ONE COMMUNITY. COUNTLESS STORIES.

JUNE 2026

OKLAHOMA RARE DISEASE COALITION NEWSLETTER

OKRDC WEBPAGE

OKRDC@OKLAHOMARARE.ORG

OKLAHOMA RARE DISEASE COALITION

Inside

Catch up on community updates, explore advocacy opportunities, mark your calendar for upcoming events, and check out our June Rare Resource Highlight.

COMMUNITY UPDATES

The Power of Connection

Rare diseases can often feel isolating. Families may spend years searching for answers. Patients may struggle to find specialists who understand their condition. Caregivers frequently navigate complex healthcare, education, and support systems while trying to ensure their loved ones receive the care they need.

Yet one of the most powerful things we've learned as a rare disease community is that no one should have to face these challenges alone.

Connection is at the heart of everything we do. It happens when a newly diagnosed family finds hope through the experience of someone who has walked a similar path. It happens when advocates come together to raise awareness, when organizations collaborate to share resources, and when healthcare professionals, researchers, policymakers, and community leaders work toward solutions that improve lives.

The Oklahoma Rare Disease Coalition was built on the belief that we are stronger together. By bringing diverse voices to the table, we create opportunities to learn from one another, amplify our collective impact, and build a more connected and supportive community for the approximately 400,000 Oklahomans living with a rare disease.

Every month, we're proud to highlight the people, organizations, and initiatives that continue to strengthen our rare disease community. Every resource shared, every partnership formed, every story told, and every act of support helps move us closer to a future where individuals and families affected by rare disease feel seen, heard, and empowered.

Thank you for being part of this coalition. Your engagement, expertise, and commitment make this community stronger, and we are grateful for the connections that continue to inspire progress across Oklahoma.

Together, we are building something meaningful and together, we will continue moving forward.

MARK YOUR CALENDARS!

Upcoming Rare Disease Coalition Meetings:

Wednesday September 2nd, 12:00 pm
Zoom

Click here to join our Coalition Slack workspace:

HELP GROW THE COALITION

The Oklahoma Rare Disease Coalition is built on the strength of our community. We invite you to share the Coalition with your networks.

June Rare Resource Highlight

We include resources in every Oklahoma Rare Disease Coalition meeting and in our newsletter because information only helps when it reaches people in a usable, timely way. Families navigating rare disease often face overwhelming systems, fragmented care, and long gaps between questions and answers. Having trusted, accessible resources helps reduce that burden and makes it easier to take the next step, whatever that may be. It also ensures that advocates, providers, and community members stay connected to tools, support networks, policy updates, and opportunities that can directly improve care and quality of life.

At its core, resource-sharing is how we turn connection into action - so no one has to navigate rare alone. We see every meeting and newsletter as a chance to strengthen that bridge between information and impact.

This month, our rare resource highlight is **Cavett Cares**, a program through Cavett Kids that helps families of children with chronic and life-threatening illnesses navigate difficult seasons with practical assistance and a caring community by their side.

From assistance with utilities, rent, groceries, gas cards, medications, and even funeral support, Cavett Cares provides tangible help when families need it most. For many in the rare disease community, the challenges of diagnosis extend far beyond medical care - daily life can quickly become overwhelming, and basic needs can become sources of stress during already difficult times.

Resources like Cavett Cares meet families where they are, offering not only financial relief but also dignity, stability, and a reminder that they are not walking this journey alone. That kind of support can make it possible for parents to focus on their child's care, for families to stay afloat during treatment, and for households to hold on to a sense of normalcy in the middle of uncertainty.

We are grateful for organizations across Oklahoma that step into those gaps with compassion and practical support, strengthening our rare disease community in deeply meaningful ways.

Learn more here: buff.ly/ImPho9s

For more resources for the Oklahoma Rare Disease community, check Oklahoma Rare's resource page here: https://www.oklahomarare.org/resources

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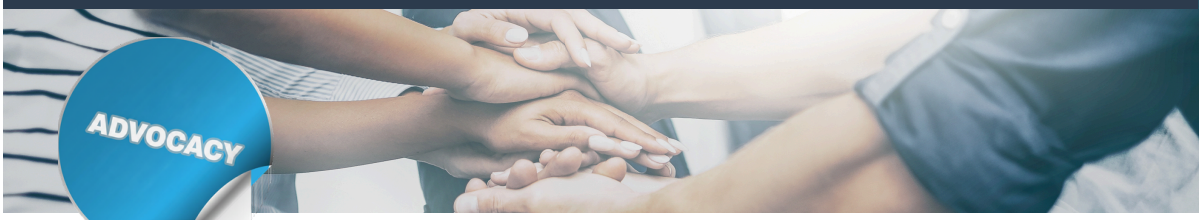

Upcoming Advocacy & Learning Opportunities

JUN 25 — Leap into Advocacy Summit 2026

The 2026 LEAP into Advocacy Summit - a hybrid event bringing together patients, caregivers, advocates, students, healthcare professionals, researchers, and partners - is an opportunity to turn knowledge into real-world impact. 📅 June 25, 2026
This year's theme: Transforming Knowledge and Innovation Into Real-World Impact
Register Here

AUG 10-21 — Rare Across America

Rare Across America is the opportunity to meet with your Members of Congress at their in-district offices and educate them on the issues that are most important to the rare community by sharing your story. An event made possible by the EveryLife Foundation for Rare Disease.
LEARN MORE and REGISTER
Registration will close on Friday, July 17.

ONGOING — Progress for Patients

Progress for Patients is an online advocacy education program and community working to help patients, advocates, and caregivers acquire the necessary tools to effectively communicate with drug researchers, developers, and regulators.

The program offers a free online advocacy education course designed to help patients, caregivers, and advocates learn about clinical trials, drug development, regulatory pathways, and opportunities to engage with researchers, industry, and policymakers. The self-paced course takes about 90 minutes to complete and is open to anyone interested in making their voice heard.

Learn more: https://progressforpatients.org/

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Upcoming Events

Mark your calendars for these opportunities to connect, learn, and engage in conversations that impact Oklahoma's rare and disability communities.Community events can be shared on the Oklahoma Rare Community Calendar HERE.

June 2026

June 26 - Oklahoma State Department of Health Newborn Screening Symposium
NCED Conference Center in Norman
REGISTER HERE
(note registration will close when at max capacity).

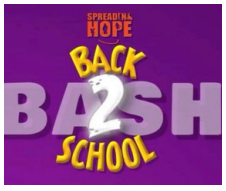
July 2026

July 20th - 10:00 am, Oklahoma State Capitol
A celebration of the Americans with Disabilities Act (ADA) and this year's theme, "Designing a World for Everyone."
https://www.facebook.com/events/2237977386778924/

July 23rd , 12-1 pm
Virtual Lunch & Learn with Adam Thiel, Digital Accessibility Coordinator with ABLE Tech, as we explore how thoughtful digital design can create more inclusive experiences for all.
Join Zoom Meeting: https://tinyurl.com/ADALunchLearn
Meeting ID: 819 106 2190
Passcode: 3niw3d See less

July 26th - 9:00 am
ADA Anniversary Solidarity Walk, Scissortail Park OKC
Participants are invited to walk alongside friends, families, neighbors, and community partners in a spirit of unity. Sign-making supplies will be available on-site, providing an opportunity to create messages celebrating accessibility, belonging, and disability pride before the walk begins.

August 2026



Date to be announced
Spreading Hope Back 2 School Bash

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Upcoming Events

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September 2026

September 19th - 9:00 am
Supporters of Families with Sickle Cell Statewide Walk, Run and Jog
Tulsa
https://runsignup.com/sicklecellok

September 29th
Skydance Bridge lighting in honor of the Inaugrual Oklahoma Rare Disease Fair

September 30th
The NW Rare Alliance in partnership with Oklahoma Rare are bringing the Rare Disease Fair to the Bethany Children's Heath Center.
LEARN MORE AND REGISTER

October 2026

October 3rd
2026 South Central Walk-Run-N-Roll
11:00 am - 1:00 pm CDT
Wiley Post Event Center 2021 S Robinson Ave, Oklahoma City, OK, United States LEARN MORE

October 7th
Cherokee Nation Rare Disease Summit