



Momentum

THE NEWSLETTER OF THE ALS ASSOCIATION OKLAHOMA

SUMMER 2021 | VOLUME 4, ISSUE 2

Maximizing Your Voice

In 2020, the ALS Association launched ALS Focus, a patient- and caregiver-led survey program that asks people with ALS as well as current and past caregivers about their needs and burdens. The goal is to learn as much as possible about individual experiences throughout the disease journey so that the whole ALS community can benefit.

You may ask yourself “How does my participation make an impact?” YOU live with the challenges of ALS every day. YOU are the expert. YOUR input is vital. All data collected is de-identified and shared free of charge with the entire ALS community.

We invite you to share your opinions and insights on your disease journey to inform change. Participants are eligible at any stage of the disease. ALS Focus provides the avenue to participate

in research in addition to clinical trials.



RESEARCH | CARE | ADVOCACY

Bringing the perspectives of people with ALS and their caregivers to the forefront.

When the survey period is complete and results are compiled, you will know how your experiences and opinions compare to the rest of the ALS community.

The first survey focused on Understanding Insurance Needs and Financial Burdens. Almost 1/2 of the respondents indicated that understanding medical insurance coverage impacted their stress level substantially. (To view the Survey One results, please visit <https://bit.ly/3xEmfAe>)

At the end of 2020, ALS Focus examined what matters most to people with ALS, both from their own perspectives and the perspectives of caregivers. In total, 691 people participated in the What Matters Most survey (273 people with ALS, 156 current caregivers, and 262 past caregivers). The results from the second survey demonstrated that the inability to do activities and limitations with mobility or walking mattered most to people with ALS. (To view these results, please visit <https://bit.ly/3i4DCDP>)

The Summer 2021 survey is now open. If you have taken one of the prior ALS Focus surveys, we want to hear from you. If ALS Focus is new to you, we want to hear from you. The current survey focuses on Telehealth.

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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.



The 2021 ALS Advocacy Conference is a wrap! We are so grateful to everyone who participated alongside us this year. The Oklahoma staff was joined by 11 advocates across the state.

We want to share with you some of the highlights - quotes, information learned, and more.

- Representative Kevin Hern asked about one of our advocates from two years ago. He was glad to hear that this advocate was doing well.

- *“We don’t focus on what has been lost; we focus on what we have and what we can do.”*
- Representative Tom Cole added *“I look forward to next year and having you in person in my office”.*
- *“We won’t have him to grow old together, but we believe with your support we will have new resources and therapies”.*
- *“We will always be an advocate with you; remember, you are a powerful voice.”* - Rep. Cole
- *“Nothing takes your breath away like hearing an ALS diagnosis.”*

- *“ALS is not an individual disease; the impact is huge.”*
- *“I was elected to serve and I will do all I can to serve the ALS community.”* - Rep. Bice
- *“We are ordinary people being asked to do extraordinary things.”*
- *“We want to change the narrative following diagnosis and your support will do that.”*

We are committed to policies that help find new treatments/cures, prevent or delay the harms of ALS, and optimize current treatments. Join us in 2022!

Maximize Your Voice (continued from page 1)

Participation is simple:

- Register one time (will take 5 -10 minutes) and then take surveys as they become available.
- Once registered, surveys should take approximately 5 - 15 minutes to complete.
- All open-ended questions are optional.
- Responses are completely anonymous.
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ALS Focus captures disease burden and experiences throughout the disease journey to put the opinions of people impacted by ALS at the center of ALS programs and policies. The National ALS Registry helps count people and new cases of ALS and looks to identify ALS environmental risk factors. Your participation helps maximize the voice of the ALS community to inform change and contribute to improving the lives of people with ALS and their families.

Sara Parvanta, Director of the ALS Focus Program, shares “ALS Focus Surveys are an opportunity to do whatever it takes in the fight against ALS. Sharing what matters to you, can have an impact on many”. For more information or to take the survey, visit <https://www.als.org/research/als-focus>.

The ALS Association is always looking for volunteers to serve on the ALS Focus Patient and Caregiver Advisory Committee. If you would like to join the PCAC, please send a message to ALSFocus@alsa-national.org.



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

LET'S TALK THE WALKS



In 2021, we are continuing to fight ALS with our Walk to Defeat ALS in both Tulsa and Oklahoma City. Currently, as things stand, to continue prioritizing safety of everyone involved, we are asking you to once again Walk Your Way in your community. Engage your family, friends, and neighbors virtually or across the street. The event is “coming” to your neighborhood. For those of you asking “I miss the old Walk format; could you pivot to an in-person Walk?” The short answer - we are still waiting for official guidance, but for now, let’s plan to Walk Your Way and celebrate each other.

Because of your participation over the last seven years, cumulatively between both Walks, we have been able to expand Care Services across Oklahoma to those living with ALS and their families and caregivers. ALS hasn’t stopped during the COVID-19 pandemic and neither have we. We need to do everything we can to raise awareness of ALS in our communities and help make ALS a livable disease.

IMPORTANT DATES TO REMEMBER:

TULSA

August 12 - Tulsa Walk Kickoff
September 20 - 25 = Team Week
October 16 - Tulsa Walk to Defeat ALS

OKLAHOMA CITY

August 28 - Oklahoma City Walk Kickoff
October 4 - 9 = Team Week
October 31 - Oklahoma City Walk to Defeat ALS

Join us Tuesday, November 16th for our **2nd Annual Post Walk Celebration** - We will celebrate **YOUR** successes in both the Tulsa and Oklahoma City Walks!

Be sure to share and post pictures of your walk and use the hashtags #OKWalks and #ALSInThisTogether. Follow along on Instagram [@alsaoklahoma](https://www.instagram.com/alsaoklahoma), Twitter [@alsoklahoma](https://twitter.com/alsoklahoma), and Facebook [@alsaoklahoma](https://www.facebook.com/alsaoklahoma)



During the 2020 Walk Your Way

71% of all Walkers were NEW Participants

29% of all Walkers were returning from prior years

45% of participants created a Facebook fundraiser

38 unique Walk Your Way events across Oklahoma

UNLOCK ALS



This year we will continue our mission area with the Unlock ALS keys during the Walks. Each key represents: the physical constraints which threaten a person with ALS everyday, the barriers to effective and compassionate care, and the medical mysteries which will someday lead us to a cure. Whether we Walk in-person or Walk Your Way, these keys will have a significant presence at each event.

WHAT COLOR IS YOUR KEY?



GOLD:
I have ALS



WHITE:
I have lost
someone
to ALS



BLUE:
I'm walking
in honor of
someone
with ALS



RED:
I support
the cause
and want
to defeat
ALS

YOUR WALK DONATIONS HELP FUND CARE SERVICES:

160+ people
living with ALS
served through
the Oklahoma Service
Area in 2020



Four support groups
offered for attendees
from five states:
Oklahoma, West
Virginia, MN/ND/SD



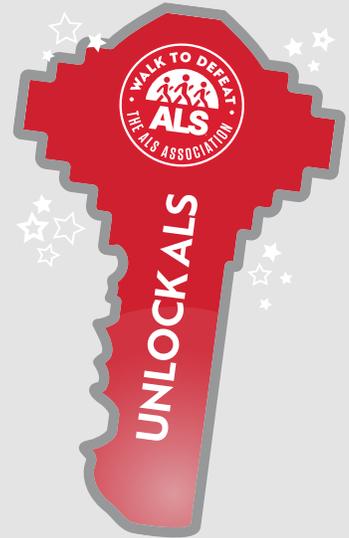
\$13,200
in care grants
provided to
22 families
affected by ALS



LET'S GET STARTED!

EASY WAYS TO JUMPSTART YOUR FUNDRAISING

1. Kick things off with your own donation.
2. Challenge 2 family members to match your donation.
3. Connect your fundraiser to Facebook and invite 10 friends.
4. Share your fundraising page with 5 co-workers, on your next Zoom meeting.
5. Tell 4 of your neighbors how they can help reach your goal.
6. Encourage 5 friends to join you in supporting the cause.
7. Ask your boss for a company contribution (or better yet, find out if your company will match what you raise!)
8. Track your progress and share your success!
9. Visit the FAQ section of the Walk Website for more Fundraising Tools!



UPCOMING EVENTS

Summer 2021: ALS Focus Survey is open.

August 12: Tulsa Walk Kickoff - Watch your email and social media for all the details.

August 18: 3:00 - 4:00 pm CST, NEALS ALS Drug Development Webinar Series Part 5: Preclinical Development of Potential Therapies, moderated by Dr. Richard Bedlack from Duke ALS Clinic. Register at this link: <https://bit.ly/36vF3ps>

August 28: Oklahoma City Walk Kickoff - Watch your email and social media for all the details.

October 16: Tulsa Walk to Defeat ALS

October 31: Oklahoma City Walk to Defeat ALS

November 16: Post Walk Celebration

November TBD: Oklahoma ALS Boot Camp

OUR VISION:

To create a world
without ALS.

OUR CORE VALUES:

Compassion
Integrity
Urgency

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Oklahoma

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