Research Matters in this Fight!

By being part of a clinical trial, you can help move research forward. 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.

Today, at least 50,000 volunteers, both with and without Alzheimer’s disease, are urgently needed to participate in more than 130 actively enrolling clinical trials about Alzheimer’s and related dementias. Recruiting and retaining trial participants is now the greatest obstacle, other than funding, to developing the next generation of Alzheimer's treatments.

We need people like you to help to change the course of this disease and improve the lives of all those it affects. Get started with Alzheimer's Association TrialMatch®, a free, easy-to-use clinical studies matching service that connects individuals with Alzheimer's disease, caregivers, healthy volunteers and physicians with current studies. Encourage family and friends to sign up so they, too, can be considered for studies that will help us end Alzheimer’s.

No new treatment advances to the clinical testing phase unless there is strong evidence indicating it will be as effective as, or more effective than, currently available therapies. (PET) Brain Scans Help Identify Alzheimer’s disease

Every clinical trial contributes valuable knowledge, whether or not the treatment works as hoped. You are invited to sign up for the Alzheimer's weekly e-newsletter, an easy way to stay up-to-date on the latest advances in Alzheimer's treatments, care and research. Subscribe now.

In March, Andrea Denny (one of our Helpline volunteers) and Jennifer Phillips (former Volunteer Manager) employees of the Charles F. and Joanne Knight Alzheimer’s Disease and Research Center at Washington University offered a Lunch & Learn program at the Chapter office. This offered an opportunity for many to refresh on the science of Alzheimer’s and learn about some of the research that is in progress at the Knight ADRC. We recorded an audio of this presentation and it is available HERE on our YouTube Channel.

Community Conversations

Learn more about Alzheimer’s and memory loss. Share your thoughts about how we can help the people in your community. Bring a friend who has been touched by memory loss! A light meal will be provided.

Wednesday, May 24 | 6 – 7:30 p.m.
Poplar Bluff Regional Medical Center
3100 Oak Grove Rd. | Poplar Bluff, MO 63901
Registration is requested. Call 800.272.3900 to register. Click here to download a flier to share.

Education: St. Louis County Libraries

There are many education classes occurring at the St. Louis County Libraries! Please check the education calendar and share this information with your support group members, faith community members or anyone who could benefit from attending.

NOW AVAILABLE – MARCH 2017 ROUNDTABLE VIDEO!

On March 6 and 9, volunteers gathered at the Chapter Office or on the phone to hear an update from our Alzheimer’s Association’s Leadership. Knowing that there are many more volunteers interested in the message than could participate, we recorded one of the presentations and the questions from the participants. You can find it on our Alzheimer's Association St. Louis Chapter, YouTube Channel. Take a look and learn about some exciting expansion plans in our programs and service area!

Watch this newsletter for an invitation to our second Volunteer Roundtable in late Fall.
Celebrate, Learn and Connect at our New Volunteer Forums!

For some years, the St. Louis Chapter has held an Annual Volunteer Appreciation event in St. Louis during April, National Volunteer Appreciation Month. This year, we are excited to take a different approach for recognition by hosting Volunteer Forums several times a year. The first Volunteer Forums will be in late April and early May at three different locations in our service area: Illinois, St. Louis and Cape Girardeau.

In addition to celebrating you, we will be offering the opportunity to learn about how Alzheimer’s and dementia present in people with developmental disability or Down syndrome, and time to connect with volunteers in other roles in the organization. The last 30 minutes of the program will offer a time for volunteers in like roles to gather with their supervisor.

It’s Not Too Late to RSVP for one of the Volunteer Forums!

Monday, April 24  | Cape Girardeau
6-8 p.m.  | Geraldine Hirsch Room
Cape Girardeau Public Library

Wednesday, April 26  | Collinsville
6-8 p.m.  | The Blum House
414 West Main Street

Saturday, May 6  | St. Louis
9:30-11:30 a.m.  | Chapter Office

Help us plan for how you will participate in the Forum by RSVPing to Erin Kelley, Volunteer Coordinator, at 314.801.0444

Haley Briggs, SIU-Edwardsville Public Health student has researched and prepared the presentation for this event. In doing so, she has also developed connections with local organizations we can now refer to when assisting families.

Early Stage Programs

Several of our early stage programs are among the Association’s best-kept secrets. We need the help of all volunteers to make them better known.

Meet-Up – Offers social/cultural events for people with memory loss and their family/friends. Once every quarter, the group has a potluck at the Alzheimer’s Association office. Other events are held at places like Laumeier Sculpture Park and the Missouri History Museum. See the Meet-Up web page for the current calendar. This program can serve people who don’t have a diagnosis and those with memory loss who would never attend an Alzheimer’s class or support group.

Dementia Mentors – Telephone-based support by experienced caregivers for early stage caregivers. This program can serve caregivers no matter where they live!

Let’s Talk – Telephone-based support by people with memory loss for people with memory loss. This program can serve people with memory loss no matter where they live and even when there is no diagnosis!

How can you help?

➤ If you’re a support group facilitator, make sure your group members know about these programs. Share the Meet-Up calendar with your members, if appropriate. Refer early stage caregivers to the Dementia Mentor program. Remember that families need ALL the support they can get.

➤ If you’re an AACE, keep these programs in mind, especially when you’re talking with caregivers or people with memory loss after your program – those who hang around and ask questions are usually letting you know that they need more support.

➤ If you’re another type of volunteer, just be aware of these programs and mention them if you’re talking with someone who might benefit.

➤ All volunteers: remember that the 24/7 Helpline is the gateway to all these programs.

On March 13, nearly a dozen volunteers gathered to learn more about our new Art and Memory program. The program will be offered in the three new locations in the community beginning in the Fall. Persons experiencing early stage memory loss will explore their creative side as they produce up to 8 different pieces. To inquire about enrolling a participant, call Deb Bryer at 314.801.0440. To learn how you can be involved as a volunteer art partner, contact Pam Gordon at 314.801.0462.
Go Purple!

June is Alzheimer’s & Brain Awareness Month! During this month is our annual Go Purple Alzheimer’s Awareness Campaign and The Longest Day fundraiser.

Why Go Purple

Go Purple presents an opportunity for faith communities, organizations, schools and social groups to help raise awareness about this disease and to be a positive influence for people to take action. As a result of your Go Purple event, awareness of the disease is heightened, myths are eliminated and people can be inspired to take action by seeking a diagnosis or calling the Association for help.

How to Go Purple

Go Purple: Participants will receive a packet complete with END ALZ stickers, Alzheimer’s awareness ribbons, disease information, activity suggestions, step-by-step instructions for planning and implementing your activity, a modifiable poster, email blasts, social media messages and talking points.

Go Purple with a Purpose: Many organizations and groups choose to supplement their Go Purple awareness efforts in June, with a variety of fundraising activities to benefit the Alzheimer’s Association. Thousands of people worldwide Go Purple with a Purpose in June by participating in The Longest Day, an event that honors those affected by Alzheimer’s on June 21, the longest day of the year. Walk teams can also Go Purple with a Purpose in June to jumpstart their fundraising efforts. Event participants, get a donation page, online resources and a variety of support materials to help them plan their activities and Go Purple with a Purpose in June.

Register early for either one so you can plan your activity!
Click here to register.

Walk to End Alzheimer’s 2017

Held annually in more than 600 communities nationwide, the Alzheimer's Association's Walk to End Alzheimer's® is the world’s largest event to raise awareness and funds for Alzheimer’s care, support and research. This inspiring event calls on participants of all ages and abilities to join the fight against the disease!

Last year, St. Louis Chapter area volunteers provided amazing support to one of more of our Walk to End Alzheimer’s events. These events represent our largest fundraising and awareness opportunity - $1.9 million was raised for research, care and support! Nearly 11,000 people participated by raising money, walking, or volunteering. Some did all of these. THANK YOU for making the events a success.

Plans are well underway for another great Walk to End Alzheimer’s season. Review the locations and dates below and start planning to help again this year. Perhaps you gathered a group last year – put it on everyone’s calendar now and commit to help again. If you are reserving for a group, include this information in your sign up so we can make certain you serve together. Please feel free to share this email with others who might be looking for a volunteer opportunity. When you participate in Walk, your fundraising dollars fuel our mission, and your participation in the event helps to change the level of Alzheimer’s awareness in your community.

Belleville, IL on September 30
Cape Girardeau, MO on September 16
Edwardsville/SIUE on September 23
Farmington, MO on September 9
Jefferson Co. on October 7
Lincoln Co. on October 24
Poplar Bluff, MO on October 14
Rolla, MO on September 23
St. Charles, MO on September 30
St. Louis, MO on September 16
Washington, MO on September 9

The time is right to form your own Walk to End Alzheimer’s Team! Gather friends and family and make a donation appeal far and wide to let everyone know you are participating. Register your team at www.alz.org/walk.

And to connect to a Walk west or south of us, visit the Greater Missouri website: www.alz.org/greatermissouri
MISSION MOMENT

A few weeks ago I was able to escape the strange weather St. Louis had been having, and I found myself enjoying the warm sun and sparkling waters of the Caribbean! As much as I like volunteering for the Alzheimer’s Association as a Caregiver Support Group Leader and as a Community Educator, I felt time off would be a good thing. And, it was – in more ways than the obvious!

I was vacationing with a group of 24 people from varied geography and backgrounds, and often found myself in the What-Do-You-Do, How-Do-You-Spend-Your-Time conversation. “I am retired” I would share, but “I am a volunteer for the Alzheimer’s Association”. This reveal always leads to questions and further discussion. Before the week was over, two different folks approached me for in-depth conversation about their loved ones whom they suspected were beginning AD. We talked, and I hope I guided them to seek more assistance and information from their local AA Chapter.

My experiences of this vacation week were not unusual - I had begun carrying on each of my trips several copies of the “Alzheimer's and Dementia” and the “Manage Memory Loss” tri-fold brochures that are so informative. Of course, I shared copies of these with my new friends who had asked for guidance. Now, they had the AA 800 Helpline number in-hand, as well as additional information. I guess the old BSA “Be Prepared” motto is still valid, though my camping days are over. JDO

Do you have a story to shares which reflects our mission in action. To share your Mission Moment, email it to Erin Kelley at ekelley@alz.org.

REMINDERS + RESOURCES

This is where you will find various reminders of events and quick links to resources. Simply click each title.

Reminders
If the office closes because of weather, an announcement will be made on Facebook and available to the 800.272.3900 Helpline.

Resources
- Report your volunteer hours
- Update your contact information
- Community Resource Finder
- Submit a Direct Connect Referral Online
- Print a Paper Direct Connect Form
- Visit Chapter & National YouTube Channels

News for Support Group Facilitators

Mission Conversations are in full swing. Thank you all for taking the time to make appointments and talk with me. If I haven’t called you yet, I will soon!

This has been an exciting month for me – meeting new people and learning why volunteers for the Alzheimer’s Association do what they do – has been truly enlightening. These conversations are made easy because I am talking to people who are passionate about moving our mission forward: 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.

Providing care and support for those dealing with Alzheimer’s disease or a related dementia is not easy. It requires time, dedication, resourcefulness, and resiliency. Through your dedication, we are able to make a difference in the lives of so many people. We are able to provide care and support to individuals and families who are faced with overwhelming difficulties every day.

So many of my conversations with have radiated passion, care, and concern for the people who attend their groups. You know what “Dad” liked to do on his days off, how much “Mom” enjoyed having the family over for Sunday dinners, and how hard it is to deal with the fact that a husband doesn’t remember who his wife is any more. You’ve been through family discussions about driving. You’ve helped spouses come to terms with the sad fact that it is time to consider long term placement. You’ve laughed and cried with these families and know them in a way not many people do.

You all do an amazing job. Your dedication, your passion, and your enthusiasm are contagious.

Thank you to those who have already shared your time and stories with me. To those I haven’t contacted yet, let’s talk soon!

Lisa Thompson

Welcome Edd Lowe, Diversity and Inclusion Coordinator!

Rev. Edmund Lowe joined the Chapter as Diversity and Inclusion Coordinator on March 6. This is a new position for the Alzheimer’s Association and is intended to bring more intentional and deliberate attention to cultural and diverse elements of employee engagement. Edd has been an ordained elder in the African Methodist Episcopal Church since 1981 and has been volunteering with the Volunteer Services and Faith Based Initiative Committees for 3 years.

His first major effort will be to bolster relationships in the North St. Louis City and County, East St. Louis and the Missouri Boot-heel, mainly engaging the under-utilized African American Community, but certainly not limited to this segment.

Over the past 30+ years, Edd provided visionary leadership in the religious community as a pastor and Presiding Elder in the African Methodist Episcopal Church, as well as a variety of management roles at AT&T, from which he retired in 2009 after 32 years and 17 assignments which took him to Mexico, Israel and South Africa.

Upcoming Events

FREE Care Consultations Near You

Thurs., April 20, 2017 | 9 a.m. - 3 p.m.
Fitness Plus – St. Sebastian Room

Saint Francis Medical Center
150 South Mountain Auburn Road
Cape Girardeau, MO 63703

Appointments are required and can be scheduled by calling 800.272.3900.

Click here for a shareable flier.

PBS Documentary

Join the Alzheimer’s Association for screening clips of the PBS documentary Every Minute Counts. Each event features a panelist consisting of a caregiver and an Alzheimer’s Association staff member, who will be available to answer questions from the audience.

Fri., May 12, 2017 | 10:30 a.m. – 12:30 p.m.
Carondelet Park Rec Complex YMCA

Mon., June 12, 2017 | 6 – 8 p.m.
West County Family YMCA