

OKLAHOMA RARE DISEASE COALITION NEWSLETTER

[OKRDC WEBPAGE](#)
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Inside

Catch up on community updates, explore advocacy opportunities, and check out our October Rare Resource Highlight.

MARK YOUR CALENDARS!

Upcoming Rare Disease Coalition Meetings:

Wednesday November 4th | 12:00 pm

Zoom -

Meeting ID: 826 1345 5099

Passcode: 984391

Wednesday December 2nd | 12:00 pm

Zoom -

Meeting ID: 894 4856 5743

Passcode: 410975

Click here to join our Coalition Slack workspace:



COMMUNITY UPDATES

Building Connections. Creating Momentum.

What an exciting few weeks it has been for Oklahoma's rare disease community!

In just over a week, our state hosted two important events that brought patients, families, healthcare professionals, researchers, and advocates together around a shared purpose: improving the lives of Oklahomans impacted by rare diseases.

On September 30, the first Oklahoma Rare Disease Fair welcomed nearly 100 attendees for a day of learning, connection, and meaningful conversations. Just one week later, the Cherokee Nation Rare Disease Summit continued that momentum, highlighting the importance of collaboration and expanding rare disease awareness across our state.

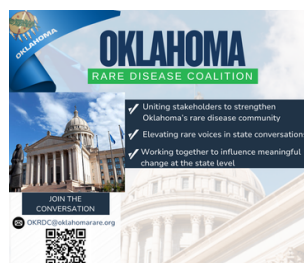
What stands out most isn't simply that these events happened. It's the connections being made, the conversations continuing, and the momentum we're building together.

As we look ahead, the Oklahoma Rare Disease Coalition is focused on turning that momentum into meaningful action through stronger partnerships, policy advocacy, provider education, and opportunities for our community to have a voice in the decisions that affect their lives.

As we look ahead, the Oklahoma Rare Disease Coalition is focused on turning that momentum into meaningful action through stronger partnerships, policy advocacy, and provider education. We're also beginning to explore plans for a Rare Disease Day at the Oklahoma State Capitol in early 2027, creating an opportunity to bring our community together, share our stories, and connect with state policymakers.

There's still much work to do, but it's encouraging to see our rare disease community growing stronger and more connected.

Thank you for being part of this work. Every voice, every connection, and every effort helps move us forward.



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.



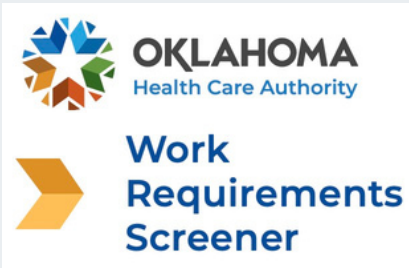
The Oklahoma Rare Disease Coalition celebrates and congratulates OKRDC advocate Velvet Brown-Watts on receiving the 2026 Advocacy Award at the 2026 Sickle Cell Convention! We are grateful for her leadership, her commitment to amplifying patient and family voices, and the many ways she contributes to Oklahoma's rare disease community.



October Rare Resource Highlight

We share resources at every Coalition meeting and in each newsletter because access to timely, trusted information matters. For families navigating rare diseases, finding the right support can be overwhelming. Sharing resources helps connect patients, families, providers, and advocates with tools, information, and opportunities that make a difference.

Resource sharing is one way we turn connection into action, helping ensure no one has to navigate rare alone.



Oklahoma Health Care Authority Work Requirements Screener

Starting in January 2027, a new law says some SoonerCare members must work or help in their community to keep their health coverage.

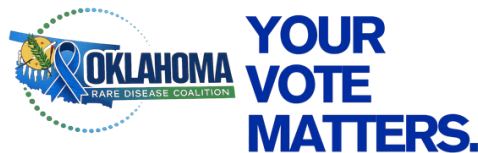
This screener from the Oklahoma Health Care Authority is a helpful tool to see if this rule may apply to you.

<https://oklahoma.gov/ohca/individuals/mysoonercore/work-requirements.html>



Upcoming Advocacy & Learning Opportunities

Vote November 3rd



<https://oklahoma.gov/elections.html>

Take Action:



Using Genomic Information from Preconception through Early Childhood: A Workshop (Virtual)

Tuesday, October 27, 2026, 7:30 AM - 4:00 PM

The National Academies will organize and conduct a public workshop to examine the role of genetic testing, from preconception through early childhood, on the health of children. The overarching goal of the workshop is to explore how genetic screening and diagnostic testing are currently applied from preconception through early childhood; to identify gaps and redundancies across these stages; and to consider how advances in technology, policy, and clinical practice could support a more integrated approach to genetic testing over time.

[Register Here](#)



FDA Rare Disease Framework Initiative Public Meeting - On October 28, 2026, the U.S. Food and Drug Administration, in partnership with the Reagan-Udall Foundation for the FDA, will convene a hybrid public meeting to seek input related to the FDA's Rare Disease Framework Initiative to reimagine the agency's approach to rare disease drug development. 12-4:00 pm Central,

[Register Here](#)



RARE Disease Week: 2027 Travel Reimbursement Application | Deadline Friday, November 6th

Join Team Oklahoma in DC! RARE Foundation travel reimbursement applications are open to help offset costs for attending RARE Disease Week in Washington, DC, March 2-4, 2027.

[Apply Here](#)



Capitol Conversations November 10th

The next installment of Capitol Conversations at the Oklahoma State Capitol will be in person Nov 10th in Room 535 from 5:30 pm - 7:30 pm.

The Topic will be: 2027 Legislation - Share your Ideas