

OKLAHOMA RARE DISEASE COALITION NEWSLETTER

[OKRDC WEBPAGE](#)

OKRDC@OKLAHOMARARE.ORG



Inside

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

COMMUNITY UPDATES

Building Our Purpose, Together

During our April meeting, the Oklahoma Rare Disease Coalition spent time reflecting on our shared purpose. This Coalition matters so deeply to Oklahoma's rare disease community. The truth is, no single organization, provider, or advocate can meet every need of the rare disease community alone. But when we come together bringing our different experiences, expertise, and perspectives to the table we create something stronger. The Coalition gives us a space to learn from one another, identify shared challenges, and work collaboratively toward solutions that can make a real difference for rare disease families across our state.

One of the most meaningful conversations from our meeting centered around access to health as a key pillar of the Coalition's work. We discussed access not only in terms of physical access to providers and healthcare services, but also the broader barriers families face every day - navigating complex systems, finding knowledgeable providers, coordinating care, accessing resources, and overcoming the many challenges that can stand between an individual or family and the support they need.

At its core, this conversation reinforced why collaboration matters. The challenges facing the rare disease community are too complex for any one group to solve alone. But together, by sharing knowledge, aligning our efforts, and leveraging our collective voice, we can help build a more accessible, connected, and supportive future for Oklahoma's rare disease community.

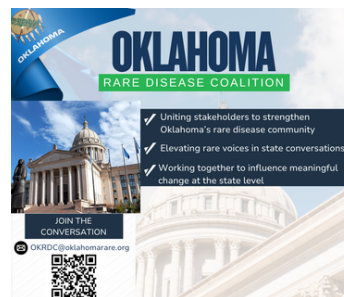
We were also excited to hear from Life's a Polyp Foundation founder Jenny Jones as our April Coalition Spotlight speaker. Jenny shared about the Foundation's work to support individuals and families affected by hereditary colorectal cancer syndromes through education, advocacy, and community connection. **Learn more at lifesapolyp.org.**

MARK YOUR CALENDARS!

Upcoming Rare Disease Coalition Meetings:

Wednesday May 6th, 12:00 pm:
[Zoom Meeting](#)
Meeting ID: 845 0873 5048
Passcode: 493951

Wednesday September 2nd, 12:00 pm:
Zoom



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.



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.



APR
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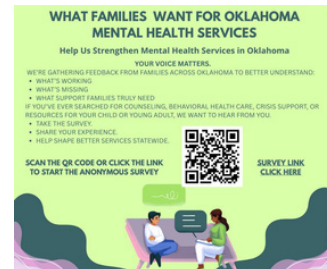
NORD April Rare Action
Network webinar

Join NORD for their April Rare Action Network® webinar focused on the U.S. Food and Drug Administration's (FDA) recently released draft guidance for the use of the Plausible Mechanism Framework for individualized genetic therapies. During this virtual event, Cara Tenenbaum, NORD's Director of Regulatory Affairs, will unpack the framework and summarize NORD's comments on this draft guidance. Tuesday, April 21 | Time: 1-2 p.m. ET | Location: Zoom.

[REGISTER HERE](#)

SURVEY

Oklahoma Mental Health
Services



Share Your Perspective: Mental Health & Substance Use Services Survey

Rare disease families often navigate mental health and behavioral health systems in unique ways and your perspective matters. Oklahoma stakeholders are gathering grassroots feedback from parents and young adults on what is working well and where gaps remain in mental health services across the state. This is an important opportunity to ensure the voices of rare disease families and individuals are included in these broader conversations. Please consider participating and sharing widely so perspectives from across Oklahoma are represented.

[CLICK HERE TO TAKE THE SURVEY](#)



Capitol Conversations

YOUR CHANCE TO LET YOUR VIEWS AND CONCERNS BE HEARD.

Join Senate and House Democrats for the 2026 Session Series of Capitol Conversations.

The next In-person Capitol Conversation will be held at the Oklahoma State Capitol in Room 535 at 5:30 PM on April 27th.

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

Upcoming Events

Mark your calendars for these opportunities to connect, learn, and engage in conversations that impact Oklahoma's rare and disability communities.



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RDLA Youth and Teen Advocacy Day (registration opens)

Registration opens on April 27th for EveryLife Foundation's Youth and Teen Virtual Hill Advocacy Day. When: Jun 18th, Virtual

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](#)



SEP
30

OKLAHOMA RARE DISEASE FAIR

Mark your calendars! On September 30th, 2026, the NW Rare Coalition in partnership with Oklahoma Rare are bringing the Rare Disease Fair to the Bethany Children's Health Center. The goal is to meet communities where they are - bringing resources, amplifying voices, expanding networks, and driving lasting change across the Oklahoma rare disease landscape. The event aims to unite families, patients, healthcare professionals, and advocates to raise awareness, strengthen community, and advance meaningful policy change. [LEARN MORE AND REGISTER](#)

APR
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Disability Caucus Meeting

Oklahoma Disability Caucus Meeting - open to the public

Contact chelsea.haecherl@okhouse.gov to be added to mailing list. **April 22 at 9 AM in room 206 at the Oklahoma State Capitol.**

JUNE
13



9th Annual Cure FA Soirée
Saturday, June 13, 2026

OMNI HOTEL · OKLAHOMA CITY
[LEARN MORE HERE](#)

Also mark your calendars for FA Awareness Day - May 17!

April Rare Resource Highlight

This month's Rare Resource Highlight is Citizen Health's AI Advocate, a tool designed specifically for rare and complex care journeys.

AI Advocate helps patients and families organize medical records, ask questions about their health history in plain language, prepare for appointments, and even summarize provider visits - all in one place. For rare disease families managing mountains of records and complex care plans, tools like this may help reduce the administrative burden of caregiving and make medical information more accessible and actionable. As AI continues to evolve in healthcare, platforms like this offer a glimpse into how technology may support patient advocacy in new ways. Learn more: <https://www.citizen.health/>

Citizen Health

Your AI Advocate for care navigation

An advocate in your pocket, built by and for families living the day-to-day of rare and complex care journeys. Integrated with all your health records. Always free & secure.

