THE FIRST SURVIVOR OF ALZHEIMER’S DISEASE IS OUT THERE

But we won’t get there without you.

alzheimer’s AWARENESS guide

2018 – 2019

alzheimer’s association

Heart of America Chapter
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Visit www.VillageShalom.org to learn more.
Welcome to this issue of the Alzheimer’s Awareness Guide, filled with informative content for anyone interested in learning more about Alzheimer’s disease.

Advertisers in this Guide are featured sponsors of Walk to End Alzheimer’s®, the signature fundraiser of the Alzheimer’s Association. We thank these sponsors for helping us to increase awareness of this devastating disease and raise funds for care, support, and research.

Thank you for taking the time to learn more. We are pleased to bring this Guide to you and all those affected by Alzheimer’s disease in the communities we serve.

BUILDING BRIDGES THAT LEAD TO THE FIRST SURVIVOR

We all bring personal experience to our volunteer work. I’m an engineer by profession; one of my specialties at Burns & McDonnell is working on complex bridges. I look at connections — how do we get people from here to there?

As President of the Board of Directors for the Heart of America Chapter, I ask the same question. The Alzheimer’s Association believes the first survivor of Alzheimer’s disease is out there. The question is: How do we get there?

We get there by moving forward. Together.

This Awareness Guide is filled with wonderful stories of people who are making connections and moving us forward. Our local young champions are raising funds with creative, personalized events that honor loved ones with Alzheimer’s. Our volunteers are active throughout the communities we serve, and in Washington, D.C. Reading their stories renews our hope for the future.

Realistic hope is a recurring theme throughout this Awareness Guide. For example, you’ll learn more about the 2018 Alzheimer’s Association International Conference (AAIC) in Chicago, an event that brought together leading scientists and researchers from more than 70 countries. These brilliant minds are building the bridges that lead to the first survivor.

When you or someone you love is diagnosed with Alzheimer’s, it can feel like you’re starting a journey you never wanted to go on — crossing a bridge into unknown territory. I understand. I’ve been there. I want you to know that you are not taking this journey alone.

The Alzheimer’s Association – Heart of America Chapter has a wealth of resources and support available and I encourage you to take advantage of all that the Chapter, and this Guide, has to offer. The infrastructure work I do as an engineer focuses on the future — just like the volunteer work I do as your Board President. As you learn more about the progress being made in the fight against Alzheimer’s, I hope you share my faith in the future: The first survivor of Alzheimer’s disease is out there, and we will get there together.

Ben Biller
Heart of America Chapter
Board President

Benjamin J. Biller
Dementia is an umbrella term for a decline in mental ability severe enough to interfere with daily life. Memory loss is an example. Alzheimer’s is the most common type of dementia.

**Frequently Asked Questions**

**How is Alzheimer’s diagnosed?**

There is no single test that proves a person has Alzheimer’s. While physicians can almost always determine if a person has dementia, it may be difficult to determine the exact cause. Diagnosing Alzheimer’s involves a complete assessment that considers all possible causes. The assessment, typically orchestrated by a neurologist, would include:

- Medical history
- Mental status tests
- Physical exam and diagnostic tests
- Brain imaging
- Neurological exam

**Who gets Alzheimer’s?**

Today, 5.7 million Americans are living with Alzheimer’s disease, including an estimated 5.5 million people age 65 and older and approximately 200,000 individuals under age 65 who have younger-onset Alzheimer’s. Almost two-thirds of Americans with Alzheimer’s are women. A family history of Alzheimer’s is not necessary for an individual to develop the disease. However, individuals who have a parent, brother, or sister with Alzheimer’s are more likely to develop the disease than those who do not have a first-degree relative with Alzheimer’s.

**Is there treatment available?**

While there is currently no cure for Alzheimer’s, drug and non-drug treatments may help with both cognitive and behavioral symptoms of the disease. Ultimately, the path to effective new treatments is through clinical trials. Find out more about participating in a clinical trial through the Alzheimer’s Association’s Alzheimer's Association TrialMatch® service, a free tool to assist people with Alzheimer’s, their caregivers, families, and physicians in locating trials based on personal criteria and location. See article on page 27.

**What are the risk factors?**

The most important risk factors are ones that we cannot change: age, family history, and heredity. However, evidence suggests there may be other factors that we can influence:

- Healthy aging: keeping your brain, as well as your body, fit by paying attention to the heart-head connection.
- Protecting your brain and avoiding head trauma by buckling your seat belt, wearing your helmet when playing sports, and “fall-proofing” your home.
10 Warning Signs of Alzheimer’s Disease

1. Memory loss that disrupts daily life
   - Forgetting recently learned information, important dates, or events; asking for the same information over and over. **Typical age-related change?** Sometimes forgetting names or appointments, but remembering them later.

2. Challenges in planning or solving problems
   - Difficulty concentrating, working with numbers, and needing much longer to do things than you did before. **Typical age-related change?** Making occasional errors when balancing a checkbook.

3. Difficulty completing familiar tasks
   - Difficulty driving to familiar locations, remembering the rules to a familiar game. **Typical age-related change?** Occasionally needing help to use the setting on a microwave or record a television show.

4. Confusion with time or place
   - Trouble understanding something if it is not happening immediately, forgetting where you are or how you got there. **Typical age-related change?** Getting confused about the day of the week, but figuring it out later.

5. Trouble understanding visual images and spatial relationships
   - Difficulty reading, judging distance, and determining color or contrast, which may cause issues with driving a car. **Typical age-related change?** Vision changes related to cataracts or other eye-aging condition.

6. New problems with words in speaking or writing
   - Trouble following or joining a conversation; stopping in the middle of conversation; struggling with vocabulary and finding the right word. **Typical age-related change?** Sometimes having trouble finding the right word.

7. Misplacing things and losing the ability to retrace steps
   - Putting things in unusual places or losing things and not being able to retrace steps to find them; accusing others of stealing. **Typical age-related change?** Misplacing things from time to time and retracing steps to find them.

8. Decreased or poor judgment
   - Giving large amounts of money to inappropriate causes (such as telemarketers) and paying less attention to grooming or hygiene. **Typical age-related change?** Making a bad decision once in a while.

9. Withdrawal from work or social activities
   - Removal from hobbies, social activities, work projects, or sports. **Typical age-related change?** Sometimes feeling weary of work, family, and social obligations, but re-engaging after a break from those situations.

10. Changes in mood and personality
    - Becoming confused, suspicious, depressed, fearful, or anxious; becoming easily upset at home or work. **Typical age-related change?** Developing very specific ways of doing things and becoming irritable when a routine is disrupted.

If you or anyone you know experiences any of these warning signs, please consult your doctor.

For more information please contact:
call 800.272.3900 or visit alz.org/10signs
10 STEPS TO TAKE FOLLOWING AN ALZHEIMER’S DIAGNOSIS

Alzheimer’s is a brain disease that causes a slow decline in memory, thinking and reasoning skills. If you notice any of the 10 Warning Signs (see page 5) of Alzheimer’s in yourself, a family member or a friend, schedule an appointment with a doctor. Early detection can help you make informed decisions about the future and focus on living in a way that’s meaningful to you.

Consider taking these 10 steps to move forward following an Alzheimer’s diagnosis.

1. **Get educated.** It’s normal to be hesitant, however, learning about your Alzheimer’s diagnosis is the first step in empowering yourself to make important decisions about how you want to live your life and how you will plan for a future. There are people who understand what you are going through, and help is available.

2. **Take time to process.** There’s no “right” way to respond to an Alzheimer’s diagnosis. Some people experience depression and may want to withdraw. Others are comforted by knowing what’s wrong and feeling empowered to prioritize what’s most important in life. There’s also no limit on the length of time someone is “allowed” to grieve. Take time to fully process the diagnosis.

3. **Explore medications.** Currently, there is no cure for Alzheimer’s, nor are there any treatments to prevent, reverse or slow the progression of the disease. However, there are medications that may help lessen the symptoms of Alzheimer’s, such as memory loss and confusion, for a limited time. An early Alzheimer’s diagnosis provides you with a better chance of benefiting from treatment.

4. **Communicate your wishes.** Do you know who you would want to make decisions for you in the event you’re no longer able to? An early Alzheimer’s diagnosis means you can put your long-term care wishes in writing. Being open with your family and support network about what you want during each stage of the disease can give you peace of mind and reduce the burden on family members.

5. **Plan your financial future.** An Alzheimer’s diagnosis can throw a wrench into your best-laid plans. Don’t put off talking about finances and future care. Take time to make sure your will and estate plans are up-to-date and factor the disease into your financial plans. Putting financial and legal plans in place now allows you to be as involved in these decisions as you’d like to be.

6. **Enroll in a clinical trial.** Without clinical trials, there can be no better treatments, no prevention, and no cure for Alzheimer’s. By enrolling in a clinical trial, you can help accelerate progress and provide researchers with valuable insights. Participating also gives you access to medical care at leading healthcare facilities, often free of cost.

7. **Stay connected.** Not all family and friends live near one another, which can complicate the logistics of long-term care. Following a diagnosis, people living with Alzheimer’s are at their most vulnerable, and it’s important for them to find better ways to stay connected and make the most of the time they have left. Be sure to keep in touch and make plans for regular communication.

8. **Find a community.** An Alzheimer’s diagnosis opens up a community of people who understand what you and your family and friends are going through. Sharing your personal journey and listening to others can be both therapeutic and insightful. You may find new ways to cope and improve your quality of life.

9. **Join the cause.** Joining the Alzheimer’s cause can give a sense of renewed purpose, whether it’s through advocating for policy changes, fundraising for research, raising disease awareness, combating stigma, or volunteering. Taking action empowers you and your loved ones to bring us closer to a world without Alzheimer’s.

10. **Live your best life.** Having Alzheimer’s may help you decide how you want to spend your time, in the way that you’re able. Everyone is different. Some people may want, and need, to continue working during the early stage of the disease, while others may decide to retire immediately. Some plan big vacations, while others spend more time at home. Whatever you and your family plan, focus on the aspects of your life that give you the most joy. Do what will be best for you.
We are honored to support

the Alzheimer’s Association’s

outstanding accomplishments in advanced research and for giving hope to the caretakers and the individuals affected by the disease.

For those who serve others, we applaud you. Thank you for making the world a better place.
10 WAYS TO MANAGE STRESS AND BE A HEALTHY CAREGIVER

Caregiving can be overwhelming, but it is important to make your health a priority. Taking care of yourself can help you be a better caregiver.

- Find time for yourself. Consider respite care so you can spend time doing something you enjoy.
- Know what resources are available. Adult day programs, in-home assistance and meal delivery are some of the services that can help.
- Become an educated caregiver. As the disease progresses, it may become necessary to adopt new caregiving skills and strategies.
- Get help and find support. Seek comfort and guidance through local support groups, our free 24/7 Helpline and ALZConnected® online social networking community.
- Make legal and financial plans. Putting plans in place after an Alzheimer’s diagnosis is important. This step allows the person with the disease to participate in decision-making and offers guidance to caregivers.
- Manage your level of stress. Try to find relaxation techniques that work for you. If stress becomes overwhelming, seek help from a doctor or counselor.
- Take care of yourself. Try to eat well, exercise and get plenty of rest.
- Know you’re doing your best. Remember that the care you provide makes a difference and that you are doing the best you can.
- Accept changes as they occur. The needs of people with Alzheimer’s change over time. For care beyond what you can provide, utilize community resources.
- Visit your doctor regularly. Take time to get checkups. Pay attention to exhaustion, sleeplessness or changes in appetite or behavior. Ignoring symptoms can cause your health to decline.

Free 24/7 Helpline: 800.272.3900
Alzheimer’s and Dementia Caregiver Center: alz.org/care
The Alzheimer’s Association has a wealth of online caregiver resources, including the Alzheimer’s and Dementia Caregiver Center, ALZConnected, Alzheimer’s Navigator, and Community Resource Finder.

Caring for a person with Alzheimer’s or dementia often involves a team of people, and these caregivers face special challenges. The Alzheimer’s and Dementia Caregiver Center at alz.org/help-support/caregiving offers invaluable assistance. Whether you provide daily caregiving, participate in decision-making, or simply care about a person with the disease — this caregiver center can help.

The Caregiver Center provides tips for early-stage, middle-stage, and late-stage caregiving, with information about specific behaviors related to those stages.

ALZConnected is a free social networking community for people with Alzheimer’s disease and their caregivers. ALZConnected includes message boards from individuals going through journeys like yours. A “Caregivers” forum and an “I have Alzheimer’s” forum are available on this site. Members connect to share their concerns and advice at alzconnected.org.

Alzheimer’s Navigator can help answer them.

Alzheimer’s Navigator is an innovative, online tool developed by the Alzheimer’s Association to help individuals living with Alzheimer’s, their families and caregivers address the many challenging issues associated with Alzheimer’s disease, including safety, caregiving, financial and legal planning, and guidance for working with your doctor.

Alzheimer’s Navigator creates personalized and comprehensive action plans based on answers families provide through short, online surveys. Surveys can be taken in a single sitting or saved and finished at the user’s convenience. Users can retake surveys to update their plans as personal circumstances change. No registration is required to take the surveys. However, if users want to save their action plans they can do so by creating a private account and saving them within the account.

Users can also easily create a care team to keep family members, friends, physicians, and other interested individuals updated and involved in the care process.

Community Resource Finder at communityresourcefinder.org provides easy access to a comprehensive listing of Alzheimer’s and dementia resources, community programs, and services. Information contained in the Community Resource Finder is compiled from information submitted by the Alzheimer’s Association, provider descriptions of their own services, and other public data sources. The Alzheimer’s Association does not endorse any of the providers listed on Community Resource Finder and the information listed is subject to change without notice.

A diagnosis of Alzheimer’s disease or another dementia raises many questions. Alzheimer’s Navigator can help answer them.

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Users can also easily create a care team to keep family members, friends, physicians, and other interested individuals updated and involved in the care process.

Visit alz.org/alzheimersnavigator for more information and to begin developing your own customized action plan today.
If someone you love has Alzheimer’s, dementia, or other cognitive challenges, Tallgrass Creek can help. Learn more. Call 1-800-981-9395 today.
10 WAYS TO **LOVE YOUR BRAIN**

**START NOW.** It’s never too late or too early to incorporate healthy habits.

- **HIT THE BOOKS**
  Formal education will help reduce risk of cognitive decline and dementia. Take a class at a local college, community center or online.

- **BREAK A SWEAT**
  Engage in regular cardiovascular exercise that elevates heart rate and increases blood flow. Studies have found that physical activity reduces risk of cognitive decline.

- **BUTT OUT**
  Smoking increases risk of cognitive decline. Quitting smoking can reduce risk to levels comparable to those who have not smoked.

- **STUMP YOURSELF**
  Challenge your mind. Build a piece of furniture. Play games of strategy like bridge.

- **FOLLOW YOUR HEART**
  Risk factors for cardiovascular disease and stroke — obesity, high blood pressure and diabetes — negatively impact your cognitive health.

- **BUDDY UP**
  Staying socially engaged may support brain health. Find ways to be part of your local community or share activities with friends and family.

- **HEADS UP!**
  Brain injury can raise risk of cognitive decline and dementia. Wear a seat belt and use a helmet when playing contact sports or riding a bike.

- **TAKE CARE OF YOUR MENTAL HEALTH**
  Some studies link depression with cognitive decline, so seek treatment if you have depression, anxiety or stress.

- **FUEL UP RIGHT**
  Eat a balanced diet that is higher in vegetables and fruit to help reduce the risk of cognitive decline.

- **CATCH SOME ZZZ'S**
  Not getting enough sleep may result in problems with memory and thinking.

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**Visit alz.org/10ways to learn more.**
Choosing the best option for a senior loved one can be a confusing and overwhelming process. At Benton House we stand ready to serve you. Let us be your resource for answers. Call to schedule your personal tour to find out more.

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Olathe - (coming soon) 770-558-3924

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Do something you love on June 21, 2019

For individuals with Alzheimer’s and their caregivers, every day is the longest day. The Alzheimer’s Association has created a fundraising event that both symbolizes the daily challenges of Alzheimer’s and honors those who battle these challenges daily.

The Longest Day events will be celebrated on the summer solstice, the longest day of the year, Friday, June 21, 2019. However, your Longest Day team can fundraise at any time prior to June 21.

• Choose an activity you love… bowling, softball, bridge, dancing, baking, etc.
• Choose a day to do the activity before or on June 21st
• Encourage friends to join your team
• Celebrate your fundraising efforts on June 21st

We walk to remember those we’ve lost and in hope to find a cure.

For more information
alz.org/thelongestday

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LOCAL YOUNG CHAMPIONS
and their extraordinary fundraising efforts

see their stories on the next two pages
Charlie Thorne remembers playing backyard games with his grandmother, Donna Blackwood — including one game not every grandmother plays: football!

With his grandmother now in the late stage of Alzheimer’s disease, Charlie thought it would be fitting to honor her by planning and hosting “Moments for Memory,” a touch football tournament to raise funds and awareness for the Alzheimer’s Association and The Longest Day, a signature fundraising event for the Association.

“My grandmother has always been my role model,” says Charlie, a senior at Pembroke Hill High School. “When my hair is grown out, everyone says it looks just like hers! I just couldn’t sit around and watch Alzheimer’s happen. It is a merciless disease and I needed to do my part.”

Taking action is a family trait: Charlie’s mother sought assistance from the Alzheimer’s Association when her mother was diagnosed. Charlie now volunteers at the care home where his grandmother lives, and brings friends to volunteer with him. One friend, Ethan, is an accomplished pianist. Before volunteering, Ethan didn’t understand how deeply Alzheimer’s affects families. Now he says he realizes the impact it has, and the importance of spending time with people who have the disease. “They just want to be listened to,” adds Charlie. “My friends and I can offer that to them.”

Charlie enlisted help from his friends to plan Moments for Memory. Everything from designing the event logo, to creating the website, designing promotional materials, and printing T-shirts was provided free of charge or deeply discounted, so Charlie could donate as much as possible to the Alzheimer’s Association.

Eight co-ed teams of seven players each played 10-minute games in a seeded bracket. The event was free to attend, teams never practiced, and there were no team captains. The mission was simple: Have fun, honor Donna Blackwood and others with Alzheimer’s, and raise money for this important cause.

Because one high school senior had a vision for a fundraiser — inspired by those childhood football games with his grandmother — Charlie’s inaugural Moments for Memory raised more than $12,000.

Morgan Belardo’s high school days look different than most. Morgan is a family caregiver for her father, José, who was diagnosed with Alzheimer’s at age 50.

Morgan navigates her day knowing that her father can’t pick her up from school and drive her to after-school activities. But he can, and does, make a fierce cup of coffee every morning (he is known as the barista of the home) and he tells Morgan to have a good day as she scurries off to school.

When Morgan was in fourth grade, she and a friend started baking treats together. “I love baking, but my favorite part is decorating cakes,” says Morgan, who will graduate from Lansing High School in 2020. “I just love the way they look when I am finished.”

Over the years, the Belardo family has helped increase awareness of Alzheimer’s disease and the Alzheimer’s Association in many ways. For her part, Morgan put her culinary skills to work with...
a “Sweet Exchange” fundraiser for The Longest Day. The sweet idea ties to the philosophy behind this signature event: The Longest Day encourages people to choose an activity they love and use it to raise funds.

To prepare for Sweet Exchange, Morgan planned the dessert list, enlisted a team of helpers and carried out the plan. On the longest day of the year, June 21, 2018, she invited the entire Lansing community to her home. For a donation to her Sweet Exchange team, they received a delicious treat. This baker’s fundraising goal was $1,600. In typical Morgan fashion, she went far beyond expectations, raising $3,838.

While that might be enough for some people, Morgan’s efforts on behalf of the Alzheimer’s Association aren’t stopping there. Morgan is working toward a Gold Award, the highest award offered by Girl Scouts of the USA. Only 5.4 percent of eligible Girl Scouts earn the Gold Award. To earn the award, Morgan had to identify and investigate a community issue she cares about, and she chose Alzheimer’s awareness. As part of her “Take Action” plan, Morgan is designing an information pamphlet for young teens who have a parent with Alzheimer’s disease.

“Everyone automatically thinks that Alzheimer’s affects only people my grandparents’ age or older, but for people like me who have a parent with the disease, a special informative brochure is really necessary,” says Morgan.

She is expected to receive the Gold Award within the next year. We have no doubt that will happen.

When Makenzie Griffel was 8 years old, she played her first volleyball game. Ever since then, she has given volleyball her heart and soul. So when Alzheimer’s disease began to take away the great-grandmother Makenzie knew, she decided to “serve” in a whole new way — putting together a volleyball tournament fundraiser for the Alzheimer’s Association.

As she thought about her great-grandmother’s personality and smile, she knew it was a plan that would make her great-grandmother happy. “Her smile has never gone away, and every time I see her, I know that this is what she would want me to do,” says Makenzie, a senior at Blue Springs South High School.

The components quickly came together: Makenzie’s father, who owns a volleyball complex, offered the venue for the tournament and her mother helped organize a silent auction and raffle. “I had the idea and the drive,” Makenzie says, “but without my entire family, this tournament would never have happened.”

Makenzie’s friends took to social media to get the word out, and more than 20 teams signed up. Each player paid a $20 fee, received an event T-shirt, and participated in a pool play tournament. Overall, the tournament raised more than $4,000. To honor both her great-grandmother and a great-uncle who has multiple sclerosis, Makenzie divided the proceeds between the Alzheimer’s Association – Heart of America Chapter and the National MS Society. She hopes the success of her tournament will encourage other high school students to host events and raise money for causes dear to them.
The Heart of America Chapter has resources and support services for those with memory loss, their families, and care partners. We are here to help you 24 hours a day, seven days a week.

- 24-hour Information and Support phone line at 800.272.3900
- Family Connections Program: Individualized care consultations in your home or our office
- Chapter Resource Library: A collection of books, videos, brochures, and resource lists
- Support Groups and Breakfast Clubs: Meet regularly throughout the area for peer support and to exchange information
- Social Engagement Groups: Engaging activities for individuals with dementia

We offer regularly scheduled classes and workshops for individuals with memory loss, their care partners, and health professionals. Utilize our extensive resource library, and pick up a copy of our Alzheimer’s Awareness Guide.

Educational programs include:
- Understanding Alzheimer’s and Dementia
- Living with Alzheimer’s
- Legal and Financial Issues
- Effective Communication Strategies
- Understanding and Responding to Dementia-related Behavior

A full listing of education programs is available at communityresourcefinder.org or by calling 1.800.272.3900.

The Heart of America Chapter staff and volunteers work to raise awareness of, and advocate for, the needs and rights of people with dementia. Join us in making Alzheimer’s a national priority.

- Action Alerts: Timely electronic updates on policies related to dementia
- Weekly e-news with national and local information
- Chapter website and social media interaction
- Chapter representatives speaking out on dementia issues at a variety of community venues
- Grassroots legislative efforts

BE AN ADVOCATE. Yours is the voice we are missing. You can urge support for critical Alzheimer’s legislative changes and work locally and nationally to advance key initiatives.
No one should go through this alone.

For more information on any of our Chapter services, please consult our website at:

alz.org/kansascity

or call one of our offices listed at the bottom of this page.

Alzheimer’s is relentless.

SO ARE WE.

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®.
For six years, Sue Wilde has honored her father, who passed away with Alzheimer’s disease, by holding the “Embrace the Moment” golf tournament to raise funds for the Alzheimer’s Association - Heart of America Chapter. This tournament, always held on the last Friday in June, has grown to more than 70 golfers and eight sponsors.

“I love to golf and this is the way I can give back,” says Sue. “I love seeing the whole tournament come together on the day of the event. The volunteers who help me are so much fun to work with and they are truly passionate about finding a cure for Alzheimer’s.” Many of the golfers are family members, friends, and business associates. Sue’s mother, Jeanne, is always there to support her daughter. “My mom is a tough cookie — she cared for my dad all but the last 14 months of his life when we had to move him to a nursing home.”

Sue’s job in sales and marketing for a food broker requires organization and planning, which explains why she is so good at orchestrating a charity golf tournament. Her goal is to increase funds raised by $1,000 – $2,000 each year. She is certainly on track. This year’s tournament raised more than $13,000.

Sue’s advice to others who are looking for ways to honor a loved one is, “Ask people to get involved with you. People want to help and they can’t if you don’t ask them. Get started as soon as you can.”

Can your diet help reduce the risk of Alzheimer’s?

Brain health is linked to heart health. Eating a heart-healthy diet benefits both your body and your brain. In general, this is a diet that is lower in fat and higher in vegetables and fruit. Research in the area of the relationship between diet and cognitive functioning is somewhat limited, but it does point to the benefits of two diets in particular: the DASH (Dietary Approaches to Stop Hypertension) diet and the Mediterranean diet. These diets can help reduce heart disease and may also be able to reduce risk of dementia.

The Dietary Approaches to Stop Hypertension (DASH) diet aims to reduce blood pressure:
- Eat foods that are low in saturated fat, total fat and cholesterol, and high in fruits, vegetables and low-fat dairy.
- Consume whole grains, poultry, fish and nuts.
- Decrease your intake of fats, red meats, sweets, sugared beverages and sodium.

The Mediterranean diet incorporates different principles of healthy eating that are typically found in the areas bordering the Mediterranean Sea:
- Focus on fruit, vegetables, nuts and grains.
- Replace butter with healthy fats, like olive oil.
- Limit red meat.
- Use herbs to flavor food rather than salt.
- Eat fish and poultry at least twice a week.
MY Brain makes movies and movements happen. It has wit, wonder, and wisdom. It has vision but is blind to excuses. It’s a writer whose dialogue will change minds by the millions and a daughter who fights for her family’s future.

My brain matters and I’m using it to wipe out Alzheimer’s.

Get involved today at alz.org/mybrain

Lauren Miller Rogen
Actor, writer, director
And co-founder of Hilarity for Charity

Alzheimer’s Association
Alzheimer’s Impact Movement

The Alzheimer’s Impact Movement (AIM) is the advocacy arm of the Alzheimer’s Association. AIM advances and develops policies to overcome Alzheimer’s disease through increased investment in research, enhanced care, and improved support. Thanks to the support of its members, AIM has driven policymakers to take historic steps to address the Alzheimer’s crisis — but much more remains to be done.

Today an estimated 5.7 million Americans are living with Alzheimer’s disease. And, at a cost of $277 billion a year, Alzheimer’s is the most expensive disease in the nation. Barring the development of medical breakthroughs to prevent, stop or slow Alzheimer’s disease, these numbers will rapidly increase.

It is because of this trajectory and the impact of the disease on families that AIM works to advance public policies to enhance care and support, as well as to accelerate research.

As a 501(c)(4), AIM is able to engage with lawmakers in all elements of their job — including activities considered electoral or political — to keep the Alzheimer’s community and our issues top-of-mind with elected officials.

AIM impresses upon our elected officials the growing crisis Alzheimer’s presents to our nation’s families and the economy. In doing so, AIM is inspiring these leaders to take action to address Alzheimer’s.

AIM amplifies the voice of Alzheimer’s Association advocates to lend them even more power. With help from advocates, AIM has passed critical legislation and quadrupled federal research funding since 2012.

Examples of what AIM can and has done include:

- Advocating for legislation that advances research, and enhances care and support services for those living with Alzheimer’s and their caregivers.
- Supporting the re-election of our Congressional champions in both parties. If they fight for us, we’ll fight for them.
- Speaking on behalf of the Alzheimer’s community throughout each election cycle, when 501(c)(3) organizations like the Alzheimer’s Association must remain silent.

The AIM website, alzimpact.org, provides information about AIM research/care/support issues, federal and state priorities, and ways to take action and get involved. Two of those ways are to become an advocacy volunteer or join AIM.

Fill out an Alzheimer’s Advocacy Volunteer application at alzimpact.org/volunteer.

AIM is a nonpartisan, nonprofit membership organization and we ask you to join! The annual membership fee is $20. AIM relies on its members to advance the Alzheimer’s agenda in Washington.

To join AIM, fill out a form at alzimpact.org/join/join_aim and learn about member exclusive benefits and opportunities.
For Jan and Len Johnson, life was good. Len was a smart, ambitious trial attorney, and Jan was a clinical nurse by trade, though she was also a skilled equestrian who loved jumping and fox hunting. They had built a home that was like a sanctuary: a gorgeous house with a beautiful patio, surrounded by 40 acres of lush pasture. There was even a multi-stall barn for their beloved horses.

When Jan got a call from her then-57-year-old husband who was completely lost and didn't know how to get back to his hotel while on a business trip, they knew something was wrong.

Upon his return, Len immediately saw a doctor and had a battery of tests, including an MRI, all of which appeared normal. The doctor attributed Len’s confusion to job stress.

As Len’s symptoms worsened, Jan insisted on getting another opinion at the Mayo Clinic. After a second MRI, just six months from the first one, and a PET scan, Len received his diagnosis — Alzheimer’s disease.

Len wanted to spend the rest of his life at their dream home, and Jan was determined to make it happen. Since her mother had just been diagnosed with Lewy body dementia, Jan took on the caregiving role for both her husband and her mother.

“I had to move out of my daughter/wife mode and into my clinical nurse mode,” Jan says. “I had to remind myself to talk to my mom and Len even though they might not respond. It is so important for people with dementia to hear familiar voices.”

Jan’s mother died in 2014 and Len passed away in 2016. Jan’s approach to coping with the loss was to “not get stuck, as people often do after losing someone to Alzheimer’s,” she says, but instead to stay active. She spearheaded an advocacy effort to lobby Kansas Congressman Kevin Yoder for support of the Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer’s Act. The bill would create a national Alzheimer’s public health infrastructure designed to increase early detection and diagnosis, reduce risk, and prevent avoidable hospitalizations.

Jan is a member of Alzheimer’s Impact Movement (AIM), see page 24. As a member, and on behalf of the Heart of America Chapter, Jan attended the 2018 Alzheimer’s Advocacy Forum in Washington, D.C. this past June; the Forum is the nation’s premiere Alzheimer’s disease advocacy event.

“I was so excited to be there. It was like a spirit rally where I had a contingency around me of people who felt just as strongly about these important issues as I do,” says Jan. “I loved hearing the individuals with Alzheimer’s disease speak. I wish Len would have had the opportunity to do that, but he was diagnosed too late and it seemed like we were always playing catchup.”

Jan’s trip to the Forum also gave her the opportunity to see more than 200 young advocates speak about Alzheimer’s disease and how this is affecting their lives. “It was so good to know we were actually talking about this disease. So many people won’t talk about it. It isn’t a crime, it is a disease.”

Jan has always been an optimist. “I always tried to see what Len could do, not focus on what he couldn’t do. It just made me so angry that Alzheimer’s took away from him the two things he was so good at — speaking and reading. But I made sure that when he couldn’t read any more, I read to him. And when he couldn’t speak any more, I spoke for him.”

Today, she’s traveling, she’s advocating, she’s remembering her loved ones by making a difference.
Like many of you, I have been personally touched by Alzheimer’s disease. This only strengthens my commitment to doing everything I can to accelerate research to prevent, slow and effectively treat Alzheimer’s. Our annual Alzheimer’s Association International Conference® (AAIC®) — the world’s largest gathering of Alzheimer’s and dementia researchers — shows that neither you nor I is alone in our commitment.

Held in July, AAIC 2018 brought a record-breaking 5,900 attendees as well as exciting data that gives us many reasons to be hopeful. For example, the reduction in new cases of mild cognitive impairment (MCI) seen in the Systolic Blood Pressure Intervention Trial and Memory and Cognition IN Decreased Hypertension study (SPRINT MIND) adds credibility to the vision of future Alzheimer’s therapy that combines drugs and modifiable risk factor interventions — as we do now in cardiovascular disease.

SPRINT MIND researchers compared two strategies for managing high blood pressure (hypertension) in older adults: an intensive strategy with a systolic blood pressure goal of less than 120 mm Hg versus a standard care strategy with a goal of less than 140 mm Hg. They found a statistically significant 19 percent lower rate of new cases of MCI in the intensive treatment group and a 15 percent lower rate of new cases when combining MCI and all-cause dementia. This study shows more conclusively than ever before that there are things you can do — especially regarding cardiovascular disease risk factors — to reduce your risk of MCI and dementia.

Another highlight was the announcement by Eisai Co., Ltd. and Biogen Inc. that their Phase 2 drug BAN2401 both cleared beta-amyloid (a protein that is a hallmark of Alzheimer’s disease) from the brain and was associated with improved cognition and function in study volunteers, who had MCI due to Alzheimer’s or early Alzheimer’s dementia. That said, the study was not large enough to definitively demonstrate efficacy in cognitive outcomes, and larger, Phase 3 clinical trials are needed to confirm the results.

Despite more than two decades of advances in both the techniques and technology used for diagnosis, symptoms of Alzheimer’s and other dementias too often go unrecognized or are misattributed. This causes delays in accurate diagnoses and appropriate care that are harmful and costly. Contributing to this is the fact that there currently are no consensus recommendations for Alzheimer’s diagnosis geared to primary care physicians. At AAIC 2018, a workgroup convened by the Alzheimer’s Association reported 20 recommendations it had developed for physicians and nurse practitioners to encourage more timely and accurate Alzheimer’s disease diagnosis and to improve patient care. The workgroup is honing the recommendations with input from leaders in the field with the goal of publishing them later this year.

At the Alzheimer’s Association, we will not stop; we will not slow down in our fight against this disease.
Don’t just hope for a cure. HELP US FIND ONE.

What is TrialMatch®?

Alzheimer’s Association TrialMatch® is a free, easy-to-use clinical studies matching service.

Who can Sign Up for TrialMatch®?

Everyone interested in advancing Alzheimer’s research can use this matching service, including:

- Individuals with dementia
- Caregivers
- Healthy volunteers without dementia

250+ Reasons for Hope

Alzheimer’s Association TrialMatch® provides access to more than 250 promising pharmacological (drug) and non-pharmacological (non-drug) clinical studies being conducted at sites across the country and online. These trials include:

- Treatment trials — test new treatments or combinations of treatments.
- Diagnostic studies — find new tests or procedures for diagnosing a disease or condition.
- Prevention trials — investigate ways to prevent the onset of diseases.
- Quality of life studies — explore different ways to improve quality of life for individuals who have a chronic illness, their caregivers and family members.
- Online studies — are web-based and conducted entirely online.

New treatments for Alzheimer’s disease require clinical trials, and many more participants are needed. Today, tens of thousands of volunteers, both with and without Alzheimer’s, are urgently needed to participate.

Wonder if there’s a clinical trial open to you or a loved one?

Finding potential studies through TrialMatch® is easy. Here’s how TrialMatch® works:

1. Create a free account.
To get started, contact us in the way that works best for you:
- Visit alz.org/TrialMatch.
- Call 800.272.3900 (option 1).
- Email TrialMatch@alz.org.

2. Create your user profile.
Complete a brief questionnaire to create a profile.

3. Fill out a match questionnaire.
Answer a few questions. Your profile information is kept completely confidential. The Alzheimer’s Association compares your unique profile to our comprehensive, continually updated clinical study database.

4. Review your study matches.
You will receive information about studies that might be a good fit based on your preferences, location, and personal characteristics. You can decide if you want to contact any of the studies for more information. You’re under no obligation to participate.

Without clinical trials, there can be no better treatments, no prevention, and no cure for Alzheimer’s disease. Scientists work constantly to find better ways to treat diseases, but improved treatments can never become a reality without testing in clinical trials with human volunteers.
ALZHEIMER’S DISEASE FACTS AND FIGURES

2018 ALZHEIMER’S DISEASE

ALZHEIMER’S DISEASE IS THE 6TH leading cause of death in the United States

16.1 MILLION AMERICANS provide unpaid care for people with Alzheimer’s or other dementias

These caregivers provided an estimated 18.4 BILLION HOURS of care valued at over $232 BILLION

IN 2018, Alzheimer’s and other dementias will cost the nation $277 BILLION

BY 2050, these costs could rise as high as $1.1 TRILLION

Between 2000 and 2015 deaths from heart disease have decreased 11% while deaths from Alzheimer’s disease have increased 123%

1 IN 3 seniors dies with Alzheimer’s or another dementia

It kills more than breast cancer and prostate cancer COMBINED

EVERY 65 SECONDS someone in the United States develops the disease

IN 2018, Alzheimer’s and other dementias will cost the nation $277 BILLION

BY 2050, these costs could rise as high as $1.1 TRILLION

5.7 MILLION Americans are living with Alzheimer’s

BY 2050, this number is projected to rise to nearly 14 MILLION

THE BRAINS BEHIND SAVING YOURS:
You give us reason to hope.

We are proud to join the Heart of America Chapter in its fight against Alzheimer’s. Together, we can continue to raise awareness to help support caregivers and patients.
At the Alzheimer’s Association Walk to End Alzheimer’s®, people carry flowers representing their connection to Alzheimer’s—a disease that currently has no cure. But what if one day there was a flower for Alzheimer’s first survivor? What if there were millions of them?

Help make this happen.

WALK, DONATE, SPONSOR, OR VOLUNTEER.

TOGETHER, WE CAN END ALZHEIMER’S.
Register today
to walk as an individual or form a Walk team!

alz.org/walk

Your fundraising efforts make a significant difference in the lives of those with Alzheimer’s!

For more information, please call 913.831.3888
I'm Margie Gardner, a licensed sales representative in Kansas. When it comes to Medicare, one-size-fits-all doesn’t cut it. What works for you and your neighbor may not be the best fit for you. And what nice things you need last year might not be the best fit this year. Now’s the time to explore your choices so you can enroll in a plan with confidence. I’m here to help. As a licensed sales representative, I know the ins and outs of Medicare. And I know how to make it easier for you to understand, as well.

Margie Gardner
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The Main Chapter office has a large selection of Alzheimer’s disease information and brochures that are free to individuals with Alzheimer’s, their caregivers, and family.
The library also has books and videos available for loan.
Stop by during regular office hours,
9 a.m. – 5 p.m. Monday – Friday
3846 W. 75th Street, Prairie Village, KS
ALZHEIMER’S AWARENESS GUIDE

With a Spring In Our Steps, We Walk Together to End Alzheimer’s

What Personalized Memory Care Looks Like
CareHavenHomes.com • 913.643.0111

Mary B’s Symphony
Bickford Senior Living’s Dementia & Alzheimer’s Program

Mission Springs • 913-831-7700
Overland Park • 913-642-5400
Raytown • 816-353-3400
enrichinghappiness.com

It is our priority to understand your loved one’s history and the things that are important to them in order to greatly increase the quality of caregiving tasks and make daily interactions with them more meaningful.

Cuetivities
As your loved one participates in an increased number of meaningful and purposeful activities throughout the day, they will experience enhanced daytime engagement, better nighttime sleep patterns and improved overall behaviors.

Setting
Our community is composed of a dedicated and intimate setting, resident safety and security, specialized dementia training for caregivers, visual and verbal communication techniques and validation therapy.

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& Veterans Benefits Planning

ALZHEIMER’S AWARENESS GUIDE
COMMUNITY EDUCATORS

The Alzheimer’s Association community education programs are designed to raise awareness about Alzheimer’s disease and offer practical strategies for care and support. These programs encourage caregivers to maintain their physical and emotional health, while caring for individuals with dementia.

These programs are presented by Community Educators, volunteers who are trained by the Alzheimer’s Association and successfully complete the Volunteer Presenter Training course.

Meet two of the Heart of America Chapter Community Educators!

GIA SMITH

Gia was born, raised, and attended college in Kansas City. Her career in global ethics and compliance flourished and she moved to Arkansas, then Florida. She moved back to Kansas City when her father, Haywood L. Smith, was diagnosed with stage four cancer, in addition to his previous diagnosis of Alzheimer’s. “Family is a core value,” Gia says. “With the second terminal diagnosis, there was no question — I needed to come home to help take care of him and help my mother.”

Gia’s father was a respected leader in health care, working first at KU Medical Center, then Trinity Lutheran Hospital, and finally at Overland Park Regional. He was fondly remembered by all those who knew him. “He was such a good human being and he touched so many lives,” Gia says. “When we had to help dad understand the danger of him continuing to drive, it occurred to me that Alzheimer’s is more than just memory loss; it’s also about losing the ability to reason. That is when I contacted the Alzheimer’s Association for assistance.”

After her father passed away in 2017, Gia decided to stay in Kansas City with her mother and family as they heal from their loss. She joined the Community Educators program to honor her dad, and use her gifts and talents to make a difference in the world. “My father always taught me to do my best,” Gia says.

“Aubrey Marez

Growing up, Aubrey lived with her great-grandmother, who had Alzheimer’s disease. “Looking back, I wish we had more resources available,” she says. Today, both of her grandmothers and an aunt have been affected by Alzheimer’s, and the family draws strength from resources at the Alzheimer’s Association.

In return, Aubrey strengthens the Community Educators program, putting her “advocacy spirit” to work as she shares information about Alzheimer’s with people throughout the community.

“I want to be a vessel to get information to those who need it,” Aubrey says. “When I heard about the Community Educators program, I knew I wanted to be a part of it.”

Aubrey, who is married and has four children, is incredibly focused on helping people. After working in physical therapy, she has shifted into palliative and hospice care. “I help arrange care so people can make educated decisions about their care and lessen the turmoil this illness can bring. I want people to get information so they can make educated decisions about where to be the rest of their lives,” she says. Aubrey also serves as a faith ambassador for several local faith communities.

“I love teaching people — especially older people — how to be their own advocate in the world.”

Join Gia and Aubrey! If you have a passion for education and increasing Alzheimer’s awareness, you, too, could be a Community Educator for the Alzheimer’s Association - Heart of America Chapter. For more information about how to get involved, please contact Erik Wray at 913.831.3888 or ewwray@alz.org.
THANK YOU
FOR YOUR CONTINUED PARTNERSHIP IN
MAKING THIS COMMUNITY A BETTER PLACE.

BlueKC.com

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Volunteer with the Heart of America Chapter

Conquering Alzheimer’s is as much a matter of education and public policy as scientific discovery, and we need your help to change the future of this devastating disease!

**Volunteer to be a:**
- Congressional team member
- State advocate
- Health fair host
- Community educator

Our Chapter programs provide vital support to people with Alzheimer’s disease!

**Volunteer to be a:**
- Support group or breakfast club facilitator
- Social engagement facilitator

Put your administrative skills to work in any of our offices!

**Volunteer to:**
- Answer phones
- Assist with mailings
- Enter computer data
- Organize and prepare materials
- Keep our library organized

Join an event planning committee or help with event day activities at our Chapter fundraising events!

**Volunteer for:**
- Walk to End Alzheimer’s
- The Longest Day

JOIN IN OUR EFFORTS!

If you would like more information, please contact: Katherine Rivard, krivard@alz.org or 913.831.3888
SEVEN FORMS OF CHARITABLE GIVING

Every dollar you give benefits those affected by Alzheimer’s disease. From face-to-face support and online education programs to promising worldwide research initiatives, your donation makes a difference.

In addition to a direct donation, there are many other ways to give to the Alzheimer’s Association. Listed below are seven of the most common ways.

1. **Employee Giving.** Workplace giving is a simple and effective way for employees to support the Alzheimer’s mission. Your gift helps fund vital research programs and services. No matter how small your contribution, your dollars add up to make a difference in the fight against Alzheimer’s. Check to see if your company has a corporate giving campaign. It is a convenient way to give your contribution through regular payroll deductions.

2. **Community Health Charities and the Combined Federal Campaign.** The Alzheimer’s Association is a member of the Community Health Charities federation, the largest workplace giving campaign devoted to health. If your employer participates in Community Health Charities campaigns, designate your contribution to the Alzheimer’s Association.

   Federal employees can donate to the Alzheimer’s Association through the Combined Federal Campaign (CFC). Designate your contribution to the Alzheimer’s Association, CFC ID # 11234.

3. **United Way.** Does your workplace participate in a United Way campaign? Then you can designate your pledge to the Alzheimer’s Association through United Way’s Donor Choice Program. Simply follow the instructions on your pledge card, or write-in our name and address. Contact your human resources department or local United Way agency for more detailed instructions about giving a gift to us through a United Way campaign.

4. **Matching Gifts.** Many companies have matching gift programs that will double or even triple charitable contributions made by their employees. Go to www.matchinggifts.com/az to see if your company has a matching gift policy.

5. **Planned Giving.** Leaving a gift to the Alzheimer’s Association in your will or by beneficiary designation is a great way to make a lasting difference in the fight against Alzheimer’s. Your gift will accelerate research and ultimately move us closer to a cure.

6. **Donate Stock.** Donating your stock or other securities supports our mission while providing you with potential tax benefits. It is important for you to notify the Alzheimer’s Association in advance of your stock transfers so that we can instruct our broker to accept delivery of your gift and acknowledge it properly for income tax purposes.

7. **Donate a Car.** If you have a vehicle that you are thinking of trading in or selling, consider donating it to the Alzheimer’s Association Donate-A-Car Program, a partnership with Insurance Auto Auctions, Inc. that accepts most vehicles, including cars, trucks, trailers, boats, and RVs.

Information about ways to give can be found at: alz.org/get-involved-now/other_ways_to_give
Life happens.
And sometimes what happens is cause for a little extra help. From assistance with mobility and self-care to helping with medication management and providing comfort at the end of life, we’re here for you. At Integrity, we dedicate a point-person to help assist you with the services, solutions and resources to live life on your terms. Let us help you chart the path to trusted healthcare, wherever you call home.
Garden Terrace at Overland Park is focused on caring for those with Alzheimer’s and other dementia-related disorders. Our facility’s unique focus gives us the ability to provide complete care for all stages of Alzheimer’s disease.

- Full time on-site physician
- Dementia-trained staff
- 8 secured communities
- Family education programs and support groups
- Music, art, and horticulture therapies
- LSVT BIG and LOUD certified therapists
- Ready Set Go — Rehab to home program
- Free WiFi

913.631.2273 gardenterraceatoverlandpark.com
7541 Switzer Road, Overland Park, KS 66214
The ultimate return on investment is measured by quality of life.

In our profession, the concept of investing is grounded in providing for a better future. For more than 25 years we have worked closely with individuals and families, and have seen all too often that future compromised by the devastation of Alzheimer’s and the sadness of seeing our friends and loved ones taken too early.

We heartily support the compassionate outreach and informed guidance provided to individuals and families by our local Alzheimer’s Association. We are honored to serve as a Local Premier Sponsor for this year’s Walk and in joining the efforts of many to improve our collective quality of life.