

# OKLAHOMA RARE DISEASE COALITION NEWSLETTER

[OKRDC WEBPAGE](#)

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## Inside

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

### COMMUNITY UPDATES

## Session has ended. Our work continues.

As the Oklahoma Legislature adjourned sine die on May 14, the 2026 legislative session came to a close - but for the rare disease community, our work is far from over.

This session brought encouraging signs that lawmakers are paying greater attention to issues that directly affect individuals and families living with rare diseases. We saw growing focus on insurance accountability, the use of artificial intelligence in health care decision-making, and efforts to expand access to services beyond traditional clinical settings. These are important steps forward.

At the same time, significant challenges remain. Too many rare disease patients continue to face delays, denials, and barriers to medically necessary care. Medicaid remains a critical pressure point for families who depend on it for essential therapies, specialized equipment, home- and community-based services, and long-term supports. Ensuring meaningful, timely, and equitable access to care for every Oklahoman with a rare disease will require continued advocacy and collaboration.

That is why the Oklahoma Rare Disease Coalition exists.

Our coalition brings together patients, caregivers, clinicians, researchers, nonprofit leaders, and other partners to identify shared priorities and advance policies that improve the lives of Oklahomans affected by rare diseases. Together, we are building a stronger, more connected voice to educate policymakers, raise awareness, and drive lasting change. While the Coalition will take a summer break and reconvene on Tuesday, September 2, our work continues throughout the coming months. We will be identifying potential interim study topics for the Oklahoma Legislature and preparing for the Oklahoma Rare Disease Fair on September 30, a powerful opportunity to connect families, organizations, providers, and policymakers.

Legislative sessions may end, but advocacy does not.

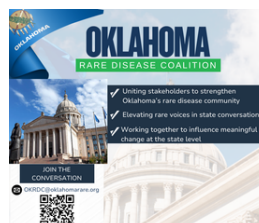
Thank you for being part of this growing movement. Every rare voice strengthens our collective impact, and together we are helping ensure that Oklahoma's rare disease community is seen, heard, and supported.

### MARK YOUR CALENDARS!

## Upcoming Rare Disease Coalition Meetings:

**Wednesday September 2<sup>nd</sup>, 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.



## May 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 **Librarey**, a collaborative, community-driven resource hub designed specifically for the rare disease, disability, undiagnosed, and chronic illness communities.

Librarey brings together educational materials, podcasts, webinars, and curated tools in one accessible space, making it easier for families, caregivers, advocates, and professionals to find trusted information without having to search across dozens of disconnected sources.

At its core, Librarey is about connection - bridging the gap between lived experience and available knowledge, and helping ensure that meaningful resources are not only created, but actually reach the people who need them most.

[www.librarey.com](http://www.librarey.com)



Where rare disease and disability communities discover and share resources.

*Thank  
you*

Thank you to Kiley Proffitt, founder of Jack's Generosity for presenting at our last Coalition meeting during the April Spotlight! Learn more here: [jacksgenerosity.com](http://jacksgenerosity.com)



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 Opportunities

Let's work together to ensure Oklahoma's rare disease community is part of the conversation. Explore these opportunities and help bring Oklahoma voices to the table.



**JUN  
18**

### RDLA Youth and Teen Advocacy Day (registration opens)

Registration is open until May 22<sup>nd</sup> for EveryLife Foundation's Youth and Teen Virtual Hill Advocacy Day. **June 18<sup>th</sup>, Virtual**

This is an inclusive advocacy opportunity for anyone ages 10–18 with a connection to the rare disease community. Participants can build advocacy skills, connect with peers, and meet virtually with their Members of Congress - all from wherever they are. Youth of all advocacy experience levels, communication styles, and support needs are welcome to participate. [LEARN MORE](#)



**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.



### Capitol Conversations

YOUR CHANCE TO LET YOUR VIEWS AND CONCERNS BE HEARD.

Join Senate and House Democrats for the final 2026 Session Series of Capitol Conversations on **June 8th, 5:30 PM at the state capitol - Democratic legislators debrief on session with public comment opportunity**

30 attendees will have the opportunity to speak for two minutes each. Those interested in speaking can sign up in person at the event.



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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](#).

### May 2026



**May 17**

FA Awareness Day Skydance Bridge Lighting

Purpose: To highlight the challenges of living with FA, support patients, and advance research for treatments.

### June 2026



9th Annual Cure FA Soirée

**Saturday, June 13, 2026**

OMNI HOTEL · OKLAHOMA CITY

[LEARN MORE HERE](#)



**June 14th**

Join our Coalition partners at Life's a Polyp in recognizing Familial Adenomatous Polyposis (FAP) Awareness Week as the OKC Skydance Bridge is lit in honor of FAP



**June 26 - NCED Conference Center in Norman**

Oklahoma State Department of Health Newborn Screening Symposium

[REGISTER HERE](#)

(note registration will close when at max capacity).

### August 2026



**Date to be announced**

Spreading Hope Back 2 School Bash



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### September 2026



**September 19<sup>th</sup>**

Supporters of Families with Sickle Cell Statewide Walk, Run and Jog  
Tulsa



**September 29<sup>th</sup>**

Skydance Bridge lighting in honor of the Inaugural Oklahoma Rare Disease Fair



**September 30<sup>th</sup>**

The NW Rare Alliance in partnership with Oklahoma Rare are bringing the Rare Disease Fair to the Bethany Children's Health Center.

[LEARN MORE AND REGISTER](#)

### October 2026



**October 3<sup>rd</sup>**

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 7<sup>th</sup>**

Cherokee Nation Rare Disease Summit