



Momentum

THE NEWSLETTER OF THE ALS ASSOCIATION OKLAHOMA

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ALS is not beating me; I'm beating ALS

In April 2020, Orlando Houston shared as the pALS highlight for the Tulsa area support group meeting. This is his story, in his own words.

March 2018. I considered it a great month. I had been working in the healthcare field for 12 years in a job I loved, and was planning a fantastic trip with my daughter to Carlsbad Cavern. It was also at the same time that I began experiencing muscle twitches and a dropped foot. Coming home from work one day, I tripped and fell and it took 20 minutes to get up and in my home.

I went to the doctor that June, thinking I had a pinched nerve. After an MRI I was told it was a bulging disc. After an EMG one week later, my neurologist spoke the words "Orlando, you have ALS."

Surprisingly, I was not shocked. I had heard of ALS but didn't know what it was. Lisa, my wife, and I left the office,

went to our van and prayed "God, we



put our trust in You." We felt complete peace. After getting home, we looked up further information about ALS and possible treatments.

Lisa met all of you in this support group before me! She met Sharon and Amanda at the Disabilities Day at the State Capitol.

I started with a cane to help me walk then got a scooter and now I'm in a

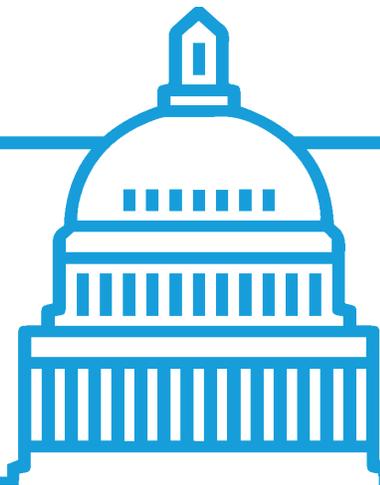
power wheelchair. My granddaughter just turned 4 and she loves going for rides with her Papa! I have decreased mobility in my right arm. Coronavirus has been easier on me than most people; I'm already confined.

I know not everyone has faith like me, and that's ok, but the one thing I've learned is to be joyful for what I have, and that is my relationship with God. Put your trust in Him and your faith. It makes the journey easier. I've been at my church for seven years. We started with 30 members and now we have 300 and two services! I love that I still get to pastor. My church family is a blessing. They have defined for me the hands & feet of Christ. A 6 year old recently asked me "Are you dying?" I smiled and replied "No, I'm living!" I lean on the verse Philippians 4:11.

Orlando beat ALS on March 3, 2021. "I ran the race and fought the good fight!"

OUR MISSION:

To discover treatments and a cure for ALS, and to serve, advocate for, and empower people affected by ALS to live their lives to the fullest.



ADVOCACY CONFERENCE

Each year, hundreds of ALS Advocates gather in our nation’s capitol to learn of the latest research and meet with their state legislators to advocate for those living with ALS. Last December, years of advocacy came to fruition when the ALS Disability Insurance Access Act was passed by both the U.S. House and Senate and signed by President Trump.

This June, we will once again gather in the digital space for the Virtual Advocacy Conference. Since 2018, we have increased the number of participants from Oklahoma and hope to do so again this year.

- 2018 = 2 (each registered separately and met in D.C.)
- 2019 = 12
- 2020 = 24
- 2021 Goal = 45

We will provide all the conference and registration details when they are released later this spring. We hope that you will consider joining us as we meet with Oklahoma legislators.

Our 2021 advocacy priorities are:

- Accelerate Development, Approval and Access to Effective New Treatments
- Increase Federal Funding for ALS Research
- Permanently Extend Access to Telehealth for People Living with ALS
- Provide High-Quality, Affordable, and Accessible Health Care
- Increase Veterans Benefits for People with ALS and their Families

SAVE THE DATE: June 8 - 10, 2021
Until we can gather together safely, we will once again meet virtually.

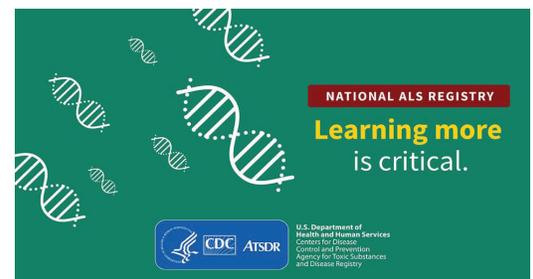
“In 2020, our ‘Behind the Scenes: Advocacy in Action’ on each call was a success,” says JoCarolyn Chambers, Care Services Manager from the Oklahoma service area. “Everyone on our video calls could hear the phone conversations with our legislators perfectly, as if we were all in their offices with them. It was a great alternative.”

We are excited to have a goal of twice as many participants this year as we did in 2020. Watch your email and our social media channels as conference information is released. We can’t wait to advocate with you.

The National ALS Registry is a program to collect and analyze data about persons living with ALS. It includes data from existing national databases and information provided by persons with ALS who choose to take part.

Researchers can use Registry data to look for disease pattern changes over time. They can also try to identify whether there are common risk factors among individuals with ALS.

For more information visit <https://www.cdc.gov/als/ALSJoinALSRegistry.html>



For the latest news and happenings in the ALS community in Oklahoma, follow us on Facebook: @ALSAOklahoma Twitter: @ALSOklahoma and also on Instagram @alsaoklahoma

Partner Spotlight



We are able to accomplish much across the state as an organization because of incredible partner organizations that we work alongside. To share with you who we work with, we will begin spotlighting these agencies and how we both, working together, best serve you and your families.

This month's partner highlight is National Seating and Mobility (NSM). One of the services we provide is a Durable Medical Equipment Loan Closet (the loan closet). With the loan closet, we are able to provide necessary equipment, at no cost

including but not limited to power wheelchairs, Tobii eye gaze machines, boogie boards, shower assists, and more.

We are fortunate to have NSM house the loan closet and provide the manpower to pick up donations as well as make deliveries to families across the state.

"We are so grateful for the partnership with NSM that has been built over the last three and half years", says JoCarolyn Chambers, Care Services Manager,

ALS Association Oklahoma. "We appreciate that NSM houses our loan closet at no charge to us as a contribution to the ALS community throughout Oklahoma."

Aaron, Brandi, Steve, Tori, Joey and everyone else at NSM, THANK YOU for all you do and for serving ALS families alongside us!



WHY I SERVE - Sarah Ehrlich

"My beautiful mother, Jeannie McDonald, was diagnosed with ALS in 2014 with her first symptoms appearing in 2013...since then she slowly fell victim to this horrible, devastating, merciless disease. She is my absolute hero."

When you first meet Sarah, you might say to yourself "WOW, her smile lights up the room!" or "Is she always this joyful?" The response to both of those is YES! Since her mother's diagnosis and battle through ALS, Sarah has worked tirelessly with the Oklahoma ALS Family to help raise awareness and fund necessities for those walking the same journey.

Sarah currently serves on the Oklahoma ALS Advisory Committee, Tulsa Walk to Defeat ALS Committee, is an Oklahoma ALS Advocate during the ALS Advocacy Conference and recently completed ALS Research Ambassador certification with the NEALS Consortium. "If I can be the hands and feet of someone living with ALS, I will!". If you don't have a team for this year's Tulsa Walk, Sarah would love to have you join Team Jeannie!

photo courtesy of Sarah Ehrlich

UPCOMING EVENTS

April: National Volunteer Month
April 18 - 24 = National Volunteer Week

April 19: Webinar - Communication Options for People with ALS
Alisa Brownlee, ATP, CLIPP, CAPS, WSP, Assistive Technology Specialist will share various communication options for people with ALS, including consumer-purchase and insurance-covered technology and devices.
Monday, April 19, 1:00 CST Register here: <https://bit.ly/3dldSRj>

May 6: National Nurses Day
Today we we raise awareness of all nurse contributions and commitments and acknowledge the vital role nurses play in society.

June 8 - 10: ALS Advocacy Conference
Once again the 2021 Advocacy Conference will meet virtually instead of in-person. Following a day and a half of trainings and general sessions, ALS advocates will travel in the digital space to Capitol Hill to share their stories with Congress.

October: Tulsa and Oklahoma City Walks to Defeat ALS
Watch for our special Walk Newsletter coming in the next month!

November: Oklahoma ALS Boot Camp

OUR VISION:
To create a world
without ALS.

OUR CORE VALUES:
Compassion
Integrity
Urgency

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