



NORD Membership Annual Meeting

October 19, 2025 from 2:00 - 6:00 p.m.

Independence Ballroom at the Grand Hyatt, Washington, D.C.

MEETING AGENDA

1:30 - 1:45 p.m. Doors Open

2:00 Welcome and Introductions

SESSION 1 - From Strategy to Sustainability

Executive Insights: Balancing Vision, Resources, and Well-Being – Executive Director Panel

Join a panel of executive directors as they share strategies for managing nonprofit teams while avoiding burnout. Discussion will focus on prioritizing roles, retaining staff and volunteers, leveraging technology, and building sustainable organizational practices.

Guest Speakers: Ryan Maple, The Global Foundation for Peroxisomal Disorders; Rhonda Rowland, Wilson Disease Association; Cynthia Ryan, Vestibular Disorders Association

SESSION 2 - Partnering for Progress

Aligning on Impact: Member Feedback Forum

Your voice matters! In this session, CEO of NORD Pamela Gavin will share how member feedback is directly informing our strategic plan and shaping new priorities. This open discussion will ensure our goals continue to reflect the needs and experiences of the rare disease community.

Networking Roundtables: Fundraising, Research, and Capacity Building

Join your peers for an interactive networking session exploring key areas that drive nonprofit success—from fundraising and research partnerships to working with industry and strengthening organizational capacity. Connect with other leaders, share insights and challenges, and walk away with new ideas and collaborations to support your mission.

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SESSION 3 - Connecting the Dots: Registries, Data Literacy & Patient Support

Registries and Member Opportunity

Explore how patient registries strengthen advocacy, research, and community impact. Hear directly from a registry member and gain practical skills through a mini-data literacy session designed to help you better understand and use registry data.

Guest Speakers: Janet Mauro, NORD; Rebecca Aune, NORD; Jennifer Levy, Coalition to Cure Calpain 3 (C3)

PAG engagement in Patient Support Services

Learn how patient assistance programs can support your community and discover ways members can get involved. This session will highlight available resources, strategies for outreach, and include time for audience Q&A.

Guest Speakers: Jill Pollander, NORD

Closing and Group Photo

Join us for a NORD Member group photo on our way to the Summit Welcome Reception!

NOTES

This meeting is being held in-person, and virtually via zoom. Slides and recordings of the panels will be available in the NORD Membership portal.

Questions?

Contact your membership team at membership@rarediseases.org and visit us at the NORD booth throughout the Summit!