



BARTH SYNDROME CONFERENCE

www.barthsyndromeconference.org



FAMILY
2026

WELCOME



AGENDA

- Code of Conduct
- Things to Pack
- Safety
- Ground Transportation
- The Venue
- Registration
- Highlights of the Agenda
 - Families
 - Youth
 - Social
 - SciMed
- Onsite Research
- The Conference App



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Code of Conduct

- Be respectful and polite
- Be empathetic
- Be thoughtful
- Be kind
- Honor privacy and diversity
- Mind the rules of the venue
- Be a Good Human!



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Protection from Florida Heat and Sun

- Avoid mid-day sun and heat exposure
 - Plan early and late day outdoor activities
 - Your skin will still burn on cloudy days **SO**
- Wear sunscreen whenever going outdoors
 - Reapply and **OFTEN** especially when playing in the water and send sunscreen with kids on outdoor Camp Barth Day
- Stay well-hydrated: **ALWAYS** have water on hand
- Wear some type of shoe when walking outdoors or when going to the private island, the sand gets really hot
- Wear sunglasses, Florida sun is painfully bright
- <https://melanoma.org/melanoma-education/prevention/>



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Safety First

- Always dial 911 first
 - EMS will be on site throughout the week but still call 911 for an emergency situation
- Be On the Look Out (BOLO) Alert
- Give EMS STARS #2000 to access information about Barth syndrome
- In Room Emergency - Dial 55
- Urgent Care
 - Lee Health System Urgent Care (1.6 miles from hotel)
 - Bonita Springs Health Care/ Emergency Department (3.1 miles from hotel)
- Hospitals
 - Golisano Children's Hospital
 - HealthPark Medical Center
- Pharmacies
 - Publix Supermarket and Pharmacy (2.1 miles from hotel)
 - Target Supermarket and CVS Pharmacy (2.7 miles miles from hotel)
 - Walgreens Pharmacy (3.4 miles from hotel)
- 5 AEDs on site
 - Security Office, Corkscrew Bar (Poolside), Stillwater Spa, Hyatt Learning Center (2nd floor, next to employee cafeteria), 9th Floor of Hotel (Housekeeping Linen Closet)



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Ground Transportation (To and From the Airport)

There are no hotel shuttles to and from the airport. Paid options include.

- Ride Share with Uber or Lyft
- ALD Limo offers **pre-arranged suburban** \$124.00 (that includes tip) each way for up to 6 people. After hour pick ups are an additional \$15.00.
- Some attendees are renting cars. If you would like to car share reach out to the attendees to coordinate on the Facebook Conference page to coordinate.
- On Demand Taxis are available. Rates are currently posted for \$44.00 for up to 4 people and an additional \$10.00 for each additional passenger. Reservations can be made in advance through ground transportation tab of the RSW website.
- A listing of rental car agencies that serve the **Southwest Florida International Airport** are available on the RSW website

For more information visit the RSW website <https://www.flylcpa.com/>



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Road Rules in Florida

Passenger Restraint: Federally approved child restraint must be provided for children 5 years of age and younger. The burden of responsibility for providing child restraining is that of the child's guardian and not that of the chauffeur-driven taxi, limousine, sedan, van, bus, motor coach or other passenger vehicles. All other passengers are required to wear seat belts. **Florida DMV 316.613 Child restraint requirements**

Cell Phones: It is illegal to use or handle a cell phone while driving

Move Over Law: Drivers must move over one lane when passing stopped law enforcement, emergency vehicles, sanitation trucks, tow trucks, and utility vehicles. If you cannot safely move over, you must slow down to 20 MPH under the posted speed limit

For more information visit the **Florida Highway Safety Motor Vehicles** Website
<https://www.flhsmv.gov/safety-center/driving-safety/>



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Registration

- Registration opens Sunday July 19th 3:30 PM - 7:00 PM
- Payment for Camp Barth
 - Explain difference between Registration and Camp Barth
- Barth Merchandise
- Program



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Welcome

Shuttles During Stay

Hotel Shuttle: Complementary shuttle service to Coconut Point Mall upon request and call concierge for pick up. A listing of stores and restaurants available on the Coconut Point Mall website

<https://www.simon.com/mall/coconut-point>

BSF Shuttle Loop: Monday July 20th and Wednesday July 22nd 5:30 PM - 10:30 PM.

Shuttles or Golf Carts to Marina: Transportation to and from the Marina available upon request



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The Venue



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Big Hickory Island Beach

One Event for Diverse Audiences

Science and Medicine

Technical and highly scientific
Primary Audience
Healthcare Providers
Scientists
Families Invited
Encouraged to attend certain sessions

18+ Sessions

Targeted, family-focused sessions offering practical information and support in an engaging small-group format.
Primary Audience
Mature teens
Adult Family Members

Tailored Programming

Youth 7 - 17

Age specific activities with small discussion groups addressing audience needs by age and familial relationships

Youth 0 - 6 Years

Age specific activities intended to build early friendships in a safe and nurturing setting



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Meals Provided

- Monday
 - Breakfast
 - Lunch for Adults Diagnosed with Barth
- Tuesday
 - Meals on your own
- Wednesday
 - Meals on your own
- Thursday
 - Breakfast, Lunch
- Friday
 - Breakfast, Lunch, Hors d'oeuvres (Social)
- Saturday
 - Breakfast



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Monday - Wednesday (Youth)

- Monday

- 2-6 Years (Barth Bunny Clinic) *NEW!*
- 7 - 12 Science Fun with Becky
- Art Fun with Dorian the Service Dog +
 - Textile Art
 - All About Me Puzzle Art
 - Painting

- Tuesday

- Art fun +
 - Textile Art
 - All About Me Puzzle Art
 - Painting
- Music Play (All Ages) +

- Wednesday

- Animal Encounters with Wonder Gardens *NEW!*



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Camp Barth 0 - 6

- Thursday

Must be enrolled in Camp Barth to Participate

- Lee County Fire Department Touch a Truck
- How the West was Fun
 - Face Painting
 - Cowboy Bandanas
 - Dance Party
 - Movie

- Friday

Must be enrolled in Camp Barth to Participate

- Perfect Pirate Party
 - Pirate Fun
 - Arts and Crafts
 - Games
 - Face Painting



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Camp Barth 7 - 17

- Thursday

Must be enrolled in Camp Barth to Participate

- Video Game Truck +
- Karaoke
- Team Building Challenges *NEW!*

- Friday

Must be enrolled in Camp Barth to Participate

- Build a Boat
- Poolside Pizza Party *NEW!*
- Swim, Splash, Slide at the pool *NEW!*
- Build a Boat Race +
- Medal Presentation during Social



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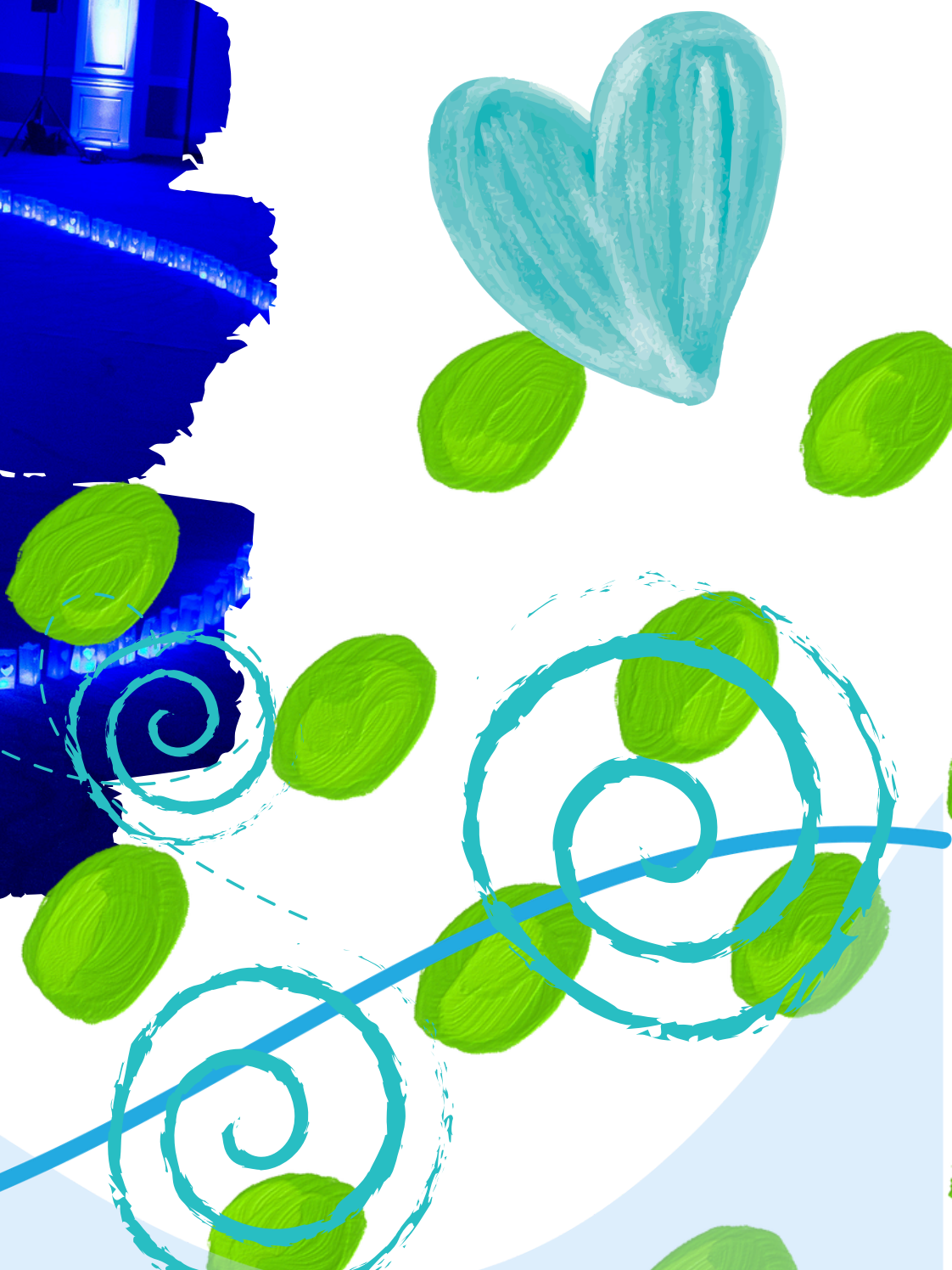




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Session Highlights



Monday - Wednesday Family Agenda

- (Mon) New Family Orientation, Welcome Session
- (Mon) CPR and AED Training *NEW!*
- (Mon) Adult Affected Individuals Luncheon (21+)
- (Mon- Wed) Onsite Research
- (Mon - Wed) Small Groups/ Caregivers, Carriers, Affected Individuals, Dads +
 - *Age and Audience Specific*
- (Mon & Tue) Painting with Brie/ Adults +
- (Tue) Adult with BTHS Evening Meetup; Steve Graessle *NEW!*
- (Wed) Grandparents Dinner Out; Laurie Shepherd *NEW!*
- (Wed) Parents of Adults with BTHS Meetup; Rosemary Baffa *NEW!*
- (Wed) Science Speed Dating, Meet the AI *NEW!*
- (Tue - Fri) Yoga



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Thursday - Friday Family Agenda

- (Thu) Care Management of Barth Syndrome; Age and Topic Specific
 - Topics *NEW!*
 - Metabolism
 - Cardiology (Cardiac Function, Electrophysiology, Transplant and Advanced Therapies)
 - Hematology
 - Interventional Therapies (Occupational Therapy, Speech Pathology, Physical Therapy)
 - Psychosocial and Education (Mental Health, Educational Interventions and Supports)
 - Ages
 - Infants, Toddlers and Preschoolers (0 - 5 Years)
 - Early School Age (6 - 11 Years)
 - Adolescence (12 - 17 Years)
 - Adults (18+ Years)
 - Parents of Adults
- (Thu) Group Photos
- (Thu) Luminaries
- (Thu) Adult Sibling Meetup; Marykate Baffa *NEW!*
- (Fri) Family Poster Sessions +
- (Fri) Build a Boat Race
- (Fri) Social



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Finale



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Friday Night Social



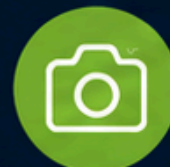
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Friday Night Social
**COME
WHERE
you're from**

CELEBRATE OUR DIVERSE COMMUNITY
AND SHARED JOURNEY. 



Bring a touch
of home to
share with all!



Stories, traditions
and a whole lot
of connection.



Wear or bring
something that
represents where
you're from!



**SPONSOR THE FUN.
SUPPORT THE MISSION.**

Explore Friday Night Social sponsorship
opportunities through the [Community
Sponsorship](#) program.



Featured SciMed Sessions

Science Speed Dating

In this interactive session with families, each researcher is given 10-minutes at a table with family participants before they rotate to the next one. Researchers will answer questions from affected families and summarize their work to families.

Meet the Affected Individual

Selected groups of affected individuals will be at tables based on body systems or symptom categories (gastrointestinal, fatigue, muscle, neutropenia, cardiac, etc.). Researchers have the opportunity to ask questions related to symptoms, hear voices of patients, to better inform their research.

Family Poster-viewing

Dedicated time for families to view ~30 posters and ask poster presenters questions about their work. Families can also vote for their favorite posters!



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On-Site Research (Mon - Wed)*



PARENT-CHILD ASSESSMENT



CARDIAC EVALUATION



INSPIRATORY ASSESSMENT



MOTOR ASSESSMENT



MICROBIOME STUDY



BarthINSIGHTS



ARRHYTHMIA: HOLTER MONITORS

*FRI & SAT ONLY



SIGN UP HERE >>



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On-Site Research: Scheduling

Fill Out the Interest Form

Based on your eligibility, preferences, and schedule, we will slot you into 'research appointments.'

Calendar Invites & Print-Out

For each study you are eligible for, you will receive a digital calendar invitation with the date/time, room, instructions, and pre-work (if applicable). You will also get a consolidated print-out schedule on-site at the registration desk.

GUID (Your Barth Research ID)

We create a global unique identifier for each affected individual. This ID maintains your privacy and allows Barth researchers to share de-identified data securely. Check in with Melissa if you don't have yours.



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What to Pack (Research)

Arrhythmia Study

If your medical facility is *outside* of University of Pittsburgh Medical Center, Johns Hopkins, Nebraska Medicine, Children's Minnesota, **you should bring a copy of your medical records** (paper, PDF uploaded onto a cloud link, or USB).

- Records to include: cardiac/cardiology clinical notes, echocardiogram, electrocardiogram, holter monitor data, cardiac device data (*if applicable*), medications and laboratory results (*if available*), in the last year and preferably for a period of at least 3 years.
- **If you participate in Dr. Carolyn Taylor's echo study, you are eligible.**

BarthINSIGHTS Registry

Photo or scanned PDF of proof of diagnosis (*only those who have not previously already provided one*), you can email in advance to Melissa.Huang@barthsyndrome.org.

Todd Cade

Barth Syndrome Motor Milestones: Covered shoes and shorts.
Gut microbiome: Remember what you ate the past 3 days!



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Download the Conference App

Why use the app?

- ✓ Manage your schedule
- ✓ Connect with other attendees
- ✓ Access resources and receive notifications during the event
- ✓ Get help from the team

How do I download it?

- Follow the QR code to the right OR
- Search for the app called “**CVENT Events**” in your iPhone or Android app store
- In the CVENT app, searching for “Barth Syndrome Conference” will pull up “2026 International Barth Syndrome Scientific, Medical, and Family Conference.” That’s us!

Download the app



Visit the desktop version



[cvent.me/
Aam7l0](https://cvent.me/Aam7l0)



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Register for sessions

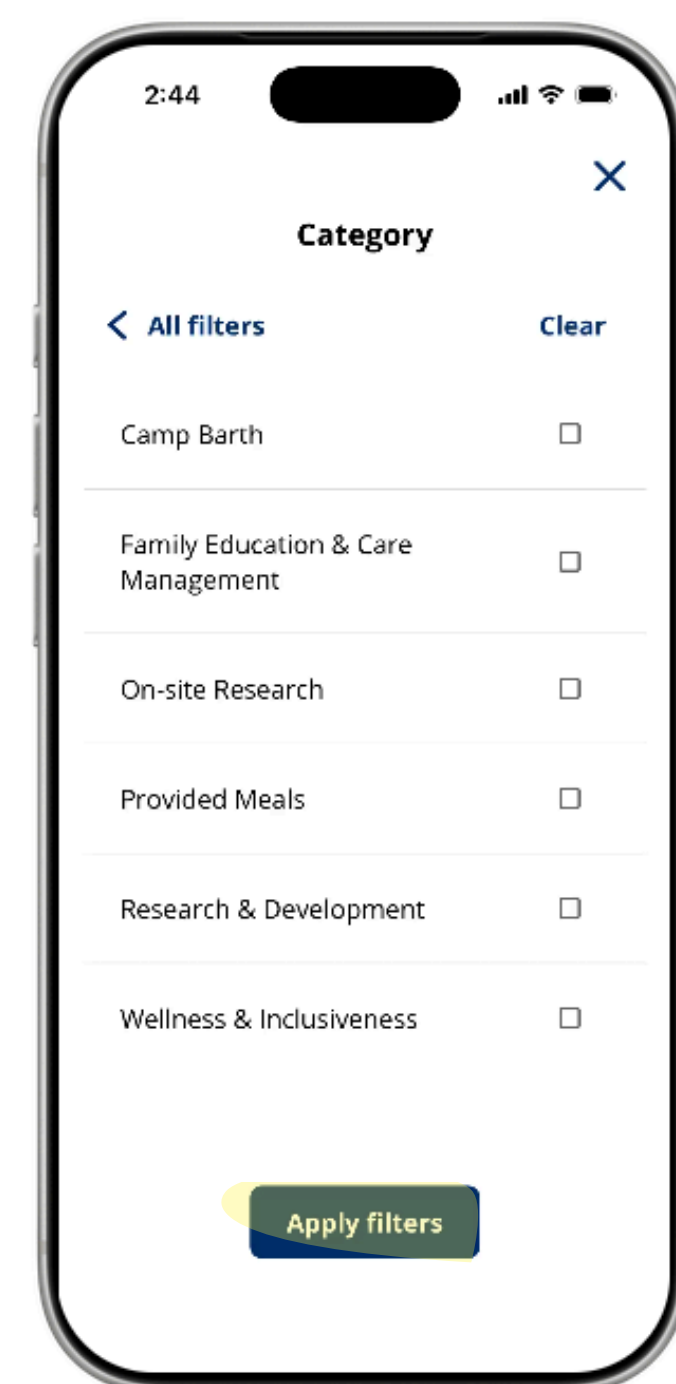
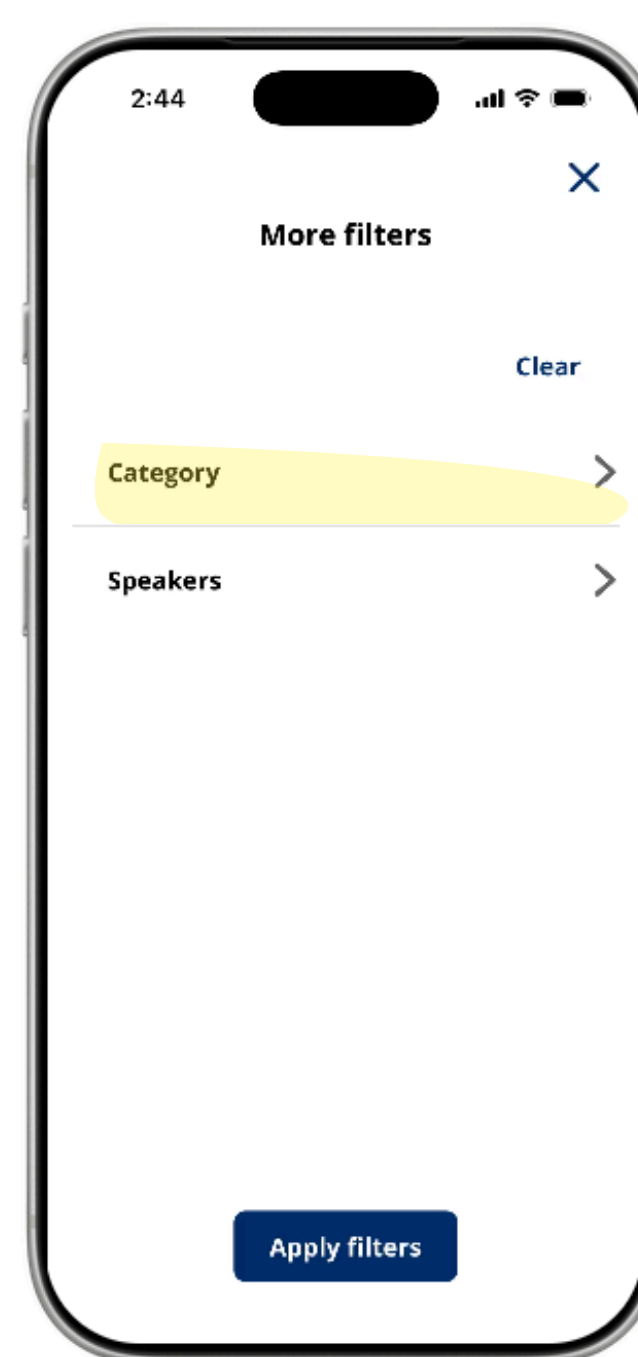
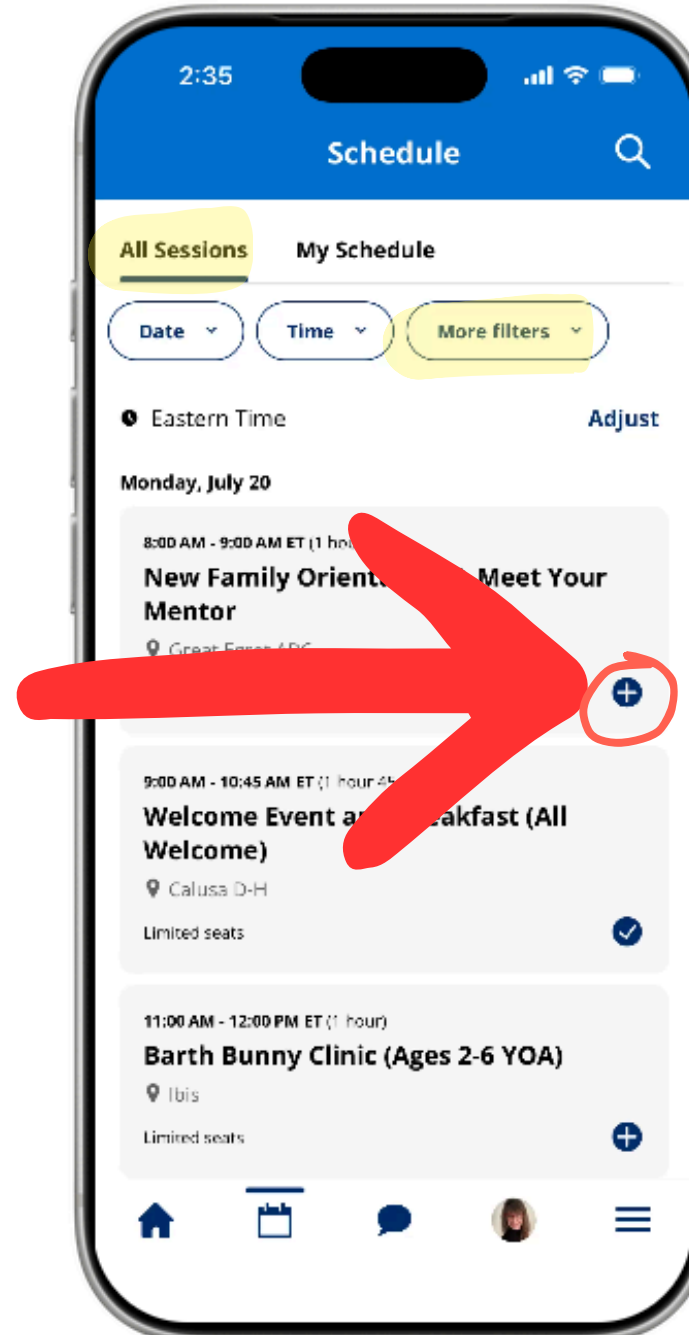
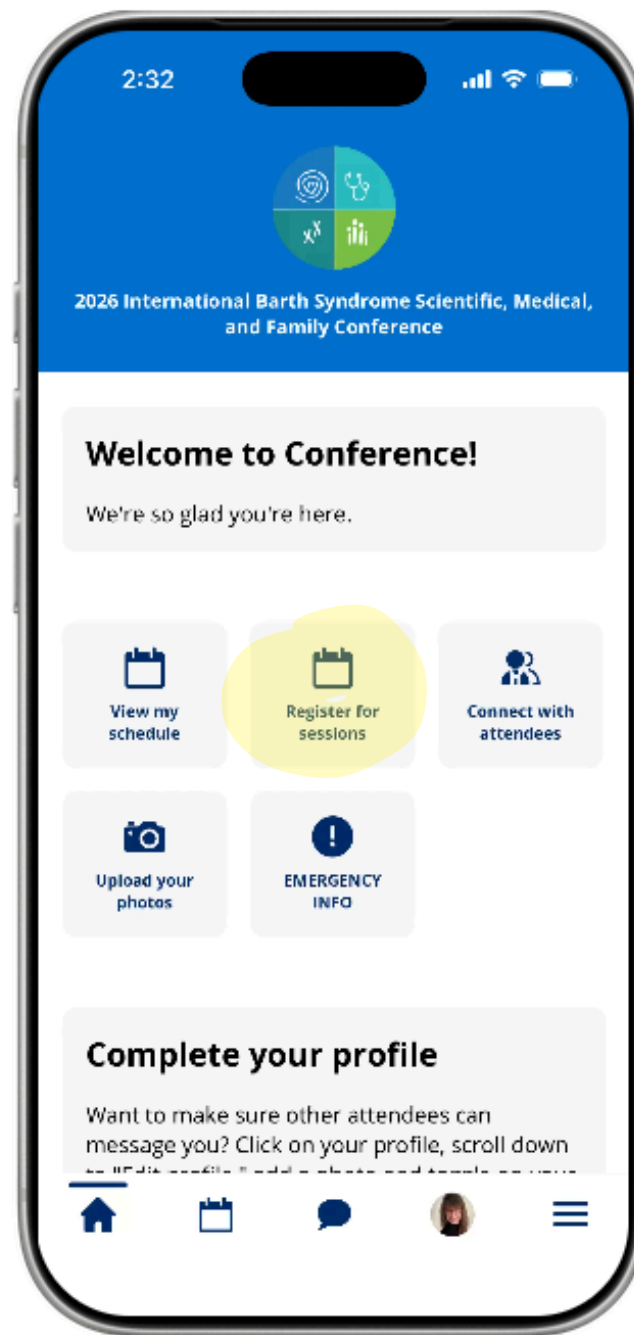
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Visit the
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cvent.me/Aam7l0

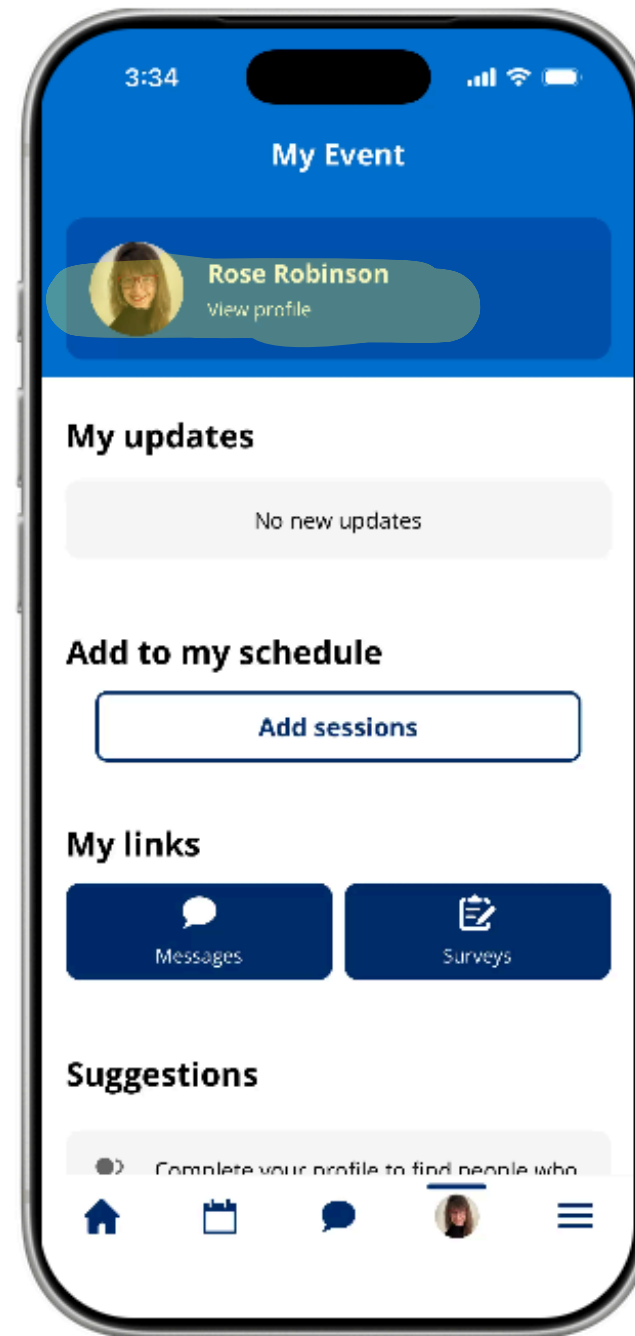
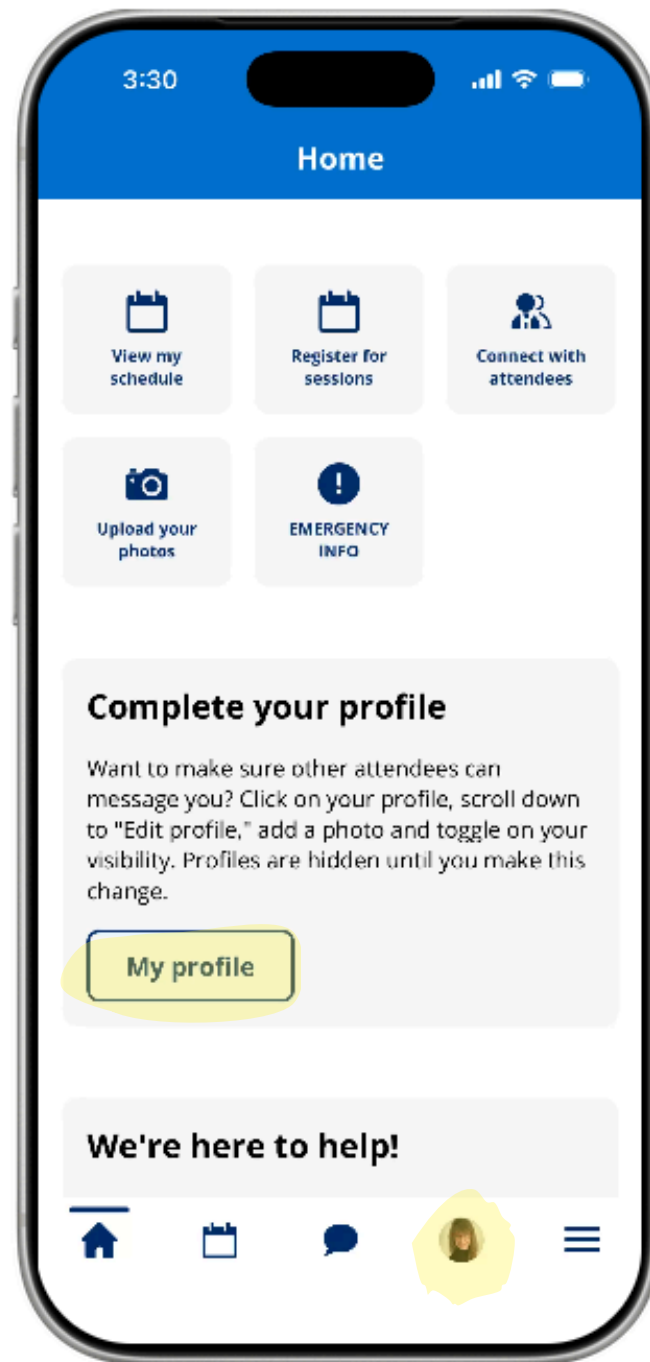


Connect with other attendees

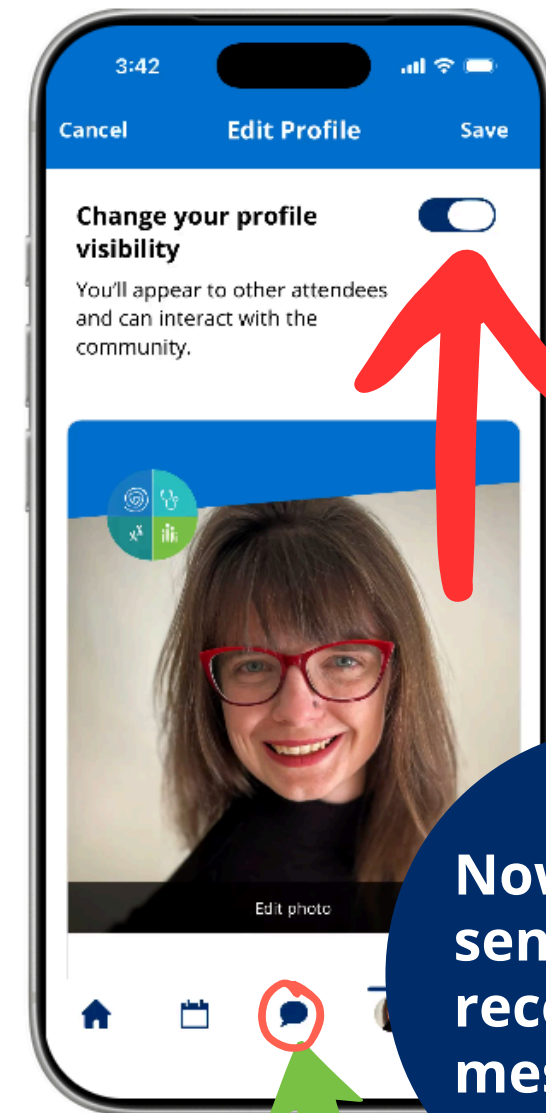
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Edit your profile:

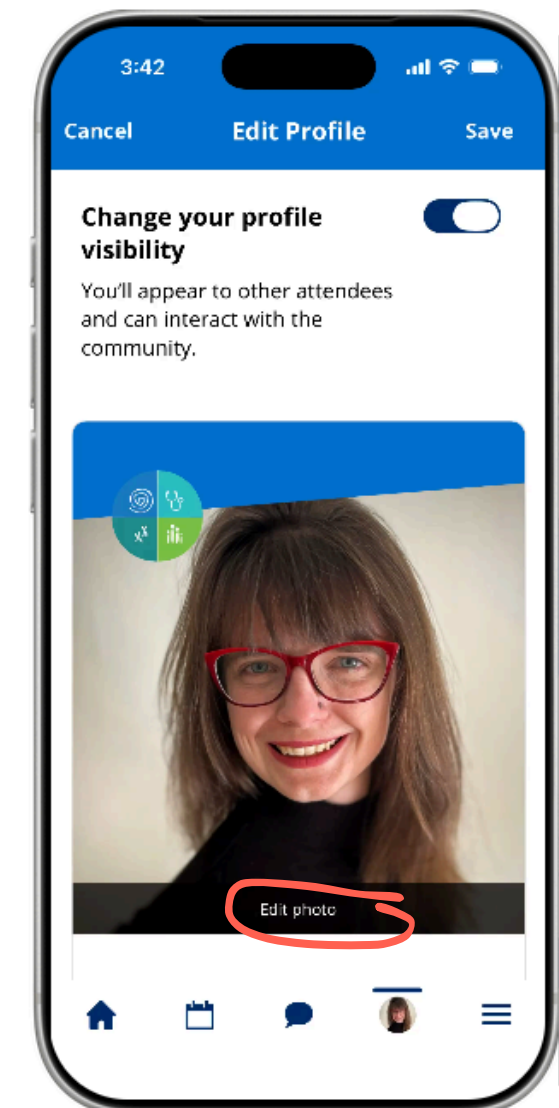


1 Make your profile visible so attendees can see and message you!



Now you can send and receive messages!

2 Add a photo and edit your bio



Need help?

Download



1

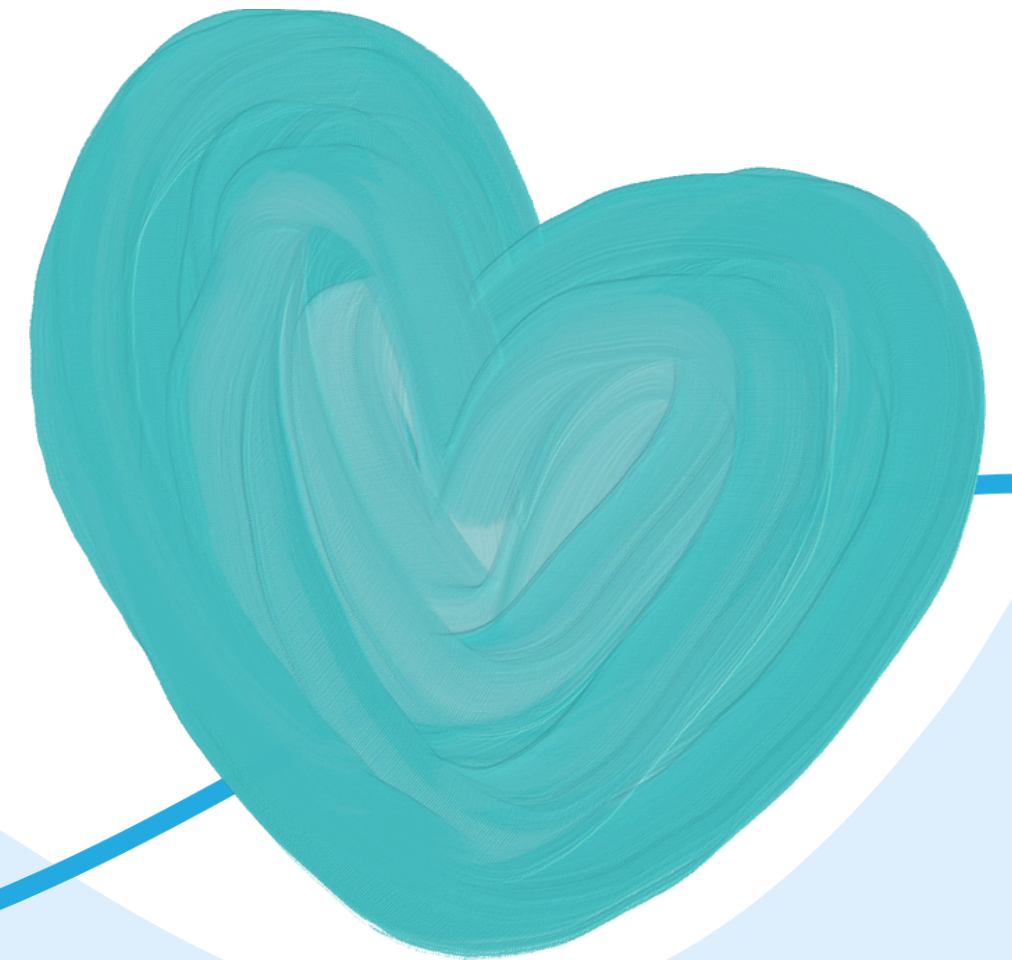
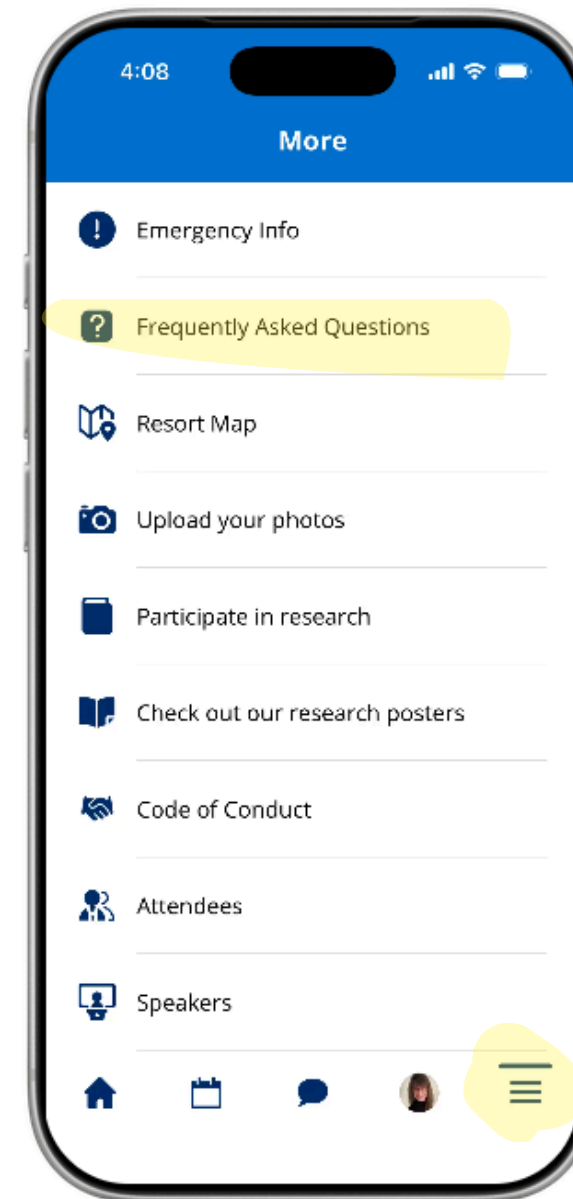
Access Conference resources in the app

2

Email general@barthsyndrome.org before Conference

3

During the event, you can message Rose Robinson (BSF Help Desk) in the app or find us at the registration desk.





thank you!



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