARTNERS WITH AD COUNCIL ON NATIONWIDE CAMPAIGN

Out of the thousands of nonprofit organizations in the United States, the Alzheimer's Association was one of a small number selected to partner with the Ad Council on a national public service advertising (PSA) campaign. The Ad Council, the nation's leading producer of PSAs, has been behind such memorable icons and slogans as Smokey the Bear and "Friends don't let friends drive drunk."

Centering on the messages "When something feels different, it could be Alzheimer's" and "Now is the time to talk," the Association's campaign was designed to encourage and empower families to address signs of cognitive decline. The "Our Stories" campaign features real individuals who noticed signs of potential cognitive decline in a loved one and took the first, difficult step of initiating a conversation.

"Discussing Alzheimer's is challenging for families, and this campaign tackles the issue directly," says Michael Carson, Alzheimer's Association chief marketing officer. "Initiating conversations sooner can enable early diagnosis, which offers many important benefits, including allowing more time for critical care planning, better disease management and providing diagnosed individuals a voice in their future care."

Developed with creative agency The Community, the campaign includes ads for television, radio. print, billboards and buses; social media posts; and more. Supporting components include customizable conversation starters, a discussion guide, a list of early signs and symptoms of Alzheimer's and information on the benefits of early diagnosis.

The Association was chosen to partner with the Ad Council based on proven expertise on dementia, an issue of critical importance to the American public. The Council engages volunteer talent from leading advertising agencies across the country and leverages more than \$1 billion in donated media annually. In addition, the Association's campaign was one of only a few handpicked by Facebook to receive \$500.000 in donated media.

"Our Stories" is anticipated to be active at least through 2021. For more information, visit alz.org/ourstories.



### AMBASSADORS EMBARK UPON SECOND DECADE OF IMPACT

Impressive annual increases in federal funding for dementia research and passage of the Building Our Largest Dementia (BOLD) Infrastructure Act of 2018 are among the many legislative victories the Alzheimer's Association has achieved over the past decade.

Central to these successes are the Alzheimer's Impact Movement (AIM), a separately incorporated advocacy affiliate of the Association, and Alzheimer's Association Ambassadors. These volunteer advocates are recruited and trained to maintain year-round conversations with their elected officials, educating them on issues and holding them accountable to their commitments to people affected by dementia. Piloted in 2010 with support from The Judy Fund, the program now has Ambassadors for all 535 members of Congress.

"Senators and representatives know they can call or email their Ambassador whenever they have a question about Alzheimer's," says John Funderburk, vice president of Advocacy for the Association and AIM.



Alabama resident and AIM Leadership Society member Stephaine Buffaloe serves as an Ambassador to both a Democratic representative and a Republican senator. "There's a great level of trust because these relationships are built over time," she says. "It doesn't matter whether you are red or blue. Ours is a purple issue that transcends party lines."

As more constituents join the fight as Association advocates. Ambassadors are increasingly taking on more leadership roles. They help coordinate advocates' activities, such as monitoring legislators' social media accounts, drafting letters to the editors of local newspapers, leading Alzheimer's Congressional Team (ACT) volunteers and organizing events. Building off the momentum of federal policy successes, the Association has begun to recruit and train State Champions to serve as ambassadors for legislators at the state level.

"Adult quardianship and dementia care training standards are among the many important issues that are addressed by state governments," says Funderburk. "We are already seeing bills getting passed and are confident that our new State Champions program will be as effective in its first 10 years as its model — the Ambassador program — has been."

For more information on AIM, visit alzimpact.org.



### **ASSOCIATION COLLABORATES** WITH LONG-TERM **CARE COMMUNITIES**

With an aging population and more people at risk of developing cognitive impairment, there's an increased need for assistance with activities of daily living, such as eating, bathing, toileting and getting dressed. In 2018, the Association published its Dementia Care Practice Recommendations, 56 evidencebased recommendations for personcentered dementia care. Today, the organization is implementing a variety of strategies to help staff in long-term care settings adopt these quality care practices.

"Of the 1 million people currently in assisted living, 42% are living with dementia," says Beth Kallmyer, Alzheimer's Association vice president of Care and Support. "Whether they enjoy a good quality of life depends greatly on whether those who care for them understand and respond appropriately to their behaviors, special needs and personal preferences."

Person-centered care practices have shown beneficial effects on well-being, behavior and everyday quality of life and have reduced the use of psychotropic medication for individuals living with dementia. They have also demonstrated success in reducing stress and mitigating burnout and job dissatisfaction among professional care providers — a perennial and costly challenge in the long-term care industry. →

## ALZ Updates CONTINUED



Last year the Association piloted Project ECHO® for Person-Centered Dementia Care in Assisted-Living Communities, using videoconferencing to train 70 participants from 15 facilities in five states. The Association has since entered into a partnership with the Leading Age Minnesota Foundation to enable additional assisted-living staff to participate in the Alzheimer's and Dementia Care ECHO® program. Two cohorts of learners come together with the Alzheimer's Association in biweekly videoconference sessions to engage in real-life case discussions and learn evidence-based best practices to better support residents in their own communities.

Another pilot is testing an in-person approach. With funding from a cadre of donors, the Alzheimer's Association Dementia Care Practice Recommendations (DCPR) Implementation Pilot Program is using and evaluating a consultative coaching model in assisted-living communities in Ohio. The Association will use the findings from this pilot and others to develop a DCPR Implementation Strategy that can be rolled out nationally.

"The number of people living with Alzheimer's and other dementias is growing, so there's also a growing need for people who can care for them with skill and sensitivity," says Kallmyer. "We are encouraged that a growing number of long-term care communities are choosing to collaborate with us."



### RESEARCH

### GLOBAL PARTNERSHIP SEEDS PUBLIC HEALTH LEADERSHIP

The Alzheimer's Association, Global Brain Health Institute and U.K.based Alzheimer's Society have united to address the growing worldwide public health crisis due to dementia. The Pilot Awards for Global Brain Health Leaders is a competitive funding program to support emerging leaders as they conduct research pilots and activities related to access to care. stigma, brain health risk factors and other key challenges.

"The prevalence of dementia is expected to triple worldwide to 152 million by 2050," says Maria Carrillo, Ph.D., Alzheimer's Association chief science officer. "Our goal is to support leadership development with an emphasis on low- and middle-income communities. The awards will drive projects, activities and research to address disparities in dementia diagnosis, treatment, and care for vulnerable populations and their families."

The 2019/2020 awards — 27 in total — span 14 countries across five continents and support research and activities in the areas of advocacy, systems change, applied research and more. Funded pilots include a study of air pollution and dementia in Brazil, an investigation of social media use as an early indication of cognitive decline in Egypt, and an arts

project in the U.S. that involves people living with dementia and their care partners in the creation of and active participation in a dance performance.

Now in its fourth year, the Pilot Awards for Global Brain Health Leaders includes awardees in Argentina, Botswana, Colombia, Costa Rica, Ireland, Israel, Mexico, Peru. Romania. South Africa. the U.K. and more. The 2019/2020 funding cycle of approximately \$675,000 includes about \$25,000 for each individual award to enable the recipients to pilot test a project and then, if successful, seek further resources to scale up their work. As of December 2019, 65 pilots across 24 countries and regions have been awarded a total of \$1.64 million.

"The awards will drive projects, activities and research to address disparities in dementia diagnosis, treatment, and care for vulnerable populations and their families."

-MARIA CARRILLO, Ph.D.



### FUEL FOR THE MISSION

#### CVS HEALTH JOINS FORCES WITH THE ASSOCIATION



The Alzheimer's Association and CVS Health have entered into a three-year corporate partnership that will provide a minimum of \$10 million for the Association's mission and increase awareness of caregiver resources and support services. The partnership includes in-store fundraising campaigns and participation in the Alzheimer's Association Walk to End Alzheimer's®

"CVS Health is a respected leader in championing important health issues impacting society," says Donna McCullough, Alzheimer's Association chief field and development officer. "Their committed support of our work will make a huge difference to millions

of Americans impacted by this devastating disease."

Beginning this year, CVS Health will join Edward Jones as a National Presenting Sponsor of Walk to End Alzheimer's, the world's largest fundraiser to fight the disease. CVS Health has also joined Walk's National Team Program, providing its 295,000 employees across the country with an opportunity to participate in the fight against Alzheimer's.

Each November, coinciding with National Family Caregivers Month, customers at more than 8.800 CVS Pharmacy locations nationwide will have the opportunity to contribute to the Alzheimer's Association at the register. The Association and

CVS Health will also communicate with customers about resources available to support family caregivers. Some of the proceeds from the campaign will be used to develop a new Association caregiver education program for in-person and online delivery in English and Spanish.

"The Alzheimer's Association is grateful for the commitment and enthusiasm CVS Health brings to the fight against Alzheimer's," McCullough says. "The funds raised through our partnership will bolster our efforts to support families facing Alzheimer's and advance much needed research that will one day change the future for millions." №

"CVS Health is a respected leader in championing important health issues impacting society... Their committed support of our work will make a huge difference to millions of Americans impacted by this devastating disease."

-DONNA McCULLOUGH

## Cycling for Sandy



"We're not all scientists." but we can support people who can find a cure. Whether you give the Alzheimer's Association \$10 or \$10 million. this is something tangible you can do today." -JOEL BERMAN

A social worker and self-described adventurer. Ethel Sandra "Sandv" Rosenbaum was passionate about helping people and seeing the world. Her husband of nearly 30 years, Joel Berman, was initially reluctant to travel, but Sandy won him over with her enthusiasm.

"We visited every continent, even Antarctica," says Joel, a native of Boxford. Massachusetts. "We'd come home and people would ask, 'Where are you going next?'"

Everything changed in 2012 when Sandy was diagnosed with myotonic dystrophy, a form of muscular dystrophy, at age 61. Then, five years later, she was diagnosed with frontotemporal dementia. The news was devastating, but they found some solace knowing that they had lived their lives fully, traversing the globe together.

"Most people think about traveling when they retire," he says. "I'm very thankful we didn't wait until our 60s because it wouldn't have happened."

As Sandy's primary caregiver, Joel remained steadfastly by her side, even after making the painful decision to move her to an assisted living facility in 2017 as her health declined. The transition was difficult; with no children and no family nearby, Joel felt isolated.

"Being unable to do anything for her was heartbreaking," he says. "It went from the two of us facing the world to me being completely alone."

The director of Sandy's assisted living facility invited Joel to connect with other caregivers by participating in the Alzheimer's Association Massachusetts/New Hampshire Chapter's Ride to End ALZ. Joel registered for the event, which challenges cyclists to pedal up to 100 miles while raising critical funds and awareness to advance research. But on June 21, 2017, just days before the ride, Sandy died of complications related to dementia. Grief-stricken, Joel considered dropping out, but ultimately he decided to stand up to the disease and forge ahead.

On the day of the event, hundreds of cyclists lined up in Rye, New Hampshire. Joel asked to say a few words to honor Sandy, and other participants rallied around him to offer comfort and share their own stories. In a moving show of support, everyone backed up at the start of the ride and encouraged Joel to go first.



"It was a really warm feeling to be surrounded by people who had gone through a similar circumstance," Joel says. "It made me feel like I wasn't alone."

Inspired by the experience, Joel worked with the Association to create Sandy's Starters, a group of caregivers who had all recently lost someone they love to Alzheimer's or another dementia. Since then, every event begins with a moment of silence to honor those living with the disease, followed by Sandy's Starters, clad in matching purple jerseys, leading cyclists over the starting line.

Joel has also become a member of the Founders Society, joining fellow donors who have included the Association in their estate plans.

He urges others to advance the fight against Alzheimer's however they can.

"I contribute to research so, someday, people won't have to go through what I did," he says. "We're not all scientists, but we can support people who can find a cure. Whether you give the Alzheimer's Association \$10 or \$10 million, this is something tangible you can do today." የህ



### Donors Plan for Bigger Impact

Alzheimer's Association donors give back in extraordinary ways. Planned gifts are one way supporters can make a significant contribution to the fight against Alzheimer's disease. They allow donors to provide for their own financial security during their lifetime, while leaving a lasting legacy for the future.

We asked several individuals about their connection to the cause and why a planned gift was the right philanthropic choice for them.



**Sue Sawyer** (left)
Gift via Retirement Account

When I was a kid growing up in small-town lowa, my mom was my rock. I will always have fond memories of sitting on my mother's lap after coming home from school, listening to her read to me. She had a wonderful sense of humor, and never lost it — not even as Alzheimer's disease began to change her world.

We first noticed issues with her memory in 2006 during her chemotherapy for colon cancer. At the time, we thought it was just a side effect of her treatment, but the issues persisted long after her cancer was cured. Every time I visited her, I noticed more changes as Alzheimer's set in. I knew my dad and our entire family would need some extraordinary help.

The Alzheimer's Association was there when we needed them. I attended support groups, went to seminars on legal and financial planning and met others facing this terrible disease. Thanks to the Association's extensive chapter network and their online resources, my dad and I were able to care for my mom until her death in 2015 at the age of 82. I will forever cherish the time I had with her — and with my dad — during her final months.

I can never thank the Association enough for all they gave our family. Because of this, I want to do what I can to ensure others receive the help they need until, one day, no family has to face the challenges of Alzheimer's.

I decided to name the Alzheimer's Association as a beneficiary of my retirement account. Doing so was really easy — I just updated a form with my retirement plan. It feels good knowing that my gift will help families like mine find hope over their despair.

"I can never thank the Association enough for all they gave our family. Because of this, I want to do what I can to ensure others receive the help they need until, one day, no family has to face the challenges of Alzheimer's."

-SUE SAWYER



Richard and Glenna Palmer Charitable Remainder Trust

My husband, Dick, has always been interested in medical science. As a pharmacist and owner of a successful chain of drug stores, he's seen firsthand how research breakthroughs can save lives.

I have my own reasons for being interested in research and supporting those impacted by Alzheimer's. We suspect there was dementia — possibly Alzheimer's —

on Dick's side of the family, which was then called "senility" or "hardening of the arteries." Scientists do not yet fully understand what causes Alzheimer's, and I worry the disease could directly impact my family. I want researchers to end this disease once and for all.

In 1996, our daughter, Kelly, became the executive of a local Alzheimer's Association chapter. We were so proud of her dedication to the organization and passion for making a difference for those living with the disease and their caregivers. As we planned Dick's retirement, we wanted to find a way to support the Association while also creating some income. We met with our attorney and, with his help, created a charitable remainder trust with the Association as the beneficiary.

We established the trust in 2003 and, for 15 years, received income from it. Then, at the end of its term, the trust made a significant gift to the Alzheimer's Association.

It's rewarding to know our gift is accomplishing something good — it feels wonderful to help other people through the Association. Our wish is that our donation will help bring us closer to a cure for this devastating disease.



### Adrienne Edelstein Gift in Will

I could always count on mv mom to be there for me. When I was a child, she organized my Brownie troop and was president of the parentteacher association. But I loved my mom most deeply when I witnessed the love she showed my

own child. She was a phenomenal grandmother. Sharing my son and nephew with her created our strongest bond and my most endearing memories of her.

Mom was only 64 when she was diagnosed with Alzheimer's disease. At first. I noticed she was forgetting birthdays; eventually, she barely recognized me. My mother died a month before her 80th birthday after living with this awful disease for 16 years.

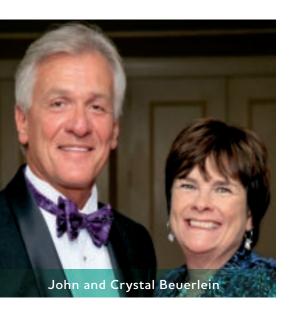
I tell people that I have not cried in five years because I am out of tears after crying every day from seeing my mom in this condition. It was the most horrific experience for all of us: me, my mother, my sister, our kids — everyone was affected.

Alzheimer's goes on for years and is alarmingly expensive for families. Even those with financial means struggle to afford the disease. I decided I had to do something to help end this, so I volunteered at my local Association chapter and with Walk to End Alzheimer's.

I also decided to do something that would allow me to have an even bigger impact. When I was updating my will, my attorney asked if there was any other gift I wanted to leave. I responded out of passion and without hesitation, "Yes. I want to leave a significant gift to the Alzheimer's Association. And I want it to go toward research for prevention or a cure."

I made my gift in honor of my mother and all the mothers and daughters in the world who may one day travel this path. It feels good to do my part to make their journey easier. የህ

## Funding a Future Without Alzheimer's



"Now is probably one of the best times you could get involved in supporting Alzheimer's research because of the attention we have from the government and because private philanthropy is stepping up in ways we've not seen before."

-JOHN BEUERLEIN

Immediately following last year's Walk to End Alzheimer's in St. Louis, event co-chair John Beuerlein boarded a plane to Florida to catch up with his children and grandchildren at Disney World. That busy day in late October epitomizes what he and his wife, Crystal, value most: family and philanthropy.

John and Crystal have been married for 43 years — their story began when they met as students at Drury College in Missouri. Upon completing a graduate program in business at Washington University in St. Louis, John was hired at Edward Jones Investments, headquartered in the city.

The opportunity led the Beuerleins to put down roots in St. Louis. They would go on to raise their three children there, all of whom still live nearby with families of their own.

In 2014, John, by then one of the firm's senior executives, began to explore charitable health care causes that Edward Jones could champion. Under his leadership, they began providing constituents with Alzheimer's Association materials and invited staff across the country to take part in Walk to End Alzheimer's. Thanks in large part to John's commitment to the cause. Edward Jones staff and

clients have, to date, raised more than \$23 million for Alzheimer's care, support and research.

Neither John nor Crystal has a family tie to Alzheimer's, but the connection they formed through John's work opened their eyes to its devastating effects.

"Our empathy level has gone way up," John says.

In October 2015, the couple joined the Zenith Society, the Association's highest and most involved level of philanthropy, designating their gift to high-potential research studies, including the DIAN-TU Next Generation trial and the Women's Alzheimer's Research Initiative. John also became co-chair of the Association's Step Up the Pace initiative, which raised nearly \$110 million for Alzheimer's research in its first four years.

"Now is probably one of the best times you could get involved in supporting Alzheimer's research because of the attention we have from the government and because private philanthropy is stepping up in ways we've not seen before," says John. "Finally, we have a real sense of momentum. I would encourage anybody who's considering funding Alzheimer's research to do it today."



Crystal and John with Alzheimer's Association President and CEO Harry Johns (right) and past Association Governing Board of Directors Chair Chris Binkley (left) at the AIM Advocacy Forum

John and Crystal help to advance public policy and funding for care, support and research by lending their voices at the annual Alzheimer's Impact Movement (AIM) Advocacy Forum. In 2018, they became charter members of the AIM Leadership Society, a group of donors working to make Alzheimer's part of the national conversation.

Their involvement with the Association and their proximity to the Charles F. and Joanne Knight Alzheimer's Disease Research Center at Washington University in St. Louis has enabled them to track disease advancements up close.

"The scientists who dedicate their lives to the pursuit of a cure are our new heroes," says John.

An avid mahjong player and member of the American Contract Bridge League (ACBL), Crystal uses her competitive spirit to

"Crystal and I hope the example we set will encourage others to stretch in their efforts to make our communities better places to live and enjoy their families late into their lives." -JOHN BEUERLEIN

fight Alzheimer's. Her league, the St. Louis Bridge Center, raised nearly \$80,000 last year for The Longest Day®, an Association fundraising event held each June.

"I'm blessed to be married to a trophy wife," John jokes. "She's keeping her brain sharp and our mantle filled with bridge trophies."

John recently retired from Edward Jones after four decades in the business, but remains committed to advancing the Association's mission. He says the organization's work "has risen among the top of the causes that we support."

The Beuerleins' commitment to ending Alzheimer's is making it possible for untold numbers of families to thrive in the future. They hope that their dedication will inspire others to find their philanthropic passions.

"We think being of service to others is why we've been put on this planet," John explains. "Crystal and I hope the example we set will encourage others to stretch in their efforts to make our communities better places to live and enjoy their families late into their lives." 95

## Add-On Studies Accelerate Research Progress



The Alzheimer's Association U.S. Study to Protect Brain Health Through Lifestyle Intervention to Reduce Risk (U.S. POINTER) and Imaging Dementia – Evidence for Amyloid Scanning (IDEAS) studies are landmark clinical trials. Research teams nationwide continue to design ancillary, or add-on, investigations that leverage the trials' infrastructure to generate new data.

Maria Carrillo, Ph.D., Alzheimer's Association chief science officer, answers donor questions about this high-impact way to advance dementia science.

### Q: What are the advantages of "add-on studies"?

A: Large, well-designed clinical trials often attract add-on studies because of the significant resources required to activate trial sites and enroll volunteers. The Alzheimer's Association has awarded grants to enable a number of add-on studies over the years because it is much more cost-effective and efficient to build on work that's already underway than to reinvent the wheel. All of our grants are funded by charitable gifts, and we are committed to investing those gifts for maximum impact.

U.S. POINTER and IDEAS are two great examples of studies that provide an ideal foundation for such ancillary research.

### Q: What makes U.S. POINTER ideal for additional research?

A: There's nothing of the scope or scale of U.S. POINTER anywhere else in the country. The study's leadership team is building multifaceted partnerships nationwide with academic medical centers, health care systems and organizations that provide high-quality adult fitness programming. For this study, we are recruiting 2,000 volunteers from diverse racial, ethnic and socioeconomic backgrounds who are believed to be at increased risk of developing cognitive decline because of their age, family history and overall health status. Every volunteer will participate in one of two lifestyle interventions over two years.

Due to the evolving impact of the novel coronavirus, U.S. POINTER has been paused to ensure the safety of participants and research staff, but our commitment to the study is unwavering.

We are excited that the National Institute on Aging (NIA) has already committed more than \$52 million in add-on studies to U.S. POINTER, which is a testament to the value of our study.

### Q: What will the U.S. POINTER Neuroimaging Ancillary Study do?

A: U.S. POINTER is designed to evaluate how two lifestyle interventions protect memory, reasoning and other aspects of cognitive function in people at increased risk for cognitive decline. The Neuroimaging Study will show how these factors — including exercise, nutrition, social and cognitive stimulation and self-management of health — affect the physical brain itself.

The NIA is making a five-year grant expected to total \$47 million to the University of California, Berkeley, to add amyloid positron emission tomography (PET), tau



PET and magnetic resonance imaging (MRI) scans to U.S. POINTER. The research team will use these advanced brain imaging technologies to assess participants at the start of the study and at year two to measure the presence and levels of amyloid and tau — two proteins linked to Alzheimer's. They'll also perform MRIs at baseline, one year and two vears to measure the size of brain regions, identify brain changes related to strokes or other vascular changes and observe changes in brain blood flow. Brain biomarkers of Alzheimer's and dementia, when measured at the beginning of the study, may predict who will respond best to lifestyle interventions.

#### Q: How will U.S. POINTER-zzz add value?

A: We know that sleep disturbances are associated with memory and thinking issues and increase the risk for Alzheimer's-related brain changes. The NIA has

awarded a grant expected to total \$5.3 million to Wake Forest University to incorporate in-home sleep assessments for 700 adults who are participating in U.S. POINTER. Our hope is that this add-on study can show us how the U.S. POINTER lifestyle interventions impact sleep, and whether this can protect cognitive function and possibly reduce dementia risk.

### Q: How are ancillary studies maximizing the impact of IDEAS?

A: Led by the Alzheimer's Association and managed by the American College of Radiology, IDEAS is the largest-ever clinical trial for Alzheimer's. This study has provided amyloid PET scans for more than 18,000 Medicare beneficiaries who have mild cognitive impairment or dementia of an uncertain cause.

The Amyloid Neuroimaging and Genetics Initiative (ANGI) add-on

study is collecting DNA samples from 3,000 IDEAS participants so researchers can look for correlations between genetics and brain changes. The Brain Health Registry add-on study is collecting longitudinal health, lifestyle, medical history and cognitive data from IDEAS participants to help identify those who might benefit from potential diagnostic tools or therapies. The Plasma Test for Amyloid Risk Screening (PARIS) add-on study is recruiting several hundred IDEAS participants to measure the efficacy of a new brain amyloid blood test.

Building on existing studies in all these ways helps to provide a path forward toward our vision of a world without Alzheimer's and all other dementia. %

For more information about research funding priorities, visit alz.org/stepup.

## Hope Runs in the Family



For the Lawson family, ending Alzheimer's is deeply personal. David Lawson lost his grandfather and father to the disease, and David and all seven of his siblings developed younger-onset Alzheimer's, a form of the disease that affects those under age 65.

But the Tulsa. Oklahoma-based family has also forged another legacy — one of fighting to end the disease that has affected too many of their relatives.

After his father's diagnosis, David, former president and chief executive officer of Capital One Auto Finance, Inc., joined the board of the Alzheimer's Association Oklahoma Chapter, launching the family's nearly 40-year history of donating time and funds to advance Alzheimer's care, support and research. Since the 1980s. David and his wife. Leslie, have given more than \$200,000 to the Association.

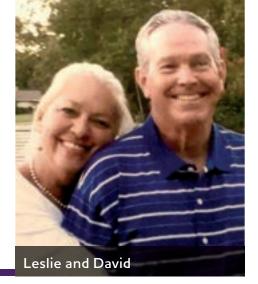
After David received his own diagnosis in 2009, Bob Thomas, a close family friend who has served on the Alzheimer's Association Governing Board of Directors, introduced David and Leslie to a

new opportunity to advance the cause — the Alzheimer's Impact Movement (AIM).

AIM, a separately incorporated advocacy affiliate of the Alzheimer's Association, advances and develops policies to overcome the disease through increased investment in research, enhanced care and improved support. Thanks to the generosity of members like the Lawsons, AIM, together with the Alzheimer's Association. has driven policymakers to take historic steps to address the Alzheimer's crisis, resulting in a more than six-fold increase in federal Alzheimer's research funding since 2011.

The Lawsons have contributed more than \$126,000 to AIM. In 2018, they became charter members of the AIM Leadership Society, a group of generous donors who help advance public policy through annual philanthropic investments.

"With AIM, we've been able to take our involvement to another level." says Leslie. "We need Congress to issue legislation to help those affected and get more research







funding. The government needs to give Alzheimer's disease more attention so we can get this cured."

AIM has also provided the Lawsons an opportunity to connect with others in a meaningful, personal way. Leslie recalls a dinner where she was invited to talk about her Alzheimer's experience with Sen. Roy Blunt (R-Mo.) and Rep. Tom Cole (R-Okla.).

"When I was able to tell my story of David and his family, it hit home for a lot of people. It seemed like everyone was relating to what I was saying," says Leslie. "To have someone with the power to change things really listen to you and your thoughts and feelings — that was very important to me."

David died in February 2019 at age 71. In his honor, and driven by a desire to ensure their three children and nine grandchildren can have a future without Alzheimer's, Leslie and her family remain dedicated to the fight.

A passion for giving has been sparked in the next generation of Lawsons. David and Leslie's 17-year-old granddaughter, Catherine, has recently taken up the banner, reaching out to schools and colleges to raise awareness of the disease among her peers and recruiting more than 200 local teens to participate in the Alzheimer's Association Walk to End Alzheimer's in Tulsa.

"Despite so much loss, our family has never given up hope," says Leslie. "Like everyone who's been affected by this disease, we're eager for a cure, and I think it has brought us together as a family to be able to go out and raise funds to help make that happen." የህ

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-LESLIE LAWSON

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### Better Care for Caregivers



"We know this disease has an unprecedented impact on families, so to support research like this made sense. It's how we can help bend the curve."

-MARY JOY STEAD

Alzheimer's is life changing — and not just for the person living with the disease. Sixteen million Americans provide unpaid care for people with Alzheimer's or other dementias and many find themselves isolated. stressed and overwhelmed as they care for the person, as well as themselves.

The Alzheimer's Association believes that no one should face the disease alone and provides support to these individuals wherever and whenever they need it through a free 24/7 Helpline (800.272.3900). From basic information to crisis management, specialists and master's-level clinicians offer around-theclock, confidential support to individuals living with dementia and their caregivers.

Satisfaction surveys have shown that Helpline callers are consistently happy with the support they receive. While these reviews indicate that the service makes a positive impact on callers, the Association recognized a need for an evidence base that proved its effectiveness

"Research is important for many reasons," says Sam Fazio, Ph.D., Alzheimer's Association senior director of Quality Care and Psychosocial Research. "Most importantly, we need to know what specifically we're doing

that's making a difference to allow our service to be replicated and shared more broadly."

Nancy Hodgson, Ph.D., R.N., a geriatric nurse scientist and associate professor and gerontology chair at the University of Pennsylvania School of Nursing, led the charge to collect that evidence base. Dr. Hodgson conducted the pilot Care Consultation Impact Study, which examined the outcomes of the Helpline's care consultations — free care navigation services offered to families facing any stage of the disease.

The study surveyed 185 caregivers who used the service between January and October of 2018. Participants were assessed at the time of their call and one week and one month later, self-reporting their emotional state and ability to manage anxiety, implement plans of action and access services.

The study's results, released at the Alzheimer's Association International Conference 2019 (AAIC) in Los Angeles, showed the Helpline's support was effective at reducing caregiverrelated emotional distress and improving callers' ability to take action. At their one-week checkin, 70% of callers reported that they had implemented the action plans provided during their care



consultation: at one month, 80% of callers had done so. In addition, over 80% said that these action steps were helpful, and 65% reported that they had accessed additional support services as a result of the call.

These preliminary findings laid the groundwork for a larger-scale study that would explore the specific components of the Association's care consultation model and how they affect caregiver outcomes. Thanks to a Zenith Society-level gift from philanthropists Jerre and Mary Joy Stead, that expansion research — the Care Consultation Intervention Study — is underway.

"My father took on all caregiving responsibilities for my mother when she was living with Alzheimer's so much so that I didn't realize just

how bad the disease had gotten," says Jerre. "He was very protective of her, but it took such a toll on his own life."

Mary Joy adds, "We know this disease has an unprecedented impact on families, so to support research like this made sense. It's how we can help bend the curve."

Similar to the pilot, individuals in the intervention study who receive a care consultation are evaluated at the time of the call and receive a satisfaction survey within 48 hours. Those who choose to participate in the study by completing the questionnaire then receive a follow-up call two weeks later by an Alzheimer's Association Helpline research specialist. Caregivers are asked about their level of confidence in handling negative

feelings or stress, and if they feel they can cope with unexpected situations. Participation in each of the three assessments is voluntary.

"A lot of them participate because they're so grateful for the help they received," says Felicia Brown, a research specialist involved in the study. "It's their way of giving back." →

"We need to know what specifically we're doing that's making a difference."

-SAM FAZIO, Ph.D.



For many caregivers, the study is also an unexpected chance to

assess their own well-being.

"Sometimes the questions we ask are so thought-provoking for them and they finally have a chance to realize how much they're going through," says Felicia. "Typically the support conversations they're having are about the person living with the disease, but this is something that's about them and how they feel."

The intervention study began in July 2019 and is expected to run until December 2020. With the Steads' support, the Association estimates it will provide about 2,000 telephone care consultations a more than 10% increase over

existing service levels — providing significant gains in availability and quality of care.

"Through this vital project, the Alzheimer's Association will create an evidence-based model of care that will make our Helpline care consultation services eligible for expanded support and replicable by other organizations delivering care to those living with Alzheimer's and other dementias," says Joanne Pike, Dr.P.H., Association chief strategy officer. "With this, we have the potential to reach exponentially more people." የህ

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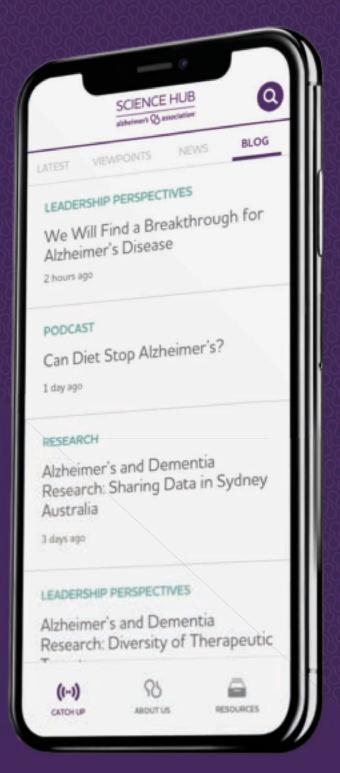
-JOANNE PIKE, Dr.P.H.

### SCIENCE HUB

alzheimer's 95 association

The Alzheimer's research scientists are talking about — and you want to know

The Alzheimer's Association Science Hub is a free app that provides the latest news, information and expert views about Alzheimer's and dementia research





Learn more at alz.org/sciencehub

Or search for "Science Hub"





## Help for Families Facing Younger-Onset Alzheimer's



"Too often, people living with younger-onset Alzheimer's have been unable to access fundamental programs and services because of their age... This legislation is an important step to ensure (they) have access to critical support services."

Michael Riley was a tough, devoted public servant. As a firefighter, he willingly risked his life to save people from danger.

Michael was a loving husband and doting father. His wife, Lani, worked part-time as a dental hygienist and homeschooled the St. Augustine, Florida, couple's two sons. On his days off, Michael taught the kids, cleaned the house and had dinner on the table when Lani came home.

Michael was fun. He participated in Scottish Highland Games competitions — proudly wearing a kilt — and took the family on vacations to zip line courses with names like "Screaming Eagle."

In his early 50s, Michael became increasingly withdrawn and forgetful. Daring adventures were replaced by silently sitting on the back porch watching birds. A concerned Lani would ask Michael if he was OK: "Nothing's wrong," he would say. "I'm just really tired."

In 2016, at age 55, Michael was diagnosed with younger-onset Alzheimer's, a form of the disease that affects individuals under 65.

No longer able to work, Michael lost his health insurance and, given his age, was ineligible for certain Medicare and disability benefits.

Lani quit her job to become Michael's full-time caregiver in addition to raising their children. Paying for insurance and other health-related expenses drained the family's savings, and finding assistance proved difficult.

"When we were referred to certain agencies for help, we were always told there was nothing they could do for us because Michael wasn't 60 yet," says Lani, 47. "I was watching my partner basically melt away in front of me daily. The worst part about getting to a point where you desperately need help is asking for it only to be told no."

Recognizing the need to address this disparity, the Alzheimer's Association and the Alzheimer's Impact Movement (AIM) worked with bipartisan congressional champions to develop the Younger-Onset Alzheimer's Disease Act, which would enhance quality of life for people living with dementia under the age of 60 and their families by ensuring access to resources available through the Older Americans Act (OAA). Since 1965, the OAA has provided support to America's seniors by organizing and delivering nutritional programs, respite for family caregivers, transportation, legal services, elder-abuse prevention and more.

-ROBERT EGGE



In June 2019, the Senate Health. Education. Labor and Pension (HELP) Committee included elements of the Younger-Onset Alzheimer's Disease Act in its draft language of the OAA reauthorization bill. This past March, Congress passed and the president signed into law the reauthorization bill with those key elements of the Younger-Onset Alzheimer's Disease Act. Association and AIM advocates built tremendous bipartisan support for this legislation.

"Too often, people living with younger-onset Alzheimer's have been unable to access fundamental. programs and services because of their age," says Robert Egge, Alzheimer's Association chief public policy officer and AIM executive director. "This legislation is an important step in ensuring individuals living with youngeronset Alzheimer's have access to critical support services."

Michael, now 58, is declining rapidly and requires around-the-clock care. Still, he and Lani continue their fight. After reading about the Younger-Onset Alzheimer's Disease Act online, Lani contacted the Association's Central and North Florida Chapter, told the couple's story and asked how they could get involved. They're now featured as part of a "Faces of Alzheimer's" video series on YouTube.

As Lani puts it, "the clock is ticking," and she knows the Younger-Onset Alzheimer's Disease Act's benefits may arrive too late for their family. But if the legislation does become law, she takes solace in being able to advocate for others on the same journey.

"Extending benefits to people living with younger-onset Alzheimer's would give their caregivers peace of mind," says Lani. "I knew there were others out there like Michael who

needed help, and I knew Michael wanted to help them get it. That's what he spent a lifetime doing helping others." የህ

To view Michael and Lani's video. visit YouTube and search "Faces of Alzheimer's."

"Extending benefits to people living with younger-onset Alzheimer's would give their caregivers peace of mind."

-LANI RILEY

## "Imagine" Delights and Inspires



"My mom died two years ago of Alzheimer's disease... We are all here to rage together and sing our rallying cry. We are at war. and we will win." -ASHLEY WILLIAMS

The Alzheimer's Association "Imagine" Fall Benefit, the reimagined Rita Hayworth Gala, at the iconic Rainbow Room in New York City raised more than \$1 million for the Association's care, support and research efforts. Princess Yasmin Aga Khan hosted the event, while Karyn Kornfeld, Steven Kobre and Greg Smith served as chairs.

The event built on the 36-year legacy of the Rita Hayworth Gala, founded by Princess Yasmin in honor of her mother, who died in 1984. The two-part evening began with an exclusive dinner for leading donors that featured a performance by renowned flutist and former CBS Sunday Morning arts correspondent Eugenia Zukerman. She shared personal remarks about her experience living with Alzheimer's disease and read from her new memoir, "Like Falling Through a Cloud."

"I am grateful to people like Eugenia who bring Alzheimer's out of the shadows," Princess Yasmin says.

After the dinner, more than 300 guests enjoyed an intimate performance by Grammy- and Academy Award-winning artist Jennifer Hudson, Actress and Alzheimer's Association Celebrity Champion Ashley Williams shared how the disease impacted her family.

"My mom died two years ago of Alzheimer's disease." Williams told the crowd. "We are all here to rage together and sing our rallying cry. We are at war, and we will win."

The event was generously underwritten by Rolex Watch USA. %

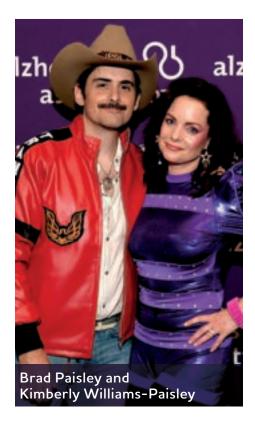
All photos courtesy of BFA NY.







## Music Stars Rally for Alzheimer's Research







Actress Kimberly Williams-Paisley and Storme Warren of SiriusXM's "The Highway" hosted the third annual Dance Party to End ALZ in September 2019, which raised nearly \$350,000 for Alzheimer's Association research efforts.

The sold-out, 1980s-themed show, held at Nashville's Wildhorse Saloon, featured performances by leading artists including Sheryl Crow, Brad Paisley, Chris Daughtry, REO Speedwagon's Kevin Cronin and Dave Amato, and Ashley Campbell. In keeping with the event's theme, the musicians sang their favorite hits from the '80s then came together on stage for a group finale of "Two Tickets to Paradise."

"The energy in the room was absolutely electric, and I am so grateful to the incredible performers and fans who danced and sang their hearts out," says event founder Williams-Paisley, who lost her mother to Alzheimer's in 2016. "Once again, the Nashville community has rallied to raise money for the Alzheimer's Association to fight a disease that has touched so many families, including my own."

Actress Bonnie Hunt joined Williams-Paisley on stage to encourage the crowd's support and share her pre-Hollywood experience as a nurse caring for a couple facing Alzheimer's disease.

Charles Esten, Hunter Hayes, Tegan Marie, Jamie O'Neal, Shenandoah and Emily West with the Whiskey Wolves of the West also contributed their talents at the event. %

"Once again, the Nashville community has rallied to raise money for the Alzheimer's Association to fight a disease that has touched so many families, including my own."

-KIMBERLY WILLIAMS-PAISLEY



## My Alzheimer's Story

I thought the brain fog, confusion and fatigue I was experiencing was due to work and life stress. For 15 years, I was a program analyst at the Department of Homeland Security and really enjoyed my job. But then something started to feel off. I visited my doctor 13 times over several years but never got to the bottom of my complaints.

My problems got worse, and in 2017, an MRI showed I had suffered a stroke and had actually been experiencing transient ischemic attacks (TIAs), or ministrokes. I was diagnosed with cerebral white matter disease and vascular dementia at age 57. My neurologist didn't explain what that meant, so I turned to the internet for answers — but wasn't sure if the information I found was credible. To my horror, one website stated the average person with vascular dementia lives only five years after symptoms start.

The diagnosis was devastating. I became very depressed, and for months I cried myself to sleep nearly every night. I wondered, "How long will I know my kids' names?" I tried to keep working but found myself slipping. By 2018, I was forced into early retirement at age 58.

When my husband had a heart attack, people brought food to the house and sent get-well cards. But when I was diagnosed with dementia, that same support wasn't there. People seemed in denial or unsure how to react. I felt isolated and alone in my diagnosis.

Things started to turn around for me when I found the Alzheimer's Association. I came across alz.org® and pored over its wealth of trustworthy information to better understand my diagnosis. Using the ALZConnected® online community, I was able to find other people with vascular dementia who shared their experiences and supported one another. I've even met people who've lived with the disease much longer than five years! You can be up late at night worrying and there is always somebody out there to chat with about your situation. We talk about our experiences and compare treatments, and it's all done in a supportive way — individuals with dementia united.

Thank you for being so generous and giving to the Association so services like ALZConnected and alz.org can continue. Without funding, these vital resources wouldn't exist, and I think even more people would really struggle with this disease.

With the support of my family and the Alzheimer's Association, I eventually came out of the darkness and accepted my diagnosis. I also learned how to fight back. I was selected to serve on the Association's National Early-Stage Advisory Group to advocate for people living with dementia. I attend online peer-to-peer support groups and events offered through my local chapter. Right now, life feels good, thanks to donors like you. የଧ

#### **UPCOMING EVENTS**

Due to the coronavirus (COVID-19) pandemic, the Alzheimer's Association has postponed the 2020 Part the Cloud Gala, Inspire Napa Valley Wine Weekend and Chicago Rita Hayworth Gala.

Rescheduled dates and information will be posted on the event websites when available. We look forward to celebrating our mission with you in the future when these events are rescheduled.



JULY 26-30, 2020 Alzheimer's Association International Conference (AAIC) Virtual conference alz.org/aaic



OCT. 4, 2020 Dance Party to End ALZ Nashville, TN alz.org/danceparty



OCT. 22, 2020 Fall Benefit (reimagined Rita Hayworth Gala) New York, NY alz.org/nybenefit

Events and dates are subject to change.



## OUR CAUSE IS URGENT.

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If you have a Donor Advised Fund (DAF), you can do even more to help address our nation's largest under-recognized public health crisis. Please contact your community foundation or financial services company to recommend a grant to the Alzheimer's Association from your account today.

For more information:

David Sandler 314.495.4023 dhsandler@alz.org alz.org/DAF

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The Alzheimer's Association does not offer legal, tax or financial planning advice. Please consult your own legal counsel, tax advisor and/or financial planner.



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The Alzheimer's Association leads the way to end Alzheimer's and all other dementia — by accelerating global research, driving risk reduction and early detection, and maximizing quality care and support.

Our vision is a world without Alzheimer's and all other dementia™.