



Living Rare, Living Stronger in Georgia

Friday, June 27, 2025

8:00 a.m. to 4:00 p.m.

Georgia Aquarium

8:00-9:00 a.m.

Check-In and Breakfast

Kick off the day with breakfast and a chance to connect with fellow rare disease patients, families and caregivers.

9:00-9:10 a.m.

Welcome and Introduction

Kelly Esperias, Chief Strategy & Operations Officer of the National Organization for Rare Disorders (NORD), opens the day with a warm welcome and event overview.

Speaker:

Kelly Esperias, EdD, MBA, CFRE, Chief Strategy and Operations Officer, NORD

9:10-9:30 a.m.

Keynote Speakers

Dr. Jill C. Flanagan and Tamekia Parence share their impactful story about their relationship and how it has helped improve the health of Tamekia's son, Carl.

Speakers:

Jill C. Flanagan, MD, FAAOS, Pediatric Orthopedic and Limb Reconstruction Surgeon, Co Medical Director – Limb Difference Program, Children's Physician Group – Orthopedics and Sports Medicine, Children's Healthcare of Atlanta

Tamekia Parence, MBA, Patient Advocate, Caregiver, Mother

Carl Mumford III, Patient, Advocate, Son

9:35-10:20 a.m.

NORD Rare Disease Centers of Excellence (CoE) Session: *Emory Division of Medical Genetics/Children's Healthcare of Atlanta*

Learn how Emory's Division of Medical Genetics and Children's Healthcare of Atlanta – a designated NORD Rare Disease Center of Excellence – are advancing rare disease care and research in Georgia.

Speakers:

Dr. Hong Li, MD, PhD, Emory University School of Medicine, Department of Human Genetics and Pediatrics

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Dr. Rossana Sanchez, MD, Emory University School of Medicine, Department of Human Genetics

Dr. Stephanie Keller, MD, Emory University School of Medicine, Children's Healthcare of Atlanta, Pediatric Neurology

10:25-11:05 a.m.

Finding Your Rare Village

Living with a rare disease can be isolating. This session explores ways to build a supportive community and meaningful connections within the rare community.

Moderator:

Leah Barber, Director of Grassroots Advocacy, NORD

Speakers:

Alison Leeds, Connecticut Ambassador, NORD Rare Action Network

Montrez Lucas, NephCure, Director of Patient Engagement

Alpa Khushalani, PPMD Connect Coordinator GA&SC, Gooseberry Research-VP Customer Success & Delivery

11:05-11:15 a.m.

Break

11:15 a.m.-12:00 p.m.

NORD: Your Connection to Support and Grassroots Advocacy

Explore NORD's resources, policy priorities, and advocacy efforts. Learn how to share your rare stories and take action on pressing rare disease policies.

Moderator:

Jake Saltonstall, MPA, Community Engagement Associate, NORD

Speakers:

Leah Barber, MPA, MSW, Director of Grassroots Advocacy, NORD

Mason Barrett, Policy Analyst, NORD

Kimberly Gonzalez, Patient, Advocate

12:00-1:15 p.m.

Networking Lunch

Enjoy lunch with the opportunity to join topic-focused discussions and connect with others, navigating similar journeys.

Topics include:

- Creative Storytelling: How To Share Your Story
- IEPs, 504 plans, SSI and Disability Navigation
- "Welcome to Holland": Coping, Grief, & Resilience
- Transitioning to Adulthood
- Coordinating Your Care Team
- Navigating Insurance Barriers

1:20-2:05 p.m.

Utilizing Technology to Improve Your Rare Disease Care

In this session, we will explore ways technology can be used to improve care, alleviate burdens, and aid you in navigating your rare journey.

Moderator:

Patrick Collins, Vice President of Community and Corporate Affairs, NORD

Speakers:

Kimberly A. Moran, PhD, MBA, CDP, Head, US Rare Diseases, UCB, Inc.

Michael Kraft, MD, Associate Chief Health Information Officer, Medical Director Virtual Care, Assistant Family and Preventative Medicine, Emory SOM

Nakisha Isom, Patient Advocate, Mother, Author, Activist, President of Living with Holt Oram Syndrome

2:05-2:20 p.m.

Break

2:20-3:00 p.m.

Genetic Testing and Why It Matters After Diagnosis

Genetic testing doesn't stop at diagnosis. Learn why it remains essential for treatment, family planning, and long-term care decisions.

Moderator:

Tiffany Sammons, Education Programs Manager, NORD, Rare Mama

Speakers:

Dawn Laney, MS, CGC, CCRC, Emory University, Division of Medical Genetics

Amanda Singleton, CGC, Director, Patient Advocacy and Biopharma, GeneDx

Jorden Albright, Director, Rise Property Group, Patient Advocate

3:05-3:25 p.m.

Closing Remarks: Rare is Everywhere

Hear a heartfelt message about the strength of our community and the power of shared stories in the rare disease journey.

Speaker:

Tiffany Sammons, Education Programs Manager, NORD, Rare Mama

3:25 p.m.

Conclude

The event concludes, and aquarium tickets will be distributed.