

CHARGE Accounts

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

Upcoming Events

8/8/2025

2nd International CHARGE
Syndrome Awareness Day

9/8/2025

Ask the Expert: Creative Café:
Person-Centered Scrapbook-
Making

9/21/2025

A Day to Remember

The CHARGE Syndrome Foundation

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The CHARGE Syndrome Foundation



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16th International CHARGE Syndrome Conference

It was a grand adventure in Phoenix! We appreciate everyone who made the trip for the 16th International CHARGE Syndrome Conference. We had just under 1,000 attendees from 47 states and 14 countries, including 334 first-time attendees, and 229 individuals with CHARGE.

We recognize that it is not always easy for our families to travel and we appreciate the effort everyone made to come together. It was an amazing opportunity to connect, learn, and have fun!

A special thank you to all of our presenters, including medical professionals, educators, parents, siblings and individuals with CHARGE syndrome, for helping us present an educational and informative program; and to our volunteers, without whom this would not have been possible.

We would also like to express our gratitude to everyone who generously made a donation during Conference, and to those who became members or upgraded their membership. [Click here](#) to support the Foundation's programs by becoming a member.

[Click here](#) to see all of the photos from Conference.

[Click here](#) to see the Presentation Handouts.

[Click here](#) to take our post-Conference survey.

Did you miss your chance to shop the Sales Table at Conference? Check out our [CHARGE Syndrome Awareness store](#).

CHARGE Family Sports and Recreation Workshop

Fourteen families had the opportunity to attend the CHARGE Family Sports and Recreation Workshop at Conference, presented by Lauren Lieberman and her Camp Abilities team.

Check out the video that captured the fun, created by Samantha Leung from RIT created [this wonderful video](#) of the workshop.



Please share with other families and your physical education teachers. Your children deserve to be engaged fully in physical education with some of the modifications in the video. Please stay active and stay in touch! -[Lauren Lieberman, Ph.D.](#), Director of Camp Abilities

17th International CHARGE Syndrome Conference

We are excited to announce that we will be returning to the Hilton Anatole in Dallas, TX for the 17th International CHARGE Syndrome Conference, July 22-25, 2027! We look forward to seeing ya'll there!

Keep an eye on social media and email for upcoming opportunities to vote on the Conference theme.



Thank You Conference Sponsors

Thank you to our incredible Conference Sponsors. So much is involved in Conference, including the cost of the hotel, interpreters, camp, and scholarships. We truly would not be able to do it if it weren't for their support.

Click on the logo to visit the sponsor's website.

Diamond Sponsors

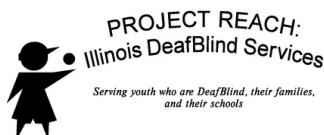


CHARGE for Connor is a nonprofit organization formed in 2014 as a way to remember Connor Logsdon and carry on his legacy. We create opportunities for CHARGE families to have a moment to feel belonging and acceptance. We fund scholarship programs to assist individual families with the cost of attending the International CHARGE conferences. We share information and resources to better support their children. We connect children to others like them. All money and resources go to families in need. We also contribute to the unique and amazing CHARGE Center at Cincinnati Children's Hospital.



The Leber Legacy Foundation is devoted to uplifting lives and advancing opportunity through compassion-driven, spiritually-rooted support. We partner with organizations that serve the overlooked and underserved—empowering individuals with disabilities, survivors of trafficking, aspiring entrepreneurs, and future leaders. Guided by faith and a commitment to lasting change, we strive to reflect love, dignity, and purpose in all we do.

Platinum Sponsors



Project Reach is a federally funded (National Technical Assistance and Dissemination Center for Children Who Are Deaf-Blind CFDA No. 84.326T) program focused on supporting adults in the lives of children and youth with deafblindness. It is currently funded until September 30, 2028. Free services include information referral, training, side-by-side coaching, and other supports, both at distance and in homes, schools, and other environments where children and youth with deafblindness learn and grow. Project staff members include deaf-blind specialists and family specialists with many years of experience.

Gold Sponsors



At DeafBlind Central (DB Central), part of the College of Education and Human Services at Central Michigan University, we maintain the belief that individuals who are DeafBlind share equally in the respect, opportunity, and life enjoyment afforded to all individuals. DB Central provides free services, year-round, for both families and professionals who support students who have combined vision and hearing loss from ages birth to 26.



Miles to Row is a unique children's book club that features diverse stories, authors, and illustrators. We aim to spark important conversations and expand your library to reflect our diverse world. Help us build a community that represents us all. With every purchase, we donate one of our diverse book selections to local schools, libraries, and nonprofits.



The New York DeafBlind Collaborative (NYDBC) is a federally funded grant (10/1/2023 – 9/30/2028) that provides technical assistance to improve services for children and youth between the ages of 0-22 who are DeafBlind.



Perkins School for the Blind is the worldwide leader in education services for children and young adults who are blind and visually impaired with multiple disabilities. An international NGO, we are infinitely innovating to solve longstanding and emerging problems facing our communities, our students and our families.

Silver Sponsors



As the global leader in implantable hearing solutions, Cochlear has helped over 700,000 people to hear with one – or two – of our implantable solutions.



Freedom Concepts custom-builds adaptive tricycles, Chill-Out Chairs, and other early intervention devices. Our products provide mobility and therapeutic benefits to thousands of individuals throughout Canada, the United States, and globally.

Silver Sponsors (cont.)



As the world's leading nonprofit on sensory accessibility and acceptance, we make the Nevers possible by creating sensory accessibility and inclusion for those with invisible disabilities.



At Rady Children's Hospital, we take pride in providing the best pediatric care and management of children diagnosed with CHARGE syndrome. Our program for patients with CHARGE is distinctive due to our expert multidisciplinary team approach, ensuring that each child receives comprehensive and coordinated care tailored to their unique needs. Medical professionals in our program include Otolaryngology (Ear, Nose & Throat), Audiology, Plastic Surgery, Nephrology, Urology, Genetics, and our Heart Institute. With the opening of a dedicated CHARGE center in San Diego, California, we recognize the critical importance of accessibility for families on the West Coast. Our goal is to bridge this gap by providing CHARGE families with the exceptional, synchronized care their child needs. A coordinated team evaluation is conducted to assess each child's individual needs and produce an ongoing care plan to help CHARGE patients based on input from all disciplines.



We provide beauty professionals with high-end, fully equipped private salon studios alongside the support and tools needed to launch your business in no time.

We take pride in being the largest, fastest-growing salon studio business with a thriving community of over 20,000 industry-leading beauty professionals and 700+ locations nationwide.

2nd International CHARGE Syndrome Awareness 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 CHARGE Connects. If you live with a rare and complex syndrome, connection to peers is vital for people's mental health and wellbeing. On August 8th, we will be joining hands around the world— literally and symbolically — to raise awareness of CHARGE syndrome. 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 favorite 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.

[Join the CHARGE Syndrome Awareness Day Facebook group](#) to share your stories and photos. Post your message on social media using the following hashtags:

#CHARGEconnect

#CHARGEstrongertogether

#CHARGEsyndromeawarenessday

#CHARGEsyndromeworldwide

Ask the Expert: Creative Café: Person-Centered Scrapbook-Making

Join us for an Ask the Expert webinar entitled Creative Café: Person-Centered Scrapbook-Making with Yumi Shirai, PhD, on Monday September 8, 7-8pm EST.

[Click here](#) to register.

Dr. Shirai is an Associate Professor at the Sonoran Center for Excellence in Disabilities at the University of Arizona. She also serves as an affiliate faculty member with the Applied Intercultural Arts Research and Innovation in Aging programs. She holds a PhD in Family Studies and Human Development and an MA in Theater/Dance, both from the University of Arizona. Dr. Shirai's work focuses on community-based programs and research projects that use creativity and the expressive arts—such as movement, theater, and storytelling—to support a meaningful and quality of life for adults with intellectual and developmental disabilities (IDD). Her approach is highly collaborative, engaging individuals with IDD, their families, and care providers in the sharing of knowledge and creation of innovative practices.

As co-director of the Family Medicine Residency Scholarly Project Program, Dr. Shirai mentors medical residents in their research and contributes to the Medical Humanities curriculum, helping future physicians connect more deeply with the human experience of healthcare.

The Creative Café: Person-Centered Scrapbook-Making Workshop invites individuals with intellectual and developmental disabilities (IDD) and their caregivers to collaboratively creating a person-centered planning supplement in a scrapbook format. This arts-based workshop offers participants a meaningful outlet for self-exploration and expression, helping them capture and share their life stories—an essential step toward healthy, community-based living.

The resulting document serves as a valuable tool to strengthen community connections and relationships for individuals with IDD, while also providing caregivers with important insights to deliver more personalized, person-centered support.

In this interactive session, Dr. Shirai will guide participants through key steps and creative strategies for generating, sharing, and synthesizing personal stories. She will lead engaging activities, present real-life examples on selected topics, and offer practical guidance on how participants can adapt this scrapbook-making approach to their own areas of interest or professional contexts.



Music Therapy for Sophia

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

Sophia is a recent EWRAP recipient and is excelling in her music therapy classes.

Mom, Amanda, says, “Thank you I really appreciate [this program] and so does Sophia! Thanks for giving her the opportunity to try something new!”

If you would like to learn more about EWRAP, read other recipient stories, and apply, please [click here](#). Everyone deserves the chance to play!



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.