BARTH SYNDROME CONFERENCE 2026

BIENNIAL INTERNATIONAL SCIENTIFIC, MEDICAL & FAMILY CONFERENCE

2026

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

MULTI-TRACK EVENT

The Barth Syndrome International Conference provides five tracks for our diverse network of healthcare providers, researchers, caregivers and affected individuals.

1. ON-SITE RESEARCH
2. RESEARCH AND DEVELOPMENT
3. FAMILY EDUCATION & CARE MANAGEMENT
4. WELLNESS AND INCLUSIVENESS
5. CAMP BARTH

THE CONFERENCE EXPERIENCE

LEARN

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

COLLABORATE

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

RESEARCH

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

SPEND TIME WITH COMMUNITY

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

DISCLAIMERS

- Sessions with clinicians, healthcare providers, and volunteer professionals leading small groups at the Conference are designed to be informal interactions. These sessions provide participants with opportunities to ask general questions, consider new approaches to care management, and discuss relevant topics with professionals familiar with Barth syndrome. **It is important to note that, unless otherwise explicitly stated, these interactions DO NOT establish a provider-patient relationship.** The information shared during these sessions is intended for educational purposes and to help the patient community make informed decisions. **All decisions regarding the care of an individual with Barth syndrome should be made in coordination with the affected individual's healthcare provider(s).**

- The Barth Syndrome Foundation does not endorse any specific treatments, products, clinical trials, or studies. Presentations, workshops, and opportunities that are part of Conference programming are informational only. The decision to use a particular product or participate in an opportunity is entirely up to the participants / their families and should be discussed with their care providers, when necessary.

Network: Hyatt_Meeting
Password: barth26

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CONFERENCE APP

Download the event app for a more interactive conference experience.

UPLOAD PHOTOS

Upload your photos from the week here!

REGISTRATION DESK HOURS

SUNDAY, 7/19 — 3:30 PM TO 7:00 PM

MONDAY, 7/20 — 7:00 AM TO 5 PM

TUESDAY, 7/21 — 7:00 AM TO 5 PM

WEDNESDAY, 7/22 — 7:00 AM TO 5 PM

THURSDAY, 7/23 — 7:00 AM TO 6 PM

FRIDAY, 7/24 — 7:15 AM TO 3:30PM

Dear Conference Guests,

Welcome to Conference! If this is your first time here, welcome! If not, we're so glad to see you again.

The Barth Syndrome International Scientific, Medical, and Family Conference (affectionately known by many of us simply as "Conference") is a unique experience for our Barth community, and in many ways, unique among rare disease community gatherings.

Conference is built upon three things that we know to be true: (1) thriving with Barth syndrome is a community effort, (2) insight is found when our community comes together — affected individuals, families, clinicians, researchers — and (3) it's important to connect in person with people who understand living with Barth.

The 2026 Conference is our first time coming together since the U.S. Federal Drug Administration (FDA) approved the first-ever treatment for Barth syndrome. This milestone is the result of decades of work and in many ways represents the evolution of what is possible for our community. We are moving into a new phase of how we can support Barth families around the world.

This year, we recognize our evolution in many ways, including by...

- Introducing an updated Mission & Vision Statement: We will collectively and tenaciously work toward saving and improving the lives of those impacted by Barth syndrome, until we see a world where everyone in our community can thrive and live the life they choose.
- Launching BarthINSIGHTS, our new registry and biorepository. You'll hear more about that in the coming days.

We hope this week brings you replenished energy, new ideas and foundational knowledge , and the opportunity to connect with our beautiful community.

Yours,

Emily Milligan, Chief Executive Officer

About the Barth Syndrome Foundation

We envison a world in which everyone impacted by Barth syndrome can thrive and live the life they choose.

We will help make that vision reality by living our mission to collectively and tenaciously work toward saving and improving the lives of those impacted by Barth syndrome. We will do this by focusing on five things:

- **Protecting the heart of the Barth syndrome community** – providing connection, support, and resources as the most trusted source of information along every step of our community's individual and collective journeys with Barth syndrome.
- **Advocating for the Barth syndrome community** to raise awareness of the community's needs and remove barriers to care and treatment.
- **Driving toward treatments and a cure**, coordinating closely with partners who are developing therapies.
- **Investing in research**, continually deepening our understanding and seeking new paths toward treatments and better health outcomes as related to Barth syndrome.
- **Never, ever giving up.**

Welcome to our Keynote Speaker Dr. Emil Kakkis

Dr. Emil D. Kakkis is the Founder, Chief Executive Officer, President, and a member of the Board of Directors of Ultragenyx Pharmaceutical Inc., a biopharmaceutical company dedicated to developing therapies for individuals living with rare and ultra-rare genetic diseases.

A pioneer in rare disease drug development, Dr. Kakkis founded Ultragenyx in 2010 with a vision of creating a company built around meaningful partnerships with patients and caregivers.

Under his leadership, Ultragenyx has challenged traditional approaches to clinical development, regulatory strategy, and patient access, helping to accelerate the availability of treatments for rare disease communities around the world.

Before founding Ultragenyx, Dr. Kakkis played a key role in the development of enzyme replacement therapies for lysosomal storage disorders, including pioneering work that contributed to the approval of treatments for Hunter syndrome and Maroteaux-Lamy syndrome. Throughout his career, he has been a passionate advocate for individuals and families affected by rare diseases, working to ensure that patient voices remain at the center of research, drug development, and healthcare policy.

As a physician-scientist, entrepreneur, and advocate, Dr. Kakkis has dedicated his career to transforming the rare disease landscape and advancing innovative therapies that offer hope to patients and families worldwide. His unwavering commitment to rare disease patients, innovative approach to therapeutic development, and leadership in advancing treatments for underserved communities have made him one of the most influential voices in the rare disease field today.

The Barth Syndrome Foundation is honored to welcome Dr. Kakkis as the keynote speaker for the 2026 Barth Syndrome International Scientific, Medical & Family Conference. His insights into patient-centered innovation, drug development, advocacy, and the future of rare disease research will inspire and inform attendees from across the global Barth syndrome community.

2026 Recipient of the Varner Award for Pioneer in Science and Medicine

The Barth Syndrome Foundation is proud to recognize Dr. Hilary Vernon as the 2026 recipient of the Varner Award for Pioneer Science & Medicine.

Dr. Vernon serves as Director of the Mitochondrial Medicine Center at Johns Hopkins Hospital and Director of the Barth Syndrome Interdisciplinary Clinic at Kennedy Krieger Institute. She is also Co-Director of the Department of Genetic Medicine Clinical Trials Unit at Johns Hopkins University School of Medicine.

Established in 2008 through the generosity of the Wilkins family, the Varner Award honors the memory of Paula and Woody Varner, maternal grandparents of John Wilkins. The Varners embodied the qualities the Barth Syndrome Foundation most values in scientific research: persistence, commitment, honor, integrity, and humility. The award recognizes individuals who have fostered innovation and excellence in biomedical research and celebrates those whose work has significantly advanced the field of Barth syndrome research, helping to build a brighter future for those living with this rare disease.

As a recipient of this distinguished award, Dr. Vernon joins an esteemed group of scientists and clinicians whose dedication and achievements have furthered the Barth Syndrome Foundation's mission to advance treatments, improve standards of care, and enhance quality of life for individuals with Barth syndrome.

The Barth Syndrome Foundation and its Board of Directors extend their deepest gratitude to Dr. Vernon for her longstanding commitment to the Barth syndrome community and her invaluable contributions to research, clinical care, and patient advocacy. Please join us in celebrating Dr. Vernon and her remarkable accomplishments during the presentation of the Varner Award at the 2026 Barth Syndrome International Scientific, Medical, and Family Conference.

To learn more about the Varner Award and the past recipients visit our website scanning the QR code.

Introducing BarthINSIGHTS

Global insight creates change

Barth INSIGHTS
Registry and Repository

Barth INSIGHTS

We're thrilled to introduce BarthINSIGHTS — BSF's upgraded registry and biorepository, launching right here at the 2026 conference. BarthINSIGHTS is a secure, modern platform where people living with Barth syndrome and their families can share their health experiences, symptoms, and daily life related to Barth syndrome. Every survey completed, every record shared, and every data point contributed helps researchers understand Barth syndrome more deeply and helps families navigate it more confidently. We've built this with you, for you, and we can't wait to welcome you in.

New features include a streamlined user experience, bite-sized modules, and progress saving so you can go at your own pace, carry over responses to make updates easier, and view real-time insights to see how your contribution fits into the bigger picture, and access our Patients As Partners appreciation program because ***we value your participation***.

Stop by the BarthINSIGHTS on-site research station in Captiva A to learn more and enroll or scan the QR code above!

Secure Database

Patient-Centric & Patient's Voice

Patients as Partners

Regulatory-Grade Data

Power in Numbers

The goal of BarthINSIGHTS is to ensure that every person and family affected by Barth syndrome — wherever they are in the world — is represented, heard, and served by this asset that advances research, informs regulatory pathways for drug development, and addresses the unmet needs of our global community.

On-site Research & Clinics

On-site research provides an opportunity for affected individuals and their families to participate in clinical studies, which enable the scientific community to collect data, further our understanding of Barth syndrome and potentially contribute to new clinical or therapeutic findings.

The clinical data captured at past conferences have contributed significantly to the scientific and medical understanding of Barth syndrome. This is only possible with the collaboration of our Barth families working with researchers in this unique setting.

Additional study opportunities that are not on this list may become available. For the latest list, please check the conference app, or scan the QR code.

Comprehensive assessment for children with Barth syndrome

Pine A

Investigators: **Yoonjeong Lim, PhD, OTR/L**; Alex Orkwis, OTD, OTR/L
Binghamton University (funded by the institution, with compensation provided)

Open to children diagnosed with Barth syndrome (ages 7 to 17) and their parents

Exclusion criteria:

- Non-English-speaking children and parents
- Children with severe comorbid physical disabilities (e.g., cerebral palsy)

Summary:

Children will complete two assessments measuring their perception and copying of different shapes, as well as their fine motor skills. They will also complete one questionnaire about their perceived fatigue (a total of 30 minutes). Parents will complete a set of questionnaires about their child's level of fatigue, ability to take care of themselves, sensory processing difficulties in everyday activities, and demographic information (a total of 30 minutes). An individual summary report will be sent to the parent's email address. As compensation, participants will receive a $50 electronic gift card upon completing this study.

Onsite Research & Clinics
Continued

Longitudinal Evaluation of Cardiomyopathy and Outcome in Barth Syndrome

Captiva B
Investigators: **Carolyn Taylor, MD**
Medical University of South Carolina

You are being asked to participate in this study because you (or your child) have Barth syndrome. This study is sponsored by the Medical University of South Carolina. We work with the BSF and other investigators to collect information on cardiomyopathy in Barth syndrome. This information is used to study changes over time in cardiac function as well as help develop echo or ECG based outcome measures that may be used for research trials. The study is open to anyone with Barth syndrome who chooses to participate. There are no specific exclusion criteria.

Procedures: You will have an echocardiogram and an ECG. Both the echos and ECGs will use your GUID as your study ID to allow better collaboration between research centers. The echocardiogram will take about 15 minutes and the ECG will take about 5 minutes. These are no different than your typical echos and ECGs that you get in your local cardiology clinic. You will be asked to fill out a brief questionnaire about your medical history, medications, activity level and education / work. The questionnaire will take about 10–15 minutes.

Risks & Discomforts: There are no known risks of echocardiograms as this test uses soundwaves. The ECG procedure may cause some mild discomfort during the placement and removal of the leads to and from the skin. There is a low risk of loss of privacy due to filling out the questionnaire.

Benefits: There will be no direct benefit to you from participating in this study and there is no compensation. However, it is hoped that the information gained from the study will help in the treatment of patients with Barth syndrome and will help researchers learn more about the natural history of Barth syndrome. We will not have time to read formally the echocardiograms at the conference, but we are happy to provide you with a copy on a DVD or USB.

Onsite Research & Clinics
Continued

Inspiratory Neuromuscular Assessment in Barth Syndrome

Calusa A

Investigators:
Leonardo F. Ferreira, PhD, PT (PI)
Vinicius M. Mariani, PhD, MS (Co-PI)

You can participate if you are:

- 3-70 years of age
- Male
- Diagnosed with Barth syndrome
- Healthy individual without Barth syndrome

Exclusion Criteria:

- Unable to participate in breathing tests
- Hospitalized in the last 3 months
- Diagnosed with Pulmonary disease
- Signs and symptoms of upper respiratory tract infections

Brief Study Overview:
Participants (3-70 years of age) will be asked to complete breathing tests to define breathing muscle strength and power outcomes in Barth syndrome. The testing is non-invasive and will be completed in a single visit that will last approximately 1h. The main breathing muscle is an inspiratory muscle called the diaphragm. Participants will perform inspiratory muscle strength (maximum inspiratory pressure) tests and airflow against different air resistances (pressure-airflow relationship) testing to estimate inspiratory power. The completion of this comprehensive study will provide a detailed picture of the overall function of patients' inspiratory muscle function. Participants will not receive any compensation to join or complete the study. The data collected in this study will show for the first time if breathing muscles are affected by Barth syndrome.

Onsite Research & Clinics
Continued

Arrhythmia Project: Collaborative Registry to Determine the Natural History of Barth Syndrome

Ibis (Friday & Saturday only)

Investigators:
Reina Tan, MD; Colin Phoon, MD; Faiz Siddiqui
New York University Langone Health

Open to individuals in the following groups, patients based in the United States or international patients who have copies of their medical records.

- Individuals diagnosed with Barth syndrome
- Family members of Barth-affected individuals who have passed away (wearable heart monitor component is not applicable for this group)

Summary: This retrospective and prospective observational study will collect medical records from you or your doctor. You will also be asked to answer some questionnaires and wear a heart monitor (the heart monitor will be placed on you during the conference on either Friday 7/24 or Saturday 7/25).

Onsite Research & Clinics
Continued

Pill Swallowing Clinic

Pine C

Led By: **Stacey Reynolds, PhD, OTR/L, FAOTA**
Virginia Commonwealth University

Being able to swallow pills is an important skill that most children must master around the age of 10-12 years, when liquid medications stop becoming available. For children with medical conditions such as Barth syndrome, pill swallowing may be necessary at an earlier age for managing symptoms of Barth or to participate in clinical trials research. Families of young children will often resort to alternative means of presenting medications, such as crushing pills and hiding them in food; however, this method rarely works, and children may learn to be distrustful of food which can lead to undesirable mealtime behaviors. Crushing pills can also lead to altered-dosage, diluting the medication's effectiveness.

The purpose of this clinic is to use evidence-based training methods to teach individuals with Barth syndrome to swallow pills comfortably and effectively. We have run this clinic at three prior conferences (2016, 2018, 2024) and had great success with all ages (5 years- adult). Our approach uses behavioral (shaping), positional, and adaptive strategies which we combine to match the needs of the individuals we are working with. Participants practice using very small candies (cupcake sprinkle) and progress through a series of candy sizes up to what would be considered a standard pain-relief pill (M & M) or something that might be used in a clinical trial (Mike & Ike). Participants can attend the clinic multiple times to practice skills, and may also be given exercises to practice at home after the conference is over.

Note: *This is NOT a research study. The Pill Swallowing Clinic is an interactive, educational workshop for affected individuals and their families.*

Onsite Research & Clinics
Continued

Barth Syndrome Microbiome Project
Calusa B/C

Investigator: William Todd Cade, PhD

Institution: Duke University (funded by a grant from the Barth Syndrome Foundation, no compensation provided)

Open to those diagnosed with Barth syndrome and healthy controls who can provide a stool sample and are on stable medications for greater than 3 months

Exclusion criteria:
1. Any active infection that could affect the composition of the microbiome
2. Currently taking/have taken antibiotics over the previous 14 days
3. History of other orthopedic, neurological, metabolic, or cardiovascular conditions

Summary:
The purpose of this research study is to describe what is in your digestive system and how it's related to what you eat and how you break down your food. This is different for children and adults with Barth Syndrome (BTHS) and those without this disease, and we would like to find out why.

Participants will provide a stool sample during the conference and complete questionnaires, which include a food diary. Once the stool sample is completed, you will return the sample to the study team.

Onsite Research & Clinics
Continued

Barth Syndrome Motor Milestones

Calusa B/C

Investigator: William Todd Cade, PhD

Institution: Duke University
(funded by the institution, no compensation provided)

Open to children diagnosed with Barth syndrome (ages 3 months to 21 years), their parents, and clinicians

Summary:
This research study is building a database to track how people with Barth syndrome move, run, and play so researchers can better understand their physical development. The goal is to figure out the best ways to measure changes in health and physical abilities over time. We are doing this in a couple of different ways and need help from multiple groups: those with Barth Syndrome completing tests (part 1), and semi-structured interviews with clinicians and parents/caregivers living with those with Barth Syndrome (part 2). What we learn could help doctors give more personalized care to you and others living with Barth syndrome.

Part 1:
At the conference, we will test children, adolescents, and young adults with Barth Syndrome (ages 3 months to 21 years) to see how they move, walk, and assess how strong they are. This will be completed by a series of age-appropriate measurements conducted by physical therapists. There is also a short questionnaire that asks about symptoms of tiredness and fatigue with daily activities. These study activities should take less than 2 hours.

Exclusion criteria:
1) Inability to participate in functional testing
2) Recent hospitalization in the past 3 months

Part 2:
To determine the appropriate motor outcomes that reflect motor deficits in children, adolescents, and young adults with Barth Syndrome, we will conduct semi-structured interviews with:

1. Clinical experts (e.g., physicians, physical therapists) in the care of children with Barth Syndrome.
2. Parents and caregivers of children with Barth Syndrome.

Sessions will occur via Zoom and explore perceived priorities, meaningful daily activities, feasibility, and preferred assessment tools. Sessions will be recorded for transcription and analysis. These interviews will take about 30-45 minutes.

Onsite Research & Clinics
Continued

BarthINSIGHTS Registry and Repository
Captiva A

Investigators: **Melissa Huang, PhD**; Lindsay Marjoram, PhD
Barth Syndrome Foundation

Open to individuals diagnosed with Barth syndrome and/or their caregivers.

Summary: Participation involves consenting or reconsenting on the BarthINSIGHTS registry and repository online platform. You will be asked to provide a proof of diagnosis (if available), fill out surveys related to basic demographics, health experiences, quality of life, and symptoms related to Barth syndrome. Your height, weight, and vitals will also be collected.

(*Optional) Blood Draw*: Affected individuals can opt to provide an optional one-time blood sample collection with a blood draw during the conference.

We will make every effort to collect the blood sample in a SINGLE blood draw; no more than 2 teaspoons per person will be collected.

For questions related to on-site research and clinic scheduling, please reach out to Melissa Huang: melissa.huang@barthsyndrome.org

Additional study opportunities may become available. For the latest list of studies, please refer to the conference app.

Market Research Opportunities

Lived Experience: Insights into Barth syndrome and experiences of treatment

BSF and its affiliates (BSF Canada, BSUK, Association Syndrome de Barth France and Barth Italia Onlus) are running a project to better understand what life is like for people with Barth syndrome.

They are collecting information through an online survey that asks about symptoms, daily challenges, mental and physical health, and experiences using elamipretide (FORZINITY™).

Right now, only some patients in the US can get elamipretide (FORZINITY™). The goal of this survey is to gather real-world experiences that can be shared—*anonymously*—with health authorities in the UK. This may help make elamipretide available to patients there through the National Health Service (NHS). Anonymized results may also be used to support access to the drug in other countries such as those in Europe, Australia, Canada, and China.

Who Can Participate?

- Adults (≥18 years old) living with Barth syndrome*
- Parents or primary caregivers of someone currently living with Barth syndrome (<18 years old)
- Bereaved parents or carers of an adult or child who had Barth syndrome

**Only one full survey can be completed per affected individual. If the person with Barth syndrome is over 18 and needs or chooses to have a parent/carer respond on their behalf (i.e. they are not completing the survey themselves), one carer may respond on their behalf.*

What Is Involved? You will be asked to complete an online questionnaire. If you choose to complete this at the conference, you will be provided access to a laptop with internet, and a facilitator will be available to help.

Individuals who complete the survey can opt-in to a prize drawing for a chance to win one of three $200 gift cards.

Interested in Participating? Stop by and speak to the BSF Research Team in **Captiva A**.

Disclaimer: This opportunity is a market research study for informational purposes only. It is not a clinical research study and has not been reviewed or approved by an Institutional Review Board (IRB) or research ethics committee.

Poster Presenters

The Poster Session showcases exciting research related to Barth syndrome. Attendees are encouraged to attend the poster hall to view the posters and talk to researchers and clinicians to learn more about their work.

1. **ELAMIPRETIDE – THE FIRST APPROVED TREATMENT FOR BARTH SYNDROME AND THE PHASE 3B/4 CONFIRMATORY TRIAL**
   Presenter: Anthony Abbruscato

2. **COMPARISON OF ZIOXT® AMBULATORY ELECTROCARDIOGRAM (ECG) PATCH ADHERENCE: PROFESSIONAL VERSUS PATIENT APPLICATION IN UK INDIVIDUALS WITH BARTH SYNDROME**
   Presenter: Gillian Alexander

3. **EXPERIENCE/EFFECT OF SAFE BLOOD GLUCOSE LEVEL MONITORING FOR BARTH SYNDROME AFFECTED INDIVIDUAL WHEN DAPAGLIFLOZIN IS COMMENCED**
   Presenter: Gillian Alexander

4. **QUALITATIVE ANALYSIS OF THE ADVANTAGES AND DISADVANTAGES OF THE SELF-ADHESIVE AMBULATORY ECG MONITORING: HEALTHCARE TEAM PERCEPTIONS VS PATIENTS' PERSPECTIVE**
   Presenter: Gillian Alexander

5. **ALTERATIONS IN AMINO ACID METABOLISM DURING REST, SUBMAXIMAL EXERCISE, AND POST-EXERCISE RECOVERY IN CHILDREN, ADOLESCENTS, AND YOUNG ADULTS WITH BARTH SYNDROME**
   Presenter: Todd Cade

6. **EFFECTS OF CANNABIDIOL ON TAFAZZIN-DEFICIENT B-LYMPHOBLASTOID CELLS**
   Presenter: John Chan

7. **BARTH SYNDROME PATIENT-DERIVED MOUSE MODELING OF CARDIOVASCULAR DYSFUNCTION**
   Presenter: Simon Conway

8. **EXPERIENCES AND DECISION-MAKING OF X-LINKED HETEROZYGOTES ON IVF FOR PGT-M**
   Presenter: Rachel Denham

Poster Presenters
Continued

9 **DIFFERENTIAL MODULATION OF CARDIOLIPIN CONTENT VERSUS COMPOSITION BY CANNABIDIOL IN B-LYMPHOBLASTOID CELLS AND RELATED OUTCOMES**
Presenter: Robin Duncan

10 **USING PATIENT-INPUTTED REGISTRY DATA TO UNDERSTAND BARTH SYNDROME MANIFESTATIONS, NATURAL HISTORY, & SURVIVAL**
Presenter: Melissa Huang

11 **USING MRI TO DETECT AND MONITOR BARTH SYNDROME INDUCED SKELETAL MYOPATHY**
Presenter: Sameh Nabil Kamil Khalil

12 **CARDIOLIPIN REGULATES RETINOIC ACID SIGNALING – IMPLICATIONS FOR BARTH SYNDROME**
Presenter: Vikalp Kumar

13 **PARTICIPATION OF CHILDREN WITH BARTH SYNDROME IN EVERYDAY ACTIVITIES ACROSS HOME, SCHOOL, AND COMMUNITY**
Presenter: Yoonjeong Lim

14 **PARENTS' PERSPECTIVES ON EVERYDAY PARTICIPATION OF CHILDREN WITH BARTH SYNDROME: A QUALITATIVE STUDY**
Presenter: Yoonjeong Lim

15 **RESPIRATORY MYOPATHY AND BREATHING ABNORMALITIES IN BARTH SYNDROME: A FORGOTTEN PUMP**
Presenter: Vini Mariani

16 **IDENTIFICATION AND TARGETING OF ABHD18 AS A STRATEGY TO ALLEVIATE TAZ MUTANT PHENOTYPES**
Presenter: Sanna Masud

17 **CARDIAC ECHOGENIC FOCI AND INTRAUTERINE GROWTH RETARD IN A MALE FETUS AS PRENATAL MANIFESTATIONS OF BARTH SYNDROME**
Presenter: Emanuele Micaglio

Poster Presenters
Continued

18 **EFFECT OF GENETIC MODIFIERS ON BARTH SYNDROME PHENOTYPES IN TAZ KNOCKOUT MICE**
Presenter: Chaehyoung Park

19 **ENZYME REPLACEMENT THERAPY ALLEVIATES DEFECTS IN CARDIOLIPIN REMODELING, MITOCHONDRIAL FUNCTION AND HEART FUNCTION IN A MOUSE MODEL OF BARTH SYNDROME**
Presenter: Raghav Rahul

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Presenter: Justina Thomas

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Presenter: Michelle Tomczewski

26 **MODELING CROSSTALK BETWEEN MITOCHONDRIA AND THE EXTRACELLULAR MATRIX IN BARTH SYNDROME USING 3D BIOENGINEERED MUSCLE TISSUES**
Presenter: Sree Venigalla

27 **ADVANCING RARE DISEASE RESEARCH THROUGH METABOLOMICS**
Presenter: Micaiah Ward

Camp Barth | 0-6 years

GREAT EGRET

Select events Monday thru Wednesday,
Please see Session Schedule

FULL-DAY CARE*
Thursday, July 23th
8:30 AM – 5:00 PM

Friday, July 24th
8:30 - 3:30 PM

*Please pick your child up for lunch both days. See schedule below.

ACTIVITIES

- Barth Bunny Clinic
- Activity Room
- Touch a Truck Firetruck Visit

FULL DAY SCHEDULES

THURSDAY, JULY 23TH
Check-In: 8:30 AM - 9:00 AM
Lunch Pick-Up: 12:15 PM
After Lunch Drop-Off: 2:00 PM - 2:15 PM
End of Day Pick-Up: 4:30 PM - 5:00 PM

FRIDAY, JULY 24TH
Check-In: 8:30 AM - 9:00 AM
Lunch Pick-Up: 12:00 PM
After Lunch Drop-Off: 1:15 PM - 1:30 PM
End of Day Pick-Up: 3:00 PM - 3:30 PM

PICK-UP POLICY
Guardians must show their ID to pick up their camper, and the person must be listed on the authorized pick-up form. Campers are not allowed to leave until check out by an authorized guardian.

Camp Barth | 7 - 17 years

Blue Heron

Select Events
Monday thru Wednesday, Please see Session Schedule

FULL-DAY CARE*
Thursday, July 23th
8:30 AM – 5:00 PM
*Please pick your child up for lunch on Thursday. See schedule below.

Friday, July 24th
8:30 - 3:30 PM

ACTIVITIES

- Science Fun
- Video Game Truck
- Sing Your Heart Out Karaoke
- Swim, Splash, & Slide at the Waterpark
- Poolside Pizza Party (Friday)

FULL DAY SCHEDULES

THURSDAY, JULY 23TH
Check-In: 8:30 AM - 9:00 AM
Lunch Pick-Up: 12:15
After Lunch Drop-Off: 2:00 PM - 2:15 PM
Thursday End of Day Pick-Up 4:30 PM - 5:00 PM

FRIDAY, JULY 24TH
Check-In: 8:30 AM - 9:00 AM
Friday End of Day Pick-Up 3:00 - 3:30 PM
*Pick-up at Pool
Children will be having lunch by the pool with Camp Barth on Friday. You do not need to pick them up for a lunch break.

PICK-UP POLICY
Guardians must show their ID to pick up their camper, and the person must be listed on the authorized pick-up form. Campers are not allowed to leave until check out by an authorized guardian.

Session Schedule

Monday, July 20

Please refer to the Conference app for the latest schedule.

8:00 AM

- **New Family Orientation**
  Great Egret ABC · 8:00 – 9:00

- **Welcome Event and Breakfast (All Welcome)**
  Calusa D–F · 9:00 – 10:45

10:00 AM

- **Info Session & Consent for Research**
  Calusa D–F · 11:00 – 12:00
- **Science Fun with Becky, Ages 7–12**
  Blue Heron A · 11:00 – 12:00
- **Barth Bunny Clinic, Ages 2–6**
  Ibis · 11:00 – 12:00

Noon

- **Adults with Barth Luncheon, Ages 21+**
  Driftwood · 12:00 – 1:30
- **Discussion Group AI,* Ages 8–12**
  Blue Heron A · 1:00 – 1:45
- **Discussion Group AI,* Ages 13–17**
  Blue Heron B · 1:00 – 1:45
- **Potential Carriers, Ages 11–14**
  Blue Heron C · 1:00 – 1:45
- **On-site Research**
  By Assignment
  1:00 – 6:00

2:00 PM

- **Discussion Group AI,* Ages 18–25**
  Blue Heron B · 1:45 – 2:30
- **Parents Discussion, Ages 12–17**
  Blue Heron C · 1:45 – 2:30
- **Activity Room Open, Ages 2–12**
  Ibis · 1:30 – 3:30
- **Parents Discussion, Ages 0–5**
  Blue Heron B · 2:45 – 3:30
- **Parents Discussion, Ages 6–11**
  Blue Heron A · 2:45 – 3:30
- **Parents Discussion, Ages 18–25**
  Blue Heron C · 2:45 – 3:30

4:00 PM

- **CPR and AED Training Program**
  Calusa D–H · 3:30 – 4:30
- **Small Group Leads Meeting**
  Blue Heron C · 3:45 – 4:30

EVENING

- **Painting with Brie**
  Ibis · 7:00 – 8:30

*AI = Affected individuals

All Attendees | Family Education | Wellness | Research & Development | Camp Barth | On-site Research

Session Schedule

Tuesday, July 21

Please refer to the Conference app for the latest schedule.

8:00 AM

- **Parents Discussion, Ages 26+** — Great Egret ABC · 8:00 – 9:00
- **On-site Research** — By Assignment, 8:00 – 12:00

10:00 AM

- **Moms Sessions** — Blue Heron ABC, 9:15 – 10:45
- **Dads Sessions** — Great Egret ABC, 9:15 – 10:45
- **Activity Room Open, Ages 2-12** — Ibis · 9:00 – 11:00
- **Carrier: Non-Carrier Adults** — Blue Heron ABC · 11:00 – 12:00
- **Young Relatives, Ages 8-12** — Great Egret A · 11:00 – 11:45
- **Young Relatives, Ages 13-17** — Great Egret C · 11:00 – 11:45

Noon

- **Carrier: Adult Carriers** — Blue Heron ABC · 1:00 – 2:00
- **Discussion AI*, Ages 8-12** — Great Egret A · 1:00 – 1:45
- **Discussion AI*, Ages 18-25** — Great Egret C · 1:00 – 1:45
- **On-site Research** — By Assignment, 1:00 – 6:00

2:00 PM

- **Discussion AI*, Ages 13-17** — Great Egret A · 2:00 – 2:45
- **Discussion AI*, Ages 26+** — Great Egret C · 2:00 – 2:45
- **Music Play** — Ibis · 2:00 – 3:15
- **Session Leads Touchpoint** — Blue Heron C · 3:30 – 4:15

4:00 PM

- **Intro to Yoga for AI*** — Estero C · 4:15 – 4:45
- **Intro to Yoga (All)** — Estero C · 4:45 – 5:15

EVENING

- **Board of Directors Dinner** ✦ — Tarpon Bay, 5:30 – 8:30
- **Painting with Brie** — Ibis · 7:00 – 8:30
- **Adults with Barth Meet Up, Ages 21+** — Belvedere Terrace, 8:30 – 11:00

✦ This session is invite only

*AI = Affected individuals

All Attendees | Family Education | Wellness | Research & Development | Camp Barth | On-site Research

Session Schedule

Wednesday, July 22

Please refer to the Conference app for the latest schedule.

8:00 AM

- **On-site Research**
  By Assignment
  8:00 – 12:00
- **Centers of Expertise Breakfast**
  Sanibel A–B
  8:00 – 10:00

10:00 AM

- **Carrier Daughters, Ages 15+**
  Blue Heron A · 10:00 – 10:45
- **Relationships: Partners**
  Blue Heron B
  9:45 – 10:45
- **Relationships: AI***
  Blue Heron C
  9:45 – 10:45
- **Potential Carriers, Ages 15+**
  Blue Heron A · 11:00 – 11:45
- **Affiliate Meeting**
  Sanibel A–B
  10:30 – 12:00

Noon

- **Grannies & Aunties**
  Blue Heron A · 12:45 – 1:30
- **Science Meet & Greet**
  Calusa Pre-Function · 1:30 – 2:00
- **Session Leads Touchpoint**
  Blue Heron C · 1:45 – 2:30
- **On-site Research**
  By Assignment
  1:00–6:00

2:00 PM

- **Science Speed Dating**
  Calusa D–H · 2:00 – 3:00
- **Ask the AI***
  Calusa D–H · 3:00 – 4:00
- **Animal Encounters with Wonder Gardens**
  Ibis · 2:00 – 4:00

4:00 PM

- **Mighty Therapeutics Update (SciMed)**
  Calusa D–H · 4:15 – 5:00
- **Yoga**
  Estero C · 4:00 – 5:00

EVENING

- **Poster Blitz & Session**
  Calusa D–H, Calusa Prefunction
  5:00 – 8:00
- **Grandparents Meet Up**
  Lobby · 6:00 – 7:00
- **Parents of Adults with Barth Meet Up**
  Belvedere Terrace
  7:00 – 9:00

This session is invite only

This session is SciMed only

*AI = Affected individuals

Conference Sponsor Session

All Attendees | Family Education | Wellness | Research & Development | Camp Barth | On-site Research

Session Schedule

Thursday, July 23

Please refer to the Conference app for the latest schedule.

Breakfast: Calusa D–H · 7:00 – 9:00

8:00 AM

Care Management Sessions
8:45 – 12:15
Parents of Ages 0–5 — Sanibel A
Parents of 6–11 — Sanibel B
Parents of 12–17 — Captiva A
Parents of 18+ — Captiva B
Barth AIs* and Partners — Pine A

Platform Talks 1A: Basic Biology of Barth
Calusa A–C
8:30 – 10:00

Camp Barth, Ages 0–6
Great Egret ABC
8:30 – 5:00
Lunch break: 12:15
See Camp Barth page for schedule.

Camp Barth, Ages 6–17
Blue Heron ABC
8:30 – 5:00
Lunch break: 12:15
See Camp Barth page for schedule.

10:00 AM

Research Spotlights 1B: Basic Biology of Barth
Calusa ABC
10:30 – 12:20

Noon

Lunch
Calusa D–H · 12:15 – 1:15

Varner Award and Keynote Address
Calusa D–H · 1:15 – 2:00

2:00 PM

Platform Talks 2A: Emerging Therapies
Calusa ABC
2:00 – 3:45

Siblings, Ages 13+
Captiva A
2:00 – 3:00

Group Photo
Calusa D–H
3:30 – 4:30

4:00 PM

Research 2B: Clinical Outcomes
Calusa ABC
4:00 – 5:45

Dads Sessions
Sanibel A–B
4:00 – 5:00

EVENING

Yoga
Estero C
5:00 – 6:00

Luminaries
Calusa D–H
7:30 – 8:00

Luminaries is a special opportunity to honor everyone who has ever lived with Barth syndrome.

Refreshments
Calusa Prefunction
8:00 – 9:00

SciMed Gathering
Driftwood
8:00 – 9:00

Adult Siblings Meet Up, Ages 21+
Belvedere Terrace
8:00 – 10:00

*AI = Affected individuals

All Attendees | Family Education | Wellness | Research & Development | Camp Barth | On-site Research

Session Schedule

Friday, July 24

Please refer to the Conference app for the latest schedule.

Breakfast: Calusa D–H · 7:00 – 9:00

8:00 AM

Plenary 1: Drug Approval
Calusa ABC
8:00 – 9:15

Arrhythmia Study Holter Placement
By Appointment

Camp Barth, Ages 0–6
Great Egret ABC
8:30 – 3:30
Lunch break: 12:15
See Camp Barth page for schedule.

Camp Barth, Ages 6–17
Blue Heron ABC
8:30 – 3:30

Plenary 2: Novel Therapeutics
Calusa ABC
9:25 – 10:45

10:00 AM

Plenary 3: Regulatory Considerations
Calusa ABC · 10:55 – 12:00

Noon

Lunch
Calusa D–H · 12:00 – 1:15

Small Group Leads Touchpoint
Driftwood · 1:15 – 2:00

Poster Session (Families Only)
Calusa Prefunction
1:15 – 2:15

2:00 PM

Platform Talks 3A: Novel Research Tools
Calusa A–C
2:15 – 3:45

Mighty Therapeutics Update (For Families)
Calusa D–H · 2:15 – 3:15

Build a Boat Parade & Race
Waterfall Pool
3:45 – 4:45

4:00 PM

Research 3B: Emerging Therapies
Calusa A–C · 4:00 – 5:45

Yoga
Estero C
4:45 – 5:45

EVENING

SciMed Conference Wrap Up
Calusa ABC · 5:45 – 7:00

Friday Night Social (All Welcome)
Calusa D–H · 7:00 – 10:00

This session is SciMed only

Conference Sponsor Session

Friday Camp Barth Note

Camp Hyatt (Ages 7+): Poolside Pizza Party on Friday — no pickup needed.
Camp Barth (Ages 0–6): Lunch pickup required from 12:30 – 12:45 , with drop-off again from 1:00 – 1:15.

All Attendees | Family Education | Wellness | Research & Development | Camp Barth | On-site Research

Session Schedule

Saturday, July 25

Please refer to the Conference app for the latest schedule.

8:00 AM

Scientific & Medical Advisory Board Breakfast
Driftwood
8:00 – 10:00

Care Management Working Group
Pine C · 8:00 – 9:00

Arrhythmia Study Holter Placement
By Appointment

Breakfast
Calusa D–H
9:00 – 10:30

10:00 AM

Conference Finale (All Welcome)
Calusa D–H
10:30– 11:30

This session is invite only

All Attendees | Family Education | Wellness | Research & Development | Camp Barth | On-site Research

Barth Syndrome Affiliates

Thank you to our International Barth Syndrome affiliates for their generous contributions of time and financial support.

BARTH SYNDROME FOUNDATION OF CANADA

BARTH SYNDROME UK

ASSOCIATION SYNDROME DE BARTH FRANCE

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BARTH SYNDROME CONFERENCE 2026

Code of Conduct for Barth Syndrome International Scientific, Medical, and Family Conference

The Barth Syndrome International Scientific, Medical and Family Conference brings together families, researchers, clinicians, and advocates united by a single purpose: ending the suffering caused by Barth syndrome. That shared mission is our greatest strength, and maintaining a safe, welcoming, and productive environment for our community is our shared responsibility.

Our Expectations

Our community is built on credibility, integrity, and compassion. We ask all attendees to bring those same values into every interaction at Conference. Specifically, attendees agree to:

- Treat all participants — families, clinicians, researchers, staff, and volunteers — with respect and
- courtesy
- Honor the boundaries and privacy of speakers and fellow attendees
- Comply with the rules and policies of the event venue
- Engage online participants with the same respect extended to those in the room

Unacceptable Behavior

The following will not be tolerated at Conference:

- Harassment, intimidation, or discrimination in any form
- Verbal abuse or sexual harassment of any kind
- Use of sexual, vulgar, or discriminatory language or imagery in presentations or discussions

Reporting a Concern

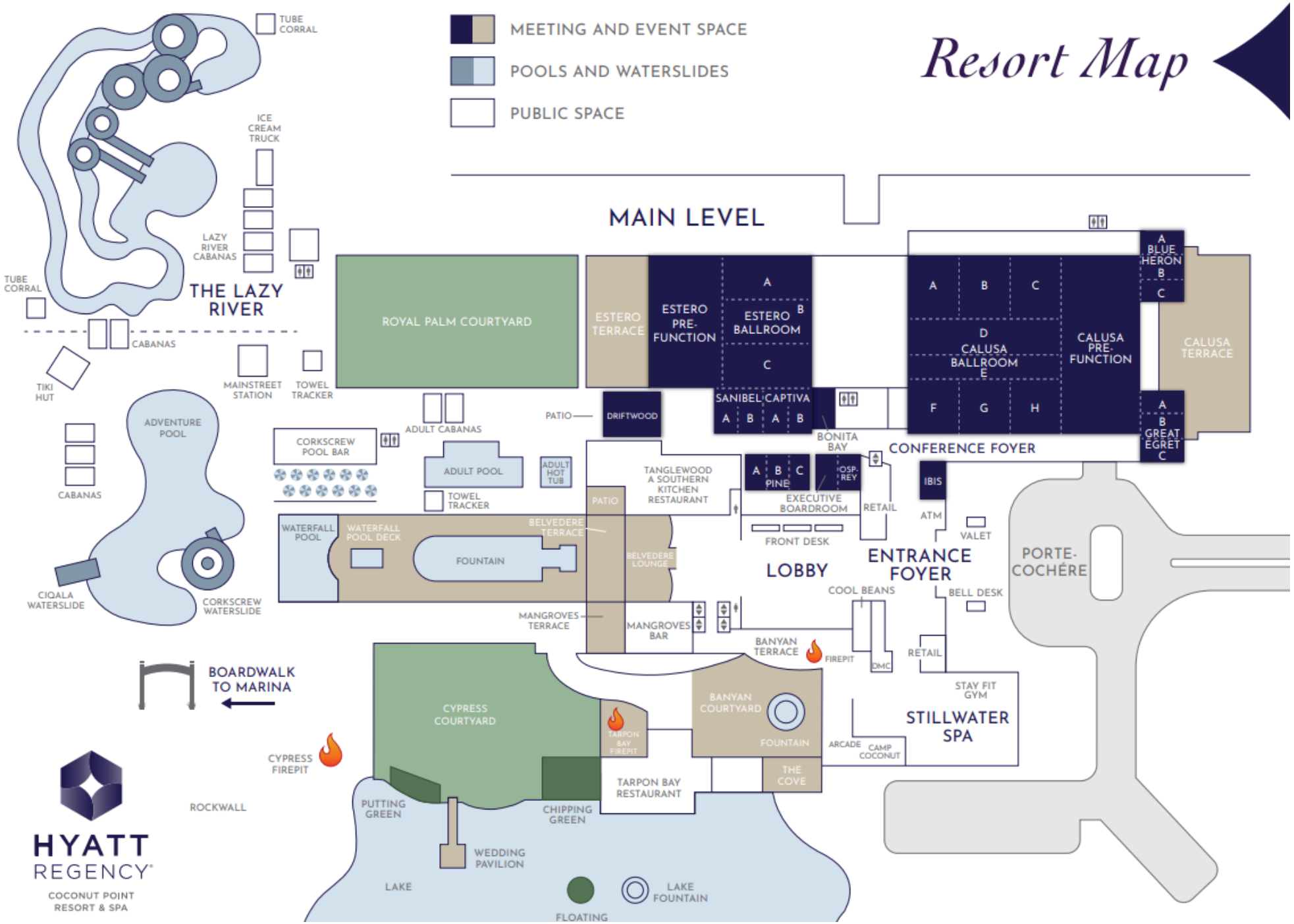
If you experience or witness behavior that violates this Code of Conduct, please alert a BSF staff member immediately. After the conference, you may report an incident by contacting general@barthsyndrome.org.

BSF will handle all reports with discretion and privacy.

Consequences

This Code of Conduct applies to all attendees and participants. BSF reserves the right to ask any individual to leave the conference if this Code is not being followed. No refunds will be issued, and the individual may be barred from future Barth Syndrome International Conferences and Barth Syndrome Foundation events.

Resort Map


MEETING AND EVENT SPACE
POOLS AND WATERSLIDES
PUBLIC SPACE
MAIN LEVEL
TUBE CORRAL
ICE CREAM TRUCK
LAZY RIVER CABANAS
THE LAZY RIVER
TUBE CORRAL
CABANAS
TIKI HUT
MAINSTREET STATION
TOWEL TRACKER
ROYAL PALM COURTYARD
ESTERO TERRACE
ESTERO PRE-FUNCTION
ESTERO BALLROOM
A
B
C
SANIBEL CAPTIVA
A B A B
DRIFTWOOD
PATIO
ADULT CABANAS
CORKSCREW POOL BAR
ADULT POOL
ADULT HOT TUB
TOWEL TRACKER
ADVENTURE POOL
CABANAS
CIQALA WATERSLIDE
CORKSCREW WATERSLIDE
WATERFALL POOL
WATERFALL POOL DECK
FOUNTAIN
BELVEDERE TERRACE
BELVEDERE LOUNGE
PATIO
TANGLEWOOD A SOUTHERN KITCHEN RESTAURANT
A B C PINE
OSPREY
EXECUTIVE BOARDROOM
RETAIL
FRONT DESK
LOBBY
ENTRANCE FOYER
IBIS
ATM
VALET
PORTE-COCHÈRE
BONITA BAY
CONFERENCE FOYER
A B C
D CALUSA BALLROOM E
F G H
CALUSA PRE-FUNCTION
A BLUE HERON B C
A B GREAT EGRET C
CALUSA TERRACE
MANGROVES TERRACE
MANGROVES BAR
COOL BEANS
BELL DESK
BANYAN TERRACE
FIREPIT
DMC
RETAIL
STAY FIT GYM
STILLWATER SPA
BOARDWALK TO MARINA
CYPRESS COURTYARD
TARPON BAY FIREPIT
BANYAN COURTYARD
FOUNTAIN
ARCADE
CAMP COCONUT
THE COVE
CYPRESS FIREPIT
TARPON BAY RESTAURANT
ROCKWALL
PUTTING GREEN
CHIPPING GREEN
WEDDING PAVILION
LAKE
LAKE FOUNTAIN
FLOATING
HYATT REGENCY
COCONUT POINT RESORT & SPA

Thank you!!!

Conference is only possible because of our community. Thank you for your support – in every shape and size.

Community Sponsors

Community Sponsorships are a meaningful way for families, loved ones, and supporters to be part of this special week. Each contribution – from coffee breaks to our social decorations – helps create a welcoming and connected experience for our entire community.

Lynn Anderson
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The Grzesiak Family
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Community Partners

Golisano Children's Hospital LEE HEALTH

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Everyone who donated through our dedicated Conference and Travel Fund campaigns!

Patching Together

All Heart

2026 Conference

Conference Volunteers who are dedicating their time and energy to making this week special!

THE NEXT ERA

Stealth BIOTHERAPEUTICS

WILL BECOME:

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A new name for what's now possible in mitochondrial medicine!

For years, we've worked side by side with this community—advancing science, building understanding, and pioneering the first FDA-approved therapy to directly target mitochondria.

We will move forward as Mighty Therapeutics. This name reflects the resilience of the people we serve and our commitment to expanding what's possible.

The future is Mighty!

Visit our table to learn more, and scan the QR code to explore our website.

MAT-0058-1 05/2026

Do You Have Chronic Neutropenia?

4WARD
A CHRONIC NEUTROPENIA STUDY

About the study

Chronic neutropenia is a rare blood disorder marked by having a low number of neutrophils, a type of white blood cell.*

Mavorixafor, the investigative study medicine, is a capsule taken by mouth.

The study will evaluate if mavorixafor, the investigative study medicine:

- May increase neutrophil cell counts
- May decrease the chance of getting infections
- Is safe and well tolerated

You may be eligible to join the study if you:

- Are age 12 and older
- Are diagnosed with chronic neutropenia (including congenital, acquired primary autoimmune and idiopathic chronic neutropenia)
- Are taking or not taking any treatment for your chronic neutropenia, including granulocyte colony-stimulating factor (G-CSF)
- Meet other study requirements. Talk to your doctor to find out if this study is an option for you.

*Reference: Donadieu J, et al. Chronic neutropenia: how best to assess severity and approach management? Expert Review of Hematology. 2021 Oct;14(10):945-960.

What does the study involve?

Duration:
This study will last about 12 months.

Cost:
Study-related treatments and procedures are provided at no cost to participants. If needed and approved, travel, lodging and meals will be reimbursed by the study sponsor, X4 Pharmaceuticals.

Study sponsor:
X4 Pharmaceuticals is conducting the study.

Why take part?

- Chronic neutropenia is a disease with few treatment options. More treatment options are needed.
- Clinical studies are needed to make sure a medicine is safe and works before it is approved for use by the FDA.

Visit 4WARDStudy.com
ClinicalTrials.gov and search for NCT06056297

Email
clinicaltrialinfo@x4pharma.com

Call
857-321-8332

anovo

Your Journey. Our Commitment.

Living with Barth Syndrome comes with unique challenges. At Anovo, we're committed to making access to care simpler, smoother, and more personal.

As proud supporters of the Barth Syndrome Foundation Conference, we're dedicated to breaking down barriers, providing expert support, and being a trusted partner throughout your care journey.

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Notes

Notes

Notes

Emergency Information

CALL 911 IMMEDIATELY

Four key pieces of information for your dispatcher:

- Exact location: hotel address and your location in the hotel
- Nature of emergency
- STARS #2000: the code set up with county dispatch to ensure first responders have critical Barth-specific information
- Your name and phone number

Locations: Automated External Defibrillator (AED)

- Security Office 239-390-4367
- Corkscrew Bar, Poolside
- Stillwater Spa
- Hyatt Learning Center, 2nd floor, next to employee cafeteria
- 9th Floor of Hotel (Housekeeping Linen Closet)

You are at the
Hyatt Regency Coconut Point
5001 Coconut Rd.
Bonita Springs, FL 34134

*I am at **the Hyatt Regency Coconut Point, 5001 Coconut Road, Bonita Springs. We are in the front lobby of the hotel.** A young man is clammy and having a hard time responding to questions. **They have Barth syndrome, the code is STARS #2000.** My name is Lois Lane and my phone number is 555-555-5555. I will wait here for first responders.*