

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.



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

*"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](https://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




**NORD®**  
National Organization  
for Rare Disorders


## 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

At 8 months old, Lucia Karloutsos (bottom center) was diagnosed with Cardiofaciocutaneous syndrome. The family has found a partner in NORD to help them navigate their journey and is involved in advocacy through the Rare Action Network®.



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 1,400+ 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](mailto: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](http://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](http://rarediseases.org/contact).

*Helpline hours:*

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

## 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.



[rarediseases.org](http://rarediseases.org)

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