CHARGE Accounts

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

Upcoming Events

3/3/2025 16th International CHARGE **Syndrome Conference Registration Opens**

3/11/2025 **Parent-to-Parent Virtual Support Meeting**

3/13/2025 **Parent-to-Parent Virtual Support Meeting**

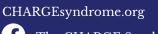
3/15/2025 **Birth-to-5 Year Parent Support Group**

3/27/2025 Familia CHARGE (Spanish-**Speaking Families Support** Group)

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The CHARGE Syndrome Foundation

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The CHARGE Syndrome Foundation



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16th International **CHARGE Syndrome Conference Registration Now Open!**

Registration is now open for our 16th International CHARGE Syndrome Conference, "The Grand Adventure," at the JW Marriott Phoenix Desert Ridge Resort & Spa, in Phoenix, AZ, July 24-27, 2025. Click here to register.

At Conference, your family will get to share experiences, learn from other families, make lifelong friendships, experience a sense of belonging unlike any other, and hear from the world's top experts in CHARGE syndrome. You don't want to miss it!

We will have a top-notch program with a wide variety of speakers who are the leading experts in CHARGE

Upcoming Events cont.

3/24/2025 Crocker Barker CHARGE Sibling Scholarship Applications Open

5/17/2025 6th Annual Walk and Roll for CHARGE

7/24-27/2025 16th International CHARGE Syndrome Conference syndrome. The four general theme areas under which most sessions are organized include: behavior, education, adult issues, and medical. In addition to the informational breakout sessions there will be events for the whole family, including the first ever Conference Art Show, camps, Sibshops, family events, auctions, meals, and more. A list of planned sessions will be posted on our website soon. There will be something for everyone! Click here to register.

We have secured a room rate of \$192 per night plus tax (for up to 4 people per room) at the JW Marriott Dessert Ridge in Phoenix, AZ. <u>Click here</u> to book your hotel room now.

If you would like to learn more about Conference, please <u>click here</u> to visit the Conference pages on our website.

The Conference Experience

By: Penni Echols, CHARGE Syndrome Foundation Vice President

I remember feeling overwhelmed at our first conference. There was so much new information, and I didn't want to miss a syllable! There were so many new faces, and I wanted to hear parts of each person's story. I left Orlando in 2017, wholly hooked on the conference experience and being with the "people who get it."



In the years since my first conference, I have enjoyed volunteering for the Foundation. Serving our mission and programs has nurtured friendships and given me a sense of purpose. I invite you to make <u>volunteering</u> part of your conference experience. It will allow you to meet others who are committed to making the world a better place for individuals with CHARGE syndrome and become fast friends.

I look forward to spending time with you all at our 16th International CHARGE Syndrome Conference, which will be held in Phoenix, AZ, from July 24 to 27, 2025. Come ready to celebrate together through art at our Friday night Art Show. Come party with us during our Saturday night CHARGE-a-palooza. Come with your mind open to fresh perspectives on our shared journey. Come with your heart open to welcoming first-time attendees. Come "home" to your CHARGE family.

Join the First-Ever CHARGE Syndrome Conference Art Show

Calling all artists! 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.





All Conference attendees are welcome to apply to participate. Limited exhibition space – first come, first served! Secure your spot now by completing the <u>Submission Form</u>. The deadline is Wednesday, June 4th, 2025—don't miss out!

Drop-off: Bring your artwork in person between July 23-25. NO ADVANCE SHIPPING

Art Show Submission Rules: Keep it positive, inspiring, and family-friendly.

BONUS OPPORTUNITY: Artists can donate their work to support the Foundation's fundraising raffle on Saturday, July 26th

Let's turn this event into an unforgettable grand adventure—submit your idea today!

Important Dates:

- Submission Form is now open.
- June 4: Submission form closes. No considerations after this time.
- June 25: Acceptance deadline. Artists will be informed of acceptance into the Art Show on a rolling basis and must confirm participation by this date.
- July 23, 12:00 PM: Art drop-off opens. Artists may begin to drop works at the Conference Registration Desk to be held until the display.
- July 25, 12:00 PM: Art drop-off closes.
- July 25, 7:00 PM: ART SHOW
- July 25, 9:00 PM: Art retrieval. Any art not being donated to Saturday's raffle must be removed from the event space.
- July 26, 6:00 PM: Fundraising Raffle. Items donated by artists will be available as a part of the raffle at our evening event.

For additional information, please contact <u>Conference@CHARGEsyndrome.org</u>.

Sibling and Adults with CHARGE Panelists

We are looking for participants for the following panels taking place during our 16th International CHARGE Syndrome Conference, July 24-27, 2025 in Phoenix, AZ. Please click on the links to fill out an interest form.

CHARGE Siblings:

https://forms.gle/jUKT8H8nawMlfjQx7 Adults with CHARGE:

https://forms.gle/EecoPbscgwJyCNuz9



We will have limited space, so participation is not guaranteed. Presenters will be live on stage, so should be comfortable sharing their story in front of a large audience.

*CHARGE Sibling panelists preferred to be aged 16+. Adults with CHARGE panel includes individuals 21+.

New Family Liaisons

Welcome our new Family Liaisons: Deanna Morelock, Ashley Bentley, and Kelly Merrifield.

Deanna Morelock lives in Arkansas with her son, Liam, who was born with CHARGE syndrome, and daughter Jane. Deanna says, "I want other families to know they are not alone. I can help provide information to help ease stress that comes along with the process"

Ashley Bentley, her husband Keith, and daughter Audrey are a military family living in South Carolina. Ashley volunteers with the Foundation "because military support is not talked about enough. There are a lot of services and programs offered through the military that can make transitions a lot smoother. I would love to give parents that sense of stability, that they are supported and loved throughout all of their journeys."





Kelly Merrifield lives in Michigan with her husband, Mike, daughters Mia (who has CHARGE syndrome) and Amelia, and son, Cass. Kelly volunteers as a Family Liaison because she wants "to help other families who are just starting their journey and support families when needed."



6th Annual Walk and Roll for CHARGE



The 6th Annual Walk and Roll for CHARGE is off to a great start! This year we want to have participants and fundraising in all 50 states - so far we have participants registered in 17 states. Click here to register, start fundraising, and help us reach our goals!

We currently have 4 teams that have reached the

\$1,000 fundraising goal and have received an official Walk and Roll for CHARGE Stanley cup (available to the first 30 teams or individuals to reach \$1,000). Qualifying teams will have their names on the back of our t-shirt (available to all teams or individuals who reach \$1,000 by April 13, 2025). Thank you to our current top fundraising teams: Ashor's Army, CHARGE On New England, Michele's Walkers, and Team Ahana!

Crocker Barker CHARGE Sibling Scholarship

Siblings of individuals with CHARGE are lifelong champions and significant supporters of their brothers and sisters. We want to recognize these siblings by providing an opportunity for them to continue their education post-high school.

The Crocker Barker CHARGE Sibling Scholarship was created, thanks to a generous donation from

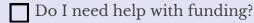


the Barker family, to help siblings of individuals with CHARGE syndrome fund their posthigh school education – including trade school, community college, or university. Scholarships are awarded based on merit and financial need. This award is payable to the post-secondary educational institution of the recipient's choice.

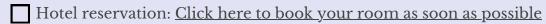
The 2025-2026 school year application cycle will open March 24, 2025. Deadline for applications is April 25, 2025.

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:



- Connect with your State Deafblind Project to inquire about scholarships
- <u>Check our funding guide</u>
- CHARGE Syndrome Foundation scholarships application window is now closed.



- 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 May 31, 2025 to receive the best pricing
- 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)

- 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
- You will receive a link to register for camp on your confirmation email once you have registered
- 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
- <u>Sibshops</u> are held during the day at the same time as Conference sessions and camp
- 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 be asked to register for Sibshops when you register for Conference
- 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). <u>Click here</u> 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? F	mail us at	Conference	@charges	<u>yndrome.org</u>
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Do you have a story, event, or news item that you would like to have included in the CHARGE Accounts newsletter? <u>Fill out this form</u> to submit submissions for review.