



BIENNIAL INTERNATIONAL SCIENTIFIC, MEDICAL & FAMILY CONFERENCE



2024

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



What To Expect



EDUCATION

Learn about the latest to help improve health outcomes in the Barth syndrome 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 Barth syndrome.

COLLABORATION

Convene largest group of world-renowned experts in Barth syndrome 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.

MULTI-TRACK EVENT

The 2024 BSF Conference will provide five tracks to cater to the requirements and preferences of our diverse network of healthcare providers, researchers, caregivers and affected individuals. In addition, for the first time, Continuing Medical Education (CME) credits will be offered for educational sessions related to Barth syndrome.



DISCLAIMER



Sessions with clinicians, healthcare providers, and volunteers 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 peers and/or professionals familiar with Barth syndrome who are volunteering their time. **It is important to note that, unless otherwise explicitly stated, these interactions DO NOT establish a provider-patient relationship nor can be considered official clinical appointments.** 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).



Network: Hyatt_Meeting
Passcode: foundation2024



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ATTENDEE HUB

Download the event app for a more inter-active conference experience.

iOS



Android



ATTENDEE IDENTIFIERS



BSF Staff & Volunteers



Families



Healthcare Providers



Scientists

Welcome Letter from our Executive Director

Dear 2024 Barth Syndrome International Scientific, Medical, and Family Conference Attendees,

We are thrilled to welcome each of you to this momentous event, marking our first in-person international gathering in six years. The Barth syndrome community eagerly anticipates this reunion after enduring the challenges of the global pandemic. Since our inception in 2000, the Barth Syndrome Foundation (BSF) has provided unwavering support, pioneering standards of care and diagnosis, encouraging therapy development, and fostering collaborative partnerships among clinicians, researchers, and patients.

The essence of our conference lies in bringing together diverse stakeholders to advance Barth syndrome research and reinforce our dedication to affected individuals and the community. With multiple tracks tailored to healthcare providers, researchers, caregivers, and affected individuals, this event promises to foster collaboration and innovation within the field. Our program, developed by dedicated volunteers and supported by generous sponsors, features esteemed speakers, valuable presentations, and networking opportunities. For the first time, we proudly offer Continuing Medical Education (CME) credits to recognize the contributions of healthcare professionals.

BSF and our affiliates in Canada, France, Italy, and the United Kingdom firmly believe in the exponential impact of our collaborative efforts. While we each make strides in our respective spheres, our collective strength is unparalleled. The conference is a testament to the power of our global community, and we are grateful to support those diagnosed with Barth syndrome and their families. I eagerly anticipate our time together and the exchange of ideas and experiences that will undoubtedly enrich our shared journey. May this conference inspire and empower you to continue your invaluable contributions to the Barth syndrome community.

With hope and gratitude,



Emily Milligan
Executive Director, Barth Syndrome Foundation



Conference Steering Committee

Michael Bowen
Barth Syndrome Foundation

Shelley Bowen
Barth Syndrome Foundation

Michaela Damin
Barth Syndrome UK

Christiane Hope
Barth Syndrome Foundation of Canada

Melissa Huang, PhD
Barth Syndrome Foundation

Lindsay Marjoram, PhD
Barth Syndrome Foundation

Emily Milligan
Barth Syndrome Foundation

Kevin Woodward
Barth Syndrome Foundation

Scientific and Medical Steering Committee

Michael Schlame, MD (Chair)
New York University School of Medicine

Jan Dudek, PhD
University Clinic Würzburg

Robin Duncan, PhD
University of Waterloo

Melissa Huang, PhD
Barth Syndrome Foundation

John Jefferies, MD, MPH
University of Memphis

Christina Pacak, PhD
University of Minnesota

Ronald J. A. Wanders, PhD
University of Amsterdam

BSF Board of Directors

Katherine R. McCurdy
Chair

James Baffa

Megan Branagh

Brandi Dague

Bruce J. Develle

Michelle Florez

Miriam Greenberg, PhD

Mark Greene

Emily Milligan
ex-officio

Jonathan Stokes

Nina Russell, MD

Peter van Loo

What does the conference mean to you...



"I always find myself at a loss of words when asked to describe the conference. I guess the only way to explain the conference is to say you just have to come to understand it and after that you know, you just know and you will never forget it." - Shelley Bowen



"I have attended every Scientific and Medical Conference on Barth syndrome since the Foundation was established. It is impossible to overstate the impact of this biennial meeting on my research. The unique opportunity to interact not only with other scientists but also with affected individuals and clinicians is highly motivating. We have initiated many collaborations at these meetings, and discussions of unpublished studies have greatly advanced the pace of our research." - Dr. Mariam Greenberg



"When I am at the BSF conference (I've been to every one) it feels like a giant family reunion. There are people there who have also been to every BSF conference and there are people there who have never been to a BSF conference. It does not matter. We immediately become family. There is a bond like no other between every family who is affected by Barth syndrome. BSF conferences are a life changing event...every time we attend." - Sue Wilkins



I'm excited to share with new families that sense of hope is real. New families will say to themselves; so it's real, there is hope! I clearly can remember that feeling which changed our lives. I wish every new family can realize that." - Paola Cazzaniga



Leave us a note



Camp Barth & Youth Activities

While some sessions may be heavier content-wise for children of a specific age group, we encourage both parents to attend sessions together if they wish, with their child supervised in our activity room.

Our Camp Barth Program offers a range of engaging, child-friendly activities, overseen by professional childcare providers. *Children must be potty trained to participate in activities on Monday & Wednesday.*

Youth Activity Room

Monday, July 29

11:00am - 12:00pm Youth Activity (ages 2-12) | Location: Ibis

2:45pm - 3:30pm Youth Activity (ages 2-12) | Location: Ibis

Wednesday, July 31

9:00am - 11:00am Youth Activity | Location: Ibis

& Camp Barth Registration Opens

2:00pm - 3:30pm Youth Activity (ages 2-12) | Location: Ibis



Camp Barth

Corporate Kids Events (CKE) and Hyatt Camp Coconut are the preferred childcare providers during Thursday and Friday educational programming.

Thursday, August 1 - Camp Day 1

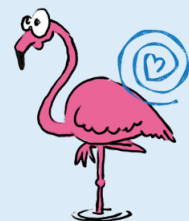
8:30am - 4:30pm Camp Barth for Ages 7-15 | Location: Ibis
& Camp Barth/CKE for Ages 0-6 | Location: Great Egret ABC

10:00am - 10:45am Science Fun with Becky | Location: Estero A

Friday, August 2 - Camp Day 2

8:45am - 1:00pm Camp Barth for Ages 7-15 | Location: Ibis
& Camp Barth/CKE for Ages 0-6 | Location: Great Egret ABC

3:00pm - 4:00pm Build a Boat Race (All Welcome)



On-Site Research & Clinics

The Barth Syndrome International Conference is the largest in-person gathering of affected individuals worldwide. There are many benefits to this gathering including community building and the sharing of scientific knowledge. One additional benefit is that scientists passionate about Barth syndrome can conduct in-person studies, also known as on-site research. 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 the conference has 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.

IMPORTANT NOTE: We will make every effort for studies involving blood collection to be done via a SINGLE blood draw; no more than 2 teaspoons per person will be collected.

Participation in Everyday Activities of Adults and Children with Barth Syndrome

Investigators: Yoonjeong Lim, PhD,OTR/L; Areum Han, PhD, OTR/L
Binghamton University

Open to individuals in the following groups:

- Parents of children diagnosed with Barth syndrome (aged between 8 and 12)
- Parents of children diagnosed with Barth syndrome (aged between 13 and 17)
- Adults diagnosed with Barth syndrome (aged between 18 and 25)
- Adults diagnosed with Barth syndrome (aged 26 or above)

Exclusion criteria: Non-English-speaking individuals, individuals with severe comorbid physical disabilities (e.g., cerebral palsy)

Summary: Participants will complete an online questionnaire during the conference (~40 minutes) and schedule an individual Zoom interview after the conference, at a time convenient for the participant. As compensation, participants will receive a \$80 electronic gift card upon completing the online survey and an individual interview.

Longitudinal Evaluation of Cardiomyopathy and Outcome in Barth Syndrome

Investigators: Carolyn Taylor, MD; Tammy Churchill, RDCS; Kristie Sanders, RDCS
Medical University of South Carolina

Open to individuals diagnosed with Barth syndrome.

Summary: Participation involves having an echocardiogram and electrocardiogram performed at the conference and the completion of a brief medical survey and obtaining vitals.

On-Site Research & Clinics Continued



Profiling of Monolysocardiolipins and Cardiolipins from Blood

Investigators: Akhilesh Pandey, MD, PhD; Seul Kee Byeon, PhD
Mayo Clinic

Open to individuals in the following groups:

- Those diagnosed with Barth syndrome by a doctor or through genetic testing
- Those who are healthy relatives of Barth syndrome-affected individuals (including unaffected relatives or carriers of Barth syndrome)
- Those who are healthy non-relatives of Barth syndrome-affected individuals
- Those who are English-speaking children or adults

Summary: Participation involves a one-time blood sample collection (< 2mL) with a blood draw during the conference. The blood sample will be used to explore and identify various ratios of monolysocardiolipin/cardiolipin species that can be utilized as additional biomarkers to enhance the diagnosis of Barth syndrome.

Barth Syndrome Registry and Repository

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

Open to individuals diagnosed with Barth syndrome.

Summary: Participation involves completing a series of online questionnaires related to Barth syndrome and obtaining biometric information like your height, weight, and vitals. An optional blood sample may also be obtained.

Longitudinal Strength and 6 MWT Performance in Barth Syndrome

Investigators: Hilary Vernon, MD, PhD; Brittany Hornby, PT, DPT, PCS; Rebecca McClellan, MCG, CGC
Kennedy Krieger Institute and Johns Hopkins University

Participation is by invitation only. Only those who have participated in a prior study by the investigators are eligible to participate.

Summary: Participation involves testing muscle strength and fatigue using a variety of tests. This includes using a small hand-held device to measure the strength with which you push or pull, grip strength testing, assessment of motion reaction, sit to stand test, and a brief questionnaire. A 6-minute walk test will also be performed, in which heart rate and blood oxygen saturation will be measured.

On-Site Research & Clinics

Continued

Understanding the Barth Syndrome Patient Journey and Burden of Disease for Affected Individuals

Sponsor: Stealth BioTherapeutics

Open to individuals in the following groups based in the United States

- Those diagnosed with Barth syndrome by a doctor or through genetic testing
- Those who are family members of Barth-affected individuals
- Those who are English-speaking children or adults

The group size will be limited to 6-10 participants.

Summary: Participation may involve a pre-meeting online questionnaire related to Barth syndrome and lived experience as well as a 60-90 minute facilitated discussion related to burden of disease, healthcare utilization, and diagnostic odyssey, among other topics.

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

Investigators: Reina Tan, MD; Colin Phoon, MD; Alekya Kaveti
New York University Langone Health

Open to individuals in the following groups based in the United States:

- 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 your doctor. You will also be asked to answer some questionnaires and learn how to use wearable heart monitor (will be mailed to you to be worn when you are back at home).

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



On-Site Research & Clinics

Continued



Pill Swallowing Clinic

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 (BTSH), pill swallowing may be necessary at an earlier age for managing symptoms of BTSH 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 medications 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 two prior conferences (2016 and 2018) and had great success with all ages (5yr- 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.

Family Portraits with Matt Steeves



We realize scheduling an appointment for family photos on top of doctor appointments, hospitalizations and school activities doesn't always happen. We also realize that it is very important to our families which is why we offer this opportunity during the conference. Matt will send copies of all photos to BSF after the conference at which time will share a link where you can download images of your family at no cost. As a sneak peak, your photos will be included in the finale slideshow.

2024 Recipient of the Varner Award for Pioneer in Science and Medicine

On behalf of the Barth Syndrome Foundation's Board of Directors, we are pleased to announce that Dr. Ronald Wanders has been selected as the 2024 recipient of the Varner Pioneer in Science and Medicine Award. The Varner Pioneer in Science and Medicine Award is the most esteemed honor in our foundation, and Dr. Wanders' record of achievement reflects the exceptional quality of research, teaching, and service to the Barth syndrome community. His dedication and commitment to advancing scientific knowledge, serving on BSF's Scientific and Medical Advisory Board, and inspiring the subsequent generation of researchers is truly commendable.



This award is generously supported through the Wilkins family and was established in 2008 in loving memory of Paula and Woody Varner, maternal grandparents to John Wilkins. The Varner's embodied the same characteristics that the Barth Syndrome Foundation admires and values in research: persistence, commitment, honor, integrity, and humility. The award was established to recognize those who have fostered innovation and excellence in biomedical research and celebrates scientists for their significant contributions to the field of Barth syndrome research in order to build a brighter future for people with this genetic disease.

As the recipient of this award, Dr. Wanders joins a distinguished group of individuals who have made remarkable contributions to the central tenets of the Barth Syndrome Foundation's mission to advance treatments, enhancing the quality of life and/or improve the standards of care for those with Barth syndrome.

The Barth Syndrome Foundation and the Board of Directors express their sincere appreciation for Dr. Wanders's contributions to Barth syndrome research. Please join us in celebrating Dr. Wanders for the presentation of the award on Thursday August 1, 2024, at the Biennial International Scientific, Medical and Family Conference on Barth syndrome in Bonita Springs, Florida.

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



STARS #2000

In the event of a health emergency during the conference, please call 911 and tell the dispatcher "STARS #2000". This will trigger the dispatcher to send out the care plan about Barth syndrome to the first responders.



Schedule of Events

Day 1 Monday, July 29

8:00am	New Family Orientation - 1 hour For new attendees: meet each other and find out more about the hotel, surroundings and what to expect of the week ahead. Let us know how we can help you make the most of this special week together! Location: Calusa A-E
9:00am	Welcome Event & Breakfast (All Welcome) - 2 hours Family introductions, slideshow and information about the week ahead. Meal provided. Location: Calusa A-E
9:00am	Portrait Photography with Matt Steeves - 6 hours by appointment only. Appointment slots will be emailed to you individually. Location: Sanibel A
11:00am	Activity Room for Youth Activities - 1 hour Volunteer lead activities for children under the age of 12. Children must be potty trained to attend. Location: Ibis
11:00am	Information Session & Consent/Assent Signing for On-site Research - 1 hour Affected Individuals Ages 12+ and parents: Learn about on-site research projects running from Monday - Wednesday. Location: Calusa A-E
1:00pm	On-site Research - 4 hours By appointment only.
1:00pm	Clear Horizons Fellowship - 1 hour Open meeting for people in recovery or who have had their lives affected by addiction or alcoholism. Location: Pine C
1:00pm	Small Group Session: Siblings Only (ages +13) - 1 hour Small informal session to share information and experiences in a safe, confidential environment. Location: Blue Heron A

Schedule of Events

Day 1 Monday, July 29 - Continued

2:00pm	Discussion Groups (Affected Individuals and Parents/Caregivers) - 45 minutes Explore common challenges and share strategies for success. We encourage the whole family to attend. <ul style="list-style-type: none">• Ages 11-14: Blue Heron A• Ages 15-17: Blue Heron B• Ages 18-25: Blue Heron C
2:45pm	Discussion Groups (Affected Individuals and Parents/Caregivers) - 45 minutes Explore common challenges and share strategies for success. We encourage the whole family to attend. Alternative youth activities are available for younger children in Ibis. <ul style="list-style-type: none">• Ages 0-4: Blue Heron A• Ages 5-10: Blue Heron B• Ages 25+: Blue Heron C
2:45pm	Activity Room Open (Ages 2-12) - 45 minutes Our activity room offers a range of engaging, child-friendly activities, overseen by dedicated volunteers. We kindly request that children attending are potty trained for everyone's comfort and convenience. <p style="text-align: right;">Location: Ibis</p>
3:30pm	Introduction to Yoga (Affected Individuals Only) - 30 minutes Instructor-led inclusive yoga classes designed to cater to all affected individuals. <p style="text-align: right;">Location: Calusa F</p>
3:45pm	Small Group Session Leads - Touchpoint Meeting - 45 minutes By invitation only. <p style="text-align: right;">Location: Blue Heron C</p>
4:00pm	Introduction to Yoga (All Welcome) - 30 minutes Instructor-led yoga classes. <p style="text-align: right;">Location: Calusa F</p>
4:30pm	Affiliate Meeting (Invitation Only for Affiliate & BSF Leads only) - 1 hour <p style="text-align: right;">Location: Driftwood</p>
7:30pm	Painting Activity - 1 hour 30 minutes Dream birds, neurographic and messy heart art. Wear a shirt that is OK to get stained. <p style="text-align: right;">Location: Ibis</p> <p>Supplies kindly donated by Westcott & Schaff</p>

Schedule of Events

Day 2 Tuesday, July 30

8:00am	On-Site Research - 8 hours By appointment only.	
8:00am	Clear Horizons Fellowship - 1 hour Open meeting for people in recovery or who have had their lives affected by addiction or alcoholism.	Location: Pine C
9:00am	Life Partners of Individuals with Barth Syndrome - 1 hour A session for significant others and domestic partners of individuals diagnosed with Barth syndrome.	Location: Blue Heron C
10:00am	Moms' Session - 1 hour Mothers and primary female caregivers are invited to connect and share their experiences, challenges & triumphs.	Location: Great Egret ABC
11:00am	Moms' Session: Carriers' Breakout - 1 hour Continued discussion with mothers and primary female caregivers to connect and share their experiences, challenges & triumphs.	Location: Great Egret ABC
11:00am	Moms' Session: Non-Carriers' Breakout - 1 hour Continued discussion with mothers and primary female caregivers to connect and share their experiences, challenges & triumphs.	Location: Blue Heron C
11:00am	Portrait Photography with Matt Steeves - 6 hours By appointment only.	Location: Sanibel A
12:00pm	Stealth Focus Group On-site Research - 1 hour 30 minutes Invitation Only. Lunch is included for participants.	Location: Driftwood



“The BSF meeting is a unique and special time to spend time with the Barth family and scientific community. I always look forward to it!” - **Dr. Hilary Vernon**

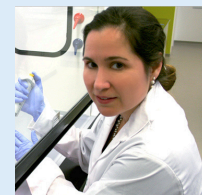
Schedule of Events

Day 2 Tuesday, July 30 - Continued

- 1:30pm **Male Caregivers and Carriers Life Partners Session - 2 hours**
Fathers, husbands and male significant others are invited to come together for a facilitated conversation on empowerment and understanding, sharing insight on their unique role in supporting their families affected by Barth syndrome.
Location: Great Egret ABC
- 1:30pm **Grannies & Aunties - 45 minutes**
Grandmothers, aunts, and other female relatives are invited to connect and share their experiences, challenges, & triumphs.
Location: Blue Heron C
- 3:30pm **Yoga (All Welcome) - 1 hour**
Instructor-led yoga class.
Location: Calusa F
- 3:45pm **Small Group Session Leads Touch Point Meeting - 45 minutes**
Invitation only.
Location: Blue Heron C
- 4:30pm **Chakra Workshop - 1 hour**
Step into our transformative Chakra Workshop designed to harmonize and rebalance individuals, offering guided practices and insights to align and restore the body's energy centers, fostering inner equilibrium and overall well-being.
Location: Calusa F
- 6:00pm **First to Know Dinner (For affected individuals only 16+ years old) - 2 hours**
A meet and greet session to acquaint and re-acquaint old friends and new and to provide a simplified summary of potential therapies and research projects for Barth syndrome. Dinner will be provided.
Location: Driftwood



“There is something emotional that comes from connecting with the incredible and dedicated friends, families, and individuals experiencing Barth syndrome that helps to inspire the quest to understand and treat this disease, and that I believe has helped to build a special commitment from the global research community. I think, overall, feeling this sense of community is probably my favourite part of the conference, and what I am most looking forward to.” - **Dr. Robin Duncan**



Schedule of Events

Day 3 Wednesday, July 31

- 8:00am **Continuing Medical Education Session - 4 hours (Virtual)**
The Barth Syndrome Foundation has partnered with the NICER Consortium to provide a virtual multi-disciplinary session on the basic biology of Barth syndrome to better understand the spectrum of clinical manifestations and highlight management options. Pre-registration required.
- 8:00am **On-site Research - 4 hours**
By appointment only.
- 8:00am **Clear Horizons Fellowship - 45 minutes**
Open meeting for people in recovery or who have had their lives affected by addiction or alcoholism.
Location: Pine C
- 8:45am **Sleep Issues (Ages 0-5) - 45 minutes**
Find out what is the normal amount of sleep at different ages and life stages. Focus will be on making small changes to routines and environments to improve sleep health, and ways to track your child's sleep.
Location: Blue Heron B
- 9:00am **Camp Barth Registration Open - 2 hours**
All youth must be registered with Camp Barth (ages 7-14) or CKE (ages 0-6) to participate in Camp Barth activities.
Location: Ibis
- 9:00am **Activity Room Open (ages 2-11) - 2 hours**
Movie morning featuring Disney's Moana
Location: Ibis
- 9:00am **Resilience & Coping Strategies (Parents Only) - 1 hour 15 minutes**
In this facilitated session, we will discuss both positive and negative coping strategies utilized by Barth individuals and their loved ones. We will discuss substance abuse, building support systems, and how to cultivate resilience. Together, we will create a safe and empowering space to support one another on this journey of healing and growth.
Location: Great Egret ABC



“The conference is a unique, fun, educational event that brings together affected individuals, families, clinicians and researchers and is truly unlike any event I have attended in my career. I have been fortunate enough to attend the 2014, 2016 and 2018 conferences. I am looking forward to everyone being together again in person.” - **Dr. Brittany Hornby**


Schedule of Events

Day 3	Wednesday, July 31 - Continued
9:30am	<p>Sleep Issues (Ages 5-12) - 45 minutes Find out what is the normal amount of sleep at different ages and life stages. Focus will be on making small changes to routines and environments to improve sleep health, and ways to track your child's sleep.</p> <p>Location: Blue Heron B</p>
10:00am	<p>Portrait Photography with Matt Steeves - 5 hours By appointment only.</p> <p>Location: Sanibel A</p>
10:15am	<p>Sleep Issues (Ages 12+) - 45 minutes Find out what is the normal amount of sleep at different ages and life stages. Focus will be on making small changes to routines and environments to improve sleep health, and ways to track your child's sleep.</p> <p>Location: Blue Heron B</p>
10:30am	<p>Potential Carriers (Pre-test Ages 11-14) - 45 minutes Intended to provide young female teens with an age-appropriate conversation to start the discussion about testing and concerns about potentially being a carrier.</p> <p>Location: Blue Heron C</p>
11:00am	<p>Setting Up for Independent Success (Parents & Teens+) - 1 hour 30 minutes What does 'independence' look like for me as an affected individual? Where do I need space and where do I need help? Family units can use this informal facilitated workshop to explore opportunities and needs to empower growth and success.</p> <p>Location: Great Egret ABC</p>
11:15am	<p>Potential Carriers Workshop (Pre-test 15 Years+) - 45 minutes This session is open to potential carriers 15 years of age and older. It will focus on making a decision about genetic carrier testing--when someone is ready, what is involved with testing and what to think about before getting tested.</p> <p>Location: Blue Heron C</p>

Schedule of Events

Day 3	Wednesday, July 31 - Continued
1:00pm	<p>Post-test Carrier Workshop - 1 hour This small group will focus on exploring the impact of learning that you are a carrier of Barth syndrome, how it might impact relationships, future plans, and reproductive options. Location: Blue Heron C</p>
1:00pm	<p>Resilience, Coping Strategies and When Coping Strategies Become Harmful - 1 hour For Affected Individuals 16+ In this facilitated session, we will discuss both positive and negative coping strategies utilized by Barth individuals and their loved ones. We will discuss substance abuse, building support systems, and how to cultivate resilience. Together, we will create a safe and empowering space to support one another on this journey of healing and growth. Location: Great Egret ABC</p>
2:00pm	<p>Activity Room Open (ages 2-11) - 2 hours Our activity room offers a range of engaging, child-friendly activities, overseen by dedicated volunteers. We kindly request that children attending are potty trained for everyone's comfort and convenience. Location: Ibis</p>
2:00pm	<p>Transforming Grief: A New Model for Understanding Grief and Loss (Beyond Loss in Death) - 1 hour 30 minutes Join us for an interactive discussion on grief and loss, focusing on a lesser known, simple to understand model of grieving. We will delve into various types of loss, the factors that influence the grief journey, and strategies to effectively support others. Location: Great Egret ABC</p>
3:30pm	<p>Yoga and Meditation - 1 hour Instructor-led yoga and meditation. Harmonizing body and mind through tranquil yoga postures and mindfulness practices, fostering balance and inner peace for all participants. Location: Calusa F</p>
5:30pm	<p>BSF Board of Directors Meeting - 2 hours 30 minutes Closed meeting for the BSF Board of Directors. Meal will be provided. Location: The Cove at the Tarpon Bay Restaurant</p>

Schedule of Events

Day 4	Thursday, August 1	
7:00am	<p>Centers of Expertise (Invitation Only) - 1 hour 30 minutes Breakfast provided.</p>	Location: Driftwood
7:30am	<p>Breakfast - 1 hour 15 minutes</p>	Location: Calusa A-E
8:00am	<p>Clear Horizons Fellowship - 1 hour Open meeting for people in recovery or who have had their lives affected by addiction or alcoholism.</p>	Location: Pine C
8:30am	<p>Welcome Campers! <i>All campers must be registered to attend.</i></p> <p>Camp Barth • Ages 7-15 Location: Ibis</p> <p>Camp Barth/CKE • Ages 0-6 Location: Great Egret ABC</p>	
8:45am	<p>Basic Biology of Barth Syndrome (All Welcome) - 3 hours 45 minutes Target Audience: Researchers, Clinicians, other Medical Professionals The talks in this session will address long-chain fatty acid oxidation, roles for pyruvate dehydrogenase, TFAZZIN structural biology, cardiolipin binding partners and the multiomics of Barth syndrome.</p> <ul style="list-style-type: none"> • Adam Chicco, PhD • Peter Rehling, PhD • Miriam Greenberg, PhD • John Ussher, PhD <p>10:45am - 11:00am Break</p> <ul style="list-style-type: none"> • Volker Zickermann, PhD • Steve Claypool, PhD • Riekelt Houtkooper, PhD 	Location: Estero B-C
9:00am	<p>Ask The Doctors: Metabolism and General Workshop - 45 minutes Find out what is the normal amount of sleep at different ages and life stages. Focus will be on making small changes to routines and environments to improve sleep health, and ways to track your child's sleep.</p>	Location: Calusa G-H

Schedule of Events

Day 4 Thursday, August 1 - Continued

- 9:45am **Ask The Doctors: Cardiology & Transplant Workshop - 1 hour**
Join this interactive, informal workshop to hear more about all aspects of cardiology as it pertains to Barth syndrome, including recent findings and new treatments.
Location: Calusa G-H
- 10:15am **Science Fun with Becky (Ages 7-15) - 45 minutes**
All living things have DNA: The chemical instructions on how to make a living thing, from humans to strawberries. Many people assume that because DNA is so small, we can't see it without powerful microscopes. But in fact, DNA can be easily seen with the naked eye when collected from thousands of cells. Have a go at completing this fun research activity to extract and view DNA from a delicious strawberry.
Location: Estero A
- 11:00am **Ask The Doctors: Neutropenia Workshop - 45 minutes**
An interactive, informal workshop to learn about neutropenia in Barth syndrome and its management.
Location: Calusa G-H
- 11:45am **Educational Workshop: Updates from Researchers in Layman's Terms - 45 minutes**
An informal session to help prepare attendees for the more complex information presented on Friday. Topics will include gene therapy, research in neutropenia and clinical trials' updates.
Location: Calusa A-E
- 12:30pm **Lunch - 1 hour**
Location: Calusa A-E
- 1:15pm **Varner Award Presentation - 15 minutes**
Location: Calusa A-E
- 1:30pm **Group Photo - 30 minutes**
Location: Royal Palm Courtyard

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Schedule of Events

Day 4 Thursday, August 1 - Continued

Biochemistry of Barth Syndrome (Sci/Med Attendees) - 2 hours 45 minutes

Target Audience: Researchers, Clinicians, other Medical Professions

Talks in this session will cover the biochemical and signaling defects in Barth syndrome and implications for neutropenia, arrhythmias, potential therapeutics and cardiomyopathy.

2:00pm

- Christopher Park, MD, PhD
- Roger Shi, PhD
- Edoardo Bertero, MD, PhD

3:30pm - 3:45pm Break

- Simon Conway, PhD
- Valerian Kagan, PhD

Location: Estero B-C

Small Group Practical Sessions: Feeding Issues (Ages 6-12) - 45 minutes

2:15pm

Small group discussion around all aspects of feeding.

Location: Captiva A

Small Group Practical Sessions: OT/PT (Ages 13+) - 45 minutes

2:15pm

Small group discussion around all aspects of OT/PT.

Location: Captiva B

Small Group Sessions for Affected Individuals - 45 minutes

2:15pm

Small informal sessions to share information and experiences in a safe, confidential environment.

- Ages 18-25: Pine B
- Ages 25+: Pine A

Small Group Practical Sessions: Feeding Issues (Ages 0-5) - 45 minutes

3:00pm

Small group discussion around all aspects of feeding.

Location: Captiva A

Small Group Practical Sessions: OT/PT (Ages 6-12) - 45 minutes

3:00pm

Small group discussion around all aspects of OT/PT.

Location: Captiva B

Yoga with Strength Training (Affected Individuals Only) - 45 minutes

3:00pm

Specialized strength training class with resistance bands, crafted specifically for individuals with Barth syndrome.

Location: Calusa F

Schedule of Events

Day 4	Thursday, August 1 - Continued
3:45pm	Small Group Practical Sessions: Feeding Issues (Ages 13+) - 45 minutes Small group discussion around all aspects of feeding. Location: Captiva A
3:45pm	Small Group Practical Sessions: OT/PT (Ages 0-5) - 45 minutes Small group discussion around all aspects of OT/PT. Location: Captiva B
3:45pm	Yoga with Mindful Breathing - 1 hour Instructor-led Yoga and Meditation class. Location: Calusa F
5:00pm	Poster Blitz - 30 minutes Poster blitz speakers were selected by the Conference Scientific Steering Committee to give a 5-minute synopsis of their research. <ul style="list-style-type: none">• Simona Lobasso, PhD• Hilary Vernon, MD, PhD• Nanami Senoo, PhD• Irma Markesina• Erin Keating Location: Estero B-C
5:30pm	Poster Session with Reception (Sci/Med Attendees Only) - 2 hours Poster Hall viewing session for sci/med attendees only. Reception includes small plates and beverages. Location: Calusa Pre-Function
6:30pm	Poster Hall Viewing Session (Families) - 45 minutes This session was created to allow families to have an opportunity to view posters and interact with researchers. Location: Calusa Pre-Function
7:30pm	Luminaries - 1 hour 30 minutes (All Welcome to Attend) The lighting of the luminaries is a heart-warming highlight of the conference when families follow the processional led by a bagpiper and pause for a moment of silence after lighting a candle in honor of all those who have ever lived with Barth syndrome. Location: Royal Palm Courtyard

Schedule of Events

Day 5	Friday, August 2	
7:45am	Breakfast - 1 hour 15 minutes	Location: Calusa A-E
8:00am	<p>Clear Horizons Fellowship - 1 hour Open meeting for people in recovery or who have had their lives affected by addiction or alcoholism.</p>	Location: Pine C
8:45am	<p>Welcome Campers! <i>All campers must be registered to attend.</i></p> <p>Camp Barth • Ages 7-15 Location: Ibis</p> <p>Camp Barth/CKE • Ages 0-6 Location: Great Egret ABC</p>	
9:00am	<p>Lessons from Barth Syndrome Clinical Trials Session - 1 hour 30 minutes A session for all attendees to hear about lessons learned from concluded clinical trials in Barth syndrome and future directions.</p>	Location: Estero B-C
10:45am	<p>Clinical Trial End-Points for Barth Syndrome Session - 2 hours 15 minutes A hybrid presentation-brainstorming session to hear about clinical trial endpoints relevant to Barth syndrome.</p>	Location: Estero B-C
10:45am	<p>Advocacy Focus for Families - 2 hours 15 minutes BSF continues to work hard to advocate for a fair, equitable, and appropriate review by the FDA of the new drug application (NDA) for elamipretide in Barth syndrome. Join us to hear the latest developments in regulatory affairs and learn how our patient community remains integral to BSF's strategic efforts in the United States, as well as in the UK and Europe. Coordinated efforts throughout the remainder of 2024 and into 2025 are crucial to doing our utmost to support the first potential new therapy for Barth syndrome becoming accessible to our community by physician's prescription.</p>	Location: Calusa G-H
1:00pm	<p>Lunch - 1 hour 15 minutes • Centers of Expertise Breakout Lunch (Invitation only) : Blue Heron A • Post-Transplant Families Breakout Lunch : Blue Heron B-C</p>	Location: Calusa A-E

Schedule of Events

Day 5 Friday, August 2 - Continued

1:45pm

Poster Hall Viewing Session - 30 minutes

This session was created to allow families to have an opportunity to view posters and interact with researchers.

Location: Calusa Pre-Function

2:15pm

Potential Therapies for Barth Syndrome (All Welcome) - 2 hours 45 minutes

Talks in this session will cover gene therapy, enzyme replacement therapy, elamipretide and therapeutic targeting of pathological microRNAs. While all are invited to attend these talks, the material will be geared toward a scientific audience.

- Jim Carr, PharmD
- Barry Byrne, MD, PhD
- William (Bill) Pu, MD

3:45pm - 4:00pm Break

- Michael Chin, MD, PhD

Location: Estero B-C

3:00pm

Build a Boat Race (All Welcome) - 1 hour

Awards will be presented during the Friday Night Social

Location: Waterfall Pool

4:00pm

Yoga with Sound Bath - 1 hour 30 minutes

Join us for a transformative experience in this class, where traditional yoga blends with soothing sound vibrations to create a harmonious healing journey of relaxation, rejuvenation, and inner alignment.

Location: Calusa F

5:00pm

Sci/Med Conference Wrap-Up (Closed Session for Sci/Med Attendees) - 30 minutes

Join us as the Sci/Med Session Chairs summarize the state of research in Barth syndrome and future directions for clinical and therapy development.

Location: Estero B-C

7:00pm

Friday Night Social - 4 hours

Join us "around the campfire" at Camp Barth for an evening of food, dancing, games, and togetherness. Wear your best "camp attire" and get ready for a lot of fun!

Location: Calusa A-E

Schedule of Events

Day 6	Saturday, August 3	
7:45am	Scientific and Medical Advisory Board Breakfast and Meeting - 3 hours (Invitation Only)	Location: Driftwood
8:00am	Clear Horizons Fellowship - 1 hour Open meeting for people in recovery or who have had their lives affected by addiction or alcoholism.	Location: Pine C
9:00am	Yoga - 1 hour Instructor-led yoga for all attendees.	Location: Calusa F
10:00am	Brunch - 1 hour	Location: Calusa A-E
11:00am	Conference Finale (All Welcome) - 1 hour Join us to relive the highlights of our conference before we depart to head home. This is a touching celebration that you won't want to miss.	Location: Calusa A-E

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Thank you for your time, goods, and talent.

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Poster Presenters



The Poster Session is an interactive showcase of 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. A NATIONAL CENTRE EXPERIENCE OF HYPOGLYCAEMIA IN INDIVIDUALS WITH BARTH SYNDROME

Presenter: Gillian Alexander | University Hospitals Bristol and Weston NHS Foundation Trust

2. DEVELOPMENT OF AN ONLINE DROP-IN GROUP TO SUPPORT MENTAL HEALTH AND WELLBEING DURING A GLOBAL PANDEMIC

Presenter: Gillian Alexander | University Hospitals Bristol and Weston NHS Foundation Trust

3. A MULTIPLEXED MONOLYSOCARDIOLIPINS AND CARDIOLIPINS ASSAY FOR BARTH SYNDROME

Presenter: Vincent Blomen | Scenic Biotech

4. A MULTIPLEXED MONOLYSOCARDIOLIPINS AND CARDIOLIPINS ASSAY FOR BARTH SYNDROME

Presenter: Seul Kee Byeon | Mayo Clinic

5. THE ITALIAN EXPERIENCE OF A STRUCTURED ASSOCIATION FOR BARTH SYNDROME (BARTH ITALIA)

Presenter: Paola Cazzaniga | Barth Italia Onlus

6. EFFECTS OF COMPOUND X ON TFAZZIN-DEFICIENT B-LYMPHOBLAST GROWTH AND MITOCHONDRIAL PARAMETERS

Presenter: EJohn Zewen Chan | University of Waterloo

Poster Presenters



7. **INFLUENCE OF COMBINED VOLUNTARY EXERCISE AND PHARMACOLOGICAL PPARB/ Δ ACTIVATION ON SKELETAL MUSCLE CONTRACTILE FUNCTION AND FATIGABILITY IN THE RODENT MODEL OF BARTH SYNDROME**

Presenter: Drake Christie | Brock University

8. **CHARACTERIZATION OF PLAAT1-/- MICE**

Presenter: Robin E. Duncan | University of Waterloo

9. **CL-DEFICIENCY LEADS TO ACYL-CARNITINE ACCUMULATION IN TAZ-KO CELLS**

Presenter: Tyler Ralph-Epps | Wayne State University

10. **TREATMENT WITH THE SODIUM-GLUCOSE COTRANSPORTER-2 INHIBITOR, EMPAGLIFLOZIN, DOES NOT IMPROVE CARDIAC ABNORMALITIES IN A MOUSE MODEL OF THE RARE GENETIC DISEASE BARTH SYNDROME**

Presenter: Amanda Greenwell | University of Alberta

11. **DEVELOPMENT OF A STRIATED MUSCLE TAFAZZIN KNOCKOUT MODEL OF BARTH SYNDROME SUITABLE FOR PRE-CLINICAL THERAPEUTIC TRIALS**

Presenter: Erin M. Keating | Boston Children's Hospital

12. **AAV9-TAFAZZIN GENE REPLACEMENT AMELIORATES ALTERED SKELETAL MUSCLE PROTEOMIC PROFILES IN A MOUSE MODEL OF BARTH SYNDROME**

Presenter: Fatemeh (Ellie) Khadir | University of Minnesota Medical School

13. **IMPROVED EFFICACY OF AAV-MEDIATED SYSTEMIC GENE THERAPY THROUGH INCREASED TISSUE PERFUSION**

Presenter: Fatemeh (Ellie) Khadir | University of Minnesota Medical School

Poster Presenters



14. CARDIOLIPIN REGULATES ALANINE AND ASPARTATE METABOLISM - IMPLICATIONS FOR BARTH SYNDROME

Presenter: Vikalp Kumar | Wayne State University

15. CARDIOLIPIN MODULATION OF MITOCHONDRIAL CALCIUM UNIPORTER COMPLEX

Presenter: Anshu Kumari | University of Maryland Baltimore

16. PERCEIVED QUALITY OF LIFE AND FAMILY FUNCTIONING OF PARENTS OF CHILDREN WITH BARTH SYNDROME: DOUBLE ABCX MODEL OF FAMILY IMPACT

Presenter: Yoonjeong Lim | Binghamton University

17. SS-31 TREATMENT IMPROVES MITOCHONDRIAL FUNCTION IN HEART OF TFAZZIN-KD MICE WITHOUT AFFECTING THE CARDIOLIPIN FINGERPRINT

Presenter: Simona Lobasso | University of Bari Aldo Moro

18. MAPPING OF BARTH SYNDROME PATHOGENIC VARIANTS LINKS TFAZZIN STRUCTURAL ALTERATIONS AND MONOLYSOCARDIOLIPIN BINDING

Presenter: Irma Markesina | University of Rijeka

19. CARDIAC ECHOGENIC FOCI AND INTRAUTERINE GROWTH RETARD IN A MALE FETUS AS PRENATAL MANIFESTATIONS OF BARTH SYNDROME

Presenter: Emanuele Micaglio | University of Milan, Italy, IRCCS San Donato Hospital of Milan, Italy

20. EFFECTIVENESS OF NICOTINAMIDE RIBOSIDE IN CHILDREN AND ADULTS WITH BARTH SYNDROME: A PROTOCOL OF AN N-OF-1 SERIES

Presenter: Annelieke Rosalie Müller | Amsterdam UMC location AMC

Poster Presenters



21. COPPER LEVELS IN INDIVIDUALS WITH BARTH SYNDROME AND CORRELATION WITH NEUTROPENIA
Presenter: Maria Pelidis | University Hospitals Bristol and Weston NHS Foundation Trust

22. ENZYME REPLACEMENT THERAPY RESCUES METABOLIC AND FUNCTIONAL DEFECTS IN A MOUSE MODEL OF BARTH SYNDROME
Presenter: Rahul Raghav | Tufts Medical Center

23. LOSS OF TFAZZIN RESULTS IN DECREASED LEVELS OF BRANCHED-CHAIN AMINO ACIDS (BCAA) AND UPREGULATION OF BCAA DEGRADATION ENZYMES
Presenter: Abu M Ramim | Wayne State University

24. MECHANISM OF ABNORMAL CHOLESTEROL BIOSYNTHESIS IN TAZ ISOGENIC IPSC CELLULAR MODEL
Presenter: Yana Sandlers | Cleveland State University

25. TFAZZIN IS REQUIRED FOR CARDIOMYOCYTE MATURATION-ASSOCIATED CRISTAE REMODELING
Presenter: Nanami Senoo | Johns Hopkins University

26. SYSTEMIC GENE THERAPY APPROACH FOR BARTH SYNDROME USING A NOVEL CARDIOTROPIC CAPSID
Presenter: Swapnil V Shewale | University of Pennsylvania

27. IDENTIFYING GENETIC MODIFIERS TO UNDERSTAND AND REVERSE THE CLINICAL SIGNS IN A MOUSE MODEL OF BARTH SYNDROME
Presenter: Douglas Strathdee | CRUK Scotland Institute

Poster Presenters



28. IMPORTANCE OF SPLICING VARIANTS IN THE TAZ GENE: A CASE REPORT
Presenter: Atsuhito (Tuck) Takeda | Hokkaido University Graduate School of Medicine

29. MATRISOMAL PROTEINS DERIVED FROM CARDIOMYOCYTES AND CARDIAC FIBROBLASTS CONTRIBUTE TO THE CARDIAC PHENOTYPE IN BARTH SYNDROME
Presenter: Jennifer Tinklenberg | University of Minnesota

30. INVESTIGATION OF INNATE INTRACELLULAR IMMUNITY ACTIVATION IN TAFAZZIN-DEFICIENT HEART TISSUE
Presenter: Michelle Tomczewski | University of Waterloo

31. SEVERE NEUTROPENIA IN TWO MATERNAL COUSINS AFFECTED BY MOLECULARLY CONFIRMED BARTH SYNDROME
Presenter: Nicola Tovaglieri | Metropolitan Hospital "Niguarda" of Milan, Italy

32. EFFECTS OF AAV-TAFAZZIN IN BARTH SYNDROME PATIENT-DERIVED IPSC CARDIOMYOCYTES
Presenter: Sree Venigalla | University of Minnesota

33. ELAMIPRETIDE ASSOCIATED WITH SUSTAINED IMPROVEMENTS IN CARDIOLIPIN MLCL/CL RATIOS IN PATIENTS WITH BARTH SYNDROME: RESULTS FROM A TAZPOWER OLE SUBANALYSIS
Presenter: Hilary Vernon | Johns Hopkins University, Kennedy Krieger Institute

Poster Presenters



34. LONG-TERM EFFICACY AND SAFETY OF ELAMIPRETIDE IN PATIENTS WITH BARTH SYNDROME: 168-WEEK OPEN-LABEL EXTENSION RESULTS OF TAZPOWER

Presenter: Hilary Vernon | Johns Hopkins University, Kennedy Krieger Institute

35. A LITERATURE REVIEW OF THE PREVALENCE AND INCIDENCE OF BARTH SYNDROME

Presenter: Hilary Vernon | Johns Hopkins University, Kennedy Krieger Institute

36. A COLLABORATIVE APPROACH TO WEANING ONTO SOLID FOOD IN BARTH SYNDROME

Presenter: Victoria Wilkins | University Hospitals Bristol and Weston NHS Foundation Trust

37. GROUP-BASED DEVELOPMENTAL SUPPORT FOR CHILDREN UNDER 5 YEARS OF AGE WITH BARTH SYNDROME: A SERVICE DEVELOPMENT PROJECT

Presenter: Victoria Wilkins | University Hospitals Bristol and Weston NHS Foundation Trust

38. INHIBITION OF ALCAT1 AS A POTENTIAL TREATMENT FOR CARDIOMYOPATHY IN BARTH SYNDROME

Presenter: Jun Zhang | UT Health San Antonio

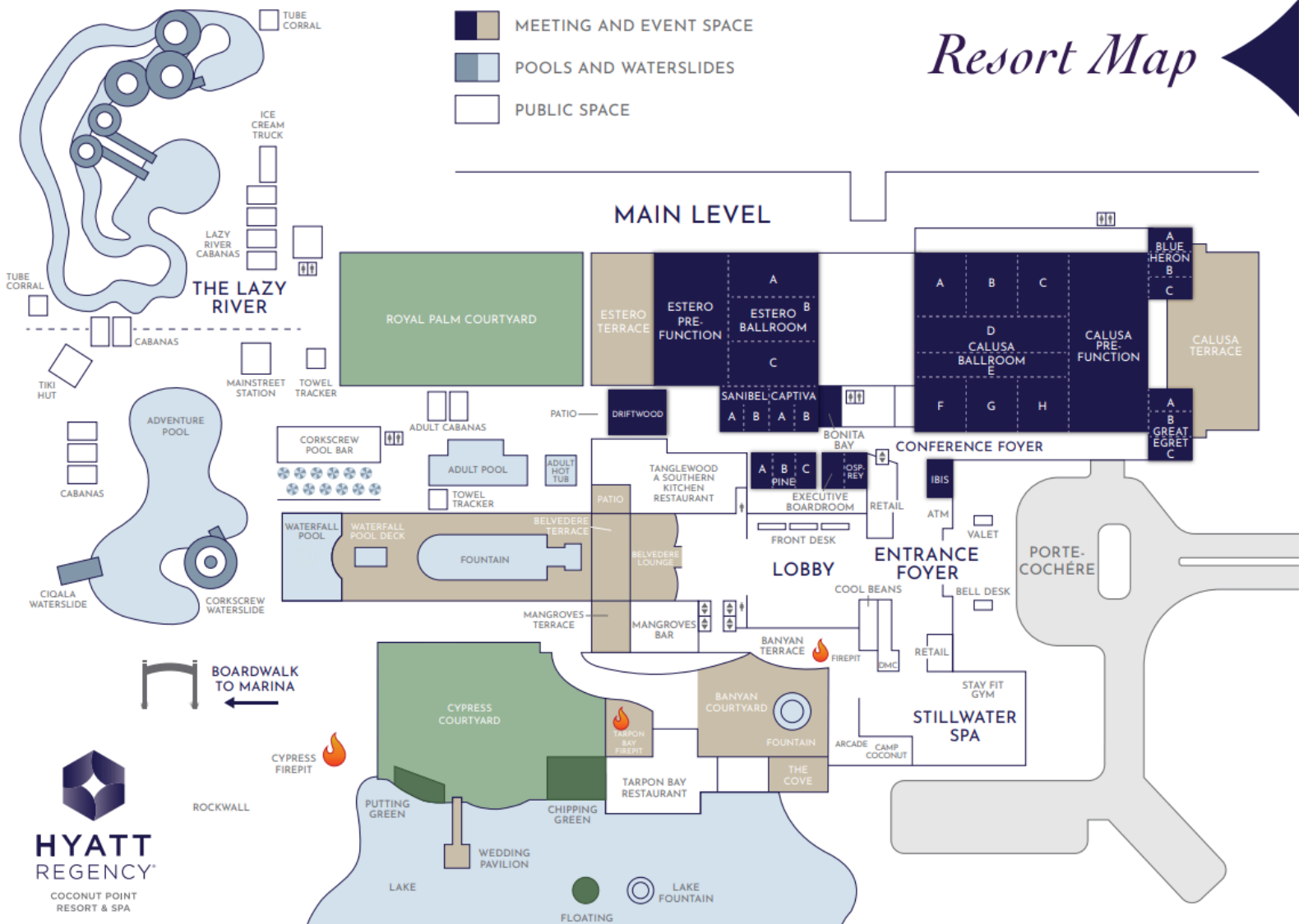
Poster Hall Hours

Thursday 5:30pm - 7:30pm for Sci/Med Attendees Only

Thursday 6:30pm - 7:30pm for Families

Friday 1:45pm - 2:15pm for Families Only

Resort Map



Conference Room Locations

- Blue Heron A
- Blue Heron B
- Blue Heron B-C
- Blue Heron C
- Bonita Bay
- Calusa A-E
- Calusa F
- Calusa G-H
- Calusa Pre-Function
- Captiva A
- Captiva B
- Driftwood
- Estero A
- Estero B-C
- Great Egret ABC
- Ibis
- Pine A
- Pine B
- Pine C
- Royal Palm Courtyard
- Royal Palm Courtyard Terrace
- Sanibel A
- The Cove at the Tarpon Bay Restaurant
- Waterfall Pool

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