



BIENNIAL INTERNATIONAL SCIENTIFIC, MEDICAL & FAMILY CONFERENCE

CORPORATE SPONSOR PROSPECTUS

July 19 - July 26, 2026 | Bonita Springs, Florida



ABOUT US

Since 2000, BSF has been a lifeline for those who are impacted by Barth syndrome, offering 24/7 support, pioneering standards of care and diagnosis, creating collaborations between clinicians, researchers and patients, driving discovery, and most importantly, making sure no person with Barth syndrome is ever alone.

VISION

A world in which Barth syndrome no longer causes suffering or loss of life.

MISSION

Saving lives through education, advances in treatments, and finding a cure for BTHS.

BARTH SYNDROME FACTS

Barth syndrome (BTHS) is an ultra-rare and life-threatening, X-linked mitochondrial disease that primarily occurs in males, impacts multiple body systems, and is caused by a genetic mutation in the *TAFFAZIN* gene.



CARDIOMYOPATHY/HEART FAILURE

73% of the BTHS population experiences heart failure or cardiomyopathy, increasing the risk of arrhythmias that can lead to cardiac arrest. 1/3 of individuals receive a heart transplant.



GLUCOSE DYSREGULATION

Serious hypoglycemic events in childhood as well as the onset of type 2 diabetes occurs in BTHS.



NEUTROPENIA

2/3 of individuals with BTHS have been diagnosed with neutropenia or found to have a low neutrophil count.



FAILURE TO THRIVE

Failure to thrive due to growth delay and gastrointestinal issues is highly prevalent. 43% of patients have had feeding tube/supplemental feeding at some point in life.



EXTREME FATIGUE

All muscles, including the heart, have a cellular deficiency which limits their ability to produce energy, creating extreme, life-altering fatigue in more than 50% of individuals.

Barth syndrome is life-limiting. A recent collaboration between Barth Syndrome Foundation and New York University has found that the highest hazard of death in individuals affected by Barth syndrome is before age 5.

BIENNIAL CONFERENCE

The Barth Syndrome Foundation's (BSF) biennial conference brings affected families, research scientists, and clinicians together in one place at one time for a multi-track meeting. BSF and our affiliates in Canada, France, Italy and the United Kingdom firmly believe that while each of these groups can make some progress in their individual efforts, together we are so much more powerful.

BSF's conference is an all-inclusive ticket to access the global community of affected individuals, leading researchers, & groundbreaking research.

BSF GLOBAL COMMUNITY



WITH HEAVIEST CONCENTRATION IN THE
UNITED STATES AND EUROPE

ATTENDEES REPRESENTED IN 2024

210

BSF FAMILY MEMBERS

Affected Individuals, Immediate and Extended Family Members

94

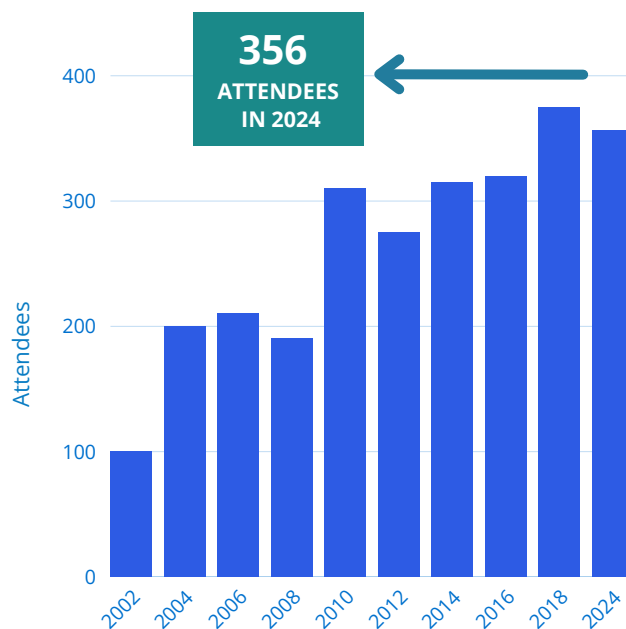
RESEARCHERS

Scientists, Clinician Researchers and Care Providers attended, 38 research posters were presented, and 200 research/clinic appointments were held over 7 studies

52

BSF EXTENDED NETWORK

Staff Members, Volunteers and Advocacy Partners



115

Sessions were offered at the 2024 international conference including: clinical care, advocacy, wellness and inclusiveness

\$7M

Through 2024, BSF has invested \$7M in research, translating into \$41M in follow-on funding and catalyzing >\$80M USD for clinical trials.

200+

Research appointments in IRB-approved studies conducted on-site at conference in 2024

SPONSORSHIP LEVELS

Sponsors gain access to the global patient community, leading health professionals from a broad array of specialties, and a first look at cutting edge pre-clinical and clinical research activities, which have diverse implications across an array of disciplines. Sponsorship revenue will have direct impact on research, advocacy and patient support.

PRESENTING \$50,000

- 4 Complimentary Registrations
- Exhibit Booth
- Welcome Reception Verbal and Signage Recognition
- Mobile App Banner Ad
- Logo and live click through on all conference emails and newsletters
- Full Page Ad in Conference Printed Program
- Mobile App Push Notification

PLATINUM \$35,000

- 4 Complimentary Registrations
- Exhibit Booth
- Welcome Reception Verbal and Signage Recognition
- Mobile App Banner Ad
- Logo on all conference emails and newsletters
- 1/2 Page Ad in Conference Printed Program

GOLD \$25,000

- 2 Complimentary Registrations
- Exhibit Booth
- Welcome Reception Signage
- Name recognition on all conference emails and newsletters
- 1/4 Page Ad in Conference Printed Program

SILVER \$10,000

- 2 Complimentary Registrations
- Shared Exhibit Booth
- Logo on two conference emails and newsletters
- 1/8 Page Ad in Conference Printed Program

BRONZE \$5,000

- 2 Complimentary Registrations
- Shared Exhibit Booth
- 1/8 Page Ad in Conference Printed Program

SUPPORTER \$2,500

- 1 Complimentary Registration
- Shared Exhibit Booth

BIENNIAL INTERNATIONAL SCIENTIFIC, MEDICAL & FAMILY CONFERENCE

When: July 19- July 26, 2026

Where: Hyatt Regency Coconut Point Resort and Spa
5001 Coconut Rd, Bonita Springs, FL 34134



Exhibitors to Expect:

- Full access to conference events
- Booth space (size and location based upon timing of reservation and financial commitment)
- Exhibitor set up: Wednesday 12:00 pm - 8:00 pm
- Exhibits will open: Thursday 9:30 am
- Exhibits will close: Friday, 3:30 pm
- Internet access throughout the Exhibitors' Hall; sponsorship available



"It is the unique collaboration that takes place at the BSF conferences between researchers, affected individuals, and clinicians that will facilitate the discovery of viable treatments for Barth syndrome."
- Carolyn Taylor, Medical University of South Carolina

What To Expect



EDUCATION

Learn about the latest to help improve health outcomes in the BTHS community with access to information about the latest healthcare advancements.

RESEARCH

Conduct IRB-approved research on-site to drive down costs and optimize time efficiencies to enrich the published landscape on BTHS.

COLLABORATION

Interact with largest group of world-renowned experts in BTHS to share scientific knowledge, stimulate ideas, and advance potential therapies.

COMMUNITY

Build connections across an international, diverse community to mitigate the loneliness and isolation that individuals and caregivers experience from a rare disease.



**Healthcare
Providers**



Families



Scientists

MULTI-TRACK EVENT

BSF will provide five tracks to cater to the requirements and preferences of our diverse network of healthcare providers, researchers, caregivers and affected individuals.

1 ON-SITE RESEARCH

**2 RESEARCH AND
DEVELOPMENT**

**3 FAMILY EDUCATION AND
CARE MANAGEMENT**

**4 WELLNESS AND
INCLUSIVENESS**

5 CAMP BARTH

EXAMPLE PROGRAM (BASED ON 2024)

MONDAY

ON-SITE RESEARCH

- on-site Research

RESEARCH & DEVELOPMENT

Begins Thursday

MEALS

- Lunch

FAMILY EDUCATION & CARE MANAGEMENT

- New Family Orientation & Meet Your Mentor
- Welcome Event Coffee & Danish
- Workshop
- Parents Session, Carriers Breakout

WELLNESS AND INCLUSIVENESS

- 12-Step Daily Meeting
- Yoga
- Grandparents Outing

CAMP BARTH

- Ice Breaker Bracelet Making
- Youth Recreational Activities

TUESDAY

ON-SITE RESEARCH

- on-site Research

RESEARCH & DEVELOPMENT

Begins Thursday

MEALS

- Lunch

FAMILY EDUCATION & CARE MANAGEMENT

- Parents Session: Breakout for people filling the traditionally binary role of dad
- First to Know Dinner: For affected individuals (16+ Years old)

WELLNESS AND INCLUSIVENESS

- 12-Step Daily Meeting
- Yoga
- Parents Getaway: For people filling the traditionally binary role of dad

CAMP BARTH

- Youth Recreational Activities

WEDNESDAY

ON-SITE RESEARCH

- on-site Research

RESEARCH & DEVELOPMENT

Begins Thursday

MEALS

- Lunch
- Barth Centers of Excellence Working Lunch

FAMILY EDUCATION & CARE MANAGEMENT

- Small Group Sessions: Feeding Issues, Sleep Issues, OT/PT Workshop
- Setting up for Independent Success (Parents, Teens+)
- Potential Carriers Workshop
- Post-test Carrier Workshop
- Grief, Loss and the Tough Conversations

WELLNESS AND INCLUSIVENESS

- 12-Step Daily Meeting
- Yoga
- Meditation
- Parents Getaway: For people filling the traditionally binary role of mom

CAMP BARTH

- Youth Recreational Activities

EXAMPLE PROGRAM (BASED ON 2024)

THURSDAY

OTHER ACTIVITIES

- Awards
- Group Photo

EVENING FUNCTION

- Wine and Cheese Event

RESEARCH & DEVELOPMENT

- Basic Biology of Barth Syndrome
- Poster Blitz
- Poster Hall

MEALS

- Breakfast
- Lunch

FAMILY EDUCATION & CARE MANAGEMENT

- Ask the Doctors: Cardiology & Transplant Workshop
- Ask the Doctors: Metabolism Workshop
- Ask the Doctors: Neutropenia Workshop
- Educational workshop updates from researchers in layman's terms

WELLNESS AND INCLUSIVENESS

- 12-Step Daily Meeting
- Addiction: Resilience, Coping Strategies and when coping strategies become harmful
- Yoga
- Mindful Breathing

CAMP BARTH

- Combined Youth Morning Activities by age groups

FRIDAY

MEALS

- Breakfast
- Lunch

EVENING FUNCTION

- Friday Night Social Event

ALL ATTENDEES: PLENARY SESSIONS

- Lessons from Barth syndrome clinical trials
- Clinical trial endpoints for Barth syndrome
- Potential therapies for Barth syndrome
- Conference Wrap up
- Collaborative Corner

WELLNESS AND INCLUSIVENESS

- 12-Step Daily Meeting
- Build a Boat
- Yoga
- Soundbath

CAMP BARTH

- Youth Recreational Activities

SATURDAY

MEALS

- Brunch

RESEARCH & DEVELOPMENT

- Scientific and Medical Advisory Board *invitation only*

FAMILY EDUCATION & CARE MANAGEMENT

- Conference Wrap Up

WELLNESS AND INCLUSIVENESS

- 12-Step Daily Meeting
- Yoga





**BARTH
SYNDROME
CONFERENCE
2026**

SPONSORSHIP FORM

COMPANY INFORMATION

Company Name : _____

Contact Title : _____

Today's Date : _____ / _____ / _____

Address : _____

Phone Number : _____ E-Mail : _____

Website URL : _____

SPONSORSHIP (PLEASE CHECK LEVEL)

☐

Presenting Sponsorship (\$50,000)

☐

Platinum Sponsorship (\$35,000)

☐

Gold Sponsorship (\$25,000)

☐

Silver Sponsorship (\$10,000)

☐

Bronze Sponsorship (\$5,000)

☐

Supporter Sponsorship (\$2,500)

DISCLAIMER

The exhibitor assumes full responsibility and liability for losses, damages, and claims arising out of injury or damage to the exhibitor's displays, equipment and other property brought upon the premises of the exhibit facility and shall indemnify and hold harmless the Barth Syndrome Foundation & The Hyatt Regency. In addition, the exhibitor acknowledges that it is the sole responsibility of the exhibitor to obtain business interruption and property damage insurance covering such losses by the exhibitor.

Signature : _____

Please email completed form to Lindsay.Marjoram@barthsyndrome.org