ALS and COVID-19

Since mid-March, our world has been turned upside with novel coronavirus, COVID-19, and its spread across the world. It has changed the way we think, work, play, eat, and shop. At the ALS Association Oklahoma, it hasn’t changed our commitment to serving our ALS Families across the state.

As we continue to adapt to this evolving situation, we will continue to take action in the best, and safest, interests of people with ALS, their families and caregivers, and our staff.

We are forever grateful to our Loan Closet partner, National Seating and Mobility, for continuing this vital program during this time. They have been, and remain, committed to ensuring safe delivery and pick up of items as requested and needed.

We have transformed our service delivery model from in-house visits and support groups to providing remote support and utilizing technology for meaningful care services. Collaborating with those who facilitate the Oklahoma City and Tulsa support groups, we are providing the technology avenue to enable these groups to continue without interruption. In providing the support groups with a virtual option, those in more rural areas are able to attend as well. In addition, our Bereavement Group has gone virtual, and we have added a Caregiver Connect group to our virtual meeting options.

We will continue to evaluate our planned activities scheduled through the summer and beyond, in accordance with the CDC and local guidance.

We are all in this together. During stressful times people may direct their fear or anxiety towards others. We stand with you, promoting the safety and well-being of everyone.

We remain committed to providing the best care and services to the Oklahoma ALS Community.
March 2016. Like for so many, it is a date that will forever live in the minds of Sean and Wendy Miller. Wendy was already pregnant with their youngest child and Sean had started feeling “sick”.

Once Kyrstie was born, Sean couldn’t hold his newborn daughter for more than 5 – 10 minutes without losing his breath. Six months later, August 2016, they had their answers…ALS. “We didn’t really know what ALS was,” shared Wendy, “but ALS checked all of the boxes for the symptoms that he had. I almost knew before I knew.”

It’s been four years since his diagnosis, and Sean is now in a wheelchair full time, and to assist with breathing and improving his quality of life, he utilizes a ventilator. He had to retire from his job with Verizon and while he doesn’t attend as often as he would like, when they can, Sean and Wendy attend church on Sundays.

Wendy is the primary caregiver with help from their older children, including their 14 year old son who is taking online school classes while helping with his father. “We have set up a schedule so that someone is always in the room with Sean; we all have three hour shifts” said Wendy.

What is your biggest advice to other ALS families?

“Seek help! Before we set the schedule, I was spending so much time taking care of him that I was dropping the ball on so many other things including the children” Wendy shared. “I literally got sick from trying to do it all by myself. It took 2 ½ months for me to get better” she added.

Sean, what is your biggest joy?

Without skipping a beat, both answered “Kyrstie”. “Kyrstie is daddy’s light; she lays in his lap and they watch movies together holding hands”. The ALSA OK staff asked Kyrstie to show us how that works and watched as she stood on the bed and climbed into Sean’s lap shouting “This is my spot!” with the biggest smile on her face. You could tell instantly that for both Sean and Kyrstie, in that moment, all was right in the world. “His lap is her favorite spot” said Wendy. “It’s the highlight of Sean’s day. So, that’s my favorite part of the day, watching them watch tv together.”

Wendy, what is your biggest joy?

“Painting. It has become a creative outlet for me.” Wendy shared about each piece that is hanging in their bedroom. “Emotions is the first painting I did” shared Wendy. “There are lots of colors going in different directions, kind of like me. The colors and directions represent the joy, anger, sadness and pleasantness.” Four other paintings she shared with us are “Lost”, “My Heart Poured Out”, “Two Sides” and “Beautiful Disaster”. “Beautiful Disaster is what I feel at times”, Wendy said. “You don’t realize that in the middle of the storm, how beautiful you actually are.” “I painted Two Sides because there are two sides to every story/every life’s journey. What he goes through, I have no idea, I can’t feel it” Wendy added. “All he can do is express it to me. And he has no idea how I feel all the time.”

What has become most important to you both?

Without hesitation, Wendy answered “Things from the kids”. She then shared the meaning behind each item on the wall; the photos, the decorative wall hangings. “A lot of things we do and have are important to us.” The final pieces she described were 2 hands sculptures. One is two adult-sized hands intertwined and the second a child-sized hand perfectly nestled in an adult hand. Wendy shared “We were at the fair and wanted to have something to leave for Kyrstie. We stopped at a sculptor’s booth and sat. One is my and Sean’s hands together and the other is Kyrstie holding her daddy’s hand. This will help her remember that her daddy is always there.” “These are more than souvenirs” Wendy shared with tears welling to the surface. “These are important. Every piece has meaning.”

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We are excited to once again host our signature event, The Walk to Defeat ALS in both our Tulsa and Oklahoma City communities. The Walk brings together hundreds of individuals who wish to make a powerful difference in the lives of those living with and affected by ALS. People like you and your fundraising efforts will help bring programs, services and hope to our Oklahoma ALS community. We thank you in advance for registering and choosing to join us supporting the fight against ALS!

We are currently planning for in-person events, but are also working on contingency plans for possible virtual events. Stay tuned to the Walk websites, social media and your email for updates.

We are looking for additional volunteers to serve on our Tulsa committee. We are also seeking corporate sponsors looking to partner with our organization and focused on community engagement. If you are interested in either of these opportunities, please contact Sharon Catalano at scatalano@alsa-national.org.

**Tulsa Walk to Defeat ALS:** Saturday, October 3rd at The Oklahoma Aquarium. For details and to register, visit web.alsa.org/tulsa

**Oklahoma City Metro Walk to Defeat ALS:** Sunday, October 25th at The University of Oklahoma. For details and to register, visit web.alsa.org/oklahomacity

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**MEET THE MILLERS (cont’d from page 2)**

As we finished our conversation, Sean and Wendy looked at each other and smiled. They don’t know how much time they have together, but they know that each moment is precious. Their faith sustains them. Sean ended our conversation with “If I’m not healed here on earth, I know I will be healed in Heaven.” He finished with a line from his favorite song *Even If*, by the group Mercy Me “I know You’re able and I know You can; Save through the fire with Your mighty hand. But even if You don’t; My hope is You alone.”

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**CARE GRANT PROGRAM**

The ALS Association Oklahoma Service Area is once again offering care grants through an application process, which will be open beginning the first week of May. Care grants funds are available for expenses incurred including home modifications, home health care services, medicines and more. For more information, contact Care Services Manager, JoCarolyn Chambers at jchambers@alsa-national.org.
Upcoming Events

MAY/JUNE 2020: THE NATIONAL ALS ADVOCACY CONFERENCE
The Conference brings together ALS advocates from across the country to learn about the latest in ALS research, care services and advocacy as well as engage with Congress on policy priorities that affect the lives of people with ALS. While Congressional offices are currently closed to visitors, we will hold virtual advocacy to advance our policy priorities on Capitol Hill. Oklahomans will have an opportunity to participate with a Behind the Scenes view on our advocacy efforts in action! Watch your email and our social media for more details.

FALL 2020: ALS BOOTCAMP/EDUCATION FORUM
As with all our events and programs, we will be paying attention to our city and state leaders for group gatherings. More details to come.

FALL 2020: WALK TO DEFEAT ALS
Join us in Tulsa October 3rd at the Oklahoma Aquarium and on October 25th at the South Oval on the campus of The University of Oklahoma, as hundreds come together to raise awareness of ALS in their communities.

Many of our upcoming activities rely on volunteers to help them run smoothly. Please contact us at scatalano@alsa-national.org to learn more about how you can help plan and execute these events!