NORD®
National Organization for Rare Disorders



Barth Syndrome Foundation Family Services Fund

EDUCATIONAL SUPPORT PROGRAM

What is the purpose of this program?

The Barth Syndrome Foundation (BSF) Family Services Fund, administered by the National Organization for Rare Disorders (NORD), provides lodging support to enable eligible individuals with Barth syndrome and their families to attend the 2026 Barth Syndrome International Conference (July 19-July 26) in Bonita Springs, Florida.

This program is referral-only. All applicants must be referred by BSF to participate.

Financial assistance for this program is generously provided by:

Barth Syndrome Foundation®

Application Process:

A referral from the Barth Syndrome Foundation is required for all applicants.

The referral confirms that the individual is registered to attend the BSF Conference July 19 - July 26, 2026.

Applicants may be a United States citizen or permanent resident; in many cases, residents from outside the U.S. may be eligible.

Applicants must fall within the program's financial guidelines and adhere to application requirements that are set in advance by NORD.

Program Priorities:

First-Time BSF Conference Attendees

BSF prioritizes funding for individuals attending the BSF Conference for the first time. This program through NORD covers 100% of lodging expense.

First-time status is verified in the BSF referral.

Returning Attendees

Returning attendees are placed into NORD's random-draw lottery, dependent on available funding.

Applications must be submitted and meet financial eligibility criteria on or before April 24, 2026 at 12:00 pm ET.

Financial Assistance Provided by this Program:

Financial assistance for lodging during the BSF 2026 conference.

NORD will book and prepay lodging for eligible attendees using BSF's approved room block and room rate.

Covered Dates: July 19–25, 2026 (inclusive)

Covered Costs: Room charges + room tax only

North American applicants who meet the program's eligibility criteria may be eligible for up to 7 nights of lodging support for conference attendance.

Applicants who reside outside of North America and who meet the program's eligibility criteria may be eligible for up to 9 nights of lodging support for conference attendance.

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

BSFtravelassist@rarediseases.org

The quickest way to apply is to click on NORD's website: bit.ly/patient-assist then scroll down to Barth Syndrone Travel Assistance and click Apply Online.

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

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

All decisions will be communicated to applicants by May 4th.

The QR code below will take you to NORD's website. Scroll to Help with Financial Assistance then Barth Syndrome Travel Assistance Fund.

Funding for this program is generously provided by:

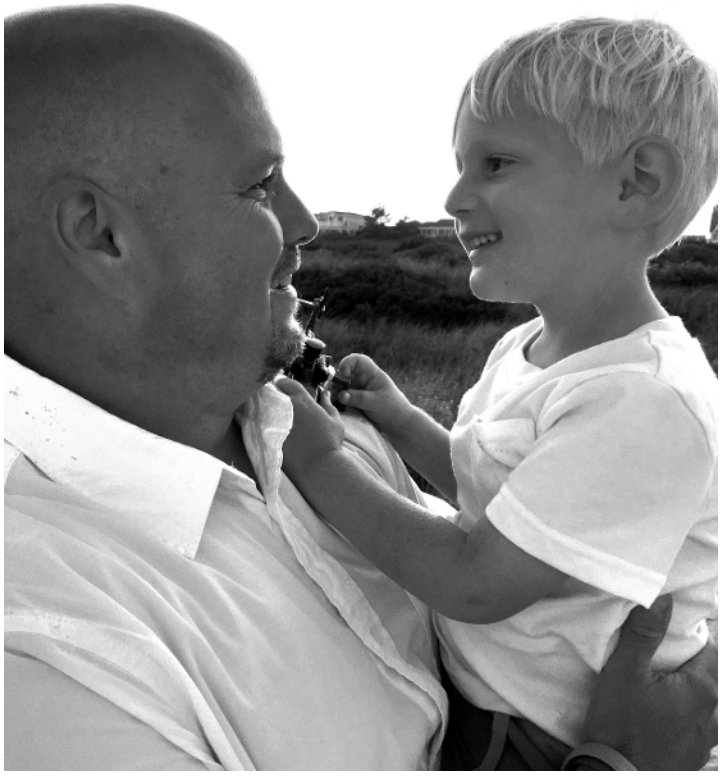
Barth Syndrome Foundation®

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.

This program was established in memory of Steven Woodward, loving father, brother, and uncle to Connor - to continue his legacy through selfless support of others.



rarediseases.org

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