NORD®
National Organization for Rare Disorders

MEMBER ORGANIZATION PARTNER TOOLKIT

This document outlines ways in which your organization can partner with NORD in advocacy, awareness, education, organizational growth, and research. We welcome your phone calls or emails at any time. Your close connection with us helps us to better serve you, as well as your patients and families.

Welcome to NORD!

How to Partner Effectively on Behalf of Your Patient Community

As a member organization of NORD, you are part of a powerful alliance amplifying the voices of those affected by rare diseases. By actively participating in this collective, your organization not only strengthens the broader rare disease advocacy community but also directly supports your own members.

NORD's network connects you with a diverse community of rare disease advocates who share insights, resources, and support. We encourage you to leverage this valuable network and engage in as many of the following ways as possible to enhance your advocacy impact:

- Connect with more than 600+ leaders of rare disease nonprofit organizations on our private Facebook Group for member organizations.
- Enhance your organization's visibility through your listing on the NORD website and NORD's medical education and outreach efforts.
- Empower organizational growth by accessing virtual and in-person opportunities to connect.
- Utilize your complimentary BoardSource membership to support board growth and nonprofit excellence.
- Develop your advocacy and policy goals and participate in broader rare disease community policy and advocacy efforts.
- Obtain support for research in your disease area through access to drug development resources and engagement in research programs (IAMRARE®, RDCA-DAP, and more).
- Participate in Rare Disease Day® and be part of the global collaboration to raise awareness for rare diseases.

1) ORGANIZATIONAL GROWTH AND OPPORTUNITIES TO CONNECT

NORD empowers our members by fostering connections and sharing the collective knowledge of the rare disease community. Members gain valuable insights from each other's experiences and receive support on critical issues. NORD encourages members to pursue new levels of organizational growth and adopt best practices to expand their effectiveness and sphere of influence.

EVENT OPPORTUNITIES

- **Exclusive member leader meeting** at the annual NORD® Rare Diseases and Orphan Products Breakthrough Summit® (NORD Summit) to network with key rare disease stakeholders, explore main topics of interest to members, and receive updates on membership benefits.

- **Financial scholarships for participation** in the NORD Summit. In 2024, NORD awarded more than $125,000 in travel, accommodations and registration to our member organizations to participate in the NORD Summit! All NORD members are eligible for complimentary registration to attend the NORD Summit.
- **Interact with other NORD member organizations and partners** at meetings throughout the United States to facilitate sharing of best practices on topics related to building organizational capacity.

VIRTUAL CONNECTIONS

- **The NORD Member Leaders Facebook group** is exclusively curated for the 800+ executive directors, board members, physicians, advocacy staff and key leaders of our member organizations.

> POPULAR MEMBER BENEFIT
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> Join the dialogue and network with more than 600 rare disease leaders on NORD's members-only Facebook group: www.facebook.com/groups/NORDMemberLeaders. We would love for you to join and take advantage of crowdsourcing your concerns and challenges, as well as network for rare leader mentoring and support.

- NORD hosts ongoing **educational and capacity-building webinars** throughout the year on topics related to medical education and research, advocacy, organizational strategy, capacity building, and growth. Contact the NORD Membership team for access to recordings of past webinars.

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> NEW MEMBER BENEFIT
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> NORD's Affinity Groups offer regular touchpoints with professionals who share similar roles, interests, and experiences within our member organizations. These focused groups provide a supportive space for targeted networking, meaningful dialogue, and peer learning. Participants can openly discuss shared challenges, exchange best practices, and collaborate on topics central to their work. We encourage all members —and their team members — to join one or more Affinity Groups to enrich their network and deepen their impact.
>
> To learn more and register for Affinity Group meetings and updates, visit the Zoom registration link for each ongoing topic below. Meetings are hosted monthly, and a summary is provided to all registrants regardless of attendance.
>
> - Board Management: Engagement and Communication Strategies
> - Fundraising: Grants, Major Gifts, Peer-to-Peer Programs, and Venture Philanthropy
> - Medical Education: Information Campaigns and Technical Communication

- State and Federal Policy: Advocacy and Mobilization
- Software and Technology: Innovations and Cost-Effective Solutions
- Volunteers: Recruitment and Engagement

- **Social media promotion:** NORD collects information from member organizations on their current events, awareness campaigns, and news. We will highlight your updates on the NORD X (formerly Twitter) platform, which currently has over 40,000 followers. We also post events to our website calendar, which receives 13 million unique web visitors a year, and we can include your news in the NORD monthly eNews that is regularly sent to over 68,000 people. Share your news for promotion through the "Member Information Submission" form.

POPULAR MEMBER BENEFIT

Members are encouraged to send their upcoming major events, awareness days/months/weeks, or press coverage (with captions and hashtags) via our Member Information Submission form to share on NORD's website and social media channels.

- NORD invites members to share patient stories, news, and insights on relevant topics for potential publication on our blog. Submitted stories may also be highlighted across multiple NORD platforms. To submit a story for consideration, please visit rarediseases.org/share-your-story. Once approved and copy-edited, NORD will publish the story with full attribution to the original author.
- Please note that blog publication is at the discretion of NORD's Marketing department, with a maximum of one guest Member post published per week. Explore the NORD blog here: rarediseases.org/news.
- **Follow us on NORD's social media channels:**
  - NORD's Facebook: facebook.com/NationalOrganizationforRareDisorders
  - NORD's Instagram: @nord_rare
  - NORD's LinkedIn: linkedin.com/company/national-organization-for-rare-disorders
  - NORD's X (formerly Twitter): https://x.com/RareDiseases
  - Rare Action Network X (formerly Twitter): https://x.com/RareAction
  - NORD's YouTube: youtube.com/user/raredisorders

2) MEMBERSHIP

NORD creates greater awareness of its members through its literature and online communications.

- **All member organizations are listed on the NORD website** in three places: Our member list, our database of organizations, and on reports in the Rare Disease Database.
- Member organizations receive regular communication from NORD via a **biweekly Member Newsletter**. The newsletter highlights member benefits and shares timely updates and relevant news from our policy, research, and education teams as well as from NORD partners like the U.S. Food and Drug Administration (FDA), National Institutes of Health (NIH), Critical Path Institute (CPATH) and more. To subscribe to the member newsletter, contact the membership team at membership@rarediseases.org.
- Member organizations can **post their research requests for proposals (RFPs), events, conferences, awareness programs, job opportunities and internships** on the NORD website and X page, as well as in our monthly eNews. Use our Member Information Submission form to request free promotion.
- **Rare cancer organizations** are invited to participate in NORD's Rare Cancer Coalition. The Rare Cancer Coalition is a program under the NORD Membership umbrella that unites advocacy organizations working in rare cancers to collaborate on issues facing their communities. To learn more about the Rare Cancer Coalition, visit https://rarediseases.org/get-involved/rare-cancer-coalition/.
- **New member welcome:** New member organizations are featured in a post on NORD's Facebook page, with a current audience of 82,000 followers.
- Members can display the appropriate **NORD 2025 member organizational logo** (pictured below) on your website to show that you have met either the platinum or gold criteria for NORD membership. Uncertain about your level? If you joined NORD in 2019 or prior, you meet our Platinum level requirements. If you joined in 2020 or after, refer to your Membership approval email or contact membership@rarediseases.org to confirm. You can review the difference between platinum and gold levels online here.

3) BOARDSOURCE MEMBERSHIP

Your organization will have membership access to BoardSource, a 501(c)(3) nonprofit dedicated to inspiring and supporting nonprofit boards and executives to lead justly and with purpose. With more than three decades of experience, BoardSource provides an extensive range of tools, training, and research to enhance board leadership effectiveness and strengthen organizational impact.

This means that every board and staff leader at your organization will have free and unlimited access to consistent and reliable information to guide their leadership and governance practices, be it understanding board roles and responsibilities, how to lead effective meetings, or how to deal with challenging board issues. With your complimentary BoardSource membership, you can access:

- **Hundreds of topic papers:** BoardSource has a collection of hundreds of papers and articles on a wide range of nonprofit governance and board leadership topics that are short and easily digestible. They are accessible online and organized by topic.
- **Ask-an-Expert email service:** Facing a challenge with your board? BoardSource's governance experts provide direct support. Send your question or dilemma through their Ask-an-Expert email service to receive advice and/or resources that meet your needs.
- **Downloadable templates, tools, and infographics:** BoardSource provides members with practical tools they can download and use right away and other valuable easy-to-access resources.
- **Additional discounts:** Discounts on BoardSource trainings, assessments, publications and bulk rate discounts on office supplies for a single chapter or the entire network.

Contact membership@rarediseases.org to receive the sign-up link for your complimentary BoardSource membership.

4) ADVOCACY AND POLICY DEVELOPMENT

NORD supports legislative and regulatory initiatives that advance fair and equitable public policies, foster innovation in the development of new therapies, and improve patient access to care. By combining NORD leadership's influence and relationships with the expertise, insights and connections of our members, we drive a powerful, united policy agenda. As a member, you will:

- **Garner opportunities to join in public policy initiatives** with others in the rare disease and associated communities through sign-on letters, action alerts, Rare Disease Advisory Councils (RDACs), and joining coalitions in support of key policy priorities. Current policy issues are listed online: https://rarediseases.org/driving-policy/public-policy-positions/

- **Receive advocacy training** for your staff and grassroots volunteers through the Advocacy Academy, a 90-minute course designed to teach nonprofessional advocates and volunteers the basics of advocacy, enabling your organization to focus your efforts on training advocates about specific policy issues. Sign-up for the Advocacy Academy here: https://advocacyaccelerator.us/groups/nord/nord-advocates/
- **Receive public policy updates and critical analysis on issues** and "calls to action" on fast-breaking issues, with opportunities to communicate directly with your legislators through NORD's website.
- NORD advocates on behalf of the entire rare disease community. We give you the opportunity to add your name and voice by **signing on to letters of support and helping develop position papers and policy-related materials for lawmakers**. See current policy statements: https://rarediseases.org/driving-policy/nord-policy-statements/
- **Shape the policy agenda**: Enjoy opportunities to participate in open discussions that help determine the direction that NORD's policy agenda will take.
- **Have special access to our Washington, DC staff for public policy guidance** and support. We invite our members to connect with our Policy team at policy@rarediseases.org.

5) NORD MEDICAL EDUCATION AND OUTREACH

NORD members have opportunities to partner with NORD to educate medical professionals and the public about specific rare diseases and the challenges of living with a rare disease. These opportunities include:

- NORD receives numerous media inquiries and often **contacts member organizations when reporters** are seeking to interview patients or patient advocates.
- NORD promotes awareness of its member organizations and their resources in its interaction with **professional medical societies** such as the American Academy of Pediatrics and the American Society of Clinical Oncology.
- NORD raises awareness of its member organizations and shares their resources throughout the **NORD Rare Disease Centers of Excellence® network**.
- Members are invited to assist in the development of new disease reports for NORD's Rare Disease Database and help update current reports on conditions they support. Email the NORD Membership team for more information about a Rare Disease Report for your disease state: membership@rarediseases.org.

- NORD is very excited for the launch of NORD Claim Your Care, a program intended 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.

6) RESEARCH SUPPORT

NORD supports and facilitates research on rare diseases in the following ways:

- The NORD Research Grant Program provides support to patient organizations that have raised enough funds to sponsor a seed grant for their rare disease but do not have the capability of administering research grants.

  Studies funded with seed grant funding can provide preliminary data on drugs, devices, or medical foods. Researchers may use this data to attract further funding from government or industry sponsors to pursue further clinical research.

- NORD member organizations can use the Member Information Submission form to post requests for proposals (RFPs) for research opportunities related to their rare disease on the NORD website, social media pages and in the monthly NORD eNews that is regularly sent to over 68,000 people

- NORD members are invited to participate in Patient Listening Sessions (PLS) and Externally Led Patient Focused Drug Development meetings (EL-PFDD) offered through the FDA's Office of Patient Engagement. These meetings are one of many ways that your patient community can share your experiences with a rare disease directly with FDA medical product centers. Your session will provide FDA's 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 FDA's Office of Patient Engagement has partnered with NORD to provide helpful tools and guidelines to design PLS and EL-PFDD meetings, which are 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.

- Developed by NORD, the IAMRARE® Registry program is designed to meet your current and future research needs. Whether you are starting out with a patient registry, launching

your first natural history study, or establishing a multi-stakeholder collaborative for your disease, our software and support services can be customized to meet your research goals. This program is available to NORD members at a discounted price.

7) PARTICIPATION IN RARE DISEASE DAY®

Rare Disease Day®, launched by EURORDIS in Europe in 2008, became a global event in 2009 as the U.S. and other countries joined in. Today, Rare Disease Day is observed in more than 105 countries worldwide.

NORD is the official U.S. sponsor of Rare Disease Day, serving as the central hub for activities that recognize and support the rare disease community each year on the last day of February.

Given that many issues impacting the rare disease community are addressed at the state level, educating state legislators and their staff members is an extremely important part of Rare Disease Day.

There are several other meaningful ways to participate in this impactful event at home or at work:

- **Join the movement on social media:** NORD has a number of tools and resources available to support social media engagement: https://rarediseases.org/rare-disease-day/rdd-resources/. Use the hashtag #ShowYourStripes and be sure to tag NORD in your posts.
- Advocate by taking part of a virtual Rare Disease Day event: https://rarediseases.org/rare-disease-day/rdd-events/.
- Pledge a building or monument for #LightUpforRare: https://rarediseases.org/rare-disease-day/get-involved/light-up-a-monument/
- Participate in the FDA-NIH Rare Disease Day event.

Learn more: rarediseaseday.us

2024 NORD ORGANIZATIONAL MEMBERS

This is a list of member organizations who were active and in good standing throughout 2024. Click here for the most current list of members in 2025.

17q12 Foundation

3q29 Foundation

A Cure in Sight

Abetalipoproteinemia and Related Disorders Foundation

Achalasia Awareness Organization

Acid Maltase Deficiency Association

Acromegaly Community, Inc.

ADCY5.org

Adrenal Insufficiency United

Akari Foundation

Alagille Syndrome Alliance

ALD Alliance

All Things Kabuki

Alliance to Cure Cavernous Malformation

Alpha-1 Foundation

Alport Syndrome Foundation

ALS Association

Alternating Hemiplegia Of Childhood Foundation

American Behcet's Disease Association

American Partnership for Eosinophilic Disorders

American Porphyria Foundation

Amyloidosis Research Consortium, Inc.

Amyloidosis Support Groups

Angel Flight of New England

Angelman Syndrome Foundation

Apbd Research Foundation

Aplastic Anemia & MDS International Foundation

Appendix Cancer / Pseudomyxoma Peritonei (ACPMP) Research Foundation

APS Type 1 Foundation

As Healthy As Possible

Association For Creatine Deficiencies

Association for Frontotemporal Degeneration

Association for Glycogen Storage Disease

Association For Multiple Endocrine Neoplasia Disorders USA

Association of Gastrointestinal Motility Disorders, Inc.

ASXL Rare Research Endowment (ARRE) Foundation

Autoimmune Encephalitis Alliance

Autoinflammatory Alliance

Avalon Foundation

Avery's Hope

Barth Syndrome Foundation

BCM Families Foundation

BDSRA Foundation

Bonnell Foundation: Living with Cystic Fibrosis

Born A Hero, Research Foundation

CACNA1A Foundation

Canadian Organization For Rare Disorders

Cardio-Facio-Cutaneous (CFC) International

Castleman Disease Collaborative Network

Cauda Equina Foundation

CHAMP1 Research Foundation

Charcot-Marie-Tooth Association

Child and Youth Care Zimbabwe

Child Neurology Foundation

Children's Craniofacial Association

Children's Tumor Foundation

Cholangiocarcinoma Foundation

Chondrosarcoma Foundation, Inc.

Choroideremia Research Foundation

Chromosome 18 Registry & Research Society

Chromosome Disorder Outreach, Inc.

Clear Cell Sarcoma Foundation

CLOVES Syndrome Community

CMT Research Foundation

CMTC-OVM

Coalition to Cure Calpain 3

COMBINEDBrain - Consortium for Outcome Measures and Biomarkers for Neurodevelopmental Disorders

Congenital Central Hypoventilation Syndrome (CCHS) Network

Congenital Hyperinsulinism International

Consortium of Multiple Sclerosis Centers

COPA Syndrome Foundation

Creutzfeldt-Jakob Disease Foundation

Csnk2A1 Foundation

CTNNB1 Connect and Cure

Cure CMD

Cure HHT Foundation

Cure LBSL

Cure MLD / The Calliope Joy Foundation

Cure Mucolipidosis

Cure SMA

Cure VCP Disease, Inc.

CureARS

cureCADASIL

CureGRIN Foundation

CureLGMD2i Foundation

CurePSP

Curing Retinal Blindness Foundation

Cushing's Support & Research Foundation

Cutaneous Lymphoma Foundation

Cute Syndrome Foundation

Cystic Fibrosis Foundation

Cystic Fibrosis Research Institute

Cystinosis Research Network

Danny's Dose Alliance

DDX3X Foundation

Defeat Multiple System Atrophy Alliance

Desmoid Tumor Research Foundation

DESSH Foundation

Diann Shaddox Foundation

Dreamsickle Kids Foundation

Dup15q Alliance

DYRK1A Syndrome US

E.WE Foundation

Ehlers-Danlos Society

Einstök börn Stuðningsfélag

Erdheim-Chester Disease (ECD) Global Alliance

Erythromelalgia Association

EURORDIS-Rare Diseases Europe

FACES: The National Craniofacial Association

Facial Pain Association

Familial Dysautonomia Foundation, Inc.

FamilieSCN2A Foundation

Fanconi Cancer Foundation

Fat Disorders Resource Society

FD/MAS Alliance

Fibromuscular Dysplasia Society Of America

flok Health

Foundation Fighting Blindness

Foundation for Angelman Syndrome Therapeutics

Foundation for Ichthyosis & Related Skin Types

Foundation For Prader-Willi Research

Foundation for Sarcoidosis Research

Foundation To Fight H-Abc

FOXG1 Research Foundation

Friedreich's Ataxia Research Alliance

Galactosemia Foundation

Gaucher Community Alliance

GBS/CIDP Foundation International

Genetic Alliance

Global DARE Foundation

Global DARE Foundation

Global Foundation for Peroxisomal Disorders

Global Liver Institute

Glut1 Deficiency Foundation

Gorlin Syndrome Alliance

Grin2B Foundation

Gut Check Foundation

Guthy-Jackson Charitable Foundation

HCU Network America

Helping Hands for GAND

Hemophilia Federation of America
Hemophilia Foundation of Southern California
Hepatitis B Foundation
Hermansky-Pudlak Syndrome Network, Inc.
Heterotaxy Connection
Histiocytosis Association, Inc.
Hope For Hypothalamic Hamartomas
Hope in Focus
HPV Cancers Alliance
HSAN1E Society
Hunters cmt4b3 Research Foundation Inc
Hydrocephalus Association
Hyper IgM Foundation
Hypersomnia Foundation
Hypertrophic Olivary Degeneration Association
Hypoparathyroidism Association
IamHH
Illness Challenge Foundation
Immune Deficiency Foundation
Indian Organization For Rare Diseases
IndoUSRare
International Autoimmune Encephalitis Society
International FOP Association
International Foundation for CDKL5 Research
International Foundation for Gastrointestinal Disorders
International FOXP1 Foundation
International FPIES Association
International Neuroendocrine Cancer Alliance
International Pemphigus & Pemphigoid Foundation
International Prader-Willi Syndrome Organisation
International Rett Syndrome Foundation
International Sacral Agenesis/Caudal Regression Association
International Society for Mannosidosis & Related Diseases
International Topical Steroid Awareness Network
International WAGR Syndrome Association
International Waldenstrom's Macroglobulinemia Foundation
Intestinal Rehab & Transplant Unwrapped
Jack McGovern Coats' Disease Foundation
Jamal's Helping Hands, Inc.
Jansen's Foundation
Joshua Frase Foundation
KAT6 Foundation
KBG Foundation Inc
Kennedy's Disease Association
KIF1A.ORG
Klippel Trenaunay (K-T) Support Group
Koolen-De Vries Syndrome Foundation
Krabbeconnect
LAL-D Aware
LAM Foundation
Lennox-Gastaut Syndrome Foundation
Li-Fraumeni Syndrome Association
Liv4TheCure
Living With XXY
Lung Transplant Foundation
Lymphangiomatosis & Gorham's Disease Alliance
Mal de Débarquement Syndrome (MdDS) Foundation
Malan Syndrome Foundation
Marshall-Smith Syndrome
Organization of the USA, Inc.
Martin Mueller IV Achalasia Awareness Foundation, Inc.
Maternal Alloimmunization Foundation
M-CM Network
Melorheostosis Association
Mission MSA
MitoAction
MLD Foundation
Moebius Syndrome Foundation
Mowat-Wilson Syndrome Foundation
MpBC Global Alliance, Inc.
MPN Research Foundation
MSUD Family Support Group
Mucolipidosis IV (ML4) Foundation
Muscular Dystrophy Association

Myasthenia Gravis Foundation of America, Inc

Myhre Syndrome Foundation

Myocarditis Foundation

Myositis Support and Understanding Association

Myotonic Dystrophy Foundation

Narcolepsy Network

National Adrenal Diseases Foundation

National Ataxia Foundation

National Bleeding Disorders Foundation

National Bone Marrow Transplant Link

National Brain Tumor Society

National Cytomegalovirus (CMV) Foundation

National Eosinophilia-Myalgia Syndrome Network

National Foundation for Ectodermal Dysplasias

National Leiomyosarcoma Foundation

National Median Arcuate Ligament Syndrome (MALS) Foundation

National MPS Society

National Niemann-Pick Disease Foundation

National Organization for Albinism and Hypopigmentation

National PKU Alliance

National Scleroderma Foundation

National Tay-Sachs & Allied Diseases Association, Inc.

National Urea Cycle Disorders Foundation

NBIA Disorders Association

NEC Society

NephCure

Neuroendocrine Tumor (NET) Research Foundation

Neurofibromatosis Network

Next Generation of Cystinosis

NF2 BioSolutions

Nr2F1 Foundation

NTM Info & Research, Inc.

Ocular Melanoma Foundation

OMSLife Foundation

Organic Acidemia Association

Osteogenesis Imperfecta Foundation

PAP Foundation

Parent Project Muscular Dystrophy

Parent To Parent

Parents & Researchers Interested in Smith-Magenis Syndrome

Parents of Infants and Children with Kernicterus

Parry Romberg Foundation, Inc.

Patient Airlift Services

Pediatric Retinal Research Foundation

Pericarditis Alliance

PFIC Advocacy and Resource Network, Inc.

PHACE Syndrome Community

Phelan-McDermid Syndrome Foundation

Pheo Para Alliance

Pituitary Network Association

Platelet Disorder Support Association

Polycystic Kidney Disease (PKD) Foundation

Prader-Willi Syndrome Association USA

Primary Ciliary Dyskinesia (PCD) Foundation

Progeria Research Foundation

Project 8p Foundation

Project Sleep

PTEN Hamartoma Tumor Syndrome Foundation

Pulmonary Fibrosis Foundation

Pulmonary Hypertension Association

Pura Syndrome Foundation

Rare & Undiagnosed Network

Rare Trait Hope Fund

Raregivers

RASopathies Network

Raymond A. Wood Foundation

Recurrent Respiratory Papillomatosis Foundation

Reflex Sympathetic Dystrophy Syndrome Association

Remember The Girls

Rett Syndrome Research Trust

Rothmund-Thomson Syndrome (RTS) Foundation

Sanfilippo Children’s Foundation

SATB2 Gene Foundation

Scarring Alopecia Foundation

SETBP1 Society

Shine Syndrome Foundation
Shwachman-Diamond Syndrome Alliance Inc
Shwachman-Diamond Syndrome Foundation
Sickle Cell Association of Houston, Inc.
Sickle Cell Disease Association of America
Siegel Rare Neuroimmune Association
Sisters' Hope Foundation
Skraban-Deardorff Syndrome Foundation
SLC6A1 Connect
Smith-Kingsmore Syndrome Foundation
Smith-magenis Syndrome Research Foundation
Snow Foundation
Snyder-Robinson Foundation
Soft Bones, Inc
Spina Bifida Association
Spinal CSF Leak Foundation
SSADH Association
Stevens Johnson Syndrome Foundation
Stichting Pierre Robin Europe
Stiff Person Syndrome Research Foundation
STXBP1 Foundation
Sudden Unexplained Death in Childhood Foundation
Superficial Siderosis Research Alliance, Inc.
Superior Mesenteric Artery Syndrome Research Awareness And Support
SYNGAP1 Foundation
Taiwan Foundation for Rare Disorders
TANGO2 Research Foundation
TargetCancer Foundation
Tatton Brown Rahman Syndrome Community
Team Telomere
Team Titin, Inc.
TESS Research Foundation
The Allo Hope Foundation
The EHE Foundation
The FPIES Foundation
The Healing Net Foundation
The KDM5C KARES Foundation, Inc
The LCC Foundation
The Marfan Foundation
The Mast Cell Disease Society, Inc.
The MED13L Foundation
The RYR-1 Foundation
The TBCK Foundation
The Wiedemann-Steiner Syndrome Foundation
Thrive with Pyruvate Kinase Deficiency Organization
TSC Alliance
Turner Syndrome Society of The United States
Tyrosinemia Society, Inc.
United Leukodystrophy Foundation
United Mitochondrial Disease Foundation
United MSD Foundation
United Porphyrias Association
Uplifting Athletes
US Hereditary Angioedema Association
Usher Syndrome Coalition
Vasculitis Foundation
Vestibular Disorders Association
VHL Alliance
Wake Up Narcolepsy, Inc.
WARD'S Foundation
Warm Autoimmune Hemolytic Anemia Warriors
Wilhelm Foundation
Williams Syndrome Association
Wilson Disease Association
Xia-Gibbs Society
XLH Network, Inc
XLID98 Foundation
Yellow Brick Road Project

About NORD

Since 1983, NORD has fought to improve the health and well-being of people with rare diseases by driving advances in care, research and policy. We're an independent and bipartisan nonprofit dedicated to reimagining a future where every person with a rare disease and their families can live their best lives.

For more information, please visit: rarediseases.org.