

CHARGE Accounts

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

Upcoming Events

5/8/2025

**Parent-to-Parent Virtual
Support Meeting**

5/13/2025

**Parent-to-Parent Virtual
Support Meeting**

5/17/2025

**6th Annual Walk and Roll for
CHARGE**

5/18/2025

**Birth-to-5 Year Parent Support
Group**

5/20/2025

**Ask the Expert - Preparing for
School Break**

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The CHARGE Syndrome Foundation

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The CHARGE Syndrome Foundation



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@chargesyndrome



The 6th Annual Walk and Roll for CHARGE is May 17th

Gather your family and friends and Walk and Roll for CHARGE on May 17th! Whether it's a big statewide event or a small family stroll, every step raises awareness and funds to support individuals with CHARGE syndrome. Join us and make an impact!

We are currently less than \$10,000 away from our Walk and Roll for CHARGE goal of \$50,000. Let's make this year's event the most successful yet!

[Click here to register today.](#)

We have special edition Walk and Roll for CHARGE Stanley cups available for the first 30 team leaders or individuals to raise \$1,000. There are lots of ways that you can earn money. In addition to sharing your

Upcoming Events cont.

5/22/2025

Familia CHARGE (Spanish-Speaking Families Support Group)

7/24-27/2025

16th International CHARGE Syndrome Conference

story and posting your fundraiser on Facebook, consider doing a fundraiser to help raise money for your Walk and Roll for CHARGE campaign. In the past, some of our top fundraiser teams have hosted bowling nights, sold handmade bracelets, and recycled cans.

We need fundraisers and participants from the following states to reach our goal of having participation in all 50 states: Alabama, Kentucky, Louisiana, Oklahoma, Michigan, Montana, New Mexico, North Dakota, South Dakota, Utah, and Vermont.

Our supplier will be shipping out the Walk and Roll for CHARGE shirts later this week, so if you ordered shirts be sure to keep an eye out!

Share your photos on social media using #WalkandRoll4CHARGE or [click here to email](#) them to our Marketing Department.

CHARGEon4Tucker's Bowling Fundraiser

By: Amanda Kutzura

On March 29th, CHARGEon4Tucker (led by the Kutzura Family in memory of Tucker), organized a bowling event to raise funds for the CHARGE Syndrome Foundation. Friends and family came together, purchasing tickets to bowl three games in support of the cause. The event also featured a bake sale and basket raffle, adding to the fundraising efforts.

“Our son, Hunter, was thrilled to add this donation to his Walk and Roll for CHARGE account in memory of his brother, Tucker. It was a day filled with love, remembrance, and a shared commitment to spreading awareness for CHARGE syndrome and honoring Tucker's legacy.”

Way to go, Hunter and thank you to all involved!

For information on ways you can fundraise, [click here](#).



Ask the Expert - Preparing for School Break

Join us for this month's Ask the Expert Webinar: Preparing for School Break, May 20, 2025, 7 PM ET, with presenters: Sara Espanet, M.Ed., Megan Schmittel, Ph.D., and Sharon Stelzer, M.Ed. Need help figuring out what to do over school break? Join us in discussing strategies and activities to do with your family during breaks from school!



[Click here](#) to register.

Sara Espanet, M.Ed is a Supervising Practitioner at Perkins School for the Blind, Watertown, MA, in the Deafblind School. Sara started working at Perkins School for the Blind in 2008 as a teaching assistant. In 2015 she became a classroom teacher after receiving her Masters in Severe Special Education from Bridgewater State University. Sara works with students who are deafblind and multimodal learners. Sara was a Fellow in the Sandra Davenport Fellowship Program in 2015. In 2024 Sara joined the Board of Directors of the CHARGE Syndrome Foundation.

Megan Schmittel, Ph.D, is an Assistant Professor in the Psychology Department at Westminster College in Fulton, MO. Prior to teaching at Westminster College, Megan worked as a school psychologist for Perkins School for the Blind and Jefferson City Public School District in Jefferson City, MO. In these roles, Megan co-facilitated small social skills groups and provided 1-on-1 social and emotional regulation instruction for children who are Deafblind. Megan received her doctorate degree in school psychology from Central Michigan University where she studied under Dr. Tim Hartshorne and was a member of the CHARGE Syndrome Research Lab. Megan's research interests include the development of social play in children with CHARGE syndrome, as well as the social-emotional development of individuals who are Deafblind.

Sharon Stelzer, M.Ed. is a Supervising Practitioner at Perkins School for the Blind. Sharon has been a teacher, lead teacher and a supervising practitioner in her 40 years at Perkins School for the Blind. She was a classroom teacher for students who are Deafblind for 35 years, including students with CHARGE syndrome. Sharon is active in the CHARGE and Deafblind communities as a consultant, mentor and presenter.

Webinar: Thoughts on Behavior in CHARGE

Join the DBI CHARGE Network for a webinar on Wednesday, May 21, 2025: Thoughts on Behavior in CHARGE, with Dr. Tim Hartshorne, Professor Emeritus of Psychology, Central Michigan University.



This presentation will address Tim's thinking about behavior in CHARGE Syndrome and how it has evolved over the past 30 years. How should we think about the challenging behavior often displayed by persons with CHARGE? Why would a person with CHARGE choose to engage in behavior which challenges parents and professionals? Tim will talk about some of the reasons for the behavior and how recognizing the communicative relationship of behavior can help us to change it. It should be noted that everyone is welcome to participate (e.g., fathers, mothers, professionals, researchers).

There will be two webinars on the same topic, at different times, so participants can choose the best time that suits their schedule. We are working with partners to provide different language interpretation. Participants will need to choose their preferred language when signing up for the webinar if your captioning has this option. (The presentation is in English).

During the webinar it is possible to ask the presenter questions.

All times are listed in Central European Summer Time (CET). To find the webinar that suits your schedule we advise you to check your local time zone:

<https://www.worldtimebuddy.com>

Session 1: Wednesday, May 21, 2025

Central European Summer Time 1500h-1630h

Presenter: Tim Hartshorne

Facilitators: Heather Colson-Osborne, Allison Mail, Lourdes Quintana Baez, Jerry Petroff

Session 2: Wednesday, May 21, 2025

Central European Summer Time 20.00h-2130h

Presenter: Tim Hartshorne

Facilitators: Anne Schoone, Heather Colson-Osborne, Jerry Petroff

[Click here](#) to send an email to register in advance for this webinar. Please include:

- Name
- Email
- Country
- Any considerations regarding accessibility or language
- Are you a person with lived experience/ parent/ professional/ researcher
- Which session you would like to attend
- What language would you like to use with the captioning

Be Paired with Davenport Fellows at Conference

We are seeking families interested in being paired with a pair of Davenport Fellows at Conference.

The child or young adult with CHARGE syndrome must be attending camp.

The Davenport Fellowship program is a prestigious program that brings early career professionals to the International CHARGE Syndrome Conferences, where they have the opportunity to learn more about CHARGE syndrome, interact with one another and get to know individuals with CHARGE syndrome and their families.



[Click here](#) to learn more about the Davenport Fellowship and the 2025 Fellows.

What is required?

- Have a child/adolescent with CHARGE who is registered for camp (the pair of Davenport Fellows will volunteer for ½ day of camp with your child).
- Communicate with the Davenport Fellows in advance of Conference.
- Meet the Davenport Fellows at the Thursday evening welcome activity.
- Eat 1-2 meals with your Davenport Fellows during Conference.

Please [click here](#) to complete the application by May 30, 2025.

Important Conference Reminders

Auction Items Needed for Conference

Our fun-filled auctions are always one of the highlights of the CHARGE Conference weekend festivities. We will be having a Silent Auction and Basket Raffle to raise money for the Foundation.

We need donations of themed baskets with a value of at least \$75 (dinner and a movie, family movie night, day of beauty, sports collectibles, kids games, coffee lovers, chocolate fanatics, wine aficionados, basket of items from your hometown or state). We also need additional higher ticket items such as sports tickets and memorabilia, timeshares or condos, fine jewelry, and electronics for the Silent Auction.

Please help us by soliciting local businesses, friends, family, and colleagues.

Click here for the [donation form](#) and [solicitation letter](#). Contact conference@chargesyndrome.org for more information.



Remember to register for camp!

We are pleased to offer a camp program for individuals with CHARGE and their siblings.

Corporate Kids Events (CKE) will run our onsite camp and will provide fun, entertaining activities for the kids while the adults attend conference sessions. Arts and crafts, magic shows, and petting zoos have been part of the camp program during prior conferences.



There are two camp options: Camp Discovery has a lower staff to camper ratio (less staff per # of campers), for siblings and more independent campers, whereas, Camp Explorer has more structure and more staff.

- Both camps will be together for certain activities.
- There will be a professionally-staffed calm room containing sensory items and a soothing atmosphere, which will be available if campers need a space/time to calm down.

- Camp is free for all individuals with CHARGE but all campers must be registered.
- Your caregiver may attend camp with your child. The caregiver must be registered for Conference.

Once you have registered for Conference, you **MUST** fill out a separate registration for camp.

[Click here to register for camp.](#)

Pre-order your Conference Merchandise

Show your support at Conference and beyond! Pre-order your family's limited edition CHARGE syndrome awareness merchandise and choose to have them 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.

Submit Your Ideas for the first ever CHARGE Art Show

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.



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

[Click here](#) to fill out the submission form and secure your spot now. The deadline is Wednesday, June 4th, 2025—don't miss out!

Become a Conference Exhibitor or Sponsor

Becoming a sponsor or exhibitor at the 16th International CHARGE Syndrome Conference will maximize your organization's exposure while also ensuring that your support directly impacts the lives of individuals affected by CHARGE syndrome. All sponsorship levels also include an exhibit space.



The 2025 Conference is expected to attract more than 1,200 people, including individuals with CHARGE, their families, and the professionals who work with them, all searching for information about the products and services you offer. Being an exhibitor offers you the opportunity to interact with:

- Individuals with CHARGE syndrome
- Family members and caregivers
- Teachers of Students who are Deaf and/or Visually Impaired
- Orientation & Mobility Specialists
- Physicians
- Physical & Occupational Therapists
- Audiologists
- Speech Language Pathologists
- CHARGE researchers
- Representatives from organizations, schools and government agencies who support people affected by deafblindness...and more

What Would Attendees Like to Learn About?

- Educational Placement and Advocacy
- ASL Learning
- Adaptive Equipment
- Sleep Aids
- Assistive communication...and more

Exhibits will be open Friday and Saturday.

[Click here to become an Exhibitor or Sponsor.](#)

Deadline for registration is June 1, 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:



☐ Hotel reservation: [Click here to book your room as soon as possible](#)

- 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)

- [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
- 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 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

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.