



NORD®
National Organization
for Rare Disorders

NATURAL DISASTER & HURRICANE EMERGENCY RELIEF

What is the purpose of this program?

Sometimes a helping hand is most needed when an unexpected emergency arises. The National Organization for Rare Disorders (NORD®) is committed to supporting rare disease patients and families and offers programs to assist in times of crisis. The Natural Disaster & Hurricane Emergency Relief Program is designed to provide limited assistance to eligible individuals in such circumstances.

**EMERGENCY
RELIEF
PROGRAM**



Who is eligible to apply?

This program is designed to help patients who:

- Have a confirmed rare disease diagnosis
- Are a U.S. citizen or U.S. resident of six (6) months or greater with evidence of residency such as a utility bill showing the patient's name and address.



What is the application process?

Patients may contact the program directly by phone, email or online application.

A NORD Patient Services Representative will guide the applicant through the application process and verify eligibility for inclusion in the program.

Awards are based on meeting eligibility criteria and funding availability and are made on a first-come, first serve basis.

NORD® is Here for You

NORD, a 501(c)(3) organization, is a patient advocacy organization dedicated to individuals with rare diseases and the organizations that serve them. NORD, along with its more than 350 patient organization members, is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.

NORD was founded by families struggling to obtain access to treatments and whose advocacy for change led to the passage of the Orphan Drug Act in 1983. NORD assists eligible patients (those with medical and financial needs) in affording the treatments and medical services their healthcare professionals have prescribed.

Alone we are **rare**. Together we are **strong**.®


How do I get more information and apply?

Contact NORD's Natural Disaster & Hurricane Emergency Relief program.

Monday-Thursday 8:30 a.m.–7 p.m. ET
(5:30 a.m.–4 p.m. PT)

Friday 8:30 a.m.–6 p.m. ET (5:30 a.m.–3 p.m. PT)

 877-291-8082

 203-486-8941

 naturaldisaster@rarediseases.org

What kinds of assistance can I request from NORD?

NORD's program can assist eligible individuals/families with expenses in a number of categories (up to the award maximum):

- The program assists eligible individuals with the cost of unexpected or emergency non-medical expenses that cannot be afforded without short-term assistance.
- Some examples of these expenses may be:
 - Short-term emergency lodging
 - Home repair (limited)
 - Auto repair (short-term car rental)
 - Cell phone
 - Rent/mortgage
 - Utilities
 - Other types of emergency requests will be considered on an individual basis.

Are there expenses which cannot be covered by NORD'S Emergency Relief Program?

NORD's goal is to be as flexible as possible in regard to patient's emergency needs. Some expenses are not permissible by law, including:

- Federal, state, or local tax payments, including property taxes, child support payments, legal fines and/or fees
- Luxury goods and services or vacation costs

How does NORD demonstrate compliance with regulations required of charities?

NORD independently designs its patient assistance programs based on the needs of specific patient communities.

- No pharmaceutical company or donor controls or influences our programs.
- Our patient assistance decisions are based on consistently applied financial eligibility criteria and diagnosis only.
- Patients have their choice of health care provider, treatment and treatment location, and can make changes at any time.
- Patients' privacy and well-being are priorities at NORD. We do not share or provide patient names or data with donors, nor do we disclose or identify donors to patients. Patients are able to make the choices that are best for them because NORD's assistance covers all FDA-approved products available for a diagnosis. Our programs also help with more than medication: patients can use their funds to pay for other physician prescribed services related to their diagnosis, such as laboratory and diagnostic testing, physical and occupational therapy, durable medical and adaptive equipment, and travel to medical appointments.

