

Cystinosis

Patient Assistance Programs



What is the purpose of this program?

NORD's Cystinosis Patient Assistance Programs offer eligible individuals diagnosed with Cystinosis financial support when faced with limited resources to pay for:

- out-of-pocket healthcare costs, and/or
- diagnostic testing costs, and/or
- unexpected emergency expenses

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

These programs are 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 expenses in a number of categories:

- **The Cystinosis Copay Program** assists eligible individuals who have health insurance with funding to cover health insurance deductibles, copayments & coinsurance costs associated with the care of Cystinosis.
 - Some examples of these expenses may be:
 - medical expenses paid toward health insurance deductible
 - copayment for a medical office visit
 - out-of-pocket cost for an Emergency Room visit
 - a coinsurance payment for a consult with a Cystinosis specialist
 - This program does not assist with copayments for medications
- **The Cystinosis Medical Assist Program** assists eligible individuals who are uninsured, or for whom coverage has been denied with out-of-pocket costs for medical expenses such as medical visits, laboratory & diagnostic testing, wound care products and other specific medical expenses. Additionally, mileage for travel to and from a Cystinosis related medical appointment may be reimbursed in this program. Medication costs are not covered.
- **The Cystinosis Emergency Relief 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 the cost of repair for a car or major appliances, unexpected utility costs or cell phone bill that cannot be afforded due to lost wages from time off related to care of ill family.
 - Other types of emergency requests will be considered on an individual basis.

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.

Is there a fee for applying for assistance?

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

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.

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 RareCare[®] Patient Services Representative will guide the applicant through the application process, verify eligibility for inclusion in the Cystinosis Program(s), determine financial eligibility using our Electronic Income Verification System (EIV) and award assistance.

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.

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.

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 Patient 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

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

Copay and Medical Assist awards are issued for a calendar year.

Emergency Relief awards are offered as payment support for a one-time capped emergency need.

How does the payment or reimbursement process work?

Copay and Medical Assist awards may be prepaid by NORD with appropriate documentation or reimbursed to the patient in accordance with appropriate receipts and documentation.

Emergency Relief awards will either utilize a NORD issued 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.

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

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