RESOURCES FOR
Patients and Caregivers
National Organization for Rare Disorders (NORD®)

NORD HELPS YOU NAVIGATE YOUR RARE DISEASE JOURNEY

Everyone who has a rare disease deserves the best possible care and support.

The National Organization for Rare Disorders (NORD®) is the first and leading U.S. organization to fight for improved quality of life and access to care for all rare diseases.

From day one, patients and caregivers have been NORD’s top priorities, making us uniquely suited to serve your specific and complex needs. We provide financial assistance, caregiver relief, educational resources, webinars and events.

“NORD’s compassion and financial support has graciously afforded me insurance premium assistance and the ability to afford life-altering medications. NORD has given me the chance to live a normal life, and that gift of support changed my world!” - C.R., rare disease patient

Find Resources
For general and disease-specific assistance programs, search here: rarediseases.org/patient-assistance-programs

Alone we are rare. Together we are strong.®

OUR IMPACT (2018-2022)

$174 million in financial assistance for patients and caregivers

The NORD Helpline responded to nearly 700,000 requests for support

Nearly 2 million Travel miles reimbursed for patients seeking treatment, clinical trial participation or specialist consultations

$2.5 million in non-medical emergency relief (ERF) provided to patients, including natural disaster and COVID-19 response funds since 2015

Rare disease patients and families build a network of supporters by connecting at events like the Living Rare, Living Stronger® Patient and Family Forum.
Patient and Caregiver Assistance

We put patients and caregivers first. Our RareCare® Patient Assistance Programs – the first of their kind in the U.S. – are dedicated to supporting you and your caregiver team by providing:

- Life-saving or life-sustaining medication, medical foods and formulas and medical equipment
- Financial assistance with insurance premiums and co-pays
- Diagnostic testing assistance
- Non-medical emergency assistance
- Rare Caregiver Respite program (the first of its kind in the U.S.)
- Travel assistance for clinical trials or consultation with disease specialists

Beyond financial support, NORD is the one-stop resource for information you need throughout your rare disease journey, such as:

- The NORD Rare Disease Database is home to 1,300+ reports on rare diseases, with information on symptoms, diagnosis, treatments and resources to share with your health care provider. New reports are added each month in English and Spanish.
- A free online library of videos and classes to learn about managing care, mental health, advocacy, participating in rare disease research and more.
- Conferences like the Living Rare, Living Stronger® Patient and Family Forum, where you can connect with others whose lives are also impacted by rare diseases (financial support may be available to attend; contact education@rarediseases.org to learn more).
- Access to the world’s top rare disease medical teams and clinical trials through the NORD® Rare Disease Centers of Excellence Network. Learn more: rarediseases.org/rare-disease-centers-of-excellence.

NORD’s Helpline is here for you. Reach us at 1-800-999-6673 or visit rarediseases.org/contact.

Helpline hours:
Monday–Thursday 8:30am–7:00pm ET
Friday 8:30am–6:00pm ET

©2023 NORD. All rights reserved. NORD®, its icon, and tagline are registered trademarks of the National Organization for Rare Disorders. Icons provided by Smashingstocks. NORD is a registered 501(c)(3) charity organization. NRD-2-301

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 live their best lives.