



NORD[®]
National Organization
for Rare Disorders

NORD[®] MEMBERSHIP



New 2025 Member Benefits

In 2025, the National Organization for Rare Disorders (NORD[®]) is unveiling exciting new membership benefits and programs designed to strengthen your organization's impact. These initiatives reflect our commitment to addressing the needs and requests you've shared with us. We invite you to explore and share these new opportunities with your teams to further your mission and continue driving lasting change for rare disease patients and families.

Your voice matters, and together, we can achieve more. Renew your membership today to take advantage of these valuable programs.



NORD Member Affinity Groups

Take advantage of regular touchpoints with like-minded professionals through NORD's Member Affinity Groups. An affinity group is a small, focused gathering of individuals who share common interests, experiences, or roles within NORD's member organizations. These groups provide a candid space for more targeted networking, creating opportunities for meaningful dialogue and peer learning among like-minded professionals. Participants will discuss shared challenges, best practices, and collaborate on relevant topics. NORD encourages all members to take part in one or more of these affinity group discussions and to consider bringing in staff from your organization to participate. **Contact membership@rarediseases.org to join a group.**



PLS/EL-PFDD Roadmap and Resources

NORD members are invited to participate in Patient Listening Sessions (PLS) and Externally Led Patient Focused Drug Development meetings (EL-PFDD) offered through the Food and Drug Administration's (FDA) Office of Patient Engagement. These meetings are one way for your patient community to provide FDA review staff with a better understanding of patient/caregiver perspectives on risk tolerance, disease burden, treatment burden, impact on daily activities, quality of life, and what is important to patients for consideration in medical product development programs.

The Office of Patient Engagement has partnered with NORD to provide helpful tools and guidelines to design PLS and EL-PFDD meetings, available to the entire rare disease community. In addition, NORD offers administrative support and coordination of these meeting resources to members who wish to host their own EL-PFDD. **To learn more about this service, contact membership@rarediseases.org.**



NORD Claim Your Care Program

The newly launched NORD Claim Your Care program was designed to raise the knowledge level of our member organizations specific to health care coverage and insurance. NORD Claim Your Care is designed with the goal of allowing our members to better advocate on behalf of your constituents. This program will be updated throughout 2025 with new resources and content. The current site contains helpful tips and information specific to open enrollment for both Medicare and Marketplace coverage. **Learn more: claimyourcare.org**



Advocacy Training

The Advocacy Academy is a 90-minute course designed to teach the basics of advocacy, enabling organizations to focus their efforts on training advocates about specific policy issues. The program covers everything from the fundamentals of advocacy and effective storytelling to navigating congressional meetings, federal appropriations, and social media outreach, equipping participants to make a meaningful impact on Capitol Hill. Also included is a video highlighting the Orphan Drug Act. **To learn more about this training, contact membership@rarediseases.org.**

RENEW TODAY

Don't miss out on these exclusive new member benefits. Contact membership@rarediseases.org to renew today! Visit rarediseases.org/membership to learn more.

Alone we are rare. Together we are strong.®