OCTOBER 2025

CHARGE Accounts

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

Upcoming Events

10/1/2025
New Charge it for CHARGE Now Open

10/5/2025
Parent Re-CHARGE Hour

10/5/2025
Adults with CHARGE Social (Email to register)

10/7/2025
Familia CHARGE

10/11/2025
Birth to 5 year Parent Support Group

10/15/2025
Research Grant Cycle Opens

The CHARGE Syndrome Foundation

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Celebrating Our Incredible Volunteers

By Penni Echols

Our conference would not be possible without volunteers. Over 400 individual volunteer assignments were filled by Conference attendees and local area partners. Volunteering at Conference is the ultimate gift of kindness to our community.

Professionals
Beginning with the planning of the conference, dozens of dedicated professionals volunteered their time and expertise to provide the educational content. In addition to their presentations in general sessions and breakout sessions, the professionals also took time to answer every question asked. Many also spent time in camp to ensure the sensory needs of the campers were met. Highly skilled interpreters, familiar with the communication needs of individuals with deafblindness and CHARGE

syndrome, donated their time to ensure that every attendee was able to participate in educational and recreational activities. Registration was staffed by a large group of volunteers from the Perkins School for the Blind, who also provided social stories on what to expect at the conference, allowing attendees to prepare for all the learning opportunities and activities during the event.

Locals

We had many helping hands from families and community supporters in the local area who assisted with the physical preparation for the conference. They received hundreds of items in advance of the event and then helped prepare handouts, merchandise, evening event activities, and camp supplies to be ready for use. Local partners included the Arizona Deafblind Project, Arizona State School for the Deaf and Blind, the Phoenix 100 Rotary Club, and Starbucks.

Attendees

Individuals with CHARGE volunteered in all areas of the conference, including presenting in general and breakout sessions. Steven Muck and his mother, Valerie, volunteered every day during the conference. They helped to greet attendees at meals, set up evening events, and arrived early to the conference to help assemble raffle baskets. Tim Halloran always lends a hand during conference. We love to see him greeting attendees at meals, and this year, he made sure that everyone at the CHARGE-a-Palooza event had as many glow bracelets as they wanted. Brandon Marshall is the captain of the unofficial “Guys Night Out,” and he always makes sure that everyone feels welcome. He helped organize conference supplies early in the week, assembled registration bags, organized and assembled raffle baskets, spent time in camp, and helped at every evening event. If you stopped by the sales table during registration, Phil Wismer was there to assist you. Everyone loved catching up with him, and he was a great salesman.

Many siblings of individuals with CHARGE made an impact as volunteers. Max and Zach Wendoll mobilized boxes of supplies for every evening event and then returned each night to help with the cleanup. Peter Lynn helped with the basket raffle setup and became an expert in using the hotel carts to move items from storage to the event space. Entire families came together to work. The Harvey family from Utah arrived early to unbox and organize conference items and moderated several breakout sessions. The Shikora family was instrumental in making sure everyone had fun on Saturday night. We were thankful for the help from the families of our Board and staff who picked up shifts in camp, worked in registration and sales tables, and were instrumental in assembling and maintaining the community art projects.

With so many valued volunteers during the conference, it is impossible to acknowledge each act publicly. The volume of your impact is truly immeasurable because it touches every minute of our time together. It is incredible what we built together in Phoenix, and together, we will do it again in Dallas. Thank you for sharing your unique skills and talents to make our conference accessible, informational, safe, and fun.

If you are interested in Volunteering with the Foundation, please click here to fill out our Volunteer Interest Form.

New Charge it for CHARGE Campaign Begins!

We have just opened up our 2025-2026 Charge it for CHARGE Campaign. Charge It for CHARGE is our Foundation's year-round fundraising platform.

It is quick & easy to set up your fundraising page!
Click here to set up your fundraising page
Click here for a quick tutorial on how to set up your fundraising page.
Click here for CIFC fundraising ideas.

There are so many ways you can use your fundraising page to raise money throughout the year:

- Share your family's story on social media or via email.
- Use as a fundraiser surrounding an event – a birthday, holidays, graduation, or other milestone.
- Use the online platform to collect money raised before, during, and after a fundraising event so you don't have to collect cash and checks.

Money raised through the Charge It for CHARGE campaign helps the Foundation fund:

- Family Assistance Programs
- Interpreters for Educational Webinars
- Conferences
- Outreach
- Research

If you set up a Charge it for CHARGE Fundraising Page in 2024-25:

- Your fundraising link and page remain the same - no need to make a new page every year going forward! You are still able to make updates to your page if you want to change your photos or your story
- Your current Fundraising Page has been rolled over to our 2025-2026 Charge it for CHARGE campaign and your fundraising total has been zeroed out (unless otherwise requested)
- Going forward, we will zero out the total at the end of each calendar year so that you are able to see how much you have raised throughout the year

Research Grant Cycle Opens

Thanks to the generosity of our donors, over the years the Foundation has been able to fund high quality CHARGE syndrome-related research projects. Many of our grant recipients have published their research in prestigious journals. Our research grant recipients have gone on to receive close to $12 million from the NIH and other government agencies.

If you are a researcher or know anyone who would be interested in this opportunity, please see the below scientific research grant program details. Grants are available for up to $50,000 each.

The purpose of these grants is to promote:

- New biomedical research into the etiology, genetic and molecular mechanisms and treatment of CHARGE syndrome, or
- New research into clinical and medical diagnosis and treatment of CHARGE syndrome.

Both established and new investigators are encouraged to apply. Proposals are for funding from April 1, 2026 to March 31, 2027 and may be in any area of basic, clinical, translational or epidemiological research. All proposals will be peer reviewed. Preference will be given to investigators who are new to CHARGE research and/or to new projects with clear potential to lead to future funding from other agencies.

Application process opens October 15, 2025. Application deadline is December 15, 2025. Award notifications March 15, 2026

Click here to learn more and apply.

The Importance of Community

by Alexis Ramirez

When you become a parent, you're constantly told "it takes a village". When you become a parent to a child with a rare diagnosis and get thrown off the deep end to a world of medical complexities and trauma that village becomes your life line. Sometimes the village you need doesn't exist in the traditional sense, not everyone has family and friends that are there for them, or you no longer know how to relate to those around you when your life is far from what you envisioned.

For me that's why becoming a part of the CHARGE Syndrome Foundation Facebook Group, and later the Birth to Age 5 Support Group, was a saving grace during the hardest time of my life. In the early days it felt like I was treading water but the shore kept moving further and further away, no one in my day to day life had gone through what I was currently going through, I had no one to talk to. When I joined the Facebook group I felt like someone threw me a life preserver. I learned more from scrolling and reading about people's experience with CHARGE than I did from any doctor. This group connected me with other moms whose kids were the same age as mine and they became the ones I talked to and still talk to daily. When we created the Birth to Age 5 Support Group, our goal was to give families in those early years a place to connect face to face, a place to talk about the good and the bad, to ask questions, be each other's sounding board and foster more connections. A place to find your village even if it looks a little different than you thought it would.

Click here to join the CHARGE Syndrome Foundation Facebook Support Group.
Click here to register for the Birth to Age 5 Support Group.

> "Becoming a part of the CHARGE Syndrome Foundation Facebook Group, and later the Birth to Age 5 Support Group, was a saving grace during the hardest time of my life."

Reflections from a Sandra Davenport Fellow

By Symone Griffin

The 2025 International CHARGE Syndrome Conference strengthened my identity as both a nurse and an individual with CHARGE syndrome. Through the Sandra Davenport Fellowship, my family match, volunteer roles, and breakout sessions, I saw how far our community has come. As an attendee since 2015, this was the first conference where I truly felt that adults with CHARGE were seen as mature individuals who have something significant to contribute—not only to society, but to the Foundation itself. For the first time, we were actively invited into the conversations about our care and our future.

Fellowship

Being a Davenport Fellow gave me the structured space to process my lived experience and to learn how to support others through a professional lens. Walking into the conference felt like entering a room where everyone already speaks the language of my life. The combination of science, story, and community made this an ideal launchpad for what I want to build next—both personally (skills, networks) and systemically (adult care pathways, research, and communication access). It was truly the perfect first chapter in my deeper journey into "CHARGE World."

During my time at the conference, I learned many key points that will help improve the lives of individuals with CHARGE. Research is crucial: from genotype/phenotype studies to behavioral and mental health outcomes, I saw how data drives funding, clinical protocols, and family guidance. Even "basic" education about CHARGE remains essential—because parents, teachers, and clinicians who are new to CHARGE need an accurate foundation to build upon. I also learned that communication barriers are more detrimental than many assume. Across sessions and stories, communication challenges consistently surfaced as the root issue complicating nearly everything else: behavior, education, health care access, and independence. Building practical, individualized communication systems (including ASL, AAC, and trained partners) is essential.

Participating in this fellowship alongside such accomplished peers was a highlight. Learning shoulder-to-shoulder with them, while also engaging with established professionals in the

CHARGE community, gave me confidence in my ability to pursue anything I set my mind to. Each of us had something phenomenal to add to “CHARGE World”. I feel honored to have worked, conversed, and laughed with such a bright and wonderful group of individuals. I also deeply admire the dedication and expertise of the mentors who guided us throughout the fellowship. Their insight and encouragement set a powerful example of leadership that I aspire to follow in my own advocacy and professional journey.

Family Match

One of the most meaningful parts of the conference for me was being matched with Cami and her mom, Lili. Cami is a joyful three-year-old whose favorite color is green. She enjoys some food but is currently 100% tube-dependent. She has two cochlear implants, communicates in sign language, and is thriving beautifully. Cami also shows many classic CHARGE characteristics, and I noticed she does some of the same exact things I used to do as a child—running in circles, crawling, and throwing herself around. She attends a deaf school and loves it, which gives her a strong foundation for communication.

Lili and her husband, Zach, are a lovely, dedicated young couple. Their love and commitment to Cami’s well-being shone through every interaction. They were attentive, proactive, and eager to learn and connect. Being able to share my story and experiences with them, while also simply being present with their family, was an honor. It gave me the chance to be a role model and show what’s possible, while also learning from the strength and dedication of parents at the beginning of this journey.

I also had the opportunity to partner with Stacey, my co-fellow, for this family match. Working with Stacey was wonderful—her warmth, insight, and energy made our partnership strong, and together we were able to support Lili and Cami in meaningful ways. This experience reminded me of the power of collaboration and how much stronger we are when we work together.

Volunteering

While volunteering at camp, I was able to connect not only with Cami but with other children with CHARGE as well. From my own experience living with CHARGE syndrome, and working every day with medically complex children, I was able to see them beyond their diagnosis. It squeezed my heart to see all the children interact with one another without judgment or worry about whether they would be included.

Camp also reminded me that Cami is, above all else, a typical three-year-old—curious, playful, and full of joy. She absolutely loved parachute time and was devastated when it was put away.

I also learned the ASL sign for “Mama” as Cami fiercely signed it when she was done playing. Volunteering at camp allowed me to connect with her not just as a child with CHARGE, but simply as a little girl living her best three-year-old life. I also volunteered as a moderator for Dr. Blake’s presentation on “Medical Issues in Adults with CHARGE.” I enjoyed taking charge (no pun intended) and supporting with directions, transitions, and informal peer support. Volunteering in this role let me contribute to the invisible scaffolding that makes the conference work, and it gave me confidence that I can take on large commitments and execute them successfully.

Professional Day

I thoroughly enjoyed Professional Day. The poster presentations were well constructed and the information was both intriguing and easy to understand. I had the opportunity to sit alongside highly accomplished professionals—people with advanced degrees, research expertise, and years of experience in the CHARGE field. Initially, I felt humbled to be among such an elite group, but what struck me most was how eager they were to talk with me. They treated me as a peer, recognizing that my lived experiences carry equal value alongside their academic knowledge. That moment showed me that my contribution was just as significant as anyone else’s.

During one of the sessions, I opened the floor with a question that has been on my heart: “What about adults with CHARGE?” Asking that question in a room full of professionals who have the influence and expertise to make real changes felt both empowering and necessary. The response was overwhelmingly positive—several professionals came up to me afterward to share how proud they were that I raised the issue. That moment affirmed for me that adult voices are not only welcome in these spaces—they are essential. It proved that one question can spark meaningful conversations and that I have a role in shaping the future of CHARGE care and research.

Glow Party

The Glow Party was pure joy! It was so refreshing to set aside the serious conversations and just dance, laugh, and celebrate with other self-advocates, families, and professionals. We had so much fun it was hard to call it a night! I got the chance to meet even more families I had only known online, which made it feel like a true reunion. The music, lights, and energy brought everyone together in such a unique way. I loved seeing the same people I had seen that morning in professional clothing now in funky outfits, letting loose and having fun. It was the perfect reminder that while CHARGE comes with challenges, our community also knows how to celebrate life.

Closing

I left the 2025 CHARGE Conference with clarity, inspiration, and momentum. This fellowship reminded me that my voice matters, my story has power, and adults with CHARGE have an essential place in shaping our community's future. I am deeply grateful to the Foundation, to my mentors for their wisdom and guidance, and to my peers for their encouragement and camaraderie. Most of all, I thank Lili and Cami for letting me share in their journey, and Stacey for being such a supportive co-fellow partner.

Research Opportunities for Families

CHARGE research could not take place without the participation of families. Please see below for some new research opportunities available. All projects have been approved by Institutional Review Boards (IRB).

EXPLORING PAIN IN CHARGE

We need your help – all ages!

The Mississippi State Bulldog CHARGE Syndrome Research Lab is currently conducting a research study exploring pain in CHARGE Syndrome. Specifically, this study aims to examine pain experiences in individuals with CHARGE throughout the lifespan. While previous research on pain has been examined in various populations of individuals with disabilities, there is little research involving those with CHARGE and no research including adults with CHARGE.

THIS STUDY IS BEING CONDUCTED BY DR. KASEE STRATTON-GADKE AT MISSISSIPPI STATE UNIVERSITY. YOU CAN CONTACT HER AT KKS196@MSSTATE.EDU. THIS STUDY WAS APPROVED BY IRB:

WHAT DO WE NEED FROM YOU?

We request that interested individuals click on the link below to complete an online survey, including an observation of your child (20-30 minutes). After completion of this survey, you will be sent a second survey approximately 24 hours later to complete a second observation (10-15 minutes).

WHO CAN PARTICIPATE?

1. Parents/Caregivers of a person with CHARGE of all ages
2. Adults with CHARGE (18+) can complete this survey. Both parties do not have to participate.

Click here to complete the survey.

You may also be eligible to win one of ten $20 gift cards to Amazon, Walmart, or Target for completion of BOTH portions of this survey!

All data collected will be stored anonymously; neither your participation nor responses will be known by others. Please contact Dr. Kasee Stratton-Gadke, Professor and Licensed Psychologist, or Jamie Moss, Graduate Student, if you are interested in participating or would like to inquire about any further information: kstratton@tkmartin.msstate.edu or jkm516@msstate.edu

Parent perceptions of genetic diagnosis in the inpatient setting in the neonatal intensive care unit (NICU), pediatric intensive care unit (PICU), and cardiac care unit (CCU)

Would you like to share your thoughts about your experience receiving your child's genetic diagnosis?

We are recruiting parents and caregivers who had a child that received a genetic diagnosis while in the NICU, PICU, or CCU to share their experiences in a 10–15-minute online survey. Responses from this survey may be used to guide medical providers in giving genetic diagnoses and support to families in the inpatient setting.

To participate, you must be 19 years or older and have a child who received a genetic diagnosis while in the NICU, PICU, or CCU.

Click here to complete the surey.

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.