SEPTEMBER 2025

CHARGE Accounts

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

Upcoming Events

9/7/2025
Parent Re-CHARGE Hour

9/8/2025
Ask the Expert: Creative Café: Person-Centered Scrapbook-Making

9/13/2025
Birth to 5 year Parent Support Group

9/21/2025
A Day to Remember

The CHARGE Syndrome Foundation

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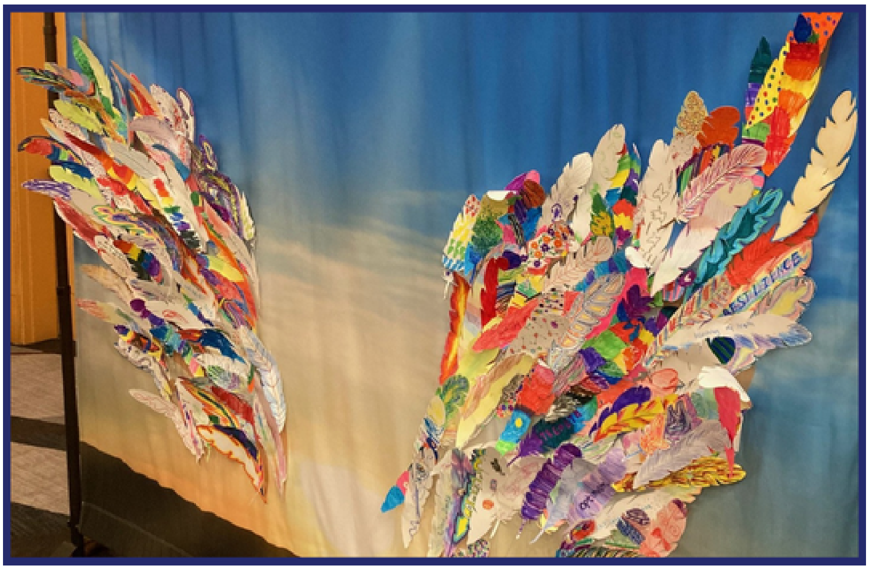


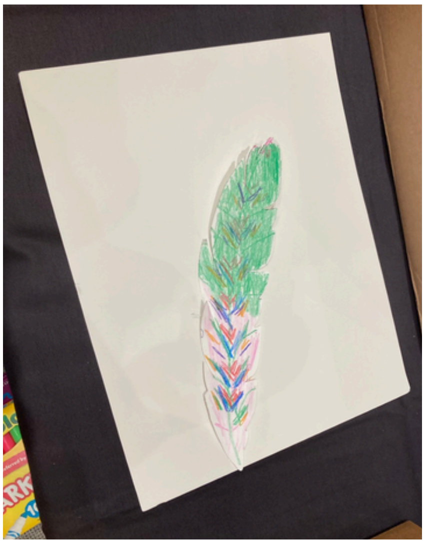
The Rise of the Phoenix at Conference

By Penni Echols

It was a delight to watch a beautiful phoenix rise during our Conference!

Attendees had the opportunity to create a feather for our community art project. One side shared a few words to describe a challenge, and the other side a colorful expression of the joy felt in conquering difficulties. Each addition to the bird's wings added dimension and strength to the collective, and it was inspiring to watch it take shape.

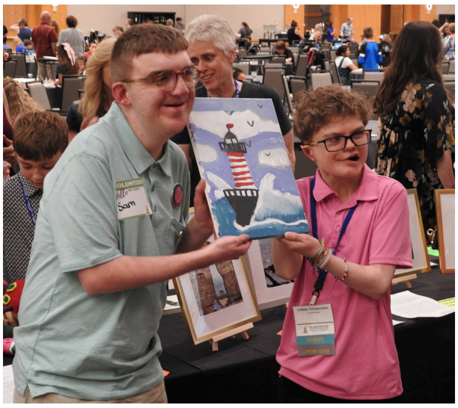
Myths about the phoenix serve as a metaphor for the human experience, where challenges and endings are not final, but rather opportunities for growth and transformation. The project was a true embodiment of the conference theme, “Rising From Challenges Together,” and served as a place where we could celebrate one another.

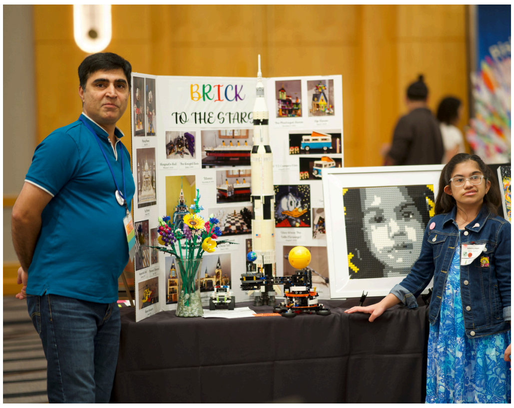


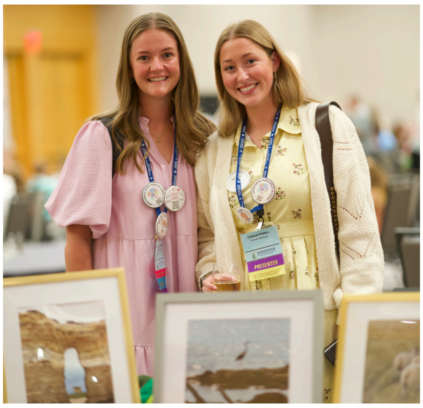
Special thanks to Allison Lewis for her inspiration and help in developing the concept and to Torrie Rathjen for creating the backdrop and outline of our giant rising phoenix.

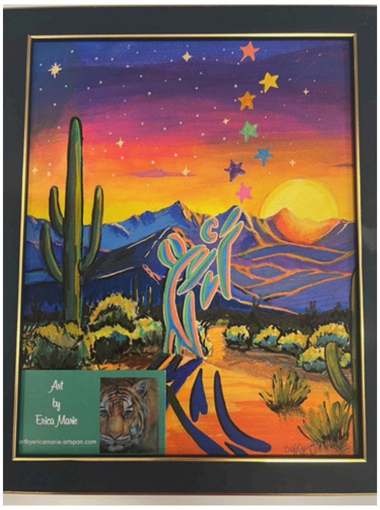
The theme of “Rising From Challenges Together” continued in the first ever CHARGE Syndrome Art Show. Conference attendees shared their inspired artwork in all types of media - from pottery to painting, drawings to lego creations, quilts to cross stitch - the creativity was overwhelming! It was a joy to interact with pieces during the art show on Friday night, and many of the artists generously donated their artwork as prizes in the basket raffle Saturday night.

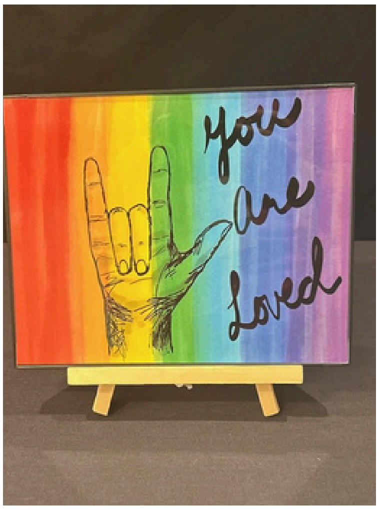
Click here to see more photos from the Art Show.

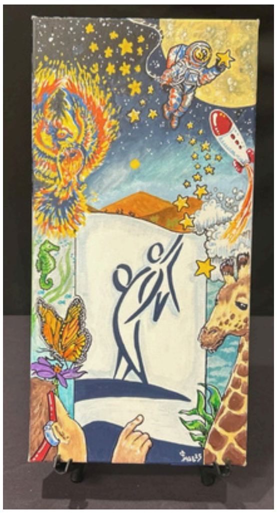


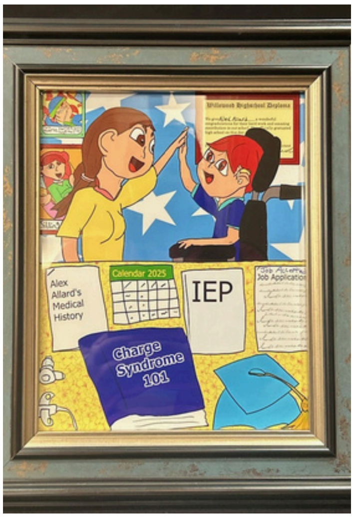




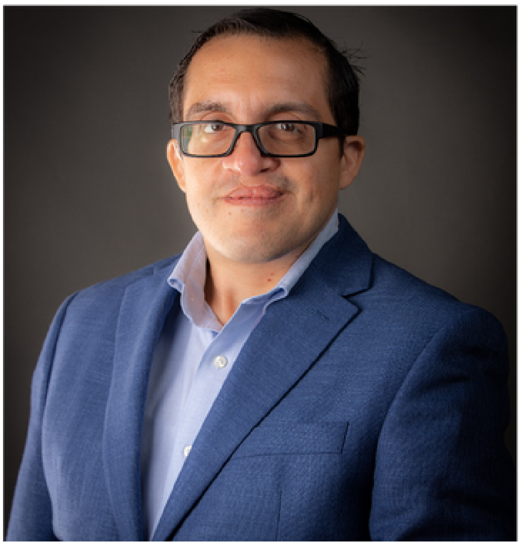








Reflections on Conference



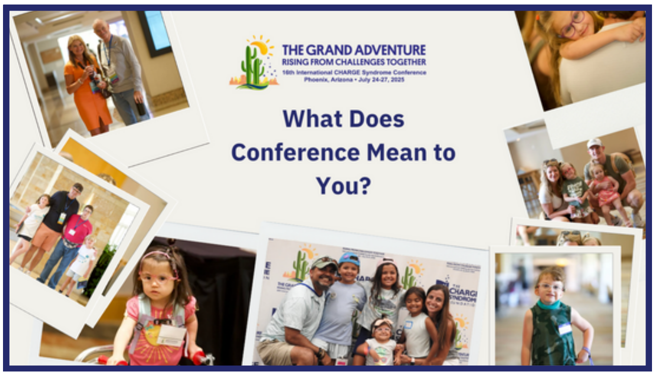
Conference means different things to different people, but it makes a big impression on all who attend.

“The 16th International CHARGE Syndrome Conference was an invaluable opportunity to connect with families and individuals living with this condition. It was an environment free of rejection and discrimination, a place where we could all be ourselves. I had the opportunity to share experiences, learn from each family and individual with CHARGE syndrome, and forge new friendships with those who understand our experiences firsthand.

From the moment I arrived at the hotel, I was greeted with joy, love, and respect. The opening ceremony was a great meeting point for all the families, where I was able to connect with people from countries like Peru, Mexico, and the United States. Over the following days, the world's leading experts on CHARGE syndrome shared their knowledge and offered us the opportunity to ask questions, always answering them with patience and willingness. Thanks to the ASL and Spanish interpreters, each presentation was an accessible and inclusive experience. In addition, the hotel accommodations and food quality met the necessary standards to ensure accessibility for all participants.

One aspect I wish to highlight is that people with CHARGE syndrome are not only spectators, but also active participants in the panel discussions, sharing their experiences and achievements and interacting with the audience in question-and-answer sessions. In my case, I had the privilege of being one of the speakers, where I shared my life story with the aim of inspiring others to move forward and, above all, to convey the message of the gospel of Jesus to them.” -Dr. David X. Ruiz Cardona, an individual living with CHARGE syndrome

We spoke with other attendees at Conference and asked them "What Does Conference Mean to You". Click here to watch our video compilation of their reflections on what makes Conference so special!



We hope to see you all in Dallas in 2027!

Volunteering with the Foundation

The CHARGE Syndrome Foundation is a volunteer-driven organization. The Foundation has a small team of 4 staff members (2 full-time, 2 part-time), and our advisors and board serve without compensation. The Foundation relies upon families and professionals to volunteer in all aspects of our programs.

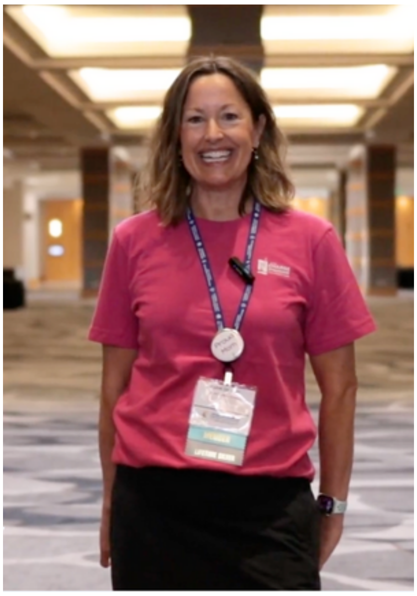
Whether you're interested in meeting new people, trying new challenges, or sharing your existing skills and experience, there is a role for you in the Foundation.

Some potential positions include:

- Conference Planning
- Board Service
- Mission Advancement – Fundraising
- Mission Advancement – Programs
- Mission Advancement – Marketing and Communications
- And More!

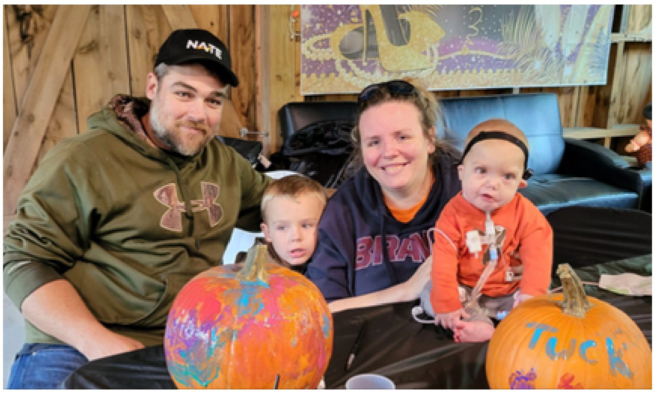
If you are interested in volunteering, please click here to fill out the Volunteer Form.

Please reach out to us directly with any questions info@chargesyndrome.org



> "I'm just really thankful to be a part of the CHARGE Syndrome Foundation family. It brings me joy to be here, to see the kids, to see the new families...and to help guide them through this very stressful time. It's nice to be a part of it, to be able to help people, maybe give them a smile, when they don't feel like smiling."
> -Karin D., Conference Volunteer

Always in Our Hearts - A Day to Remember



“Losing Tucker has been the hardest thing I have ever experienced. The grief is deep, ever-present, and life-changing. The kind of loss that shifts your world. It changes how you think, how you live, how you breathe.

What is Normal After Your Child Dies?

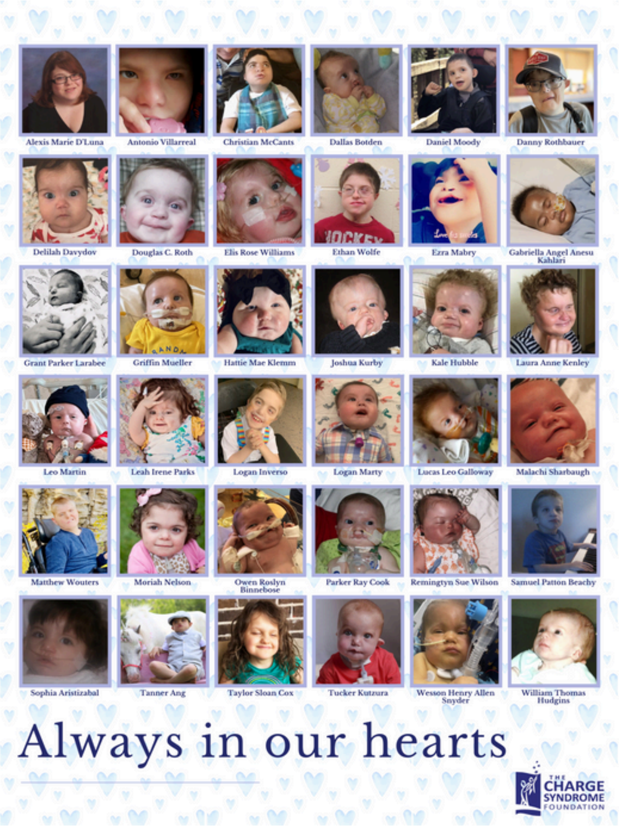
Normal is having tears waiting behind every smile because your child is missing from all the important events in your life.

Normal is not sleeping very well because a thousand ‘what if’s and ‘why didn't I’s go through your head constantly.

Normal is reliving the day your child died, continuously through your eyes and mind.

Normal is telling the story of your child’s death like it’s routine, then seeing the horror in someone’s eyes and realizing that—somehow—it’s become part of your everyday reality.

Normal is figuring out how to honor your child’s memory each year—on birthdays, anniversaries, and ordinary days—and trying to survive them.



Normal is a heartwarming, but aching, feeling when you see something your child once loved.

Normal is when some people avoid mentioning your child’s name.

Normal is making sure they are still remembered.

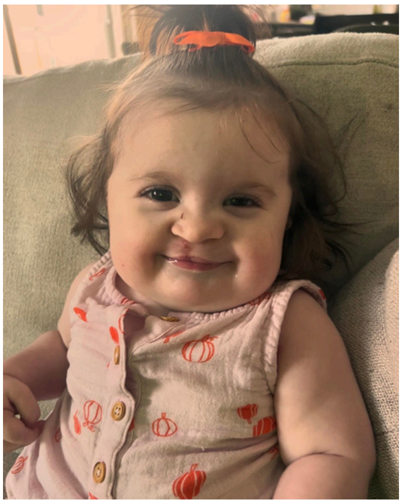
To honor the children with CHARGE who have passed away, the Foundation created A Day to Remember on September 21—the International Day of Peace. On this day, we ask everyone to perform an act of kindness and share it on social media.

Whether it's sending an encouraging message, making a donation, or simply spending time with someone you love—these acts of kindness spread hope.

It's a powerful reminder to all grieving families: you are not alone. Your CHARGE family sees you, remembers your child, and walks with you." -Amanda Kutzura, Tucker's Mom

- Click here to learn more about a Day to Remember
- Click here for some ideas of things that you can do for A Day to Remember
- Click here to print out a Day to Remember sign

Millie's Medical Travel Journey



"Our journey with Millie's medical appointments began when she was just two weeks old, requiring an 8-hour round trip drive. We were fortunate to have the Charge Syndrome Foundation's support, which helped cover our travel expenses and alleviate some of our financial stress. When Millie had her first surgery at eight months old, the Foundation's assistance was crucial in helping her receive her 'forever smile.' As parents, having financial support during challenging times makes a significant difference. We're deeply appreciative of the Foundation's help and feel grateful to have them supporting Millie." -Rylee H., Millie's Mom

The Medical Travel Assistance Program may be used by U.S. families to cover transportation, meals, lodging, and parking for medical care that requires out of state/long distance travel. The program is intended for families who would benefit from assistance to cover the cost for travel to receive medical care.

Click here to apply.

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.