



# BIENNIAL INTERNATIONAL SCIENTIFIC, MEDICAL & FAMILY CONFERENCE

**CORPORATE SPONSOR PROSPECTUS**

**July 20 - July 25, 2026 | Bonita Springs, Florida**





# BARTH SYNDROME CONFERENCE 2026

## 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.



# BARTH SYNDROME CONFERENCE 2026

## 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 GLOBAL COMMUNITY



WITH HEAVIEST CONCENTRATION IN THE UNITED STATES AND EUROPE

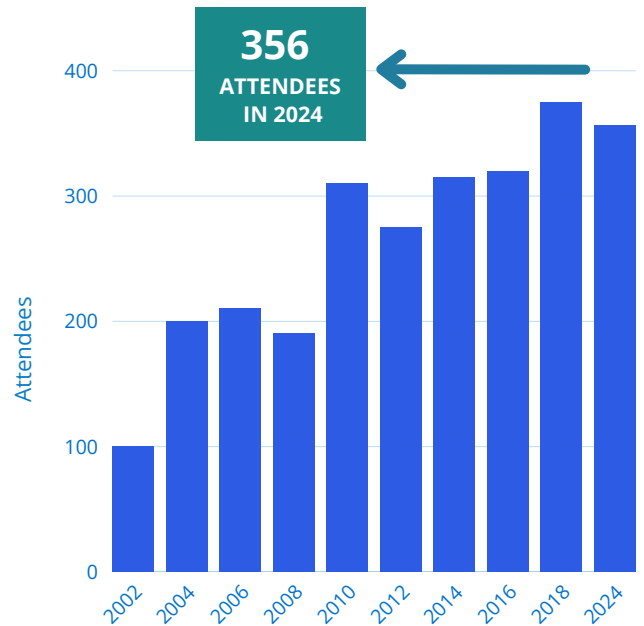
*BSF’s conference is an all-inclusive ticket to access the global community of affected individuals, leading researchers, & groundbreaking research.*

## 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.

### PREMIERE \$100,000

- **Sponsored Platform Talk to SciMed Attendees (30-minute talk followed by 15-minute Q&A)**
- **Sponsored Platform Talk to Affected Families (45-minute talk followed by 15-minute Q&A)**
- **3 Research Spotlight Talks (15-minute talks followed by 5-minute Q&A)**
- **8 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**

### 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**

## SPONSORSHIP LEVELS

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### 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



# BARTH SYNDROME CONFERENCE 2026

## 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

<b>ON-SITE RESEARCH</b> <ul style="list-style-type: none"> <li>on-site Research</li> </ul>	<b>RESEARCH &amp; DEVELOPMENT</b> <i>Begins Thursday</i>	<b>FAMILY EDUCATION &amp; CARE MANAGEMENT</b> <ul style="list-style-type: none"> <li>New Family Orientation &amp; Meet Your Mentor</li> <li>Welcome Event Coffee &amp; Danish</li> <li>Workshop</li> <li>Parents Session, Carriers Breakout</li> </ul>	<b>WELLNESS AND INCLUSIVENESS</b> <ul style="list-style-type: none"> <li>12-Step Daily Meeting</li> <li>Yoga</li> <li>Grandparents Outing</li> </ul>	<b>CAMP BARTH</b> <ul style="list-style-type: none"> <li>Ice Breaker Bracelet Making</li> <li>Youth Recreational Activities</li> </ul>
	<b>MEALS</b> <ul style="list-style-type: none"> <li>Lunch</li> </ul>			

### TUESDAY

<b>ON-SITE RESEARCH</b> <ul style="list-style-type: none"> <li>on-site Research</li> </ul>	<b>RESEARCH &amp; DEVELOPMENT</b> <i>Begins Thursday</i>	<b>FAMILY EDUCATION &amp; CARE MANAGEMENT</b> <ul style="list-style-type: none"> <li>Parents Session: Breakout for people filling the traditionally binary role of dad</li> <li>First to Know Dinner: For affected individuals (16+ Years old)</li> </ul>	<b>WELLNESS AND INCLUSIVENESS</b> <ul style="list-style-type: none"> <li>12-Step Daily Meeting</li> <li>Yoga</li> <li>Parents Getaway: For people filling the traditionally binary role of dad</li> </ul>	<b>CAMP BARTH</b> <ul style="list-style-type: none"> <li>Youth Recreational Activities</li> </ul>
	<b>MEALS</b> <ul style="list-style-type: none"> <li>Lunch</li> </ul>			

### WEDNESDAY

<b>ON-SITE RESEARCH</b> <ul style="list-style-type: none"> <li>on-site Research</li> </ul>	<b>RESEARCH &amp; DEVELOPMENT</b> <i>Begins Thursday</i>	<b>FAMILY EDUCATION &amp; CARE MANAGEMENT</b> <ul style="list-style-type: none"> <li>Small Group Sessions: Feeding Issues, Sleep Issues, OT/PT Workshop</li> <li>Setting up for Independent Success (Parents, Teens+)</li> <li>Potential Carriers Workshop</li> <li>Post-test Carrier Workshop</li> <li>Grief, Loss and the Tough Conversations</li> </ul>	<b>WELLNESS AND INCLUSIVENESS</b> <ul style="list-style-type: none"> <li>12-Step Daily Meeting</li> <li>Yoga</li> <li>Meditation</li> <li>Parents Getaway: For people filling the traditionally binary role of mom</li> </ul>	<b>CAMP BARTH</b> <ul style="list-style-type: none"> <li>Youth Recreational Activities</li> </ul>
	<b>MEALS</b> <ul style="list-style-type: none"> <li>Lunch</li> <li>Barth Centers of Excellence Working Lunch</li> </ul>			

## EXAMPLE PROGRAM (BASED ON 2024)

### THURSDAY

<p><b>OTHER ACTIVITIES</b></p> <ul style="list-style-type: none"> <li>Awards</li> <li>Group Photo</li> </ul>	<p><b>RESEARCH &amp; DEVELOPMENT</b></p> <ul style="list-style-type: none"> <li>Basic Biology of Barth Syndrome</li> <li>Poster Blitz</li> <li>Poster Hall</li> </ul>	<p><b>FAMILY EDUCATION &amp; CARE MANAGEMENT</b></p> <ul style="list-style-type: none"> <li>Ask the Doctors: Cardiology &amp; Transplant Workshop</li> <li>Ask the Doctors: Metabolism Workshop</li> <li>Ask the Doctors: Neutropenia Workshop</li> <li>Educational workshop updates from researchers in layman's terms</li> </ul>	<p><b>WELLNESS AND INCLUSIVENESS</b></p> <ul style="list-style-type: none"> <li>12-Step Daily Meeting</li> <li>Addiction: Resilience, Coping Strategies and when coping strategies become harmful</li> <li>Yoga</li> <li>Mindful Breathing</li> </ul>	<p><b>CAMP BARTH</b></p> <ul style="list-style-type: none"> <li>Combined Youth Morning Activities by age groups</li> </ul>
<p><b>EVENING FUNCTION</b></p> <ul style="list-style-type: none"> <li>Wine and Cheese Event</li> </ul>	<p><b>MEALS</b></p> <ul style="list-style-type: none"> <li>Breakfast</li> <li>Lunch</li> </ul>			

### FRIDAY

<p><b>MEALS</b></p> <ul style="list-style-type: none"> <li>Breakfast</li> <li>Lunch</li> </ul>	<p><b>ALL ATTENDEES: PLENARY SESSIONS</b></p> <ul style="list-style-type: none"> <li>Lessons from Barth syndrome clinical trials</li> <li>Clinical trial endpoints for Barth syndrome</li> <li>Potential therapies for Barth syndrome</li> <li>Conference Wrap up</li> <li>Collaborative Corner</li> </ul>		<p><b>WELLNESS AND INCLUSIVENESS</b></p> <ul style="list-style-type: none"> <li>12-Step Daily Meeting</li> <li>Build a Boat</li> <li>Yoga</li> <li>Soundbath</li> </ul>	<p><b>CAMP BARTH</b></p> <ul style="list-style-type: none"> <li>Youth Recreational Activities</li> </ul>
<p><b>EVENING FUNCTION</b></p> <ul style="list-style-type: none"> <li>Friday Night Social Event</li> </ul>				

### SATURDAY

<p><b>MEALS</b></p> <ul style="list-style-type: none"> <li>Brunch</li> </ul>	<p><b>RESEARCH &amp; DEVELOPMENT</b></p> <ul style="list-style-type: none"> <li>Scientific and Medical Advisory Board <i>invitation only</i></li> </ul>	<p><b>FAMILY EDUCATION &amp; CARE MANAGEMENT</b></p> <ul style="list-style-type: none"> <li>Conference Wrap Up</li> </ul>	<p><b>WELLNESS AND INCLUSIVENESS</b></p> <ul style="list-style-type: none"> <li>12-Step Daily Meeting</li> <li>Yoga</li> </ul>	
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## COMPANY INFORMATION

Company Name : \_\_\_\_\_

Contact Title : \_\_\_\_\_

Today's Date : \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_

Address : \_\_\_\_\_

Phone Number : \_\_\_\_\_ E-Mail : \_\_\_\_\_

Website URL : \_\_\_\_\_

## SPONSORSHIP (PLEASE CHECK LEVEL)

**Premiere Sponsorship (\$100,000)**

**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](mailto:Lindsay.Marjoram@barthsyndrome.org)**