



NORD[®]
National Organization
for Rare Disorders

Barth Syndrome Foundation Family Services Fund

What is the purpose of this program?

The Barth Syndrome Foundation Family Services Fund administered by NORD is designed to provide the Barth syndrome community an opportunity to participate in BSF sponsored conferences, programs and workshops.

The program provides limited financial support with associated travel and lodging costs for participation in BSF programs.

**EDUCATIONAL
SUPPORT
PROGRAM**

*Financial assistance is generously provided by:



Barth Syndrome
Foundation



Who is eligible to apply?

This program is designed for individuals diagnosed with Barth syndrome, and their families who meet the following eligibility criteria:

- Referral from Barth Syndrome Foundation.
- Be a United States citizen or permanent resident; in many cases, residents from outside the U.S. may be eligible.
- Fall within the program's financial guidelines and adhere to application requirements that are set in advance by NORD.



What is the application process?

- Individuals who meet the above eligibility criteria, may apply for financial assistance by phone, fax or email.
- Awards are granted on a first come, first served basis.
- A NORD RareCare[®] Patient Services Representative will guide the applicant through the application process, verify eligibility for inclusion in the program, determine financial eligibility using our Electronic Income Verification System (EIV) and award assistance.

What is NORD?

NORD, the National Organization for Rare Disorders, is 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: Barth Syndrome Foundation Family Services Fund

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

☎ 203-242-0497

🖨 203-516-2398

✉ BSFtravelassist@rarediseases.org

✉ US MAIL to: NORD
Attention: BSF Family Services Fund
7 Kenosia Avenue
Danbury, CT 06810

What is the financial limit to this assistance?

The Barth Syndrome Foundation Family Services Fund has an award maximum of \$2,500/eligible applicant/household and per BSF event.

*Award limits may be changed and are subject to funding availability.

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

The RareCare® Patient Services Representative will offer to e-mail, fax, or mail the brief program application and disclosure forms to the applicant. 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.

What types of assistance may I request?

The Barth Syndrome Foundation Family Services Fund administered by NORD provides eligible individuals with limited financial support to attend BSF sponsored programs. This may include:

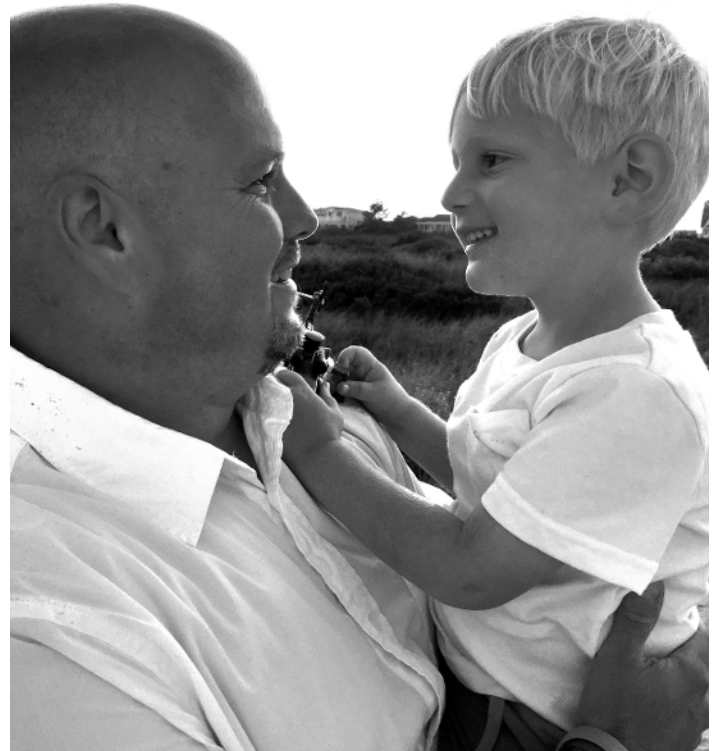
- Lodging (hotel) arrangements and expenses for BSF programs
- Ground transportation
- Mileage reimbursement
- Meal expense reimbursement
- Limited airfare assistance may be available

*NORD will pay on your behalf eligible expenses, up to award maximum.

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.

Program Sponsor:



rarediseases.org

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