NORD®

BARTH SYNDROME EMERGENCY RELIEF PROGRAM

EMERGENCY RELIEF PROGRAM

What is the purpose of this program?

The National Organization for Rare Disorders (NORD®) recognizes the burden that managing a rare diagnosis places on a patient and their family. This financial burden may impact a patient's ability to afford unexpected or emergency essential (non-medical) expenses. The Barth Syndrome Emergency Relief Program is designed to provide limited assistance to eligible individuals in such circumstances.

NORD's Barth Syndrome Emergency Relief Program opened thanks to a generous donation from the Barth Syndrome Foundation.

Who is eligible to apply?

This program is designed to help patients who:

- Have a confirmed diagnosis of Barth syndrome and hospitalization or qualifying event within 12-months of application to the program.
- Are a United States citizen or US resident of six (6) months or greater with evidence of residency e.g.: a utility bill, school enrollment showing the patient's name and address.
- Meet the program's financial eligibility criteria.

What is the application process?

Patients may be referred to the program by their health care provider, Barth Syndrome Foundation, their case manager, or they may self-refer.

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 300 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 Barth Syndrome Emergency Relief Program

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

203.292.0293

475.206.0898

Barthsyndrome_assist@rarediseases.org

US MAIL to: NORD
Attention: Barth Syndrome ERF
55 Kenosia Avenue
Danbury, CT 06810

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 Barth Syndrome 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:
  - > *Rent or mortgage assistance*
  - >*Emergent home repair (limited)*
  - >*Emergency lodging*
  - >*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 illness or care of ill family.*
  - > *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 regards 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 are not eligible for consideration.

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

The NORD 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 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.

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