



Momentum

THE NEWSLETTER OF THE ALS ASSOCIATION OKLAHOMA

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THE YEAR THAT WAS

2020. It started like any other year: weariness from the holiday rush, excitement over the new year with new things to come, and great plans for programs & services for our Oklahoma ALS families.

The ALS Association Oklahoma staff attended the annual ALS Leadership Conference with staff and board leadership from across the country. We learned of exciting updates with regard to research, a new website to come, and we honored ALS heroes who overcome the toughest of challenges in a positive manner.

In January we held the second ALS Oklahoma Boot Camp, bringing together 48 people living with ALS and family members along with 39 vendors/presenters. Our most important take-away, as with the inaugural Boot Camp in August 2019,

was the camaraderie and interaction between everyone who attended.



In mid-March, our work was halted 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 didn't change our commitment to serving our ALS families across the state.

We have transformed our service delivery model utilizing technology

for meaningful care services.

In June, the first Virtual Advocacy Conference was held with great success! With the assistance of 14 people with ALS and family members, we were able to speak with each member of the Oklahoma Delegation to the U.S. Congress, sharing with them the impact of ALS, requesting their support on vital legislation, and advocating on YOUR behalf. Because this year's conference was held virtually, we were able to utilize our technological resources and invite our Oklahoma Family to "Behind the Scenes: Advocacy in Action". We thank the members of our Advocacy Task Force who helped provide insight and wisdom into how we as a state would approach this virtual experience.

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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.

HOPE

Hope. By definition, it means “a feeling of expectation and desire for a certain thing to happen.” Its definition also includes “expect with confidence and to cherish a desire with anticipation.” An inherent part of our nature, we are all hoping for something: better weather, that job interview to go well, that repair to not be so expensive.

With ALS, we are hoping for: an incorrect diagnosis, the progression to slow down, the right treatment path, the right external help. We are always hoping for better. Being hopeful can help the hard days seem easier to bear.

The director of the OU-Tulsa Hope Research Center, Dr. Chan Hellman, focuses his research on hope as a psychological strength helping children and adults overcome trauma and adversity. “Hope is the belief that the future will be better than today and that we have the power to make it so.”

Hellman shares his belief that hope is based on three simple ideas – the goals we set, the pathways that allow us to achieve these goals, and the ability to generate willpower to pursue these pathways, especially in the experience of adversity.

Living in a world with ALS, hope is always a reach away. It is an ever-present thought and desire. Hoping for new treatments, new therapies, and a cure. There have recently been numerous break-throughs in the ALS space, Amylyx being one. A first in class investigational drug helped people with ALS retain function longer.

As we enter into the holiday season and the new year, there is much in which to have hope. Hold on to it; believe in it.



ALS Advocacy Victory



December 8, 2020. This date gives new reason to celebrate; to have hope. Because of your advocacy, your championing, and your persistence, the U.S. House joined the U.S. Senate in approving the ALS Disability Insurance Access Act.

Once President Trump signs the bill into law, the arbitrary five-month wait for Social Security Disability benefits will be waived for people living with ALS. With only 3% of bills introduced in Congress actually passing, this is an important victory that has been four years in the making.

We are grateful to the members of the Oklahoma delegation who co-sponsored this bill in both the House and the Senate. Their support was critical in having the leadership bring the bill to a vote as well as its passage.



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

ALS SUPPORT GROUPS

Are They For Me?

Did You Know: JoCarolyn Chambers facilitates or assists facilitating four different support groups each month: Oklahoma City (in partnership with Wendy Beson), Tulsa (in partnership with Amanda Holcomb), Caregiver Connect, and Pathways (Bereavement). All persons living with ALS, family members, and caregivers are welcome to attend the Tulsa and OKC groups; Caregiver Connect is limited to just Caregivers and Pathways is limited to those in bereavement following the loss of a loved one or friend to ALS.

Each meeting is unique to its purpose; for example, the Tulsa Support Group, has a positive message opening, pALS share time, cALS (Caregiver) share time, a vendor or partner as well as social time. The Pathways meeting is focused on a different topic each month as individuals journey through the many stages of grief.

All groups are virtual, due to COVID-19, and will continue to remain so for the near future. Links for these groups are never shared on social media but are sent via email.

Gema Ramos, RN, Care Services Coordinator at the ALS Association Greater Chicago Chapter has led support groups for over 4+ years, and has seen the benefits of it first-hand and has learned so much from it as well. She shares with us her thoughts on the benefits of attending support groups. *(article is printed with permission)*

“After leading support groups for

many years, I’ve learned that the attendees can benefit from the fellowship, emotional support and knowledge from attending a support group. By definition, a support group is a small gathering of individuals who share similar struggles, interests or concerns. They deliberately come together as a group to provide one another with moral support, information and tips about problems relating to their shared experience. Support groups help individuals living with ALS, families and caregivers feel connected with others who are living with the disease.

There is a substantial benefit in finding that one is not alone, that feelings and reactions are normal, and that some problems have been successfully navigated by others.

There is a significant benefit in the fellowship found in attending a support group. The world of individuals living with ALS, their families and caregivers is like a culture in itself. It’s a world with its own language, way of life and a myriad of equipment that one has not encountered before unless they worked in a medical field. This is likely one of the only safe and confidential places that one can come to where people “speak your language,” a place to express your feelings and concerns and ask questions. No one can understand the feelings and emotions involved better than another person with ALS or caregiver. Basically, the ALS Association Greater Chicago Chapter support group is a place where a collection of people who share the challenges of life with ALS come together. It

brings people together to make friends and boost each other’s morale and help one another. Also, sharing feelings and experiences with others facing similar challenges can reduce stress, fear, and anxiety.

Additional benefits include exchange of emotional support, information and practical experience. Individuals experiencing varying stages of the disease’s progression learn what’s ahead or are in a position to share tips and expertise from having “been there.” It’s a place for sharing tips about dealing with doctors, employers, friends, relatives, insurance issues and household barriers.

Another benefit of attending a support group is that it is an educational gathering where one can come to learn about current research and clinical trials and hear guest speakers who are experts in their fields such as a speech therapist, a financial planner, a social worker, researcher and many more.”

We believe the benefits of attending far outweigh not attending. Come check them out! If you have any questions, reach out to Care Services Manager, JoCarolyn Chambers at jchambers@alsa-national.org.

Pathways Group - First Wednesday of the month

OKC Support Group - Second Tuesday of the month

Caregiver Happy Hour - Third Wednesday of the month

Tulsa Support Group - Fourth Wednesday of the month.



THE YEAR THAT WAS *(cont'd from page 1)*

As we transitioned from summer to fall, our focus shifted to our signature event, the Walk to Defeat ALS. We knew that this year would have to be different. We implemented a Walk Your Way style event in both Tulsa and Oklahoma City and many of you shared with our ALS family how you championed this event.

Finally, we implemented our newest initiative, a Care Services Collaboration with the ALS Association West Virginia. Monthly, JoCarolyn and Sara Hoten, WV's Care Services Manager, host an informational-style "talk show" on Zoom which is then posted to both site's Facebook page. They discuss upcoming trainings and webinars, have special guests, share encouraging and uplifting thoughts and more. If you haven't seen it yet, check out our Facebook page and watch for a brand new show each month!

As we wrap up this year, remember that we are all in this together. We are here to serve you, and as our mission states "...**empower people affected by ALS to live their lives to the fullest.**"

We remain committed to providing the best care and services to the Oklahoma ALS Community. Thank you for allowing us into your homes and your lives and trusting us to tell your stories. Serving you is our privilege.

OUR VISION:
To create a world
without ALS.

OUR CORE VALUES:
Compassion
Integrity
Urgency

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