

PHOENIX

ARIZONA



* All times are MST

FRIDAY, MAY 8, 2026

10:00 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.

10:30 a.m. Opening Keynote Address

Jonathan Cottor, CEO/Founder, National Center for Pediatric Palliative Care Homes, Rare Caregiver

10:50 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:

Vinodh Narayanan, MD, Child Neurologist, Arizona Pediatric Neurology & Neurogenetics Associates (APNNA)

Stephanie Rankin, Patient Advocate; Rare Caregiver; Customer Advocate Team Lead, DNM1

Taejong (TJ) Song, PhD, Assistant Professor, Department of Cell and Molecular Medicine, University of Arizona College of Medicine

11:40 a.m. Networking & Exhibiting

Enjoy the opportunity to connect with others, navigating similar journeys and explore our exhibitor section.

12:05 p.m. Tips for Accessing the Resources and Services You Need

Living with a rare disease does not come with a manual or how-to guide. In this session, we will share tips to access the resources and services you need that are available in your local area.

Moderator: Taylor Vaughn, MS, CGC, Phoenix Children's Hospital

Speakers:

Melissa Meyer, DNP, PMHNP-BC, Doctor of Nursing Practice, Psychiatric Mental Health Nurse Practitioner, Arizona State University; Grossman & Grossman; Stiff Person Syndrome

Keri Ramsey, MS, CGC, RN, Department of Clinic Genomics, Mayo Clinic

Tabby Wallace, Rare Caregiver, Fly Little Bird Foundation

12:50 p.m. Closing Remarks

1:00 p.m. Lunch & Conclude

We hope you've enjoyed today's program! Grab some lunch and feel free to continue networking.