

Cystinosis Emergency Relief Fund



What is the purpose of this program?

NORD's Cystinosis Emergency Relief Fund offers small grants to families or individuals diagnosed with Cystinosis and in need of financial support when faced with limited resources to pay for unexpected or emergency expenses.

Who is eligible to apply for NORD's Cystinosis Emergency Assistance grants?

This program is designed to help patients who:

- Are a United States 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
- Have a diagnosis of Cystinosis
- Fall within the Program's financial guidelines and adhere to application requirements that are set in advance by NORD

What kinds of assistance can I request from NORD?

NORD's program can assist eligible individuals/families with two types of expenses:

- Unexpected or emergency expenses that an individual or family living paycheck-to-paycheck cannot afford without short-term assistance.
 - *Some examples of these expenses may be the cost of diapers or repair costs for cars or major appliances, as well as travel expenses for clinic visits (lodging, gas cards).*
- Monthly bills that an individual or family living paycheck-to-paycheck cannot afford to pay at the time of their application to NORD because of a documentable extenuating circumstance.
 - *For example, if a parent or caregiver is required to take unpaid leave from work to care for an ill family member and cannot then afford the monthly cost of cell phones, auto insurance, or rent/mortgage payments, then with these types of emergency situations, NORD would consider making a one-time payment to established monthly bills with the opportunity to reapply if necessary and funds are available.*

FAQ

What is NORD?

The National Organization for Rare Disorders (NORD), a 501(c)(3) organization, is an independent charity dedicated to the identification, treatment and cure of rare "orphan" diseases such as Cystinosis through education, advocacy, research and patient service programs.

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.

Funding for NORD comes from a variety of sources including corporate donations, foundation grants, public contributions, and membership dues.

Are there expenses which cannot be covered by NORD'S emergency assistance program?

Yes, NORD's goal is to be as flexible as possible in regards to patient's emergency needs, but some expenses which are not permissible, by law are:

- Federal, state, or local tax payments, including property taxes, child support payments, legal fines and/or fees
- Luxury goods and services or vacation costs are not eligible for consideration
- Insurance premiums and copay out of pocket costs

What is the application process?

Awards are granted on a first come, first served basis. Patients may be referred to the program by their health care provider, their case managers, or they may self-refer. The RareCareSM Patient Services Representative will guide the applicant through the application process during the initial phone call, at which time the representative will complete the Electronic Income Verification (EIV). If the tool identifies that the patient falls within the program's financial guidelines and the patient then agrees to NORD's Disclosure Agreement during a recorded telephone call, the application process will be concluded and the patient approved for assistance.

How long before a decision is made on an application for assistance?

The application decision process can take as few as 5 minutes over the telephone. Applications completed and submitted via email, fax or US mail will be processed within three (3) business days of receipt.

What happens if an applicant does not meet the criteria of the Electronic Income Verification?

The RareCareSM Patient Services Representative will offer to e-mail, fax, or mail the brief program application and disclosure forms to the patient. The applicant may then complete the application, sign the disclosure form, provide the appropriate financial documentation to verify financial need, and return them via fax, email, or USPS mail.

Is there a limit to a patient's financial award?

A decision to place a "cap" on funding or limit the scope of assistance to beneficiaries is at NORD's discretion and is determined based on the amount of donations made to the fund, as well as the anticipated volume of applicants expected to utilize the program, and their anticipated financial need.

How do I apply for assistance from NORD's Cystinosis Emergency Assistance Program?

Phone: 855-201-5087

Fax: 203-486-8033

e-mail: cystinosis_assist@rarediseases.org

9am - 7pm (E.S.T.) Mon – Thurs and 9am - 6pm Fri

US MAIL to: NORD

Attention: Cystinosis Program

55 Kenosia Avenue, Danbury, CT 06810

Is there a fee for applying for assistance?

No, NORD does not charge our applicants when applying for help.

Once a patient is accepted into the assistance program(s) how long are they eligible?

Awards are offered as payment support for a one-time emergency need. Beneficiaries may reapply within that same year if funding continues to be available.

How does the payment or reimbursement process work?

NORD will either utilize a debit card allowing authorized purchases or will reimburse the patient directly for their approved expenses.

All claims submitted for reimbursement must be provided within 30 days and include receipts or other evidence of payment, such as a credit card statement.

Reimbursements will be made within ten (10) business days of receipt by NORD.

NORD does not recommend or endorse any particular medical treatment but encourages patients to seek the advice of their clinicians. Donations to NORD for this and other programs may be made by contacting NORD at rarediseases.org.