



WISCONSIN

NOV. 8

* All times are ET

SATURDAY, NOV. 8, 2025

8:00 a.m. Check-In and Breakfast

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

9:00 a.m. Welcome and Introduction

Pamela Gavin, CEO of the National Organization for Rare Disorders (NORD®), opens the day with a warm welcome and event overview.

9:10 a.m. Keynote Speaker

The day will start with Henry Heren sharing his impactful story on how he navigates his journey with Histiocytic Sarcoma.

SPEAKER:

Henry “Hank” Heren, Retired, Veteran, Professional Trial Patient, Rare Disease Advocate

9:30 a.m. Advancing Rare Disease Care and Research in Wisconsin

Discover how NORD’s Rare Disease Centers of Excellence at **Children’s Wisconsin/Medical College of Wisconsin and the University of Wisconsin Center for Rare Diseases** are working to improve health outcomes for you and your family as you navigate the challenges of living with a rare disease.

MODERATOR: Pamela Gavin, CEO, NORD

SPEAKERS:

Donald Basel, MD, Medical Director, Genetics Center; Co-Program Director Neurofibromatosis and RASopathy; Professor and Section Chief, Pediatrics (Genetics), Medical College of Wisconsin/Children’s Wisconsin

Brett Bordini, MD, Pediatric Hospital Medicine, Associate Professor, Medical College of Wisconsin/Children’s Wisconsin

April Hall, PhD, MS, CGC, Assistant Professor and Genetic Counselor, Department of Pediatrics, Division of Genetics and Metabolism, Center for Precision Medicine at the University of Wisconsin

M. Stephen Meyn, MD, PhD, Professor, Medical Genetics and Genomics Residency Director; Co-Director of the UW NORD Center of Excellence for Rare Diseases, University of Wisconsin

Mike Muriello, MD, Associate Professor, Clinical Genetics and Genomics, Pediatrics, Medical College of Wisconsin/Children’s Wisconsin



10:15 a.m. Finding Your Rare Village

Living with a rare disease can be profoundly isolating. This session provides actionable, real-world tools for patients and caregivers to break through isolation and build a reliable, supportive community.

MODERATOR: Elizabeth Kellom, MS, CGC, Genetic Counselor at The Waisman Center & UW Health Ophthalmology

SPEAKER:

Niki Grossheim, BS, Rare Patient Living with Myasthenia Gravis, Advocate, MG Wisconsin Support Group Leader, Member MG Holistic Society

Lani Knutson, Rare Mom and Caregiver; Legislative Advocacy Team, Cure CMD; Board Member, Wisconsin Rare Disease Alliance

Stacey Walthers Naffah, Rare Mom and Caregiver; Chair of the Foundation Board of Children’s Wisconsin

John Darrin Washburn, Lifelong Learner and Educator

11:00 a.m. Break

SATURDAY, NOV. 8, 2025 (continued)

11:15 a.m.

Connect, Share, Advocate: Your Role in the Rare Disease Movement

Our stories are our greatest strength. Learn how your personal and lived experiences can fuel grassroots advocacy. Discover NORD's resources and how to use them to influence public policy and build a stronger, more connected rare disease community.

SPEAKERS:

Darby Gavin, MS, Senior Community Engagement Manager, NORD

John "JJ" Geeleher, Advocate; Patient; Wisconsin Ambassador, NORD Rare Action Network

Jake Saltonstall, MPA, Community Engagement Associate, NORD

12:00 p.m.

Networking Lunch

Enjoy lunch and connect with others, navigating similar journeys.

1:00 p.m.

Navigating Your Care Pathway

Gain the knowledge and tools needed to effectively manage a rare disease journey, from diagnosis to treatment.

MODERATOR: Tiffany Sammons, Rare Mom, Education Programs Manager, NORD

SPEAKERS:

James Griffin, Patient; Legislative Advocate; Community Board Member, Medical College of Wisconsin

Gretchen Heckel, MSN, RN, Nurse; Program Manager, Genetics Clinic; Children's Wisconsin

Courtney Miles, Rare Mom; Patient Advocate; Program Manager, Digital Health & Experience, Children's Wisconsin

1:45 p.m.

Closing Remarks: Rare is Everywhere

Hear heartfelt messages from NORD Education Programs Manager Tiffany Sammons, caregiver and rare mama, about the strength of our community and the power of shared experiences in the rare disease journey.

SPEAKER:

Tiffany Sammons, Rare Mom, Education Programs Manager, NORD

2:00 p.m.

Networking Activities

This dedicated time is designed to help you build a vital support network and exchange hard-won knowledge. Connect with fellow rare disease patients, families, and caregivers to share coping strategies, exchange resources, and find the practical and emotional support necessary to navigate your journey.

OR

Enjoy the Milwaukee County Zoo

The Milwaukee County Zoo is home to over 2,200 animals and 340 species. Join us for a fun-filled afternoon exploring some of the zoo's most popular habitats. The zoo is open until 4:30 p.m. for you to enjoy.

3:00 p.m.

Networking Concludes