



PROGRAM

Stronger Together World Tour: Gurnee, IL
Great Wolf Lodge: 1700 Nations Dr., Gurnee, IL 60031

Jul 24th – 26th, 2022

Agenda

Sunday, Jul 24th

6:00 – 7:00 PM

White Oak II

Welcome Dinner

Welcome

Tee shirt distribution

Monday, Jul 25th

8:00 AM – 9:00 AM

White Oak II

Breakfast

9:00 AM – 9:20 AM

White Oak I

Registry and Research Identification

[Melissa Huang, MPhil](#)

Help us learn more about the natural history of Barth syndrome by joining the Barth syndrome Registry and Repository. When we design clinical trials, it's important for drug developers and regulators to learn about the natural progression of the disease. The way you can help is by providing us information through the registry. We'll do a quick registration walkthrough for those who are new and demonstrate how to do annual updates as an existing registrant. We'll also collect information to generate a ResearchID card for affected individuals, which we recommend using when participating in research studies. Using this Research ID help us further advance Barth science and link valuable data points across different studies.

9:20 AM – 9:50 AM

White Oak 1

Planning Ahead (Biorepositories)

[Conrad Epting, MD, FAAP](#), Associate Professor of Pediatrics, Northwestern University
Feinberg School of Medicine

Join us as Dr. Conrad Epting leads a discussion about parents and patients' engagement in research through banking of cardiac tissue and cell lines.

[Fontan Futures Initiative](#)

[Mending Broken Hearts: Cutting-edge Research Finds Clues to Regenerating Failing Hearts](#)

9:50 AM – 10:00 AM

Break

10:00 AM – 12:00 PM

White Oak I

Story Telling Workshop (Appropriate for mature teens and adults)

See workshop preparation below

[Kevin Friert, MBA](#), Principal and Founder, Salem Oaks

Our lives are full and having, or caring for someone with, a rare disease makes them even more full. When so much is happening, it is a real challenge to distill our stories down to just a few minutes in a way that invites the listener to want to hear more.

At the end of the workshop, participants will be able to:

- Deliver a compelling three-minute version of their story
- Stimulate and answer questions - crisply and understandably
- Use the story to foster longer, ongoing conversations and calls to action
- Prepare for a longer version of their story for presentations and interviews

12:00 PM – 1:00 PM
White Oak II

Lunch

5:45 PM – 6:00 PM
Great Wolf Main
Lobby

Group Photo

Wear your Stronger Together World Tour Tee Shirt

6:00 PM – 7:00 PM
White Oak II

Dinner

Tuesday, Jul 26th
8:30 AM – 9:30 AM
White Oak II

Breakfast

Time to say goodbye before heading for home

**Registry Enrollment
and Updates**

We will be collecting height and weight measures on affected individuals throughout the weekend to add to the individual's registry record. This will only take about 5 minutes. Stop by before or after dinner on Friday night or before heading out to play on Monday.

We will be scheduling appointments for individuals to enroll in the registry or for those who are already enrolled update your registry profile.

If you would like to schedule an appointment prior to the event, contact Melissa Huang.

COVID – 19 Health Protocol

Things we want to share: Laughter, conversation, and togetherness

Things we **DO NOT** want to share: Germs

If feeling sick, please take care of yourself and others.

STAY HOME

Procedures

- FDA-approved COVID-19 vaccination/booster(s) highly encouraged in accordance with CDC guidelines.
- COVID-19 negative test within 24 hours of event highly encouraged.
- KN95 masks, hand sanitizers, COVID tests available for free onsite.
- Daily non-contact temperature readings for event participants before entering meeting rooms.
- Color- coded wrist bands (red, yellow, green) to show social distancing comfort levels. Can be swapped out if comfort levels change.

In the Event of an Emergency

In the event of a medical emergency while at the hotel

Call 911 FIRST

Then call the front desk who will initiate emergency procedures and send onsite emergency responders who will help until emergency responders arrive.

Before leaving home complete the [Guidance on Emergency Department Management](#) fillable form, print out the completed form and pack it to bring with you. It's good practice to have your medical information organized whether you are at home or away. It is particularly helpful for medical providers to have access to these records when treating a patient with a complex condition such as Barth syndrome.

IMPORTANT Information about Great Wolf Lodge

Great Wolf Lodge is a cashless hotel: The hotel requires all attendees to provide a credit card or debit card upon arrival. All charges made at the hotel will be charged to the card that you provided at check in.

Use your wristband to pay. It's also your water park ticket & room key!

- Be prepared with a credit card or set up your lodge wristband to make purchases; Great Wolf Lodge does not accept cash at check-in or any outlets within the resort.
- Download the [Great Wolf app](#) for contacting the front desk, easy mobile check-in, ordering food, a resort map, and more.
- If arriving prior to 4:00 pm check in time, your room may not be available, yet you can access the indoor water park beginning at 1:00 pm on your day of arrival. SO, bring swimsuits and water shoes for the water park and closed-toed shoes for some of the dry-land activities.
Please note that no outside food or drink can be brought into the water park.
- Have your valid ID & the credit card you used to book your reservation available for check-in, even if doing online or mobile check-in.
- A **\$100 per night** authorization hold will be placed on your debit or credit card. Unused funds will be released upon checkout based on your bank's terms.

There are LOTS of free activities at Great Wolf Lodge. All scheduled free events and attractions are available on the app.

Take photos and make sure to share!

Nothing says family like photos. Unfortunately, we never have enough photos because we just don't have enough opportunities to capture our moments together. And when we are together, we don't always think about taking photos. Please take lots of photos and upload them to our SmugMug page. We will remind you when you get there.

Story Telling Workshop Preparation

Story telling is something we do more than we realize. Stories are the human testimonials that change the world. People who are often in the position of making decisions about your life want to hear from the people who have Barth syndrome and their caregivers. They want to know the human impact of Barth syndrome in real terms. The stories of the people within the Barth syndrome community are the most powerful tools we have in making a difference for the people we care about.

The challenge with telling our story is we only have a brief window of time to make a big impact. That's where Kevin comes in. Our story telling coach, Kevin Friert is a master storyteller and hosts two podcasts featuring the stories of people living with rare disease. During the Stronger Together event, we will be working together to refine, improve, and practice telling our stories. So, it's important for us to give some thought to what we want to say when we get there.

To make the most of our time with Kevin, you will need to do a little homework.

- Answer the question, "*Why am I telling my Barth Syndrome story?*"
- Write out your story in a very short form. Try for no more than 2 pages, double spaced.