

VOLUNTEER NEWSLETTER

TAKE A PEEK INTO ADVOCACY FORUM 2018

On June 17, dedicated and highly motivated advocates converged on Washington, D.C. to be a voice for five million people living with Alzheimer's. This was my eighteenth advocacy forum, but I still felt the excitement of seeing friends, meeting new advocates, and feeling the hum of energy that brings us together year after year.

After two days of training and inspiring messages, we stormed Capitol Hill. Never underestimate the impact of 1,000 determined people wearing purple sashes! Armed with alarming statistics and colorful handouts, we delivered our message with one voice. Our strongest motivation was the undeniable hope that someday survivors will carry white pinwheel flowers at our walks.

This year, for the first time, I spent my birthday with the amazing Missouri Alzheimer's advocates. Through our personal stories, we put a face to the disease. We asked our senators and representatives to support an increase in Alzheimer's research funding, to cosponsor the BOLD Act to build an Alzheimer's public health infrastructure and PCHETA to increase palliative care and hospice training.



*Ambassadors with staff from
Senator Claire McCaskill's office*

I strongly encourage you to join the Alzheimer's Impact Movement (AIM) and take your advocacy to the next level by joining a congressional team. Never underestimate the importance of building a year-round relationship with your elected officials. Alzheimer's can leave you feeling adrift and helpless, but advocacy is an empowering experience.

I hope to see you in D.C. next year March 31 – April 2, 2019! Together, we can end Alzheimer's.

Linda Fisher, Ambassador to Congresswoman Hartzler



*Linda Fisher meeting with Congresswoman
Vicky Hartzler of Missouri*



*Preparing for the day at our
nation's Capitol.*

DIVERSITY & INCLUSION UPDATE

From Rev. Edd Lowe, Sr.



This month, I am offering a reflection of how much of a difference volunteers make every day on behalf of those who are on the Alzheimer's journey. Whether you are a volunteer presenting our education, sharing information at a health fair or

preparing training folders, the good work drives the mission. I would like to introduce you to **Mrs. Stephanie Griffin**, a former caregiver and current volunteer. I asked her to share why she volunteers and tell us where her volunteer work has taken her.

"What encouraged me to be an advocate for the Alzheimer's Association is witnessing the disease firsthand when my father was diagnosed in 2008. Following his passing, I developed a hunger to help people understand this disease. It affects not only the person diagnosed but the entire family. I wanted to share my father's story while simultaneously helping to bring awareness of this disease.

Being diagnosed with Alzheimer's disease or being a caregiver to someone who has been diagnosed is a very trying journey. The Alzheimer's Association provided my family with helpful resources and welcomed us. The process becomes easier when you have a team of individuals offering you their comfort and support. I learned that it takes a village to conquer Alzheimer's disease and that being an advocate would ensure that more people dealing with this disease wouldn't have to do it alone".

In January of this year, Stephanie decided to increase her family's volunteer involvement to reach more people in St. Louis city—particularly African Americans—with information about Alzheimer's and dementia and the available support. She asked our Programs team to help formulate a plan and brought in the Gamma Omega Chapter of Alpha Kappa Alpha (AKA) and her Health Ministry team of Friendly Temple Missionary Baptist Church to support this vision. Volunteers have been trained to lead and provide support to participants who gather in the community room at Friendly Village apartments. They also hear about the Alzheimer's journey from caregivers, receive education from about the disease, and most recently, participate in a Health Care Decisions Day. Before and after each offering, participants have an opportunity to talk with others about their concerns and connect to resources. The meetings take place on the third Saturday of each month at 10 a.m. at Friendly Village Apartments, located at 5545 Wells Ave. in St. Louis and are open to all. To learn more about the meetings, call 314.439-5799.

Like Stephanie, each of you has a passion for ending this disease. You may also have connections in the community that can join in this work to extend reach. I would love to hear your ideas and talk about your connections. A call to me at 314.801.0409 could be the conversation that creates a ripple that leads us to reaching more people.

Thank you and keep doing good.

Rev. Edd Lowe, Diversity and Inclusion Coordinator

CARE

CONSULTATIONS

SUPPORT FAMILIES AT EVERY STAGE

A care consultation is a service we offer to provide families support while they are coping with the impact of dementia. By participating, participants receive assistance that enables them to better understand the disease, manage care and make better-informed decisions.

"I know you deal with these issues on a daily basis, but you were so patient with us and dealt with us in a way that was individualized for our situation. I plan on using the tips you suggested and have already shared them with my family."

Care consultations are available by phone or in person at any of our three offices. We are also hosting them at the following locations within the next few months:

- O'Fallon, MO - Aug. 31
- Joplin, MO - Sept. 6 & 7

Register online [HERE](#), or call 314.801.0414 to schedule your time. Appointments are necessary. Care consultations are FREE.

COMMUNITY CONVERSATIONS

LISTENING & RESPONDING

More than a year ago, our chapter looked for a way we could meet people in underserved communities, hear what they have to say about how Alzheimer's and dementia is affecting them and generate ideas for how we can help. The *community conversation* was introduced as the way to accomplish this. The work starts by identifying communities where we aren't reaching many people through helpline calls, education, support groups or awareness events. We then develop an invite list – often quite long – which includes professionals in the community, elected officials, families we have talked to, churches and more. Each is invited to a community meeting, where some time is spent sharing basic information about Alzheimer's and dementia before hearing about their greatest needs. These conversations inform our plan for the community and often bring more people to the table to help.

From time to time, you may see information about an upcoming community conversation in your area. You can help raise awareness by sharing information about the event with anyone you know who lives or works in or around that community. As always, people can sign up to participate by calling our 24/7 Helpline.

The following Community Conversations are planned for the near future:

Sedalia, MO / August 2, 6 – 8 p.m.
Bothwell Regional Health Center

Macon, MO / August 16, 11 a.m. – 1 p.m.
Senior Center of Macon

Kirkville, MO / August 9, 5:30 – 7:30 p.m.
Village '76 Nutrition Center

Fulton, MO / August 23, 6 – 8 p.m.
Callaway Senior Center

Lebanon, MO / September 6, 11 a.m. – 1 p.m.
Hughes Senior Center

Watch for information in the near future on events in Edwardsville, Illinois, Macon and Rolla, Missouri.

A FAREWELL

CARROLL RODRIGUEZ, VP OF PUBLIC POLICY



On August 9, Carroll Rodriguez, VP of Public Policy will retire from our chapter. This bittersweet day comes just short

of her 26th anniversary with the Association. She started with our organization as a Respite Coordinator. In 1996, our chapter was one of two that received a grant from Home Office to ignite advocacy work, and Carroll was asked to be lead for this work for Missouri on the local, state and national level.

I sat down with Carroll to find out what she would consider the highlights of her career. I looked around her office admiring the framed House and Senate bills and the pens used to sign them into legislation. I wondered which one Carroll would call out as her favorite achievement. Carroll never disclosed a favorite. Instead, she focused on the HOW and WHO of her many years as an advocacy leader.

Carroll's HOW and WHO of advocacy is grassroots efforts and volunteers. "Working with volunteers has been the best part of my job – hands down! Their passion and commitment is remarkable," she said. Carroll attributes the success of the program to giving families and volunteers opportunities and outlets to tell stories that leave a lasting impression on elected officials and their staff.

She recalled a time when assisted living legislation was not moving forward at the end of general session. Carroll and her colleagues at AARP and Area Agencies on Aging in Missouri activated advocates to contact the Speaker of the House. Before the end of the day, they received a call to "call off the seniors." The bill was heard and passed that day! Another time, advocates gathered with Roy Blunt after his visit to Washington University to talk about research funding. He set aside about an hour to hear from them. Advocates were surprised when, at the end of their hour, he insisted he needed to hear from everyone in the room, no matter how long it took. These stories leave a lasting impression and are often recounted by elected officials who are advocating for our families and bills that affect them.

Carroll leaves her position confident that the relationships our advocates have forged will continue to produce positive results for our organization. She is also grateful for the time she has been afforded to work closely with Lucy Tran Williams, our newest advocacy coworker in Columbia and knows that she too will ensure the momentum continues.

Carroll's retirement plans include a lot of travel – visiting daughters in Seattle and New York – gardening and spending time with family friends whenever and wherever opportunities arise.

Pam Gordon, Director of Volunteer Services

24/7 HELPLINE

OFFERS SUPPORT TO THOSE ON DEMENTIA JOURNEY



The Alzheimer's Association's 24/7 Helpline is a round-the-clock service available to anyone and everyone with dementia related questions or needs. The chapter is lucky to have a team of talented and knowledgeable volunteers that work as Helpline Specialists to help answer questions and provide information.

Many of our Helpline Specialist volunteers have been in the role for many years and feel that working on Helpline is a wonderful way to serve those currently on the dementia journey. We are lucky to have them!

Helpline conversations can cover a wide variety of topics, and we often help people learn about the disease, offer information about our chapter programs and provide referrals to outside medical professionals or community resources. We also discuss difficult behaviors, safety, long-term care planning and provide emotional support. The connection of having someone from Helpline available to provide support at any time of day or night is one that is highly valued and cannot be replicated.

How can you help? Volunteers in other roles can be a huge asset in getting others connected to Helpline. If you know someone who could benefit from a Helpline contact and has given us permission to contact them, please complete a [Direct Connect Rapid Referral](#) form online, or send your supervisor a completed Direct Connect form. Hard copies of the Direct Connect forms are available at the local chapter offices anytime. You can also refer individuals to contact the Helpline directly at 800.272.3900.

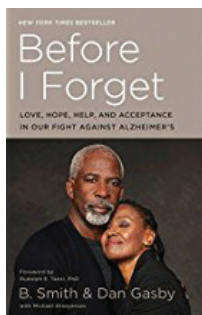
Interested in becoming a Helpline Specialist? If serving on Helpline sounds interesting to you, please reach out to Pam Gordon, Director of Volunteer Services, at 314-801-0462. Helpline training is offered twice each year. Volunteers must be able to work out of the St. Louis office and offer a one-year minimum commitment. Proficient computer skills are required.

STAYING ACTIVE & CONNECTED THROUGH EARLY STAGE SOCIAL/CULTURAL ACTIVITIES

The Alzheimer's Association Greater Missouri Chapter offers "meet-up" events or social/cultural activities for individuals with mild memory loss and their family members, friends and/or other supporters. Activities are offered at least once a month and might include visits to local cultural institutions or events, group gatherings or activities at the St. Louis office. The activities are planned by Deb Bryer, a group of volunteers and our partners at our activity venues.

Registration is required for any of the meet-up events on the calendar. Our July – September calendar can be seen [HERE](#). Instructions for registering is provided on the calendar.

IN OUR LIBRARY



For the past couple months, we have highlighted some books available in our chapter's library. This month, we would like to share a short reflection on one of our books received from one of our social work interns. Here's what Harold Crawford had to say about "Before I Forget."

I've been making an effort to read as many books as possible about Alzheimer's disease. Last week, I picked "Before I Forget" off the shelf. This book is authored by Dan Gasby, the husband of B. Smith, an African American restaurateur, magazine publisher and celebrity chef. I enjoyed this book because it was packed with scientific information about Alzheimer's disease and examples of how this disease, prominent in the African American community, is faced by caregivers. At a young age, I lost my own grandmother to the disease. Before I read this book, my knowledge about the disease didn't even register on the scale of 1 to 10. It is a great weapon in the battle against Alzheimer's. This book increased my knowledge, and now, I have decided to focus more on the subject of Alzheimer's and dementia more closely.



Harold is an undergraduate social work student from University of Missouri – St. Louis. He is a summer intern assisting with health care outreach and community events in the African American community.

HAPPY NEW YEAR!

You are probably thinking – New Year? Yes, at the Alzheimer’s Association, the end of a fiscal year is more significant than the turning the pages of a calendar year. It is a time of reflection and signifies the beginning of our work for the coming year. As I reflect on what we’ve accomplished together in the last year, I’d like to thank you all for your hard work and dedication. As support group facilitators, you provide an important connection for emotional

support, continuing education and social engagement for care partners, caregivers and family members who have loved ones diagnosed with some form of dementia. The contributions you make each month are far-reaching and powerful.

It has been my privilege to get to know so many of you, and I look forward to getting to know those I haven’t yet had the pleasure of meeting. Working with you all has been my great pleasure. We’ve navigated many changes together and will continue to improve upon our program.

This month, as I have in month’s past,

I would like to recognize a handful of facilitators: **Cindy Jung, Erika Nilles-Plumlee, Kristen Conard and Ashley Stockman.** Cindy and Erika facilitate the Adult Child Group that meets at the St. Louis office. Cindy has been active as a volunteer or intern since 2010. Erika joined more recently in 2016. Kristen and Ashley lead the Caregiver group hosted by the “Adult Day at the J” and started their service in 2016. A heartfelt thank you to these four dedicated facilitators!

Let’s forge ahead to make the next year the best yet for support groups!

Lisa Thompson, Rural & Support Group Specialist

THE LONGEST DAY 2019!

Although The Longest Day 2018 events are still taking place through August, we are already planning for our next year! We are forming local committees in Illinois, Springfield, St. Louis and Columbia,, and we will be ready for when event registration opens September 21. You don’t have to live in these communities to be on the committee – we’ll include you in meetings by phone!

Who’s a great candidate for the committee? Creative and outgoing volunteers with interests or connections to a variety of hobbies love The Longest Day! They find it easy to spread the word about our second signature event and help engage new participants. Full training and support will be provided by The Longest Day team!

What are my options for helping out?

1. Fall Volunteer Team (September - December)

Help plan local kick-off events and set up monthly dine out events January to July.

2. Spring Volunteer Team (January - June)

Distribute flyers, hang posters and help identify leads for the Event Manager to pursue in sectors like corporate, hobbies, athletics, fitness, parties, students.






3. Year-round volunteers who can come to the St. Louis office can help with mailings and making welcome calls to new participants, coaching them to success.

4. An internship for academic credit is available in each of our offices and is ideal for a student studying Business, Marketing or Nonprofit Management.

For more details on volunteering for The Longest Day, contact Betsy Brown at bmbrown@alz.org, or call 314.801.0445 today!

SOCIAL MEDIA

Social media is an extra way we can interact with our supporters. That’s why boosting our chapter’s social media presence has become increasingly important. Social media helps us engage and connect, drive traffic to our site, share content and extend our reach. Everyone has a role in contributing toward our success. If you haven’t already, follow us on the following channels:

-  Facebook: facebook.com/alzgreatermo
-  Twitter: [@alzgreatermo](https://twitter.com/alzgreatermo)
-  Instagram: [@alzgreatermo](https://www.instagram.com/alzgreatermo)
-  LinkedIn: linkedin.com/company/alzgreatermo/
-  Website: alz.org/greatermissouri

We’re always on the lookout for good stories. If you have compelling Association-related content, please send it to Don Thompson, Digital Media Manager, at dothompson@alz.org.

SHINING A LIGHT ON A COMMUNITY EDUCATOR

Our chapter is incredibly proud of and inspired by our volunteers. It is through your support that we are able to strive toward our vision of a world without Alzheimer's disease®. In my role, I have the fortune of working with some of our community-based volunteers who venture out to raise awareness, drive early diagnosis and connect those affected to support. In the course of their work, they often go above and beyond to ensure great programming! In June, our Community Educator, **Daniell Hill**, demonstrated this in an extraordinary way. He was teaching an education workshop for South Grand Senior Ministry, one of our Faith Outreach partners, on a stormy evening when water began flowing into the meeting room where the class was being held! Daniell stepped in to assist and even went out into the rain to assess what the problem was. "It really was beyond the call of duty. He is quite a gentleman," the education host shared with me in a follow-up message.

While volunteers are not often called upon to literally brave the elements, this is just one example of the ways how the volunteer spirit and tenacity have a positive impact on those with whom we work. Thank you all for be such wonderful representatives of the Alzheimer's Association!

Elyse Murrell, Education and Outreach Manager

EXPLORING ALZHEIMER'S: LIVED EXPERIENCES

Presented in collaboration with the St. Louis County Library and Maturity and Its Muse.

Dr. Lonni Schicker will discuss her experience living with cognitive impairment. A panel discussion will offer multiple perspectives on living with dementia.

Tuesday, August 28 | 6:30 p.m.
St. Louis County Library
Headquarters
1640 S. Lindbergh Blvd.
St. Louis, MO 63131

Registration requested at
314-994-3300 or [HERE](#).

GO PURPLE & GO BIG!



Living Word Fellowship in Caseyville, Illinois celebrated Alzheimer's and Brain Awareness Month in a big way this year because frankly, this awareness is too important to do anything else! Yvette Tart, Faith Outreach Ambassador and co-Pastor of the congregation set the stage for the celebration by asking everyone to come dressed in purple and be open and ready to receive information her important message about Alzheimer's and dementia, especially in the African

American community. In her message from the pulpit, she focused on how the disease impacts many families in the congregation, the prevalence in their community and the need for greater more awareness about the disease and the services provided by the Alzheimer's Association. Brochures were distributed, conversations were started and all things purple, including candy, were offered up!



Yvette knows firsthand how the disease can impact a family. She lost her grandmother Madea and uncle Lionel to the disease. About five years ago, shortly after losing her grandmother, she received an invite to a luncheon event hosted by the Alzheimer's Association. That invitation to come learn more motivated Yvette, Madea's oldest grandchild, to start a Walk to End Alzheimer's team – Madea's Redd Family – and become a Faith Outreach Ambassador. Her Walk team has grown to about 100 friends and family who fundraise for the Edwardsville Walk. Beginning in June, they call on their community for donations and appeal to those among them with a sweet tooth by selling slices of her daughter's homemade gooey butter cake after each Sunday service. Every \$1 slice offers promise to end this disease.

JOIN US FOR THE 2018 WALK TO END ALZHEIMER'S!

Register your team [HERE](#), or register to volunteer [HERE](#). Please call Jordan Brennan at 314.801.0444 if you have questions about either opportunity!

Belleville, IL Sept. 29	Lake of the Ozarks Area, MO Sept. 30
Branson, MO Sept. 8	Lincoln County, MO Oct. 13
Cape Girardeau, MO Sept. 15	Macon, MO Sept. 15
Columbia, MO Oct. 14	Poplar Bluff, MO Oct. 6
Edwardsville, IL Sept. 22	Rolla, MO Sept. 22
Farmington, MO Sept. 8	Sedalia, MO Sept. 8
Hannibal, MO Sept. 15	Springfield, MO Sept. 15
Jefferson City, MO Oct. 7	St. Charles County, MO Sept. 29
Jeff County/Arnold, MO Oct. 6	St. Louis, MO Oct. 28
Joplin, MO Aug. 25	Washington Area, MO Sept. 8
Kirksville, MO Oct. 16	

WELCOME TO MADELINE DAVIS



Madeline Davis joined the chapter's Walk to End Alzheimer's team in June as Walk Coordinator for the St. Louis Walk. Her relationship with the Association began long before her employment as an undergraduate social work student and Sigma Kappa at University of Missouri-Columbia. Her sorority is a national partner and leading fundraiser for Walk to End Alzheimer's events. She recently earned her Masters of Social Work in Social Change and Innovation through the University of Southern California. She completed internship and practicum opportunities in nonprofits, which helped prepare her for the work ahead. She will be focused on team retention and fundraising and day-of-event logistics to ensure a great experience for all on event day.

Madeline is a lifelong St. Louisan, growing up in Brentwood and attending high school at Ursuline Academy. She enjoys spending time with her family. One of their traditions is to take turns enjoying The Muny shows together, an activity inspired by her grandmother's investment in season tickets.

EDWARD JONES ASSOCIATES WALK ACROSS AMERICA FOR ALZHEIMER'S AWARENESS



Financial services firm Edward Jones has launched Walk Across America, a one-time, 16-week event taking place across 12 states to raise awareness of Alzheimer's. More than 1,000 Edward Jones

associates will complete the 3,100-mile, relay-style journey, taking at least 5.7 million steps — one for every person in the United States living with the disease. Walkers from the west and east coast connected with others as they head toward St. Louis, MO, ultimately meeting at the St. Louis Walk to End Alzheimer's event on October 28. Edward Jones is the national presenting sponsor of the Alzheimer's Association Walk to End Alzheimer's® in more than 600 communities nationwide. Learn more about this exciting endeavor and follow the event [HERE](#).

REMINDERS & RESOURCES

If the office closes unexpectedly, an announcement will be made on Facebook and available at 800.272.3900.

The chapter offices will be closed on Labor Day (Monday), September 3.

[Greater Missouri Staff Directory \(NEW\)](#)

[Report your volunteer hours.](#)

[Update your contact information.](#)

[Submit a Direct Connect Referral online.](#)

Visit [chapter](#) & [national](#) YouTube channels.

[Support Group List](#)

[Community Education Programs](#)

[Community Resource Finder](#)

