



alzheimer's  association®

THE BRAINS BEHIND SAVING YOURS:

ALZHEIMER'S ASSOCIATION
ASPIRE
PHILANTHROPY MAGAZINE

FALL 2017

Sheila Konar: Inspired to give by
her husband's fighting spirit. Page 4

President's Letter

Dear Friends,

We're fortunate to have philanthropic partners like you across the country — in small towns, big cities and every area in between. Your stories about fighting Alzheimer's are just as unique as you are, and we're highlighting several in this issue of *Aspire*.

On the cover, we feature Sheila Konar of Rochester, New York. Two years ago, Sheila lost her beloved husband, Bill, to Alzheimer's. Despite Bill's early struggles as a Holocaust survivor and orphaned immigrant, he built a successful life — one that was unfortunately cut short by this devastating disease. Today, Sheila channels Bill's fighting spirit through her unwavering commitment to the work of the Alzheimer's Association®. Read more about this remarkable couple inside.

With the help of our generous donors, the Association is able to provide quality care and support to people facing the disease nationwide. However, we're unable to help everyone affected by this growing crisis alone — our federal and state governments must take action. To that end, we're dedicated to ensuring that every state has an Alzheimer's plan to address the disease on a local level. Currently, 46 states plus Washington, D.C.,

and Puerto Rico have plans, and in this issue we explore another under development in South Dakota.

Despite this progress, there's more work to be done. Together with the Alzheimer's Impact Movement (AIM), our 501(c)(4) sister organization, and our nationwide network of advocates, we gained strong bipartisan support of the Health Outcomes, Planning, and Education (HOPE) for Alzheimer's Act. As a result, the Centers for Medicare & Medicaid Services announced its decision to cover care planning for those with cognitive impairment, a ruling that can transform the patient and caregiving experience. Learn more about this victory in the pages that follow.

As always, we're committed to ultimately ending this crisis. That's why we're leading a special philanthropic initiative to fund the scientific breakthroughs needed to find methods of treatment and an eventual cure. The enclosed insert, *Step Up the Pace: Accelerating Alzheimer's Research*, highlights how donors have responded to our call to advance dementia science — and how you can help us achieve the national goal of treating and preventing Alzheimer's by 2025.



Thank you for your continued generosity. Your leadership and support are not only deeply appreciated, they are essential to our ability to drive this cause forward.

Sincerely,

A handwritten signature in blue ink, appearing to read 'Harry Johns', written over a white background.

Harry Johns
President and CEO
Alzheimer's Association

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ALZHEIMER'S ASSOCIATION
ASPIRE
PHILANTHROPY MAGAZINE

Private philanthropy is the driving force behind the care, support and research efforts of the Alzheimer's Association — and you are a valued and instrumental partner in our fight against this disease. We are committed to investing your contributions efficiently and effectively, while connecting you with the outcomes you help us achieve.

COVER PHOTO
Zenith Society member
Sheila Konar at her home
in Rochester, New York.

Philanthropy in Action

HOAG RECEIVES ASSOCIATION'S TOP PHILANTHROPY AWARD



Dr. Maria Carrillo, Alzheimer's Association chief science officer, and Mikey Hoag



Jay and Mikey Hoag

Michaela “Mikey” Hoag of Atherton, California, received the Jerome H. Stone Philanthropy Award for Alzheimer’s Research during the Alzheimer’s Association International Conference® 2017 in London. This annual award, which honors the legacy of the Association’s primary founder, recognizes individuals and organizations that have made a significant impact in the global Alzheimer’s research field through their philanthropy efforts.

In partnership with the Association, Hoag launched Part the Cloud in 2012 to advance critically needed Alzheimer’s research and raise awareness of the disease. Since its inception, the movement has generated more than \$20 million in funding. Part the Cloud awards are specifically designed to accelerate the transition of findings from the laboratory into possible therapies — an area of Alzheimer’s research where promising ideas often stall due to lack of funding.



2017 Part the Cloud luncheon committee

“Mikey Hoag is a passionate and relentless champion,” says Harry Johns, Alzheimer’s Association president and CEO. “We are deeply appreciative of her leadership and commitment.”

ZENITH SOCIETY CONTINUES TO GROW



Clay and Debbie Jones, Zenith Society co-chairs, with John Beuerlein

The Association's Zenith Society represents the highest and most involved level of giving to advance Alzheimer's care, support, research and advocacy. Members join the society with a gift of at least \$1 million, setting the bar for philanthropic leadership, engagement and impact.

The Zenith Society welcomes:

» **John and Crystal Beuerlein** –
St. Louis, Missouri

» **Ronni Fallows** –
Bainbridge Island, Washington

» **Bob Gross and Nadine Pike**,
dedicated by **Cheryl Gross** –
Walnut Creek, California

» **Jeanne N. Hunter** –
Richmond Heights, Missouri

» **Vicky Patel** –
Saratoga, California

» **Patrick and Jaleh Peyton** –
Miami Beach, Florida

» **Dan and Diane Riccio** –
Los Gatos, California

EISENBERG FAMILY TRUST CONTINUES GENEROUS SUPPORT

The **Eisenberg Family Trust**, a longtime philanthropic leader in the fight against Alzheimer's, has continued its support of the Association's policy efforts with a recent gift of \$255,000 to the National Alzheimer's Project Act (NAPA) Implementation Project.

In addition to funding numerous policy and research-related initiatives, the trust has worked with the Association since 2011 to encourage the federal government to implement an effective national Alzheimer's disease strategy under the guidelines of the plan.

The trust's latest gift will facilitate engagement with Congress and federal executive agencies to address the Alzheimer's crisis, specifically focusing on efforts to increase the federal Alzheimer's research investment, create early detection and care-planning initiatives, and implement state policy priorities.

DONORS DOUBLE THEIR IMPACT WITH MATCHING GIFT CHALLENGES

Matching gift challenges — in which a donor pledges a certain amount if the same sum or more is raised by a determined date — offer donors an opportunity to double the impact of their contributions and inspire others to give. Matching gift challenges, including two extraordinary campaigns, yielded nearly \$15 million this past year.

The **Kahlert Family Foundation** pledged a \$210,000 matching gift. Donors rose to the challenge — and then some — giving more than \$2.3 million, over 10 times the foundation's original request.

Cheryl Gross honored her mother, who she lost to Alzheimer's disease in 2011, by establishing a \$1 million matching gift challenge. Donors responded overwhelmingly by contributing more than \$8 million.

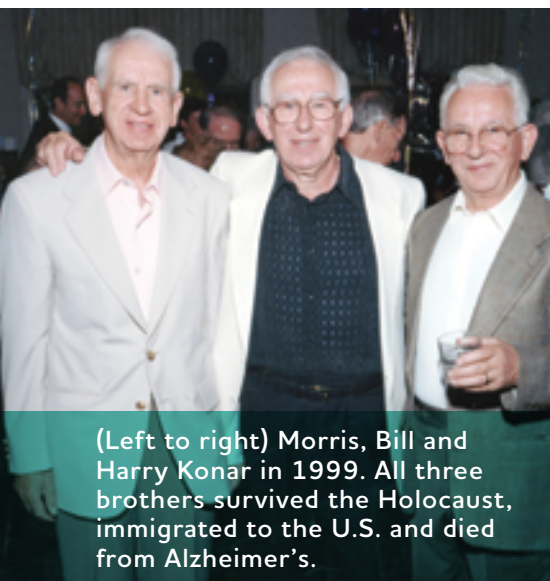


Greg and Roberta Kahlert



Cheryl Gross and her mother, Nadine

Husband's Fighting Spirit Inspires Commitment to Cause



(Left to right) Morris, Bill and Harry Konar in 1999. All three brothers survived the Holocaust, immigrated to the U.S. and died from Alzheimer's.

"We had the life dreams are built on. Then this terrible disease changed everything."

-SHEILA KONAR

William "Bill" Konar used to take one look at a map and drive straight to his destination. With a natural aptitude for numbers, he could calculate square roots in his head with ease. But when he began confusing directions and experiencing difficulty with simple math, Bill and his family knew something wasn't right.

"He was a brilliant man," says his wife, Sheila. "Alzheimer's was the last thing I expected, but unfortunately, after a series of doctor visits, the diagnosis was confirmed."

The Konars had to face the devastating reality that there is no defense against Alzheimer's — even Bill's intelligence, resilience and strength from overcoming a perilous childhood couldn't stop the disease.

Born in 1929 in Radom, Poland, Bill was only 4 when he and his three older siblings lost their father. After the German invasion of Poland during World War II, Radom's Jewish population was separated into labor and concentration camps. Bill and his brothers were ordered

into a 100-mile march and, at its end, sent to a work camp outside Stuttgart, Germany. He never saw his mother and sister again.

In 1946, a year after American troops liberated the camp, Bill immigrated to the United States as a teenage orphan. He settled in Rochester, New York, where he and Sheila met and fell in love. In 1954, they married and started a family.

Despite the tragedies he endured as a Holocaust survivor, Bill pursued his dreams with unbreakable ambition. A skilled salesman and innovative entrepreneur, he started a chain of discount drugstores that later became CVS and established a successful real estate development company.

As his businesses thrived, so did his passion for philanthropy. Bill became a founding member of the U.S. Holocaust Memorial Museum in Washington, D.C. As a result, he and Sheila socialized with dignitaries and world leaders, often hosting them in their home. Bill lived for what he loved most: his family, his country and his business. →





Sheila and Bill Konar on their wedding day in 1954

“Becoming a caregiver — that’s when I became who I was supposed to be. My new self astonished me.”

-SHEILA KONAR

“We had the life dreams are built on,” Sheila recalls. “Then this terrible disease changed everything.”

Bill was diagnosed with Alzheimer’s in 2000. Unsure of what to expect, Sheila turned to the Alzheimer’s Association for support and information. Sheila immersed herself in literature about the disease and articles on the latest research, even attending the Alzheimer’s Association

International Conference when it was held in Boston.

“Becoming a caregiver — that’s when I became who I was supposed to be,” Sheila says. “My new self astonished me.”

In 2007, determined to help other families facing the disease, Sheila and Bill made a \$1 million gift to the Association and became members of the Zenith Society, the organization’s highest and most involved level of philanthropy.

Bill passed away in June 2015, but Sheila remains committed to fighting Alzheimer’s.

“I have to continue what I’m doing and hope that others will do the same,” she says. “There’s no way to cure this disease without money.”

In 2017, Sheila took her giving to another level by joining the Association’s Founders Society, naming the organization in her estate.

“Sheila is one of the most passionate people I know,” says Teresa Galbier, president and executive director of the Rochester and Finger Lakes Region Chapter. “She faced so much heartbreak and adversity during Bill’s journey with Alzheimer’s, but she remains committed to the Association’s vision of a world without Alzheimer’s.”

Learn more about estate giving opportunities at alz.org/founders.



Jeff Borghoff: My Alzheimer's Story

When I was diagnosed with younger-onset Alzheimer's disease at the age of 51, my world came crashing down around me. But because of the Alzheimer's Association and its community of advocates, champions and supporters like you, I didn't give up.

In July 2015, I started experiencing some facial twitching and drooping. Despite my family history of Alzheimer's, doctors initially wrote the disease off as a potential diagnosis because I was so young. During almost a year of testing, I grew increasingly frustrated with my worsening symptoms: full-body twitching, memory loss, and trouble with speech and balance.

Eventually, my wife, Kim, who never quits on anything, contacted the department of Neurology at Columbia University Medical Center, where I received my diagnosis in March 2016.

Sharing the news with my children was extremely difficult. My youngest daughter, 18, was very vocal and angry. My middle daughter, 20, cried and said, "You're gonna forget me." This was devastating to hear. My son, 22, tried his best to deny I was ill. He finally accepted it and cried in my arms like a babe.

I'm overcome with sorrow thinking I'll leave my wife a widow and that I may never walk my daughters down the aisle or play with my grandchildren. I hate thinking of these things that will very likely be my reality.

But I've never been one to sit idle. A few days after my diagnosis, I said to Kim, "I want to do something about this."

My neurologist, Dr. Karen Bell, suggested we contact the Association. In doing so, we found valuable resources, such as alz.org and the ALZConnected® online community. Kim started attending a caregiver support group at the Delaware Valley Chapter. Thanks to the generosity of donors like you, these services and many more are free to families like mine.

We also took action. I became a member of the Association's National Early-Stage Advisory Group — individuals living in the early stage of the disease who share their perspectives, help reduce stigma, and advise the Association on programs and services. My family created an annual fundraising event called Walk to Remember in our hometown of Forked River, New Jersey, and I also participated in several Walk to End Alzheimer's® events, raising close to \$5,500. So many of my friends, family and community members came out to walk alongside me. The feelings of love and support were overwhelming.

My involvement with the Association has given me purpose and hope in my time of greatest need. It's been said that big things are done by a series of small things brought together. I know that, together, we can defeat this disease. 🌀

Advocates Drive State Plans to Address Alzheimer's



Lisa Griffin is a caregiver for her husband, who is living with dementia.



Ron Grant, who is living with Alzheimer's, and Herb Magley, a former caregiver, were vital contributors to Oklahoma's plan.

Alzheimer's Association advocate Lisa Griffin has always enjoyed the small-town feel of her home in Sioux Falls, South Dakota. However, when her husband, John, was diagnosed with frontotemporal dementia at age 49, a downside of living in the predominantly rural state became evident.

"When it came time to find a facility for John, there were some wonderful places," Griffin says. "But we were unable to find one with staff equipped to provide the specialized care we needed, especially to accommodate John's unique situation of living with dementia at such a young age. South Dakota just doesn't have the state-mandated training that other states have."

Griffin ultimately moved her husband, a former radiation oncologist, to a residential facility in Minnesota. She stays in a condo nearby so she can visit daily, but her permanent home and allegiance remain in South Dakota.

"Most people can't pick up and go elsewhere to get the care they need. And they shouldn't have to," says Griffin. "That's why I'm fighting so hard for a state Alzheimer's plan."

Currently, 46 states plus Washington, D.C., and Puerto Rico have state Alzheimer's disease plans — a testament to the dedication and efforts of the Association and its nationwide network of advocates. The plans, which outline short- and long-term services and supports for families affected by Alzheimer's

and other dementias, are essential to addressing the growing epidemic.

Working alongside the Association's South Dakota Chapter and other stakeholders, Griffin serves on the executive committee leading the effort to create the state's first Alzheimer's plan.

"The planning process has allowed us to connect with other like-minded groups, organizations, physicians and medical directors," says Leslie Morrow, executive director of the South Dakota Chapter. "We live in a vastly spread-apart state, but we're all in this together."

To help shape the plan, Griffin calls on her experiences as a caregiver.

"One day, as John and I were leaving for our daily car ride, I let him go out the door ahead of me as I lagged behind chatting with someone," Griffin says. "I came out to find a firefighter talking to John — and John can no longer speak. The firefighter had no idea why."

"We should be able to rely on first responders to help our loved ones with dementia in emergency situations, but they can't do that without proper awareness and education."



Lisa Griffin (center), an Alzheimer's Association Ambassador to Rep. Kristi Noem (R-S.D.) (left), along with fellow South Dakota advocate, Janice O'Connor (right).

However, the circumstances in South Dakota are different than in Oklahoma, where due to a well-established state plan, first responders take a mandatory training to identify people with dementia and appropriately respond. In addition, all University of Oklahoma medical students are required to participate in an Association education program that includes observation of support groups.

Ron Grant of Oklahoma City, an alumnus of the Association's National Early-Stage Advisory Group, was diagnosed with Alzheimer's in 2007. The outspoken advocate was instrumental in the creation and implementation of Oklahoma's state Alzheimer's plan in 2009 and its revision in 2016.

"After I was diagnosed, I didn't have a clue what to do or what to expect until I found the

"Most people can't pick up and go elsewhere to get the care they need. And they shouldn't have to. That's why I'm fighting so hard for a state Alzheimer's plan."

-LISA GRIFFIN

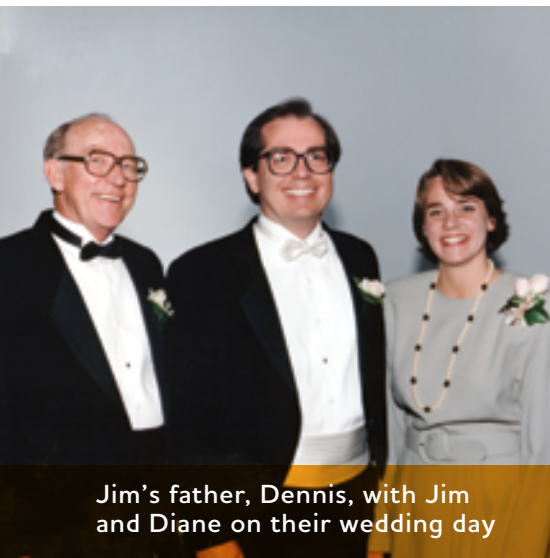
Association," Grant says. "The organization is a wonderful resource, but it can't be the only resource. States need to be prepared to face this crisis, and a state plan is the way to do it. We've proved that with the strides we've made in Oklahoma."

Herb Magley of Edmond, Oklahoma, also helped shape the revised state plan. After losing his wife to Alzheimer's in 2015, Magley became even more involved with the Association as a volunteer, advocate, Aspire-level donor and one of the top Walk to End Alzheimer's fundraisers nationally.

"The support I received from the Association during my 11 years as a caregiver saved my life, and I want to pay it forward," Magley says. "One way I can do that is by helping the Association lead the implementation of the Oklahoma state plan, so we continue to move in the right direction." ❧

Learn more at alz.org/stateplans.

Reaching Out to Rural Communities



Jim's father, Dennis, with Jim and Diane on their wedding day

Jim Prugh has a special place in his heart for small towns. As a child, he lived in Williams Bay, Wisconsin — a village with 1,500 people. In high school, his family moved to an even smaller community in Wyoming with a population of only 300. “My graduating class had 31 students, and I knew everyone whether I wanted to or not,” he jokes.

Although Jim lived and worked as an engineer around the world, he eventually settled in the Denver area and made a career shift to real estate development. He now renovates historic buildings in Lindsborg, Kansas, a 3,500-resident city that enchanted him during a family cross-country drive.

Despite the charm of small-town life, Jim knows it has challenges — a reality he faced when his widowed father, Dennis, was diagnosed with Alzheimer's disease at age 62.

“By their nature, rural communities are underserved,” says Jim, who moved Dennis from Illinois to suburban Denver to be closer to family and resources.

“When my father was diagnosed, our family experienced what many families do: confusion, frustration and anger, along with the extraordinary effort it takes to manage everything that an Alzheimer's diagnosis brings,” Jim says. “I think my anger forced me out of my comfort zone and to push the boundaries of what can and must happen, especially in the small towns that helped shape me.”

In 2016, Jim and his wife, Diane Fatheree, funded the Rural Outreach Alzheimer's Disease (ROAD) program — a pilot initiative led by the Alzheimer's Association Colorado Chapter to identify and address unmet needs in less-populated areas. “Through ROAD, we want to identify and remove the barriers that families like ours face,” Diane explains.

ROAD is a marketing-driven outreach program to raise awareness of Association services in four rural counties in eastern Colorado. To get the word out, information will be shared at schools, clubs, places of worship and libraries, as well as through social and print media. The program also seeks to



Diane Fatheree and Jim Prugh are dedicated to extending Alzheimer's outreach into rural Colorado.

create stronger partnerships with local health care providers and agencies; provide training and instruction for firefighters, police officers and other first responders; and recruit additional volunteers to facilitate support groups and care consultations.

Jim and Diane hope ROAD will serve as an inspiration, rather than a model, for donors in other areas of the country. "Every community is different, and what works in one may not in another," Jim says.

The couple's gift to create ROAD is a continuation of their long-standing philanthropic and visionary partnership with the Association. In 1998, Jim and his siblings joined the Zenith Society, the Association's highest and most involved level of giving, to fund cutting-edge research. Jim and Diane have

"I think my anger forced me out of my comfort zone and to push the boundaries of what can and must happen, especially in the small towns that helped shape me." -JIM PRUGH

served in volunteer leadership roles at chapter and national levels. In 2007, they started an initiative to increase participation in Walk to End Alzheimer's in the Southeast Wisconsin and Colorado Chapters by providing matching funds for each new walker or team in addition to every dollar raised above the previous year's fundraising total. To date, the Prugh Challenge has created much-needed awareness and raised nearly \$250,000 to benefit the Association's care, support and research efforts.

"It's hard for rural initiatives to gather momentum, but ROAD allows our chapter to build awareness of our services in outlying areas," says Gene Sobczak, executive director of the Colorado Chapter. "We're grateful to Jim and Diane for their partnership and vision." ∞

New Medicare Coverage Enhances Dementia Care



Ken and Barbara Johnson

“Families and individuals don’t have to feel lost or alone like we did. They’ll have resources to help them understand what they’re up against.”

-BARBARA JOHNSON

Ken Johnson, 76, of New Baltimore, Michigan, was diagnosed with mild cognitive impairment (MCI) in 2011 after three visits to two different doctors. He was taken aback by the way the second physician delivered the news to him and his wife, Barbara.

“The doctor sat down, looked at the papers in his hands and said, ‘Mr. Johnson, you have mild cognitive impairment,’” says Ken, an alumnus of the Alzheimer’s Association National Early-Stage Advisory Group. “He prescribed a couple medications to help my symptoms and told us to return in a year, then walked out. We were dumbfounded and left the office like two robots.”

“I said to Ken, ‘What the hell was that all about?’” Barbara recalls. “I spent the next day trying to learn everything I could about MCI. I was fueled by anxiety and frustration, wondering, ‘What do we do now?’”

THE IMPORTANCE OF DIAGNOSIS AND CARE PLANNING

Unfortunately, many families find themselves in the same situation as Ken and Barbara — with a diagnosis but unsure of what comes next. Even more alarming, many find themselves unaware of what they’re facing altogether: Only 33 percent of seniors age 65 and

older report being told of their Alzheimer’s diagnosis. Studies have determined one reason physicians are hesitant to diagnose or to disclose a diagnosis is because they lack time and resources to provide information and support.

To bridge this critical gap in dementia care, the Alzheimer’s Association and its advocates, along with the Alzheimer’s Impact Movement (the Association’s 501(c)(4) sister organization), recently led the way to a major victory that provides access to care planning for people facing the disease.

Thanks to a decision by the Centers for Medicare & Medicaid Services, Medicare began covering cognitive and functional assessments and care planning for patients with Alzheimer’s and other cognitive impairments in January 2017. The decision followed rapidly growing bipartisan support in Congress for the HOPE for Alzheimer’s Act.

SUPPORT FROM HEALTH CARE PROVIDERS

Under this new coverage, physicians, physician assistants, nurse practitioners, clinical nurse specialists and certified nurse midwives can be reimbursed for a wide range of detailed care planning that includes evaluating cognition



and function, identifying caregiver needs, assessing care directives, planning for palliative care and referrals to community services.

“For far too long, individuals were given a diagnosis and little else,” says Beth Kallmyer, Alzheimer’s Association vice president of Constituent Services. “Proper care planning results in fewer hospitalizations, fewer emergency room visits and better management of medication — all of which improves the quality of life for both patients and caregivers, and helps manage overall care costs.”

TOOLS FOR CLINICIANS

To help clinicians implement care planning services covered by Medicare, the Association, with input from an expert task force, developed the Cognitive Impairment Care Planning Toolkit (alz.org/careplanning). The toolkit provides easy access to validated measures, such as the Mini-Cog™ cognitive impairment screening tool and the Dementia Severity Rating Scale, and includes newly designed assessment tools, such as the Safety Assessment Guide and Checklist, Caregiver Profile Checklist and End-of-Life Checklist.

HEADED IN THE RIGHT DIRECTION

Task force member Dr. Soo Borson, research professor of Neurology at the University of Minnesota, a practicing physician and a developer of the Mini-Cog, calls Medicare’s reimbursement of care planning “a revolutionary step in the right direction.”

“The main difficulty providers have had with cognitive screening has been their lack of comfort with what to do next. This gives them the answer they’ve been looking for,” Dr. Borson says. “People who may develop Alzheimer’s or another form of cognitive impairment and dementia will benefit from the advance preparation taken to design effective and efficient ways of meeting patients’ and families’ needs.”

Barbara Johnson is optimistic. “Families and individuals don’t have to feel lost or alone like we did,” she says. “They’ll have resources to help them understand what they’re up against and tools to continue to live a full life.” 🐾

Learn more at alz.org/medicare.



ABOUT THE HOPE FOR ALZHEIMER’S ACT

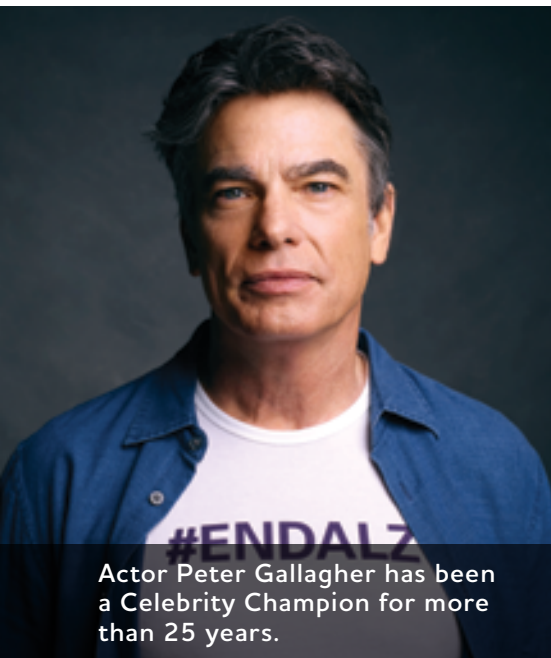
The bipartisan Health Outcomes, Planning, and Education (HOPE) for Alzheimer’s Act was designed to provide comprehensive care planning services for individuals diagnosed with dementia and their caregivers. The Centers for Medicare & Medicaid Services (CMS) included the largest element of this legislation — coverage of care planning — in its general rule update in July 2016.

The Alzheimer’s Association and the Alzheimer’s Impact Movement played an instrumental role in achieving this milestone. Association advocates and staff have held thousands of congressional meetings to secure support for the HOPE for Alzheimer’s Act since the bill’s introduction in 2009, providing expertise on how clinician reimbursement for care planning would positively impact people living with cognitive impairment.

The Association will continue to work with CMS to ensure the ruling has maximum impact for everyone affected by the disease.

Learn more at alz.org/hope.

Dedicated to Ending Stigma



Actor Peter Gallagher has been a Celebrity Champion for more than 25 years.

“Alzheimer’s is excellent at making everyone involved feel powerless and alone. That’s why I think the Association is so important, because it’s somewhere you can turn to counter those feelings and take action.”

-PETER GALLAGHER

When actor Peter Gallagher was young, his grandmother, who was living with Alzheimer’s disease, frequently wandered the streets of their New York neighborhood. He often had to search for her, occasionally encountering classmates who teased him for her behavior. Unwilling to accept their judgment, Gallagher engaged in a scuffle or two.

As an adult, Gallagher, whose recent work includes television hits “Law & Order: SVU,” “New Girl” and “Grace and Frankie,” came face-to-face with Alzheimer’s again when his mother, Mary Ann, was diagnosed. As the disease progressed, the family lost their “navigator in life.”

“When my mother started to decline, we struggled,” Gallagher says. “I was surprised at the depths of feeling defeated. We tried to cope and adjust, but our family was never the same.”

Searching for an antidote to his feelings of helplessness, Gallagher reached out to the Alzheimer’s Association in the early 1990s and became a Celebrity Champion. More than 25 years later, he continues to be an outspoken supporter committed to fighting stigma and rallying others around the cause.

“Alzheimer’s is excellent at making everyone involved feel powerless and alone,” he says. “That’s why I think the Association is so important, because it’s somewhere you can turn to counter those feelings and take action.”

Gallagher’s steadfast commitment has spanned a broad range of activities. Most recently, he served as emcee of the National Alzheimer’s Dinner, part of the 2017 Alzheimer’s Association Advocacy Forum. From the first show in 1992 to the last in 2016, he was a regular on stage at “A Night at Sardi’s,” a celebrity musical revue and awards dinner benefiting the Association. Gallagher has also participated in Walk to End Alzheimer’s, helping to raise critical awareness.

Gallagher embraces opportunities to share his family’s story with the hope that others will be empowered to do the same.

“We have to ignore any concern that we’ll be judged because pretty soon, there won’t be anyone in our country who doesn’t know someone with Alzheimer’s,” he says. “It’s important for all of us to take action now.”

Family First in Fight Against Alzheimer's

In 2015, Richard Lui knew he would have to make a career move if he wanted to help care for his father, who had been diagnosed with Alzheimer's disease.

Reducing on-air time should have been a difficult decision for a TV journalist in the prime of his career, but it wasn't for Lui. "Considering what my family was facing, going from full- to part-time was pretty logical. Logical isn't even the right word. The right thing to do was just 'in the air,'" he says.

Today, Lui literally spends a lot of time in the air, flying weekly from New York, where he's MSNBC's weekend dayside anchor, to San Francisco, where he helps his mother and three siblings care for his father. He is one of more than 15 million Americans caring for someone with dementia without compensation.

"Family caregivers represent the largest working group in America, but they're unpaid and unnoticed," says Lui, an Alzheimer's Association Celebrity Champion. "We have to find a way to make this part of our conversation. If I can get one person to understand this by sharing my story, then maybe their energy can help bring us closer to solutions."

Lui's approach to caregiving focuses on education. After his father's diagnosis, he set out to learn as much as he could about the disease.

"I've found that the best way to understand Alzheimer's, especially as a long-distance caregiver, is to stay overnight," he says. "Seeing my father get up five, six, seven times to use the bathroom or take a shower really puts into perspective how difficult this disease is, particularly on the caregiver. If I just came for dinner, I wouldn't fully appreciate what my mother is going through."

In his quest for knowledge, Lui has found a trusted source in the Alzheimer's Association. He recently consulted the Association's website, alz.org, and discovered that his father's difficult behavior in the evening was likely due to sundowning, a syndrome that causes increased confusion, anxiety, agitation and disorientation late in the day. The Lui family takes comfort in the Association's reliable and easily accessible resources.

Laughter has also brought solace to the family. "I believe that when you laugh at someone's foibles, you've reached the point of true love," Lui says. "I can't help but smile as my once emotionally reserved father now kisses and hugs me, and tells me he loves me every 30 seconds. He's the happiest he's been in his entire life." 🌸



Celebrity Champion and MSNBC anchor Richard Lui is an active supporter of the cause.

"Family caregivers represent the largest working group in America, but they're unpaid and unnoticed. We have to find a way to make this part of our conversation."

-RICHARD LUI

Risk Factors and Prevention: What We Know



Dr. Maria Carrillo

Everyone with a brain is at risk for developing Alzheimer's and researchers are continuing to uncover more information. Alzheimer's Association Chief Science Officer Maria Carrillo, Ph.D., discusses some known risk factors and how this knowledge may lead to possible prevention and treatment strategies.

Q. WHAT ARE THE BIGGEST RISK FACTORS FOR ALZHEIMER'S DISEASE?

The greatest risk factor is increasing age: After age 85, the risk reaches nearly 50 percent. The next strongest risk factor is family history. Those who have a parent, brother, sister or child with Alzheimer's are more likely to develop the disease, and the risk increases if more than one family member has the illness. However, we are learning every day that Alzheimer's risk is influenced by both genetics and lifestyle.

Thanks to our philanthropic supporters, we've launched a number of research projects that could help clarify these factors. The Longitudinal Evaluation of Amyloid Risk and Neurodegeneration (LEARN) study is following cognitively normal volunteers to see who develops signs of Alzheimer's — and when. LEARN could lead to the creation of Alzheimer's risk profiles in the way the Framingham Heart Study led to risk profiles for heart disease. And our Women's Alzheimer's Research Initiative is funding scientists studying biological, genetic, epidemiological

and lifestyle factors that may explain why Alzheimer's affects women disproportionately.

Q. HOW MUCH OF A ROLE DOES HEREDITY PLAY?

For most people, genetics contribute to their risk of Alzheimer's by an estimated 5 to 50 percent, and for a very small minority the risk is nearly 100 percent. We know this thanks in large part to initiatives the Association has invested in, including the International Genetics of Alzheimer's Project, which identified an additional 20 genes associated with the disease. We also helped fund the whole genome sequencing of more than 800 people living with Alzheimer's, which generated an unprecedented amount of new genetic data.

We expect to learn even more through a new study we're funding. The Amyloid Neuroimaging and Genetics Investigation will collect and analyze DNA samples from 3,000 individuals who are undergoing imaging of their brain. We believe this project has tremendous potential to further define the role genetics play in Alzheimer's and other dementias.



Mikey Hoag, Dr. Roberta Brinton, Carol-Ann O'Mack, Elizabeth Gelfand Stearns, Lisa Fedler Swiontek, Sarah Womble and Dana Eckert are among the leaders of the Women Alzheimer's Research Initiative.

Q. HOW ARE GENETICS HELPING TO GUIDE PREVENTION TRIALS?

Researchers are using a growing understanding of Alzheimer's genes to make clinical trials and other studies more targeted and, we hope, effective. For example, the Dominantly Inherited Alzheimer Network Trials Unit (DIAN-TU) is testing whether experimental Alzheimer's treatments can prevent the disease in people who inherit one of several rare genetic mutations that cause Alzheimer's in almost 100 percent of these individuals. Because the age of Alzheimer's onset is predictable for this population, we should be able to tell whether the drugs are having an impact. Even though we are testing in individuals with familial Alzheimer's, we believe a treatment that works for them could also prevent the kind of Alzheimer's that the majority of people are at risk of getting.

Q. CAN I DECREASE MY RISK OF COGNITIVE DECLINE?

More and more research indicates that what's good for the heart is good for the brain, and there's growing evidence that mental and social activity can increase cognitive resilience as well. For instance, the Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER) study found that individuals who are at a higher risk of developing Alzheimer's showed improvements in memory and other thinking skills after just two years of combining diet, exercise and other lifestyle interventions.

Recently, the Association announced the launch of a \$20 million clinical trial replicating the FINGER model. The large U.S. study, Protect Brain Health Through Lifestyle Intervention to Reduce Risk (U.S. POINTER), aims to test FINGER's promising prevention strategy on a larger, more diverse population. We're now seeking philanthropic partners to advance this work. 🌀

“Our Women’s Alzheimer’s Research Initiative is funding scientists studying biological, genetic, epidemiological and lifestyle factors that may explain why Alzheimer’s affects women disproportionately.”

-DR. MARIA CARRILLO

Email leadershipgiving@alz.org or call **800.272.3900** to learn how you can advance research into risk factors and prevention.

Businessman's Legacy Inspires Family Fund



Diane Dean (far right) with Alzheimer's Association President and CEO Harry Johns and Dr. Mehul Trivderi

"[Howie] would be very pleased that money given in his name is helping researchers seek answers for those facing Alzheimer's."

-DIANE DEAN

Above all else, people were important to Howard "Howie" M. Dean, former CEO of Dean Foods.

"Howie was very generous and always donated to causes that would improve people's lives," says Diane Dean, his wife of 52 years. Sadly, Howie's vibrant life was shadowed in his final years by Alzheimer's before he died of a heart attack in 2012.

"When Howie developed the disease, he turned inward, he wasn't himself. He didn't want to be with people he didn't know," Diane says. "That was so unusual because he loved to meet people. He stopped shooting skeet and golfing — two of his passions. He would just sit and stare out the window. It was very hard for us to see this former head of a Fortune 500 company and loving family man disintegrate in front of our eyes."

As the third-generation leader of Dean Foods, Howie enjoyed meeting and encouraging employees across the company, but he was also a fun-loving father and grandfather. He spent weekends

and vacations teaching younger family members to golf and water-ski.

"Our children and grandchildren still talk about Howie regularly. He was an example to them," says Diane. "He always seemed to do the right thing."

Howie placed great value on his friendships. He met Sandy McNally and John Keller in the early 1970s when he joined the Young Presidents' Organization, a networking group for corporate leaders. "We got to know each other well," John says. "We exchanged ideas about business and life."

Their discussions evolved from sharing management strategies to celebrating grandchildren and supporting each other through tragedies. Alzheimer's was no exception: Sandy's mother died with the disease, and all three friends knew others touched by it. But when Howie was diagnosed, it brought Alzheimer's into their lives in a new way.



Howie and Diane Dean

“It’s always a shock, especially when it’s your peer,” says John. “We knew he was slipping, but it’s hard to tell what’s happening when you don’t see someone every day,” adds Sandy.

After Howie’s death, Sandy, John and Diane wanted to honor him. “We threw around the idea of a bench in a park with his name on it, but for Howie we knew we had to do more,” says John.

They worked with the Alzheimer’s Association to create the Howie Dean Fund, which supports early career researchers through the Association’s International Research Grant Program. Establishing a family fund to fight Alzheimer’s was the best way to honor the dynamic and devoted husband, father, grandfather and friend that dementia stole from them. Howie

is with his loved ones in spirit as they sit down with scientists to discuss projects and progress the fund supports.

“It’s terrific to meet the researchers and hear how they’re advancing this fight with our funding,” John says. “It gives you hope.”

Hope is a legacy that would make Howie proud.

“He would be very pleased that money given in his name is helping researchers seek answers for those facing Alzheimer’s,” says Diane. “I’m so grateful to honor Howie in this way.” ☯

STUDIES SUPPORTED BY THE HOWIE DEAN FUND

INHERITED RISK FACTORS

Mehul A. Trivderi, Ph.D.

Rush University Medical Center

- » How do inherited risk factors, including a parent with Alzheimer’s and risk genes, affect cognitive efficiency in middle age?
- » Results may find ways to detect and predict risk for Alzheimer’s, so when treatments become available they can start earlier.

PROTEINS AND SIGNALING PATHWAYS

Carole Deyts, Ph.D.

University of Chicago

- » How do certain protein fragments activate signaling pathways in nerve cells?
- » Results may uncover targets for potential new drugs to slow or prevent brain damage in Alzheimer’s disease.

ONLINE SPEECH THERAPY

Emily Joy Rogalski, Ph.D.

Northwestern University

- » Speech therapy may help people with Alzheimer’s maintain their ability to communicate. The study aims to improve access to care with personalized internet video speech therapy sessions.
- » Results could offer evidence to modify insurance coverage for speech therapy.

Family Charts Course Through Alzheimer's



Eleanor Campbell

“She just couldn’t understand or follow along as well as she used to — and she was an incredibly bright person.”

-LEE CAMPBELL SR.

For much of their 60-year marriage, Judge Levin “Lee” Campbell Sr. and his wife, Eleanor, would spend their summer vacations sailing the Atlantic Ocean along the coast of Maine. The Cambridge, Massachusetts, couple also embarked on voyages to locales such as Bermuda and Halifax, Nova Scotia.

Eleanor often served as captain thanks to her nautical skills.

“If we had difficulty getting the boat to sail as well as it could, I’d turn it over to her because she was a better sailor than I was,” Lee says. “She did a lot of racing as well. My job was to carry home the hardware she won at the end of the summer.”

But when Eleanor was diagnosed with Alzheimer’s in 1997, Lee and their three children — Eleanor, Levin “Lee” Jr. and Holly — knew they would eventually have to take over as navigators.

Eleanor was high functioning in the early stage of the disease, to the point that Lee wondered if there was another explanation for her memory lapses.

“There were days when she’d be very good, and I’d question whether she was ill at all. I would think maybe it was just an illusion,” he says. “Then the next day would be worse and I’d realize there really was a problem.”

Eleanor’s symptoms began as difficulty performing simple tasks such as balancing the checkbook or buying food. “She would bring groceries home and later ask, ‘Where did these come from?’” Lee says.

Lee Jr. would often accompany Eleanor, a former teacher, to hear authors speak about subjects ranging from travel to music. It was during one of these talks when he started to realize his mother wasn’t quite herself. “She’d complain increasingly that she couldn’t



Lee Campbell Sr. and Eleanor enjoying sailing, their favorite pastime.

hear, even though the sound was well amplified,” he says. “She just couldn’t understand or follow along as well as she used to — and she was an incredibly bright person.”

Soon after Eleanor’s diagnosis, the family found the Alzheimer’s Association in a way that seems quaint in the digital age: Holly spotted the Massachusetts/New Hampshire Chapter’s sign while driving past the office.

“At that point, I was buying every book on the shelf about Alzheimer’s, so I decided to call,” she says. “I discovered this class the Association was offering and I didn’t even know what I was going to be learning. I remember just being blown away; we learned so much. It also functioned a bit as a support group. You went, ‘Oh, I’m not the only one dealing with this.’”

The Association became a go-to resource for the family over the years, offering guidance in 2006 when they decided it was time to choose a care

“This disease is very hard on families.

One minute you’re dealing with a perfectly bright, functional, intelligent person, and the next minute they’re having these difficulties.

How do you handle it? ...

The Association has been very helpful to us and to others.”

-LEE CAMPBELL SR.

facility for Eleanor, where she still resides today. Grateful for the assistance, the family began donating to the Association, both personally and through their foundation.

Their gifts help fund the Massachusetts/New Hampshire Chapter’s dementia care coordination program, which encourages health care providers to refer affected families to the Association for care and support services.

“This disease is very hard on families,” Lee says. “One minute you’re dealing with a perfectly bright, functional, intelligent person, and the next minute they’re having these difficulties. How do you handle it? Most of us don’t have the knowledge we’ll need. The Association has been very helpful to us and to others.” ☪

Forget Me Not Days Still Blooming



Scott Goldberg, Bankers Life president (right), collects donations.

“With Alzheimer’s devastating effects on the baby-boomer population, Bankers Life is committed to supporting the important work of the Alzheimer’s Association.”

-SCOTT GOLDBERG

When Bankers Life volunteers first started handing out packets of flower seeds to raise awareness and funds for the Alzheimer’s Association in June 2003, they couldn’t have imagined how their grassroots initiative, Forget Me Not Days, would flourish.

Over the past 15 years, the two-day fundraiser has grown from seven cities to more than 170 and has raised nearly \$5 million to benefit the Association’s care, support and research efforts.

As a firm that focuses on the life and health insurance needs of middle-income Americans who are in or near retirement, Bankers Life recognizes the impact Alzheimer’s will have on its clients. Each year, Bankers Life and its parent company, CNO Financial Group, kick off the Forget Me Not Days campaign with a generous corporate donation.

“Alzheimer’s disease is a real concern for many of our customers,” says Bruce Baude, executive vice president of CNO Financial Group. “Many of our associates and agents have experienced its effects in their families or have known customers affected by the disease. Forget Me Not Days is a way to plant a seed of hope in their local communities.”

On June 2 and 3, during Alzheimer’s & Brain Awareness Month, 1,600 volunteers nationwide, mostly Bankers Life agents and associates, took to the streets with donation canisters and flower seeds while donning green Forget Me Not Days aprons. The fundraiser is simple: Passersby drop a donation in the canister and receive a packet of flower seeds that can be planted in honor of the more than 5 million Americans living with Alzheimer’s. However, the volunteers come away with much more than donations for the cause.

“Our agents and associates really value the opportunity to connect directly with individuals



Bankers Life agents and associates hit the streets of Chicago to collect donations for the Association during the Bankers Life Forget Me Not Days event.

in the community one person at a time,” says Baude, who serves as board president of the Association’s Greater Indiana Chapter in addition to his role at CNO. “People will share a personal story from their own experience as they put a few dollars or coins into the collection can. It creates an emotional connection that’s very powerful.”

In its 15-year history, Forget Me Not Days has grown to multiple channels: In addition to street campaigning, the event includes an online component, creating an alternate way for people to make a contribution. For the past six years, the event has featured a grand kickoff with Alzheimer’s Awareness Night at Bankers Life Fieldhouse in Indianapolis during an Indiana Pacers game.

“Many of our associates and agents have experienced its effects in their families or have known customers affected by the disease. Forget Me Not Days is a way to plant a seed of hope in their local communities.”

-BRUCE BAUDE

The first 5,000 fans receive forget-me-not flower seeds and enjoy special activities around the stadium, which goes purple for the night — even the cotton candy. For each sale of the limited-edition purple treat, Bankers Life donates \$1 to the Association.

“The momentum behind the Alzheimer’s cause is due in large part to innovative partners like Bankers Life,” says Donna McCullough, Alzheimer’s Association

chief development officer. “This dedicated organization and its volunteers raise critical funds and awareness across the country while encouraging others to join our movement, and we are so thankful for their support.”

Celebrating 30 Years of Fundraising



Princess Yasmin Aga Khan established the Rita Hayworth Gala in 1984 as a tribute to her mother, the renowned actress who lived with Alzheimer's for many years before passing away in 1987. Under Princess Yasmin's leadership, more than \$72 million has been raised through the Chicago and New York Rita Hayworth Galas, and the Palm Beach Rita Hayworth Luncheon. These funds have greatly accelerated the Association's progress in its mission to eliminate Alzheimer's disease.

The 30th annual Alzheimer's Association Chicago Rita Hayworth Gala was held May 13. The event theme, "The Big Picture," acknowledged progress as well as the work still needed to eliminate Alzheimer's disease.

Thanks to the generosity of the over 800 philanthropists, civic leaders and advocates in attendance, and many dedicated sponsors, more than \$1 million was raised to advance the Association's care, support and research efforts.

Gala Chairs Betsy and Dave Goltermann led a large planning committee to produce an elegant and energetic event that had guests dancing long into the night. The Goltermanns became involved with the gala to honor Betsy's mother, who had dementia, and her father who was his wife's caregiver.

"This cause is personal and urgent to our family," says Dave, who also serves as vice chair of the Association's National Board.

Princess Yasmin Aga Khan, Rita Hayworth's daughter, returned as general chair for the event. Jon Harris, senior vice president and chief communications officer for ConAgra Brands, served as emcee.

The Murphy family — Daniel and JoAnn, along with sons Dan and Jim — accepted the Alzheimer's Association Family Philanthropy Award. After his grandmother passed away from Alzheimer's in 2011, Dan joined the Rita Hayworth Gala Young Champions Committee, and Jim soon followed, bringing a younger generation to the cause. In 2012, Daniel and JoAnn became Champion Sponsors of the gala and their annual support has helped drive the event to the next level.

RECOGNIZING CATHY EDGE

Association volunteer Cathy Edge accepted the Civic Award for her extraordinary contributions over nearly two decades. Cathy has had a significant impact on the cause as a fundraiser, Aspire Society-level donor, advocate and tireless volunteer leader on the boards at



(Left to right) Jon Harris, James Murphy, Dan Murphy Jr., Daniel Murphy Sr., JoAnn Murphy, Blaise Labriola, Princess Yasmin Aga Khan, Cathy Edge, Ken Edge, Betsy Goltermann, Dave Goltermann

both the Greater Illinois Chapter and the national level.

Cathy's father was diagnosed with Alzheimer's in 1997, and soon after she began to look for opportunities to get involved with the cause. "I read that the Alzheimer's Association had opened up an office in Rockford," Cathy recalls. "I walked in and said, 'I need to volunteer.'"

As she grew in her work with the Association, Cathy also managed her father's increasing care needs. She was heartbroken when she had to move him to a nursing facility. "I will remember that day and the sadness I felt until I die," she says. However, she was grateful for the information she received from the Association, which helped her advocate for her father's well-being while he received long-term care.

Cathy's father passed away in 2001, but she continued serving as an active board and committee member. One of Cathy's key achievements was raising a then-record-breaking amount through the 20th annual Chicago Rita Hayworth Gala, which she co-chaired with her husband, Ken. Cathy has also made personal contributions to the Association, including a major, multi-year pledge to the Dominantly Inherited Alzheimer Network Trials Unit (DIAN-TU). Other highlights include: participating in 16 Advocacy Forums, joining other advocates to help pass the National Alzheimer's Project Act and increase research funding; and supporting the growth of Association programs, including the 24/7 Helpline and TrialMatch®.

"I am so honored to accept this award on behalf of all those living with Alzheimer's, their families and caregivers," Cathy remarked at the gala. "I will battle this disease until there is a cure or a treatment. My greatest hope is that my grandkids will one day live in a world without Alzheimer's disease." ❧

"I will battle this disease until there is a cure or a treatment. My greatest hope is that my grandkids will one day live in a world without Alzheimer's disease."

-CATHY EDGE

Country Music Artists Get Funky to Benefit the Association

On June 4, musical worlds collided at Nashville's Wildhorse Saloon during a new event benefiting the Alzheimer's Association.

Created by Association Celebrity Champion Kimberly Williams-Paisley and Blair Garner of "The Blair Garner Show," the high-energy event featured Williams-Paisley's husband, Grammy Award-winning country singer-songwriter Brad Paisley, Charles Esten, Hunter Hayes, Jerrod Niemann and other artists performing disco hits from the '70s and '80s in front of a packed house. The evening raised more than \$300,000.

Williams-Paisley started this one-of-a-kind event in honor of her mother, who died from Alzheimer's in 2016.

"After we lost my mom to this devastating disease, we wanted to help raise more awareness and funds for research," says Williams-Paisley. "What better way to do that than to harness the amazing talent here in Nashville? All of the performers showed their funky side for a great cause." 🐾



Eric Garner and Blair Garner



Brad Paisley



Kimberly Williams-Paisley and Brad Paisley



Hunter Hayes



All Disco Party performers

UPCOMING EVENTS



OCTOBER 24, 2017

New York Rita Hayworth Gala

Cipriani 42nd Street

New York, NY

alz.org/galas/NY



SPRING 2018

Palm Beach Rita Hayworth Event

Palm Beach, FL

alz.org/palmbeach



APRIL 28, 2018

Part the Cloud Gala

Rosewood Sand Hill

Menlo Park, CA

alz.org/partthecloud



APRIL 29 – MAY 1, 2018

Alzheimer's Association Advocacy Forum

Washington, D.C.

alz.org/forum



MAY 12, 2018

Chicago Rita Hayworth Gala

Hilton Chicago

Chicago, IL

alz.org/galas/chicago



Alzheimer's Association
225 N. Michigan Ave., Fl. 17
Chicago, IL 60601



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The Alzheimer's Association is the leading voluntary health organization in Alzheimer's care, support and research. Our mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

Our vision is a world without Alzheimer's®.