

DENVER

COLORADO



* All times are MST

FRIDAY, MAY 15, 2026

- 9 a.m. Check-in and Networking**
Kick off the day with coffee and a chance to connect with fellow rare disease patients, families and caregivers.
- 9:30 a.m. Opening Remarks and Keynote Address**
Pam Gavin, CEO, NORD
Lily Emmanuel, Patient Advocate; Student, University of Colorado Denver; Recipient of the 2026 Community Champion NORD Rare Impact Award
- 9:50 a.m. Innovative Approaches to Improving Your Rare Disease Care**
In an era of scientific and technological advances, rare disease care is changing every day. Join us for a robust panel discussion diving into different approaches to navigate and improve your rare care throughout each step of your journey.
Moderator: Marybeth McAfee, MA, GC, Vice President of Community & Medical Affairs, NORD
Speakers:
Megan Abbott, MD, Assistant Professor, Pediatric Epilepsy, University of Colorado
Alisa Gaskell, PhD, Chief Genomics Officer, Precision Medicine Institute, Children's Hospital Colorado
Margaret Macy, MD, Associate Professor of Pediatrics, Section of Hematology, Oncology & Bone Marrow Transplantation
Lianne McLean, RN, BN, MN, Senior Global Medical Safety Clinician, Terumo Blood and Cell Technologies (Terumo BCT)
- 10:40 a.m. Networking & Exhibiting**
Enjoy the opportunity to connect with others, navigating similar journeys and explore our exhibitor section.
- 11:05 a.m. Overcoming Insurance Barriers**
If you are impacted by a rare disease, you are likely spending countless hours navigating health insurance. In this session, we will discuss common insurance barriers faced by patients and caregivers living with a rare disease, and tips to overcome them. This panel incorporates several unique perspectives for every step in your journey that you won't want to miss!
Moderator: Tiffany Sammons, Community Engagement Manager, NORD
Speakers:
Nick Kirchhof, Rare Caregiver, Head Men's Soccer Coach, Metropolitan State University of Denver (MSU)
Kavita V Nair, PhD, FAAN, Professor of Neurology and Pharmacy, University of Colorado Anschutz Medical Campus
- 11:50 a.m. Closing Remarks**
- 12 p.m. Lunch & Conclude**
We hope you've enjoyed today's program! Grab some lunch and feel free to continue networking.