

# CHARGE Accounts

*The latest news, events, and announcements from  
The CHARGE Syndrome Foundation*

## Upcoming Events

**7/24-27/2025**  
**16th International CHARGE**  
**Syndrome Conference**

**8/8/2025**  
**CHARGE Syndrome**  
**Awareness Day**

## The CHARGE Syndrome Foundation

info@chargesyndrome.org

CHARGEsyndrome.org



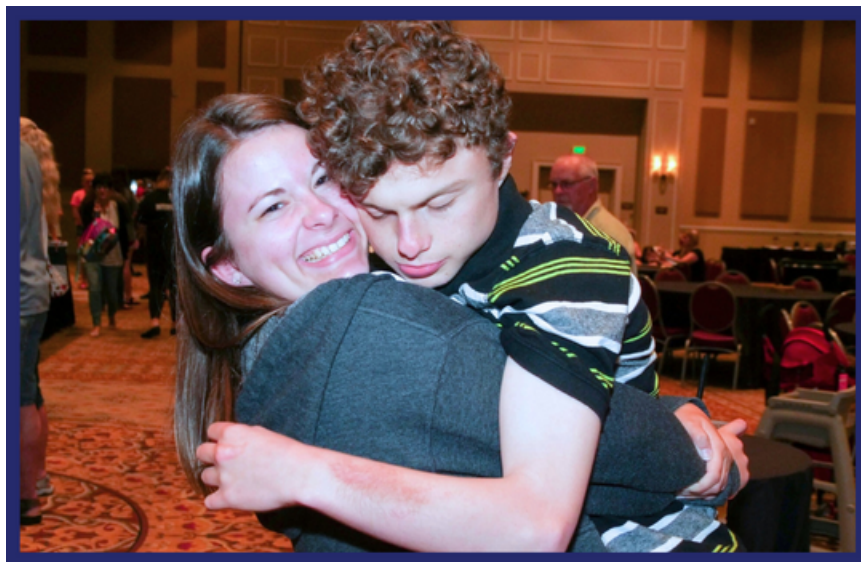
The CHARGE Syndrome Foundation



@charge\_syndrome\_foundation



@chargesyndrome



## Growing Up at Conference - A Sibling's Perspective

**By: Sarah Lent**

I've attended every CHARGE Syndrome Conference since my family started going in 2003, when I was seven. Conferences were our family vacations. My parents always made sure we got to explore the area - some highlights were the San Diego Zoo, the White Sox perfect game in 2009, and Disney/Universal trips in Orlando.

While at Conference, my favorite thing was going to Sibshops. I was lucky enough to attend the first Sibshops at conferences in 2005, attending as many as I could as a kid before helping as a Junior Leader, and as a Sibshops leader now.

I also vividly remember going to one of David Brown's

presentations about the eye when I was 13 and thoroughly enjoying it.

I didn't fully realize how magical Conferences were until I was a teenager. Having decided I wanted to go into Special Education because of my brother, I was so lucky to meet professionals in the field that I look up to. As an adult, I've loved getting to know other siblings, participating in Sibling Panels, and going off-site to In-n-Out or to the movies.

Conference has been such an important part of my life, and it always leaves me inspired. I'm looking forward to Phoenix, and all the Conferences to come.



[Click here](#) to watch Sarah's video about Sibshops and [click here](#) to learn more on our website.

Keep an eye on our [social media](#) in the upcoming weeks for all of the latest information about Conference, and be sure to [visit our website](#) for answers to all of your questions.

## 6th Annual Walk and Roll for CHARGE

Thanks to you, this year's Walk and Roll for CHARGE raised just over \$68,000 for the Foundation, with more than 420 people participating across the United States and Canada. Your efforts will increase awareness of CHARGE syndrome and help support our community through outreach, research, and direct assistance.



We loved seeing your photos and videos from far and wide. [Click here](#) to see a montage of the fun events around the world. In our "battle of the states" - New York came out in the lead with over \$8,370, followed closely by Massachusetts with over \$8,300, and California with over \$7,700!

Shout out to team CHARGE On New England for being at the top of our leader board. Their 49 team members raised over \$8,600!

Other top teams include Team Cyrus Wolf, raising over \$5,500; Team Danny Forever, raising over \$5,300, and CHARGE Forward with Harlen, raising over \$4,500.





Congratulations to the top individual fundraisers, Deanna Rothbauer, raising \$3,000, Kate Stone, raising over \$2,100, and Penni Echols, Suzanne Chen, Kristen Abaira, and Archer Miller, all raising \$1,500 or more!

And a special thank you to our sponsors: Perkins School for the Blind, Rady Children's Hospital, Texas Chargers, Mark Weiss Excavation, and Freedom Concepts, Inc.

## Logan Marty BBQ Fundraiser

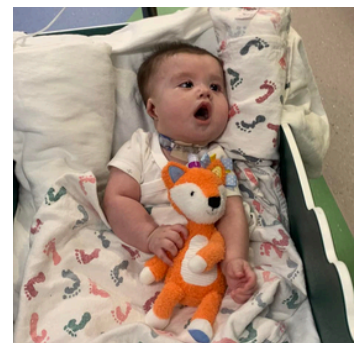
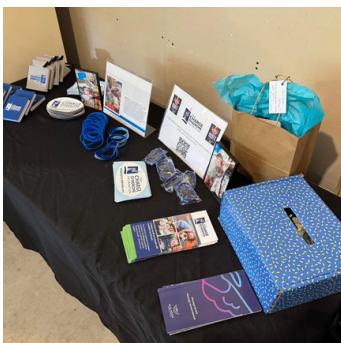
By: Caitlyn Marty

Our son, Logan, was born 10/26/21 and was eventually diagnosed with CHARGE syndrome from rapid genome sequencing when we were staying in the PICU. He was a strong little boy but sadly passed away 5/22/22, just shy of 7 months. He was a happy little guy who loved music, lights and his favorite fox toy. My husband and I do competition barbecue and started a catering company called Marty Party BBQ, our logo is a Mardi Gras theme with a pig, we created a fox logo to keep Logan with us.



In 2023, we hosted our first fundraiser BBQ to celebrate Logan's life and raise money for the foundation. We raised around \$5,500 in 2023, \$6,500 in 2024, and \$6,600 this year. At our BBQ, we serve free meals for our friends, family and neighbors and ask for free will donations. We have been blown away by the support our support system has given us and are so happy that everyone comes together to celebrate Logan every year. This year we welcomed Logan's little brother, Asher, and he was happy to help host our BBQ.

For more fundraising ideas, [click here](#).



# International CHARGE Syndrome Awareness Day

Save the date for the 2nd International CHARGE Syndrome Day.

CHARGE Syndrome Awareness Day is an international day to raise awareness of CHARGE Syndrome across the world, held every year on August 8th, marking the day the paper on the discovery of CHD7 gene was first published.

This year's theme is:

**STRONGER TOGETHER**

Connecting CHARGE around the world



For CHARGE Syndrome Awareness Day 2025, we're joining hands around the world—literally and symbolically — to raise awareness of CHARGE syndrome, a rare and often misunderstood condition. Whether it's a group hug, a people chain, or a virtual hi-five, it all counts. Together, we will show the world that no one faces CHARGE Syndrome alone.

## Connect with a group hug

Connect with family and friends for a group hug. It could be two people or 20 people. You could include a pet, or a favourite toy. Add your country's flag to show what country you come from.

Not into hugging? Create a people chain. Or a paper one. Make a short one and spell out the word C-H-A-R-G-E. Or make the longest one you can.

Share your creation on social media on 8 August and tag us using the following hashtags:

#CHARGEconnect #CHARGEstrongertogether #CHARGEstrongertogether  
#CHARGEsyndromeawarenessday #CHARGEsyndrome

[Join the CHARGE Syndrome Awareness Day Facebook group](#) for posts announcing this year's theme and to share your stories and photos.

# New Bikes for Christian and Logan

The Foundation's Ethan Wolfe Recreational Assistance Program (EWRAP) provides individuals with CHARGE syndrome the opportunity to participate in recreational activities.

Recently, we were able to award Christian with a Catrike Pocket Lava Red bike. His father, Jon Hay, says, "We are so grateful for Christian to have the opportunity to experience riding comfortably balanced. Thank you and the rest of EWRAP for supporting him."

This Spring, Logan received his new bike, and was excited to ride it around his favorite campground as soon as the weather warmed up! Logan's parents, Richard and Jenn, said, "This bike will give him so much fun, exercise and

freedom! We are so grateful to the CHARGE Syndrome Foundation, EWRAP and the Wolfe family for this magnificent gift of love. Thank you from the bottom of our very full hearts!"

We love providing individuals with CHARGE the chance to ride bikes specifically tailored to their needs. So we have partnered with Freedom Concepts and will be raffling off a custom-built bike at Conference! Be sure to visit the Sales Table at Conference to purchase your raffle tickets.

## Be a Part of the First Ever CHARGE Art Show!

Be part of history at our inaugural CHARGE Syndrome Conference Art Show on Friday, July 25th! Showcase your creativity—whether it's painting, sculpture, jewelry, digital art, or crafts—and inspire our community with your unique vision.

Theme: The Grand Adventure: Rising from Challenges Together





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All Conference attendees are welcome to apply to participate. Limited exhibition space – first come, first served!

Secure your spot now by [completing this form](#). The deadline is Wednesday, June 11th, 2025 —don't miss out!

## Why Art?

**By: Michelle Milder**

Why Art? Because of the endless benefits to development, mental health and self expression. In our home, we love making art, in all forms. Whether drawing pictures, coloring, making pretend galleries, writing stories, singing, or making clay sculptures, the benefits of participating in art making are countless and invaluable.

Engaging various art forms allows individuals, old and young, to explore imagination, and express thoughts, feelings, and ideas in unique and creative ways. It can even help with comprehension and understanding of more difficult concepts.

Participating in and enjoying the arts also has therapeutic benefits, allowing individuals to process experiences, feelings, and thoughts more thoroughly, which leads to better self-understanding.

As an art teacher myself, I have always valued what art appreciation brings to the table and have encouraged [my daughter] Stella to express herself in ways which she is most comfortable. Some of her favorite art activities include drawing, painting, writing stories, making pretend 'art galleries' and even playing with clay on her child-size throwing wheel. At school she also participates in Chorus with other students from her grade level. She's able to share her thoughts, mood and creative thinking that she may not be able to express otherwise.

I encourage everyone to try their hand at an artistic endeavor, whether drawing, painting, singing, or just appreciating art in the world around them. Notice the effects it has on you and the people around you.



# Pre-Order Your Conference Merchandise!

Show your support at Conference and beyond! Pre-order your family's limited edition CHARGE syndrome awareness merchandise. Your order can be shipped to your home prior to Conference, or choose "Pick up at Conference" to avoid a shipping fee and your items will be waiting for you at Conference Check-In. Check out our special "Glow Night" Conference t-shirts, perfect for Saturday's CHARGE-A-Palooza!



[Click here to shop now.](#) The deadline for pre-ordering is June 20, 2025.

## Conference Sessions Agenda Now Available

Find out all there will be to learn at the 16th International CHARGE Syndrome Conference!

We highly recommend that everyone look online at the Conference Agenda, prior to arriving in Phoenix, to get a preliminary idea of sessions you might want to attend. It can be a lot to figure out once you get to Conference after traveling with family, trying to get settled at the hotel, and so on.

[Click here](#) to view Conference Sessions Agenda to see the sessions that will be offered.



The four general theme areas under which most sessions are organized include: behavior, education, adult issues, and medical.

In addition to our information-packed program, there will be activities for the whole family. To learn more, visit [What to Expect](#) on our website. There will be something for everyone!

# Conference Family Checklist

Our 16th International CHARGE Syndrome Conference will be here before you know it! Here are some things you can do now, and some dates to keep in mind:



## ☐ Hotel reservation:

- [Click here to book your room](#). Deadline to book is June 29.
- Most families will come sometime Thursday and leave Sunday afternoon
- If you want to extend your stay, you can come in 2 days earlier and stay 2 days after Conference for the same rate of \$192.00
- You need a credit card to make a reservation

## ☐ Registration

- [Click here to register](#)
- **Register by June 30, 2025 to avoid additional late fees**
- Registration for individuals with CHARGE syndrome of any age is free; however they **MUST** register
- Other family members that will be attending Conference sessions, other Conference activities and participating in meals must register (including children 6 months and older)
- If you have any support personnel, such as nurses or interveners, traveling with you to Conference, they must also register

## ☐ CAMP (childcare)

- [Click this link to register for camp](#)
- **A separate registration is required for camp.** Individuals with CHARGE syndrome of any age, and and their siblings ages 12 and under, can attend camp
- Camp is free for individuals with CHARGE syndrome of any age, but they **MUST** register
- There are two options for CAMP: Camp Discovery has a lower staff to camper ratio (less staff per # of campers), for siblings and more independent campers; Camp Explorer has more structure and more staff
- Caregivers can attend Camp with your child, but they must be registered for camp and for Conference



## ☐ Sibshops

- For siblings ages 8-13
- Sibshops are held during the day at the same time as Conference sessions and camp. [Click here](#) for a short video about Sibshops
- If a sibling is attending camp, the Sibshops leaders will escort the sibling to and from camp
- A sibling may attend one half-day session of Sibshops
- You will have the opportunity to register for Sibshops when you register for Conference. If you have already registered, email [Conference@chargesyndrome.org](mailto:Conference@chargesyndrome.org)
- If there is enough interest, a teen Sibshop will be offered for siblings ages 14-18. The teens will gather together to share their experiences of having a sibling with CHARGE
- Junior leaders are siblings 16 years and older who will assist the Sibshops facilitators (Preference is given to siblings who have attended Sibshops at a previous Conference). [Click here](#) for more information and to apply to be a Junior Leader

## ☐ Volunteer

- Be part of the fun!
- We are seeking volunteers with a wide range of skills and time commitments
- [Use this application](#) to find the right fit for you
- Donate items for our silent auction and basket raffles
- We are seeking items for the silent auction with a value over \$250
- Gift baskets for raffle must have a combined value over \$75
- [You can donate items for the auction here](#)

## ☐ Questions? Email us at [Conference@chargesyndrome.org](mailto:Conference@chargesyndrome.org)

The 16th International CHARGE Syndrome Conference, “The Grand Adventure,” will be held at the JW Marriott Phoenix Desert Ridge Resort & Spa, in Phoenix, AZ, July 24-27, 2025. [Click here](#) to learn more.

**Do you have a story, event, or news item that you would like to have included in the CHARGE Accounts newsletter? [Fill out this form](#) to submit submissions for review.**