

You're Invited to

Rare Disease Day 2026



Akron
Children's



Join us for Rare Disease Day, an afternoon dedicated to raising awareness, sharing knowledge and building support around those diagnosed with rare conditions.

This event welcomes families, caregivers, health care providers and research professionals to come together to celebrate resilience, connect with the community and advocate for the 300 million people worldwide living with a rare disease.

This event will provide attendees with education on multiple topics, inspiring patient stories and connection opportunities.

- **Keynote Speaker:** Lindsay Davis, former Miss Ohio and youth sports health advocate, was diagnosed with hypertrophic cardiomyopathy at 17. She championed "Lindsay's Law" in Ohio, requiring coaches and teachers to learn sudden cardiac arrest symptoms, and now advocates for similar legislation nationwide plus mandatory CPR training for high school graduation. Davis writes for USA Today High School Sports and serves as associate editor of the online cardiology edition of the British Medical Journal.
- **Patient-Focused Session:** Discover tips and strategies for communicating effectively with health care providers about rare diseases, including personal stories and real-world experiences from patients and families.
- **Provider-Focused Session:** Explore ethical considerations in rare disease care, illustrated through case examples and practical insights for health care professionals.
- **Rare Disease Clinic Spotlight:** Learn about multi-disciplinary approaches, patient stories, and innovative programs in rare disease clinics, with insights on diagnosis, care coordination, and community support.

**Thursday, March 5
11:30 a.m. - 4:15 p.m.**

**In-person* and virtual
options are available
for this free event;
registration is required.**

**Lunch and refreshments
are included.**

**Akron Children's Hospital
Considine Professional Building
Level 2, Auditorium
215 W. Bowery St., Akron, Ohio**

**In-person spots are limited, so register early.*

Register by Thursday, Feb. 19



**In-Person
Registration**



**Virtual
Registration**

Contest

Games, prizes and giveaways will be available to those who attend in person along with the opportunity to visit booths with information on local resources.

Attendees can enter a contest to share a written story, poem, picture or short video clip about their personal experiences with a rare disease diagnosis, including struggles and/or accomplishments. Those who participate have a chance to win a prize and have their entry shared during the event. Email your contest entry to geneticsforms@akronchildrens.org.

akronchildrens.org/raredisease