

SERVING
KANSAS,
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MISSOURI

CREATE
A WORLD
WITHOUT ALS.



Help Line
(800) 878-2062

Website
www.alsa-midamerica.org

Kansas City Office
6950 Squibb Road
Suite 210
Mission, KS 66202
P: (913) 648-2062

Omaha Office
900 S. 74th Plaza
Suite 106
Omaha, NE 68721
P: (402) 991-8788

Springfield Office
2209 Petrus Circle
Ozark, MO 65721
P: (417) 886-5003

Wichita Office
3450 N. Rock Road
Suite 211
Wichita, KS 67226
P: (316) 612-0188

Why Walk?

Sometimes, it can feel as though you are alone in this fight. But, when attending the Walk to Defeat ALS, you realize that you are in fact not alone. You see that there are hundreds of other people walking, fundraising and spreading the word for the same reason as you — to find a cure. Walking with all of the others who have also gone through what you have, or may still be going through, makes you feel the love and hope. It is almost like the silver lining of this disease. Everything counts — every drop, every volunteer, every penny and every voice. You ALL make a difference in this fight.

For the past nine years, Wendy Layton has served as the team captain for Special K at the Wichita Walk to Defeat ALS. She shares why she walks to defeat ALS year after year, “The annual Walk to Defeat ALS means

first and foremost “HOPE” to me... hope for less suffering, hope for support for those struggling with this dreadful disease, and most of all... hope for a CURE! My son Kurt, an incredibly gifted musician, battled ALS for over two years. He lost the ability to sing or carry on a conversation with friends and family. He lost the ability to swallow or even take a good breath. He battled the disease with courage, unwavering faith, and with dignity.”

She said, “The Mid-America Chapter of The ALS Association played a big part in that battle. They directed him to the best care at the ALS Certified Center and clinic in Kansas City, and provided Kurt and his family with support throughout his journey. They provided education as he and the family needed it as the disease progressed, and advice regarding medications and clinical trials

that were available to him. They were instrumental in helping to obtain a speech communication device and breathing aids when that became necessary, and toward the end they were instrumental in helping to obtain hospice care at home.”

“Without the funds raised at the Walk, none of this help would be possible... help that eased the struggles of battling the devastating Lou Gehrig’s disease. Without those funds there would be no research... no hope for finding a cure. I will continue to walk with those who can still walk and for those who are no longer able until I myself am not able to walk.”

If you are ready to join this fight and Walk to Defeat ALS, please contact Erin McNamara at emcnamara@alsa-midamerica.org. You can also call our office at (913) 648-2062.

The Chapter’s Care Services numbers for 2018

The Care Services team of 5 professionals is committed to the mission of serving, advocating for, and empowering people affected by ALS to live their lives to the fullest.

So far this year, the Mid-America Chapter:

- has registered 91 new ALS clients
- has lost 61 individuals to ALS
- has consulted with ALS families over 1,200 times
- has worked with 79 veterans
- has participated in 44 ALS multidiscipline clinics
- has seen over 285 individuals in the ALS multidiscipline clinics
- has provided 48 Quality of Life Grants
- has enrolled 234 individuals in the ALS Care Portal
- has held 36 support group meetings attended by over 190 individuals
- has loaned over 250 equipment items through the equipment loan pool

The Care Services Team is here for you!

Hollie Baker, MSW, Central & Western Kansas
Juliet Pierce, RN, Kansas City & Eastern Kansas
Shannon Todd, MSW, Nebraska
Sherri Murray, RN, BSN, Central & Southern Missouri
Tara Dhakal, MSW, Kansas City & Northwestern Missouri

Support Groups

Please RSVP for all support group meetings by calling (800) 878-2062 or (913) 648-2062.

Thursday, June 7

Kansas City Support Group
2 p.m.
The ALS Association
6950 Squibb Road
Mission, KS 66202
4th floor training room
Meets first Thursdays

Thursday, June 21

Columbia Support Group
4 p.m.
The Wyatt Guest House
(Dining Room)
1580 Jewell Ave.
Columbia, MO 65203
Meets the Thursday before Clinic

There will be no Kansas City Caregiver/Survivor Support Group in June.

Walk to Defeat ALS team captain tips

Captaining your Walk to Defeat ALS team is a big, yet rewarding job. Keeping your team members motivated, reminding them to send emails, raise funds and also helping them think of new and fun ways to get the word out can be a lot. That is why we suggest designating a cocaptain.

The term 'It's easier to get by with a little help from your friends' stands true in this situation. By recruiting a cocaptain, you are able to motivate one another and split up the jobs of working with the rest of your team. These two positions are best fulfilled by someone who has positive leadership skills, a strong, driven spirit, as well as great organization methods. Just like any coaching, it's best to lead by example.

To get your 2018 Walk journey started, I would suggest updating your personal page. It's easy-- just log in to your participant center and keep your story, your reason for walking, up to date. Upload a picture of you and even your team! Next step would be taking the plunge to self donate. Your dedication will motivate others to take action, too! The more members, the more success; grab your family, friends, neighbors, coworkers, grocery store clerk, etc. The larger your team, the more money you can potentially raise!

Once you have your team recruited, make sure they get registered. Participants who register at least 60 days prior to the event raise over 50% of the total revenue. Once you have your team in place, communicate regularly. Let them know about any special events being held, remind them of your team fundraising goal and help them to understand the importance of each person becoming a fundraising participant and making an impact in the fight against ALS. Research shows that it takes an average of three messages before a person will take action and make a donation. Encourage your team to ask, ask, and ask! Send thank you notes to those who have donated. Let them know how close you are to hitting your goals. Share your success with your teammates and teach them how to do the same thing! Make this a fun memory, so your members want to return the following year. Returning walkers raise nearly FOUR TIMES the amount of a new walker.

If you have any questions, contact your local Development Manager. Together, we are in this fight!



Golf tournament a success!

The 35th Annual Joe McGuff ALS Golf Classic Presented by Davis, Bethune and Jones was held on May 14 at Nicklaus Golf Club at LionsGate in Overland Park, Kan. More than 100 golfers enjoyed a beautiful day of golf and dinner with local celebrities, including Tom Watson, George Brett and Trent Green.

The annual ALS golf tournament that originated in 1983 by former Royals player and Baseball Hall of Famer George Brett offered its players a unique day of fun on the course in conjunction with raising much needed funds to fight ALS.

A stellar list of corporations once again pledged their support to the annual event, including Davis, Bethune and Jones; Capitol Federal; and Tech, Inc. Food and Beverages were provided by BRAVO Cucina Italiana, Kaldi's Coffee, PB&J Catering and Holladay Distillery.

Larry Vilmer was this year's honoree and was diagnosed with ALS in 2017. At the event, Larry enjoyed riding on a golf cart around the course with his grandson and meeting local celebrities. During dinner, Larry and several of his family members, including his caregiver, visited with Tom Watson. Larry also delivered a speech to all the golfers about his continuous perseverance battling ALS and finding joy every day, even while struggling with this disease.

In his speech, Larry said, "My goal each day is to make someone feel better about themselves, of who they are, unconditionally. Showing kindness, courtesy, and respect for others are values that we can give away freely. That gives us strength to battle the hard times we face each day. Above all it gives us hope, hope to live a happier life and hope to find a cure for ALS."

Thank you to everyone who contributed and participated in the 35th Annual Joe McGuff ALS Golf Classic!

"I made a promise to a friend and I intend to keep it."

Those were the words George Brett said nearly 40 years ago. His friend, Keith Worthington had passed from ALS, and George had promised him he would stay in the fight until a cure is found. Recently The Chapter asked George, what he would tell Keith today? His response was "I can't believe it's taken this long, but a lot of people know more about ALS because of you. We're not going to quit, we're going to keep fighting for you."

Another sports figure who has joined forces with The ALS Association is golfer Tom Watson. Tom lost his long-time caddie, Bruce Edwards to ALS. He has been participating in the Joe McGuff ALS Golf Classic for 15 years and is a tireless advocate for ALS research. Tom promised Bruce that he would do "everything in my power to raise funds for ALS research until we find a cure." We also asked Tom about what he would tell his caddie today, he says "Bruce, sadly we aren't any closer to find a cure, but we are closer to finding the address of where the cure resides. That's the faith I have. To make that cure a reality."

The Mid-America Chapter is fortunate to have two dedicated men who have given their word to stay in the fight until a cure is found.



Mark your calendars!



Walk to Defeat ALS Team Week

July 23-27, 2018

Kansas City Walk to Defeat ALS

Saturday, October 6, 2018

Richmond Walk to Defeat ALS

Saturday, October 13, 2018